

## Next Meeting

Our next meeting will be on October 4th at 6:30 PM at the Centre for Global eHealth Innovation on the fourth floor of the R. Fraser Elliott Building at 190 Elizabeth Street.

Please come and **invite someone** you think might be interested in joining us.

A light supper will be served.

Please RSVP via email:  
aileen.odowd@adppa.org

I look forward to seeing you there.

Patiently Yours,  
Sholom Glouberman

## Bastille Day Bash (July 27)

The weather was perfect for PAC's delayed Bastille Day Dinner, bringing almost 30 people together for good conversation.

Hosted by Sholom and his wife, the evening began with drinks followed by a summer barbecue with lots of food and wine. Sarit, Neil Seeman's wife, brought a wonderful blueberry dessert.

To complete the evening, we crowded into the living room for Zal Press's presentation describing his 30 years living with Crohn's Disease. A provocative, funny, and heartwarming narrative, Zal took us through his experience of coming to terms with chronic disease – various approaches to treatment, changing relationships with family and professionals, and ultimately, the need to accept the uncertainties around the disease and its unexpected flare-ups.

Great food, stimulating conversation and thought-provoking entertainment was also a great way to welcome PAC first-timers Colleen Young, Andrew Ignatieff and Neil Seeman.

## PAC Meeting at the CSI (August 24<sup>th</sup>)

Our last PAC meeting was at the Centre for Social Innovation on Spadina. I gave a brief history of PAC, explained what we were about, and what we hope to achieve, followed by an overview of our current activities. We had a good discussion and wrapped up with members joining our various committees, to further their involvement with PAC.

## Our Public Launch

We have started planning for PAC's public launch in February 2011. The Launch Committee members are Laura Alper, Zal Press, Anita Stern, Ryan Devitt, Christina Spencer, and more recently, Kathy Kastner and Alan Engelstad. In June, Michaela Cornell, a seasoned publicist who chaired *WordontheStreet.ca*, also joined us to help coordinate the launch.

The launch will include an all-day series of events:

- Unconference (self-organized conference) on patient engagement
- Book launch of *My Operation*
- Keynote speaker (tbd)
- Big party with lots of guests
- Food and entertainment

The MARS building on College Street is a possible venue for the launch, but other locations are also being considered for the event.

The next Launch Committee meeting will take place in early October. New members are welcome. If you have skills and interest in organizing a big public event, please get in touch with Aileen O'Dowd (aileen.odowd@adppa.org) to join us.



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## The Patients' Choice Awards Update

Our project with the Ontario Medical Association is happening!

After a meeting with the OMA communications committee, our pilot project has been approved. We are just waiting on the final board approval to go ahead. The first meeting of the Patients' Choice Awards Committee has begun to prepare for the pilot project in Peterborough.

Members of the PAC Patients' Choice Awards Committee are Saeed Hydralli, Alex Jadad, Kathy Kastner, Anita Stern and Elke Grenzer.

## Public Talks

Our colleagues Cathy Fooks, Alex Jadad, Kevin Leonard, Neil Stuart and Neil Seeman will be speaking at the OHA-sponsored conference on *e-Patients: Changing the Health Care System in Real Time* on Sept 21 at the Novotel, Toronto.

The conference offers us an opportunity to make the patient perspective front and center. For my part, I will sum up the day. It promises to be a fun and instructive event.

## Our Web Site

Aileen O'Dowd and Elke Grenzer have taken the lead on our web site. Alan Dixon, our Drupal expert, will upgrade the site and expand its capacity so that it can effectively support our interactive activities.

Colleen Young has agreed to work on some of the content to bring it up-to-date, and make it more accessible to a wider audience.

## Collaboration with Other Organizations

In early June, PAC member Kevin Leonard suggested that patient-oriented organizations should collaborate to strengthen the patient voice.

During the summer we met with Patient Destiny (Kevin Leonard), Innovation Cell (Neil Seeman), the Centre for Global eHealth and Innovation (University Health Network) (Alex Jadad), and the Faculty of Health at York University (Harvey Skinner) to set things in motion. We have also discussed potential partnership opportunities with Patients for Patient Safety (Kathy Busija), the Change Foundation (Cathy Fooks), St Elizabeth's Health Care (Laura Jakob), and the Canadian Health Services Research Foundation (CHSRF) (Nina Stipich and Diane Gagnon).

## CHSRF Application

As our first collaborative effort, we have applied for a CHSRF grant to study the recent partnership between CHSRF and the Canadian Patient Safety Institute (CPSI), to create more effective governance of quality and patient safety.

Our research team includes researchers and patients: Sholom Glouberman, Alex Jadad, Elke Grenzer, Marina Englesakis, Patricia Trbovich, David Anderson, Neil Seeman, Kevin Leonard, Ted Ball, Anita Stern, Marie Claire Richer and Laura Alper.

The winning application will be selected in a few weeks, Wish us luck!

## Application to Trillium

After consulting with Marilyn Struthers, our Trillium Foundation advisor, we have tailored our application to request first-year funding for our educational project. We will use the year to design and launch two types of educational programs:

- *Organization Days* will focus on helping organizations who want to increase patient engagement throughout their organizations.
- *Patient workshops* will be three day events that prepare patients to bring the patient point-of-view to governing bodies of health care organizations.

We are negotiating with the Canadian Auto Workers Union to use their conference centre in Port Elgin for the Patient Workshops.

Our application will be a collaborative affair. We will lead the group, and will be requesting letters of agreement from our potential collaborators shortly. Our understanding is that collaborative applications stand a better chance of success at Trillium.

Work on the application begins in earnest in October with a November 1st deadline. Help will be needed.