

Oral Public Comments

**IACC Full Committee
Meeting**

January 16, 2019

List of Oral Public Comments

Eileen Nicole Simon, Ph.D., R.N. 3
Shari Chase..... 4
W. John Martin, M.D., Ph.D. 6
Aimee Doyle..... 9

Note: Personally Identifiable Information (PII) has been redacted in this document. Additional materials are available upon request.

Eileen Nicole Simon, Ph.D., R.N.

January 16, 2019

Comment for oral presentation at the IACC meeting on Jan 16, 2019

Eileen Nicole Simon, PhD, RN
[PII redacted]

Missed Diagnosis?

Language disorder is the most serious problem of children who receive a diagnosis of autism.

I am attending the IACC meeting in person to add emphasis to the many written comments I have submitted for discussion by members of the IACC. Many parents of non-verbal children have come here to plead for attention for these most severely affected victims of this affliction.

I cannot understand the need to look for adults who were not diagnosed with autism as children, and who did not have problems learning to speak.

The IACC was formed as part of the effort, 20 years ago, to seek-out reasons for the increase in autism that became evident in the early 1990s. Why has this mission been set aside?

My oldest son is now 56 years old. Too many people have tried to tell me I should be more accepting of his autism. Does anyone believe that childhood cancer should simply be accepted?

Autism is a serious neurological disorder. Autism, like cerebral palsy and spinal cord injury, must be made the focus of research on ways the brain can become damaged in the perinatal period. And, what measures can be adopted to prevent brain damage, in children as well as adults?

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Shari Chase

January 16, 2019

Hello all

I am a mom of two young men. One has Autism and is 22 and has fallen off the cliff since leaving high school last year. His days are not meaningful and he thrives when being creative and accomplishing meaningful jobs and roles. My son Alec is extremely bright young man but he is ruled by meltdowns. These meltdowns come in a moments notice and he sometimes has no control over them. We've been told by his doctor is that he has something called Sunct headaches And that these are secondary to Autism. His Neurologist stated that often people with autism end up pulling some of their hair out of her head hit their head and scream. These headaches last for 15 seconds to 15 minutes and never over 15 minutes but they are like an ice pick stabbed into your face. I have been hoping for years that we can find something that can detect some of his precursors that are non-obvious prior to even common meltdowns and the various biological symptoms that occur before the Sunct headaches occur. I have been searching for years to Find something that can give us a warning system prior to these headaches happening, so we can utilize some of the resources we have including breathing techniques removal from the situations etc. But until recently I saw no hope. My older son is a biomedical and is now completing his masters degree. He's devoted a great deal of his life to finding ways to help those people in the Spectrum that have meltdowns control them and give them back the ability to steer their own life and self advocate. He has done this through a device that is a wearable.

Excitement for this so needed device is shining bright light in the future for those people on the spectrum and those who suffer from anxiety and other meltdowns. it will be more than a life preserver it is a springboard to being able to rise to each person's fullest potential for often as is the case in my younger son Alec's life, the meltdowns prevent him from working or attending college which is what he so badly wants to do.

Next I want to alert that my son had a TBI and I have combed the metro DC area and no practitioner will treat a person with both Autism and a mild brain injury, this is an immediate area of need. Medicare and ASD must crack down on this void.

Finally, we need a national job training program for those with Autism. It needs to be visual for learning and a place where you learn your skills in a classroom then move it to practical application as a mentor and finally in an independent job. We can use our retiring work force as trainers and recreate the old vocational schools. It will be a win win situation. This can be further paired to a work, live and and play environment.

You must make sure these programs and the people who are willing and able to provide devices and therapies are covered by some of the social programs that we can offer. We can't leave people behind that can contributory citizens for that is not only a waste of life but it's a drain on society that does not need to happen. Let's work together to find social programs to help many find ways for individuals to control their meltdowns and other tics that prevent them from being completely employed and integrate into society. This way if one wants to utilize it they can, this could be a springboard for them to earn an income that makes them self sufficient, give him back the pride of control of their own body, it also takes

eventually a burden off of society because these individuals that are on the spectrum that become contributory citizens I, can give back to help others who are in need . This can give those that do not have the ability currently, the right mind set to have vocational and behavior training modification. I'm not saying to be very clear that we need to a erase the characteristics of autism , what we need to do is to be able to give a hand to those that want the ability to be able to assimilate so that they can reach her own for potential. Finally I did not touch with housing Housing is extremely important I have been preaching the model of pairing individuals that are at retirement age with those people that have autism in a housing unit similar to a residential wonderful campus community. I believe you can bid jobs within the commercial businesses that are attractive. The workers who are retiring tmost likely will need more funds to enjoy their lifestyle and can pass expertise on that is second to none for hands on training usually is the most effective with individuals there on the spectrum. Just imagine a viable community where you live work and play with no ways to be locked in but only ways to springboard out and enjoy a full life and always feel welcome and excepted. Those people who are senior citizens eventually will be in need a physical companions and perhaps others to work with them on the cognitive level you now have an additional work for us on the property that bridges for now some of ASD community can be pre-trained by these individuals to assist the aging and become the heroes of those on the spectrum . We can further this by opening commercial and professional sites all through this campus and attracting therapists and medical practitioners of all types for localized medical care it is a win-win situation for everyone involved.

I ask you to take these very important needs that are not being met and make sure they are met in the most expeditious way. I do realize that many of these are or appear to be daunting tasks but they're not things that we can say we will have work committees think about these are task that must be taken on ow and pushed forward mediately!!!

A question why do we not have current web sites talking about therapies that are used, drugs and supplements that are used that are very helpful so we don't have to remake the wheel on every day basis and also talk about what has not worked so we don't waste our valuable precious resources and time. We need to be more functionally coordinated and directive.

I thank you so very much and I hope that my son will come on and speak to you on details about what he is creating and has created for people on the spectrum it is a lifeline. I spoke about to help those on the spectrum to regain their own self control and dignity and assist in being able to live up to their individual put fullest potential on a daily basis ! Let's get moving on this. My guess if you need more for soldiers most family members will help in whatever professional know how they have so let's get moving! I volunteer my services and let's see who else in the country steps up to do the same.

Shari Chase
[PII redacted]

Note: Additional materials available upon request.

W. John Martin, M.D., Ph.D.

January 16, 2019

Dear IACC Members,

With all due respect, I want to point out a shortcoming of the IACC. Specifically, for as long as I have listened to the proceedings, there has been no mention of brain-damaging viruses that are not effectively recognized by the immune system. These viruses differ from the viruses from which they are derived in that they do not evoke an inflammatory response. This is because of deletions or mutations in the genes coding for the relatively few virus components that are normally targeted by the cellular immune system.

I referred to this immune evasion mechanism as stealth adaptation. Stealth adapted viruses were described in a major pathology publication in 1994 and were first reported in children with autism in 1995.

This research met with resistance from public health officials when it became clear that some stealth adapted viruses arose from the cytomegalovirus of African green monkeys.

Cytomegalovirus infected African green monkeys were routinely used to produce live polio vaccines. Contaminating DNA from monkey cytomegalovirus has been detected in previously approved polio vaccines.

I wanted to bring the topic of stealth adapted viruses to the attention of the IACC. Even though the cellular immune system generally fails to respond to stealth adapted viruses, the viruses can be inhibited by an alternative cellular energy pathway. This energy pathway is different from the cellular energy provided by the calories in food. It is expressed as a dynamic or kinetic quality of the body's fluids.

There is now a better understanding of the alternative cellular energy pathway. It can be easily enhanced using various therapies in virus infected patients, including children with autism. Updated information is included in my written comments. I would hope the committee will review this information and help expedite the optimal uses of these therapies in children with autism.

Thank you for listening. W. John Martin, MD, PhD

Attachments:

1. Supporting information on the early detection of stealth adapted viruses and on later studies on the alternative cellular energy (ACE) pathway:

I am a Board-Certified pathologist with sub-specialty certifications in Immunopathology and in Medical Microbiology. I began my research on CFS in 1986 at the University of Southern California (USC). I originally used the polymerase chain reaction (PCR) to test for HHV-6 in CFS patients and in patients with more severe neurological diseases. Although HHV-6 was only rarely detected, at least a third of tested patients yielded positive results using low stringency PCR on blood samples and, when available, on cerebrospinal fluid (CSF). Particularly striking was the positive PCR on a brain biopsy from a patient with cognitive impairment and severe expressive dysphasia. The biopsy was obtained from confluent areas of periventricular opacities, as seen on magnetic resonance imaging (MRI). In spite of the positive PCR, there was no accompanying inflammation. The diversity in PCR assays using different sets of primers suggested a range of viruses, with a common characteristic of failing to evoke a cellular immune inflammatory response. I described these viruses as "stealth" and the apparent immune evasion mechanism as "stealth adaptation."

This early work was followed by the successful cultivation of cytopathic viruses from numerous CFS patients, patients with more severe neurological symptoms, and the majority of tested children with autism. Positive results were seen in approximately 10% of controls, generally with lesser degrees of cytopathic damage.

Initial DNA sequencing of a virus repeatedly cultured from a CFS patient showed some homology to human cytomegalovirus. Upon further sequencing, the CMV-related sequences were unequivocal of African green monkey simian cytomegalovirus (SCMV) origin. So too was a virus isolated from the CSF of a comatose patient with a four-year history of bipolar psychosis. Yet another virus isolated from a cognitively impaired SLE patient showed no PCR cross-reactivity with the SCMV-derived viruses. All of the viruses induced a somewhat similar foamy, vacuolating cytopathic effect with syncytia.

The CFS and SLE patient-derived viruses were pathogenic when inoculated into cats. The viruses acutely caused marked behavioral changes in the cats with widespread cellular pathology in the absence of inflammation. The behavioral changes lasted several weeks, followed by apparent clinical recovery. Evidence was obtained for transplacental transmission of infection in the cats, consistent with the culturing of stealth adapted viruses from children with autism.

The more recent research has focused on the mechanism of the apparent non-immunological mediated mechanism of clinical recovery. It is attributed to what I call the alternative cellular energy (ACE) pathway. This non-food metabolism derived source of cellular energy is reflected in an added dynamic (kinetic) quality of fluids. Various approaches exist to enhance the ACE pathway, including the use of energized water. The potential benefits of enhancing the ACE pathway extend to other virus infections, including HIV, and to certain bacterial infections, including drug-resistant tuberculosis.

A listing of some of the published articles on stealth adapted viruses is provided below for your consideration. I would be pleased to discuss any aspect of the research and can be reached at wjohnmartin@hotmail.com or by phone at 626-616-2868. Kind regards, John.

2. Selected Publications:

Martin WJ, Zeng LC, Ahmed K, Roy M. Cytomegalovirus-related sequences in an atypical cytopathic virus repeatedly isolated from a patient with the chronic fatigue syndrome. *American Journal Pathology* 145: 441-452, 1994.

Martin WJ, Ahmed KN, Zeng LC, Olsen J-C, Seward JG, Seehrai JS. African green monkey origin of the atypical cytopathic 'stealth virus' isolated from a patient with chronic fatigue syndrome. *Clinical Diagnostic Virology* 4: 93-103, 1995.

Martin WJ, Glass RT. Acute encephalopathy induced in cats with a stealth virus isolated from a patient with chronic fatigue syndrome. *Pathobiology* 63: 115-118, 1995.

Martin WJ. Stealth virus isolated from an autistic child. *Journal Autism Developmental Disorders* 25: 223-224, 1995

Martin WJ. Severe stealth virus encephalopathy following chronic fatigue syndrome-like illness: Clinical and histopathological features. *Pathobiology* 64:1-8, 1996.

Martin WJ. Stealth viral encephalopathy: Report of a fatal case complicated by cerebral vasculitis. *Pathobiology* 64: 59-63, 1996.

Martin WJ. Simian cytomegalovirus-related stealth virus isolated from the cerebrospinal fluid of a patient with bipolar psychosis and acute encephalopathy. *Pathobiology* 64: 64-66, 1996.

Martin WJ, Anderson D: Stealth virus epidemic in the Mohave Valley. Initial report of viral isolation. *Pathobiology* 65: 51-56, 1997.

Martin WJ. Detection of RNA sequences in cultures of a stealth virus isolated from the cerebrospinal fluid of a health care worker with chronic fatigue syndrome. Case report. *Pathobiology* 65: 57-60, 1997.

Martin WJ. Bacteria related sequences in a simian cytomegalovirus-derived stealth virus culture. *Experimental Molecular Pathology* 66: 8-14, 1999.

Martin WJ. Stealth adaptation of an African green monkey simian cytomegalovirus. *Experimental Molecular Pathology* 66: 3-7, 1999.

Martin WJ, Anderson D. Stealth Virus Epidemic in the Mohave Valley: Severe vacuolating encephalopathy in a child presenting with a behavioral disorder. *Experimental Molecular Pathology* 66: 19-30, 1999.

Martin WJ. Complex intracellular inclusions in the brain of a child with a stealth virus encephalopathy. *Experimental Molecular Pathology* 74: 179-209, 2003.

Martin WJ. Stealth virus culture pigments: A potential source of cellular energy. *Experimental Molecular Pathology* 74: 210-223, 2003.

Martin WJ, Stoneburner J. Symptomatic relief of herpetic skin lesions utilizing an energy based approach to healing. *Experimental Molecular Pathology* 78: 131-4, 2005.

Martin WJ *Stealth Adapted Viruses; Alternative Cellular Energy (ACE) & KELEA Activated Water.* Author House Bloomington, IN pp321, 2014.

Martin WJ *Stealth adapted viruses. A bridge between molecular virology and clinical psychiatry.* *Open J Psychiatry* 5(4): 311-319, 2016.

Martin WJ *Co-infection with stealth adapted viruses may explain Zika virus associated microcephaly.* *J Human Virology & Retrovirology* 3(1): 00080, 2016

3. YouTube Presentations:

<https://www.youtube.com/watch?v=o520BTyCFRw&t=34s>

4. Chapter 4 in Book: *Martin WJ Stealth Adapted Viruses; Alternative Cellular Energy (ACE) & KELEA Activated Water.* Author House Bloomington, IN pp321, 2014.

Chapter 4 is available in its entirety upon request



**Comment to the Interagency Autism Coordinating Committee Provided by
SafeMinds Advocacy Committee Member Aimee Doyle, Esq.
January 16, 2019**

I am pleased to present my testimony on behalf of the national autism nonprofit organization, SafeMinds, to the Interagency Autism Coordinating Committee for its January 2019 meeting. SafeMinds remains concerned about the Federal Government's lack of urgency related to autism disability. Urgency and a commitment to rapidly improving outcomes are desperately needed due to the increased prevalence of autism over the past 18 years, from 1 in 150 American children in 2000, to 1 in 59 today; the significantly increased mortality of those with autism; and the lower quality of life associated with autism.

In an effort to obtain feedback from the autism community on the Federal response to the autism crisis, SafeMinds, in collaboration with Autism Action Network, TACA, and the Thinking Moms Revolution developed an online survey and sent it to their constituencies in the Summer of 2018. We received 1,405 unique responses via Survey Monkey. The autism community stakeholders who completed our survey included people with autism, caregivers of people with autism, family members of people with autism, autism service providers, physicians, and others.

Today, I will share the themes that arose from the survey results. They center around effectiveness, responsiveness, and accountability. Concerningly, almost half of the respondents had not even heard of the IACC before they completed the survey.

In their optional written answer sections, respondents said they were concerned that the IACC has not coordinated or promoted research that would identify the causes of autism; how to appropriately prevent or treat autism; how to effectively ameliorate or eliminate commonly co-occurring conditions such as epilepsy and gastrointestinal issues, or how to help address the commonly co-occurring mental health issues such as anxiety, depression, and suicidality.

By way of example, a person who self-identified as a retired school psychologist whose job included diagnosing people with autism stated, "I don't think the IACC is doing enough to uncover the causes of the explosion in autism cases since the mid-eighties."

The survey results show that many autism community stakeholders feel disenfranchised by the IACC. Almost 94 percent of respondents said they had not provided comments at an IACC meeting. Of the respondents who did provide public comment, over 95 percent thought that the IACC had not appropriately addressed their concerns or issues. These respondents further stated that they were not given an opportunity to discuss their concerns with the committee, and were not provided enough time to properly explain the context and relevance of their issues.

Over 46 percent of 1,400 respondents reported that the work of the IACC has affected their life either “not at all” (24 percent) or “negatively” (22.21 percent). Conversely, 4.93 percent stated that the work of the IACC has affected their lives positively.

Further, over 56 percent of 1,370 respondents said that the work of the IACC is not improving the lives of people with autism and their families, while 38 percent stated that they did not know if it was. Conversely, six percent stated that the IACC is improving the lives of these stakeholders.

When asked if the IACC members represented their interests when it comes to addressing autism in the United States, nearly 60 percent of the 1,402 respondents answered “no.” and 33.38 percent of respondents said “I don’t know.” Conversely, seven percent of respondents found that the IACC members represented their interests when it comes to addressing autism.

By way of example, a self-identified service provider to people with autism stated, “The autism community is not being well represented by the IACC. If the IACC wants to make a positive difference in the lives of those suffering from autism and their family members, you must seek out and listen to organizations which represent that demographic.” It seems that outreach to the leadership of the many autism nonprofit organizations representing people with autism and their families would be in order.

When asked if they think the IACC is accountable to its autism community stakeholders, 56 percent of the 1,375 respondents reported that they did not, and 31 percent stated they didn’t know if the IACC is accountable to its autism community stakeholders. Twelve percent of the 1,375 respondents answered that they did think the IACC was responsible to autism community stakeholders.

It appears there is much to be done to improve the efficacy, responsiveness, and accountability, and responsiveness of the IACC. We hope that we can work together during the year to move forward together, as a community. The full report is available on SafeMinds website, www.safeminds.org.

Thank you.