Written Public Comments

IACC Full Committee Meeting

July 9, 2013

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M. L. Ferreira

April 9, 2013

Subject: Re: Release of the 2012 IACC Summary of Advances in ASD Research

At this point, the only possible reaction is Are you kidding me?
Let´s see about the questions and relevant manuscript that in many times show how the genetic paradigm has demonstrated to be at this point, a failure that is not acknowledged
Not one of the manuscripts cited helped in one bit; the following manuscripts addressed at least partially what parents like me are finding around the world: systemic impact, multiple systems affected, need of systems biology at the XXI level, immune dysfunction with autoimmune conditions (like PANDAS)....and so on.
A different list- at least for me partially useful but much more useful than the published one.

Question 2

Hum Mol Genet. 2012 Nov 1;21(21):4781-92. doi: 10.1093/hmg/dds301. Epub 2012 Jul 26.

Individual common variants exert weak effects on the risk for autism spectrum disorders.

Anney R, Klei L, Pinto D, Almeida J, Bacchelli E, Baird G, Bolshakova N, Bölte S, Bolton PF, Bourgeron T, Brennan S, Brian J, Casey J, Conroy J, Correia C, Corsello C, Crawford EL, de Jonge M, Delorme R, Duketis E, Duque F, Estes A, Farrar P, Fernandez BA, Folstein SE, Fombonne E, Gilbert J, Gillberg C, Glessner JT, Green A, Green J, Guter SJ, Heron EA, Holt R, Howe JL, Hughes G, Hus V, Igliozzi R, Jacob S, Kenny GP, Kim C, Kolevzon A, Kustanovich V, Lajonchere CM, Lamb JA, Law-Smith M, Leboyer M, Le Couteur A, Leventhal BL, Liu XQ, Lombard F, Lord C, Lotspeich L, Lund SC, Magalhaes TR, Mantoulan C, McDougle CJ, Melhem NM, Merikangas A, Minshew NJ, Mirza GK, Munson J, Noakes C, Nygren G, Papanikolaou K, Pagnamenta AT, Parrini B, Paton T, Pickles A, Posey DJ, Poustka F, Ragoussis J, Regan R, Roberts W, Roeder K, Roge B, Rutter ML, Schlitt S, Shah N, Sheffield VC, Soorya L, Sousa I, Stoppioni V, Sykes N, Tancredi R, Thompson AP, Thomson S, Tryfon A, Tsiantis J, Van Engeland H, Vincent JB, Volkmar F, Vorstman JA, Wallace S, Wing K, Wittemeyer K, Wood S, Zurawiecki D, Zwaigenbaum L, Bailey AJ, Battaglia A, Cantor RM, Coon H, Cuccaro ML, Dawson G, Ennis S, Freitag CM, Geschwind DH, Haines JL, Klauck SM, McMahon WM, Maestrini E, Miller J, Monaco AP, Nelson SF, Nurnberger JI Jr, Oliveira G, Parr JR, Pericak-Vance MA, Piven J, Schellenberg GD, Scherer SW, Vicente AM, Wassink TH, Wijsman EM, Betancur C, Buxbaum JD, Cook EH, Gallagher L, Gill M, Hallmayer J, Paterson AD, Sutcliffe JS, Szatmari P, Vieland VJ, Hakonarson H, Devlin B.

Source
Autism Genetics Group, Department of Psychiatry, School of Medicine, Trinity College, Dublin 8, Ireland.

Abstract
While it is apparent that rare variation can play an important role in the genetic architecture of autism spectrum disorders (ASDs), the contribution of common variation to the risk of developing ASD is less clear. To produce a more comprehensive picture, we report Stage 2 of the Autism Genome Project genome-wide association study, adding 1301 ASD families and bringing the total to 2705 families analyzed (Stages 1 and 2). In addition to evaluating the association of individual single nucleotide polymorphisms (SNPs), we also sought evidence that common variants, en masse, might affect the risk.

Despite genotyping over a million SNPs covering the genome, no single SNP shows significant association with ASD or selected phenotypes at a genome-wide level. The SNP that achieves the smallest P-value from secondary analyses is rs1718101. It falls in CNTNAP2, a gene previously implicated in susceptibility for ASD. This SNP also shows modest association with age of word/phrase acquisition in ASD subjects, of interest because features of language development are also associated with other variation in CNTNAP2. In contrast, allele scores derived from the transmission of common alleles to Stage 1 cases significantly predict case status in the independent Stage 2 sample. **Despite being significant, the variance explained by these allele scores was small (Vm< 1%). Based on results from individual SNPs and their en masse effect on risk, as inferred from the allele score results, it is reasonable to conclude that common variants affect the risk for ASD but their individual effects are modest.**

Question 3

J Clin Bioinforma. 2012 Oct 8;2(1):17. doi: 10.1186/2043-9113-2-17.

Modeling autism: a systems biology approach.

Randolph-Gips M, Srinivasan P.

Source
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Abstract
Autism is the fastest growing developmental disorder in the world today. The prevalence of autism in the US has risen from 1 in 2500 in 1970 to 1 in 88 children today. People with autism present with repetitive movements and with social and communication impairments. These impairments can range from mild to profound. The estimated total lifetime societal cost of caring for one individual with autism is $3.2 million US dollars. With the rapid growth in this disorder and the great expense of caring for those with autism, it is imperative for both individuals and society that techniques be developed to model and understand autism. There is increasing evidence that those individuals diagnosed with autism present with highly diverse set of abnormalities affecting multiple systems of the body. To this date, little to no work has been done using a whole body systems biology approach to model the characteristics of this disorder. Identification and modeling of these systems might lead to new and improved treatment protocols, better diagnosis and treatment of the affected systems, which might lead to improved quality of life by themselves, and, in addition, might also help the core symptoms of autism due to the potential interconnections between the brain and nervous system with all these other systems being modeled. This paper first reviews research which shows that autism impacts many systems in the body, including the metabolic, mitochondrial, immunological, gastrointestinal and the neurological. These systems interact in complex and highly interdependent ways. Many of these disturbances have effects in most of the systems of the body. In particular, clinical evidence exists for increased oxidative stress, inflammation, and immune and mitochondrial dysfunction which can affect almost every cell in the body. Three promising research areas are discussed, hierarchical, subgroup analysis and modeling over time. This paper reviews some of the systems disturbed in autism and suggests several systems biology research areas. Autism poses a rich test bed for systems biology modeling techniques.

Entropy 2012, *14*(11), 2227-2253; doi:10.3390/e14112227

Review

Empirical Data Confirm Autism Symptoms Related to Aluminum and Acetaminophen Exposure

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Received: 24 September 2012; in revised form: 16 October 2012 / Accepted: 5 November 2012 / Published: 7 November 2012 original version is still available [441 KB, uploaded 7 November 2012 08:37 CET]

Abstract: Autism is a condition characterized by impaired cognitive and social skills, associated with compromised immune function. The incidence is alarmingly on the rise, and environmental factors are increasingly suspected to play a role. This paper investigates word frequency patterns in the U.S. CDC Vaccine Adverse Events Reporting System (VAERS) database. Our results provide strong evidence supporting a link between autism and the aluminum in vaccines. A literature review showing toxicity of aluminum in human physiology offers further support. Mentions of autism in VAERS increased steadily at the end of the last century, during a period when mercury was being phased out, while aluminum adjuvant burden was being increased. Using standard log-likelihood ratio techniques, we identify several signs and symptoms that are significantly more prevalent in vaccine reports after 2000, including cellulitis, seizure, depression, fatigue, pain and death, which are also significantly associated with aluminum-containing vaccines. We propose that children with the autism diagnosis are especially vulnerable to toxic metals such as aluminum and mercury due to insufficient serum sulfate and glutathione. A strong correlation between autism and the MMR (Measles, Mumps, Rubella) vaccine is also observed, which may be partially explained via an increased sensitivity to acetaminophen administered to control fever.
Keywords: autism; vaccines; MMR; HEP-B; glutathione; sulfate; cholesterol sulfate; aluminum; mercury; acetaminophen
http://www.mdpi.com/1099-4300/14/11/2227
Maedica (Buchar). 2012 Jan;7(1):38-48.

Toxic Metals and Essential Elements in Hair and Severity of Symptoms among Children with Autism.

Blaurock-Busch E, Amin OR, Dessoki HH, Rabah T.

Source
Lecturer and Advisor, International Board of Clinical Metal Toxicology & German Medical Association of Clinical Metal Toxicology, Hersbruck, Germany.

Abstract
Objective: The objective of this study was to assess the levels of ten toxic metals and essential elements in hair samples of children with autism, and to correlate the level of these elements with the severity of autism. Method: The participants were 44 children, age 3 to 9 years, with Autistic Spectrum Disorder (ASD) according to Diagnostic and Statistical Manual of Mental Disorders 4th Edition, (DSM-IV). The severity of autistic symptomatology was measured by the Childhood Autism Rating Scale (CARS). Hair

analysis was performed to evaluate the long term metal exposure and mineral level. Results: By comparing hair concentration of autistic vs. nonautistic children, elevated hair concentrations were noted for aluminum, arsenic, cadmium, mercury, antimony, nickel, lead, and vanadium. Hair levels of calcium, iron, iodine, magnesium, manganese, molybdenum, zinc, and selenium were considered deficient. There was a significant positive correlation between lead & verbal communication ($p = 0.020$) and general impression ($p = 0.008$). In addition, there was a significant negative correlation between zinc & fear and nervousness ($p = 0.022$).Conclusion: Our data supports the historic evidence that heavy metals play a role in the development of ASD. In combination with an inadequate nutritional status the toxic effect of metals increase along with the severity of symptoms.

Front Psychiatry. 2012;3:118. doi: 10.3389/fpsyt.2012.00118. Epub 2013 Jan 18.

Environmental factors in autism.

Grabrucker AM.

Source
WG Molecular Analysis of Synaptopathies, Neurology Department, Neurocenter of Ulm University Ulm, Germany.

Abstract
Autism is a neurodevelopmental disorders characterized by impairments in communication and social behavior, and by repetitive behaviors. Although genetic factors might be largely responsible for the occurrence of autism they cannot fully account for all cases and it is likely that in addition to a certain combination of autism-related genes, specific environmental factors might act as risk factors triggering the development of autism. Thus, the role of environmental factors in autism is an important area of research and recent data will be discussed in this review. Interestingly, the results show that many environmental risk factors are interrelated and their identification and comparison might unveil a common scheme of alterations on a contextual as well as molecular level. For example, both, disruption in the immune system and in zinc homeostasis may affect synaptic transmission in autism. Thus, here, a model is proposed that interconnects the most important and scientifically recognized environmental factors. Moreover, similarities in how these risk factors impact synapse function are discussed and a possible influence on an already well described genetic pathway leading to the development of autism via zinc homeostasis is proposed.
Arch Med Sci. 2012 May 9;8(2):324-31. doi: 10.5114/aoms.2012.28561.

Low serum IgA and increased expression of CD23 on B lymphocytes in peripheral blood in children with regressive autism aged 3-6 years old.

Wasilewska J, Kaczmarski M, Stasiak-Barmuta A, Tobolczyk J, Kowalewska E.

Source
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Abstract
INTRODUCTION:
Immune system dysfunction is considered to be one of many medical disorders found in children with autism. The primary objective of the study was to assess if blood tests reflecting humoral immunity (IgA,

IgG, IgM, IgE) are useful in identifying children with regressive autism. The secondary objective was to evaluate a part of the cellular arm of immunity (CD4/CD25 Tregs, CD4/CD23 cells) in those children.

MATERIAL AND METHODS:

Using a clinical case-control design, the systemic levels of immunoglobulins and lymphocyte subpopulations analysed by flow cytometry were compared in children aged 3-6 years old with a new diagnosis of regressive autism (n = 24; mean age: 4.25 ±1.70 years; male 23/24) and in sex- and age-matched healthy children (n = 24; aged 4.25 ±2.20 years; male 23/24).

RESULTS:

The humoral immunity profile, described by three binary variables, IgA < 0.97 g/l, IgE > 36 IU/ml, and IgG > 6.3 g/l, with a sensitivity of 79% and a specificity of 83% ($p < 0.0001$), was able to identify children with autism. The highest risk of autism diagnosis was associated with IgA < 0.97g/l (OR - 23.0; $p < 0.001$). A higher number of CD19/CD23 was found in children diagnosed with autism than in the control group (36.82 ±6.72% vs. 18.20 ±3.95%; $p < 0.02$). No correlation between the number of CD23-positive cells and serum IgE levels was observed.

CONCLUSIONS:

A subtle shift of serum immunoglobulins consisting of low-normal IgA and B cell activation expressed by an increase of CD23-positive cells may characterize children with regressive autism aged 3-6 years old.

Question 4

With the paramount importance of immune dysfunction in autism- and the findings in low IgA-, the lack of attention to PANDAS (PITAND-.PANS) research is amazing

Brain Dev. 2012 Nov 8. pii: S0387-7604(12)00261-6. doi: 10.1016/j.braindev.2012.10.003. [Epub ahead of print]

Autoimmune neurological disorders associated with group-A beta-hemolytic streptococcal infection.

Hachiya Y, Miyata R, Tanuma N, Hongou K, Tanaka K, Shimoda K, Kanda S, Hoshino A, Hanafusa Y, Kumada S, Kurihara E, Hayashi M.

Source
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Abstract
Although central nervous system (CNS) disorders associated with group-A beta-hemolytic streptococcal (GABHS) infection occur only rarely, Sydenham's chorea is a well-recognized disease that can arise following infection. Children may develop a tic, obsessive compulsive disorder (OCD), and extrapyramidal movement subsequent to GABHS infection. These disorders have been termed pediatric autoimmune neuropsychiatric disorders associated with streptococci (PANDAS). Herein we report one case each of acute disseminated encephalomyelitis (ADEM), PANDAS and subacute encephalitis associated with GABHS infection. To evaluate the pathogenesis of the CNS disorders associated with

GABHS infection, we measured levels of neurotransmitters, cytokines, anti-neuronal autoantibodies, and performed immunohistochemistry using patient sera to stain human brain sections. All three cases showed psychiatric behavioral disorders. Immunotherapy was effective, and homovanillic acid levels in the cerebrospinal fluid (CSF) were elevated at the acute stage in all three cases. In each case of ADEM and PANDAS, immunohistochemistry demonstrated neuronal impairment in the basal ganglia during the acute stage. Neuronal immunoreactivity was visualized in the cerebral cortex at the acute stage in the case of subacute encephalitis. There was no direct correlation between immunoreactivity of patient sera on the brain sections and positivity of anti-neuronal autoantibodies or CSF biomarkers. The results suggest that autoimmune responses may modulate neurotransmission, and the use of patient serum for immunohistochemistry is a sensitive screening method for the detection of anti-neuronal autoantibodies in CNS disorders associated with GABHS infection.

M.L.Ferreira

Argentina

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

Marcia Hinds

May 4, 2013

Imagine a world… Where increasing numbers of children show up in our schools without speech, lost in their own worlds and have no hope for the future.

Imagine a world...Where children with severe sleep disorders, limited speech, nutritional deficiencies, stomach problems and severe allergies are sent to psychologists and psychiatrists.

When you have a child with autism, you don't have to imagine anything. If your child is one of the 1 in 50 diagnosed with autism, this is the world you live in! How can we just stand by and let this happen?

Some say the increase in autism is because of better diagnostic tools and awareness. Don't believe it! The increase in autism is REAL!!! No one can MISS a child with autism. They have epic meltdowns in the grocery store and throw award-winning tantrums in restaurants. They do and say strange things. And some never say anything at all, including "I love you."

And yet there is hope… The solution to the autism crisis seems complicated, but in reality is simple if you know *the truth about autism.* Autism is a complex medical condition caused (in most part) by an immune system that is not working properly.

My son, [PII redacted], was diagnosed with autism at age four. I was told there was nothing I could do. The psychiatrist who was a "leading authority" on autism said my son would probably need to be institutionalized. But she was wrong.

[PII redacted]'s recovery helped me realize autism is a treatable and changeable condition. Treating him medically took time and the road was long and difficult. It felt like forever and our family made many sacrifices as well as mistakes along the way. But the only institution [name redacted] ever ended up in was the university where he graduated Magna Cum Laude. NASA paid for most of his master's degree after he completed a paid internship with them. Today at age 24, he works as an engineer at Boeing, when he is not surfing or going out with friends.

We need to stop looking at this backwards. Autism is not the cause of the many medical conditions our children suffer from. In reality, it is the other way around. The problem in the function of our children's immune systems results in autistic symptoms. Autism needs to be taken out the psychiatric journals and put in the medical books where it belongs. Physicians who know how to treat autism medically understand that once the body works, the brain follows.

Unfortunately, there is no easy fix or magic bullet to heal our children. It takes time to repair a child's compromised immune system. Once the body has healed, they still need focused educational and behavioral interventions to catch up on what they missed when they were too sick to develop typically. Autism awareness is no longer enough! We need a doctor on every corner who says I know what this is and I know how to treat it. The world needs to realize our children are not broken. They are sick. And they can get better. With proper medical treatment combined with focused rehabilitation, many

children have already made the long, difficult journey to recovery. If these children can be healed, more can be helped. We no longer have to sit and watch helplessly while our children slip away.

We began [PII redacted]'s journey burdened by the medical community's false belief that his autism was incurable and untreatable. We ended our journey enlightened by the knowledge that his autism is a complex medical condition caused (in most part) by an immune system that is not working properly and that autism is, in fact, treatable. It is time to retire the antiquated belief that autism is a psychiatric and developmental disorder. This diagnosis needs to be ripped out of the Diagnostic and Statistical Manual of Mental Disorders and indexed in the medical books, where it belongs.
We must join together to give our children a future. We can agree that this is a medical and treatable condition. This must be our message; unwavering, unapologetic and most of all, unified. The infighting among different groups about what causes autism and how to fix it must stop. This is the only way we will win the war on autism. We must never give up until we find the answers for our children!

Thank you,

/Marcia Hinds/
Marcia Hinds

Please watch this news story about [PII redacted] who can teach us so much about our children and how it feels to have autism and not be able to communicate.
https://www.facebook.com/photo.php?v=451214254956059

[PII redacted] is truly amazing!!! Our children are so intelligent, even though they are often said to have low IQ's and even retarded. [PII redacted] is a great example of why we can't give up and need to solve the autism problem. We need to put an end to this disease that is taking our children and robbing them of happy and productive lives.

Even if you don't have a child on the autism spectrum, you probably have one in your child's classroom. When a child is ill they can't get better no matter how much money we spend on their education. Our educational funds are limited. Currently, they are not being used effectively, and taking away from all our children, including the healthy ones.

Look for Marcia's book that tells [PII redacted]'s story, *"I Know You're in There -- Our War on Autism.*"
(To be published soon)

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

Beth Secosky

May 22, 2013

Subject: Co-occurring conditions associated with autism

Dear IACC,

Please see my son's story below. It outlines the medical conditions that co-occurred with his Asperger's and how dietary changes resolved his medical and behavioral issues.

Please make this information available to all citizens. Our autistic citizens suffer needlessly!

Sincerely,

Beth Secosky

This Couldn't Be Happening

When our then two-year-old son's teacher asked if the school psychologist could attend our semi-annual parent-teacher conference, I didn't think twice. Our son had some unusual behaviors she had been observing in the classroom. As the meeting started, she didn't mince words. She opened the meeting with, "Your son has Asperser's." *WHAT?* "We can teach him some rote skills such as making eye contact, and he is so high functioning, he'll do well. It's possible he could even have a job and get married someday." *WHAT!*

This couldn't be true. Neither my husband nor I had anything like autism in either of our families. *This couldn't be happening!*

We found [PII redacted] the speech therapy and occupational therapy the psychologist recommended, but we kept this news a secret from others, and for three years spent most of our energy trying to prove to ourselves he did *not* have Asperser's or autism.

Yet, with 20/20 hindsight, he had the classic symptoms of Asperser's:

- A large vocabulary but little use of pragmatic language
- Spinning in circles
- Staring at objects for long periods of time
- Inability to engage with other children appropriately
- Constant rocking and moving
- Uncontrollable noise making
- Frustration with transitions
- Sensitivity to sound
- Worst of all --- violent tantrums that sometimes lasted for hours.

I learned to watch [name redacted] closely around babies, because he couldn't tolerate their lack of predictability. He would step on their fingers and once even tried to push one down the stairs.

At age five, we finally had him officially diagnosed. Surprisingly, it was a relief to have a diagnosis, and it gave us avenues in which to seek help. That's where the miracle began.

Facing the Challenges

But back to the years B.D. (before diagnosis). Our son had many health issues, most of which his father and I, as well as his pediatricians, considered minor. Certainly, none of us had ever made a connection between his *health* issues and his *behavior* problems.

Within a week of his birth, [PII redacted] had lost significant weight. It was shocking and heart breaking to see how emaciated he looked. His suck wasn't strong enough to produce enough milk. He was failing to thrive and needed supplemental formula.

His condition soon improved, and the doctors calmly assured us he was fine. I know now that his suck wasn't strong enough to produce enough milk.

But…Was He Really Fine?

Was [name redacted] truly healthy? I am still plagued with guilt that I all but ignored the symptoms of poor health the pediatricians seemed to dismiss as just typical childhood issues while I paid no heed to my mother's intuition that "…something isn't right." Some examples:

- In preschool, [PII redacted] had a nearly constant runny nose. Sure, many of the kids in the one and two-year-old class had frequent runny noses, but none so constant as our son's. I felt I could not take enough days off work to keep him home as much as he needed. The pediatrician wasn't overly concerned. We later discovered the constant runny nose resulted from allergies and indicated a weak immune system.
- And there was the eczema that flared up frequently. I remember a specific incident when [name redacted]'s poor legs were covered in a rash – with raw spots where he had scratched. The doctor prescribed various creams, but nothing really helped. I recently had a mild rash lasting over a week. I was *miserable*. I cringe imagining how miserable our son was with the intense rashes he suffered.
- Then came the worst. It was before my kids started day care, and I was trying to work part time while home with them. [Name redacted] (then a year old) was crying in his crib, and I was trying to finish an e-mail when my three-year-old daughter rushed to my office, her face showing alarm, and said, "Mommy, [name redacted] needs you real bad." I ran to his room and found him gasping for breath. The pediatrician had us come immediately to the office and gave him a nebulizer treatment. He had developed asthma!
- When he was four or five he started having stomach aches. Suspecting constipation, the doctor sent him for an x-ray. [Name redacted] had severe "compacted feces." The doctor said nonchalantly all we needed to do was give him Miralax to clear it up. His explanation for the cause of the constipation was that my son *was "holding in his stool because he'd rather play*."

We cleared the constipation, but [PII redacted] continued to experience chronic stomach discomfort. It wasn't until we changed his diet, and he became more conversational, that I understood this wasn't discomfort. *He had severe pain!* To this day, he is afraid to eat anything he suspects might trigger that stomach pain.

We moved during this three-year period, so we worked with two different large pediatric practices. Both pronounced [name redacted] a perfectly healthy little boy who simply needed his asthma monitored.

All along, as we battled these health issues, came *seemingly* unrelated behaviors caused by the Asperger's. For example, my daughter and I walked on egg shells in fear of triggering another violent tantrum. I flinched every time I saw the school's name on the caller ID, because it almost always meant trouble. I was pained each time I saw my son's heart break because he had been rejected by yet another child.

Then…Everything Changed

For two years, my best friend and health-food fanatic, [PII redacted], told me about biomedical treatment (diet, supplements, etc.) of autism. She even sent me a book by controversial actress, Jenny McCarthy, whose son has recovered from autism. I never opened the book, and I didn't believe it could help our family. I was too stubborn to learn about biomedical -- even from Tracy, a loving friend.

I had to stumble upon it myself. In a Google search, I found a YouTube interview with Dr. Natasha Campbell-McBride who specializes in the treatment of autism, AD(H)D, learning disabilities, anxiety, bi-polar disorder, etc. I as floored to find out:

- [PII redacted]'s seemingly unrelated medical issues are all part of interrelated biological disturbances in his body.
- A comprehensive list of the medical issues commonly found in autism, as well as mood and learning disorders, included *every one of* [name redacted]*'s medical conditions*.
- Best of all, I learned lifestyle changes could help heal the *medical issues* and reduce or possibly eliminate the Asperger's *behavioral issues.*

Once I found the information myself, and "owned" it, I was driven to learn more. I bought Dr. Campbell-McBride's book, *Gut and Psychology Syndrome* and read it several times. I found videos of autism-recovery stories on the web and watched them repeatedly to build my hope and motivation.

I took my son to Beverly Goode, MD, who has special training in holistic medicine. After she completed her thorough examinations, she sat me down, turned slowly to me and said gravely, "Your son is a very sick little boy."

To her surprise, I was happy to hear that his medical issues were real. I understood that meant they could be treated. At last there was hope that [name redacted] could experience a significantly improved quality of life and possibly recover.

Under Dr. Goode's guidance we immediately removed gluten, and dairy and reduced sugars in his diet. She explained that all three foods can cause inflammation. She also prescribed supplements for his nutritional deficiencies and tested him for food sensitivities. He was sensitive to 69 foods!

Though it was very difficult, to implement her dietary suggestions, with effort and planning it were also manageable. And…[PII redacted]'s health began to improve! We watched as the:

- Asthma disappeared
- Allergies came under control
- Severe rashes vanished
- Colds and flu came in line with other children's

Much of his physical suffering was reduced or eliminated. A few of his autistic behaviors such as spinning in circles and staring at objects were resolved. Still, the most disruptive behaviors, especially the violent tantrums, social awkwardness and poor focus persisted. By this time, I had watched every video on line I could find regarding children with autism who had recovered or significantly improved to maintain my motivation. I resolved to aim higher.

A Week to Remember

Then, one week after [name redacted] had a particularly violent tantrum, I decided I couldn't go on with the status quo. I had to make something more happen. So after 10 months on a gluten-free/dairy-free diet, we started closely studying the Specific Carbohydrate Diet (SCD). SCD not only eliminates gluten and dairy, it removes all grains, starchy foods, all sugar, and processed foods.

The thought of a diet free of any starchy or processed foods was overwhelming. What would we eat if we couldn't have cereal, potato chips or rice? It took me months to get up the nerve and the fortitude to give SCD a try. But I took off work one Friday to prepare a supply of SCD foods. Our family started SCD on Saturday calling it a one month test.

Before starting, I gave a presentation to the kids using baker's yeast and sugar to explain why we had to cut out starches and sugars. They understood, but weren't thrilled with the SCD food limitations. But, that graphic presentation helped them grasp why we were changing, and they coped very well. I think my years as a consultant and coach, helping other people work through the issues of lifestyle change, assisted our family in this. Many delicious foods were still available to us.

The Miracles

And then miracles started happening! On day two of SCD, now six-year-old, [name redacted], told me felt "stupendous." He probably didn't remember a day in his life free of stomach pain and the many other health problems that plagued him.

At the end of week one, I knew we were on the right track. We had a new neighbor over for dinner. [PII redacted] walked right up to her, looked her straight in the eye and started chatting with her. I said to her, "OMG, am I crazy or did he just make total eye contact with you and chat with you!" I started pinching myself; it was almost too good to be true.

Then, I looked over to my neighbor's baby who was lying on the floor. [PII redacted] was lying next to her smiling and saying "goo goo gaa gaa." It was such a momentous moment! I remember my neighbor saying, "Don't cry. Don't cry." It was all so surreal, I didn't cry.

At the end of our “one month test,” we kept right on going. Within 3 months, [name redacted] was performing so well in school, that his Individual Education Plan (IEP) was removed.

A Year Gone By…

It’s been a year-and-a-half since we started the Specific Carbohydrate Diet, and [name redacted] never asks to go off it. He remembers the pain he experienced before and doesn’t ever want to go there again. Having to take his own food to parties and eating differently than everyone else is a small price to pay for being in control of his own behavior, feeling good and being free of pain.

I believe an examination would show that [PII redacted] is no longer considered to have Asperger’s. He does still have Attention Deficit Disorder and we now work with an autism spectrum specialist (a DAN/MAPS doctor) who is helping us find the last pieces of his health/behavior puzzle. We also work with a Relationship Development Intervention therapist (RDI) who is helping us give [name redacted] the developmental skills he missed during his first years of life. His remaining symptoms and difficulties are melting away.

Today, I was at a neighbor's, and her 2-year-old son asked, "Where's [PII redacted]?" I carried him back to our house to see [name redacted]. When we came in, [name redacted] immediately stopped his computer game, jumped up, and ran over saying, "Hi Neel! in a perfect talking-to-babies voice. What a change from 3 years ago when relating to babies caused him so much stress that he tried to push one down the stairs!

[PII redacted] is an amazing child, and his healing and behavioral changes never cease to amaze me!

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

Misty Haney

May 24, 2013

Subject: Re: Action Alert: Medical Needs of Children with Autism

My son [name redacted] was evaluated in May 2003 by the developmental pediatrics department at a children's hospital. He was 2 years 8 months old at the time. He was indicated to have autism at that time.

When [PII redacted] was 15 months old, I told his doctor that he had almost completely stopped eating. The doctor responded, "He looks fine to me. He'll eat when he's hungry." At that time, [name redacted] was suffering from severe diaper rash, abdominal distention and irregular bowel movements (combined diarrhea and constipation). My concerns were waved off as typical of a child his age. Note that my doctor thought [name redacted]'s abdominal distention was healthy baby fat. And when we returned for his 18 month visit, [name redacted] had lost weight. [Name redacted]'s doctor then referred us to a speech therapist that referred us to an occupational therapist who has worked diligently for years to help us work with [name redacted] through his severe oral and tactile aversion.

[Name redacted]'s gastrointestinal needs were not met until he was seven years old. [Name redacted]'s second pediatric gastroenterologist agreed to seek out the cause of [name redacted]'s severe constipation and abdominal distention. He discovered an enlarged bowel and was able to tailor a treatment that resulted in [name redacted] having regular bowel movements and a healthy looking, flat tummy. Imagine the six years of discomfort [name redacted] could have avoided if either his primary care physician or the developmental pediatrics physicians had referred us to a pediatric gastroenterologists when he was just a toddler and said gastroenterologist had sought out the cause of [name redacted]'s symptoms. In an effort to keep this short and avoid dramatics, I am going to trust that you understand the pain [name redacted] suffered rather than describe it for you here. Note that [name redacted]'s first gastroenterologist attempted but failed to alleviate [name redacted]'s constipation because he assumed it was a typical case of constipation.

At age seven [PII redacted] was also determined by a nutritionist to have mitochondrial dysfunction based on biomarkers. I didn't fully understand what that meant at the time; but I gave [name redacted] the recommended supplements. His energy level increased significantly and he grew from a size 5/6 to a size 10/12 by his 9th birthday. School and play also became a more joyful and productive experience for [PII redacted]. If only one of [PII redacted]'s doctors had recognized his low energy, low muscle tone, etc. as symptoms of a treatable problem much sooner.

Thank you for this opportunity to share a portion of [PII redacted]'s story. My hope is that [PII redacted]'s story will motivate all of us to do a better job for the next generation.

Sincerely,

Misti Haney

Audrey Flack

June 5, 2013

It is important to study non verbal people with autism. They make up at least 50% of the spectrum and the methods they have devised to communicate....particularly the ones who cannot speak or use the computer, are often incredible. Almost no studies have been done on these people and enormous amounts can be learned from them. As the mother of an adult daughter in this category, I have long been fascinated by the workings of her brain.

Sincerely,

Audrey Flack

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

Laura Keene

June 7, 2013

Subject: Help Safeminds Educate the IACC and AAP

Here is our story, as requested. Please let me know if I can be of any further assistance.

June 7, 2013

Our son, [PII redacted], was diagnosed with autism at age two years and one month on May 2, 2006. [Name redacted] is now significantly healthier and doing significantly better overall (verbally/socially/academically/etc.) because of the years of biomedical intervention he has received from our DAN (Defeat Autism Now) doctor, Elizabeth Mumper, M.D. in Lynchburg, Virginia. My husband and I are very strong believers that many children with autism suffer from numerous medical issues and behaviors that are treatable and preventable with appropriate medical interventions. We have experienced this first-hand with our son, [name redacted].

In [PII redacted]'s initial biomedical autism history and evaluation at Dr. Mumper's office, on Sept. 10, 2007, Dr. Mumper reported the following:

Impression:

Previous Diagnoses: Allergic Rhinitis Due To Pollen (477.0), Mineral Deficiency, Not Elsewhere Classified (269.3), Other Specified Intestinal Malabsorption (579.8), Disturbances Of Sulphur-bearing Amino-acid Metabolism (270.4), Other And Unspecified Noninfectious Gastroenteritis And Colitis (558.9), Unspecified Disorder Of Metabolism (277.9), Long-term (Current) Use Of Other Medications (V58.69), Candidiasis Of Unspecified Site (112.9), Allergic Rhinitis, Cause Unspecified (477.9), Other Abnormal Clinical Findings (796.4), Abdominal Pain, Unspecified Site (789.00), Delayed Milestones (783.42), Diarrhea (787.91), Lack Of Coordination (781.3), Expressive language disorder (315.31), Congenital Anomalies Of Skull And Face Bones (756.0), Unspecified Chronic Suppurative Otitis Media (382.3) Methionine Metabolism Disturbance.

In more basic terms, [name redacted] suffered from severe seasonal allergies, he had big black circles under his eyes, his head was proportionally too large for his body, he was very thin but had a very bloated stomach, his stool was orange mush for years, he was extremely (in a scary way) oblivious to pain, his pupils were dilated, he woke up in the middle of the night giggling uncontrollably for hours, he spun in circles, he didn't know how to play with toys, he only dangled things in front of his face for hours, he couldn't look at anyone in the eyes, he wouldn't speak to anyone, he was almost non-verbal until he was over four years old…he was constantly on antibiotics for ear infections, he was very clumsy and had difficulty walking and running, he was terrified of public places/groups of large people/loud noises/the happy birthday song/etc. he would hide under tables, avoid people, cry all the time…he was basically a mess.

Please see these photos to see the difference in our son before and after we began biomedical intervention. You can just see the difference in his eyes…the spark is missing in the "before" photos, and the spark is back in the "after" photos.

Before and After Photos

Before 1 **[Photo redacted]**	**Before 2** **[Photo redacted]**	**Before 3** **[Photo redacted]**
After 1 **[Photo redacted]**	**After 2** **[Photo redacted]**	**After 3** **[Photo redacted]**

Over the years, [PII redacted] has gotten better and better due to a serious of biomedical treatments we've done under the guidance of [PII redacted]: vitamins, minerals, prescription antibiotics and antifungals, B-12 shots, hyperbaric oxygen therapy (HBOT), chelation, etc. We have seen HUGE IMPROVEMENTS from all of these wonderful treatments – I could write a book with all the information and notes I have…it's hard to summarize in one small letter a miracle of improvement and near-recovery in a child who was merely a ghost of himself today: a bright, energetic, social, talkative, adorable joy…I wish you could understand how amazing his transformation has been. It's not been easy, and it's been a long, dedicated journey that has been expensive, stressful, exhausting but definitely worth it. To see the improvement in my son gives me hope for the future, and hope that other children will also be able to get better and better if they are able to receive biomedical treatments that [name redacted] has received. We are fortunate to have been able to afford it, and my heart aches for the families who are not financially able to help their children like we have.

As I've said before, this is only a small letter in a long story of [name redacted]'s recovery…please feel free to contact me at [PII redacted] if you would like any additional information. I would be happy to answer any questions, provide more documentation, etc. Thank you so much.

- Laura Keene ([PII redacted]'s mom)

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

Eileen Nicole Simon

June 10, 2013

Autism should be diagnosed as a neurological disorder, with language handicap as its most serious feature. Shouldn't social disorder be viewed as part of the more serious disorder of general awareness?

Please read Can [PII redacted] comment on the sfari.org website
http://sfari.org/news-and-opinion/specials/2013/dsm-5-special-report/evidence-weak-for-social-communication-disorder

Following is a comment I submitted in response to the discussion of DSM-5 on the sfari.org website: Autism is a neurological disorder. Its symptoms are also distinctive, thus the controversy over diagnosis is surprising. The most serious handicap is failure to acquire normal language. Brain impairments that interfere with the well-known stages of learning to speak should be the primary focus of research.

I am glad to see [PII redacted] working on the language disorder. She was a student of Roger Brown, who amassed huge amounts of data on early language development. He determined that infants respond to stressed syllables, then put syllabic parts of words together in unique "telegraphic" phrases.

[PII redacted] became interested in the language of my autistic son, [name redacted], and he wrote a chapter about Conrad in his textbook of psychology. [Name redacted] was echolalic. He remembered and recited whole sentences and phrases, but then applied these fragments totally out-of-context in new situations. [Name redacted] referred to this as metaphorical language.

[PII redacted] also performed an interesting extemporaneous experiment while watching [name redacted] sitting on the floor, rocking back and forth looking at a book. Professor Brown took a stack of examination books from on top of his file cabinet, and slammed them down behind [name redacted]'s back. [Name redacted] didn't flinch, but continued rocking back and forth with his book.

Too much emphasis is put on the "social" disorder. Failure in social engagement should be viewed as part of the more serious failure of general awareness. [Name redacted] did not orient to environmental sounds. However, he was terrified at even the sight of a telephone, which might suddenly begin to ring.

Auditory centers in the brainstem are susceptible to injury by anoxia at birth and toxic substances. Perinatal injury of subcortical structures disrupts maturation of target areas in the cerebral cortex, such as the language areas. Much more effort should go into preventing anoxia and toxic exposures in the perinatal period.

Sincerely,
Eileen Nicole Simon, RN, PhD
Lexington, MA
[PII redacted]
--

Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

Attachment

Brain Research, the Priority

First, as always, I want to emphasize that the brain must be the priority for research on autism. Language development is aberrant in autism, and this is the most serious handicap. Whether and to what extent a child masters language determines the trajectory of academic achievement and ability to participate in society.

What prevents or stunts full development of connections in the cerebral cortex? For nearly 4 decades I have tried to suggest perinatal injury of auditory centers in the brainstem [1]. Auditory nuclei (especially in the midbrain) are susceptible to damage by anoxia or toxic substances. Blood flow to brainstem auditory nuclei is higher than to any other area of the brain [2]. This high blood flow is now visible in fMRI scans [3].

Attempts to produce a primate model of cerebral palsy were undertaken in the 1950s by William Windle and his colleagues [4]. In the beginning, at birth the head of the infant monkey was delivered into a saline-filled sac, and the umbilical cord was clamped. Resuscitation had to be initiated after about 8 minutes. Damage in the brain was most severe in the brainstem centers of high blood flow, and especially in the auditory system.

The more widespread damage of the cerebral cortex associated with cerebral palsy was later found to result from prolonged partial hypoxia during gestation [5].

Brainstem damage was initially thought to be minimal and compared with what was known as “minimal cerebral dysfunction” (MCD) in human children, but maturation of the cerebral cortex did not follow a normal course in asphyxiated monkeys [6].

Maturation of the language areas of the cerebral cortex is not complete at birth. Ongoing postnatal development depends upon integrity of the brainstem auditory pathway.

Also, several case reports have been published that describe loss of the ability to comprehend spoken language following injury of the inferior colliculi in the midbrain auditory pathway. How much more serious this should be for an infant.

Umbilical Cord Clamping, Cause of Ischemic Brainstem Damage?

Autism attributed to vaccinations might go away if the IACC could be instrumental in stopping the practice of umbilical cord clamping.

Below are links to three video presentations that I hope members of the IACC will view. All discuss the dangers of clamping the umbilical cord at birth, an obstetric protocol that has been in place for 20 to 25 years. Note that this corresponds to the time when the current controversial vaccine schedule was begun.

Until the mid 1980s textbooks of obstetrics taught that pulsations of the umbilical cord should cease before tying (or clamping) the cord. This teaching was based on the understanding that pulsations are evidence of ongoing blood flow to the placenta. Circulation to the placenta continues (by nature's plan) until full redirection of blood flow to the lungs has taken place.

Clamping the cord disrupts transition from fetal to neonatal respiration in unpredictable ways. If the first breath does not occur before the cord is clamped, the infant may suffer injury of brainstem auditory nuclei similar to that produced in the early experiments on asphyxia at birth in monkeys. According to authors of the 2010 American Heart Association guidelines for neonatal resuscitation, "Approximately 10% of newborns require some assistance to begin breathing at birth." [7, e1400]

Many obstetricians, midwives, and pediatricians have long objected to clamping the umbilical cord [8-12]. In April I attended a conference in England at which Drs. Mercer, Hutchon, and Raju spoke. The videos below are thankfully bringing this issue to a wider audience on the internet [13-15]. Please take time to view (or listen) to these.

Umbilical Cord Clamping should be stopped

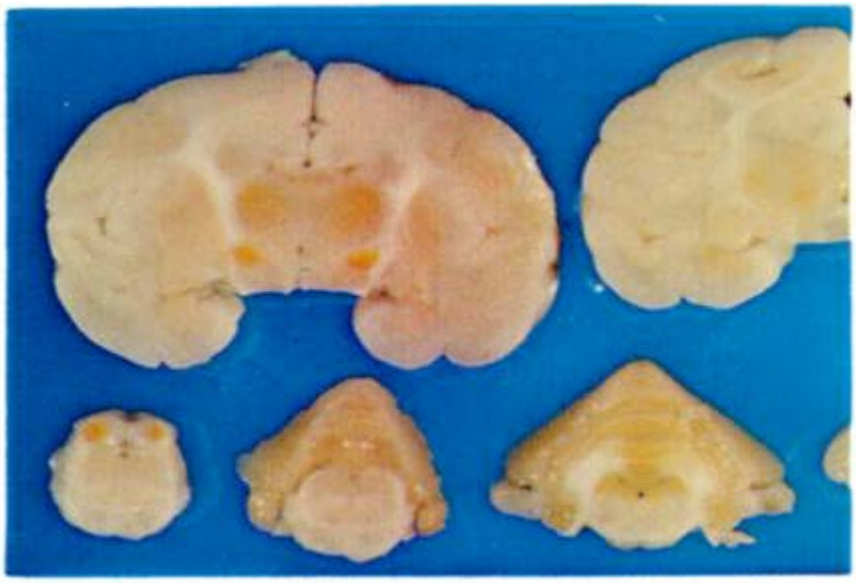
[PII redacted] in his TED talk discusses the importance of two atoms, oxygen and iron. He points out that one-third of a baby's blood is in the placenta at the moment of birth, and this is lost when the cord is clamped according to the current protocol. He discusses how this has led to childhood health problems worldwide. This video is 18 minutes long, and I would like to ask all members of the IACC to watch (or listen) to it. http://tedxtalks.ted.com/video/Alan-Greene-at-TEDxBrussels;Featured-Talks

Videos of presentations by [PII redacted] and [PII redacted] were given at a seminar held at McMaster University in Hamilton Ontario. These are 18 and 29 minutes long. Scientific members (at least) of the IACC should watch these.

[PII redacted] compared the placenta to the gill of a fish, the respiratory organ from the beginning of embryonic life. [PII redacted] describes how transfer of placental blood to the capillaries surrounding the alveoli initiates pulmonary function at birth. [PII redacted] also discussed the convulsive syndrome of thoroughbred foals caused when the human protocol of umbilical cord clamping was adopted. Many of these carefully bred foals died following failure of normal lung expansion [16, 17]. Neuropathology was similar to that seen in monkeys subjected to experimental asphyxia at birth [18, 19]
https://www.youtube.com/watch?v=t3EvxuQ3RiA

[PII redacted] discussed timing of cord clamping in pre-term and term infants. In preterm infants, delayed clamping led to decreased cases of intra-ventricular hemorrhage and necrotizing enterocolitis. Delayed clamping is now recommended for preterm infants.
https://www.youtube.com/watch?v=j09DkMns0Fo

[PII redacted] discussed bilirubin as an ongoing concern for term infants. However, Ranck and Windle (1959) reported that the pattern of ischemic brainstem damage seen in monkeys subjected to asphyxia at birth resembled the pattern of damage seen in kernicterus. Further experimentation revealed that the yellow discoloration of affected subcortical centers only occurred with infusion of bilirubin in monkeys with injury caused by asphyxia [20]. This can be seen in the following picture from that report:



Asphyxia disrupts the blood-brain barrier. Bilirubin only entered subcortical nuclei damaged by asphyxia. Note intense staining in the inferior colliculi, lower left. From Lucey JF, Hibbard E, Behrman RE, Esquival FO, Windle WF. Kernicterus in asphyxiated newborn monkeys. *Experimental Neurology* 1964 Jan; 9(1):43-58.

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[12] Raju TN. Timing of umbilical cord clamping after birth for optimizing placental transfusion. Curr Opin Pediatr. 2013 Apr;25(2):180-7.

[13] TICC TOCC, drgreene.com, Alan Greene (18 minutes) http://tedxtalks.ted.com/video/Alan-Greene-at-TEDxBrussels;Featured-Talks

[14] Contemplating the Cord. A seminar with Dr. Bruce Wainman (18 minutes) https://www.youtube.com/watch?v=t3EvxuQ3RiA

[15] Contemplating the Cord. A seminar with Dr. Eileen Hutton (29 minutes) https://www.youtube.com/watch?v=j09DkMns0Fo

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Eileen Nicole Simon

June 14, 2013

Autism is a tragic catastrophe for every family with a severely affected autistic child, and none of us deserves a quick brush-off.

Sincerely,
Eileen Nicole Simon

UNIVERSITY OF BIRMINGHAM

Centre for Professional Development

Cutting the Cord

19th April 2013

Hosted by University of Birmingham, College of Medical and Dental Sciences

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 conference is unusual in that it will bring together professionals to engage in lively debate about childbirth and best practice. This will have important implications for clinical care and practice by obstetricians, midwives and paediatricians, and exciting developments leading to improved neonatal outcomes.

Obstetricians, Paediatricians, Senior Midwives and Advanced Neonatal Nurse Practitioners are encouraged to attend.

http://www.birmingham.ac.uk/transitional-care

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Email: med-cpdbookings@contacts.bham.ac.uk
Website: www.birmingham.ac.uk/mds-shortcourses

Eileen Nicole Simon's poster can be viewed here.

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

Marcy Mullins

June 14, 2013

Over several weeks, many parents, including myself sent requests and made phone calls asking the Department of Justice to help [PII redacted], a child with Autism in Chicago who was restrained to a hospital bed for WEEKS. Nothing was done. It took a benefactor to get him removed from the hospital and he has since been murdered senselessly. He had no support - his mother had no support. She begged -- we begged.....

I received this response "The Disability Rights Section has received your email. This is an automatic response generated by computer" and nothing else.....

NOTHING was done to help this child. NOTHING is being done to help ANY of our children with Autism. They are the silent victims in a web of greed and lies perpetuated by pharmaceutical companies, doctors, and our government.

PLEASE, I beg you - DO the studies - ASK the questions why 1 in 50 of our kids is now afflicted. It is NOT better diagnosis - there are more of them.

Very very soon, the government is going to have an entire generation of "adults" unable to function on their own. Are you prepared for this? I know I'm not.

We ARE the majority now - please, please give our children a voice and start ASKING the questions we ALL deserve the answers to.....

Sincerely,

Marcy Mullins

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

Eileen Nicole Simon

June 14, 2013

Attached is a file with comments I am submitting for members of the IACC to read before the meeting on July 9. I hope it underscores the need for this committee to promote research on brain impairments underlying this life-long disability, and also to understand that autism is a life-sentence for most of its victims. Lifespan care must be anticipated for most, and I can tell you that autism has not simply gone unrecognized in the past.

My son at age 50 stands out like a sore thumb in the adult mental health system. He has been a difficult case turned over to the Massachusetts Department of Mental Health (DMH) by the police and the courts. The DMH philosophy is based on the idea that motivation has to come from the "consumer" himself. My son has autism. He suffers from a general obliviousness of his environment, except for islets of special interest like high-scoring Scrabble words and automotive history. He needs a behavioral plan. He needs a "Progress Plan" not the "flexible supports" DMH provides as part of a "Recovery Plan."

I wish my son were capable of recovery, but he started out life severely impaired in motor and language development. How could recovery be defined for most such severely afflicted people with autism?

When I was half the age my son is now, I could never have imagined the sad situation of our lives now. However, I keep trying. DMH for the past 10 years has kept claiming, "He's not ready." But we have now co-authored two memoirs, available as e-books on Kindle and Nook. In the attached file I have selected three short essays that he wrote. I hope these illustrate his sad situation in life, and that faced by the large number of soon-to-be adults with autism.

Sincerely,
Eileen Nicole Simon, RN, PhD
Lexington, MA
[PII redacted]
--
Conrad Simon Memorial Research Initiative
To seek understanding of brain system impairments in autism.
http://conradsimon.org/

Attachments:

Background

Autism (for most of its victims) negates everything looked forward to in life.

Awareness, acceptance, early identification, early intervention, special education, the miracle of language development, and special talents may make life look hopeful. But then puberty, and limitations (for most) of social, educational, and vocational opportunities must be recognized. The abyss of an empty future is all that's left.

This scourge must be stopped. Autism is no more acceptable than leprosy, tuberculosis, diphtheria, or polio. The IACC was created to investigate the cause of autism, and reasons for its dramatic increase over the past 2 decades.

I had wanted to bring my high-functioning son, [name redacted], to the IACC meeting in July. I had even reserved a 2-room, 2-bathroom suite at the Marriott Residence Inn in Bethesda, but soon had to realize this would never work. He would have 3 minutes to speak, but that might just be when he would suddenly disappear to have a smoke or to go to the bathroom.

What my son needs now, and for the rest of his life, is housing and some sense of purpose and enjoyment. He was too high-functioning for services in Massachusetts from the Department of Mental Retardation. He lived mostly at home until he was 29 years old, but too often came to the attention of the police.

Over the 4th of July weekend in 1992 he was found in an inebriated state and was taken to Westborough State Hospital. The 10 years he spent in this beautiful and historic asylum were among the best of his life. Then he was discharged to the "community" to a group home with alarms on the doors. He ran away several times, and was re-hospitalized on 3 occasions.

At his last Community Based Flexible Supports (CBFS) meeting, we were told that the Department of Mental Health (DMH) no longer guarantees community housing, and that if [name redacted] doesn't follow the rules he could be discharged. What then? He would have to make use of homeless shelters. This is what DMH in Massachusetts already does with its most severely mentally ill clients, the homeless mentally ill.

DMH in Massachusetts has a loathsome slogan, "Recovery is Real."

Recovery? That is not possible for the most severely mentally ill, most of whom had developmental problems even before their teenage years.

The slogan should be changed to "Progress is Possible," but who am I to be listened to? My son continues to make progress, mainly because I take him out at least one or two days a week to work for me. He writes for me, and we recently published (on Kindle) our second memoir together. What follows are excerpts from our latest memoir.

I hope that members of the IACC will discuss some of these short essays.

A Career Beginning at Age 50

One month before his own 50th birthday, [PII redacted] wrote the following:

Friday August 17, 2012

I was at Atlantic House for Day Program from 9 to 2:30. Right now I'm in Quincy waiting to get a haircut at Supercuts in Pilgrim Plaza. It's now the middle of August and the weather has been very hot and humid.

This weekend old shows of Julia Child the French Chef from Cambridge will be aired on Channel 2 in memory of her cooking and gourmet cooking career which started back in 1962. In 1962 Julia Child was 50. She was born in Bordeaux, France in 1912. She died about 8 years ago when she was 92 years old. Her TV shows ran from 1962 until the late 1980s when she retired. She would've been 100 on August 15 had she lived to celebrate her 100th birthday.

Julia Child the French Chef: August 15, 1912 to December 21, 2004. She was 92 and lived a very long and very fulfilling life even though her cooking career didn't start until she was 50 in September 1962. She lived in Cambridge at the time and drove a grey 1958 or 59 Volkswagen Beetle which she drove for several years until she couldn't drive anymore by 1991. In 1992 she moved to California to live at a deluxe retirement home in Los Angeles. She would live there until she died in December 2004.

I met her in person once at a Star Market Super Market in the spring of 1973 one Friday afternoon when my mother was grocery shopping. It was March or April 1973. She was grocery shopping and I met her at the seafood section where Julia was selecting some live lobsters. Some of her famous recipes and entreés included lobster including lobster bisque and some kind of seafood casserole. I can remember Julia Child selecting about 7 or 8 live lobsters for a gourmet entreé recipe which later aired on channel 2 around 1975 or 1976. I watched Julia Child on TV occasionally until the late 1980's and then Julia Child retired her cooking career in 1988 or 1989. And then she moved out to California in the early 1990's to a deluxe retirement home in sunny Los Angeles.

God bless Julia Child:
Born: Bordeaux, France on August 15, 1912
Died: Los Angeles, California on December 21, 2004.

Between August 17 and August 31 Channel 2 (WGBH Public Broadcasting) will air old TV shows of Julia Child every evening for the remainder of August honoring what would've been Julia's 100th birthday.

Julia Child
1912-2004

MY COMMENT
[PII redacted] wrote this one month before his 50th birthday, about Julia Child who was 50 years older than [PII redacted], and who began her famous career at age 50 in September 1962, which is when [PII redacted] was born.

I remember the time [PII redacted] spotted her in the supermarket. She had recently described cooking a lobster, which she began by removing it from the lobster trap. [PII redacted] ran up to her in the store, and told her how much he enjoyed watching her lobster show! She told him she had never had such a compliment from such a young viewer.

[PII redacted] would like to work, and have a career. Julia Child's story was inspiring to him. Age 50 is not too late to begin a new career. I began my nursing career at age 50 too. [PII redacted] has decided to try to get a GED diploma first, and is attending classes four days a week. My hopes for him are renewed now too.

The New England Auto Show

Sunday January 22, 2012

FEATURED CARS
Last Sunday's auto show went really well. We attended the Auto Show on Monday, Martin Luther King's birthday. Mostly brand spanking new cars were the feature. There were a few muscle cars from the late '60's early '70's on exhibit as well. The most expensive cars on display last weekend were: Bentley, Rolls Royce, Lamborghinis and Ferrari Testarossa ('84) the very same type of Ferrari seen on "MIAMI VICE" a TV series that ran from September 1984 until Jun 1988. They also featured the 2012 Volkswagen Beetle. The 2012 Toyota Prius "V" is just like the Prius models: 2005 thru 2011.

There were several older foreign makes and models including: BMW, Honda, Hyundai, Isuzu, Jeep Wrangler (Chrysler Division), Lamborghinis, Mazda, Nissan, Renault (from France), Saab, (the cube), Toyota, Volkswagen, Volvo, and one 2011-2012 Aston Martin that can reach speeds up to 260 MPH on the Autobahn in Germany.

American makes featured were: Buick, Cadillac, Chevrolet, Dodge & Chrysler, Ford, Lincoln, Mercury, Oldsmobile, Plymouth, Pontiac, Studebaker (1952-58), a Packard from 1930 or '31. Hummer and Saab were also featured including a Saab Sonnett III from 1969 or '70.

Scrabble

Friday April 27, 2012

I am now at the Thomas Crane Library in Quincy. The weather today is fair. One of my housemates [PII redacted] is celebrating his 57th birthday. We will have a little party at the house for [PII redacted] this evening at about 8pm.

I have a bit of an addiction to the game of Scrabble, a popular word game invented by 2 men named Selchow and Righter. It was created in 1948. Today I kept at it at Atlantic House between 12:30pm and 2 this afternoon.

The following words in Scrabble will give you the most points: popquiz, quizwiz, quizzical, jazz, apple orchard, peach orchard, and a few others.

The most points anyone can get in a game of Scrabble is between 700 and 775 or 776. Depending on the words and the triple letter scores and triple word scores. The letters J, X, Q, and Z have the most points: either 8 or 10.

Selchow and Righter created this unique game in the summer of 1947. A year later it became an official game trademark product by September 1948.

At Atlantic House, I'm the only client there interested in Scrabble. The other clients either just listen to music or read the daily newspaper, or arts & crafts whenever it's available. Every Thursday at Atlantic House we have an AA group meeting lead by a lady named [name redacted], who lives over in Randolph. The meeting is from 1pm to 2:30 and there's usually about 6 of us attending. Sometimes 7 or 8.

[Photo redacted]

1969 - [Name redacted], artist and future automotive history expert, with mother and brother

Paula Bartholomeus

June 22, 2013

Reattach Therapy and autism: promising results on a variety of developmental areas.

Author: Paula Bartholomeus (orthopedagoge NVO)

Autism Treatment Evaluation is very important in the development of an intervention in its early stage. “ReAttach” is such a new intervention and it is based on “attachment”.

Practical research has taught us that “ReAttach-Therapy” can be of great importance for people with autism. We have taking the first steps in exploring the benefits of adults and children with Asperger Syndrome, PDD-NOS, autistic disorder, and people with both autism (ASD) and Intellectual Disabilities.

The Autism Treatment Evaluation Checklist has made it clear that there are different developmental areas in which people with autism can make significant positive changes in a period of only 3 months. The results on children with communication difficulties (that had lost their speech or have not spoken for several years) were amazing. We have seen three similar cases with Disintegration disorder (CDD or known as Heller’s syndrome) and all three children have regained their rudimentary speech patterns again. They also have shown similar growth in the areas of play, sociability and behavior.

We look forward in presenting to you the formalization and status of the scientific research at your Conference. In the coming year we expect to make significant strides with the existing evidence-based therapies .

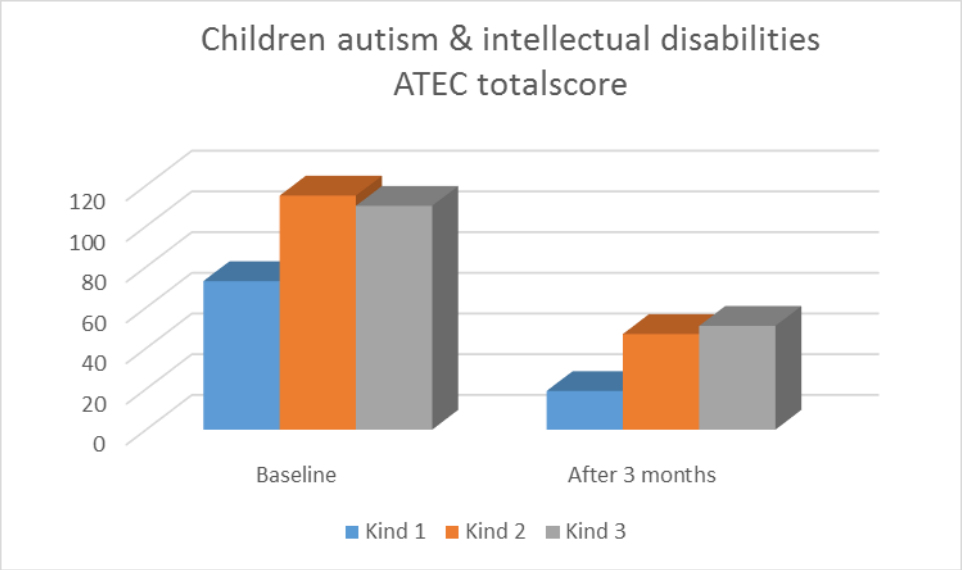
Appendix: ATEC scores of 3 children with autism and intellectual disabilities
different developmental areas baseline / after 3 months

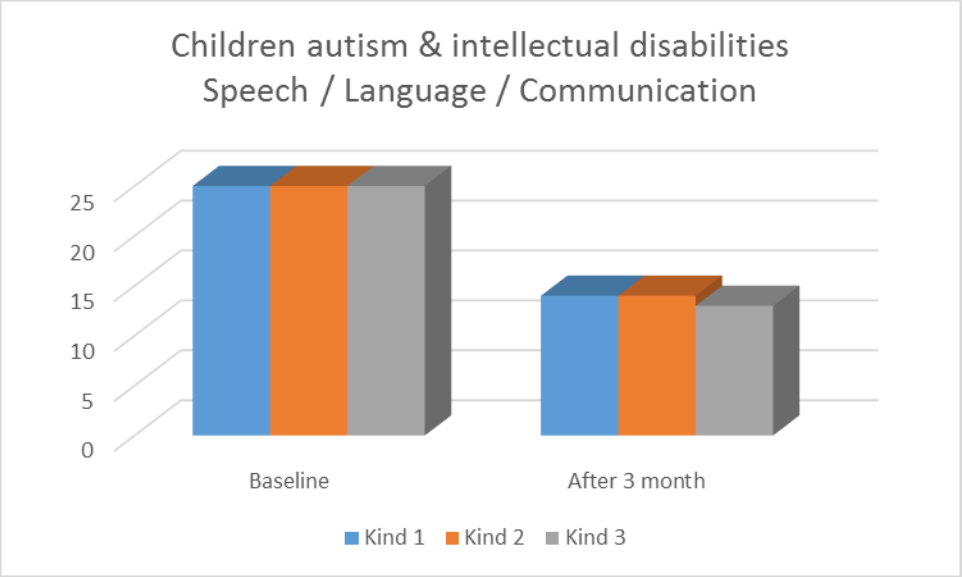
Group statistics of 75 ATEC scores of 19 clients diagnosed with Autistic Disorder, 33 clients diagnosed with Asperger Syndrome and 23 clients with PDD-NOS.

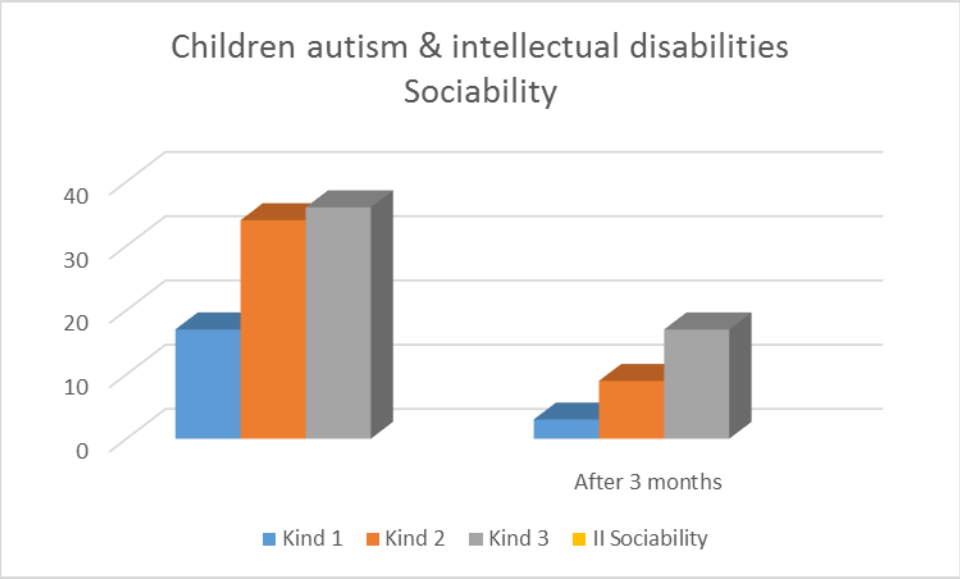
Attachment

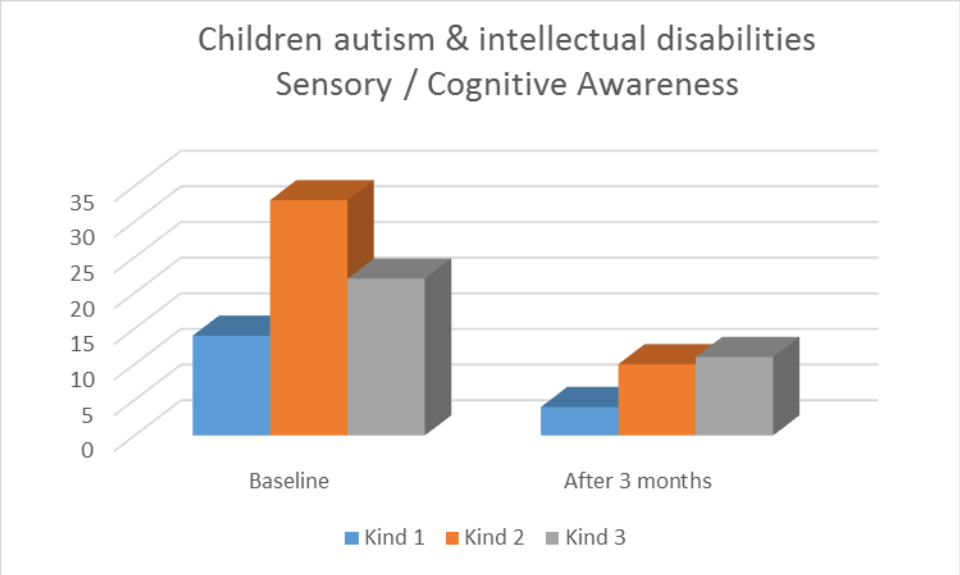
ATEC scores children autism & intellectual disability
Kind 1 = child 1, 9 year old boy
Kind 2 = child 2, 8 year old boy
Kind 3 = child 3, 12 year old girl

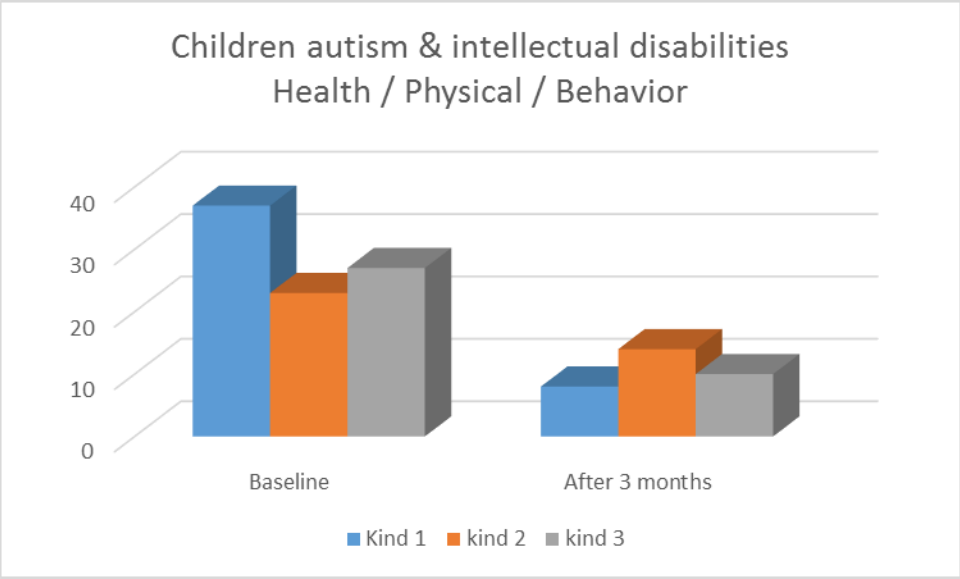
Baseline: level of problems
After 3 month: reduction of problems






Children autism & intellectual disabilities
Sociability
40
30
20
10
0
After 3 months
Kind 1
Kind 2
Kind 3
II Sociability


Children autism & intellectual disabilities
Sensory / Cognitive Awareness
35
30
25
20
15
10
5
0
Baseline
After 3 months
Kind 1
Kind 2
Kind 3


Children autism & intellectual disabilities
Health / Physical / Behavior
40
30
20
10
0
Baseline
After 3 months
Kind 1
kind 2
kind 3

Group statistics ATEC / ReAttach therapy d.d.21-06-2013

Diagnose Autistic Disorder N =19

Diagnose Asperger Syndrome N=33

Diagnose PDD-NOS N=23

Group Statistics

	Meting	N	Gemiddelde	Std. Deviatie	S.E. Mean
ATECtotal	baseline	75	77,16	24,71	2,85
	after 3 months ReAttach	75	31,48	20,62	2,38
Speech/Language/ Communication	baseline	75	7,63	6,31	,73
	after 3 months ReAttach	75	3,59	4,23	,49
Sociability	baseline	75	26,19	8,58	,99
	after 3 months ReAttach	75	9,51	7,02	,81
Sensory/Cognitive Awareness	baseline	75	19,09	5,78	,67
	after 3 months ReAttach	75	8,73	5,37	,62
Health/Physical/ Behavior	baseline	75	23,88	9,47	1,09

Independent Samples Test

		Levene's Test for Equality of Variances		t-test for Equality of Means			
		F	Sig.	t	df	Sig. (2 tailed)	Gemiddeld verschil
ATECtotal	Equal variances assumed	4,08	,05	12,29	148,00	,00	45,68
	Equal variances not assumed			12,29	143,40	,00	45,68
Speech/ Language/ Communication	Equal variances assumed	3,83	,05	4,61	148,00	,00	4,04
	Equal variances not assumed			4,61	129,27	,00	4,04
Sociability	Equal variances assumed	8,15	,00	12,02	148,00	,00	16,68
	Equal variances not assumed			13,03	142,45	,00	16,68
Sensory/ Cognitive Awareness	Equal variances assumed	1,45	,23	11,37	148,00	,00	10,36
	Equal variances not assumed			11,37	147,17	,00	10,36
Health/ Physical/ Behavior	Equal variances assumed	6,20	,01	10,59	148,00	,00	14,19
	Equal variances not assumed			10,59	133,18	,00	14,19

Michelle Ewart

June 26, 2013

I am writing because I believe autism is a medical problem. My child was diagnosed with autism, but also suffered/suffers from a slew of medical conditions such as mitochondrial dysfunction, gut dysbiosis, and brain inflammation. As we treat the medical problems, his autistic state improves. Cognition improves; there are attempts to communicate, etc.

A generation of children is being affected by a condition that starts with metabolic problems and end up affecting the neurological. Please see this growing epidemic as one that needs urgent attention. We need to look at the environmental factors that are triggering and causing the devastating condition known as "autism".

Sincerely,

Michelle Ewart
--

http://www.autism.com/
http://www.autismyesterday.com/trailer.html

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

Margaret Tipton

June 26, 2013

I won't go into my "whole story". It's a book of many pages. But please just know that my son, [name redacted], born normal on April 25, 1995, became autistic over time. [Name redacted] was an incredibly picky eater, he "played" with his toys by lying on his side (sitting up seemed like it required too much effort). [Name redacted] had few words to communicate. He had stomach aches, and in his preschool class, at age 4, [name redacted] was known as "the screamer". In Spring of 2000, I read about a special diet to cure Autism, and I started [name redacted] on it right away. I took him to see a special "alternative" M.D. who treats Autism, and she gave me fish oil and supplements to start giving [name redacted]. Within two weeks of seeing this doctor, [name redacted]'s stomach aches and screaming stopped.

I have to say that, as a family who, by the grace of God, had the ability to pay for it---Children's Hospital in Boston, and even Dartmouth Hitchcock Hospital could not help [name redacted] with his health. His "alternative" doctor in Newton, Massachusetts, helped [name redacted] more than anyone.

I hope you will be able to change the status quo, and begin to help these sick children. And if you need to ask someone who would have many stories of how ill these children are-----[name redacted]'s doctor's name is:

Jeanne Hubbuch, M.D.
[PII redacted] Newton, MA
[PII redacted]

Sincerely,
Margaret "Peggy" Tipton
Hampton, NH

Cindy Harrell

June 26, 2013

Regarding health issues that accompany the autism my son has; gastrointestinal problems, anxiety, and some weight issues, as he has sensory issues with food. We have had to supplement his food with pedia sure with fiber for years so he gets the variety of nutrients that children need. We also do our best as far as exercise goes, but due to struggling with fine and gross motor skills, he does not ride a bike and do a lot of the physical activities that NT children do. I also know that epilepsy is a possible part of our future. I hope not, but we are aware that it is common especially when puberty starts.

Thank you for the opportunity to share.

Sincerely,

Cindy Harrell

María Luján Ferreira

June 26, 2013

As the mom of a child diagnosed with autism, living outside of USA, I am profoundly affected by the situation that concerning autism, the only word used is mystery. The mystery that is not much for many of us , that through incredible struggle and with the help of local committed doctors and very few doctors (and the published work of researchers) from USA and other parts of the world, found like in my son´s case, dozens of non-genetic medical conditions concomitant to the diagnosis of ASD. These dozens of medical conditions would have remained untested, undiagnosed and untreated without a personal struggle against almost all odds that was done by us, the family. These conditions were central to the progress of, at least, my child. There is no learning, no social inclusion, no school integration and no life´s quality without ordered biology, properly addressed under the light of the system´s biology updated at XXI century.

I am talking about gastrointestinal, metabolic, biochemical, nutritional, toxicological, endocrinological conditions, non-genetic mitochondrial dysfunction, immune (such as dysfunctions) and autoimmune medical problems (such as PANDAS-PITAND-PANS and many others), viral-fungal-parasitic and bacterial infections (being them GI or not, acute or chronic subclinical or not), oxidative stress, inflammation and microglial activation.

My son presented a complex combination of many of the cited medical conditions, being a general pediatrician or a general doctor the most suitable doctor to be in charge of the testing, diagnosis and treatments of them. These medical conditions require specific study, research and training for ASD and autism due to the complexities presented, especially because many of these are present in different individuals diagnosed with ASD in different forms and presentations. There are at least 500 pages of abstracts with published literature on these topics- and increasing in number and quality each week- that remains fragmented, unanalyzed, unattended, not read (it seems), not known (it seems) and not systematized by those with the tools to systematize, protocolize and to make these protocols to be known, learned and applied with the sense of urgency required, today-not in 10 years. This way, there are no goals for systematization to obtain the needed protocols that are urgent to improve the health and life´s quality of children like mine and to dream in prevention. The work is left to us, the families that around the world struggle to get the needed, proper medical help (not medicalization or pharmacology or simply drugs to control symptoms or methods to make learning possible or behavior acceptable) that they desperately require.

Sincerely,

M. L. Ferreira-PhD Chemistry-Argentina

Mom of a child diagnosed with autism

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

Kathy Blanco

June 26, 2013

Subject: Public Comment on Health Care Bias against Autistic Children

Dear IACC Committee,

As a parent of two with autism now in their third and second decades of life, I have been through numerous occasions when physicians would not as much even touch my children for examination. They have seizures, gut problems, heart problems, thyroid problems, skeletal problems, diet problems, podiatry problems, neuromuscular, mitochondrial and neuroimmune system issues etc. Every occasion to explain these problems were met with eye rolling, disbelief, spurning, and even labeling that "this is just autism"...or, "it's complex", or "we don't understand why". When pressed why, or what their belief system was, invariably it would come back to the word mysterious, we don't know, and that's not possible. Our stories somehow become unbelievable to physicians, as if the A word is presented as a branding label to display numerous prejudices and archaic medical thinking. Had a normal child been presented to them with these difficulties, there would be immediate alarm bells going off, and calls to insurance companies to get coverage for therapies and surgeries and procedures and recommendations pronto.

At one point my son ASYSTOLED (FLATLINED) in the ER after a series of seizures, which required emergency surgery for a heart pacemaker. When hospitalized at another occasion, I emphatically stated that my son's behavior changed overnight, he was sleep resisting, and aggressive for no darn reason, and doing odd compulsive behaviors. They spurned my advice that he may have PANDAS (and autoimmune disorder associated with strep and other infections infecting the basal ganglia). This was at a teaching hospital, a known center for excellence in Portland, Oregon. All they offered me were antipsychotics and "good luck with that" attitudes. I immediately had him tested with [PII redacted] a PANDAS expert, and he as raging positive for antibodies against his basal ganglia.

Another occasion or occasions I would say, is when my son was wasting like an AIDS patient. I have pictures of him where he looked like a BIAFRA child. No physician dared to press his stomach to see why he was so bloated and distended, and yet had no fat on his body. In his later years, I did find ONE gastroenterologist who believed this was Autistic Enterocolitis and was willing to scope him like Andrew Wakefield and [PII redacted]. This was met with great disfavor at the hospital setting. At one point, we were on the wait list to MAYO CLINIC. Even they turned us down to see us, even when my son lost over twenty five pounds in three weeks. I had to be the expert on every occasion. I had to call researchers. I would get tests, and tests would come back positive for infections they don't recognize as being harmful to the CNS. I would reach out and get assays they needed. I would have to educate physicians on every occasion what "the next step should be".

When we went to Defeat Autism Now Doctors, their hands were tied. They could not test outside of the parameters of "what autism is" as well. Protocols that could save (if not cure) my kids WERE NOT OFFERED or COVERED, which would include IV antibiotics, IV infusions, IV antivirals, Hbot, Stem Cells, Plasmapheresis, Chelation, IvIG, Nutritional Foods, Speech Therapies, Play Therapies, SPECT SCANS, and even simple LOOKING AT THE EVIDENCE of harm that they suffered some type of vaccine reaction,

which resulted in severe brain inflammation and an ongoing viral persistence.

My daughter's health has slowly declined since the non-touching has begun as well. She has a curved spine, which, they find "acceptable", when in fact she walks with a slight bent to her body. She has as well as my son, has, thyroid issues, which when tested in normal fashion APPEARS to be ok, but, if given a TRH or antibody test (which is not normally offered) is completely abnormal. No medicines or interventions are offered them. When I did get concern over that, compounded medicines cost a great deal of money out of pocket. And speak of out of pocket....nothing that ever was offered by the mainstream physicians ever touched their autism, not one. The only things that do, or have some positive effect, are mitochondrial cocktails (out of pocket), nutritional interventions (out of pocket), and other immune regulating/boosting supplements or IV's) as well as special diets. PKU patients get more respect.

My son later required a stimulator device to stop his seizures, VNS. Apparently even that is questioned if the person has mental disabilities as well. Are they not deserving of a quality of life? When I tried to get spect scans on our brains (including self), our doctor was met with WHY, and for WHAT REASON. Even though we had positive lyme tests, and markers of brain inflammation. After much cajoling with the insurance companies, mind you, a doctor we paid for practically out of pocket, we got the scans, and all our brains were COMPLETELY ABNORMAL. VERY ABNORMAL. We paid thousands of dollars out of pocket for those scans. Our scans were later put in an article by Dr. [PII redacted], head of [PII redacted], and it basically says that the presence of maternal autoantibodies to fetal brain presents an elevated risk for autism. The presence of particular anti-fetal antibodies to mothers during pregnancy might be a possible trigger to have an effect on neurodevelopment heading to autism.

What on God's green earth would cause such a prejudice in the medical field? Aids patients get more respect. Is it because looking at the accident scene implicates involvement in the accident? I think so.

Why do mothers and fathers of these children have to be thrown into the "have to be the expert" fields? Because no one is willing to look at the obvious. That these susceptible children suffered some type of triggering event, regressed, and then regressed in front of parents eyes, and are not to be believed or sanctioned as having brains, having been researched to such an extent, that physicians crawl and slither away when they approach us? This is against all Hippocratic oaths. Why do parents have to inform the surgeon of the protocol for anesthesia when these people need to know their stuff? Why do we have to throw their own money (with related financial suicide) at therapies and practices that help their children, when the medical fields refuse to look at the unguarded science?

Shame on the AMA, shame on the AAP, shame on the CDC and NIH and DHS. Shame on any physician who takes an oath to do no harm, and then harms by spurning parents belief systems, based on SCIENCE. Before my son's event in ER requiring a pacemaker, I PLEASED with the mitochondrial "expert" at OHSU Portland that my son was neurodegenerating right before my eyes, and where is your concern? Given all the information in front of them, printed articles on OXPHOS disorders, and the like? If I would have spurned him as well, he would have dead in his bed one morning (SUDAP) without me knowing he had severe conduction issues due to mitochondrial dysfunction. Every test where I ordered myself from a researcher, WHOM I CALLED, was positive and concerning.

This is why I will not stop at being their advocate. If I do stop, it's because my heart stops as well. Apparently, the hearts of our medical system have stopped a long time ago.

Although I have no illusions that your concerns will be met with dual concern, nor, that your committee even cares about the lost generation due to medical neglect, and have no illusions that things will change, I only offer this one thing. Do the right thing. Recognize...that the complex medical disorders presented in the A WORD diagnosis, is not autism. Stop CALLING IT WHAT IT ISN'T. In fact it is a complex medical disorder with hydrbranches of medical issues associated with neuroimmune gastro intestinal upsets, which can spread to other organ systems, on a molecular cellular level, such as what mitochondrial disorders present as. Uptake of folate, or creatinine or even VIT D are disturbed. Blood brain and gut barriers are breached. Cellular organization, even ATP and Kreb Cycles are off.

Muskuloskelatal and Connective Tissue is often problematic, such as POTS and Dysautonomias. Veins are not right, even CCSVI is detected in our kids! What will it take, until physicians recognize the entire systems of the body are under autoimmune attack? What will it take, when sorrow is displayed for a cancer child, and not a child with autism? Are they not just as vulnerable of a death sentence by wandering or seizures?

Sincerely,

Kathy Blanco
Ione, California

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

Liz Parker

June 26, 2013

Subject: Co-occurring conditions associated with autism

The IACC strategic plan for Autism research, back in 2011, acknowledged the need to better understand the scope and cause of co-occurring conditions, and the need for multidisciplinary heath assessments and effective treatment guidelines. In response, I wish to inform the Committee about those co-occurring conditions my daughter faces, and what has made a difference in her health and developmental trajectories, and ultimately, her outcomes.

My first comment (and I hope this will not stop you from reading the rest of this letter) is that there are certain newborns and infants who should not receive vaccines; unfortunately, though we recognize in the AAP guidance that children with metabolic challenges, autoimmunity, and mitochondrial dysfunction should not be vaccinated until they are stabilized, we are vaccinating all, with impunity. I have two children, who are not related, who are suffering from adverse outcomes after vaccination; my eldest is adopted, the other is my natural child. My younger child got her vaccines at 6 months and stopped breathing while still on the exam table, before I even got her dressed! She was resuscitated and brought to the hospital, where, after a number of hours and treatments, she was discharged with a diagnosis of Severe Asthma, covered in eczema, and given prescriptions for hourly nebulizer treatments with Xopenex, liquid Albuterol, steroids, allergy medicine, and an inhaler (puffer); there is no family history of Asthma, however, autoimmunity is rampant. She has recovered from the eczema and we now have the Asthma under control, but she is left with mild AD/HD; it has been nearly 12 years since her adverse event.

My eldest received her vaccines at 3.5 months, left the appointment screaming, screamed for numerous hours, and finally crashed into sleep which lasted six times longer than normal, when she awoke, she did not want to eat, and when I went to change her diaper, her legs fell to the changing table when I let them go; the doctor's office told me this was not of concern and to continue to give her Tylenol. We continued to have almost every symptom on the Vaccine Information Statement, to which the doctor's office always responded that we should not be concerned; until she hit the symptom on the VIS that was linked to the directive, "Go to the hospital," nine days after vaccination; she shrieked in a non-stop, high pitched wail for numerous hours, despite every effort we made to calm her. At the hospital, the VIS was thrown in the trash, the hospital generalist gave us a prescription for Amoxil, and we were dismissed. My daughter never recovered from this event, and with each new set of vaccines, sunk further and further into poor health, failure to thrive, and the behaviors we use to diagnose Autism. By age 2, she was diagnosed with Severe Autism; the Developmental Pediatrician told me, "She has Severe Autism, she will never speak with intent or toilet train. She is cute, now, but by the time she is 5, she will need to be institutionalized. You need to get her onto a wait-list, now;" I immediately sought information from every Journal I could get my hands on, and began to pursue more information to understand what was at the root of the symptoms which had earned her this diagnosis. We saw numerous pediatric specialists, including neurology, endocrinology, developmental ophthalmology, orthopedic, and more. We found a pediatrician who had decided to focus on helping children with Autism by addressing their symptoms by determining their root causes. We found a group of parents traveling the same road, and worked together as a community to share what we knew, what was working, and what seemed

dangerous or hopeful. As recently as when she was 5, I was informed by the School District that she was "retarded and in-educable." The problem is "Autism" is not a psychiatric disability - it is a medical disability. Her epilepsy, antibodies to her own myelin, hypotonia, mitochondrial dysfunction, hippocampal sclerosis, irreparable vision disturbances, hypoxia, heavy metal toxicity, global developmental delay, failure to thrive, and many other diagnosis' work together to create her "Autism." She was not born with these disorders, she developed them, starting with the neurological event following her vaccines at her 4-month "well-visit!" She does not have autoimmunity, but she has metabolic dysfunction of low Biotinidase and low Carnitine; according to the AAP guidance, she should have had these levels stabilized prior to vaccination – they were not identified, nor addressed.

She was born, perfect, at 42 weeks gestation. She was meeting and exceeding expectations up until she was 3.5 months old (4 month "well visit"). After this, she descended into: head banging, drooling, screaming for hours on-end, not sleeping, having copious putrid diarrhea upward of 7 times daily, being covered in rash, driven to pica, and grew to be non-verbal and elopement-prone, and more. Mainstream medicine was willing to simply throw her future away. Had I listened, she would now just be considerably bigger and less controllable with all of these issues.

We opted to pursue "recovery." Her "recovery" moves slowly, but surely, forward, using the pillars which include Organic, Allergen-free Nutrition (to address her core health and assure her regular participation in behavioral therapy), Daily Intensive Behavioral Therapy to enable her to learn EVERYTHING (self-care, safety, eating adequate amounts of food, how to play, understanding social cues, learning to speak, learning to toilet, learning to take pills, learning new words, learning to pay attention, learning to control impulses to stim, learning to learn, and so much more – all the things "typical" children just pick-up naturally) – she has logged 17,000 1:1 hours of the therapy so far, Supplementation to address neurologic, gastro-intestinal, metabolic, and other imbalances (this allows her to participate successfully in the mainstream world), and Quality Inclusive Education which sets the academic bar high and utilizes measurable milestones which address independent functioning, social capability, academic and life skills (this enables her to develop the skills she will need to reach an independent and capable adulthood). My child, destined to "never speak with intent or toilet train" at 2 and deemed "retarded and in-educable" at 5 is now almost 14, she is toilet trained (and preparing for her period), fully verbal, on age-level academically, behaviorally able to hide her Autism from strangers, sleeps 10 hours each night, swims on a swim team (though she is not competitive, due to her metabolic challenges), rides horses independently, has friends, and is getting excited about maybe being able to get her driver's license in a few years, going to high school, and maybe having a boyfriend; yes, she still has "Severe Autism" and permanent brain injuries and myriad dysfunctions, but she is learning to compensate, work-around, and make-do with what is left.

Her diagnoses include:

Biotinidase deficiency,
Carnitine deficiency (Free and Total),
Global developmental delay,
Severe Autism,
Frontal and Temporal Partial Complex seizure disorder,
Convergence disorder (she closes one eye to deal with this and vision therapy made no difference),
Hypotonia,
Hippocampal Sclerosis,
GI dysfunction,

Tibial torsion,
Motor planning disorder.
Apraxia,
Antibodies to her myelin (MBP)
IgM to her brain endothelial cells,
Heavy metal toxicity
SPECT scan shows deep frontal ictal activity/ring of fire/and other misery
Allergy tests positive for: gluten, casein, soy, pork, beef, apple, canola, potato, nightshades, tomato, egg, and citrus

Additional labs have shown:

Elevated Propenoyl (C3:1), elevated Tetradecadienoyl (C14:2)
Elevated plasma ethanolamine (component of myelin).
Low zinc compared to copper level
Despite over 1 year on a Mito Cocktail, first biopsy (sample too small, all tests ordered could not be performed) showed atrophic Type II myofibers, and a clear excess of lysosomes, and prominent lysosomes.
Despite over 5 years on a Mito Cocktail, second muscle biopsy shows her Complex IV Freeze/Thaw is below the 5th percentile
She has far too many mitochondria
Elevated oxalic
Elevated suberic
Elevated citric acid
Elevated Kynurenic Acid
Elevated glyceric acid
Elevated succinic
Low arginine
Low isoleucine
Low urine values of: asparagine, isoleucine, phenylaline, tyrosine, ornithine, lysine, threonine, 3-methylhistidine, and arginine.
She also shows low serum IgA.
Regarding hepatic function, she has shown low total protein and high Alk Phos and AST
She has consistently low CO2
Consistently high MCV and BUN/Creatinine ratio
Elevated alanine and 2-aminobutyric.
Elevated lactate to pyruvate ratio.

What we have done, which has resulted in her emerging from rashes, not sleeping, self-abusive behavior, elopement, food refusal, failure-to-thrive, hours-long screaming jags, behavior which endangered others, being non-verbal, not toilet-trained, and reducing and/or eliminating the many other behaviors known as “Autism:”

- We are (and have been, since she was 2) GF/CF/SF ALL ORGANIC
- Purified water for drinking, cooking, bathing
- No chemicals in our home

- Early Intervention: Speech/Language, Occupational Therapy, Physical Therapy, Behavioral (total of 6 hours a week for 1.5 years) – would have been more beneficial on the GF/CF organic diet & supplements – she was dismissed because she was not deriving benefit
- Speech/Language Impaired Public School classroom with Speech Language Pathologist as teacher (2 years) – useful, but not as effective as the ABA/VB/PBS/DTT, below (which incorporates ALL therapies); she was on GF/CF organic diet and supplements for this period
- 1:1 ABA/VB using Positive Behavioral Supports and Discrete Trial Training for 25 - 35 hours a week (for 8 years), incorporating ALL therapies in the natural environment and in a mainstream classroom - extraordinarily beneficial, she was on the GF/CF organic diet and supplements

We have spent years trying to figure out the best combination of supplements for her; to–date this is what is working:

Variety of Probiotics
Digestive enzymes
B Complex
Magnesium Glycinate
Magnesium Malate
Vitamin A
Vitamin E
Sphingolin
K2
Carnosine
Ubiquinol
Folinic Acid
EPA/DHA
Milk thistle
Zinc
Grapeseed Extract
L-Theanine
Multi Vitamin
MSM
Phosphatidyl Choline
Biotin
Acetyl L-Carnitine
Chromium
Vitamin C
CoQ
Riboflavin 5 Phosphate
MT Promoter
Phosphatidyl-Serine
Alpha Lipoic Acid
Alpha Ketoglutaric Acid
Glutathione 100 mg
ATP with Ribose
Vitamin D

Early-on, we cycled through viracin, itrakonazole, and ketoconazole; and we limited her sugar to the naturally occurring sugars in fruits/vegetables/carbs for a long time. We also fed her cultured foods, and supportive nutrition.

She is almost 14, today. She is fully verbal and age-level for academic subjects. She is behind about 2 years, socially and about 4 years in self-care. Overall, she is an amazing young lady who I am very proud to parent – she is a very hard worker!!! My daughter has sacrificed her childhood to therapies (over 18,000 hours, to-date), but is facing her teens and adulthood in a position which just might allow her to go to college and live a full and productive independent adult life.

While I recognize that not every case of "Autism" results from vaccine injury, I believe that the exponential rise in "Autism" cannot be explained, nor staunched, without addressing the 32-plus needles in the lives of newborns and infants. PLEASE, study the life/death, and health outcomes of entirely unvaccinated children versus fully vaccinated children, born between 1996 and 2005. Until this research is complete, at least propose to the CDC that our childhood vaccines should not commence until children are over 6 months of age (infants younger than 4 – 6 months of age are incapable of producing antibodies, anyway!), and we have assured each child is free from autoimmune, metabolic, and mitochondrial disorders (those who can be stabilized, should be stabilized before vaccination). With these interventions, alone, the dramatic rise in Autism will likely falter and probably plummet; and families, like mine, will not suffer the financial, emotional, physical, and psychological devastation that accompanies life with autism…

If you need more information, I am always available at [PII redacted]. Please let me know if I can provide any more information?

Thank you for taking meaningful action to stop the meteoric rise in children being impacted by symptoms which result in the diagnosis of "Autism."

Liz Parker

Rebecca Magliozzi

June 26, 2013

Subject: Children with Autism Need Proper Health Care and Screenings

My son with autism suffered from allergies, multiple food allergies and intolerances, extreme fatigue and weakness for years. I was told by pediatricians and even developmental pediatricians he was completely healthy, that food allergies could not possibly contribute to his highly hyperactive and out of control behaviors, etc. We noticed he stopped raging as much and his chronic congestion lessened a lot when we put him on a GFCF diet. Is it normal to sneeze after every time you eat wheat or dairy and get a runny nose, bloated stomach, etc? He had seven food allergies uncovered when we did the testing, and very low vitamin D levels. That's not perfectly normal or healthy in my book.

Finally, a doctor who listened to me when he developed psychotic symptoms in first grade and thought to test him for PANDAS. My son has chronic lyme, strep, mycoplasma, active Epstein Barr virus and active HHV-6 (Roseola) virus. He was also developing dysautonomia by the time we found all this out. Luckily, most of the dysautonomia symptoms have disappeared since we have put him on treatments for these illnesses. What about other kids who aren't so lucky somebody finally listened to the parents? The severely autistic boy in another state who was chained to a bed in the psych ward because of self injurious and other behaviors, when he really had horrible GI pain? Every child with autism needs to be screened for food and environmental allergies, GI issues, PANDAS/PANS and immune deficiencies. Almost every autistic child I know has at least one of these issues. We cannot continue to fail our children, because within the next 20 years, most of them will eventually have autism, due to the huge increase in mandatory vaccinations (six at once is too much!), environmental pollution, chemicals and toxins in food, etc.

Rebecca Magliozzi

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

Holly Bortfeld

June 26, 2013

I am the mother of 2 children with Autism Spectrum Disorder, soon to be 18 and 20 years old. My son [PII redacted] was born normal, healthy, full term, 12 lbs, 9/9 Apgars. At my son's 2 month old check up, he got 5 vaccines and a few days later, his first of 17 ear infections. Being a good parent, I never missed one vaccine appointment despite his now chronic ear infections and systemic yeast overgrowth caused by the unending antibiotics. At the last appointment that he ever received a vaccine, the MMR, and 4 other vaccines, within 2-3 weeks he fell off the cliff into autism. He had been talking in short, developmentally appropriate sentences, and met or exceeded EVERY DEVELOPMENTAL MILESTONE until that day he received the MMR. Little beknownst to us, it was only the beginning of his illness. For the next 2 years, we would be turned away from countless medical practitioners and refused care for treatable medical conditions merely because he carried the label "autism". Since the diagnostic criteria for autism involves NO medical criteria, then medical care should never be denied, as it clearly has nothing to do with autism, right? Tell the AAP that. I mean, would you refuse treatment for a broken leg to a kid with cancer, just because he also has cancer? No? It's the same with "autism".

My son spent almost two years in agonizing pain with caustic diarrhea that burned his skin, nonstop ear infections (17 in 20 months), he didn't sleep for 2 years, which meant I didn't sleep for 2 years. He eloped twice putting himself in grave danger when he was 3 and 4. He spent his days screaming and posturing to relieve his gut pain, banging his head and biting his arms until he bled. His rib cage bones grew outward to fit over the giant impacted chunk of stool that caused his belly to swell, aka "Ethiopian belly". His skin was sallow and bumpy. He couldn't feel pain, temperature and had no fear- a dangerous combination. The list goes on and on.

Fast forward to finding real medical practitioners who tested and treated his many co morbid issues, he can do all the things the "best specialists in Florida" promised me he'd never do. And I have no doubt that had I listened to them and medically drugged him into submission rather than treat the underlying cause of his autism - vaccine injury - they would have been right. He would have rotted and like many of his peers, died from wandering or seizures or spent the last 15 years in unnecessary pain.

Just some highlights of the things my son has been diagnosed with:

Colitis (in remission since 2006)
GERD (in remission since 2004)
Immune dysfunction with hyperimmunity
Heavy metal toxicity
Lead poisoning
Cachexia (10x elevated TNFa)
Allergies (too many food allergies to count)
Viral encephalopathy
Vitamin and mineral deficiencies
Pancreatic dysfunction

So, with proper medical care seeking truth and remedy, rather than burying science in the sand, my son can and does independently, ski (water and snow), work, play, talk, like to ride roller coasters and go to the movies. I have calculated that it's cost me, insurance and the state $1.4 Million dollars to get him to this point. He is not recovered and will still need lifelong care, but he's not sick anymore and that's priceless.

When my son got sick, my plans of homeschooling my daughter [PII redacted], who is 2 years older, were cut short as I needed to figure out this thing called autism and help my son. So, I vaccinated her with her kindergarten boosters on her 5th birthday so she would be ready for school 3 weeks later, and within 2 weeks, she fell apart. Even the pediatrician who missed my son's autism said "Wow, what happened to her?" as my daughter was DEVELOPMENTALLY APPROPRIATE at her 5th birthday appointment, when she received the vaccines. She could read at a second grade level when she was 4. Had a 135 IQ at age 6, a familial trait. Within 2 weeks of these kindergarten boosters, she now had ADD, Central Auditory Processing Disorder, immune problems, and later was diagnosed with Aspergers, CAPD, ADD, Heavy Metal Toxicity, Immune and Mitochondrial dysfunction, allergies, OCD, PITANDS, anxiety and many more.

Over the years, with intensive MEDICAL interventions for these issues, and NO traditional therapy (no speech, OT, PT, ABA) she's now a Junior getting her degree in Mechanical Engineering, in the Honors program, at one of the top engineering universities in the country. She can drive, has friends, and is an amateur silver jewelry designer and maker.

Obviously, my children have never been vaccinated again since those fateful rounds in 1998, nor will they ever be again, as they clearly have a predisposition that cannot tolerate vaccination. It's taken a lot of time, effort, money, services, pain and supposedly 'alternative' treatment from some of the most prestigious hospitals in the country and also some nondescript practices to get my kids healthy. The medical establishment has fought us the entire way, never a partner in our health care needs. I would not have healthy children if I didn't fight the medical establishment and their status quo of "do not question" and "don't ever touch the third rail of public health - vaccination - or we'll fire you from our practice, report you to CPS and keep you from an education". Parents should not have to fight their doctors for medical care or travel all over the country to get help like we did, and still do.

Our kids have treatable medical conditions that can turn them from sick children to healthy taxpayers when we can get proper medical care. All you need to do is look at the body and what's wrong with it, then fix those things, and you'll be amazed. Autism is treatable. Autism is recoverable. It really is.

Holly Bortfeld
Mom to 2 amazing kids

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

Nora Fitzpatrick

June 26, 2013

I understand that Dr. James Perrin, president of the American Academy of Pediatrics has been invited to attend the July 9th IACC meeting to participate in a discussion on how to improve the health of children with autism. I would like to share some of our story with you.

Our daughter [PII redacted] started to regress around age 1. You can see the changes in the pictures between 12-18 months. [Name redacted] suddenly started to look sick. Around this same time, [name redacted] developed an underarm rash that was quite painful for her. I couldn't even get her to lift her arm to clean it out. Yeast developed in the creases of the redness. Our pediatrician said it was like diaper rash and not to worry about it. A dermatologist said essentially the same thing. It persisted for a year, and I brought it up at every appointment. Finally, it was cleared up when a pediatrician recommended a cocktail of aquaphor, lotrimin, and other topical antibiotic/antifungals from over the counter.

From this point on, [name redacted] was always sick, or prone to illness. We joked that she was the kid we would try to keep our older daughter away from. She had constant ear infections until she had tubes put in her ears.

Things took a rough turn just over two years ago. [PII redacted] was progressing wonderfully in preschool and then she got four strep infections in three months. Huge outbursts of temper at school. Obsessions with a classmate's water bottles, biting, aggression. She had her tonsils removed and I noticed that for the first time ever, [PII redacted] did not feel warm to the touch. She returned to school in the fall and got strep twice more. She was officially diagnosed with PANDAS and is treated for it with rifampin each time she has a flare. We haven't done IVIG yet since it is not covered by insurance.

[PII redacted] has historically broken out in hives. No explanation why.

[PII redacted] was in the autism subtype study at NIH. In this study, it was discovered she had Wolff-Parkinson White. It was corrected by an ablation. In this study, it was also determined that [PII redacted] had low folate levels in her brain fluid. The folate levels in her blood are fine. Why is this? No one knows. And it was difficult to find a doctor to treat her. She has been taking leucovorin and her levels are normal now.

Back in the fall of 2012, [PII redacted] started having lots of outbursts and renewed aggression. Another autism mom friend who has pursued biomedical treatments for her son, suggested that [name redacted] possibly had yeast overgrowth. I have always been very skeptical of biomedical treatments but [name redacted] was miserable, so I looked at the link. [PII redacted] had nearly every symptom. I called my pediatrician who is wonderful and conservative but also open minded. He agreed that [PII redacted] fit the bill for yeast overgrowth. He prescribed fluconazole and [name redacted] improved within hours. Hours. I'm not kidding. Three hours later, [PII redacted] was creating detailed drawings on the ipad of the Mickey Mouse clubhouse. She hasn't done that in two years.

[PII redacted] had a endoscopy and no yeast was found. She finished her prescription of fluconazole and within a day, she was screaming and miserable again. So, the pediatric GI specialist agreed to keep [name redacted] on a low dose.

Just recently, I added a second dose of priobiotics to her daily regime. After this change, [PII redacted]'s skin no longer felt like sandpaper as it always has. It feels like a newborn. No diet changes. No new lotion. Also, she is talking up a storm. So much that when we went to Kennedy Krieger to look into assistive technology, we were told [PII redacted] talks far too much for it to be beneficial. This is all since we added the second dose of probiotics.

What is going on with our kid? PANDAS seems to disproportionally affect children with autism. She gets exposed to strep now and her behavior changes. We know from the folate issue there are blood brain barrier issues. Medicines and probiotics work for her but we don't know why. She's a little adorable science experiment. And while we have a fabulous pediatrician who is open and helpful, there's no standard of care for children with autism. Many things I found out through a study. I can't get people to work to figure this stuff out for her. It's ... kids with autism have this... we don't know why.

Nora Fitzpatrick
[PII redacted]
Gaithersburg, MD

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Shannon Johnson

June 26, 2013

My name is Shannon Johnson and I live in Harpswell, Maine. My 18 year old son was physically restrained on a hard floor by 5+ people over 1000 times in an 18 month period-- sometimes up to 8 times in one day. Under the current law, there is nothing inappropriate about such treatment. The law simply requires that a doctor or nurse sign off on the restraint, that it be documented, and that a report be filed in 24 hours if death occurs. There is no limit to the number of restraints or the length of restraint. There is also no call for assessment of the behavior plan or medical assessment to determine the factors that have led up to the restraints. There is no escalation of this information to administration once a certain number of restraints or time spent in restraint has been reached. As a result, the opportunity for abuse and injury is significant. I'm not sure my son will ever recover from the trauma.

As attention to restraints and seclusions in school settings is being raised, I think it is important to recognize that those same concerns apply to hospital/autism unit settings as well.

Thank you for your time-
Shannon Johnson
[PII redacted]

Links to the attachments included in the email are below:

- **Children's Health Act of 2000**
  http://iacc.hhs.gov/events/2011/051911/childrens_health_act_051911.pdf

- **Principles for the Elimination of Restraint by Peter R. Breggin, M.D.**
  http://breggin.com/index.php?option=com_content&task=view&id=96

- **VI. & VII. FREEDOM FROM UNNECESSARY SECLUSION AND RESTRAINT IN RESIDENTIAL SETTINGS**
  http://www.maine.gov/dhhs/ocfs/cbhs/policy/children-rights-recipients.pdf

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Raymond Gallup

June 27, 2013

Subject: RE: public comment on health care bias against autistic children

Dear IACC Committee,

I totally agree with [PII redacted] on the issues she brings up below since I know about our experience over the years with our adult son, [PII redacted] who has regressive autism caused by the MMR vaccine and other vaccines.

Sincerely,
Raymond Gallup
Lake Hiawatha, NJ

PS: The autism epidemic will never stop until the autoimmune aspects/vaccine link of this epidemic is addressed. See the attached figures from US Government agencies.

ATTACHMENT

COUNTS FOR ADULTS AND CHILDREN
RECEIVING SSI BENEFITS
FOR AUTISTIC DISORDERS
YEARS 2006 - 2011

Year	Under 5 to 64	Increase
2006	84,217	
2007	97,455	13,238
2008	112,414	14,959
2009	130,772	18,358
2010	151,260	20,488
2011	173,946	22,686

Year	All Ages	Under 5	5-12	13-17	18-21	22-25	26-29	30-39	40-49	50-59	60-64
2011	173,946	13,719	67,621	25,588	31,428	19,503	9,051	4,787	1,412	690	147

http://www.ssa.gov/policy/docs/statcomps/ssi_asr/2011/sect06.html
Online Tables 34 &35 on link above

Yearly increase in the number of children with autism age 6-21 in US Schools Since DSM IV (1994

School Year	Students	Increase
1994	22,780	
1995	28,813	6,033
1996	34,082	5,269
1997	42,487	8,405
1998	53,561	11,074
1999	65,391	11,830
2000	78,717	13,326
2001	97,847	19,130
2002	118,603	20,756
2003	140,920	22,317
2004	166,302	25,382
2005	193,481	27,179
2006	224,415	30,934
2007	258,095	33,680
2008	294,302	36,207
2009	335,199	40,897
2010	369,664	34,465
2011	406,957	37,293

Increase in the number of children with autism Age 3-5 (2000 to present)

School Year	Students	Increase
2000	15,581	
2001	17,032	1,451
2002	19,017	1,985
2003	22,724	3,707
2004	25,902	3,178
2005	30,276	4,374
2006	35,071	4,795
2007	39,434	4,363
2008	45,166	5,732
2009	47,602	2,436
2010	49,213	1,611
2011	51,252	2,039

US Department of Education Source:
Online
https://www.ideadata.org/PartBChildCount.asp

6-21
https://www.ideadata.org/TABLES35TH/B1-3.xls
3-5
https://www.ideadata.org/TABLES35TH/B1-2.xls

Figures below received through mail

COUNTS FOR ADULTS AND CHILDREN
RECEIVING SSI BENEFITS
FOR AUTISTIC & OTHER PERVASIVE DEVELOPMENT DISORDERS
AS OF DECEMBER IN 2002 - 2010

As Of December For Year	Children 21 and under	Adults 1/	All Recipients
2002	38,324	7,360	45,684
2003	44,076	9,282	53,358
2004	51,581	11,450	63,031
2005	59,479	13,647	73,126
2006	68,050	16,190	84,240
2007	76,448	19,139	95,587
2008	88,734	22,993	111,727
2009	94,725	34,988	129,713
2010	103,700	41,462	145,162

1/ INCLUDES PERSONS AGE 65 AND OVER WITH CLAIM TYPE = DISABILITY.

Carolyn Shepherd

June 27, 2013

Subject: July 9th IACC Meeting to Improve Healthcare for Children with Autism

I am the mother of 4 children, all with neurological issues. My oldest daughter has Tourette Syndrome and ADHD. My youngest daughter has Asperger Syndrome and has had many health issues.

My identical twin boys are severely affected by autism and are non verbal. This is a brief list of their diagnoses over the past 7 years.

Autism (299.00)
Expressive language delay (315.31)
Severe Childhood Apraxia of speech
Partial hearing loss/fluid in ears
Impaired metabolic processes (277.9)
Impaired mitochondrial function (277.87)
Impaired immune system (279.9)
Inflamed GI tract with impaired digestion and absorption (558.3, 579.9)
Mineral/vitamin deficiency (269.3)
Sensory integration disorder (781.8)
Hypotonia (728.87)
Lack of coordination (781.3) - gross motor, fine motor skills, and visual motor planning
Global developmental delay
Feeding issues
Hyperactivity
Absence seizures
Behavioral and attentional issues
Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS)

Currently we have been on a wait list at the Marcus Autism Center for almost a year after requesting emergency help for our son's behavior at home. We are still on this wait list. Our insurance does not cover ABA therapy to help them learn how to function in daily life at school or at home, despite the fact that our doctors have been telling us they need it for years. We have no respite care as it is very limited and comes with a lot of red tape. We spend a large portion of our income on medical insurance, between this and the Katie Beckett waiver the boys care is covered by what the insurance company will allow. My daughter with Asperger Syndrome does not receive therapy outside of school because we can't afford the multiple co pays and deductibles and because she does not require nursing home level of care does not qualify for the waiver. One of the boys lost their medicaid 7 months ago due to an error at the agency handling our case and we have to file all over again because we had to wait 5 months for our school district to provide a report they require as we can't afford to pay for psychological evaluations out of pocket.

Our family is struggling more than anyone should have to. Our twins need much more than we are able to afford that insurance and Medicaid don't provide. Their medical issues drive their behaviors, and even if we have insurance and Medicaid the lack of providers and proper settings that can help us coupled with long wait lists mean we are trapped in our home. WE NEED HELP.

The wait lists need to be dealt with. It needs to be less difficult to access services through Medicaid and insurance. Doctors and state providers need to realize that "age adjusting" for prematurity delays early intervention services that needs to start as soon as possible. Our twins were repeatedly denied services through our state Babies Can't Wait program due to "age adjusting"; we had a special nurse evaluate them from the medically fragile unit who used this to say they were within normal limits despite their severe delays and medical history. Doctors need to be able to prescribe treatments other than just prescription drugs that can help and that will be covered by FSA's, insurance and Medicaid. We need for doctors to be trained that just because a child has autism does not mean that is the end of the story and nothing else needs to be investigated or tested. We need GI specialists that can and will run tests on children with autism with gut issues instead of telling us to "give Miralax every day" and send us away. We need more than anti psychotic and SSRI drugs not developed for children and definitely not for children with autism to help with behaviors. Autism is not a psychiatric disorder you treat with medication. We need real help; our children deserve a chance like any sick child and not to be dismissed because "there is nothing you can do for autism." Many children, like mine, have real co morbid conditions that affect their behavior, yet we have no behavioral support.

Autism affects us all, and awareness does nothing if nothing changes for the better and no real action is taken. We need real help now, not more research chasing an autism gene that has not led to any meaningful treatments.

Sincerely,

Carolyn Shepherd
Decatur, GA

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

Valerie Boergesson

June 27, 2013

I thank you for having a meeting regarding the autism epidemic and I hope some progress can be made during this time. It has been incredibly frustrating as a parent with a child with autism to watch our government do very little for all these very ill children and now adults. My son developed autism after his 18 month DPT vaccine, prior to this vaccine; he had a 90 word vocabulary, normal play skills and was meeting all developmental milestones ahead of schedule. After this vaccine, he screamed and cried and ran a fever for three days and over a period of a few weeks, lost all language, ability to feed himself, respond to his name, stopped playing with toys and just wandered around the house. He was completely gone, his mind completely wiped out, and he became incredibly ill. I have waited a long time for our government to start addressing this crisis, this epidemic, my son is now 18. I am tired of waiting.

My son has been ill most of his life from vaccine injury. He suffers from severe colitis, gastritis, intractable epilepsy, mitochondrial disorder, autonomic nervous system dysfunction, bladderneck dyssnergia, and allergies. These children are so medically sick and our medical system has completed turned their back on an entire generation of children. Doctors dismiss most complaints from parents as behavioral issues associated with autism, and if fact, the children are in horrible pain. I have taken my son to "top gastroenterologists in NYC" that have completely dismissed my son's pain, and then when he had an endoscopy and small bowel camera study by a competent GI doctor that understands autism, he was found to have severe gastritis, h. pylori, and ulcerations and inflammation throughout his entire GI tract. This is criminal. We treat animals better than we treat patients with autism.

Enough of the genetic studies!! Autism is rising at an astronomical rate, and we continue to waste time and money on genetic studies. We need real studies done by research doctors that have no interest in the vaccine program in any way. We need to study the vaccinated vs. non vaccinated population. We need to give [PII redacted] a huge grant to do the research on our children's GI disease.

http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0058058 click here to view his recently published paper on children with autism, proof of their very specific bowel disease. The biggest and most important thing that can be come out of this meeting, is to treat autism as a medical disorder, autism is medical, these children are so incredibly sick, their bodies broken in so many ways, and there is very little help for these patients and their families. The first wave of these children, like mine are reaching adulthood. The parents are exhausted physically, emotionally and financially from trying to care for them with no help in sight. What will become of them, when we, the parents are too old ourselves? This is a national crisis, and it is time that it is treated as one.

Valerie Boergesson
[PII redacted]
Southold, NY

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

Jill Escher

June 28, 2013

Subject: Proposed Additions to Strategic Plan for Autism Research

Escher Fund for Autism
[PII redacted]

Dear IACC members:

Based on emerging science demonstrating plausible connections between past exposures, epigenetic germline and somatic alterations, and abnormal neurodevelopment that may include autism as a manifestation, the Escher Fund for Autism respectfully submits for your consideration the following proposed additions to the Strategic Plan for Autism Research.

Additional research opportunities

• **Survey** of multiplex ASD families, including families with children with related disorders including ADHD, learning disabilities, and mental illness, seeking to ascertain potentially relevant ancestral exposures, including pharmaceutical drugs, smoking, and endocrine disrupting environmental chemicals, that may have impaired pre- or postconception germline epigenetics. Special attention should be paid to "windows of susceptibility" such as the sensitive period of fetal germline development.

• **Epidemiological studies** of grandchildren of women given acute doses of various pharmaceutical drugs in first half of pregnancy, or who smoked. Epidemiological studies of children and grandchildren of people exposed to Agent Orange (dioxin) and other military-related pharmaceutical and chemical exposures.

• **Animal model studies** of multigenerational effects of prenatal exposures to various compounds of interest, including exposures common in the past (synthetic hormone drugs, smoking, EDCs) and the present (antidepressant drugs, anti-nausea drugs, hormone drugs, others).

• **Epigenetic and genetic assays** of individuals with ASD, where ancestral exposures are known or reasonably suspected.

Additional short-term objectives

• Ensure the FDA, NIEHS and EPA **collaborate** to take appropriate steps to determine adverse epigenetic effects, on germline and fetal neurodevelopment, of synthetic chemical and pharmaceutical exposures, particularly during key windows of susceptibility.

• Ensure policies that entitle all Americans full **access to records** about their prenatal and early life pharmaceutical exposures.

Proposed amendments to existing language in the Plan

(*Proposed amendments are in bold.*)

Genetic and epigenetic variations in ASD and the symptom profiles associated with these variations, **and where possible, ascertain past exposures that may be associated with the variations**.

Studies in simplex **and multiplex** families that inform and define de novo genetic differences and focus on what role the environment might play in inducing these differences.
Better understanding environmental and biological risk factors during **germline,** prenatal and early postnatal development in "at risk" samples.

Cross-disciplinary collaborative efforts to identify and analyze biological mechanisms that underlie the interplay of genetic, **epigenetic,** and environmental factors relevant to the risk and development of ASD, including co-occurring conditions.

Initiate studies on at least 10 environmental factors, **including factors that may affect germline synthesis,** identified in the recommendations from the 2007 IOM report
"Autism and the Environment: Challenges and Opportunities for Research" as potential causes of ASD by 2012. *IACC Recommended Budget: $56,000,000 over 2 years.*

Emphasis on environmental factors that influence **germline,** prenatal and early postnatal development is particularly of high priority. Epidemiological studies should pay special attention to include racially and ethnically diverse populations. *IACC Recommended Budget: $12,000,000 over 5 years.*

Support at least ~~three~~ **ten** studies that focus on the role of epigenetics in the etiology of ASD, including studies that include assays to measure DNA methylations and histone modifications and those exploring how exposures may act on maternal or paternal genomes via epigenetic mechanisms to alter gene expression, by 2012. *IACC Recommended Budget: $20,000,000 over 5 years.*

Support two studies and a workshop that facilitate the development of vertebrate and invertebrate model systems for the exploration of environmental risks and their interaction with gender and **epigenetic and** genetic susceptibilities for ASD by 2012. *IACC Recommended Budget: $1,535,000 over 3 years.*

These suggestions appear to be complementary to current research directions, and a logical extension of current efforts to assess the role of gene-environment interaction in the etiology of some forms of autism. Your consideration is greatly appreciated.

Very truly yours,

Jill Escher

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

Joseph M. Jason

July 2, 2013

Subject: Public Comment Regarding Criminalization of Asperger Syndrome In Iowa City

I am President of the National Alliance on Mental Illness BA. I would like to address the Criminalization of Asperger Syndrome going on in Iowa and the Federal government. The following excerpt summarizes my concerns:

Recent actions of the prosecution in Iowa City are indicative of the criminalization of Asperger Syndrome. My wife and I met with the prosecutor in December of last year and explained Asperger Syndrome and mental illness. We explained that our son's behavior is childlike rather than criminal. We told them he needs treatment and not incarceration.

We gave them a forensic psychiatrist's report that demonstrates he is not violent. He is a nuisance. We told them that his behavior according to [PII redacted] is typical of one with Asperger Syndrome. We told them he has an organic brain disorder. One of the prosecutors told me everyone in jail is mentally ill, and the head of the office seemed sympathetic to the chronic sorrow. His criminal behavior consists only of phone calls and emails.

I had a deposition recently and they tried to twist [PII redacted] report. They not only want to lock him away for 55 years, but they extended the time period of the stalking to include the time he has been in jail. That is punishment fit for a major drug dealer and/or murderer. This case, as it always has, cries out for treatment and not incarceration.

[PII redacted] was living with us for the entire time and did not go to Iowa. This has not stopped the charges of stalking and extortion. This is not what our founding fathers envisioned that America should be. [Name redacted] has already been in jail and prisons for most of the time since 2007.

[PII redacted] has stated that [name redacted]'s so called criminal conduct is caused by his Asperger Syndrome. "[PII redacted] cannot legitimately be considered morally responsible for his misconduct." [PII redacted] also states that "The lack of significant history of violence is important."

As stated in the article, Forensic aspects of Asperger's Syndrome by Justin B. Barry-Walsh and Paul E. Mullen in the Journal of Forensic Psychiatry & Psychology, "It behooves us to draw to the court's attention the obvious: that patients with Asperger's Syndrome suffer from mental disorder and that their offending and subsequent disposition must be placed in this context. The core features of Asperger's Syndrome and how they determine what the individual knows and understand of the world should form a basis for sophisticated assessment of the issues of disability."

A recent tragic development is that my son fired his Attorney on February 19th and he believed this was a winnable case. NAMI National does not get involved in individual cases. I think they should on a limited basis. Even [PII redacted] received less of a sentence than my son is facing.

Please see my radio broadcast:

http://www.thekimfoundation.org/html/notalone/about_show.html

June 2013

June 25: ***Family Perspective***
Our guest will be Joseph Jason, President of the National Alliance on Mental Illness in the Barrington, IL community. Imagine that your young son had Asperger Syndrome. Imagine that your son, unable to make sound decisions regarding appropriate behaviors because of his disorder, made poor social choices. Instead of receiving an assessment and mental health care, he is facing 55 years in the Iowa State Penitentiary. We will hear a family perspective on this broadcast.

Joseph M. Jason, President NAMI BA (847)537-3009
Member of Criminal Justice Advocacy for People with Mental Illness

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

Jennifer Margulis

July 2, 2013

I am writing to urge the Office of Autism Research Coordination to study the effect of prenatal ultrasound exposure, especially in the first trimester, on the developing embryo. We have focused our time and attention on post-natal causes of autism but there is a growing body of scientific evidence over a variety of disciplines that shows that ultrasound exposure makes profound changes on the cellular level in plants, animals, and possibly humans. This is urgent research that needs to be conducted immediately. For more information, you can consult with Dr. Manuel Casanova, M.D., at the University of Louisville and David Blake, a researcher at the University of North Carolina at Pembroke. Each of these scientists has evidence that ultrasound exposure may trigger autism, though they have different theories about how.

All best,
Jennifer Margulis
****
Jennifer Margulis, Ph.D.
Investigative Journalist
The Business of Baby: http://amzn.to/15LtzWe
[PII redacted]

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

Melissa Schneider

July 2, 2013

I would like the IACC to recognize that Autism for the most part is a medical disease caused by environmental triggers. There may be a small subset of children who present with a genetic predisposition, however, continuing to bury our heads in the sand is not helping these children or families who are struggling with the medical costs of treatment and education. Insurance rarely covers appropriate treatments and it is largely in part because it is still, to this day, seen as a behavioral disorder, instead of a physiological disease.

[PII redacted] of NY Presbyterian at Columbia has successfully treated gastrointestinal and bowel disease in children with Autism, and this treatment has significantly reduced many of the repetitive behaviors (stims) and self-injurious behaviors previously seen in these patients. Please refer to the Atlantic Monthly for June 10, 2013

http://www.theatlantic.com/health/archive/2013/06/in-autism-the-importance-of-the-gut/276648/

Furthermore, we know that the Vaccine Injury Compensation Program has paid out millions and millions to families who have successfully proven vaccine related brain damage. In 2002, nearly 5,000 families filed petitions claiming that vaccines had caused their children to develop Autism, and those are only the families who were made aware of the VCIP. Thousands of other families were left in the dark to fend alone for their children and struggle horrifically, losing their homes and families.

Those in the Autism community who continue to deny that Autism is medical and deny that a correlation and/ or causation between Autism and a combination of environmental factors and/ or vaccine damage exists, are setting back the efforts of families and researchers all over the world in trying to help recover our children. This unconscionable, selfish and callous disregard for a generation of lost children must be addressed by your agency and rectified immediately.

The numbers are now a staggering 1 in 50, and we must act now to not only prevent Autism in the future, but we must also help the families struggling now.

We need to provide more community supports and fully fund local agencies to prevent tragedies like the [PII redacted] story, and we must help these families by holding accountable those hospitals (like [PII redacted] in Illinois) and medical providers who continue to deny access to appropriate medical treatments to alleviate G.I. distress and disease to help children heal and recover.

[PII redacted] death should serve as a reminder to all in our community that we must start approaching Autism treatment much differently. The mainstream medical community must also approach it differently by educating themselves on the underlying health issues children with ASD experience.

The status quo isn't working or benefitting anyone but the pharmaceutical and mainstream medical industry. We are no closer to finding solutions than we were ten years ago. Autism is a medical disease, not psychological, and not a psychiatric disorder.

Progress is stagnant and the consequences will be of great catastrophic and epidemic proportions to future generations if changes are not implemented now to help children and families struggling with ASD right now.

Thank you for your attention to these comments.

Respectfully,
Melissa Schneider

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

Amy Rosenquist

July 2, 2013

I would like to submit public comments regarding the current issues in autism treatment.

My 15 year old autistic son is currently attending a self contained high school classroom and therapeutic recreation summer camp. I am concerned that over the course of his lifetime, the state of pediatric knowledge and usefulness has not improved.

When my son was an infant and toddler he displayed very serious GI symptoms in addition to his developmental delays including but not limited to significant bloating such that he could not wear any pants (including elastic waist or "husky"), living in overalls until age six; diarrhea several times per day; feeding difficulties; and chewing/eating objects such as clothing and board books. He also displayed significant eczema and signs of possible headache/head pain. I took my son to over 15 physicians, from specialists to "holistic" pediatric MDs to well regarded pediatricians affiliated with university hospitals. In every case I was told his medical symptoms were simply "autistic behaviors" and there was "no reason" why autistic children displayed symptoms such as chewing difficulties, digestive problems, or gastrointestinal distress. His concurrent medical conditions were never explored and he never received any testing or treatment from his physicians.

Eventually I drove out of state and paid for a visit to a physician who was willing to run labs through Quest laboratories. My son was diagnosed with concurrent GI conditions. Upon appropriate medical treatment, his GI symptoms resolved. He had also been too ill to attend school approximately twice per month. After medical treatment for his diagnosed medical problems, he no longer became ill frequently, and has had perfect school attendance for many of the past several years.

My concern is that even today if I take my son to a medical appointment to fill out physical forms for school or Special Olympics, I have not been able to find a single pediatrician or family practice doctor in Chicago who is aware of the concurrent medical conditions. The American Academy of Pediatrics published a 200 page resource for physicians on the frequency and symptoms of concurrent medical conditions with autism, including the fact that these often present as bizarre behaviors or unrecognizable symptoms as opposed to the presentation seen in typically developing children. It appears that no one has read it.

Children with autism are not being medically treated for their very frequent concurrent medical condition. They are often in pain or distress, but their manner of expression is unfamiliar, and so they are dismissed rather than having the basic human right to have their medical conditions accurately diagnosed and treated. The severity of a child's autism may also be affected by a degree of GI distress. Who among us as a functional adult can work or learn at their best when the symptoms of minor but uncomfortable conditions such as lactose intolerance, much less the more serious illnesses such as Celiac or Crohn's disease, are causing symptoms? Surely a non or low verbal child with little understanding of his or her distress and no relief in sight cannot be expected to function at his or her best, much less make use of educational or behavioral therapies.

I have repeatedly been told throughout my son's life that I was imagining his symptoms or that his GI distress was caused by me - due to being under stress, due to not paying enough attention to him, due to paying too much attention to him, due to "looking for things to worry about," etc. Surely we are no longer in the 1960s when we are blaming mothers for symptoms, yet that has been the very best that pediatricians can come up with, rather than ordering a single blood, urine, or stool sample.

I urge you to closely investigate the state of understanding, knowledge, diagnosis and treatment of co-morbid medical conditions with autism, and make intensive training and compassionate, appropriate treatment for these co-morbid conditions a high priority. If more children were diagnosed and treated, their symptoms and pain would improve, and they could make better use of the educational and behavioral interventions offered to them, as well as function at their best, as anyone would do when healthy rather than ill. To this day I have spent any medical visit I have attended for my son educating the physician. As a recipient of state respite services, my son has a medical card, which means that in many cases the state taxpayers paid for physicians to be fully directed and trained by a lay parent in every aspect of autism. Surely after you have been in existence for this long, this should not be happening.

Amy Rosenquist
[PII redacted]
Chicago, IL

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

Meghan Dawson

July 2, 2013

I would like to submit a comment for the committee to read regarding the treatment of Autism. My contact info is below, if there are any questions or issues with this submission please don't hesitate to contact me.

Hello, my name is Meghan Dawson and I have two children with a form of autism (PDD-NOS). I understand that the president of the American Academy of Pediatrics is attending your meeting taking place on July 9th and I would like to contribute some information for the committee's consideration regarding the medical treatment of children with autism by pediatricians in general family practice.

My main concern is that pediatricians are not educated on the conditions that commonly accompany autism in kids. Or that some of these conditions are present from birth onwards and are often indicators that something is very wrong with our children and that the parents and doctor should be keeping an eye on that child for potentially developing an autism spectrum disorder.

I would like to start with the bowel problems that plague so many children with autism. Chronic constipation and diarrhea cannot afford to be ignored as unimportant or something a kid will just "grow out of." Constipation and diarrhea are signals that something is very wrong in the gut and if they are chronic and never ending then it is medically necessary for doctors to look deeper into the problem. And yet all that many pediatricians will say is "well you can give them MiraLax or Immodium and they'll probably outgrow it" as if bowel problems were a phase like biting other children or mouthing objects. I believe I have read that 40% or more of kids with autism suffer from chronic bowel issues. My son certainly did and yet our very educated, very autism-savvy pediatrician simply dismissed his chronic constipation as "well kids with autism often have bowel problems". She was aware of the problem and the link between the bowel issues and autism and yet had no training and/or desire to DO anything about it. And that is simply unacceptable.

At the very least pediatricians should be knowledgeable of and capable of recommending food allergy and sensitivity testing (IgG allergies which can be tested with a simple blood test), diet and nutrition counseling starting with but not limited to a Gluten Free Casein Free (GFCF) diet, stool testing for bacterial, parasite, and yeast overgrowth, the use of probiotics, and follow-up stool testing to make sure the bacterial imbalances are resolved. I am aware that many of these practices are not scientifically proven but given that none pose any potential harm to the child I feel it is completely reasonable that a general pediatrician be aware that there are treatment options for the bowel issues associated with autism and to be able to discuss the pros and cons with concerned parents.

Next I'd like to touch on non-bowel related co-morbid conditions that often accompany autism, the first being thyroid dysfunction. Many kids with autism suffer from thyroid issues which are easily diagnosed with simple blood work (in as much as drawing blood from any child is ever 'easy') and easily treated with prescription medications. The thyroid and its hormones are crucial to brain functioning and growth and I have seen several studies linking maternal thyroid issues to increased risk of autism in offspring. And yet, even for our family where both myself and my husband were diagnosed with hypothyroidism prior to having children, at no point did our pediatrician suggest testing our children for thyroid

problems. I believe it is because it would require drawing blood which is never a pleasant process with young children and at no point were our kids ever falling behind on growth, only on brain development. And while my son was born weighing 10 lbs and has only grown rapidly from there, when we did get his thyroid tested at age 2 his TSH was 11.5. For reference, a TSH of 12 is when CHOC children's hospital begins treating aggressively because of the potential for developing a goiter. So my 2 year old son who was always 100th percentile for height and 75th+ for weight was 0.5 away from developing a goiter. Here. In the US. In 2012. It is a REAL problem and one that required prescription medication and yet our pediatrician was either unaware or too hesitant to order the blood test.

There are other non-bowel issues related to autism such as L-Carnitine deficiency which our pediatric neurologist knew to test for but our general pediatrician was unaware of in relation to autism. Many kids with autism also have low tone in their muscles and L-Carnitine is crucial for muscle development and growth as well as brain function. It is a simple encapsulated supplement but can also be prescribed in liquid form for young kids... but only if a pediatrician knows to test for it and prescribe it. Additionally folinic acid is often found to be deficient which can be supplied in a sub-cutaneous shot with very little hassle (our kids have it added to their methyl-B12 shots). I could go on about vitamin and mineral levels being off as well but really just having a pediatrician know to recommend a REAL multivitamin that includes trace minerals as well as the usual calcium, iron, zinc, etc. would be enough, but Flintstones are not good enough for kids with autism who often have extremely restricted diets and guts which don't function properly.

I guess in closing if I can get across nothing else I'd like to make it known that our kids who have autism need their other physical ailments taken seriously and not dismissed as just being "part of autism". Many of the treatments, diets, and supplements/medications listed above have greatly improved the functioning of my two children on a physical level but also on a mental level. With a GFCF diet, yeast treatments, L-Carnitine, thyroid medication, vitamins, and B12 shots my son's chronic constipation vanished overnight with the removal of milk, he started talking for the first time, his puffy sore belly has gradually improved, and his ABA and speech therapists couldn't be happier with his progress. None of these conditions were hard to diagnose, none required trips to a specialist, they just required someone to LOOK for them. And that is what I am asking for all autistic kids - PLEASE LOOK BEYOND THE AUTISM. Look for the physical illnesses and deficiencies which are highly treatable because as these kids do better physically, they do better mentally.

Thank you,

Meghan Dawson
Irvine, CA
[PII redacted]

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

Jill White

July 2, 2013

Subject: Re: Dr. James Perrin meeting July 9th

Aloha,

I just wanted to take a moment to share my experience since my son was born in 2006. I believe he had an adverse reaction to the antibiotics he was given at birth. My birth plan said no vax but I was coherence by the hospital staff while I was alone, post surgery and receiving two blood transfusions. [PII redacted] had jandace, thrush & was such a poor eater his "failure to thrive" and had an extremely large head later diagnosed as benign external hydrocephalus. The most difficult symptom was his inability to sleep. He would wake every five minutes. After a few months he was only up to ten minutes at a stretch. He was under the care of a neurologist since he was two months old. We did everything conventional medicine suggested CT, EEG, etc but no one had any answers. When we gave him the "two month old round of vax" when he was eight months old he lost all the words he had gained. At fifteen months we began Early Intervention services. He got pneumonia from a therapist and after two types of antibiotics he lost eye contact. He was diagnosed sever ASD at eighteen months. Or pediatrician only suggested behavior therapy & moms support group. No information on diet, supplements, or biomedical therapy was ever offered.

When we finally got a doctor at 20 months old he had never slept more than 90 minutes at a time. He never had a formed bowel movement until we found another naturopathic doctor when he was 3.5 yrs old. My son will be seven this month and only has a couple of words he can clearly say. My point is that the conventional medical community did nothing to help my son. It was only through parent organizations like TACAnow.org that I was able to learn about alternative solutions that have led us to address his medical issues. He has parasites, virus, bacterial, inflammation, and intolerance to many things that were completely ignored by traditional medicine & the State Early Intervention.

We have spent over $350,000 of our own money (beyond what insurance & the State has provided) treating his autism and can say there are huge gains to the quality of life for our family as a result. I am begging you to reevaluate the vaccine schedule, give parent the tools to understand how important diet, toxins, probiotics, cod liver oil, etc can be in helping their child. I will never stop trying to recover my son from the damage that has the label "autism." What that word truly means is "we don't know" or "we refuse to admit the damage living in today's society is causing to a generation." but this is a battle that must be won.

Every person has their own unique problems but the bricks that build up to the "autism wall" are not a mystery. Genetic testing would be a huge step in helping identify who is at risk before vax. GMO, grocery stores filled with "food like products" that are devoid of all natural nutrition & have some vitamins sprinkled back in, toxic chemicals in plastic, mercury, lead, fire retardants, birth control, antibiotics given without probiotics, arsenic chicken & apple juice, and so many more... 1 in 6 kids in the US is chronically ill. Our ASD children are the canaries showing us that our industrialized food supply & health care are making us sicker each generation. This must be addressed on a global level if we ever hope to save society as we know it. I can't begin to convey the hardships we face just as one family;

multiply that times the millions currently suffering & the many more statistics show are on the way to the same fate. It must be stopped & that means putting people before big business profits. EVERYTHING is at stake. God help us all....

Mahalo,
Mrs. Jill White
Wahiawa, HI
[PII redacted]

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

YADIRA and [PII redacted] V. Moshopoulos

July 2, 2013

Subject: Re: Autism is Medical - Treat it Now!

I am writing to urge the Office of Autism Research Coordination to make it obligatory that every doctor treating a child with autism reads this:
http://xa.yimg.com/kq/groups/21528364/670281790/name/Medical+Comorbidities+in+ASD+2013.pdf

It is so frustrating talking to many doctors - private and thru Medicaid -- when you explain the medical aspect of my child's sickness and we are brushed off immediately... if we do not speak from a behavior/psych perspective we are not heard... And they would not even consider reading this protocol - which involves using medicines, not supplements - https://stopcallingitautism.org/ -- and testing my daughter's immune markers to determine which course of action to take and provide the adequate medication to heal her.

Another example - All Children's Hospital in St Pete FL - Autism Ctr (Dr. [PII redacted]) - Full evaluation was done, charged to Medicaid - plus 3 additional evaluations (OT, ST, PT) - again, more money... In not one instance the medical issues were talked about, discussed. When I brought up the spectacular changes that have taken place in [PII redacted] since June 2011 when I began the biomedical approach (plus homeopathy, plus plenty of suggestions from parent groups) and drastically changed her nutrition and only 5 months of OT and 3 months of Language Therapy have been a part of her progress and my daughter from a moderate to severe autism diagnosis in 2011 is now relabeled as high functioning autism , she is speaking, reasoning, laughing and is getting ready to begin kindergarten in the fall -- still, the medical issues were not discussed, inquired or referrals made to deal with the parasites (one came out May 25, 2013) in her intestines or deal with the metal toxicity in her system (aluminum water was prescribed by a doctor in Greece to apply to her skin when a bruise was present) -- and she was bruised all the time!

This is my daughter now:
http://www.youtube.com/watch?v=mlHtXQzAM5g&feature=youtu.be

Dec. 2012
http://www.youtube.com/watch?v=mlJq27UZbUI

April 2012
http://www.youtube.com/watch?v=vfcRxgTZVHk

January 2011
http://www.youtube.com/watch?v=nZuxpUDGNgY

December 2010 - she stopped talking (was dealing with 3 languages, interacting and responding to all three normally for 2.5yrs old), stopped interacting socially, walking the perimeter of a park, turning around a tricycle and never sitting on it, waking up at 2am-4am scripting and stimming, tantrums, detesting certain sounds, we'd call her and she would not respond, etc.

Plus, constant diarrhea, vomiting white globs, having allergic reactions in thighs, eating only bread, pasta, potatoes, milk, ice cream

I could go on and on. Feel free to contact us any time, we'd be happy to share even more.

Thank you for your consideration.
Change can only happen from above...

--
YADIRA and [PII redacted] V. Moshopoulos
Haviland, Ct
Palm Harbor, FL
[PII redacted]

NOTE:

On March 14 I had sent a similar note to the American Medical Association and this was their response -- this is unacceptable!

Dear [PII redacted]:

Thank you for contacting the American Medical Association (AMA) regarding being brushed off immediately when explaining the medical aspect of your child's sickness.

We are very sorry for the unfortunate experience you reported.

The AMA is an organization that promotes the art of medicine and the improvement of public health. Although the AMA supports the principles of competent, compassionate care and good physician-patient communication, we are not a body with primary disciplinary authority.

To file a complaint about a physician, please contact your state medical licensing board. For a complete listing of state medical boards, please visit our web site at http://www.ama-assn.org/ama/pub/category/2645.html

Sincerely,

[PII redacted]
Customer Service Representative
American Medical Association
membership@ama-assn.org

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

Sarah White

July 2, 2013

Dear Dr. Perrin and IACC,

Many autism parents feel the medical establishment has not been listening to us and, despite advancements in research, many medical professionals continue to view autism as a developmental disorder of unknown etiology despite increasing evidence that autism is a physiological (neuro-immune) dysfunction likely the result of environmental exposures. Many of our kids are in medical distress and need medical help but in order for our kids to get better, there needs to be a paradigm shift on how autism is viewed by the medical community.

Environmental factors in the autism increase seem to be constantly overshadowed by genetics. I think environmental factors and toxic exposure contribution to the autism increase should be given equal consideration as genetics. I think toxicologist should be at the table with doctors and scientists and geneticists talking about this issue. I request that toxic exposure to our children be an ongoing part of the discussion on autism whether the exposure is from pesticides sprayed on food and /or chemical additives to medicine for which many of the active ingredients are manufactured overseas. I ask the AAP take a stronger leadership role in educating doctors about environmental health issues related to the autism increase. Perhaps AAP could advise doctors to help recommend measures parents can take to minimize toxic exposure to their children.

To be frank, I feel our children are showing symptoms of poisoning. I talk to many other autism parents and hear story after story of how their once healthy children regressed into autism. The stories are heartbreaking. I witnessed my own son regress at age 2 after a period of typical development. Despite the fact that my son's genetic screening came back "normal" per the lab report and we have no family history of autism, he lost language, became echolalic, stopped hitting his developmental milestones and withdrew socially. He is in third grade and is currently is on an IEP and enrolled a special needs program at school where he gets OT, PT and speech therapy.

Many children with autism present with physical symptoms of underlying dysfunction including severe gastrointestinal distress, chronic stomach pain, inflammation and diarrhea. With the exception of a few doctors, it is very difficult for parents to get medical help for their kids because most doctors are trained to view autism as treatable behaviorally not medically. Parents maintain that the behaviors associated with autism are behavioral symptoms of an underlying neurological dysfunction involving the immune and neurological systems. With the right medical treatment our kids can and do improve. Our kids need medical help!!

Here is an example of children with autism in medical distress:

http://www.youtube.com/watch?v=5lTGrAkW8hU&feature=player_embedded

With 1 in 88 children and 1 in 54 American boys now affected, I am greatly concerned about the long term impacts of autism on our country's future when you that consider 1 in 88 children have a lifelong

disability. I feel we are losing a generation of children to autism. The cost of autism care is staggering estimated to be $3 million per child for lifelong care.

I want to share with you testimony from a hearing I attended at the State House in Boston, Massachusetts. As you listen to the parents describe their children's condition this is more than just behaviors something(s) is environmental is making our children very sick. Many parents believe that their children adversely reacted to something in the vaccines. The CDC has never done a safety studies on key elements of the schedule including the timing, age, frequency, order and number of shots given. So what is the cumulative effect?

http://www.youtube.com/watch?feature=player_embedded&v=5m_1X_iLVGA

This next video is of a hearing held in November 2012 before the Congressional committee on Oversight and Government Reform. This video is in three parts.

"1 in 88 Children: A Look Into the Federal Response to Rising Rates of Autism"

http://oversight.house.gov/hearing/1-in-88-children-a-look-into-the-federal-response-to-rising-rates-of-autism/

So to recap I ask the AAP and IACC to please give equal consideration to role of environmental factors (toxins) in the autism increase, explain ways parents can minimize risk of toxic exposure to our children and to investigate and treat underlying medical problems that many of our children with autism suffer from.

I greatly appreciate all your ongoing attention to this issue.

Thank you,

Sarah White
[PII redacted]
Hull, MA