

Welcome New e-Members!

The Patients' Association of Canada (PAC) has many new members since its launch. The numbers keep growing and more than 700 people will receive this newsletter. For most of you this is the first mail from us. Welcome!

These occasional newsletters are meant to help everyone keep track of what we have been doing since the last newsletter. At the bottom of this newsletter you will find links to our web site to find more frequent updates and contact information if you have any questions. We answer all emails as quickly as we can.

Because many of you are new to the Patients' Association we have included a link to our Introductory Package that tells you a little bit about us, some of our activities, and gives you a chance to volunteer and to donate funds to help us continue to grow.

New e-Members

Each new e-member enhances the voice of patients and a large number of e-members indicate that patients want to be engaged in the health system and want to join the deliberations about its future in Canada. After you've read the newsletter and feel like you want to contribute, the most important thing you can do is help us increase membership size.

Please ask one other person to register for e-membership and our membership will **double**. You can also share this newsletter with others and ask them to do the same.

Open Organization

We are a patient-led and patient-governed organization. At the moment we are working hard to ensure that we are transparent to all our e-members. We are constantly re-organizing our web site to make more information available. Our meetings are open and announced on our website in the Events section. Please visit it regularly for meeting notifications.

Our funding sources are transparent: they include member donations, project funding and publicly acknowledged grants from charitable foundations. We now have a small executive committee to take us to the creation of a small working board of directors for the first year of operation. We will try our best to keep everyone informed as we proceed.

Launch on February 15, 2011

The formal launch of the Patients' Association of Canada (PAC) was a great success. It began with a self-organized conference on Improving Patient Experience. The space at the Toronto Reference Library was bright and airy and wonderfully suited for our needs. Misha Glouberman, who has a lot of experience designing and leading these kinds of conferences, helped facilitate the discussions.

More than 100 participants from all areas of the health field came up with ideas about how to improve the patient experience at clinical levels, through changing methods of service delivery and by developing innovative health policy. Many participants were very pleased with the conference and together we developed a lot of ideas about how to strengthen PAC's ability to promote the patient voice.

There were more than 25 different discussion groups and the notes of the meeting were prepared for analysis at a group meeting on March 23. More than 30 volunteers attended to analyze the reports.

They broke up into four groups to find the main recommendations for increased patient engagement at

- clinical levels when we have direct encounters with the system ,
- at the level where services are planned
- in places where health policies are decided
- and to think about the future of PAC itself, what should be our next steps.

The results are now ready and available online. They are posted in our Patient Forum for comments and discussion.

The conference was followed by a party. The crowd swelled to over 250 and there was a buzz in the room. There were lots of delicious goodies and wine. Carolyn Bennett MP, the Public Health Minister under the Liberal government, spoke about the beginnings of PAC and the need for our organization then introduced Sholom Glouberman. He welcomed everyone to the celebration and spoke about *My Operation: A Health Insider Becomes a Patient*, his new book describing his health care experience and the genesis of PAC. A good time was had by all.

The Patients' Choice Awards

The success of the first Patients Choice Awards in Peterborough Ontario has led us to develop them further in 2011. We have agreed with the Ontario Medical Association to have three competitions this year in different parts of Ontario and are looking to grow them across the country in the future. There has also been some initial discussion about having similar awards for other parts of the system including other health professions and health care organizations. They will be a significant part of our educational efforts.

Canadian Health Services Research Project

The Canadian Health Services Research Foundation (CHSRF) and the Canadian Patient Safety Institute (CPSI) have chosen PAC to lead a research project to help them improve the governance of quality and patient safety. The research project began at the beginning of March. Sophie Afriat has been hired to coordinate the project and two Post-Doctoral researchers, Elke

Grenzer and Saeed Hydaralli will gather and analyse the data. The research team includes Sholom Glouberman and Alex Jadad, principal investigators; Laura Alper and Neil Stuart, patient members; David Anderson and Neil Seeman, governance experts; Ted Ball, policy expert; Marina Englesakis health care literature librarian; Kevin Leonard, statistical analysis; and Marie Claire Richer, appreciative inquiry.

Trillium Application

Our first Trillium application was rejected as being too big and too expensive, but we were encouraged to re-apply and so we put in a new application for their March 1st deadline. We submitted a much more modest project. We await their decision which is due in May or June. Wish us luck.

Charitable Status

We have been granted charitable status by the Canadian Revenue Agency. We can now provide tax receipts for donations. We will soon introduce an automated transactions service to facilitate online donations. We will let you know when the process is complete and in the meantime we accept donations by mail.

Patiently yours,

Sholom Glouberman

The Patients Association is a patient-led and patient-governed non-profit organization that seeks to increase the engagement of patients in health care. We believe that more involved patients can help improve everyone's health care experience. If you would like to learn more go to our website at www.patientsassociation.ca or write to Communications@patientsassociation.ca.