



October 3<sup>rd</sup>, 2007

Honorable Tony Clement  
House of Commons  
Ottawa, Ontario  
K1A 0A6

cc: Rémi Quirion, PhD  
Scientific Director  
CIHR Institute of Neurosciences, Mental Health and Addiction

cc: Barbara Beckett, PhD  
Assistant Director  
CIHR Institute of Neurosciences, Mental Health and Addiction

Dear Honorable Tony Clement,

Autism Society Canada (ASC) recently received an invitation to send a representative to the previously cancelled (June 2007) Canadian Institutes of Health Research **Autism Symposium** now taking place on November 8<sup>th</sup>-9<sup>th</sup>, 2007 in Toronto. The CIHR is hosting this event in collaboration with Health Canada and the Public Health Agency of Canada.

The symposium was described in our invitation as ***“part of a package of federal initiatives that the Honourable Tony Clement, the federal Minister of Health, announced in November 2006 to improve knowledge and research on autism spectrum disorders (ASD) and to help address the challenges facing individuals with ASD and their families.”***

The symposium goals stated in the original March 2007 letter were as follows:

- ***Provide latest research results for families, health care professionals and other service providers, policy makers & administrators.***
- ***Provide researchers with perspectives of families and service providers regarding what types of interventions are perceived as most effective and need to be further investigated .***
- ***Provide families, service providers, researchers, and policy makers & administrators with information about what is being done in Canada and abroad, to identify best practices in intervention and service delivery.***

The revised goals outlined in this new invitation are as follows:

- ***To inform service providers, policy makers, and those with autism and their families about the scientific evidence base on autism.***
- ***To assist the research community in planning further research.***

We are deeply concerned by what seems like a redirection of this meeting. ASC hosted the first Canadian Autism Research Workshop in Toronto in 2002, with lead sponsors: the Canadian Institutes of Health Research (CIHR) and the National Alliance for Autism Research (NAAR) in the

U.S. While we appreciate and welcome this opportunity to participate in moving the autism research agenda forward, we do have concerns about what appears to be dwindling community input into this process as well as how exactly this event will **“address the challenges facing individuals with ASD and their families.”**

We would like to know if this research symposium is meant to replace the broader stakeholder symposium you announced last November – ***an ASD stakeholder symposium in 2007 to further the development of ASD knowledge and dissemination among health care professionals, researchers, community groups, teachers, individuals and family members?*** There is great community concern that your department has chosen to respond only to the research components of both your 2006 promises and the Senate recommendations of May 2007.

In its final report entitled, *PAY NOW OR PAY LATER: Autism Families in Crisis*, the Senate Committee made many important recommendations to the federal government, prioritizing the following:

- an autism strategy to address the complex needs of our community – one that would be inclusive of all stakeholders, including those with ASD;
- to convene a federal/provincial/territorial ministerial conference to look at innovative funding arrangements for the purpose of financing autism therapy in order to establish an “appropriate level of funding by the federal government”; and,
- creation of an Autism Research Network with substantial new funding through CIHR.

While the research component is important, there are currently glaring gaps in the availability of fully funded treatment for children with Autism Spectrum Disorders, as well as damaging service gaps for adults and youth with ASD. Autism Society Canada strongly believes that federal leadership is needed to develop and commit to a comprehensive National Autism Strategy. The lifespan needs facing our community are complex. The treatment, training, service and accommodation needs across the ASD spectrum are multi-faceted. Families and people with ASD are tired of waiting.

As you are aware, ASC represents a federation of Canada-wide provincial and territorial autism societies whose collective memberships include a very large community of individuals with ASD and their families in Canada. We have carefully outlined our concerns regarding the process by which this research symposium has come about in our letter to you of [August 6th, 2007 letter to Hon. Tony Clement](#) . Some of the concerns centered on the last-minute notice for representatives with ASD who need time to make plans and prepare. We have yet to receive a reply to this letter.

We are being asked by many members of our community, including researchers, whether CIHR has ensured fair regional representation at this closed meeting. Our members provide direct services to the ASD community. They are very well-positioned to provide comprehensive regional input by identifying the practical needs and realities for children and adults with ASD in their respective areas. They feel this input should inform the planning of future research initiatives. They have requested that CIHR, if it has not already done so, ensure that each member society of ASC is invited to put forward a representative of their choosing to this research symposium.

Quite a number of people have made enquiries of CIHR about representation and have been told by CIHR that this is a complex scientific meeting – the implication being that community representatives will find the content somehow confounding. CIHR staff should be aware that when

they are speaking with ASD parents, people with ASD and community representatives, they are in fact, speaking with “experts in the field”. In the invitation letter, CIHR has referred to the research symposium as being, above all..... ***an opportunity for knowledge exchange, networking, and community-building***. Can a closed research meeting with a private invitation list and no available agenda, help to build community?

Finally we would like to remind the Minister that expecting people with ASD and their families, who are already shouldering serious financial burdens, to front the costs for attending this meeting in advance was unrealistic and actually sets up a barrier to participation. We are sure this is not what you or CIHR intended.

ASC looks forward to working with you and CIHR to further the ASD research agenda. We also look forward to addressing the other key National ASD Strategy issues brought forward in your November, 2006 announcement and especially in the 2007 Senate Report. October is Autism Awareness Month, let’s work together to ensure that all Canadians with ASD will one day be able to reach their full potential.

Sincerely,

A handwritten signature in cursive script that reads "Christine Dade".

Christine Dade, President,

On behalf of ASC’s Board of Directors