Arthritis Consumer Experts™
joint action for Canadians with arthritis

October 15, 2007

Dr. Brien Benoit
Ms. Sylvie Dupont
Secretary of the Board
Patented Medicine Prices
Review Board
333 Laurier Avenue West
Ottawa, Ontario
K1P 1C1

sent via email:
sdupont@pmprb-cepmb.gc.ca

Re: Bilateral Meetings of the Board on the Review of its Excessive Price Guidelines

Dear Dr. Benoit and Ms Dupont:

We would like to start by thanking you both, as well as the rest of the Patented Medicines Prices Review Board (PMPRB) for providing an opportunity for Arthritis Consumer Experts (ACE) to participate in its bilateral meeting on September 12, 2007. As a national organization led by people living with arthritis and providing research-based education and information, advocacy training and leadership to Canadians with arthritis, we feel very strongly about including consumer/patient input into health care and policy decision-making in Canada.

Many of the issues currently on the PMPRB's reform agenda are of critical importance to people living with arthritis, but four specific aspects of the reform process stand out:

1. Arthritis Consumer Experts is encouraged to see that the board has decided to include public and consumer/patient members on their working groups. This change should ensure better transparency, and, from our perspective, result in the most robust and thoughtful decision-making. We have spoken with Anne Dooley, from the Canadian Arthritis Patient Alliance and are in full support of the inclusion of Linda Wilhelm for the working group on therapeutic improvement. She is a knowledgeable and thoughtful consumer who will provide an educated and informed perspective on the issues facing people living with chronic disease.

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2. Arthritis Consumer Experts reiterates the concern it raised during the September 12 meeting on how to distinguish between little to no, or moderate improvement in "category 3" drugs. As people living with disease, we know from first hand experience that there are important but challenging to measure differences in medication efficacy. While clinical trial data can provide useful evidence to inform policy reform or development, there are important limitations to this type of evidence as many patients, particularly those living with complicated or rare types of inflammatory arthritis, are excluded from clinical trials. In addition, clinical trial data does not capture unique differences in medication responses or "real world" outcomes – whether good ones or bad.

   In order to address these deficiencies, it is important that head-to-head drug trials be conducted as well as standardized post-marketing surveillance processes established ("real world" data collection). Only then will policy making bodies and regulators capture robust measures demonstrating the value of medications for patients, both in clinical trials and post-licensing.

3. Arthritis Consumer Experts reiterates the concern it raised during the September 12 meeting on the pricing of "category 3" drugs. If a certain medication does not prove to deliver moderate to significant benefit to patients as other medications in the same class, then pricing should be set accordingly. A medication that cannot deliver improvements as measured through standardized, validated study methods could be considered a "me too" drug, whether it is a patented medicine or a generic one.

4. Arthritis Consumer Experts believes that the PMPRB should expand its mandate to include oversight of generic drugs. Canadians are paying exorbitant prices for generic medications that offer no scientific innovation. Savings in this area could be returned to the health care system.

We thank you again for the opportunity to participate in PMPRB consultations and look forward to receiving timely updates from the working groups.

Sincerely,

Jay Fiddler
Advisory Board Member
Arthritis Consumer Experts