



August 6th, 2007

Honorable Tony Clement
House of Commons
Ottawa, Ontario
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EMail: Clement.T@parl.gc.ca

Dear Honorable Tony Clement,

In October 2002, Autism Society Canada (ASC) hosted the first *Canadian Autism Research Workshop* in Toronto, with lead sponsors: the Canadian Institutes of Health Research (CIHR) and the National Alliance for Autism Research (NAAR) in the U.S.. ASC's [Canadian Autism Research Agenda and Canadian Autism Strategy: White Paper](#) (March 2004) grew out of work accomplished at this meeting where autism community stakeholders, government representatives and research experts from across North America set some benchmark research priorities to improve outcomes for people with ASD.

In November, 2006 you announced new Health Canada initiatives in support of Canadians with ASD, including significant targeted funding to Canadian funding organizations such as CIHR and Genome Canada for ASD research.

In its final report entitled, *PAY NOW OR PAY LATER: Autism Families in Crisis*, the 2006 Standing Senate Committee on Social Affairs, Science and Technology Enquiry on the Funding for the Treatment of Autism made many important recommendations to the federal government, including the following:

- to develop 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
- to create an Autism Research Network with substantial new funding through CIHR.

The Senate report urges the government to include all stakeholders and partners in developing an autism research agenda:

The Committee is aware that CIHR is prepared to take the lead in a federal autism research program and work with all partners and stakeholders in order to define the priorities. It is important for CIHR to work inclusively with such partners as the Autism Society Canada, Autism Speaks and the Canadian Autism Intervention Research Network to develop a comprehensive research agenda. The development of this agenda should: include multidisciplinary research teams; encourage more programs that train autism researchers; provide the long-term, randomized, controlled trials

required to properly measure treatment effectiveness; facilitate collaboration; and, include public policy research. Moreover, CIHR must also consult with autistic individuals in identifying priorities.

In April of 2007 Christine Dade, the President of the Autism Society Canada, was contacted by letter by Barbara Beckett, Assistant Director, Institute of Neurosciences, Mental Health & Addiction of CIHR asking ASC to put forward the names and contact information of family members of individuals with autism as well as individuals with an ASD from the autism community that ASC could recommend to attend (and in some cases present at) an autism Symposium in Ottawa on June 14th-16th, 2007.

ASC is a federation of Canada-wide provincial and territorial autism societies whose collective memberships represent a large body of individuals with ASD and their families in Canada. We were asked to put together a list that was regionally representative, gave information on affiliation and any necessary companions needed for candidates with ASD. The letter stated that invitations would be sent to as many people as could be accommodated. The letter indicated that this was to be the Symposium announced by the Minister of Health in his announcement in late November 2006.

Following is an excerpt from this letter:

There will be a reception on the evening of June 14th, and full day meetings on June 15th and 16th. An estimated 120 people will participate in the event, representing autistic individuals and their families, service providers, researchers and government officials.

The goals of the symposium are 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 event will primarily be an opportunity for knowledge exchange, networking, and community-building.

Autism Society Canada and other organizations had a very short timeframe in which to pull together nominations and affiliation and contact information from our membership, with a due date of April 25th. The reason given for this short response time was that invitations needed to be sent out as soon as possible in order to allow participants time to make their arrangements.

Working hard to try to meet this tight deadline, ASC sent requests out to its member societies who then took the time to contact their respective candidates and ask if their names could be put forward. Member societies also took the time to collect information on e-mail address and short bios in most cases. In addition ASC communicated with its Advisory Committee of Adults with ASD to find out who was interested in attending this meeting and what their requirements might be. A number of our Committee Members had presented to the Senate Committee hearings in December 2006 and were very eager to continue to take part this process.

In the end, ASC put forward a detailed list of over 60 nominees including individuals with ASD, parents and family members who were very involved in the ASD community as well as some other ASD professionals. At the time, CIHR could give us no indication of how many of these nominees would be invited to attend the meeting, how the nominees would be chosen, or exactly what would take place there – nor was there any web site or written information about the meeting to direct

people to. Colleagues were asking if there was to be a call for papers, and/or nominations for research presentations but there was little information coming forward.

On May 16th, 2007 ASC was advised by CIHR that the June ASD Research Symposium had been postponed by the Minister due to “logistical problems”. CIHR suggested that the meeting would likely take place in the fall of 2007 but we were told that no date had been set and that we would be informed as planning progressed. We then communicated this information to all the people involved in helping to develop the nominee list.

It is now the beginning of August and there is still no date set for this Symposium. With no information coming from CIHR, the community has lost any hope that this meeting will actually take place and vague assurances of a fall meeting from the Minister in response to public enquires has not done anything to inspire confidence.

Adequate prior notice, preparation and planning is an essential accommodation for people with ASD in order to allow these individuals to take part in an event of this nature (and in some cases prepare presentations) and we believe no consideration has been given to this special requirement. The planning and time commitment needs of family members responsible for children with ASD is also of utmost sensitivity to this community, most of whom are already pressed to the maximum trying to provide the necessary supports for their children.

On behalf of our membership across the country and all of the nominees who were put forward to bring their expertise to this gathering, Autism Society Canada would like to know why the original Research Symposium was postponed, why any public communication about this Symposium has been non-existent, whether the meeting will indeed take place, and if so, when.

You should also be aware that many people have serious concerns about the goals of this Symposium. Although the goals of the Symposium, as outlined in the correspondence from CIHR, indicate the purpose of the gathering is to fulfill the Minister of Health’s promise, it is not clear to the Canadian autism community if the Government of Canada is intending this Symposium to also fulfill the function of consultation on a comprehensive National ASD Strategy, and/or the FPT ministerial conference to examine funding arrangements for the purpose of financing autism therapy, both of which are also discussed in the Senate Report. It would seem to make sense to work efficiently and cost-effectively on these combined issues while representatives of all stakeholders are gathered in the same place at the same time. Has there been any indication from the Government of Canada regarding addressing the other recommendations in the Senate Report, in particular the ones mentioned that require policy-makers and other autism stakeholders to be actively involved?

If there has not been any concrete response, it may make sense to take advantage of this gathering to move forward very quickly with at least the recommendations in the Senate Report that require the gathering and consultation of policy-makers and stakeholders. Perhaps the gathering could be extended by a day to provide time to address the multiple issues. Canadians with ASDs and their families should not have to wait another year to see some movement forward on these recommendations and no doubt the community involved will be considering how this is addressed when the federal election is announced.

As Lisa Simmermon, past president of ASC and one of our nominees for the Symposium so aptly stated: ***Research holds the key to understanding, enabling and empowering people with Autism Spectrum Disorders.*** We look forward to continuing the work begun with the *Canadian Autism Research Workshop* in 2002 to further the development and implementation of a Canadian research agenda.

We also look forward to addressing the other key National ASD Strategy issues brought forward in the Senate Report in concert with our provincial and territorial member societies, with government, other autism organizations, the autism community and our many research partners 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

c.c: Barbara Beckett, Ph.D.
Assistant Director, Partnerships and Government Affairs, Institute of Neurosciences, Mental Health and Addiction, Canadian Institutes of Health Research