

Centre for ADD/ADHD Advocacy Canada (CADDAC)
17 Briarwood Road
Unionville, ON
L3R 2W7

28 February 2008

Sylvie Dupont,
Secretary of the Board
Patented Medicine Prices Review Board
Box L40, Standard Life Centre
333 Laurier Avenue West, Suite 1400
Ottawa, ON, K1P 1C1

Dear Sylvie:

Re: Discussion Paper, Options for Possible Changes to the *Patented Medicines Regulations*, 1994 and the Excessive Price Guidelines

Thank you for the opportunity to comment on the Discussion Paper: Options for Possible Changes to the *Patented Medicines Regulations*, 1994 and the Excessive Price Guidelines.

The Centre for ADHD/ADD Advocacy, Canada (CADDAC) is a national, not-for-profit organization providing leadership and support in advocacy and education for ADHD organizations and individuals across Canada.

CADDAC's mandate is to take a national, leadership role in networking all organizations, professionals, patients, caregivers and other stakeholders involved in ADHD related issues, and to then support those people through education and advocacy.

Our vision is a future in which all Canadians living with ADHD are understood and appreciated for who they are and for what they can contribute to society. This vision sees these individuals and their families being served by effective, comprehensive, evidence-based health care and educational systems that maximize their outcomes in a spirit of acceptance and understanding. Our goal – to reduce the emotional and financial distress associated with ADHD while allowing access to best practices in medical treatments and educational support, all across Canada.

Unfortunately, CADDAC did not become aware of this discussion paper until recently and was not aware that patient input was accepted by the PMPRB. We found out about this accidentally because someone said something in passing to one of our members.

We note from the document that the Board issued a *Stakeholder Communiqué* on May 31, 2007, however we were not included in this communication. We also note that the Board undertook face-to-face bilateral consultations with stakeholder groups in September 2007. Again, we were not included. In addition, we could not find a place in the discussion paper that listed the patient groups that had been consulted. We feel this is a significant issue for the PMPRB in terms of the credibility of their stakeholder consultations that needs to be addressed.

General Comments

1. The issues discussed in the paper are very complicated and our organization would like more information about the implications of the proposals.
2. CADDAC participated in a teleconference with PMPRB on 19 February 2008. There were only a few participants in the meeting. Therefore, CADDAC recommends that PMPRB use a wider distribution list of patient organizations when issuing information for stakeholder consultations. In addition, CADDAC recommends that PMPRB hold information sessions and ensure a wide distribution of the notice to patient support groups across Canada. CADDAC would be pleased to assist the PMPRB in identifying a wider distribution list that would encompass more of the smaller patient support organizations in Canada.
3. The Board should publish the names of patient-oriented groups that responded to the request for comments in the interests of transparency.

Specific Comments

Background

In the case of CADDAC, none of the first line medications used to treat ADD/ADHD are covered on any publicly funded drug plan in the country. A significant portion of young patients, eligible for publicly funded drugs are at serious risk due to co-morbid conditions such as Oppositional Defiant Disorder (ODD), Bipolar Disorder, Anxiety, Depression, Fetal Alcohol Syndrome, Tourette Syndrome etc. In addition, they may also have challenging home situations. For example, one or both parents absent, substance abusing parent, parent with mental illness etc. The situation for these children is critical and the only option they have is to access compassionate drug supply.

In Ontario, there is a very limited allowance of Section 16 (old Section 8) exceptional access. However, the criteria are such that there is a forced clinical trial of a drug or drugs not covered on the ODB plan. Therefore, patients are either out of pocket for this trial (most cannot afford this) or in some cases compassionate drug supply may be available.

Recommendations

1. Due to the fact that access to compassionate drug supply is critical to our patient population, CADDAC respectfully requests that the Board take NO ACTION that would lead to a decrease in the supply of compassionate drugs. It is CADDAC's position that the Board, as part of the Health portfolio of the Government of Canada, in order to support the health care of Canadians, should encourage and not discourage the availability of compassionate drug supply.

2. In terms of "services", the Discussion Paper does not indicate what these services might be. For clarity, understanding and transparency, activities that would be considered services should be listed so that patient groups can have a better understanding of the impact of these changes. CADDAC respectfully requests that the Board take NO ACTION that would result in the discontinuance of patient centered support programs such as counseling services, adherence programs, and educational programs. We feel the Board should support patients by encouraging, not discouraging the availability of patient centered services. With our health care system in crisis, these services can be very important to patient outcomes.

4. Again, the Board, as part of the Health portfolio of the Government of Canada, in order to support the health care of Canadians, should ensure that the revised regulatory framework will not dissuade existing manufacturers or new manufacturers from bringing new drug technologies to Canada. It is important that the revised regulatory framework be used as a tool to ensure Canada is considered a first tier country for launching new products.

Conclusion

It is CADDAC's position that if the Board undertakes the recommendations included in this letter, the Board will become an important participant in enabling Canadians to be among the first in the world to reap the benefits of new discoveries which will allow them to lead healthy and productive lives. In this way, all Canadians regardless of their health situation will be able to maximize their contribution to society.

Sincerely,

Dianne Azzarello, BSc. Phm.
Director