Written Public Comments

IACC Full Committee Conference Call and Webinar

December 18, 2012

List of Written Public Comments

Note: Personally Identifiable Information (PII) has been redacted in this document

Marian Dar

May 29, 2012

AUTISM + SOUL in CONNECTICUT

Last weekend my 24 year-old autistic son, [PII redacted], bolted down the road on his bike and promptly disappeared out of sight.

Where to begin a hunt like this -- you hear all the stories. [PII redacted] verbal skills are not so great. What about the traffic, a hasty or rowdy traveler, [PII redacted] general naiveté about much of what and who we encounter in the course of a day, on the road etc., etc.

We searched for hours driving past the many outdoor holiday barbecues -- thinking [Son's name - PII redacted] might have visited for a "taste;" we stopped cyclists, joggers and motorcycles -- had anyone seen a "wandering biker" in a yellow T-shirt and jeans (talking to himself quite probably) -- all to no avail.

Finally and fortunately and just as the sun was setting, some local shops, the Police, and I connected with [Son's name - PII redacted] on -- Main Street, in the heart of downtown!

Understand that the most direct route to this location from [PII redacted] starting point would be an 8-mile trip up and over a steep mountain, mostly back -country roads. No big deal with the amazing navigation skills of many people with autism.

Still it is a small and lovely miracle -- how many strangers came together... to have [PII redacted] back safe and sound. It could have been much different.

One store manager saw him not cross the street so well and became concerned; another saw him load up on "donut sticks and Laffy Taffy" (about $15 worth) with no money or purchase intent and became concerned; a restaurant owner saw [PII redacted] walk away from his precious bike to get some sweets and brought "his vehicle" ([PII redacted] bike) inside to look after it; the Police knew about autism and offered assistance and support.

Many of those who enabled this rescue and response said they were aware, open and able to deal appropriately with this and other community efforts because of AUTISM SPEAKS. How heartening to see that people are listening and so many benefitting.

I take this opportunity to share our story with you, and ask that you support AUTSIM SPEAKS and its many important programs that go so far and do so much good. Thank you.

Sincerely,

Marian Dar,
[PII redacted]'s mother

Martin Zanna

June 29, 2012

FROM: Martin T. Zanna, M.D., MPH, Acting Executive Director
New Jersey Governor's Council for Medical Research and Treatment of Autism

SUBJECT: *New Jersey Autism Center of Excellence (NJ ACE) and IACC Strategic Plan*

Thank you for the opportunity to inform the IACC of the New Jersey Governor's Council for Medical Research and Treatment of Autism's (Council) most recent funding initiative, namely the New Jersey Autism Center of Excellence (NJ ACE). The NJ ACE is a clinical research initiative aligned with the national IACC Strategic Plan and funded by the Council.

In developing the Request for Application (RFA) for this initiative we were particularly interested in encouraging collaborations among New Jersey researchers while funding clinical research that would have the greatest potential for improving the physical and/or behavioral health of persons with ASD across the lifespan. Grants are awarded to New Jersey researchers. However, the researchers were encouraged to collaborate with researchers out-of-state who could contribute additional professional expertise or consultation. We referenced the IACC Strategic Plan in defining the requirements of our RFA given our interests are similar to those reflected in the IACC Strategic Plan.

The NJ ACE is an $8M five-year initiative consisting of a Coordinating Center and up to three Clinical Research Program Sites. The Coordinating Center serves as the voice of the NJ ACE in providing common management and support functions to the NJ ACE Clinical Research Program Sites while working with the Council to facilitate new collaborations both among the Program Sites and with new entities.

This NJ ACE initiative parallels the national research agenda for autism as established by the National Institutes of Health (NIH) and the Interagency Autism Coordinating Committee (IACC). The applicants for the Clinical Research Program Sites select one of the IACC objectives for their research projects and, for the first time, researchers funded by the Council will share research data with the NIH National Database for Autism Research (NDAR). We encourage researchers to utilize the IACC Strategic Plan as a resource in developing their projects.

All applications are reviewed by an Independent Scientific Merit Review Panel, consisting of nationally known experts in autism clinical research. The review process is designed to closely approximate the National Institutes of Health (NIH) standards and procedures to provide an impartial and rigorous review.

On June 28, 2012 grants were awarded to Montclair State University, Center for Autism and Early Childhood Mental Health to serve as the NJ ACE Coordinating Center and Rutgers University, Human Genetics Institute as the Clinical Research Program Site. The Council anticipates awarding grants to two additional Clinical Research Program Sites by the end of 2012.

The work of the IACC has been invaluable in guiding our decisions in developing a framework for clinical research in New Jersey. This will result in new and innovative ways to help families impacted

by ASD while positioning the researchers to potentially secure funding from additional sources from within New Jersey and nationally.

We would welcome the opportunity to discuss the NJ ACE and the IACC Strategic Plan with you.

Thank you.

Marian Dar

July 12, 2012

Subject: Autism TREATMENT: A Situation that NEEDS TO BECOME MORE SCIENTIFIC, ORGANIZED and Accessible

Good morning:

As a parent of an adult autistic who wears many hats, and a "listen-only" mode audience of July 10, thank you IACC for your large and great efforts. Yes, the mission here is daunting, urgent...And though so much has already been accomplished, there is sadly so much more to do -- it is difficult to keep up with the burgeoning numbers and heaps of issues.

I would go further than Mr. Robison (below) and his talk about ABA and other educational therapies... and say that we ***(govt., families, educational and clinical institutions, and insurance industry) need to broaden our perception and management of autism.***

Autism involves diverse and overlapping body systems and, as such, requires multiple, simultaneous interventions. One therapy might help, partially, learning and social. Another might help balance and coordination. GI is cited more and more as a factor. *Is there subtle malnutrition that affects immune, neurotransmitter competency?* Can and does diet play a role*?*

As John mentioned there needs to be some kind of government body to bring in, standardize and formalize adjunct therapies that are necessary and efficacious; after rigorous review and analysis to define quality and range of service, reasonable and just costs -- we can hope to ultimately refine and integrate these programs and benefits into traditional and existing care.

I have talked to senior third-party payers and asked what it would take for them to offer coverage for these programs. I was told it is something that they are looking at seriously, but need data. The kind of research they would need would require working with large retailers and combining clinical and consumer (food, pharmaceutical, medical) information. It could be a collaborative effort between industry, business and government.

Government and payers: we are talking about preventive health, chronic disease and most of all, the beyond quantifiable costs every day and over time of Autism.

Marian D

On Thu, Jul 12, 2012 at 5:03 AM, Autism Speaks Official Blog <contactus@autismspeaks.org> wrote:

Autism Speaks: Blog

Autism Therapy and Insurance—A Situation That Has to Change
Posted: 11 Jul 2012 10:31 AM PDT
Author:
Autism Speaks

This post is by John Elder Robison in My Life With Asperger's. John Elder Robison is a member of the IACC and serves on the science board of Autism Speaks but the opinions expressed here are strictly his own.

One of the most shocking (to me, at least) presentations at yesterday's Interagency Autism Coordinating Council (IACC) autism meeting detailed the status of insurance coverage for autism behavioral therapies around the country. [PII redacted] of Autism Speaks presented a number of charts that showed a mix of hopeful and disturbing news.

On the hopeful front, he showed a chart of states that have passed legislation making autism therapy a medical treatment, as opposed to mental health counseling, which gives better coverage through private insurance plans.

Yet at the same time he highlighted the extreme differences between individual insurers within some states. Even now, one family on a street can have a kid receiving 40 hours a week of therapy where a family two doors down has a kid who gets next to nothing, due to different employer insurance policies. That is a disparity we should continue working to eliminate. As he said, we've come a long way. Five years ago, almost everyone was in the same boat, with no coverage. Now quite a few people have some coverage, but "quite a few" and "some" are not words a progressive society should be using when it comes to autism interventions that can be life changing.

Unfortunately, there was more. [PII redacted] went on to cite a few states whose programs have denied behavioral therapies on the grounds that they are "experimental" or "not proven to work." I thought we were past that kind of shabby behavior. I guess not. I immediately opened a dialogue to discuss how that could happen.

When a new drug is developed, the Federal government (via the Federal Drug Administration) reviews test results and approves it to treat certain conditions. We've all heard how vital FDA approval is to the success of drugs. That's because the FDA stamp of approval means the drug will be accepted as a legitimate treatment for the conditions it's approved for anywhere in the US. An insurer cannot decline it arbitrarily, as they do now for many autism therapies.

I was shocked to hear that there is no analogous mechanism for approving behavioral therapy in this country. As National Institute of Mental Health Director and IACC chair Tom Insel explained, in the absence of a government approval system insurers look to the professional organizations themselves. What do they find? There is a good national program (BCBA certification) to train and certify ABA practitioners. The result – ABA is the most (indeed, the only) broadly approved behavioral intervention for autism.

Why? Because it's the only one with uniform certification standards nationwide. I know – many of you will tell me the quality of ABA varies widely and I agree – but the BCBA training standard is indeed uniform and it's all we have.

Yet ABA is only one therapy, and it's only useful to some of our autistic population. What about all the social skills therapies we've developed in recent years, things like PEERS or Unstuck, or RDI? What about social skills training or job coaching for adults? The idea that ABA would be approved but the latest cutting edge technology we develop is not . . . that is akin to saying none of the newest drugs will be

offered unless people are willing to pay for them personally. What is the point of pushing for new treatments in medicine if our archaic insurance rules keep them out of reach for most people??
The sorry truth: Very few of the many autism therapies developed in the past decade are covered by health insurance in the US. That means families must struggle to pay on their own, take what they can get (even if it's ineffective) or get into research studies that provide experimental therapy.
As someone who is working to get new therapies developed and deployed, that state of affairs is totally unacceptable.

I've written about new therapies on this blog, and indeed many show great promise. Their effectiveness has been shown in many studies, yet they are not widely available, and rarely covered by insurance. Why? Because there is no way for an insurer to know that the intervention being delivered in North Dakota is the one designed and vetted at UCLA (for example).

University research centers develop these therapies and even do training to propagate them in the field. Important as those efforts are, they cannot roll out a new intervention on a national scale to augment ABA. It's just not realistic for any single group to undertake that except over a period of decades, which we do not have.

So what do we do about this?

[PII redacted] and others have worked to get autism therapy classified as a medical treatment as opposed to mental health counseling. That means it's got to be covered by insurers and it's not subject to the "six visits a year" sort of limit that renders mental health coverage almost worthless under most US insurance plans.

Some in the autism community don't like the stigma of "medical treatment" as applied to something like social skills therapy but at this moment it's the only path we have to coverage, paltry as it is.
I think we need Federal action that mandates insurance coverage for a much wider array of behavioral intervention. Valuable as ABA is, is it not a path that works for every kid, and frankly, it is "old news." We need to get our insurers covering the deployment of new therapies that will help a broader range of kids.

Dr. Insel and I talked about that after the meeting. He shared my concerns, and said this is a problem we could address fairly easily but it would require legislation that would be resisted vigorously by the insurance industry. He told me there are groups working on this very question in other fields, like depression. His comment made me wonder if we need to band together to solve this as one lobbying group.

The fact is, many behavioral interventions have been developed and proven to work for depression, autism, and other conditions, but they are seldom covered by insurance because they are not classified as medical treatments and they lack any equivalent of FDA approval.

I want to thank [PII redacted], his group, and everyone else who has worked so hard to get the insurance coverage we have today. And I want to thank him for opening our eyes to the true nature of the next obstacle we must surmount – the development of a mechanism by which new autism therapies can be delivered and covered by insurance. Without that, all the intervention in the world will be worthless to most people, because they will have no way to pay for it.
And that is wrong.

Note: Personally Identifiable Information (PII) has been redacted in this document

Anonymous

July 20, 2012

I Am Director For Organization Savoy Youth & Orphans Development Center , S,Y,O,D,C, /

Thank You Again I Am Resource For Autism East African Community Immigrant Refugee

Because For The Last 20 Years For Immigrant In Born All Majority Mostly In Autism For

North America, In European , London , Canada , Sweden Holland , Denmark , U.S.A

Why In Mostly East African Community Any African Autism I Thing So For Vaccine Shot Does Why In

Happening,

One He's My Nephew He's Autism Now Almost 4 Years Before 4 Year Is Ok Because In Happening

The Shot Vaccine Does In Problem , He's From London , Is Boy ,

One My Young Sister Still She Confuse She's Not Ok Her Mom Is [PII redacted]

Now I Am Resource For Autism For The Last 2 Years Why '

Thank You Again Please Contact Me Any Time Still Under construction

My Website = www.savoyorphans.org (IACC Note: URL is not valid.)

JaLynn Prince & Desiree Kameka

July 27, 2012

Subject: MHAF Comments

RE: Madison House Autism Foundation's Comments on July 10, 2012 IACC Committee Meeting

Dr. Insel:

On behalf of our board and staff, we thank you and the IACC Committee for all the work that you have done and continue to do. Madison House Autism Foundation (MHAF) has been present at many IACC meetings both in-person and over video conferencing. We are pleased with the continuation of IACC through the Combating Autism Reauthorization Act 2011 and have confidence in IACC's Strategic Plan, which offers movement towards planning and research for the future of millions of children who will enter adulthood on the autism spectrum.

Madison House Autism Foundation was established in 2008 and is one of the first and few organizations to focus solely on the issues of adults with autism. MHAF gets calls, emails and letters from parents across the country asking for help, hoping for answers and begging for action. A mother, [PII redacted], wrote recently: *"Someone has to speak up for the ones who are not children of movie stars or famous athletes."*

We are troubled at the lack of discussion and urgency of the imminence of individuals on the autism spectrum aging out of school-based entitlements into the next 2/3 of their lifetime without adequate housing, support services, job opportunities, and community involvement. There is a desperate need for research funding for lifespan issues, especially housing and lifelong financing to stop the currently headed catastrophe and move in the direction of sustainable solutions. Moreover, research findings must be translatable to the real world. The economic costs are staggering and the social impact of not responding is devastating:

1. **Lack of residential Facilities:** According to the 2012 Residential Information Systems Project (RISP) Report from the University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD) at the University of Minnesota, "The national average rate of placement in residential settings for people with ID/DD [including autism] in 2010 was 151.2 people per 100,000 of the general population compared to 118.8 in 1977."[1] In other words, 85,000 of every 100,000 people are turned away every year and most of those are in or nearing crisis.

2. **Projected losses of homes and primary caregivers:** Since January 2011, 10,000 Baby Boomers turn 65 every day for the next 19 years[2], if more than 1% of the population is on the autism spectrum, and it is reported that 70% of adult children with disabilities are currently living with their parents and/or guardian[3], than 70 individuals are getting significantly closer to losing their home and primary caregiver every day. This is followed closely by another wave of the autistic population under 30 in which 96% are currently living with their parents or primary caregiver.[4]

3. **Waitlists:** Equally tragic is the housing crisis: Forty-four states have reported a waitlist for residential services in 2010 with an estimated 115,059 people waiting for residential services.[5]

Secretary Sebelius has charged IACC to guide research on autism in line with the HHS Strategic Plan and states, "*To achieve these goals [strategic plan], we must always keep an eye on the future – to prepare for the next potential public health emergency, to pursue the next lifesaving cure, and to support the development of the next generation of Americans. But at the same time, we must also examine old programs and existing services and ask: How can we serve Americans better? What can be done less expensively, faster, and more transparently?*"[6]

Two Requests to the IACC Committee:

1. MHAF would like a better understanding of why there is such a void of research on lifespan issues despite the fact that for individuals on the spectrum, the greatest economic need and social imperative is spent in adulthood. MHAF is actively pursuing a multi-disciplinary study and comprehensive study to provide the data to create a national roadmap and we would welcome IACC's active engagement and support.

2. As you are deeply aware and committee's report acknowledges that "…adults with ASD struggle with ongoing and mostly unmet needs for employment, housing, services, and support," MHAF would like to suggest that IACC add a member from the US Department of Housing and Urban Development and a professional in the field of adult issues with autism to IACC. MHAF would be willing to assist in finding these potential members.

Solutions exist if we work together to find ways to allow the millions of people with autism to live as independently and productively as possible, contributing positively to economic growth, community development, and medical understanding. There must be more attention on lifespan issues for those on the spectrum and the dissemination of solutions to mitigate this national crisis– our country cannot afford to neglect research in adult issues on the spectrum.

Thank you for allowing the submission of comments on behalf of Madison House Autism Foundation.

Sincerely,

JaLynn Prince
President, Cofounder and Mother of 22-year old Autistic son
Madison House Autism Foundation
Website: http://www.madisonhousefoundation.org/

Desireé Kameka
Director of Community Education and Advocacy
Developer of the Autism Housing Network
Madison House Autism Foundation
Website: http://www.madisonhousefoundation.org/

1. Larson, S.A., Ryan, A., Salmi, P., Smith, D., and A. Wuorio (2012). *Residential Services for Persons with Developmental Disabilities: Statues and trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community

Integration. Accessed online July 25, 2012 http://rtc.umn.edu/docs/risp2010.pdf (IACC Note: URL is not valid.)

2. CBS news: http://www.cbsnews.com/stories/2010/12/30/eveningnews/main7199116.shtml

3. Easter Seals, *Living with Disabilities Study* Accessed Online, July 25, 2012 http://www.easterseals.com/site/PageServer?pagename=ntl_living_with_disabilities_study_home&s_src=LWDstudy&s_subsrc=bannerad

4. Easter Seals, *Living with Autism Study*

5. Larson, S.A., Ryan, A., Salmi, P., Smith, D., and A. Wuorio (2012). *Residential Services for Persons with Developmental Disabilities: Statues and trends through 2010*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. Accessed online July 25, 2012 http://rtc.umn.edu/docs/risp2010.pdf (IACC Note: URL is not valid.)

6. From the generic response when emailing the desk of Secretary Sebelius

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Kenneth Seaton

August 5, 2012

Subject: national health and national hygiene research abstract of 30 years Autism research

Ronald Campbell CDC director executive secretariat wrote July 30 2012 and suggested I send the attached abstract covering approximately 30 years research that solves the many mysteries of autism spectrum. Comments and questions welcome. Help in further testing is requested. President Obama has written personally several times regarding this matter.

Respectfully
Kenneth Seaton

Attached Abstract:

UNDERSTANDING AND PREVENTING AUTISM
National Hygiene Foundation, National Health Federation
Kenneth Seaton D. Sc.
This research 1985-2012 submitted to the NIH in 2012

ABSTRACT

Background: Serum albumin is the "The Life Factor" (PBS TV June 3, 1994). Serum albumin levels in pregnancy have remained (35-20g/L), over the last 175 years and are low. Evolution today, in this electronic age of computers, smart phones, and Internet require a more advance human brain development. This requires higher serum albumin of 45-35g/L during gestation. The fundamental basis of evolution is the quality and quantity of albumin during fetal development. Albumin with its 585 amino acids is the perfect building block of human life.

Theme question: Is the cause of Autism Spectrum Disorders the fact that serum albumin in pregnancy is to low in millions of births?

Method: From 1985 in Australia to 2012 in the USA I have attempted to collect data in over 10 major birth hospitals in thousands of pregnancies. High serum albumin in the mother, commencing at over 45g/L in the first trimester and slowing falling to no less than 35g/L in the last trimester prevents Autism in infants at 3 years of age. Further, the level of serum albumin from birth in infants should be a >45g/L for healthy child development. High hygiene is more important than diet in achieving high serum albumin because it lowers the stress proteins causing a healthy rise in serum albumin. Super children can have albumin >54g/L.

Results: The Mother's albumin level controls the level in the fetus and the amniotic fluid (5g/L at 26 weeks).The Mother's albumin should remain as high as possible. In many pregnancies, mainly because of stress serum albumin falls to less than 20g/L causing a high risk of birth defects including Autism Disorders and sub-optimal childhood development.

Conclusion: Higher serum albumin in pregnancy is required today because of evolution. The medical establishment has been negligent in failing to understand that we humans are still evolving. High serum albumin ensures the genetic machinery works efficiently and prevents mutations. It is very disappointing that the NIH, CDC, NIAID, NICHD etc., including most birth hospitals have failed to keep accurate public records of serum albumin levels in pregnancy. The shocking result worldwide is over 100 million children with Autism Disorders.

Email: [PII redacted]
Questions and comments welcome

Eileen Nicole Simon

August 6, 2012

Subject: Discussion of public comments

I was not able to listen to the conference call on July 27 during which public comments submitted for the July 10 meeting were to be discussed. Will a transcript of this webinar/conference call be made available?

If some comments were not discussed, could some reason be given? If what I submitted is not of interest, I would like to know why.

I would like to know what evidence can be provided that refutes the issues I raised: (1) The need for research on language development as a priority, (2) The vulnerability and importance of the auditory system for language development, and maturation of the language areas of the cerebral cortex during the first 4 to 5 postnatal years (3) The increased vulnerability of subcortical nuclei in the brain to 2 or more injuries, such as ischemia plus bilirubin. (4) Consideration of how the many different genetic abnormalities found in people with autism (including Downs syndrome) might all affect nuclei in the subcortical motor and auditory systems, and (5) Most important: Consideration that the obstetric protocol for clamping the umbilical cord before the first breath can lead to ischemic injury of the brain.

Please let me know. Thanks.
Eileen Nicole Simon

Chris W. Houghton

August 13, 2012

Subject: Senior Citizen Concern Related to IACC

Seeing the mobilization for the recent Swine Flu (H1N1) pandemic, I was surprised at the large body of people that had gotten motivated to move to protect Americans from that deadly disease. As it turned out, there much ado about nothing, and even the CDC admitted that they stopped recording statistics on that pandemic.

However, given that the rate of occurrence of Autism Spectrum Disorders (ASD) has increased to at least 1 in 88 children, and children being far more motivating than just adults, I am very confused why your group doesn't seem to do much but have meetings and congratulate each other for doing little or nothing about this pandemic. Are you trying to keep this terrible disease out of the public eye? It is pandemic attacking our children and the IACC seems to be doing little or nothing about it.

We the people need to depend on you the specialists in this disease to do the proper and obvious testing and research that will lead to determining the source of this disease, and I'm not talking about the silly business that now we are testing better and recognizing it more readily. The disease is 1 in 88, and has steadily increased for years, and long ago most physicians have been able to see the symptoms and refer a patient to a specialist that can issue the final diagnosis of ASD.

Along with the real testing and research that I am recommending, I suggest another look at the Amish, and this time with a clear eye to the real cases. A census of those that have used vaccination, and those that have not, and the numbers of ASD patients among that same collection of people polled. The current numbers from a doctor that worked with the Amish found some very disturbing statistics, and we need to know if they are true.

At the same time, since I'm sure you have resources laying around doing useless things, it might be nice to talk to a physicians that say that they have made inroads with the patients with the disease. One of those is Natasha Campbell-McBride, MD, whose Curriculum Vitae is available here: http://www.gaps.me/preview/?page_id=35

This doctor says she has cured some children of the disorder, and I for one would like to see if that is true, and also see that the government has enough intelligence to listen to that doctor if she proves to be right.

I await your decision and reply.

Chris W. Houghton

Eileen Nicole Simon

September 5, 2012

Subject: Re: Upcoming: IACC's Basic and Translational Research Subcommittee Conference Call and Webinar – September 7, 2012

Autism is associated with many different etiological factors. All causes of autism disrupt normal language development. Research on autism should, therefore, focus on brain systems involved in normal language development, not on finding any more causes.

Kulesza et al. (2011) reported malformation of a brainstem auditory nucleus in nine individuals with autism. They then examined the same brain site in laboratory rats exposed to valproic acid during gestation, and found a comparable malformation. Prenatal exposure to valproic acid (VPA) is one of the many known causes of autism. Promote/suggest use of this "probe" to further explore its effects on initial brain impairment, and brain maturation.

The auditory system should be considered essential also for environmental awareness. The auditory system never sleeps. This is why we use alarm clocks. The auditory system can be viewed as the vigilance center of the brain. Beyond vigilance, the auditory system has been described as the "information seeking" system of the brain. For the human species, language has been described as the pinnacle of the "information seeking" instinct, and even locus of the conscious state.

References

[1] Kulesza RJ Jr, Lukose R, Stevens LV. Malformation of the human superior olive in autistic spectrum disorders.Brain Res. 2011 Jan 7;1367:360-71.
[2] Lukose R, Schmidt E, Wolski TP Jr, Murawski NJ, Kulesza RJ Jr. Malformation of the superior olivary complex in an animal model of autism. Brain Res. 2011 Jun 29;1398:102-12.
[3] More on attention, awareness, and the conscious state can be provided.
[4] More on other potential brain-damaging "probes" also can be provided. I might start with pyrithiamine, which produces brainstem pathology similar to that resulting from VPA.

Note: Personally Identifiable Information (PII) has been redacted in this document

Kenneth Seaton

September 10, 2012

Subject: Autism Spectrum mystery

It has been suggested by the NIH Press Office, Robert Bock, that I email the attached research which clearly solves the mystery of Autism Spectrum Disorders. Tests over the years have clearly shown that higher levels of serum albumin (45-35g/L) prevent Autism Disorders. I have sent this research since 1987 to various departments of the NIH. More importantly my quest is for optimal childhood development which requires higher serum albumin during gestation. That can only occur by reducing the level of inflammation such as acute phase reactions allowing more osmotic room for albumin. The hundred million dollars grant from the NIH to solve Autism must consider my simple solution. Also enclosed is my research sent to the Journal NEURON which shows that high serum albumin prevents mutations.

I welcome your questions and comments.

Kenneth Seaton

A SUPER SCIENCE REPORT ***OPTIMAL PREGNANCY*** FEB 2012

HIGH SERUM ALBUMIN (45-35g/L) DURING PREGNANCY AND (>45g/L) IN THE FIRST FIVE YEARS OF LIFE PREVENT AUSTISM SECTRUM DISORDERS.

Kenneth Seaton D. Sc.

Facts in support of the Quest for Optimal Pregnancy 1960-2012
Low Serum Albumin during pregnancy is the major cause of birth complications
All measurements in the International range grams per liter, not g/dL

Super Science **Acknowledgement: Arlene Hale Assistant**

Can High Serum Albumin Prevent Autism Spectrum Disorders and PDD

Kenneth Seaton D.Sc
Search for Optimal Pregnancy and Child Development 1960-2012

Abstract: Autism is a mysterious multi-potential mental disorder, WHO predicts one hundred million affected. It appears before 3 yrs, in some areas >1/60 boys have Autism Disorders, males> 4.5X more susceptible than females. Male brains are potentially larger; more evolved and today requires higher serum albumin during pregnancy. Mutations on areas such as chromosome 16 where rapidly evolving genes have been linked to Autism. Today higher modern intelligence requires higher serum albumin levels in pregnancy, and during infant brain development, especially for the first 5yrs, requiring serum albumin >48g/L. Inflammation is the major cause of low albumin NOT diet. My 50 yr quest is for "Optimal Pregnancy" not just for prevention of Autism. The NIH and NICHD failed to understand my numerous attempts to have them raise the public medical serum albumin level, especially during pregnancy, essential to neutralize the medications and drugs used today, as the levels, currently used (23-35g/L) are over 150 yrs old and are far too low. Low serum albumin during pregnancy and infancy is the Basic cause of Autism Spectrum Disorders and NIH failed to correct it for 25 yrs. Infusion of albumin in premature babies can reduce the risk of autism, however, is not the answer. Eggs are an excellent source of breakfast albumin as they contain ~50% of albumen, converted to human albumin in the liver. More scientific testing is required, and the NIH should help. **High Albumin buffers against stress, makes the stronger. High serum albumin ensures Neuroplasticity and Neurogenesis for super learning and adapting.** Serum Albumin testing is neglected in pregnancy resulting in millions afflicted with Autism weird spectrum horror disorders. Test Tube babies have lower serum albumin levels and very high Autism incident>10%. Fathers and Mothers must have high serum albumin > 45g/L before conception. Serum albumin in Humans and Dolphins must >35g/L in pregnancy.

Method: The mysteries of Autism Spectrum are answered below by higher serum albumin in pregnancy and infancy. **Serum Albumin must not fall below 35g/L during pregnancy and remain above 48g/L during the first 5 yrs of infancy**. **The higher the natural serum albumin profiles the better. An albumin/globulin of 4.0 is seen in super clean, super intelligent infants.**

1. Autism is linked to rapidly evolving genes, thus modern intelligence today requires higher serum albumin in pregnancy compared to 100 yrs ago. Consider today humans live over 85 yrs compared to 38yr in 1850. A lesson is Bowhead Whales with giant brains, endless singing (compared with human speech), and living over 250 yrs. with high serum albumin 54g/L in pregnancy. The human fetus baths in, drinks, and breaths amniotic fluid and it must contain minimum 4g/L for proper human brain and baby physical development. High serum albumin is required for the development of speech, singing, social life, understanding and development of the human, intelligent mind. In the future humans will need 5g/L albumin in the amniotic fluid@ 25 wks.

2. Identical twins develop Autism over 90% of the time; however, when grown in different higher levels of albumin it prevents Autism in that twin. This indicates that higher serum albumin ensures correct and full gene transcription and also full brain development. This has important implication for All congenital mental disorders and intelligence. Fragile x syndrome is linked to low serum albumin and autism.(request report)

3. Childhood immunization is NOT a cause. Albumin neutralizes mercury that is often used as a preservative. Elevating stress serum proteins during infection and inflammation, reduces albumin, and this is the real risk. Evolution requires more serum albumin in pregnancy than 100 yrs ago. Today, pregnant women are older with lower serum albumin, and this leads to a higher risk of Autism. Today the need for higher brains to operate complex smart phones, computers, multi-channel TV, and advanced learning from the Internet requires a larger brain. Babies born with high serum albumin are very gregarious, the opposite of Autism, also incredibly intelligent and beautiful! The extreme rarity of Analbuminemia reflects non-survival of gestation proving that albumin is essential for life. Infusion of albumin is foolish and futile also very expensive, yet may prevent Autism in preterm babies, No drugs, alcohol, or tobacco should be used during pregnancy. Compare a human male brain weight~1500 gms to pigs~180 gms.

4. Serum Albumin is a perfect packet of 585 amino acids (20 in variety) made by the liver, essential for optimal growth of fetus, especially the amazing human brain. High serum albumin levels ensure correct birth weight (7.9 lbs) to prevent Autism. Albumin also acts like a 'mother ship' to supply other carrier proteins with a reservoir of essential nutrients for delivery to the correct cells. The fetal liver assists the Mother's liver re the production of albumin, it is the Mother's high albumin level that is the foundation of a health pregnancy. High albumin makes the brain stronger, and more Super plastic.

5. The higher the quantity and quality of albumin the more advanced the brain in the animal kingdom. Human babies are made of albumin and its many cargos, such as fatty acids, consider the remarkable complexity of our fabulous brain! The amazing transport of fatty acids by albumin appears to be a foundation for building a complete brain.

6. Humans require very high levels of pure serum albumin in the blood at all times, to remove the amyloid and wastes from the brain and in excess of albumin required for transport of nutrients and waste (see Seaton's research in NHF 2011). The fetal liver cannot produce enough perfect albumins for at least the first 6 months, this depends upon the Mother to produce sufficient serum albumin for both and this is minimum 35g/L. This is vital for robust birth weight and to prevent Autism Disorders. Swimming at the beach and exercise are excellent for maintaining high serum albumin in the Mother.

7. During pregnancy albumin levels can fall dramatically, especially during infections followed by secondary infections, stress and immune overload. (This is why super hygiene is vitally important in pregnancy) Albumin is a measure of inflammation, stress on the immune, complement function, not just nutrition.

8. The reason why albumin falls is that infections, stress on the immune system, trauma etc, causes the stress serum proteins (acute phase reactants APR's) to rise dramatically, forcing serum albumin to decline dramatically. (This cannot be corrected by diets) Remember, autoimmunity, inflammation and stresses are linked to Autism in the baby.

9. Albumin plays a fundamental role ensuring perfect gene replication, also chromosome stability, protects the DNA against mutation, ensures basic cell stability and neutralizes any chemical toxicity. High Albumin is a remarkable purifier against almost all environmental toxins; however it must be at high levels.

10. Serum Albumin is lower during pregnancy because of the Mother's fluid expansion and can often fall to below 20g/L (dangerous). Remember, healthy non-pregnant adults should maintain albumin at > 48g/L with an A/G ratio of 2.0. Countries with higher albumin in pregnancy have far less Autism and other mental Disorders. The Amniotic fluid needs to contain 4g/L for the baby to continually drink (this is far richer than cow's milk).The Mother's Albumin level ensures proper development of the baby as it is used by the baby to drink, breath and bath in. It is "The Life Bath". This amniotic aluminous fluid also ensures correct function of the lungs and gastrointestinal tract after the baby is born. This helps to explain the gastro intestinal and lung problems that appear common in Autism children.

11. *Pregnancy requires >40g/L of albumin during the First Trimester and at all times > 35g/L (3.5g/dL) to prevent Autism Disorders. The higher the natural serum albumin the better for childhood development and evolution.* I have requested NIH to assist. Compare dogs, pigs and cats as they only need <15g/L during pregnancy.

12. From birth, infants must have super hygiene to ensure super serum albumin is maintained above 45g/L (50-54g/L is best) in the first 5 yrs for optimal brain development and to prevent and reverse Autism Disorders. Higher hygiene prevents infections and inflammation. Inflammation (fever) reduces albumin. Raw eggs / honey milk shake are excellent.

13. Low birth weight and premature births have a shocking 20X higher rate of Autism Spectrum, the result of low albumin in pregnancy and in premature birth, and it is only 18-19g/L. Most will have some form of Autism Spectrum. Infusions of albumin can reduce the risk of Autism

14. **"***Optimal Pregnancy ensures an optimal life*" This is my quest that Albumin is: "The Life Factor" See Kenneth Seaton's PBS TV national interview June 3 1993 the Tony Brown's Journal. Albumin concentration is the basis of beautiful perfect babies from puppies to piglets to mice, kittens, whales and Humans. High serum albumin in the amniotic fluid must bath the fetus, feed it for nourishment and healthy gastro tract development and breathe it for health lungs to function to breath air. This can only be achieved perfectly when the Mother's albumin is high.

15. Albumin is the most dominant anti-oxidant known. It is abundant and sacrificial, also protects all other tissues including the fetus from damage. It can easily be recycled and binds/inactivates a range of toxins, carcinogens and waste products protecting all the cells from free radicals. Albumin buffers pH, protects against radiation, stabilizes the blood and maintains homeostasis of the Mother, fetus and amniotic fluid levels. A full list of albumin as "Super Antioxidant" is available.

16. Albumin appears to be the "Life Factor" via donating and collecting electrons. This helps to explain why no human has ever been found without albumin. Cells grow stronger, far longer and none convert to cancer lines in the presence of high albumin. This is why it is so important to have high albumin during fetal growth. Albumin also transports fatty acids, protecting them from peroxidation, vital in building a human super brain.

17. The findings in the recent California study which links highly educated families to high rates of Autism is supported by the desperate need, at this modern time, for a larger more advanced brain in children. Higher concentration of albumin in the Mother is required to build a more advanced brain in the baby. All Doctors should understand that all Mother's should enter gestation with serum albumin at least 45g/L (50g/L is better) Also in the Father and then maintain it as high as **naturally** possible to delivery. Breast feeding, is essential, because it supplies the foundation to a strong immune system, also the right supply of human albumin milk, far superior to cows or goats milk. Consider that the albumin in the amniotic fluid, which the baby drinks, should be minimum of 4g/L compared to cow's milk which is only 1g/L, thus the baby is being prepared to drink breast milk before birth. Mother Nature is very wise!

18. Mutations in the area of the DNA containing strange genes that historically have changed very rapidly as humans evolve may contribute to Autism; explaining the genius factor seen in 10%. These genes require higher levels of albumin, a minimum of 35gL in pregnancy and 48g/L in the first 5 yrs of childhood development. This can only be achieved by practicing higher hygiene that lowers the acute phase reactants and other globulins to make more "osmotic room" for albumin. "*Cleanliness is indeed medically next to Godliness*". As we evolve we need higher serum albumin from Mother and for the fetus, for a higher brain development. The fetus must drink, bath and breathe the amniotic fluid and it must contain at least 4g/L, especially during the early stages of pregnancy to ensure a perfect manufacture of the brain.

19. The British heart study (1989) proved a 7X lower all-cause mortality rate when serum albumin was 48g/L, compared to only 40g/L (See Lancet Chart at rear), foolishly the media warned that cholesterol from eating eggs was a heart risk causing millions foolishly to stop eating eggs .This proved to be scientific nonsense, yet by 2004 Autism became a Tidal wave. Eggs are a true essential Super Food.

Conclusion

Higher levels of Serum Albumin during gestation, answers all the mysteries of Autism and ensures optimal childhood mental and physical development, including Speech, Understanding Mind and Social –Inter-Action. The human brain is capable of great love, understanding, learning, wisdom, social interactions, also kindness and caring which forms the human mind. These things are absent if the brain is not fully developed by sufficient concentration of albumin during fetal and infancy development. "The genius of nature's engineering is profound".

For human history countless millions of children have been born with sub-optimal serum albumin levels resulting in countless physical and especially mental disorders. Today we have the medical and scientific ability to ensure optimal levels of serum albumin in almost all pregnancies, to ensure optimal child development in most children. This new era of human potential can change the world and help humans preserve this unique and beautiful planet.

The human brain is fabulous, has amazing potential for great genius for us all, amazing ability to help others, care for all the other animals, bring peace to the world, end addiction, poverty, filth, hunger, evil, insanity and greed (A sign of sub-optimal brain development). I repeat No drugs, alcohol or smoking can be used during pregnancy.

Maintaining serum albumin levels in humans, equal to Bowhead Whales 48-59g/L may allow humans to live 200 yrs, as the whales do and with a very low risk of cancer, heart disease, and Alzheimer's (Please read my recent research in the NHF on Bowhead Whales, aging and preventing Alzheimer's). Super high serum albumin ensures stability of the brain, prevents kidney failure, mental disorders, criminal behaviors and arthritis etc. At last we humans can achieve our full potential for all races. The Autism Spectrum Disorders has taught us the value of a fully developed brain in the ability to speak, sing, socialize, understand, observe, empathize, relate, love and to sense what others are thinking, and know what others feel, towards what we are thinking. High serum albumin ensures the human brain can imagine, read others thoughts, need other persons company, speak to others at meetings, parties relate back and forth, and know what to say, and where and when to say it.

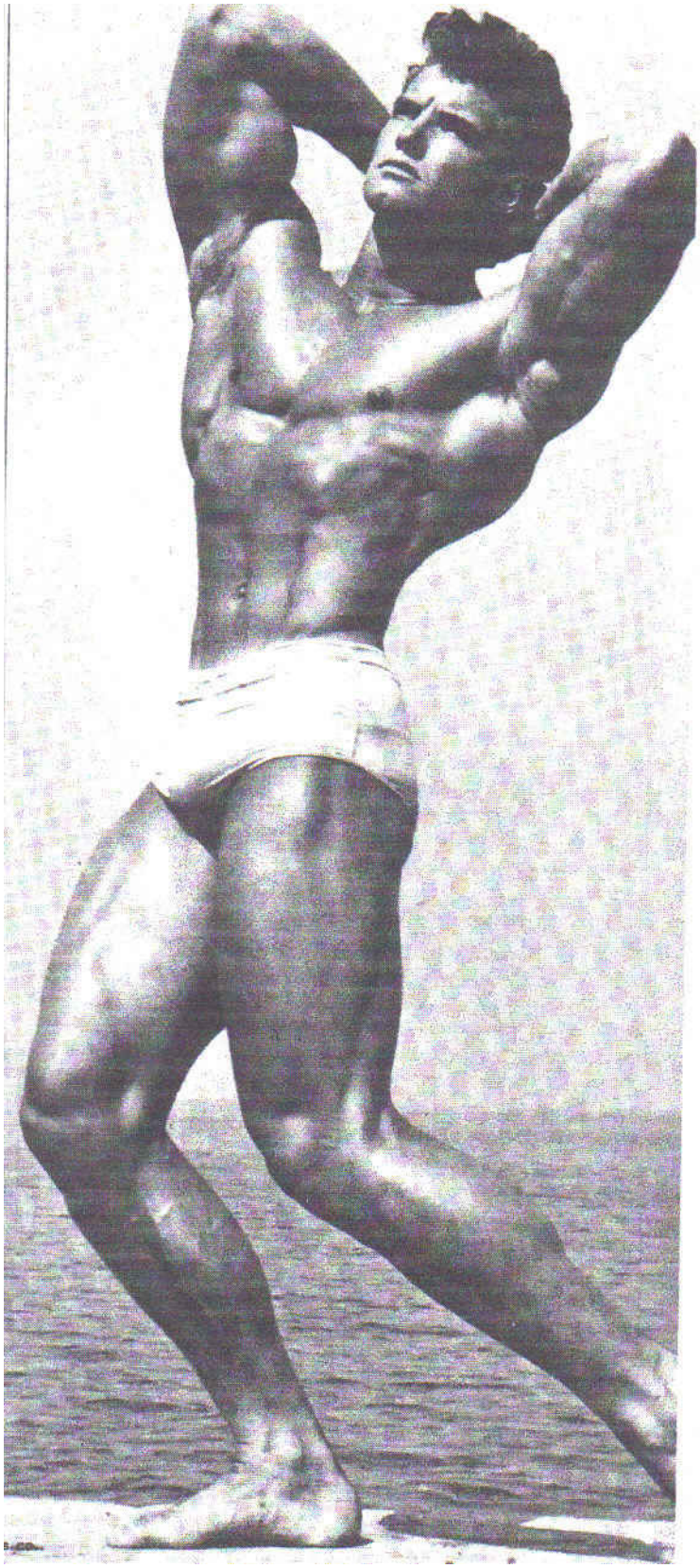
A fully formed modern human brain has the ability to understand that it has a Mind of its own and can relate to another Mind, can form lifelong friendships, share information, and just hang out with others like us. This is sadly missing in those with Autism Disorders because that higher function of the human brain is not completed due to insufficient levels of albumin in development. The studies with identical twins with the Same Genes, yet one without Autism because of higher serum albumin during growth in the womb highlights the amazing importance of a generous supply of albumin, to every fetus in development, sleeping inside the amniotic fluid, inside the amniotic sack and the many wonders of the complexity of the human mind.

Remember the words of the famous song, made famous by the great singer Barbara Streisand "People, who need other people are the luckiest people in the world". A world filled with children that are Autistic will be absent of the special human ability to understand the remarkable astronomical universe that we are a part of, yet we are insignificant creatures that can realize our own insignificance, thus cannot be insignificant. To know thy self is being human without Autism. Albumin >35g/L in maternal blood is required in human and Dolphin fetus perfect development.

Foolishly the National Institute of Health and National Institute of Child Health and Development refused to even answer my letters for over 10 yrs, as I requested, that the levels of serum albumin be raised during pregnancy. If the NIH had taken the simple step to help me 25 yrs ago when I began sending my research, millions of children afflicted by Autism Disorders could have been prevented from this horror and $$$trillions saved. I cannot even conceive where this research is wrong and welcome the reader's strongest criticisms. Higher serum albumin during pregnancy and infancy is a wonderful natural benefit regardless of Autism Spectrum Disorders. **High serum albumin also prevents cancer JMNA Dec 2001,V93:490-3**

Ref: "All about Albumin" T Peters, world's leading authority. Academic Press 1996. This book of 432 pages represents a life time study of the amazing Albumin molecules and has over 2,000 references. It concludes that Albumin is the most studied yet least understood of all proteins. It cites the famous Japanese study that righty concludes "***The quality of life, medically, is the quantity of Albumin".*** **Infusions of exogenous albumin lowers the risk of PDD otherwise most premature babies would all have autism, however, it will never be the answer for optimal pregnancy.**.

Questions, comments and suggestions welcome.

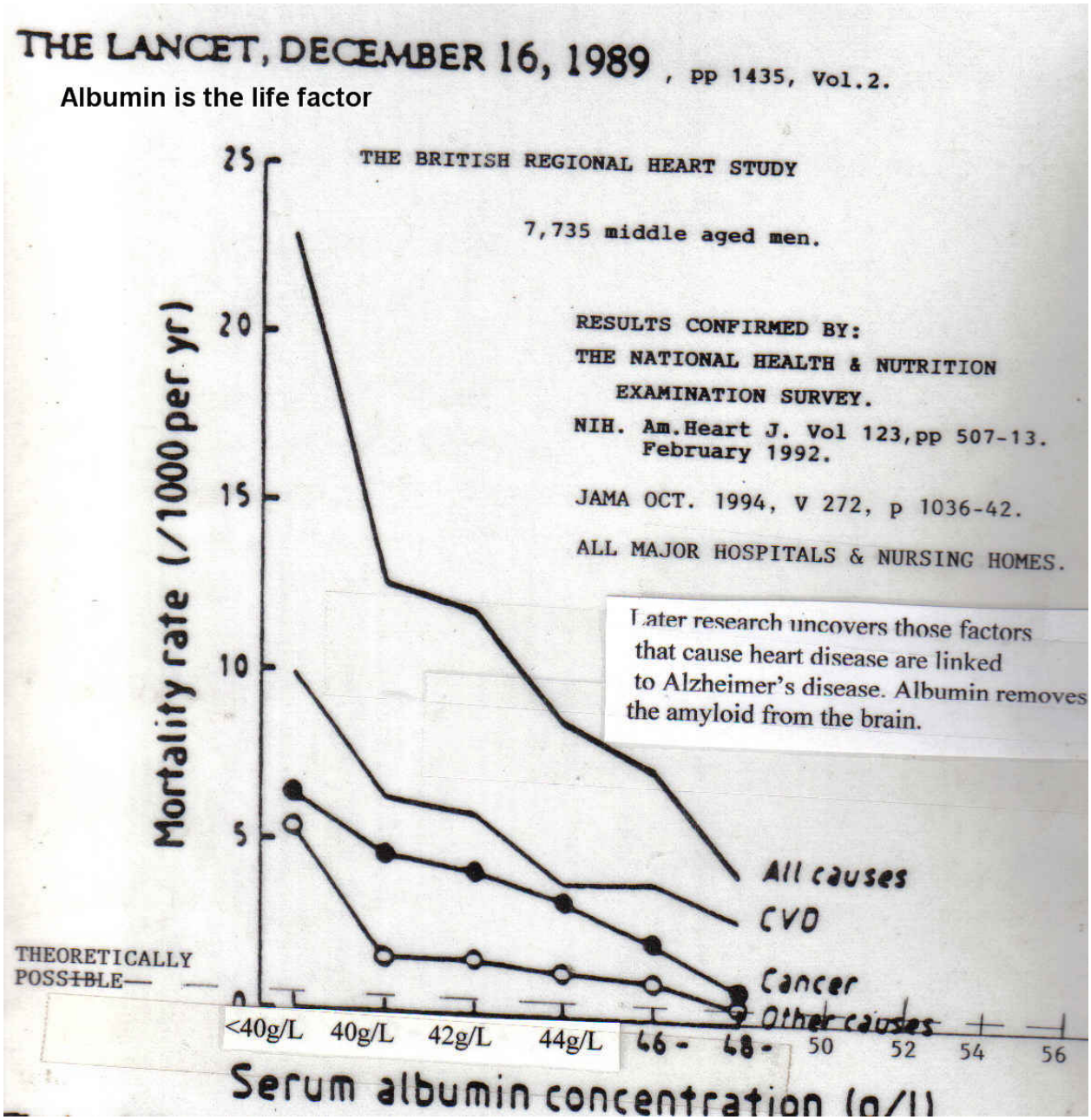


The great Steve Reeves (Hercules 1950's) showed the power high serum albumin could bring via his wonderful Mother Goldie, a great health expert, she insured her albumin was super high in pregnancy. He won the most beautiful baby and was Super intelligent, an actor, singer, dancer, inventor, writer, health expert and athlete, not just a Super strong man. A lesson for all!
Note: Some women can maintain albumin > 40g./L in pregnancy. In the future the amniotic fluid may need 5g/L albumin for evolution.

Babies born with high serum albumin are very robust and gregarious.
The Human Brain can only be manufactured from high human albumin no other substance.
Inflammation is the major cause of low albumin not diet.
The human mind needs to understand and love other human minds, cooperate and protect the planet and other humans and animals. That requires high albumin in the developing fetus and in the infant, also the teenager. I understand this as a Grand humanity absent of Autism, (an abnormal absorption with self).

Summary Autism facts that support Seaton's findings

1. High levels of albumin in the mother's blood purifies the fetus, protects it from toxins and wastes.
2. High levels of albumin feed and nourish the fetus, maintain the mother's health..
3. Human albumin is the only substance that can fully form a complete human brain.
4. High serum albumin stabilizes the DNA, prevents mutation and allows cells to grow correctly.
5. Insufficient concentration of albumin during gestation results in pervasive development disorder (PDD).
6. Higher serum albumin levels are needed as we evolve.



NOTE: the amazing fall in all-cause mortality with rising albumin, at 53g/L it hits Zero.

Albumin is the "Life Factor", the building block of the human mind, intelligence, social ability, understanding, speech, wisdom, invent, and imagine, also Love, caring, humanity and God- like ability of the human brain. Today humans require very high concentrations in the liquid portion of the blood called plasma or serum, also to neutralize the many drugs/chemicals. During pregnancy the levels must be maintained as high as possible to ensure optimal brain and physical development and a long productive life. To lift the albumin levels would also save trillions $$ in health care costs. Hygiene is the hidden secret to super high albumin not just an excellent diet. **Albumin in the amniotic fluid at 25weeks must be 4g/L.**

Optimal Pregnancy and Childhood Development

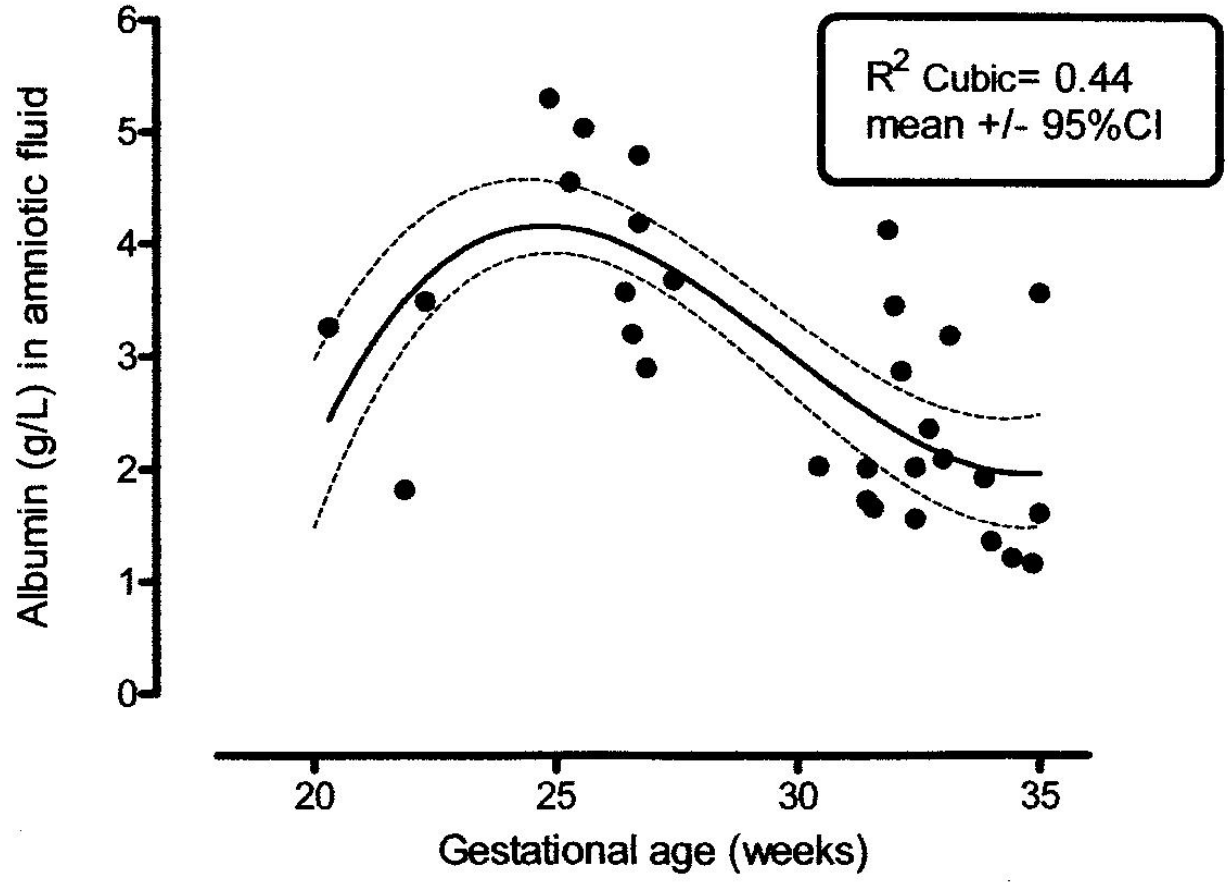
Husband and wife should have serum albumin levels above 45g/L (4.5g/dL) before conception. High serum albumin insures healthy birth canal, stabilizes the egg, DNA and sperm in the semen.

1 Albumin cleans / maintains kidney function with 38,000 gms (84lb) of albumin circulating through the kidneys per 24 hours. High Albumin also insures homeostasis of renin and aldosterone to control blood pressure. Infusion of albumin is foolish and futile.
2. Albumin stabilizes the blood, prevents platelet aggregation, red blood cell clumping, via Zeta potential and insures fat homeostasis by transporting fatty acids.
3. Albumin is a growth/stabilizing factor for immune cells. White blood cells will not grow and divide properly when albumin is low, this causes poor immunity.
4. Albumin insures proper growth of throphoblast cells creating a healthy Placentia to insure nutrients flow correctly to the fetus.
5. Albumin insures proper functioning and exchange of nutrients and wastes through the Placentia and maintaining correct osmotic pressure.
6. Albumin insures urate homeostasis demonstrated in analbuminic rats.
7. Albumin maintains the amniotic fluid stability. Note: amniotic fluid should average 4-2g/L and be changed 12 times per 24 hours to feed and nourish the fetus, especially the brain.
8. Albumin maintains the proper function and stability of the cerebral spinal fluid for the baby developing its brain and for the Mother. It should be changed 4-5 times per 24 hours removing metabolic waste and stabilizing the CNS. Note: 1 in 230 molecules are specially selected to enter the CSF. High Albumin makes the brain stronger and more plastic, subtle powerful.
9. Inflammatory/clotting and immune proteins have to be reduced naturally, by raising albumin imparting a triple benefit
10. Selective transport of nutrients and growth factors through the Placentia, also 5% of the Mother's albumin is permitted to pass through the Placentia, insuring optimal albumin for the fetus.
11. Albumin acts as a packet of perfectly balanced amino (585) acids in controlling proper fetal growth. Remember babies are made of albumin.
12. Albumin insures safe and efficient removal of wastes as natures greatest purifier
13. Albumin detoxifies the fetal and Mothers fluids. Note: Albumin is the best purifier; it is used in wine making, photography, and refining.
14. Albumin insures cell stability, and prevents DNA mutations and fragile areas.
15. Albumin transports drugs including aspirin and prevents toxicity from drug side effects.
16. Albumin insures homeostasis of the changing biochemistry/physiology of Mother and fetus.
17. Albumin buffers excess hormones, including Cortisol, common during pregnancy.
18. Albumin maintains liver function, and is produced by the liver both in the Mother and the fetus.
19. Albumin appears to regulate gene transcription, vital to insure no defects in the baby.
20. Prevention of Autism Disorders, mental decencies and physical disabilities are all prevented by high serum albumin throughout gestation.
21. High Albumin insures that the heart pumps easily and safely during the stress of pregnancy on the Mother.
22. Optimal birth conditions, 41-42 weeks (283 days) and a birth weight of 7.9 lbs is ideal.

Dr Oliver Wendell Holmes, the greatest medical genius, in 1843, after his son was born, claimed '***A healthy pregnancy ensured a healthy life'***. His son Oliver remained on the Supreme Court until he was 92yrs old perhaps the most famous of all Justices'

Conclusion: a generous concentration of serum albumin is the basics of optimal pregnancy and childhood development. Father and mother must have albumin > 45g/L before conception.

Pregnancy	Conception	first trimester	2nd trimester	3rd trimester	Postpartum
Current range:	G/L 41-53	31-51	26-45	23-42	41- 48
Optimal range:	G/L 45-54	40-51	36-45	35-42	40-48



Albumin concentration in amniotic fluid during gestation

Courtesy Dr Suzanne A Pasman

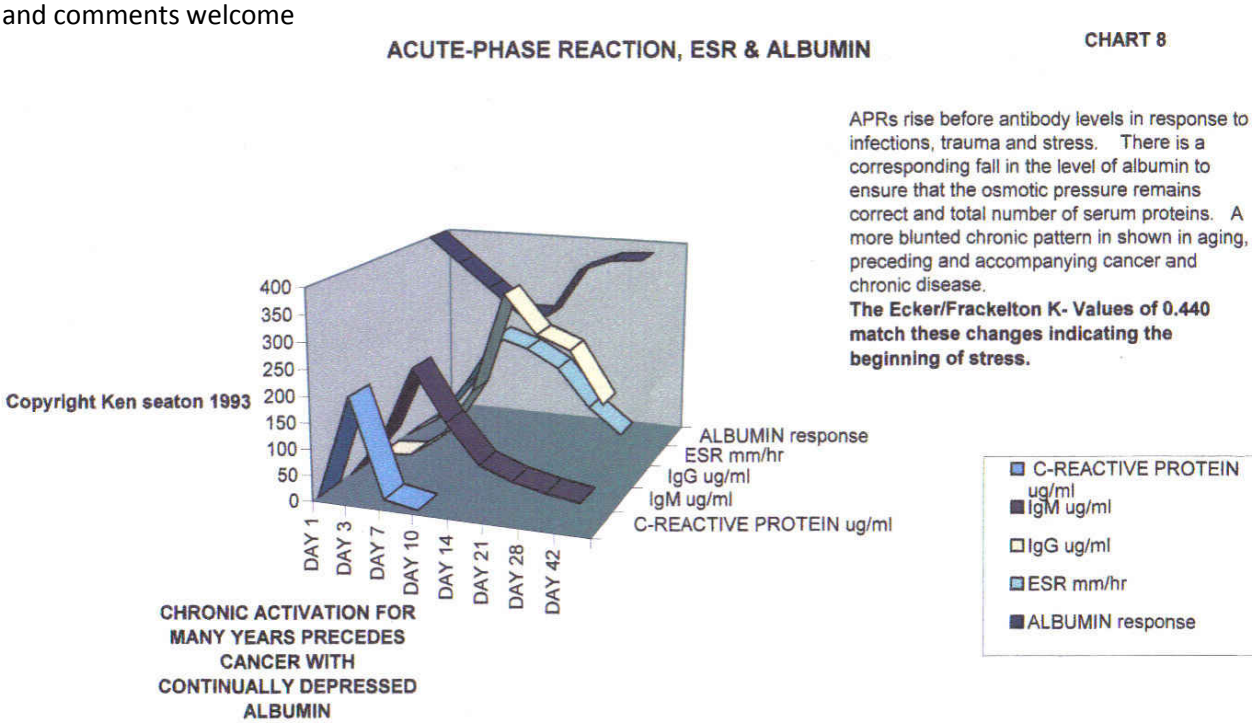
Super Neuroplasticity secret is high serum albumin

The albumin concentration and quality in the amniotic fluid is critical for perfect brain formation similar to the finishing touches and tuning on a new Ferrari Super car with a Super computer that must deliver Super perform for >100 yrs. The concentration of serum albumin in the Amniotic sack (***The life container***) should be above 4g/L at 25wks when the fetal brain is being completed ,then falling slowly to ~2g/L for the fine finishing touches from 28wks- 40.4 weeks(Birth). The mother's serum albumin levels must stay above 35g/L (>45g/l 1st trimester). This ensures no Autism weird disorders, no mental retardation and ensures Super brain and physical performances in a magnificent baby full of love and caring, the Hallmark badge of Humanity.

The love, caring and understanding of the husband, parents, friends and medical experts are vital during pregnancy to ensure security and correct medical/social decisions are made and followed. **Mother's serum albumin must be tested every 3months during pregnancy**. "A healthy pregnancy results in a long, healthy, intelligent, rewarding and loving life".

Test Tube babies often have lower albumin resulting in high Autism disorders.

Super Science reports: are for the public and scientific community to promote a Duty of care. Questions and comments welcome



Fever results in low Serum Albumin

The chart shows how the end result is low serum albumin and if fever persists for years as chronic inflammation serum albumin will remain low and cancer, heart disease, Alzheimer's, kidney failure then are high risk.

During pregnancy fever can result in birth defects and brain damage in the baby including Autism Spectrum Disorders all the result of low albumin. Fever (Inflammation) is the major factor that controls serum albumin levels not diet. In pregnancy the preventions of activation of the Acute Phase Reactants is the only way to maintain serum albumin 45-35g/L so that optimal fetal and childhood development can be ensured and the risk of Autism Spectrum Disorders Extinguished.

Today with the epigenist change the need for higher levels of serum albumin in pregnancy and infancy is critical and any fever can stress the full development of the brain resulting in weird Autism disorders. This is why the old reference range for Albumin namely 35-23g.L in pregnancy and 34-50g/L normal Adult are Prehistoric and today all humans require a minimum of 45-35g/L in pregnancy also in the Mother, 4-5g/L in the amniotic fluid at 26 weeks, and 47-57 g/L in children and adults.

Questions, comments welcome. Copyright Kenneth Seaton 1993

Stressed Babies; A simpler term for Autism

Original research Seaton K, JAM 1998, 11,2;73-94 Albumin level prevents Stress.

Birth stress- complications are the basis the weird variation of the problems termed as "Autism Spectrum Disordered" (ASD). Fundamentally, something is basically wrong with the full development of the baby's brain, for some reason, it is not completed perfectly. ASD emerges usually before 3 years old, the critical development period of the infant's brain. Because ASD is worldwide it is very unlikely that

some environmental agent is the cause. Clearly, some basic substance is missing during the manufacture of the brain inside the mother. It surfaces before 3 years old, emerging as a strange array of brain development problems.

ADS appear to be a recent human problem of the mind that has emerges like a tidal wave in the last 75 years and today afflicts ~100 million worldwide. It causes mayhem such as financial stresses, divorce, and fear of a second child being afflicted, continuing emotional problems and the need for life-time very expensive care. In order to solve ASD a very wide variety of answers are required listed below, proving something biochemically- fundamental is missing when the fetus is developing. I Kenneth Seaton propose that the single and simple answer to all these complex questions is serum albumin is **too low** during modern fetal and infant development. Occam's razor teaches; the simplest answer to an array of complex questions is the most likely one to be correct and that is "the Life Factor" as follows:

Question	**Answer**
1. 5X more boys than girls are afflicted.	Male brains require more albumin to make
2. Genetic factors are involved	Higher albumin prevents mutations
3. Higher social failings	Higher albumin ensures gregariousness
4. Fever causes Autism	Fever reduces serum albumin
5. Stress causes Autism	Albumin level is the measure of stress
6. Serum albumin <25g/L causes Autism	Higher levels >35g/L prevents Autism
7. Immune stress causes Autism	High albumin levels stops it
8. Identical twins both have Autism	Higher albumin prevents it
9. Gene mutation causes Autism	Higher albumin prevents mutations
10. Low birth weight causes Autism	High albumin prevents it low birth weight.
11. Premature babies have Autism	High albumin prevents prematurity
12. Low ammonic albumin causes Autism	Albumin 4g/L in the amnion prevents it
13. Invitro babies have Autism	High albumin prevents it
14. Modern electronic age babies have Autism	High albumin prevents this
15. Prescription drugs cause Autism	High albumin neutralizes drugs
16. Infants can regress to Autism	Albumin >45g/L in infants prevents this
17. Toxemia causes Autism	High albumin prevents toxic Pregnancy
18. The human brain is large and complex	High albumin ensures brain perfection
19. Complex brain cargos are required	Albumin carries them

Conclusion: High serum albumin in pregnancy and infancy easily answers all the complex questions of Autism Spectrum Disorders. Comments and questions welcome.
Email: (PII redacted)
Original research in; J Advancement in Med Vol. 11,2.1996; pge73-94

A generous supply of Serum albumin is Vital for life, especially in pregnancy.

NATIONAL HEALTH FEDERATION RESEARCH

ONE HUNDRED MILLION CHILDREN WORLDWIDE ARE AFFECTED BY AUTISM DISORDERS. THEY COST THE GOVERNMENT FOUR MILLION DOLLARS EACH. THE *Strange* MYSTERY HAS BEEN SOLVED.

The bottom line is serum albumin must remain above 35g/L in Pregnancy

Serum albumin >45g/L-35g/L during pregnancy prevents Autism Spectrum Disorders

All measurements in Gram per liter, not G/dL

Kenneth Seaton D. Sc.

Super Science

Acknowledgement: Arlene Hale Assistant

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Category: Newsletter

Understanding and Preventing Autism

By Kenneth Seaton D.Sc

February 17, 2012

My 50 year search for optimal pregnancy in humans, pigs, dogs, cats and horses never received any help from the National Institute for Child Health and Development despite requesting it over the many years. Now we have the tidal wave of Autism about to wash all of our beloved children away into the land of Autistic loneness. In the next decade, the U.S. will see the number of autistic children costing the Nation 3.3 million over the lifetime of these children.

Autism is a mysterious multi-potential mental disorder Worldwide and like China, increasing the disorder at approximately 20% a year. It affects~ 1/110 children born in the USA and UK. The WHO (World Health Organization) predicts a critical problem with a rough estimate of 100 million people affected by Autism. Males are over 4X (1/60) more susceptible than females, and the answer is below. In the related Rett Syndrome males rarely ever survive.

The cause of Autism is thought to be a complex combination of genetic, environmental, and infectious factors all answered by the simple amazing natural solution below. There is a 90% risk of an identical twin developing Autism, proving that genetics is important.

The first step to understand is that something is happening during pregnancy and the stressful period carrying the beloved baby, for all Mothers, is the low serum albumin, which is the" Life Factor" and often falls below 20g/L from the normal 45g/L. The Mother has to produce enormous amounts of albumin from her liver for herself and the developing baby and it has to be changed 12x every day in the fetus and also has to remove all the wastes. Evolution requires more serum albumin in pregnancy and the normal lifespan (37yrs-88yrs) today than it did 100 years ago; also consider operating complex cell phones, computers, TV and advanced learning into old age.

(No drugs, alcohol or cigarettes should be used during pregnancy)

Babies born with high albumin are highly gregarious the very opposite of Autism!!

Serum Albumin is a perfect packet of approximately 585 amino acids, made by the liver (1/2 ton in a lifetime) and essential for optimal growth of each species fetus, especially the large human brain. Serum Albumin is the dominate serum protein in all animal life. The higher quantity and quality the more advanced the brain in the animal kingdom. Babies are made of it and humans must have very high concentration that must match evolutional changes.

During pregnancy, albumin levels can fall dramatically, especially during viral infections, stress, and immune overload. This is why super hygiene is so vitally important in pregnancy. One reason why albumin falls in pregnancy is due to major fluid expansion. Also, infections in the Mother or baby can

stress the immune system, any trauma, etc. can causes the stress serum proteins (acute phase reactants APR's) to rise, forcing serum albumin to decline dramatically. (This cannot be corrected by diets.) There is compelling evidence that if albumin levels are kept at 35g/L during pregnancy (compared with the normal 25g/L in the last period of pregnancy) that the autism rate will fall from 1 in 3350 from the current 1/100 as many (older women and those that are stressed) cannot reach the 35g/L).

I have considered that if one in 5,000 could be reached, there would be almost the total elimination of Autism disorders. It must be considered that there will be failures due to alcohol, drugs, etc. However it may be possible to achieve 1/13,000.

Albumin plays a fundamental role to ensure perfect and complete gene transcription to avoid any genetic mistakes. Further, it is the finest purifier known and binds and neutralizes any toxins that may damage the fetus. This prevents any environmental substance that may cause Autism. Never forget, Albumin is a remarkable purifier against any toxic substance from the environment.

Serum albumin must be maintained during pregnancy at all times <u>above</u> 33g/L (3.3g/dL) to prevent Autism. The higher the natural serum albumin levels, the better for evolution.

Babies must have super hygiene from birth to ensure only mild controlled infections so that serum albumin is maintained above 45g/L in the first 3 years for optimal brain development. For the best results (especially to repair any brain damage during pregnancy) is when serum albumin is 50g/L. Low weight babies (caused by low albumin in gestation) have over a 5X higher incidence of Autism and it is more severe and higher in boys).

Pinto-Martin JA, et al *Prevalence of autism spectrum disorder in adolescents born weighing 2000 grams* Pediatrics 2011; 128: 883 - 891. http://pediatrics.aappublications.org/content/128/5/883

Understanding the Mystery of Autism in a Nutshell

Worldwide, perhaps as many as 100 million people have some degree of Autism including its weird spectrum of disorders. Some of these children become amazing geniuses like the boy shown on 60 Minutes Jan 2012 highlighting a link to the genius genes. Most Autistics have great problems socially and also lower mental potential. Male babies are over 4 times more susceptible because male brains are more evolved and need higher serum albumin during pregnancy. Evidence points to a complex genetic interaction and Identical twins have a 90% chance of similar problems. Mutations on chromosome 16 have been linked to Autism. The glitch is in a DNA region that contains strange genes that historically have changed very rapidly as humans evolved. In other words, the same genes that helped evolve human intelligence may contribute to Autism, explaining the genius factor. These genes require higher levels of albumin in pregnancy and the first 5 years of childhood with development such as 50g/L only achieved by higher Hygiene that lowers Acute Phase Reactants (inflammation) for more "Osmotic Room" for albumin. "Cleanliness is indeed next to Godliness." A good diet with eggs for albumin is wise. High serum albumin prevents genetic mutations that can cause Autism spectrum Test tube (Invitro) fertilization usually as low quality and quantity of albumin thus 10.5 % or more have Autism incidence in the child also low birth weight and are premature. **Albumin 35-23g/L in pregnancy is suitable for a Chimpanzee not a modern human Super Brain.**

Babies who are premature, low birth weight, stressed, and also Mothers who develop diabetes during pregnancy, all resulting in low serum albumin, and have a far higher risk of Autism. I have asked the CDC, NIH, and NIMH for help in further testing. Every Mother should have the right to an Optimal Pregnancy, love, and the caring of her husband.

Ref: "All about Albumin" T Peters, world's leading authority. Academic Press 1996..

"Optimal Pregnancy ensures an optimal life" "Albumin is the Life Factor" See Kenneth Seaton's PBS TV national interview on June 3 1993 Tony Brown's Journal Questions welcome

Can High Serum Albumin prevent Autism Spectrum disorders?

I wrote the book "*Breaking the Devils' Circle*" in 1986 about Super hygiene, prevention of infections and stress on the immune system resulting in higher serum albumin and a greater potential for the human brain. By 2002 the horror of Autism and its weird spectrum of disorders had surfaced like a monster out of the Devil's dungeon. Today an estimated 100,000,000 in the world are touched by Autism Spectrum Disorders and it costs approx $4,000,000 per person and ensures divorce, emotional nightmare and poverty to millions of good families. I have continually sent my research to the NIH, NIMH, and NICHD, appeared on PBS TV '*The Life Factor"* June 3, 1993 (Tony Brown's Journal) and published the importance of high serum albumin in health, aging, mental potential and cancer. My claim is that sub-optimal serum albumin during pregnancy and early childhood development, prevents the full biochemical development potential of the human mind resulting in Autism disorders. In support of genetic mutations as the cause of autism and cancer, in pregnancy, due to lower serum albumin, cancer and Autism are far higher,

Evidence: Measure in g/L

Finally, the evidence to prove my 30 years of research is correct and has arrived via the results of the study conducted by Molly Losh, PhD, director at the Northwestern University Neurodevelopment Disability Laboratory. The study was released on Jan 19, 2012 and reported by "*HealthDay*" on the internet in "*Psychological Medicine.*" This study of 3,700 pairs of identical twins from the Swedish Twin Registry showed that Autism risk was 3x higher in the identical twin, however, with a low birth weight. This is compelling evidence because the only factor that can cause low birth weight, less robust condition and lower mental potential, despite the same genes is low serum albumin as I predicted 25 yrs ago. These discordant twins can have one amniotic sack or two, (one each) yet can have different levels of albumin available, (the life building packet of amino acids) to build their minds and bodies when they are both growing in the womb and in early childhood. Sub-optimal serum albumin in the amniotic fluid is a major factor in failure of the fetus to achieve optimal brain development, especially in this brainy-time of smart phones, computers, internet, and multi-channel TV when the humans genes are appearing to be evolving for greater intelligence. Sub-optimal albumin can happen when the twins share the same birth sack or one amnion each. During gestation, the Mother's serum albumin must remain above 34g/L at all times to ensure sufficient albumin is available to the fetus and in the amniotic fluid **(this level is 4g/L at 25 wks for perfect brain formation)**. Remember, the fetus drinks and breathes this super fluid* amazingly for full mental development. A healthy pregnancy today should commence with the Mother's albumin above 45g/L and never fall below 34g/L in the 2nd and last trimester. At 6 Months (24 wks) fetus should be> 36g/L, amniotic fluid > 4g/l. Baby shortly after birth should be ~ 40g/L.
Authors added notes Father and mother must have serum albumin > 45g/L before conception, High protein diet with eggs, good vegetables, fruit and grains, good water, good sleep, vitamins, excellent hygiene and exercise are very important for high serum albumin.

Worldwide the major cause of Autism is birth complications all the result of sub-optimal serum albumin levels. Fever in mother or child can cause autism because it results in low albumin.
From Birth the babies serum albumin must remain as high as possible (over 48g/L, (4.8g/dL) (Only Achieved by reducing inflammation) as this insures optimal continuing brain development in the natural world, as the child confronts all matters. This also allows the brain to repair any damage or incomplete development that may have happened during pregnancy. During the first five years the brain is very plastic and has great powers to correct and adjust, however, serum albumin, the basic building block of the brain must remain as high as possible. My Granddaughter at 2 yrs old achieved serum albumin of 54g/L, with globulins 13g/L giving an A/G ratio of 4.15, compared to a normal 2 yr old with Albumin 42g/L, globulin 30g/L, giving an A/G ratio of only 1.4.The human brain requires high serum albumin profiles to self-repair and develop full potential. Many infants have a regression to Autism in the first three years, especially following a common childhood infection with inflammation, causing a major reduction in serum albumin thus very good Hygiene is required to prevent this. Low weight, premature babies have can have a 20x higher rate of Autism. Low serum albumin in mother and fetus fails to bind and removes drugs, many toxic to developing brains. **Modern day use of drugs, prescription and illicit, makes higher serum albumin in pregnancy today totally essential. High serum albumin is also the best prevention of cancer, see Seaton K JNMA 2001,V93: 490-3. "He who solves Autism also solves Cancer" Prof James Thompson Qld University**

These premature babies are normally low weight and serum albumin of only 19-20g/L. Infusion of albumin in these babies can often prevent or lower the risk of Autism Spectrum., however hospital albumin loses much of its "Life Factor" Note: NIMH report Mar 2012 states 1:38 in South Korea afflicted with Autism= 1:25 boys is possibly more accurate. Approx 1:20 births have low serum albumin in pregnancy, predicting that ~1:20 boys afflicted.
*Note: Cow's milk is only ~1g/L of Albumin compared to amniotic fluid in the birth bag with 4g/L, this helps to understand the vital importance of high concentration of albumin in the Mother's blood at all times during gestation to insure 4g/L in the amniotic fluid. The fetus drinks ~80% of the amniotic fluid every day to build the brain. Nature is Amazing. Autism has larger, heavier brains thus need more albumins to make.

Conclusion: Every child subject to sub-optimal serum albumin levels during development in the womb, and in infancy, at some stage, will have some -degree of Autism Spectrum Disorders and that explains the massive increase in diagnosing the problem. My 50yr quest is for "Optimal Pregnancy" resulting in optimal childhood development and that is a new evolutionary dimension for the human race, solving Autism Spectrum automatically. Sub-optimal serum albumin levels answers the three basic causes of Autism spectrum (environmental, genetic, and infectious) all prevented by high albumin.
Note: The NIMH report Mar 29 2012 of 1:38 in S Korea confirms my findings.
Scientific research is urgently needed to confirm high serum albumin prevents Autism Spectrum Disorders. Hospitals have refused to help in collecting Data, WHY??

Blood is a liquid organ and albumin is the "Life Factor". Higher Hygiene is the most powerful way to reduce inflammation. Questions welcome. [PII redacted] **Note: Human serum albumin is superior to all other Albumins and the only substance that can make a perfect human brain with amazing Neuroplasticity for learning, adapting and repair.Sub-0pimal levels cause the amazing spectrum of disorders.** Note: Even if Children have autism if serum albumin is high ~47g/L they are intelligent and can function well at school or work. Psych. Med 2002,32.1457-1463.

Preventing Stress in Pregnancy: the major cause of Autism Spectrum Disorders

Albumin levels are foolishly neglected by the medical profession in pregnancy resulting in millions with Autism disorders.

Albumin G/L	A/G Ratio	Pregnancy Stress Rating . Grams/liter. 42g/L
	1.3	Excellent (1st trimester). At conception 48g/L
36 g/L#	1.0	Good (2nd-3rd trimesters)
30 (Not High Enough)	0.7	Normal (Autism Possible) Higher serum albumin is required today
25*	0.6	Toxemia borderlines (Autism risk) Inflammation
20	0.4	Pre Eclampsia risk (High Autism Risk)
15	0.3	Eclampsia risk/seizure (very high Autism Risk)
7	0.1	Risk of death to mother and fetus

14 g/L Note: Prehistoric woman with only a 1000gm brain compared to modern women 1365 gm Brain, then only 14g/L albumin was required during pregnancy and the quality of the albumin molecule lower. Dogs and cats today need 18g/L in the pregnant mother,

Note: Do not get confused with g/dL, convert by removing the decimal point.(42g/L = 4.2g/dL)

A/G ratio is albumin divided by the globulin a good measure of health (>2.0 is low stress)

Serum albumin> 25g/L is potentially dangerous to Mother and fetus, today a minimum 35g/L is required. Fetus albumin: 35 wks 35g/L, birth 42g/L, 46g/L at 6 months, 47g/L 12mths, >48g/L at 2yrs. Serum albumin is "The Life Factor" the more you have of it in the blood the more beautiful and greater the potential of the brain and mind. (Brains are made of albumin amino acids and its many cargos such as Fatty acids and high net charge). Ideal Birth at 40.45 weeks (283 days) weight 7.9lbs.

Obesity, hypertension, diabetes cause lower, also Glycated serum albumin and higher Autism risk

Achieving high Serum Albumin: Autistic brains are larger and heavier thus need more albumin.

1. **High Protein diet with a wide variety of meats, fish, sardines, poultry, sea foods, eggs, nuts, cheese and milk. Vegetables, fruits, grains, honey and oatmeal.**
2. **Very good hygiene of the hands, fingernails, hair, teeth, and skin, including daily sinus baths, regeneration bath at night before sleeping to reduce the globulin (Inflammation)and to make more osmotic room in the serum for albumin. Albumin stabilizes the blood and insures less stress on the immune system. Swimming in the sea is excellent.(Hygiene prevents inflammation leading to higher albumin)**
3. **Sensible living conditions, early to bed, clean environment, clean clothes and continuing education. Regular sensible exercise and avoid stress.**
4. **A healthy human below 70 yrs old should have serum albumin higher than 48 g/L, globulin Lower than 24g/L giving an A/G ratio of > 2.0.**
5. **# Healthy Pregnancy 48g/L, 1st trimester >40g/L, 2nd >36g/L, 3rd >35g/L, post 40g/L return to 48g/L. High globulins in the fetal brain and blood cause havoc**
6. **High serum albumin with correct levels of globulin stabilizes the DNA, Chromosomes and cell growth . High Albumin buffer against stress**
7. **Prediction**: with optimal pregnancy autism rate will be >1/15,000 compared to 1/60 boys today.

 Questions welcome [PII redacted]

I spoke and emailed six large birth hospitals and found that data on serum albumin in pregnancy was being suppressed and that it was far too low; Highly suspicious.

BRAIN FACTS

(For greater understanding of how complex the human brain is to manufacture in the amniotic sack)

1.	**Adult Human**	**1,300-1,460 gms (3.2 lb male)(2.85 female) High Neuroplasticity.**
2.	**New Born Human**	**350-400 gms (less than one pound)**
3.	**Elephant**	**4,800 gms (11 lb) (highly intelligent)**
4.	**Sperm Whale**	**7,800 gms (17 lb) (sonar use for very deep diving)**
5.	**Bottle Nose Dolphin**	**1,500-1,600 gms (3.5 lb) (mostly used for sonar)**
6.	**Grizzle Bear**	**235 gms (Same genes as polar bear)**
7.	**Polar Bear**	**500 gms (swims in salt water enhances the brain(albumin 50g/L)**
8.	**Gorilla**	**500 gms (large males 600 gms less ½ human size)**
9.	**Chimpanzee**	**420 gms(far smaller than humans)**
10.	**Lion**	**250 gms (tigers have larger brains that is linked to swimming)**
11.	**Pig**	**180 gms (note the massive differs in brain size to a human)**
12.	**Cat**	**30 gms**
13.	**Dog**	**72 gms (large dogs may have over 200 gms)**
14.	**Shark**	**32 gms (evolution requires higher albumin and brain size)**
15.	**Human Brain**	**2% of body weight , Elephant .11 % of body weight.**
16.	**Neurons (Human)**	**100 Billion (Autism has heavier and larger brains)**
17.	**Octopus**	**300 Million (neurons)**
18.	**Oxygen consumption**	**white matter 6 %, gray matter 94% (20% of total bodies use)**
19.	**Neocortical neurons**	**19.3 Billion (female)**
20.	**Neocortical neurons**	**22.8 Billion (male) Human brain is very Neuro-plastic for learning.**
21.	**Cerebral area**	**2,500 cm^2 (human)**
22.	**Cerebral area**	**6,300 cm^2 (African elephant)**
23.	**Cerebral area**	**3,745 cm^2 (Bottle Nose Dolphin)**
24.	**EEG (brain produces radio waves)**	**13-30 hz beta, alpha 8-13 hz, theta 4-7 hz, delta 0.5-4 hz**
25.	**Neuron growth**	**250,000 neurons/minute (early pregnancy) 4000 neurons per second**
26.	**Cerebellum weight**	**142 gms (human) (the brain floats in the CSF)**
27.	**Cerebellum weight**	**36 gms (cow)**
28.	**Cerebrospinal fluid**	**125-150 ml (produces 500 ml per day)**
29.	**Turnover of CFS**	**3-4 times per day (to clean the brain)**
30.	**CFS**	**50 ml (infant)**
31.	**CFS**	**99% water (albumin, purified and highly important)**
32.	**Hearing range**	**20-20,000 hz (human)**
33.	**Hearing range**	**100-60,000 hz (cat)**
34.	**Hearing range**	**1-20,000 hz (elephant)**
35.	**Taste buds**	**10,000 (human)**
36.	**Smell**	**12 million receptor cells (human)**
37.	**Smell**	**1 billion receptor cells (dog) (Blood hound 4 billion)**
38.	**Touch**	**17,000 tactile receptors in hand**
39.	**Touch finger tip**	**2,500 cm^2 (blind can read with fingers)**
40.	**High serum human albumin ensures the brain has great Neuroplasticity for learning/adapting.**	

[1] The human brain develops rapidly (245,000 neurons/min.) early pregnancy and 1000gms in the first five years of infancy and adult to 18 yrs and requires serum albumin of >48g/L in the infants for optimal development and repair to any damage that may have occurred during pregnancy such as Autism spectrum. More Albumin makes the brain stronger, better wired. Mutations such as Fragile X are also prevented by high serum albumin. Questions welcome

OPTIMAL PREGNANCY

Premature Babies are normally low weight, and far less Robust. This is the result of low serum Albumin, average only 19g/L* compare to healthy correct-term, more beautiful babies with ~40g/L of perfect serum albumin. Albumin is the Super protein building block and multi-transporter of nutrients and remover of toxic wastes for babies and adults. Infusions of serum albumin in Preterm babies to save their lives and finally raise the serum albumin concentration from 19g/L to 40g/L can also help to reduce pervasive development disorders (PDD) and Autism risk by > 60% in child development. This is powerful evidence that insufficient serum albumin during pregnancy is the fundamental cause of pervasive development disorders such as Autism and other birth defects because the concentration of albumin for the full biochemical development of the fetal brain is not high enough. Higher Serum albumin is required today compared to 150 years ago. We Humans are still evolving! Infusions of hospital - stored albumin is not perfect albumin and highly expensive especially for use in child birth and cannot ever match a natural healthy pregnancy with high perfect Mother-made serum albumin (45-35g/L) and breast feeding for optimal child development. To achieve high serum albumin >46g/L in the normal population, remember the stress on the immune system(inflammation), not just the diet is highly important in optimal serum Albumin profiles because stress and poor hygiene can raise the serum globulins causing ,via osmotic pressure, serum albumin levels to be too low. *

Fathers should have high serum albumin (>45g/L) before conception to ensure sperm is sound and to prevent mutation. Albumin in the semen ensures healthy active sperm that can swim to the egg.

Note: that 19g/L of serum albumin in preterm babies matches the low level found in the Mother's blood, in stressful pregnancy resulting in horror of PDD and Autism Spectrum. .
1986 Press Conference Sydney Australia

Conclusion: Serum Albumin in pregnancy is much neglected in Birth wards and confirms Dr Oliver Wendell Holmes:" **Harvard Medical School is the most ignorant place to have a Baby".** Millions afflicted with Autism by 2012 is now very obvious to understand and frightening.

Update 2012. During Jan-June we contacted over 10 of the most esteemed birth Hospitals in the USA and requested by email, telephone and letter any data on serum albumin levels in pregnant mothers when serum albumin was higher than 45g/L-35g/L and any incident of autism spectrum disorders in babies up to 3 yrs of age. No data was received and we concluded that our research below on the following test during 1985-1987 was correct; namely high serum albumin during pregnancy prevents Autism Spectrum Disorders.

Conclusion: Autism is the result of sub-optimal serum albumin during pregnancy resulting in incomplete brain development. This explains why Millions are affected and negligence of the medical professions is the shocking fault. The NIH must act immediately to prevent it in countless millions more.

More Scientific Testing is required and the Government must help.

Birth Defects and Incidence of Autism Spectrum Disorders

This study 1985- 1987 was arranged by the eminent Dr George Cockburn MD, BS, (Hons.)F.A.E.C.G, Fellow Royal Society Medicine, Surgeon and Physician.

Abstract: Data was gathered from pregnancy records at various hospitals in the North Shore area (upper Socio economic), from Sydney Harbor to Palm Beach a distance of approx 25 miles. Education to the medical staff was given on the vital importance of very good Hygiene to reduce the globulin and make more osmotic room for serum albumin. During pregnancy Acute Phase Reactants serum proteins rise, causing serum albumin to be far too low in every stage of pregnancy causing birth defects and Autism disorders.

More Studies Required.

Background: Birth rate per 1000 in Australia 12.33. USA 13.82. China 12.29.Sweden 10.8, Japan 7.31

Autism disorder rate at Infant 2 years: At 1985-87 the rate in **Australia** was~ 1.8 per 1,000

Birth Defect rate per 100: Australia 3, USA 3, France 3, Germany 3. Sudan 8.3

Method: Data on 2312 births with serum albumin in the: **First trimester above**: **40g/L, 2nd trimester above 38g/L, 3rd Trimester above 35g/L**, was noted.

Results: **Birth Defects per 100** fell to: 1.2 (1.12%), from 3%. Examined by Dr Cockburn and mother's medical expert, this is far lower than controls and any country of the world.

Autism Disorder rate: at 2 years old the incident in 2312 pregnancies was Zero. All examined by Mother's medical experts. The rate equivalent to less than 1: 15,000 with ASD (Autism spectrum disorders).

All babies born with Mother's serum albumin higher than the **above ref** were robust and perfect, far more beautiful than normal and the controls.

Today (2012) the rate of Autism in Sydney Australia is >1 in 100 and in boys is 1:60.

Conclusion: the birth defects and Autism disorders were markedly lower in pregnancy with high serum albumin in the mother (**45g/L- 35g/L**) compared to the controls with normal serum albumin **35g/L-25g/L**. The Ref. range for albumin levels worldwide in pregnancy should have been upgraded in 1930's to prepare for the epigenetic changes that would evolve with the inventions of the radio, 2nd world war, TV, computers and the internet. The entire human race is threatened with genetic mayhem resulting in a planet of Pervasive Development Disorders (PDD) unless serum albumin levels are raised to modern evolutionary requirements for today during pregnancy in the 21st Century. Note: Dr Cockburn was in his eighties when he conducted these tests.

Prediction: Further studies in 10,000 pregnancies are required and I have requested help and data from CDC, NIH, NICHD, NIMH, also several state health Depts. and Governors.

Based on this study and the years from 1987- current (2012) I predict the level of birth defects can be reduced to 1:100 and Autism disorders to 1:15,000. FURTHER more scientific STUDIES REQUIRED.

Alarmingly Serum albumin concentrations in pregnancy is much neglected in birth wards, explaining why autism spectrum is found in millions and increasing alarmingly.

How to reduce Globulin and raise Albumin.

Sound health requires serum albumin of a minimum of 48g/L with globulin < 24g/L. This profile for life also for optimal childhood development and prevent regression to Autism Disorders. To achieve this serum profiles I developed 1982-2012 a special fingernail cleaning soap to prevent self-inoculation, a Sinus bath to clean the nasal passage each day and a daily Ion bath for regeneration.

RESULTS OF SERUM ALBUMIN TESTS ON ELDERLY MALES and pregnant females…FROM NOVEMBER 1986 TO JULY 1987(HYGIENE IS THE "SECRET" OF AGING

INTRODUCTION A simple test is needed to establish if the daily use of a new method of hygiene can rejuvenate elderly healthy humans. This is predicted in the book, "**IS IT POSSIBLE TO PREVENT THE COMMON COLD, CANCER, AIDS, ETC AND SLOW THE AGING PROCESS?**", and in "**Breaking the Devil's Circle**" at page 53 Kenneth Seaton, March 1987.& 1989 Library of congress both books are available. Further studies on over 2,200 pregnant women in the North shore of Sydney Australia found that those who maintained serum albumin 45g/L-35g/L avoided Autism and birth defects in infants. Further testing in the USA will be sought. The blood of healthy old persons has little difference to that of healthy young persons, except for a well-documented decline in the protein ALBUMIN. This protein is the most abundant in the blood and has a very important function in maintaining the correct water levels of the connective tissue. This is accomplished by a suction called Osmosis that is created by the molecule albumin that is too large to normally pass through the tiny walls of the capillaries. In aging, the complex water holding ability of the connective tissue is damaged and nutrients and wastes are not efficiently transported to and from cells. In the book, Seaton claims that a combination of microbes/ toxins / autoimmunity / radicals is the most important cause of this inability to structure water correctly. The book claims a new method of personal hygiene of the fingernails, eyes and nose can prevent this from occurring.

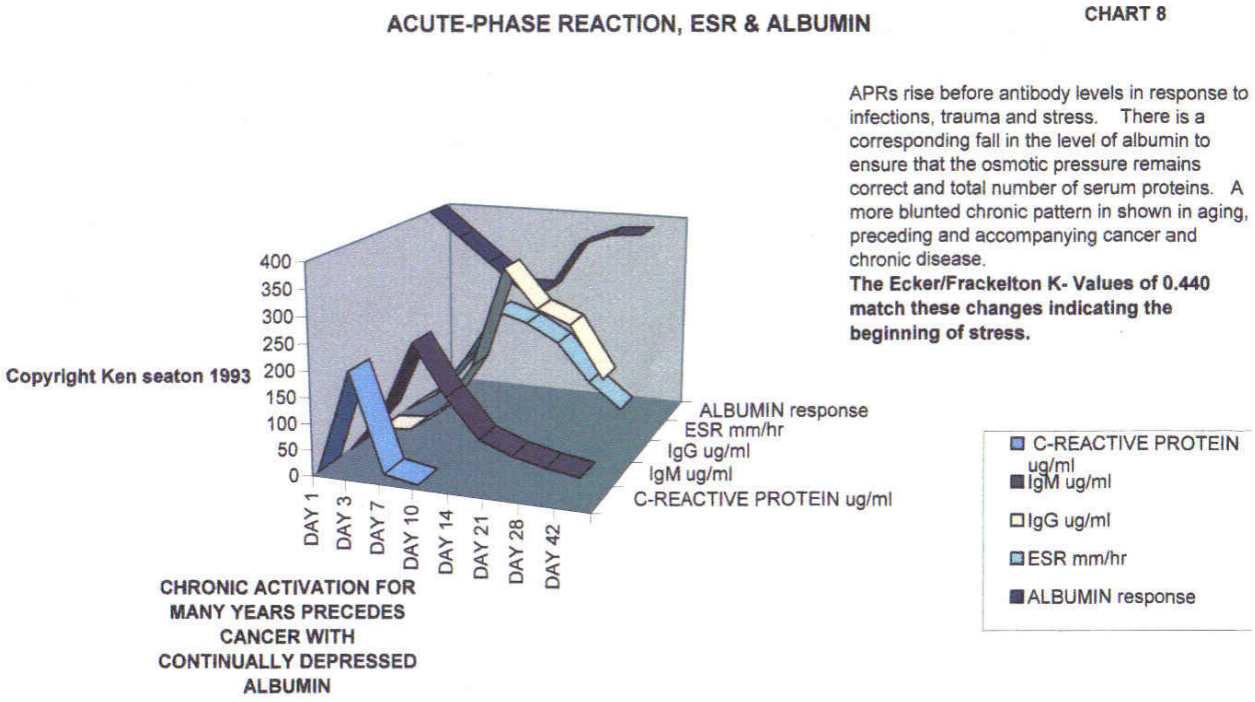
METHOD: Eight elderly, reasonably healthy males, retired professional men's club volunteered to use this method of hygiene for several months. The volunteers were above average intellectual standards, meticulous about their personal hygiene and lived in above average socio-economic areas surrounding Palm Beach (Sydney, Australia). They were asked to dig their fingernails into a tub of super soap and wash their hands with the residue. They washed their hands with normal frequency (4 to 5 times a day). The Face Dip was performed morning and night by immersing the face to the hairline in a basin of 5 liters of very warm water with a small amount of Super Face wash added. The eyes were opened several times under water, the face was withdrawn, the nose blown on a clean tissue and the method repeated. Most volunteered complied with this regime during the next 6 months, except for 1 who did not use the Face Dip.*Blood tests for albumin levels were performed by the independent, well respected pathologists FEAIN, LYNCH, McDonald et al of St. Ives, Sydney. These tests were taken on commencement and seven months later. Dr. George Cockburn, a physician and surgeon, assisted Seaton in the test. PREDICTION: This method of hygiene would allow the immune system to rest and function accurately and efficiently. This in turn would allow the connective tissue to be restructured correctly, that wastes and nutrients would flow more efficiently and that the serum albumin would rise to the level of a younger person. Normally one would expect a slight decline in these aged volunteers.

RESULTS:

AGE	ALBUMIN		AGE	ALBUMIN	
	Nov.'86	July '87	Nov.'86	July'87	
70yrs.	42	45	70yrs	42	41*(not using Face Dip)
77	43	52	73	42	47
85 (started using before)	46	48	62	43	45

NOTE: 2 volunteers away (no results) some volunteers started using the soap and dip a few days before having tests. Kenneth Seaton © Copyright 1987

[Photo redacted] Granddaughter approximately 2 years old with the highest Albumin profiles ever seen Albumin 52g/L A/G ratio 4.12. **Note**: most blood tests are in g/dL, simple remove the decimal point e.g. 4.2g/dL =42g/L. Questions/comments welcome.



Fever results in low Serum Albumin

The chart shows how the end result in fever is low serum albumin and if fever persists for years as chronic inflammation serum albumin will remain low and cancer, heart disease, Alzheimer's, kidney failure are very high risk. See Malignant Flame Scientific American 2007.

During pregnancy fever can result in birth defects and brain damage in the baby including Autism Spectrum Disorders, all the result of low albumin. Fever (Inflammation) is the major factor that controls serum albumin levels not diet. In pregnancy the preventions of activation of the Acute Phase Reactants is the only way to maintain serum albumin 45-35g/L so that optimal fetal and childhood development can be ensured and the risk of Autism Spectrum Disorders Extinguished.

Today with the epigenist change the need for higher levels of serum albumin in pregnancy and infancy is critical if Homo-Sapien is to survive and any fever can stress the full development of the brain resulting in weird Autism disorders. This is why the old reference range for Albumin namely 35-23g.L in pregnancy and 34-50g/L are Prehistoric and today all humans require a minimum of 45-35g/L in pregnancy in the Mother, 4-5g/L in the amniotic fluid at 26 weeks, and 47-57 g/L in children and adults. Albumin is foolishly neglected by Doctors.

Harvard Medical School is the most ignorant place to have a Baby. **Dr Oliver Wendell Holmes Harvard 1850**

Questions, comments welcome. Copyright Kenneth Seaton 1993

Eileen Nicole Simon

October 13, 2012

Subject: Question 2 (How can I understand what is happening?)

I listened Friday to the conference call on question 2. First of all, thank you Drs. Koroshetz, Amaral, Choi, Insel, and Carlos?? from Johns Hopkins??? for participating.

First I have to agree with the final comment (made by Dr. Insel I believe) that some things should be left out of the update. The focus (I believe, as a stakeholder) should be: How can I understand what is happening with language development?

Language is the most serious handicap. Question 2 is different from question 3. What is happening is the result of injury to the brain, but autism has many causes. Fragile X, tuberous sclerosis, Rett's, etc. all affect a "final common pathway" in the brain. Question 2 should address what interference with maturation of the language areas of the cortex occurs with all causes of autism.

Dr. Amaral, I do think brain systems are most important to investigate, especially the auditory system, and there are probably more than 200 papers on inhibitory versus excitatory neurons and neurotransmitters within the brainstem auditory pathway. The brainstem auditory pathway is fully myelinated by 29 weeks gestation [1, 2], and a timed sequence of transient neurotransmitters guides the maturation of target regions in the developing cortex [3]. The language areas of the temporal and frontal lobes continue to develop during the first four to five postnatal years [1].

Before the first conference call I submitted comments (via Lina Perez), and if this update must be based on recent papers, then the papers by Kulesza et al. and Lukose et al. (both published in 2011) should be included [4, 5]. After finding malformations of the superior olivary complex in 9 cases of autism, they then produced the same malformation by administering valproic acid during gestation to laboratory rats.

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Eileen Nicole Simon

October 15, 2012

Subject: Question 2 (How can I understand what is happening?)

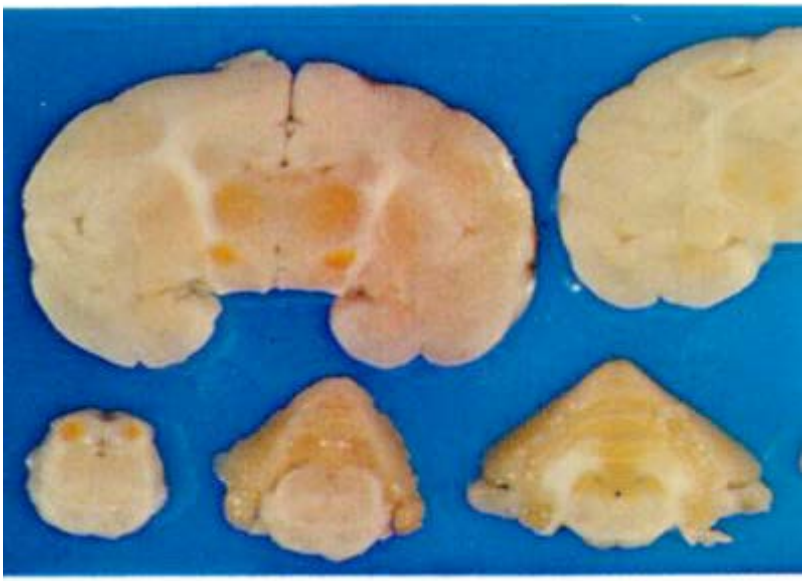
I listened to the conference call on Question 2 Friday, and I want to thank those who participated, Drs. Koroshetz, Amaral, Choi, Insel, and Carlos?? from Johns Hopkins. However, what is happening should be what is happening in the brain. The brain is not a uniform organ, thus systems within the brain should be the focus of research.

The picture below is from a paper by Lucey et al. (1964) that may show areas most likely to be the initial site of injury in autism, the basal ganglia and nuclei of the auditory system, and may account for motor stereotypies and auditory system impairment that impedes language development.

The picture shows how, in monkeys, asphyxia at birth (damaging the blood-brain barrier) followed by even normal levels of circulating bilirubin affected the brain. Many papers have documented difficult birth in children who develop autism, and a few have documented high bilirubin. Problems at birth and the early neonatal period must be counted among the many causes of autism. The picture below shows how two coincident problems can affect the brain.

The affected subcortical nuclei (especially in the auditory system) have higher blood flow than any other area of the brain. See figure 2 in the paper by Kety (1962),
at www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed . These areas of the brain are thus likely to be susceptible to impairment by all of the many known causes of autism (i.e. what is happening as result of all causes). Please focus on what is happening, not the causes. Thanks.

Sincerely,
Eileen Nicole Simon, RN, PhD (Biochemistry)



Eileen Nicole Simon

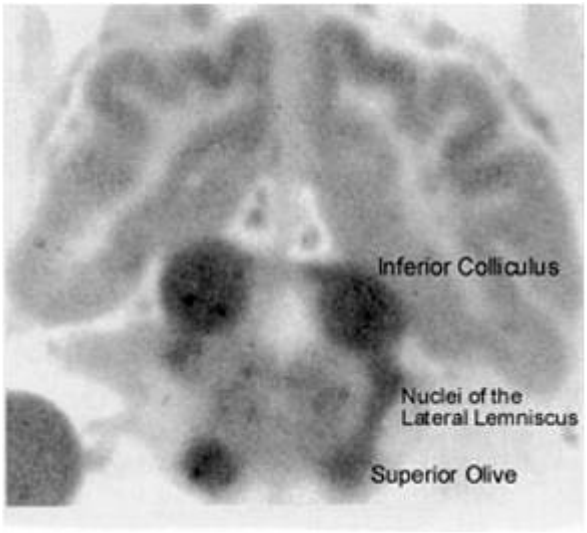
October 21, 2012

Subject: Question 2

First, thank you Dr. Amaral for responding to my comment on the last conference call on Question 2. During the workshop on Oct 30 I hope that the two papers I pointed out (on malformation of the superior olive in autism, and in lab rats subjected to valproic acid during gestation) will be discussed and included in the update to Question 2, Kulesza et al. (2011) and Lukose et al. (2011).

The superior olivary complex is among the brainstem auditory of highest blood flow in the brain, which can be seen in the picture below from the paper by Kety (1962). High blood flow exposes nuclei of the auditory system to more of any circulating substance like valproic acid.

Auditory nuclei were also prominently affected in experiments with monkeys on asphyxia at birth. Asphyxia at birth produced a pattern of damage similar to that seen in infants dying of kernicterus, but without the yellow staining caused by bilirubin. Lucey et al. (1964) demonstrated that bilirubin staining only occurs in subcortical nuclei damaged by asphyxia, including the basal ganglia.



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Anne Jackus

October 21, 2012

Subject: What caused this to happen?

While I am very pleased to see this topic is being addressed, I do hope it isn't the usual "disappointment" (as I'm expecting it will be, given your previous track-record of paying lip-service to certain areas, but never addressing them properly). If your group is not going to actually look at the environmental factors that most parents feel are contributing factors to their child's illness, then you will, once again, be wasting time and taxpayer dollars (not to mention creating continued ill-will with the parent community. Most of us feel you have been utterly useless in actually improving the lives of those effected by autism).

I am the parent of 3 vaccine injured children (1 still on the spectrum, 1 has totally recovered using biomedical approaches including chelation, M B12 injections and targeted supplements and dietary approaches, and one mostly recovered using the same treatments). Yet, sadly, these therapies are not studied as to why they work with some children but not others.

The IACC's continual failure to address the real issues behind the autism epidemic is frustrating and inexcusable. I am a physical therapist, and fairly well-educated. Parents know something is happening to their children. It's not "just genetics" or "older dads", or "better diagnosis", or the latest excuse you guys toss out to make it look like you are actually doing something productive. To date, I feel your group has been pretty useless. While you sit around avoiding the obvious questions, more and more children are harmed and their lives turned upside down by this terrible illness that effects the entire family. There are likely genetic predispositions with environmental triggers. LOOK FOR THEM!!!

Until you finally do a proper, legitimate vaccinated vs. never vaccinated study on children who have receive the entire recommended vaccine schedule (on time) vs. children who have received none, no parent will believe vaccines have nothing to do with it, no matter how you continually try to spin in (especially when they have witnessed with their own eyes, a regression in their own children, as I did). I realize vaccines are not the only environmental cause, and I know children who have never received vaccines who have autism. However, in our family, all 3 of my children regressed after their vaccines, most notably after their 2nd MMR. So, I, like thousands of other parents, want to know what the mechanism of injury is for kids like ours and what role vaccines play, so that they can be made safer for future generations of children. Please don't answer back with the usual "it would be unethical to withhold life-saving vaccines from even one child". We all know there are now literally thousands of children out there who have never received vaccines because their parents are too terrified to give them. Many of them would gladly volunteer to be part of a legitimate study! That excuse rings very hollow!

Please try to actually answer the question you are asking. **What caused this to happen?**
My guess is that, once again, you'll all be too afraid of what you might find to really ask the hard but necessary questions and follow up with the appropriate research (but someday, someone will, and won't you all look not only foolish, but criminal!). If you don't ask the right questions, you'll never get the right answers!

Please surprise me by doing the right thing!

Sincerely,

Ms. Mac Donald

My feeling is that your committee is either [offensive language redacted], but to date, not much has really been accomplished on the environmental studies front (and I'm pretty sick of all those tax payer dollars just going into genetic research).

Eileen Nicole Simon

October 21, 2012

Subject: Comment on Question 3: What caused this to happen and can this be prevented?

Autism is associated with many etiologies, including genetic metabolic disorders. What is needed is to look for a final common pathway in the brain affected by all predispositions for autism. Phenylketonuria (PKU) was a genetic cause of autism in the past. Note that discovery of the metabolic defect in PKU, and treatment by dietary restriction of phenylalanine, predate discovery of the structure of DNA. PKU is caused by a defective enzyme. Abnormal metabolites of this defective enzyme (like phenylpyruvic acid) are clearly toxic to the brain.

Within the brain, the auditory system has the highest rate of blood flow and is therefore more exposed to abnormal metabolites like phenylpyruvic acid in the circulation. Developmental language disorder is the core handicap of children with autism. The brain impairment underlying language handicap is the final common pathway of all etiologies of autism, and likely includes the auditory system.

The effects on the brain of trauma and asphyxia at birth must also be considered as causes of autism. Experiments with monkeys done more than 50 years ago demonstrated that clamping the umbilical cord and preventing the first breath caused ischemic damage within the brain stem, which was most severe in the midbrain auditory nuclei (the inferior colliculi, Windle 1969). Children learn to speak through hearing.

On my website I have cited 12 cases in which the ability to comprehend speech was lost following injury of the inferior colliculi. See references 72-83 at http://conradsimon.org/SpeechComprehensionLoss.html. How much more serious injury in this area of the brain would be for an infant.

Investigations of perinatal "sub-optimality" in autism are numerous. Most document low Apgar scores and need for resuscitation, and therefore implicate likely injury of brainstem auditory nuclei. See recent references below [2-5], and annotated references from the last 40+ years [6-41].

Since the mid 1980s clamping the umbilical cord immediately after birth has been adopted as standard practice. This cannot be considered safe, especially when the clamp is used before the first breath. This protocol may be quietly going away. A young mother-to-be told me recently that in the Boston hospitals they are no longer clamping the cord, and they are not giving the hepatitis (Hep) B vaccine immediately after birth. Could the IACC encourage the obstetric profession to stop using the clamp, and not to encourage prospective parents to salvage umbilical cord blood?

Note: At birth transition from placental to pulmonary respiration is the physiological priority. If this transition is disrupted by clamping the cord, a large portion of the newborn's blood may be left behind in the placenta. Blood will then be drained from other organs, even the brain, which may produce the same kind of ischemic injury found in monkeys subjected to asphyxia at birth (by clamping the cord and preventing the first breath).

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" Seven characteristics at the time of delivery were significantly associated with autism in the unadjusted analyses and all these characteristics had an odds ratio of at least 2 except for cesarean delivery: abnormal gestational age including preterm (16.9% in cases vs. 4.2% in controls) and postterm (8.4% in cases vs. 4.2% in controls), nuchal cord (23.2% in cases vs. 6.3% in controls), cesarean delivery (50.0% in cases vs. 35.8% in controls), delayed crying (11.6% in cases and 2.1% in controls), newborn complications (29.5% in cases and 4.2% in controls), apnoea (11.6% in cases and 1.1% in controls), and neonatal jaundice (11.6% in cases and 1.1% in controls)"

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"According to our review, 3 parental characteristics and 2 obstetric conditions emerge as potential risk factors for autism: namely, paternal age, maternal age, maternal immigration, growth restriction, and newborn hypoxia. In analyses that adjusted for confounding variables, these factors usually remained statistically significant."

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" We also found strong associations between children with infantile autism and mothers with foreign citizenship, children with congenital malformations and children who needed treatment at Neonatal Intensive Care Unit (NICU) after birth. When the caesarean sections were categorized into scheduled and unscheduled procedures, we found only scheduled caesarean sections to be associated with infantile autism."

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"... in a population-based study of moderate and severe term newborn encephalopathy (NE) in Western Australia ...infants with NE were 5.9 (95% CI 2.0–16.9) times more likely to be diagnosed with an ASD than controls... this was not an expected association at the outset of the study"

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”For 58 of 99 children, some kind of abnormality was noted in their neonatal record. ... Twenty-two had had hyperbilirubinemia (plasma bilirubin more than 200µmol/l), ... Hyperbilirubinemia occurs in about 10% of newborn infants... Forty-five of 92 children (49%) for whom fairly detailed data about early language development were available, clearly did not have normal language development at 2 years of age. It cannot be concluded that the remainder had normal language development.”

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"Cases were more likely to have experienced fetal distress during labor (OR, 1.64; 95% CI, 1.15-2.34). **Apgar scores calculated at 1 minute showed that significantly more cases achieved a score of 6 or less** (54 [19.5%] of 277 cases with data recorded since 1991..." "[12.9%] of 512 control subjects with data

recorded since 1991)(OR, 1.6; 95% CI, 1.1-2.4), and **cases were more likely to have taken more than 1 minute before the onset of spontaneous respiration** (OR, 1.4; 95% CI, 1.0-1.9)."

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"Children with autism spectrum disorders have lower optimality (higher rates of complications) than unaffected siblings…"

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"The **risk of autism** was associated with daily smoking in early pregnancy (OR = 1.4; CI = 1.1-1.8), maternal birth outside Europe and North America (OR = 3.0; CI = 1.7-5.2), cesarean delivery (OR = 1.6; CI = 1.1-2.3), being small for gestational age (SGA; OR = 2.1; CI = 1.1-3.9), a **5-minute Apgar score below 7** (OR = 3.2, CI = 1.2-8.2), and congenital malformations (OR = 1.8, CI = 1.1-3.1)." **Note: The OR (odds ratio) was greatest for 5-min Apgar score below 7."**

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"… specific complications that carried the highest risk of autism and PDD-NOS represented various forms of pathologic processes with no presently apparent unifying feature."

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"Among the children with a serious medical condition, 34.4% also had ante- or perinatal antecedents. Among the 33% without any medical factor, 77% also had ante- or perinatal antecedents."

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"**AD was identified in 18 of the 5,271 children** and the incidence was 34 per 10,000 (0.34%). This value was more than twice the highest prevalence value previously reported in Japan. **Children with AD had a significantly higher history of the meconium aspiration syndrome** (p = .0010) than the controls. Autistic patients had different risk factors than CP." **Note: CP (cerebral palsy) occurred in 57 of the 5,271 children."**

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"…[obstetric] optimality score (OS), were compared in two groups: 78 families containing an autistic proband (ICD-10 criteria) and 27 families containing a down syndrome (DS) proband… RESULTS: Autistic and DS probands had a significantly elevated OS compared with unaffected siblings, regardless of birth order position. The elevation was mainly due to an increase in mild as opposed to severe obstetric adversities."

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"Abnormal presentation at birth is the only factor that occurred more frequently for the autistic sample…"

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Concordance for autism was determined in 4 of 11 pairs of monozygotic twins. Of 21 twin pairs, 17 pairs were discordant for autism and in 12 pairs autism was associated with a perinatal event likely to cause brain damage.

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"There were more complications of labour in the experimental group than the controls ($p=0.001$) ...Abnormal conditions of the child noted at delivery occurred significantly more frequently in the experimental group, e.g. difficulty with resuscitation, cord around neck, fractured skull, cyanosis, head moulding, bruising, jaundice ($p<0.0004$)."

Richard Weston

October 22, 2012

Subject: New approach for Autism research

I thought that the committee might be interested in this potential approach for autism research. The Childhood forms of Myotonic Dystrophy have a high incidence of Autism and ASD (50%) There is a known mechanism of action and an antisense drug that is in development that may be able to reverse the symptoms of autism in these kids. Funding and attention to this might be helpful and a real breakthrough.

http://myotonicdystrophy.com/http:/mytonicdystrophy.com/biogen-isis-partnership-readies-autism-drug-for-human-clinical-trials/

Please pass to your colleagues in the upcoming meeting next week.

Richard Weston

Pam Rockwell

October 24, 2012

Subject: comments about IACC strategic plan – medication advances

I am the mother of an autistic child who has developed some language skills after using several off-label prescription medications that are not typically prescribed for the treatment of autism. I have been listening to the work of the IACC, and I am really disturbed about the lack of support for medical treatments of autism. While I was unable to read the materials that you and your committee have produced and were reviewing, it sounded like you felt that there had been no progress in the last year besides some confirmation that anxiety meds help anxiety in autism.

I really disagree with this point of view. I attended the International Meeting of Autism Research (IMFAR) in Toronto in this past summer. These were some of the topics (abstracts or panel discussions) that relate to the medical treatment of autism:

Antipsychotics and Antidepressants: Ariprozole joins Rispiridone as an atypical anti-psychotic that can control behavior in autism. Prozac does help fight depression in autism. (I think you had these covered already…)

Stimulants: Ritalin, marketed as Concerta for ADHD also helps autistic individuals with focus – this is important because there is already a lot of childhood safety data for many stimulants used to treat ADHD, including amphetamines, other forms of ritalin, and focalin (an isomer of ritalin.) Most of these drugs are already available as generics, so there is no reason that pharmaceutical companies will do studies to see if they would work for autism – so this is a place where the IACC can have an impact by targeting studies that test the off label use of ADHD medications for autism. Many physicians are already prescribing these meds for autism by giving their patients a provisional ADHD diagnosis to justify the use of the meds to insurance companies. Data about how these drugs are already being used in the autism community could be helpful in designing future studies and developing dosing guidelines for use in autism.

Oxytocin: Oxytocin is being tested to help with core social symptoms of autism and emotional control. This developed because blood oxytocin levels were reduced from the norm in many adults with autism. Several genetic studies also support reduced gene expression of oxytocin in autism. This is important to discuss because oxytocin is already available by prescription, so if these tests show that oxytocin really helps with autism there may be a rush to prescribe this off-label. Blood levels of oxytocin may be a biomarker for whether oxytocin is an effective treatment for autism, so the committee might also want to consider a recommendation that testing blood levels of oxytocin should be part of regular screenings for children diagnosed with autism.

Glutamate receptor system: Several different lines of autism research are all pointing to one particular synaptic organization that might be responsible for some symptoms of autism. This is the glutamate receptor system. Glutamate is released during stress and learning. The release of glutamate is modulated by GABA, which inhibits the release of glutamate from the pre-synaptic neurons. The post-synaptic neurons have several different types of receptors that respond to glutamate, and some of these receptors are known to be associated with genetic disorders that are linked to autism. One of these receptors, mGluR, controls mTOR (molecular target of rapamycin) a molecular signaling system

that initiates translation of mRNA into proteins. Genetic variations of mTOR are also linked to schizophrenia and obesity. There are several different types of medications that are being tested in autism that relate to the GABA/glutamate/mTOR system, and many of them have generic analogs:

· GABA agonists: a GABA agonist will theoretically reduce the amount of glutamate released and therefore the amount of proteins produced by the mTOR cascade by blocking the GABA receptors on the presynaptic neuron without triggering the natural function of the GABA receptor. Baclofen is a prescription GABA agonist that is used as a muscle relaxant in cerebral palsy and gastrointestinal reflux, and anecdotal data about baclofen helping core symptoms of autism have led many physicians to prescribe baclofen at the first sign of muscle spasms or reflux in autistic patients. Arbaclofen is a particular isomer of baclofen that is being developed specifically for treatment of fragile X syndrome. While arbaclofen trials are not complete, the same issues as oxytocin apply: should the committee be collecting data about off-label use of baclofen (much cheaper than arbaclofen) and recommending testing for biomarkers for success (genetic tests for fragile X).

· NMDA receptor modulators: NMDA receptors that are a particular type of glutamate receptor which is pivotal in learning and memory. NMDA receptors have been implicated in several mental illnesses, including Alzheimer's disease and autism. There are many NMDA receptor antagonists already on the market, which block the reception of glutamate on the post-synaptic neuron. Memantine, an Alzheimer's drug, was shown to reduce core symptoms of autism. (My son actually takes an NMDA antagonist called amantadine, which has never been formally tested to treat autism.) Other NMDA antagonists are PCP(angel dust), ketamine (an anesthetic tested to treat dangerous depression), eliprodil (an antiseizure drug), and dextromethorphan (Robitussin). The success of memantine trials raises questions about whether it should be used more widely, or whether other NMDA antagonists should be tested (these are all out of patent- no drug company wants to test them.) Also, whether eliprodil might be indicated for autistic individuals who also have epilepsy.

· mGluR5 receptor modulators: The glutamate receptor that is implicated in fragile X syndrome is mGluR5, and there are two companies that have developed modulators of this receptor, Seaside Therapeutics and Pfizer. Seaside has shown that this drug reduces core autism symptoms in fragile X and there are ongoing studies about non-genetically linked autism.

· Rapamycin: Rapamycin is an old antifungal medication that turns out to be a strong immune suppressant most often used in organ transplants. Rapamycin acts downstream of the glutamate receptors, increasing translation of RNA into proteins when it binds the molecular target of rapamycin (mTOR). It has been shown to cause remission in tuberose sclerosis patients, and it reduces their core autism symptoms. Variations in the mTOR gene have been linked to schizophrenia, and rapamycin is being tested as a treatment for schizophrenia.

This past year, autism researchers have compared mouse models of two different disorders that are known to cause autism: tuberose sclerosis and fragile X. While both diseases cause autism and are related to the glutamate receptor system, they do it in the opposite way, fragile X by increasing protein production, and tuberose sclerosis by reducing it. This means that it is really important to know how the autism symptoms are being caused before you try a particular medical treatment – rapamycin will help tuberose sclerosis patients and hurt those with fragile X, while mGluR5 modulators will hurt those with tuberose sclerosis and help those with fragile X. This really emphasizes how important genetic screenings and other biomarkers are for selecting medical treatments.

Nutritional supplements: From the moment my son was diagnosed, people started trying to sell me vitamins that would cure him. Two important studies have come out this year. Prenatal folic acid supplements help prevent autism (we already knew they prevent spina bifida) and large doses of omega-3 fatty acids can reduce core autism symptoms. Because there is so much unsupported information about vitamins and autism, and because there are some vitamins that you can overdose on, the committee might want to consider whether the strategic plan should include some way of relaying this information to physicians and the general public.

Glutathione modulators: I thought this was the most exciting thing I saw at IMFAR. Kuvan (tetrahydrobiopterin) is a drug that was developed to treat PKU, but there are very few people who have PKU and it is very expensive. Research this year has shown that it treats core autism symptoms without a lot of side effects. This is important because it is a new use for kuvan, but also because it is a hot research topic to use drugs that target glutathione to treat conditions that are associated with inflammation. Currently the only drugs that treat inflammation are immune suppressants that make the patient susceptible to infections, and NSAIDS which a can cause heart disease. These glutathione modifiers (I'm not sure I'm using the right term here – this is biochemical, not receptor modulation) are basically super antioxidants. Another glutathione modulator, Biogen's BG-12 (dimethyl fumarate), made a big impact when it was shown to reduce multiple sclerosis relapses, although this mediation appears to have more side effects than kuvan. Besides the fact that kuvan is effective, this is important for the committee to consider in the strategic plan because new drugs that target glutathione will be in the pipeline for a variety of illnesses – autoimmune disorders, heart disease, obesity etc. – and autism researchers should be encouraged to coordinate with clinical trials for other disorders when these drugs are tested.

As a mom, I am concerned about how the IACC is approaching the task of rewriting the Strategic Plan, or even about how it considers its role. I want to believe that the IACC would be a collection of experts who would come to the committee with a lot of knowledge about the topics that they are expected to evaluate and write about. I think it is unfortunate that the same IACC sub-group that is writing about advances in behavior, speech, OT, social, & psychological therapies are also supposed to become experts about receptor systems, genetics, psychopharmacology, and biochemistry so that they can write intelligently about advances in medications for autism.

I imagine there will be a lot of pressure to ignore advances in the medical science for yet another year, until the committee has more time to write. But I think that would be doing a disservice to the intent of the US Congress. I think Congress expected that in creating the IACC they would be encouraging a group that would connect the dots and take a leadership role in making sure that no important aspect of autism research was overlooked: like medical treatments that are not particularly profitable for drug companies, genetic tests that might be expensive for health insurance companies but could help shape treatment plans, or medical treatments for different disorders are also treatments for core autism symptoms. I think that requires more than a google search of autism papers to really understand what is going on in this field. I think it requires getting to know the researchers in the field and being able to ask them how the research is going and what the implications of their research might be, above and beyond what is published.

I think that when Congress created the IACC they expected that designating a person on the committee from each government agency would mean that there would be a person at each agency who really understood what was going on in the world of autism research and services. But they did not actually designate funds to pay a person at each agency to be an expert at autism. People who do these jobs

(like you) are expected to do their full time jobs and be also become an expert in autism to serve on the committee. As you try to keep up with all the reading and writing that you have to do to get up to speed with your responsibilities just to write one small piece of the many policy papers that will be produced by the committee in the next year, think about whether it would be a good addition to the Strategic Plan to ask Congress to actually fund staff positions that are experts at autism at each of the government agencies that serve on the committee.

I hope my comments about medical treatments for autism has encouraged you to look a little deeper before the meeting next week. I appreciate all the hard work that community volunteers have put in to help the IACC with its work.

Thank you,

Pam Rockwell

Eileen Nicole Simon

October 25, 2012

Subject: Comments for the Services Workshops

Following are from comments I submitted in response to the IACC requests for public input (RFI) in 2009 and 2010:
http://iacc.hhs.gov/public-comment/2009/rfi_comments/q5/index.shtml
http://iacc.hhs.gov/public-comment/2010/rfi_comments/index.shtml

Please consider: (1) The idea proposed below that mandatory insurance should be required for every child, from birth. This may seem unrealistic, but I notice from the transcript of the conference call held September 19 that the suggestion to seek advice from private insurance companies came up more than once. Note that automobile insurance is mandatory, and from private insurance companies, not federal or state governments. (2) Private builders of housing, and especially hotels like the Marriott Residence Inns, are far more knowledgeable on what works (and sells) than government planners.

In 2009 (as respondent 0013), for Strategic Plan Question 5; Where can I turn for services? My responses were:

a. Gaps and underrepresented research areas.
Where can we turn? Who will pay for lifelong care? Actuarial scientists from Social Security should be included in the IACC panel of agency experts. Actuarial scientists may be more aggressive at seeking environmental causes of the increased prevalence of autism. They might bring a new perspective on what kind of research could more quickly lead to prevention.

Another way to involve actuarial scientists would be to require long-term-care insurance be purchased by parents of every child born. . .

b. New opportunities.
Housing and food are basic human needs, and our capitalistic democratic society is clearly failing to ensure these needs are met for everyone. Financial bailouts for mortgage lenders are the disgrace of the current American system. The right to private ownership should not be denied to those fortunate enough to be able to accrue sufficient assets to provide for their own needs. However, we need socialism to the extent required to provide for those who are disabled and unable to survive without assistance.

I suggested to my legislators that rather than bail-out banks, they should give the money to Marriott Hotels to build enough Residence Inn Hotels to ensure housing for everyone. I am sure entrepreneurs at Marriott would know how to take the money, build the hotels, and eventually make a profit by encouraging those they housed to work toward shared ownership of their homes–providing jobs as housekeepers, cooks, maintenance, grounds keepers, etc. Please look into this.

c. Research priorities.
Put the $16,700,000 and $7,000,000 proposed in the Strategic Plan for evidence based services and effective interventions in community settings up for bid. Encourage companies like Marriott to consider what opportunities this might provide for them.

Encourage partnerships between companies like Marriott and current community service providers, like Vinfen in Massachusetts. Put out a bid for real and thoughtful new strategies.

In the following section on what the future holds, you state that little is known about autism spectrum in the criminal justice system. I work in the Massachusetts Department of Correction, and know that statistics can be gathered. First, autism and Asperger spectrum disorders can clearly be seen as part of a wider spectrum of developmental disability. Further, many physical problems like gastro-intestinal disorders, asthma, and diabetes are clearly evident to direct care-givers. Note also: Incarceration is the costliest kind of long-term care.

In 2010 (as respondent 6) the comments I submitted again for Question 5 were:

a. What has been learned about the issues covered in this chapter in the past year?
The American capitalist society is based on every individual being self-sufficient, self-supporting, and a productive tax-paying citizen. America's answer to communism is private insurance. We can't really turn anywhere else for lifespan support for the disabled.

b. What are the remaining gaps in the subject area covered by this chapter?
I used to fear dying young. Now I fear becoming totally disabled and dependent on others. None of us knows if or when we might suffer a debilitating injury. We need a better system for anticipating disaster and providing long-term care.

The IACC should promote enactment of a law to require mandatory long-term-care insurance for every child born. Then if lifespan care is needed, funding will be available without having to beg for legislatures to come up with allotments from tax revenues. Mandatory long-term-care insurance would also involve actuarial scientists in identifying the most important areas of research into the causes of autism. See http://conradsimon.org/Society.html.

Below is a picture of me and my son on the roof of the Massachusetts State House (outside the office of MA Senator Susan Fargo). Many of the legislators in Massachusetts know us quite well, but have very little to offer in the way of public funding. Turning to the private sector (private insurance companies) must be considered.

[Photo redacted]

Note: Personally Identifiable Information (PII) has been redacted in this document

Eileen Nicole Simon

October 25, 2012

Subject: Adult Services

I am especially interested in the ideas of outside experts Paul Shattuck and Peter Gerhardt. I heard Dr. Shattuck at IMFAR, and responded from the audience about the abyss we are facing. I have great respect for Peter Gerhardt's ideas. Dr. Gerhardt works directly in the milieu, which is the source of the best ideas for how to proceed.

My son, [PII redacted], turned 50 last month. He lives in a group home from which he ran away on March 10, 2009 and was not found until May 2, seven weeks later. Below is a picture I took last month of the day program schedule for September 28. His younger brother pointed out that the 8 had been written over the 7, so what they do often follows the same (or similar) schedule day after day.

Notice that the only regularly scheduled activity is smoking, every hour on the hour. I would like to bring [PII redacted] to an IACC meeting, but his hourly need for a cigarette makes traveling difficult, even when we attend activities fairly close to home.

How did my son end-up in this group home? "Can't he live at home with you?" some people ask. He is 50 years old, and for most of my life now I have had people trying to tell me what I should do, and what I did wrong. For how long could he live with me?

My son suffered head trauma and anoxia at birth. The forceps mark is still visible under his right eye. At 20 months of age, and not yet able to walk, we were told he had "mild" cerebral palsy. He started walking one month later, but then not learning to speak became our greatest concern.

[PII redacted] loved his story books, and his speech became clearer as he would sit (for long periods of time) looking at his books and reciting the stories. When he was two years and two months old, someone gave him a new book, which he immediately began reading out loud, to everyone's amazement!

At age 5 he could read anything, but he only spoke using phrase fragments. He was kicked out of kindergarten after only a few weeks. He was admitted to the Children's Unit (Ward 6) at the Massachusetts Mental Health Center. His miracle recovery began there under the guidance of an expert teacher, [PII redacted], and wonderful Mental Health Workers, some of whom were conscientious objectors working in a mental hospital in lieu of service in Vietnam.

By age 7 we thought [PII redacted] had completely recovered from autism. By age 17 it was clear he had not. He did not quite finish high school, and when special education ended at age 21 he started coming to the attention of the police. I was blamed by many for that too. Well-meaning people thought I should quit my job to look after him. But, he was not an easy person to look after.

I will never forget the correctional officers at the Barnstable County Jail telling me, “Look lady, he’s not easy to take care of. If we could, we’d pack him up and send him home with you today.” When he did come home, he immediately got into trouble again.

When apprehended by the police, he was often taken (or ordered in court to be taken) to the nearest state hospital, Northampton, Taunton, Bridgewater (Department of Corrections), Metropolitan, Massachusetts Mental Health Center, and finally Westborough.

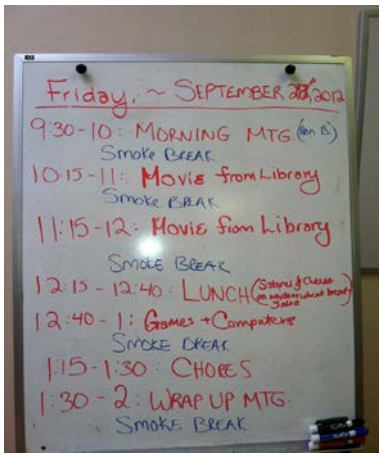
Often when he went missing it was days or weeks before I could locate him. In the state hospitals, where no one had his developmental records, he often got a diagnosis of schizophrenia or schizo-affective disorder. Later, no one wanted to accept my “excuse” that he was injured at birth and had been developmentally disabled.

[PII redacted] has lived at the group home now for almost ten years, following his discharge “into the community” from Westborough State Hospital. He was better off at Westborough. He had paid employment there, he lived in a beautiful house, one of the former physicians’ residences, refurbished to accommodate 12 patients. He could sign out (and later back in) to go to the patients’ cafe, clothing exchange, or just take a walk on the path along the lake.

The group home is on a busy, noisy, and ugly city street. The doors are alarmed (but not locked). When my son ran away, he went out a window in the kitchen. Weekend staff are mainly part-time “relief staff,” and often the only activity is one cigarette, every hour, on the hour, on the back porch, looking out at the garbage cans.

I have been taking [PII redacted] out almost every Sunday for fresh air, exercise, and also to continue writing our memoirs. Our first memoir is an ebook available on Barnes & Noble’s website, link at http://ow.ly/9ZLr8

[PII redacted] is capable of doing useful work. Why can't this be the focus of his "day program" rather than smoking? He loves to read, and loves to go to the library to peruse and borrow books. Why has he been kicked out of every GED class he has attended? With a GED and employment, he could live with much less funding required from public resources for programs like that shown in the daily schedule below.



Marìa Lujàn Ferreira

October 25, 2012

You have had a lot of answers about these proposals; please do translational research, to help right now right here children /teens/adults with autism /ASD and to address the gastrointestinal, metabolic, biochemical, nutritional, endocrinological, hormonal, toxicological, immune , autoimmune (PANDAS/PITAND/PANS) , infectious (viral, bacterial, fungal and parasitic) conditions- chronic or acute, inflammation, oxidative stress and microglial activation issues children /teens and adults diagnosed with ASD have, reported with high quality evidence around the world.
Otherwise, this is not a productive effort.

Sincerely
M. L. Ferreira
mom of a child diagnosed with autism with dozens of medical comorbidities- non genetic
Argentina

Lara Lohne

October 29, 2012

Subject: IACC 2012 Strategic Plan Question

With the annual review and update of the IACC 2012 Strategic Plan coming up, I felt the need to chime in with topics that I feel are important, that affect my life personally and feel need additional attention and/or resources.

I have a son who was diagnosed with mild to moderate autistic disorder in May 2011, along with other co-morbid disabilities and disorders, but the year before in June had been given an educational label of ASD through the school districts Early Intervention program that he had been participating in since October 2009 when he was just over two and a half. The services he has received have been sparse, but he has made progress and is now attending a main stream school in kindergarten with special supports. Obviously the more intervention a toddler can receive the better his or her progress will be, and perhaps much of that is determined from state to state rather than on a federal level, but there are many things in my state that are not covered, and many more things that are difficult for a family in the situation mine is in to actually partake of, or participate in. For us, transportation is a huge issue, we don't have a car and the public transportation system is not managed or run by the government, but is a privately owned company, and they make all the policies and changes with regard to it and the routes and they recently made a big change which just makes it that much more difficult for us to get anywhere, and the buses never run as they are scheduled and sometimes by pass miles of their route all together if they happen to be running too far behind. Getting my son to the therapy appointments he had were too much of a stress for both me and for him, so we ultimately discontinued going. Public funding for transportation, vouchers to pay for a taxi or something similar, maybe a monthly transportation allowance sent along with SSI would be a huge benefit, particularly for families like mine, who pay $50 per month for bus fare and still have to minimize the number of times we go out.

Another area that I believe needs attention and funding is evaluation for adolescents and adults for ASDs. Since we know ASDs have always been around, and there is only just now the ability for most children to be diagnosed, there is a huge population of adolescents and adults that are being left behind, and many insurances won't cover the cost of an evaluation, even with a referral. My partner is one of these adults that was overlooked as a child. Born in 1972, he was always 'the odd one' in school, but when they tested him in elementary school, thinking he had a learning disability, he tested gifted and was placed in accelerated learning program. However, that only further distanced him from the other children in his class and he still had a difficult time blending in with them. He had suspicions all his life that he was crazy and didn't know it because there were just certain things, aspects of life or human interaction he couldn't quite get, no matter how much he observed and re-wrote his social software (as he refers to it as.) He has long believed that the world is backward to how logic says it should be, based on his observations. After the diagnosis of our son, and everything that we began learning about autism and ASD, we came to realize many of my partner's "quirks" were very similar to my son's stimming (lining things up and organizing by size, shape, color, etc.) We started then, about a year and a half ago now, to try and get him an evaluation, but while there are specialists who have experience evaluating adults for ASD, being able to take into consideration this is a person who has grown up writing and rewriting software to 'fit in' and not using evaluation tactics for a child, but the insurance we have through state medicaid does not cover adult ASD evaluations. His only hope for getting on SSDI or SSI himself (he is currently on medical leave from his work from home job and has been for 6 months) is for

someone to then diagnose one of his multiple co-morbid conditions, (those being bi-polar disorder, general and social anxiety, agoraphobia and possibly dissociative personality disorder [multiple personalities]) which we believe have developed over the course of his life as a response to growing up with ASD. It is his only hope because, if he could get even one of these diagnosed (so far he's only had a psychiatrist put in his record he probably has these things) then he would get supplemental security income (SSI) or supplemental security disability income (SSDI) and would potentially also qualify for medicare, which would then allow him additional coverage for additional services and he may then be able to get the evaluation he really needs, that being ASD.

To wrap this up, here is a bit of background on my family situation: My son was born in March 2007 and I knew he was different from the start. I had five neurotypical (NT) children before him, therefore I was aware that certain things he did, were not 'normal' behaviors for a new born. I didn't know what it was at the time, but when we were told he has autistic disorder they all made much more sense. My partner and I had both been laid off from the same company, who outsourced our jobs to India the end of 2006. We both tried to find work, but the economy never really recovered here (Oregon) since the dot com crash in the late 1990s. Not a lot of companies are willing to hire a woman is if 5 months pregnant either, knowing she's just going to be going on maternity leave before long. After our son's birth, I got a contract position that lasted all of two and a half weeks, until I was let go because I wasn't able to adhere to the 10 minute breaks and 30 minute lunches because it took me longer than that to express my breast milk, and they weren't willing to make accommodations for me, since it was only a temporary contract anyway. My partner got a part time position disc jockeying (DJing) at night clubs on the weekends. Not the best job for financial stability since he didn't get a wage, only tips. After a couple of months my partner was given a total of 5 nights per week where he was DJing and it was enough for us to cover our rent, but not much else. I started looking for another job and was given an offer to start on August 7th 2007. I was only making $11.50 to start, but it was better then what we had been making. My partner continued to work DJing at night. We had found day care for our son, but due to a cockroach infestation in the apartments we were living in, she had to ask us not to come back, because she saw a roach in his carseat. She refunded me the money I had paid her for the first month, and we used that to move, and were in a new place, roach free a week later, but her day care spot for an infant had been filled already. I tried looking for another place I could take him, trying to keep in mind that I wasn't sure how I was going to be able to afford that and everything else. My partner had a break down (something that has happened since I've known him a handful of times, and something he says has happened frequently throughout his life, which we attribute to just overload, emotional and mental, dealing with life, trying to be normal but not being normal) and he lost his DJ position about mid October 2007. He had been pushing himself really hard, as he was working 5 nights a week, and then going all the moving after work, not getting done until 5am some times and then coming home to sleep for a couple of hours and then watching our son while I went to work. And our son didn't sleep, not at night, not during the day, not for more than two hours here and there, so both of us were greatly fatigued, and it took its toll on my partner and he broke down. We both decided then he would be stay home daddy and I'd work. That worked out ok until our son reached the age of two and became prone to prolonged and constant meltdowns, what we thought were just simply tantrums that go along with being two. They were atypically severe though and it took us a few months before we were able to put all the little things together and come to the conclusion that he might possibly have autism. It took a few months to figure out where to take him for an evaluation, but once we got him in, his intervention began, and things made more sense as far as our son went. But my partner continued to be emotionally tried all day and then would collapse after I got home, sleep for three hours until dinner time, get up, eat and go back to bed for the rest of the night. I learned also that while he supplied our son with everything he needed (food, diapers changes, drinks, hugs when asked for, etc) there was very little interaction and it was

more of its time for a snack so get a snack, which didn't always get eaten. They actually engaged in what many of my son's specialists called parallel play, which is common in those with ASD, and it was actually them that led us to first suspect that my partner might fall on the spectrum also. I also learned that while our son's needs were being met, my partner was not able to meet his own. He did not eat, didn't shower, and didn't do anything except slim really, all day, listening to music or working with his CG art program. I tried my best to remind him to eat, but even with a reminder, he still had trouble fixing himself food and would stand in the kitchen trying to start making food, but paranoid about waking our son form his nap (he was always a very light sleeper) and just riddled with anxiety over making himself food. He'd leave the kitchen after standing there, unable to move for 30 to 40 minutes and collapse on our bed into sleep. We only had a pre-paid cell phone, which we only used for emergencies. So my only means of staying in contact with him, was email. I had explained my situation to my manager, explained that my son is disabled and my partner may very well be also, and suffers great anxiety sometimes and I need to be able to stay in contact with him to keep him grounded so I don't have to leave work and go home to take over. She seemed to understand, but still ended up writing me up for having my personal email open during work hours. I started using my work email to stay in contact with him and I got written up a year and a half later for that. She then began monitoring me daily at work, checking my computer, removed all permissions from my computer rendering it nearly impossible to do my job, yet I persisted, and had stopped using email to contact my partner. But he had a particularly bad day when he received a summons to court for contempt due to no payment of child support for another child that he had never met or seen. Even though he had told them he had not been working since prior to this child being born and was stay at home daddy for his disabled son. I took time off work go with him to court. I came back from work and things were even worse. My manager had resorted to intimidation and bullying tactics, writing emails to the department that were clearly about me, even though she didn't use my name, stalked up and down outside my cubical while monitoring all my calls, in or out, and checking my computer any time I left my desk to make sure I wasn't violating policy. One time I sent an email to my partner, forwarded one that she had sent to me, which i was intending to use as evidence in a bullying law suit against her. Turns out I had no case because there wasn't any constitutionally protected reason that she was bullying me, I was just an easy target. I went to lunch, came back from lunch and was called into her office and told i was fired. She didn't even wait until the end of the day, she clearly wanted to humiliate me by walking me out of the building in front of the entire department. So in October 2010 I lost my job and couldn't get on unemployment because she perjured herself in the telephone hearing by claiming she fired me for a different reason then what she had told me she fired me. I tried to get another job, but decided against it after learning how truly difficult it was for my partner to watch our son, but my partner was able to find a work from home position in December. My partner worked full time, or at least was scheduled full time, but rarely worked his full 40 hours per week, due to emotional stress and being overwhelmed with anxiety. He received a notice from the psychologist he was seeing that he shouldn't work more than 20 hours per week, so his hours were cut in half. A couple of months later, when he realized he was still not working his full scheduled hours, he got another noticed from the psychologist to work no more than 16 hours per week and 4 hours per day. But then shortly after this change, he had another breakdown and has been on medical leave every since. We are getting my son's SSI and we get food stamps (SNAP) and we are now on TANF. But we don't have enough income to cover our expenses. My partner is scheduled to go off medical leave the end of the month, but we worry that he may have another break down and we would find ourselves in this same situation again. If he could get SSI, or SSDI, it would help for those times when the breakdowns happen and he can't work. Like a safety net, but it's apparently a lost cause since he can't get the evaluation he needs by people with experience, because we can't afford to pay outright and medicaid doesn't cover most mental health issues, drug and alcohol addiction, depression, maybe some other minor things that wouldn't actually render a person disabled, but that doesn't fit my partner, not

with the number of breakdowns he's had that make him completely dysfunctional and that even when he is more functional, he has a hard time taking care of his own basic needs. We are struggling financially, probably more so then most people in this country, getting by on just $1130 per month in actual spendable cash, and then another $446 in food stamps, which can only be used to buy food. We also struggle emotionally with two disabled people in the household but only one of them acknowledged as such and I am sole care giver for both of them and it is hard to do. Perhaps by me telling my story you might see additional areas where assistance can be given or is needed, but all I can think of right now are our immediate needs, additional funding or coverage for those who are transportation challenged and more coverage or assistance for adult ASD evaluations.

Thank you for your time and for hearing me out and I am sorry this is so long, but I felt it necessary to relay our entire story and situation to give you the full impact of how our lives are affected by ASD and lack of services for those who needed it.

Lara Lohne

Sarah Finney

November 2, 2012

Subject: What do autistic people want from science?

Greetings,

Just finished reading an article in Forbes with the above title, written by Emily Willingham. A woman I know who posted the article on facebook suggested that we (a group of women diagnosed with Asperger's) contact this e-mail (which was mentioned in the article) to help provide input, but I have to admit I'm not certain what type of input /comments you require from people on the autism spectrum.

I have been diagnosed with Asperger's three times over, and my son has been diagnosed with both Asperger's and Attention Deficit Hyperactivity Disorder. I am in my mid-40s and only received my diagnosis in the last few years, which certainly explained a few things in my life. That said, perhaps it was better that I did not receive my diagnosis earlier because I didn't *know* that I was *supposed* to be lesser than other people (if one goes by autism stereotypes). For example, I have been employed all my adult life, and yet according to statistics, very few people on the spectrum are employed.

The friend who asked us to write you, if I recall correctly, may have recently done some type of study, which included an MRI, for your organization. I am not interested in doing such a study as I abhor MRIs, however, should there be some other way I can contribute, whether in writing or perhaps in person, please let me know.

thanks

Carol Greenburg

November 2, 2012

Subject: What autistics need in emergencies

I am the autistic mother of an autistic 10-year-old in Brooklyn. I want to share something that happened to this morning, in the aftermath of Hurricane Sandy. My son, who has not had school or therapy for a week and is disconsolate over the disruption of his routine, finally had some therapy scheduled for this morning. Public transit is not yet well restored enough for us to have used public transportation to get him to that therapy.

We have a car, but due to the citywide fuel shortage, we couldn't find any open gas stations, so we were worried we wouldn't have enough gasoline to bring our child home. I called Access-a-ride, explained that because neither my son nor I have mobility issues, we have never registered for any kind of para transit. I got a polite but firm refusal from the MTA staff person with whom I spoke. I understand the necessity for registration policies and that qualification takes time. But the employee I spoke to did not even offer to ask a supervisor about our unusual circumstances to see if some emergency accommodations could be made.

Hurricane Sandy was no one's fault, and overall I am very impressed by the federal, state, and local response. I also understand that though I can speak and my son cannot, our disabilities are not immediately obvious. But they are real and especially in an emergency like this, relevant. So with all respect that is very much due government workers during this crisis, I see a need for greater flexibility and creativity in serving autistics like us, a population so reliant on structure especially during an emergency.

A No to services for autistics in a disaster area, however politely phrased, is still a No. The only appropriate response to me, my son, and the many, many other people with disabilities in similar circumstances is "Yes, we will work with you until we find a solution."

Sincerely,

Carol Greenburg
East Coast Director
Autism Women's Network

Hillary Leonard

November 4, 2012

Dear IACC,

We believe our child's autism was caused by immunizations over stimulating our son's immune system, starting with the haemophilus influenza B (HIB)/hepatitis (Hep) B shots given in the hospital. He suffered from some sort of reaction or virus that caused him to go semi-conscious, lethargic and very difficult to wake. He was taken to the ER for fluids because of the amount of time that had passed and we could not wake him. This symptom was recently been identified in peer reviewed research. We feel this long time between feedings contributed to the problem. We allowed immunizations until 7 months when we saw a seizure and stopped all immunizations.

In hindsight, we feel he was high risk due to family metabolic sensitivities and immunizations damaged his immune system. He has had positive and near immediate improvements to biomedical supplementation. His self-regulation, information processing and executive functioning improved within a week of starting probiotics and supplements to correct nutritional deficiencies. The damage went as far as mitochondrial damage which he also is supplemented for.

We are still trying to sort out how to get his enzyme system working normally. We strongly believe that his 5 methylation pathways were disrupted by immunizations and caused nutritional deficiencies that spiraled him down into mineral imbalances, hormone imbalances, amino acid imbalances and ultimately brain damage from the imbalances and inflammation. http://www.heartfixer.com/AMRI-Outcomes-Non-CV-Autism-Methyl%20Cycle.htm see methylation map

We are angry that at risk populations were not identified before asserting that immunizations were good for all kids. This has bankrupted us and left us renters at 52 years old, making our golden years and his transition needs or college needs and future at high risk for destitute. We spent our entire savings, home equity and 50K of retirement. Insurance has paid for nothing. Our life has been nutritional trial and error, fighting with public schools, bullying, and discrimination. Our lives have been devastated by something that was preventable.

Hillary Leonard
Seattle, WA

Pam Rockwell

November 5, 2012

Subject: Public comments for the IACC about the 2012 Strategic Plan update

I am concerned that some new issues that were discussed at the International Meeting of Autism Research (IMFAR) in Toronto in this past summer are being overlooked during the quick and storm impacted process to update the IACC strategic plan. I have been listening in on the IACC conference calls and it is quite possible that you have already addressed some of these concerns in the 2012 Strategic Plan in written materials that were only available to committee members and invited experts, but I wanted to be sure that these concerns are addressed and not left another year. In particular I am concerned about:

1 Animal models of non-specific autism and specific gene variations of autism are essential to the successful translation of research discoveries into medical interventions and biomarker products. They should be addressed as a global issue under question 7. There are some mouse models for non-specific autism (such as BTBR T+tf/J and C58/J mice), as well as genetically engineered mouse models that match specific gene-associated types of autism (by removing a gene like the fmr1-/- mouse used to model fragile X, or adding a human gene, or modifying a gene for something associated with a gene product that is damaged in autism like the CNTNAP2 mouse model of oxytocin deficiency.) There are also mouse models that use antibodies to block specific proteins or receptors to model autism. In order to do real pharmaceutical testing, these models need to be developed in larger animals, like rats. In order to do real behavior and safety testing, these models need to be scaled up to primates. Research from the Bear lab comparing autism caused by fragile X and tuberose sclerosis shows that medications which treat one type of autism can cause harm in another. New treatments will need to be screened against every possible type of autism so they can be targeted safely. The IACC needs to make sure these animal models are ready before the treatments are… which is now. The IACC also needs to encourage scientists to look outside the field of autism for animal models of co-occurring conditions and see if these animals also present with symptoms of autism.

2 Reduced pupillary light reflex speed may be an early biomarker for autism. At IMFAR, there were several abstracts that discussed slowed pupil constriction as a biomarker for slow processing speed in autism, including one that had a computer aided measure for infants. This warrants additional resources because it is possible that this concept could develop into an inexpensive in-hospital screening test to identify children at birth who would benefit from genetic testing, EEGs, and early intervention even though they have no family history of autism.

3 Family Planning is a big issue for parents with an autistic child or autistic relatives. There are micro-chromosomal array tests already on the market. This year the maternal antibody test will be available. Other genetic screening tests will also be available this year for children with autism. Parents will use this information for family planning whether physicians and researchers present it that way or not. (I know of a family with a girl with Retts who used extraordinary methods to conceive a boy, and planned to abort if it was a girl…) The IACC needs to be summarizing information about which kinds of testing can be used to guide contraception (maternal antibodies, heritable gene mutations) and which can only be evaluated in a child after it is conceived (de nova mutations.) These tests are out there, so discussing ethics is not going to prevent their use. For instance, a maternal antibody test can be used before a woman gets pregnant and give her a sense of whether she might want to choose not to get pregnant

again, but if she does not know that the test exists until she is already pregnant, then she might use it to decide to have an abortion. While I am a big supporter of abortion rights, I think we all agree that contraception is a better choice than abortion. We do not want to be inadvertently causing more abortions because we were unable to get information to parents when contraception was still an option. We also do not want uninformed opponents of abortion thwarting genetic research and funding because they believe that the only use of the information is to select for abortions. The IACC needs to facilitate the transformation of new genetic and biomarker information into practical information for physicians and parents for family planning purposes and the IACC needs to keep that information up to date.

4 Pharmaceutical interventions for autism need more attention from the IACC. Many of the medications that are under development for autism have older, generic equivalents that are not being evaluated by pharmaceutical companies because they are not patentable. Research into these medications should be supported by the IACC. Currently, patients are doctor shopping to find medications, and physicians are diagnosing other conditions more liberally in order to justify the use of medications like baclofen for autistic patients. Once results from studies of oxytocin become available, the same can be expected.

I was particularly concerned about the IACC's understanding of advances in medical treatments for autism when I listened to Noah Britton (who seems to be responsible for writing the draft of this section of the document) make comments that he felt that no treatment that used a reduction in arm-flapping could be considered valid because autistic individuals take comfort in that behavior, so it shouldn't be reduced. (I may not have quoted that word for word, but I think I did represent Mr. Britton's position accurately.)

In additions to the rehashing of the use of atypical anti-psychotics (Rispiridone and Ariprozole) amd SSRIs (Prozac), there were these interesting developments in medications for autism mentioned at IMFAR this year:

> ***Stimulants:*** *Ritalin, marketed as Concerta for ADHD also helps autistic individuals with focus – this is important because there is already a lot of childhood safety data for many stimulants used to treat ADHD, including amphetamines, other forms of ritalin, and focalin (an isomer of ritalin.) Most of these drugs are already available as generics, so there is no reason that pharmaceutical companies will do studies to see if they would work for autism – so this is a place where the IACC can have an impact by targeting studies that test the off label use of ADHD medications for autism. Many physicians are already prescribing these meds for autism by giving their patients a provisional ADHD diagnosis to justify the use of the meds to insurance companies. Data about how these drugs are already being used in the autism community could be helpful in designing future studies and developing dosing guidelines for use in autism.*
>
> ***Oxytocin****: Oxytocin is being tested to help with core social symptoms of autism and emotional control. This developed because blood oxytocin levels were reduced from the norm in many adults with autism. Several genetic studies also support reduced gene expression of oxytocin in autism. This is important to discuss because oxytocin is already available by prescription, so if these tests show that oxytocin really helps with autism there may be a rush to prescribe this off-label. Blood levels of oxytocin may be a biomarker for whether oxytocin is an effective treatment for autism, so the committee might also want to consider a recommendation that testing blood levels of oxytocin should be part of regular screenings for children diagnosed with autism.*

Glutamate receptor system: *Several different lines of autism research are all pointing to one particular synaptic organization that might be responsible for some symptoms of autism. This is the glutamate receptor system. Glutamate is released during stress and learning. The release of glutamate is modulated by GABA, which inhibits the release of glutamate from the pre-synaptic neurons. The post-synaptic neurons have several different types of receptors that respond to glutamate, and some of these receptors are known to be associated with genetic disorders that are linked to autism. One of these receptors, mGluR, controls mTOR (molecular target of rapamycin) a molecular signaling system that initiates translation of mRNA into proteins. Genetic variations of mTOR are also linked to schizophrenia and obesity. There are several different types of medications that are being tested in autism that relate to the GABA/glutamate/mTOR system, and many of them have generic analogs:*

GABA agonists*: a GABA agonist will theoretically reduce the amount of glutamate released and therefore the amount of proteins produced by the mTOR cascade by blocking the GABA receptors on the presynaptic neuron without triggering the natural function of the GABA receptor. Baclofen is a prescription GABA agonist that is used as a muscle relaxant in cerebral palsy and gastrointestinal reflux, and anecdotal data about baclofen helping core symptoms of autism have led many physicians to prescribe baclofen at the first sign of muscle spasms or reflux in autistic patients. Arbaclofen is a particular isomer of baclofen that is being developed specifically for treatment of fragile X syndrome. While arbaclofen trials are not complete, the same issues as oxytocin apply: should the committee be collecting data about off-label use of baclofen (much cheaper than arbaclofen) and recommending testing for biomarkers for success (genetic tests for fragile X).*

NMDA receptor modulators: *NMDA receptors that are a particular type of glutamate receptor which is pivotal in learning and memory. NMDA receptors have been implicated in several mental illnesses, including Alzheimer's disease and autism. There are many NMDA receptor antagonists already on the market, which block the reception of glutamate on the post-synaptic neuron. Memantine, an Alzheimer's drug, was shown to reduce core symptoms of autism. (My son actually takes an NMDA antagonist called amantadine, which has never been formally tested to treat autism.) Other NMDA antagonists are PCP(angel dust), ketamine (an anesthetic tested to treat dangerous depression), eliprodil (an antiseizure drug), and dextromethorphan (Robitussin). The success of memantine trials raises questions about whether it should be used more widely, or whether other NMDA antagonists should be tested (these are all out of patent-no drug company wants to test them.) Also, whether eliprodil might be indicated for autistic individuals who also have epilepsy.*

mGluR5 receptor modulators*: The glutamate receptor that is implicated in fragile X syndrome is mGluR5, and there are two companies that have developed modulators of this receptor, Seaside Therapeutics and Pfizer. Seaside has shown that this drug reduces core autism symptoms in fragile X and there are ongoing studies about non-genetically linked autism.*

Rapamycin*: Rapamycin is an old antifungal medication that turns out to be a strong immune suppressant most often used in organ transplants. Rapamycin acts downstream of the glutamate receptors, increasing translation of RNA into proteins when it binds the molecular target of rapamycin (mTOR). It has been shown to cause remission in tuberose sclerosis patients, and it reduces their core autism symptoms. Variations in the mTOR gene have been linked to schizophrenia, and rapamycin is being tested as a treatment for schizophrenia.*

This past year, autism researchers have compared mouse models of two different disorders that are known to cause autism: tuberose sclerosis and fragile X. While both diseases cause autism and are related to the glutamate receptor system, they do it in the opposite way, fragile X by increasing protein production, and tuberose sclerosis by reducing it. This means that it is really important to know how the autism symptoms are being caused before you try a particular medical treatment – rapamycin will help tuberose sclerosis patients and hurt those with fragile X, while mGluR5 modulators will hurt those with tuberose sclerosis and help those with fragile X. This really emphasizes how important genetic screenings and other biomarkers are for selecting medical treatments.

Nutritional supplements: *From the moment my son was diagnosed, people started trying to sell me vitamins that would cure him. Two important studies have come out this year. Prenatal folic acid supplements help prevent autism (we already knew they prevent spina bifida) and large doses of omega-3 fatty acids can reduce core autism symptoms. Because there is so much unsupported information about vitamins and autism, and because there are some vitamins that you can overdose on, the committee might want to consider whether the strategic plan should include some way of relaying this information to physicians and the general public.*

Glutathione modulators: *I thought this was the most exciting thing I saw at IMFAR. Kuvan (tetrahydrobiopterin) is a drug that was developed to treat PKU, but there are very few people who have PKU and it is very expensive. Research this year has shown that it treats core autism symptoms without a lot of side effects. This is important because it is a new use for kuvan, but also because it is a hot research topic to use drugs that target glutathione to treat conditions that are associated with inflammation. Currently the only drugs that treat inflammation are immune suppressants that make the patient susceptible to infections, and NSAIDS which a can cause heart disease. These glutathione modifiers (I'm not sure I'm using the right term here – this is biochemical, not receptor modulation) are basically super antioxidants. Another glutathione modulator, Biogen's BG-12 (dimethyl fumarate), made a big impact when it was shown to reduce multiple sclerosis relapses, although this mediation appears to have more side effects than kuvan. Besides the fact that kuvan is effective, this is important for the committee to consider in the strategic plan because new drugs that target glutathione will be in the pipeline for a variety of illnesses – autoimmune disorders, heart disease, obesity etc. – and autism researchers should be encouraged to coordinate with clinical trials for other disorders when these drugs are tested.*

I imagine there will be a lot of pressure to ignore advances in the medical science for yet another year, until the committee has more time to write. But I think that would be doing a disservice to the intent of the US Congress. I think Congress expected that in creating the IACC they would be encouraging a group that would connect the dots and take a leadership role in making sure that no important aspect of autism research was overlooked: like medical treatments that are not particularly profitable for drug companies, genetic tests that might be expensive for health insurance companies but could help shape treatment plans, or medical treatments for different disorders are also treatments for core autism symptoms. I think that requires more than a google search of autism papers to really understand what is going on in this field. I think it requires getting to know the researchers in the field and being able to ask them how the research is going and what the implications of their research might be, above and beyond what is published.

I think that when Congress created the IACC they expected that designating a person on the committee from each government agency would mean that there would be a person at each agency who really had

a global view of what was going on in the world of autism research and services. But they did not actually designate funds to pay a person at each agency to be an expert at autism. People who serve on the committee are expected to do their full time jobs at their agency or organization and also become an expert in autism to serve on the committee. As you try to keep up with all the reading and writing that you have to do to get up to speed with your responsibilities just to write one small piece of the many policy papers that will be produced by the committee in the next year, think about whether it would be a good addition to the Strategic Plan to ask Congress to actually fund continuing staff positions that are experts at autism at each of the government agencies that serve on the committee.

I know that you have certainly been given a daunting task to bring new committee members up to speed and update the strategic plan so quickly. I hope my comments will help with your work.

Thank you,
Pam Rockwell

Eileen Nicole Simon

November 20, 2012

Subject: Basic and Translational Research call, Nov 26

The brain (not traits, genes, or the gut) should be the primary focus of research on autism. Autism is a neurological disorder with two prominent features: (1) Developmental language disorder and (2) Repetitive stereotyped movements.

The language areas of the cerebral cortex develop postnatally guided by trophic neurotransmitters produced in nuclei of the brainstem auditory pathway [1-4]. Myelination (maturation) of the brainstem auditory pathway is complete at the time of birth.

Nuclei of the auditory pathway are susceptible to impairment by prenatal exposure to toxic substances and anoxia during birth [5, 6]. This is because blood flow is higher in these nuclei than anywhere else in the brain [7]. Subcortical motor nuclei are also susceptible to perinatal injury; see the picture below from Lucey et al. showing common sites of bilirubin staining, and that bilirubin staining is not uniform throuout the brain [8].

Note that this understanding should have been common knowledge decades ago.

What is new are the reports by Kulesza et al. and Lukose et al. of malformations of the superior olivary complex found in postmortem brains from people diagnosed with autism, and in laboratory rats exposed to valproic acid during gestation [9, 10]. Please include these in updates to the Strategic Plan.

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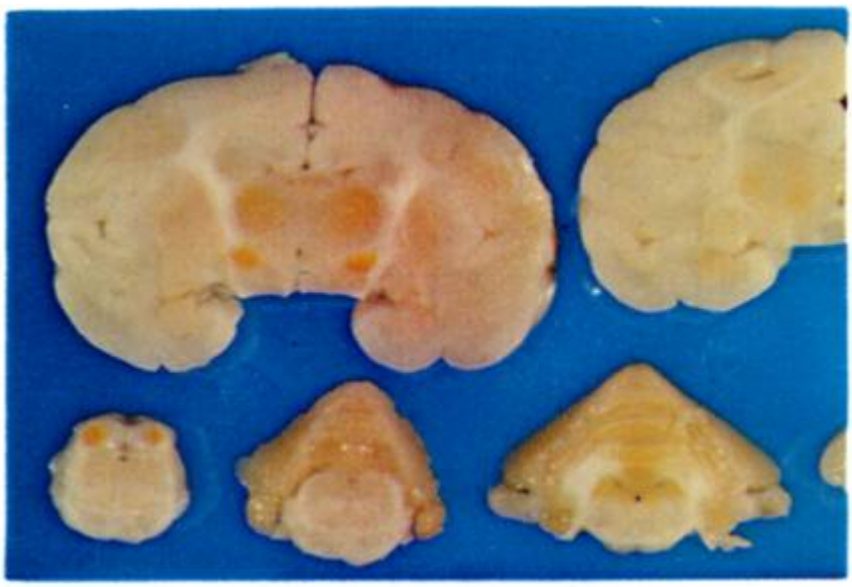

Eileen Nicole Simon

November 21, 2012

Subject: Mandatory long-term-care insurance from birth

I submitted comments on October 25 to the subcommittee led by John O'Brien and Jan Crandy on Questions 5 and 6 for the Strategic Plan, with the following links to my responses to requests for public input (RFIs) in 2009 and 2010:
http://iacc.hhs.gov/public-comment/2009/rfi_comments/q5/index.shtml
http://iacc.hhs.gov/public-comment/2010/rfi_comments/index.shtml

My son turned 50 in September. Some people criticize me for not having him live at home with me, but when he did live at home he came to the attention of the police almost daily. Now near the end of my miserable life, what should happen when I suddenly am gone? Below is a picture of us from 5 years ago (Autism Awareness Day 2007) on the roof of the Massachusetts State House. Autism Awareness Day is an annual event at the State House where parents meet with legislators to beg for more money. Private insurance would be a better alternative, but this would have to be mandatory for every child born.

My son's developmental problems, diagnosed as autism when he was 4, were the result of severe head injury and anoxia at birth. He was one of the earliest victims of avant-garde obstetrics. Use of the umbilical cord clamp immediately after birth terminates placental respiration before the lungs are fully functional. This should be investigated as one cause of increasing autism prevalence, because of the way the brain is affected by anoxic-ischemic insult. The basal ganglia (subcortical motor control) and nuclei in the auditory pathway are involved in a predictable pattern of damage. This should have become common knowledge decades ago.

Umbilical cord clamping is hopefully on the decline due to a quiet grass-roots movement. But what about the autistic children born during the last 2 to 3 decades? Public funding cannot be expected to cover the lifespan care that will be required for the huge increase in people unable to live independently. My suggestion is that purchase of private long-term-care insurance should be required for every child born. Insurance companies know how to deal with evaders, as they do for people without car insurance, and actuarial scientists should not be reluctant to investigate obstetric procedures.

Mandatory long-term-care insurance for every child born would not be as expensive as the policies middle-aged people are encouraged to take out. During the conference call held September 19 the suggestion to seek advice from private insurance companies came up more than once. I hope members of the Services Subcommittees can explore this possibility.

Note: Personally Identifiable Information (PII) has been redacted in this document

Eileen Nicole Simon

December 2, 2012

Subject: Hearing held by the Committee on Oversight and Government Reform

I listened to part of the hearing held November 29 on rising rates of autism. Below is the response I sent this morning to thank members of the Committee on Oversight and Government Reform. Appended to the response are comments I sent in advance of the hearing, to which I also appended a presentation I made in person at the IACC meeting four years ago, in November 2008.

Dr. Guttmacher told the oversight committee that the IACC is responsive to public input. This is not true, and it has been very disappointing because the ideas of stakeholders have been totally disregarded in formulation of the Strategic Plan. Focus of the Strategic Plan should be the language disorder (the major and most serious handicap) of children with autism, and brain systems essential for learning to speak should be the major research activity encouraged. Evidence in the medical literature from decades ago should also not be disregarded. The brain impairments underlying language, attention defects, and movement disorder in autism could also perhaps have been understood decades ago.

Please forward this e-mail to members of the IACC, and I hope some of them might take time to review my comments to the Committee on Oversight and Government Reform contained in the PDF file below.

Sincerely,
Eileen Nicole Simon, RN, PhD

Response to Committee on Oversight and Government Reform:

December 2, 2012
To: Representative Darrell Issa, Chairman, and
Members of the Committee on Oversight and Government Reform

CC: Members of the IACC
From: Eileen Nicole Simon, RN, PhD

Thank you for the excellent hearing on the Federal Response to Rising Rates of Autism. I watched from 2 to 4pm while in the library with my autistic son (who is hard at work writing a second memoir with me).

I was especially impressed by the comments and questions posed by House committee members.

I believe it was Representative Elijah Cummings who suggested maybe the IACC committee should be composed of members outside NIH. Three years ago I suggested that we need something like the National Transportation Safety Board (NTSB) to investigate the catastrophe of autism. See http://conradsimon.org/files/IACC4feb2009.pdf

Dr. Guttmacher tried to say that the IACC is receptive to public opinions, but it is not. Representative Paul Gosar described his personal affliction, and frustration that "Researchers don't listen," and that this is a slap in the face.

Vaccination was not the cause of my son's autism. He suffered trauma and anoxia at birth, and was born before the era of so many vaccinations given in infancy. However, I liked Representative Carolyn Maloney's comment, "Why so many shots in such a short period of time?" She correctly pointed out the clear evidence that before the increase in infant vaccinations autism rates were low, then began increasing with the large numbers of vaccinations given at earlier ages. Then Representative Vern Buchanan's question, "What about interactions between all these vaccines?" Representative Cummings comment should be heeded, "Let's put the brakes on this situation. Shouldn't we err on the side of safety for children?"

Chairman Issa, thank you for stating, "We need a systematic approach to what we are putting in our bodies."

Another (less prominent) intervention that should be questioned is the obstetric protocol for clamping the umbilical cord immediately after birth. This practice was recommended in the 1950s for preservation of the "sterile field" when episiotomy was adopted as a routine procedure, as well as for Cesarean deliveries.

However, until the mid 1980s all textbooks of obstetrics taught that the umbilical cord should not be severed until pulsations in it had ceased. Pulsations of the umbilical cord are evidence that the anatomy of the heart has not completed the change from directing blood to the placenta for oxygen, to the lungs. Clamping the cord risks causing a lapse in respiration, which is dangerous even if the period of oxygen deprivation is brief.

Damage in the brain caused by a brief period of asphyxia is most prominent in the auditory pathway and basal ganglia (centers for subcortical control of coordination and movement). This was shown in long-forgotten experiments with monkeys, but is also evident in brains of babies who died of asphyxia. Damage of the auditory system should be investigated as relevant to the language disorder in autism, and injury of the basal ganglia as the cause of repetitive and stereotyped movements.

I hope members of the House Committee on Oversight and Government Reform received the comments I submitted before the meeting on November 29, to which I appended a presentation that I made at the IACC meeting held November 21, 2008.

Thanks again for this excellent hearing. I hope more hearings are planned to investigate the catastrophe of autism.

Comments submitted to the United States House of Representatives, Committee on Oversight and Government Reform, Representative Darrell Issa, Chairman

1 in 88 Children: A Look Into the Federal Response to Rising Rates of Autism
From: Eileen Nicole Simon, RN, PhD
Conrad Simon Memorial Research Initiative
http://www.conradsimon.org/
For the hearing on November 29, 2012

2 p.m.
Rayburn Building, Room 2154

Introduction
Dear Chairman Issa and members of the Committee on Oversight and Government Reform. Following are comments from my perspective as a parent and longtime follower of research on autism. I believe the brain impairments underlying the language handicap and repetitive stereotyped movement disorder of children with autism should have been well understood decades ago. How can such a tragedy have been allowed to persist for so long?

50 Years Ago
My son with autism is now 50 years old. He was born in September 1962, and suffered head trauma and anoxia during birth. By Christmas 1962 we recognized that he was not developing normally. Thus it was 50 years ago that I began reading everything I could find on child development. In 1969 I was accepted into the Medical Sciences Program at the Boston University School of Medicine, and I received a PhD in Biochemistry in 1975.

Research
I had barely begun my graduate studies when the October 1969 issue of the Scientific American arrived in my mailbox, with an article by William F. Windle, Brain Damage by Asphyxia at Birth [1]. The primary site of damage in monkeys subjected to asphyxia at birth was found in the midbrain auditory pathway, and I realized right away that such damage could prevent language development in human infants. The effects of oxygen insufficiency at birth became the topic of my dissertation research, which led to publication of three papers in the medical literature [2-4].

I continued doing research for one post-doctoral year, but quickly realized it would be difficult to obtain funding for research that implicated birth injury as a cause of autism. I chose motherhood over research, and returned to my former career as a software engineer. I also, of course, continued to follow the literature on autism and the brain.

Letters-to-the-editor were all that I could get published.

http://www.conradsimon.org/
In April 2000 I setup a website, http://www.conradsimon.org/, and posted my views on the brain impairments underlying the language disorder in autism. I soon was contacted by people concerned about the “drive through” methods involved in childbirth. In addition to uterotonic drugs to initiate and speed-up labor, I learned that against all traditional teaching, clamping the umbilical cord within seconds following birth had become the norm.

Clamping the Umbilical Cord
Clamping the umbilical cord immediately after birth is extremely dangerous. It immediately stops blood flow from the placenta, which according to older textbooks should be allowed to continue until the baby’s lungs have taken over the function of respiration. The experiments with monkeys involved delivering the head into a saline filled sac then clamping the umbilical cord. That the most prominent injury was found in the auditory pathway is what is most significant to consider as a possible cause of autism. Learning to speak is dependent upon intact hearing.

Since 2003 (for 9 years this month) I have been trying to urge the Interagency Autism Coordination Committee (IACC) to investigate immediate clamping of the umbilical cord at birth as a possible reason for the increasing prevalence of autism. They have been totally unresponsive. If clamping the cord at birth is safe, they should be able to provide evidence of this, not just respond with silence.

Focus on Neurology, not Behavioral Traits

Language disorder is the most serious handicap for children with autism, but this is referred to only in passing in the IACC Strategic Plan for research. This is wrong, and members of the committee should be asked why language development is not a priority issue in their Strategic Plan.

Autism diagnosis is based on traits: Language delay, social obliviousness, and repetitive stereotyped movements. These represent a neurological disorder, and impairments in the brain should be sought as the cause. Instead great efforts have been made to link traits to genes, and to traits in parents and siblings. This is stigmatizing and offensive.

Autism Has Many Causes

Autism is associated with many different medical conditions. Many of these are genetic, like phenyketonuria, neurofibromatosis, tuberous sclerosis, fragile-X, adenylosuccinate lyase deficiency, and even Down's syndrome. But autism is also associated with prenatal exposure to the anti-seizure medication valproic acid (Depakote), thalidomide, and in some cases of fetal alcohol syndrome. Many reports of complications at birth (most associated with low Apgar scores) have been published, but then dismissed as non-specific for autism, and with only passing mention of the brain.

Vulnerable Sites in the Brain

Damage of nuclei of the auditory pathway have been reported in many investigations of toxic substances. Auditory system damage was found last year in the brains of 9 people diagnosed with autism, and the same neuropathology then produced in laboratory rats exposed to valproic acid (Depakote) during gestation [5, 6]. I have suggested these papers be included in the update to the IACC Strategic Plan, but I don't hold out much hope.

Stakeholder Ideas

I would appreciate acknowledgement and discussion of my ideas about brain impairments that may be involved in cases of autism. I don't see any reason to continue funding the IACC unless they can be required to discuss stakeholder ideas, and provide specific evidence for dismissing any suggestions made for why autism prevalence continues to increase.

Actuarial Science is Needed

Actuarial scientists from Social Security and private insurance companies should have been included as members of the IACC. They might have been more likely to recognize the relevance of research with monkeys on asphyxia at birth, and the numerous reports of birth complications among children later diagnosed with autism. They would surely have recognized the danger posed by clamping the umbilical cord before the first breath, and the significance of injury to nuclei in the auditory pathway.

The brain impairments that prevent learning to speak, and how they come about, should have become common knowledge decades ago.

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Addendum:
My first two sons, [PII redacted], suffered trauma and asphyxia at birth. [PII redacted] was delayed both in motor and speech development. Although he had to be resuscitated at birth, [PII redacted]'s motor development was right on time, but he never gained normal use of language. [PII redacted] died at the age of 31 of a prescribed overdose of Thorazine. The shocking and sad details are on the website I setup in his memory, at: http://www.conradsimon.org/.

Following is a presentation I made at the IACC meeting November 21, 2008. I had rehearsed the time limit I thought I had been given, and managed to present all of my slides, but I was abruptly cut off at the point I had hoped to ask for comments. This committee has not adequately discussed any of the stakeholder comments presented. I have added one more slide to this presentation, which shows that the auditory pathway is one of the earliest maturing (myelinated) systems during development of the brain. The language areas of the cerebral cortex develop under the guidance of trophic neurotransmitters produced in the brainstem auditory system. This maturational process will be disrupted if the auditory nuclei are injured during a traumatic anoxic birth.

Slides available at: http://www.conradsimon.org/IACCfor21nov2008.pdf

Eileen Nicole Simon

December 4, 2012

Subject: Re: Library Question – Answer [Question #8187599]

Thank you for your quick response to my request for written comments submitted for the last IACC meeting. I counted 30 people, and I think a 2 to 3 page list with a summary of each person's comments should be provided along with the transcript of the meeting. The anger is over being completely ignored. At the Committee on Government Reform hearing, Dr. Guttmacher said that the IACC includes ideas brought up by the public in written and in-person comments, but they don't. He also said progress is frustratingly slow, but that's why ideas from the public should be addressed. A lot of people have a lot of ideas, and responses to all should be provided. Soy products, fructose, prenatal ultrasound, maternal antibodies, vaccines, obstetric procedures, and all medical interventions should be looked into, and at some point responded to. None of these ideas should just be dismissed because no evidence exists. Please forward this email to members of the IACC. Thanks.

Eileen Simon

Eileen Nicole Simon

December 11, 2012

Subject: Written comments for the IACC meeting on Dec 18

QUESTION 2:
Developmental language disorder needs to be the primary focus of research on autism. Failure to develop language is a clear sign of neurologic impairment within the speech areas and/or association tracts of the brain. Ample fMRI data of "underconnectivity" has been published in the medical literature over the past 8 years. Maturation of the language areas takes place during the first 4 to 5 postnatal years [1]. The cause of neurologic injury may begin during prenatal development, but developmental deviation may begin as late as the first 2 to 3 years.

Trophic neurotransmitters produced in nuclei of the auditory pathway guide the postnatal development of target areas in the cerebral cortex, which in humans includes at least the receptive language area [2]. Nuclei in the auditory pathway were selectively damaged In experiments with monkeys subjected to asphyxia at birth [3]. This damage was almost missed because of the small size of the auditory nuclei, but Kety (1962) suggested looking in the auditory pathway because his recent experiments had revealed that blood flow in the brain is highest in the auditory system, especially in the inferior colliculi and superior olivary complex [4].

Two papers published in 2011 reported malformations in the superior olivary complex (a) in the brains of 9 people who were autistic, and (b) in the brains of laboratory rats exposed to valproic acid during gestation [5, 6]. I have tried to point these papers out to the subcommittee working on Question 2 of the Strategic Plan, but it appears my comments have been ignored. Please reconsider this omission.

REFERENCES
[1] Yakovlev PI and Lecours A-R. The myelogenetic cycles of regional maturation of the brain. In A. Minkowski (Ed.), Regional Development of the Brain in Early Life (pp. 3-70). Oxford: Blackwell Scientific Publications, 1967.
[2] Friauf E, Lohmann C. Development of auditory brainstem circuitry. Activity-dependent and activity-independent processes. Cell Tissue Res. 1999 Aug;297(2):187-95
[3] Windle WF. Brain damage by asphyxia at birth. Sci Am. 1969 Oct;221(4):76-84.
[4] Kety SS. Regional neurochemistry and its application to brain function. Bull N Y Acad Med. 1962 Dec;38:799-812. www.ncbi.nlm.nih.gov/pmc/articles/PMC1804882/?tool=pubmed
[5] Kulesza RJ Jr, Lukose R, Stevens LV. Malformation of the human superior olive in autistic spectrum disorders.Brain Res. 2011 Jan 7;1367:360-71.
[6] Lukose R, Schmidt E, Wolski TP Jr, Murawski NJ, Kulesza RJ Jr. Malformation of the superior olivary complex in an animal model of autism. Brain Res. 2011 Jun 29;1398:102-12.

QUESTION 3:
Obstetric and neonatal procedures must be considered in looking for causes of the increased prevalence of autism over the past 20 years. The most dangerous and foolhardy of these interventions is use of a surgical clamp on the still-functioning umbilical cord at birth. In 10th grade biology (in the 1950s for the New York State Regents) we learned that the anatomy of the heart must change at birth before the lungs can take over the function of respiration, and that placental respiration continued until the umbilical cord stopped pulsating.

Apgar and colleagues (in New York City) in the 1950s were clamping the cord immediately after birth to preserve the "sterile field" for surgical repair of the episiotomy, which they were promoting as part of standard care during childbirth [1]. Thus the need for Apgar's scoring system, and her comment that it is common for an infant to breathe once, but then become apneic for many minutes, and that "A satisfactory cry is sometimes not established even when the infant leaves the delivery room." [2, p260]

Traditional textbooks into the 1950s (most until the 1980s) taught that the umbilical cord should not be severed until the infant was clearly breathing, and preferably not until its pulsations had ceased. How can a whole profession have become ignorant of basic physiology that used to be taught in the 10th grade?

The heart is the first functioning organ of the embryo, its purpose to circulate blood first from the yolk sac then the placenta. The foramen ovale and ductus arteriosus must close after birth, and blood redirected to the lungs via the pulmonary artery. It has long been known that these changes do not take place at the instant of birth [3].

Clamping the umbilical cord immediately at birth is dangerous. Most infants appear to suffer no harm, but a lapse in respiration can occur. Statistics reported for "respiratory depression" at birth are eerily similar to those for prevalence of autism. Respiratory depression at birth (anoxia or asphyxia) is likely to cause damage in the auditory pathway, which in turn may prevent normal development of the language areas of the cerebral cortex [5].

The IACC should quietly negotiate with the obstetric profession to stop clamping the umbilical cord. A mother-to-be recently told me they no longer clamp the cord in Boston hospitals. If so, watch and look for decreasing numbers of children with autism born in Boston.

[1] Apgar V, Holaday DA, James LS, Weisbrot IM. Evaluation of the newborn infant – second report. JAMA 1958; 168(15):1985-9.
[2] Apgar V. A proposal for a new method of evaluation of the newborn infant. Curr Res Anesth Analg. 1953 Jul-Aug;32(4):260-7.
[3] Gunther M. The transfer of blood between baby and placenta in the minutes after birth. Lancet. 1957 Jun 22;272(6982):1277-80.
[4] Baskett TF, Allen VM, O'Connell CM, Allen AC. Predictors of respiratory depression at birth in the term infant. BJOG. 2006 Jul;113(7):769-74.
[5] Windle WF. Brain damage by asphyxia at birth. Sci Am. 1969 Oct;221(4):76-84.

Note: Personally Identifiable Information (PII) has been redacted in this document

Eileen Nicole Simon

December 13, 2012

Subject: International Conference on Transitional Care

This is the announcement of a conference to be held April 19 in Birmingham England. Please note the subjects to be presented, and the presenters. See the full announcement with links at http://www.birmingham.ac.uk/facilities/mds-cpd/conferences/obstetric-conference/index.aspx (IACC Note: URL is not valid.)

Note that many people now question umbilical cord clamping as currently practiced following birth of a child. I hope that some of the IACC members and those who work in their agencies will consider attending this important conference.

Sincerely,
Eileen Nicole Simon, RN, PhD
[PII redacted]

University of Birmingham

International Conference on Transitional Care

Hear about and debate new developments from human and animal studies that have advanced our understanding of the physiology of transition at birth. This will have important implications for clinical care and practice by obstetricians, midwives and pediatricians, and exciting developments leading to improved neonatal outcomes. Obstetricians, pediatricians, senior midwives and advanced neonatal nurse practitioners are encouraged to attend.

Programme

Childbirth today is safer than it ever has been throughout history. Modern medical technology allows us to detect problems early, and to tackle these problems effectively. But many births are free from problems, so the challenge for obstetrics today lies in understanding and supporting the natural process of childbirth, without over-medicalising it.

There's no need for a conflict between a scientific approach to childbirth and a 'natural' one. Evidence-based practice should enable practitioners and parents to make informed decisions, limiting intervention to those cases where it is necessary for the health of mother and baby.

As well as cord clamping, other topics for discussion include:
How safe is home birth?
Can positions speed up childbirth or help to reduce obstetric trauma?
What are the pros and cons of different forms of pain management?

Friday 19th April 2013

Transition and cord clamping (Healthcare Professionals)

08.30 Coffee and Registration

Session 1 - Chairs: Dr Andrew Gallagher & Dr Clare Willocks

09.30 Welcome and Introductions
Physiology as taught in medical text books
Dr David Hutchon

09.50 Effect of cord clamping on cardiac output and the cerebral circulation
Dr Tonse Raju

10.30 The value of the placental transfusion in preventing circulatory problems during transition at birth. Transition at birth – the natural pace
Professor Susan Niermeyer

11.00 Changes in the umbilical blood gases in the cord vessels during transition
Dr Nana Wiberg

11.30 Refreshments

Session 2 - Chairs: Professor Sir S Arulkumaran & Amanda Burleigh

12.00 Delayed cord clamping in term babies
Dr Ola Andersson

12.30 Outcomes after delayed cord clamping at birth in very preterm babies
Professor Judith Mercer

13.00 Lunch

Session 3 - Chairs: Professor Susan Bewley & Dr David Hutchon

14.00 Analysis of the Dublin records
Dr John Monaghan

14.20 The pathological approach to diagnosis of perinatal cerebral ischaemia
Dr Tom Jacques

14.40 Sudden Asystole Hypothesis
Professor Judith Mercer

15.00 Neonatal resuscitation required?... Wait a minute!
Dr Patrick van Rheenen

15.2 Assessment of the trolley
Dr Bill Yoxall

15.40 Refreshments

16.00 Panel debate and questions - evidence and best practice

17.00 Close

20.00 Conference Dinner

Eileen Nicole Simon

December 13, 2012

Subject: Discussion of public comments

Looking at the schedule for the meeting on Dec 18, will the discussion of public comments include the written comments people have sent in? I hope so, and I hope discussion will not just be based on whether or not committee members offer to discuss a particular comment. Please pass this on. Thanks.

Eileen Simon