



## The Patients' Association Wins the CHSRF-CPSI Competition

We are the winners! We have successfully applied to the Canadian Health Services Research Foundation (CHSRF) and the Canadian Patient Safety Institute (CPSI) to study their efforts to engage citizens to improve the oversight of quality and patient safety. Our research team will meet later this month to organize our review. The grant will be administered through the University Health Network and Alex Jadad will be my co-Principal Investigator. We are looking forward to seeing how citizen engagement affects board activity on the quality and safety aspects of the patient experience.

## Our Public Launch

Our Launch plans are progressing. We have a date! Put it in your calendars – FEBRUARY 15 2011 - One day after Valentine's Day. Michaela Cornell has found an excellent venue - the Toronto Reference Library right near the Bloor and Yonge subway station. It is easy to get to and the space is large and lovely. We are planning an all day Unconference followed by a launch cocktail party from 5:00 to 7:00 PM. More details will come out soon but for now keep the whole day free if you can.

## Changes

Staff is changing. We are sorry that Aileen O'Dowd had to leave us, but happily it was to pursue her new career in naturopathy and nutrition and she assured us that she would remain an active member of PAC. So we will still see her at meetings and on committees. And we welcome Rita Tourkova and Christina Spencer who will support me as everything speeds up. I look forward to working with them.

## We Are Incorporated as a Not-for-Profit Corporation

In late October, the Patients' Association of Canada/ l'Association des patients du Canada was federally incorporated as a not-for-profit company. We owe thanks to Helen Ferrigan and her firm of Osler, Hoskin and Harcourt, who got us through the process in record time. It now remains for us to hear from the Canadian Revenue Agency about our application for charitable status.

## The Patients' Choice Awards

The Patients' Choice Awards process has begun. Ads have been put into the Peterborough paper and people have begun to submit stories about medical doctors who are especially sensitive to patients and who are concerned about the patient experience in health care. A jury made up of members of PAC will select two people to receive the award – a family practitioner and a hospital specialist. The award plaques will be made by Zal Press, one of our members, and the award ceremony will take place on December 1 in Peterborough. If all goes well we will have Patients' Choice Awards for all of Ontario next year.



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## Our Website

Alan Dixon, our Drupal guru, has been active and has made substantial changes to improve the web site in the last month guided by the capable hands of the web committee led by Elke Grenzer. Take a look. The blog has been taken over by Christina Spencer and remains a rich source of information about health care and especially the patient experience. We are always looking for more stories and yours are always welcome.

## Patients' Association Meeting October 4, 2010

We are very pleased to have more people join us at each meeting. The last meeting was made lively by new members with strong ideas about patients and our place in the health care system. As ever, the discussions were a great help in moving our thinking forward and preparing for the next steps of building a true patient-led and patient-governed association to improve the health care experience for everyone.

The next meeting of the Patients' Association of Canada will be on November 17 at the Centre for eHealth Innovation on the fourth floor of the R.Fraser Elliott Building at 190 Elizabeth Street at 6:30 PM. We will design the meeting to allow everyone to engage in the discussion after a brief overview of where we are. Please come and invite someone you think might be interested in joining us. We will have a light supper and lots of discussion.

Christina Spencer will poll you on Doodle to ask if you are coming to the meeting. Please respond so that we can set out the chairs and have enough food.

Patiently yours,

Sholom Glouberman.

## Application to Trillium

Our application to the Ontario Trillium Foundation has been submitted. It is a collaborative application from five organizations led by PAC. Our partners have been generous in their support. They are Patient Destiny, represented by Kevin Leonard, the Health Strategy Innovation Cell by Neil Seeman, the Change Foundation by Cathy Fooks, and the Culture of Cites, by Alan Blum. We have applied for almost \$200,000 to run our educational programs. The application had the invaluable help of Aileen O'Dowd, Ryan Devitt, Colleen Young and Laura Alper. We made the November 1 deadline with days to spare. Wish us luck. We will learn of the results in February. We hope that this grant will be the beginning of a longer relationship with major funders like the Trillium Foundation and the J.W.McConnell Family Foundation.

## Talks Talks Talks

October has been a month of talks. I went to Ottawa on October 14 to bless the Patient Engagement Projects as a result of a CHSRF competition. The meeting was interesting because, as usual, there were very few patients in the room and much of the talk was about how to overcome the difficulties of engaging patients. I pointed out that these were early days and that things will change. Patients will soon be able to take a greater role in health care and that this beginning was a momentous event in itself. I then suggested that a good way to move things forward was to think of their own patient experiences and how they might be made better with the help of engaged patients. Several of the patients in the group came over afterwards for quiet chats about the need to remind everyone what "patient engagement" was about.

On October 21 I was in Montreal for the McGill University Health Centre. My role was to sum up the day's discussion about the future of information technology in health care. I reminded them that IT was originally ICT and that communications was the middle letter. Computers had the capacity to do two things: manipulate ever larger data bases and communicate with others. I suggested that the day had been largely about the nature of the databases and how they could be manipulated and I was going to talk mostly about the communications part. I suggested that given that we are now faced with the reality that the vast majority of illness was chronic rather than acute it has become critical to involve patients in their own care and listen carefully to how they might contribute to it. This required a substantial change in what and how to whom information was communicated by ICT systems. The use of social networking was quickly becoming a substantial contributor to health care and this too would bring unforeseen changes to how health care would be delivered in the future.

On November 3 I spoke on the Patient Experience at the Bioethics Seminar at the Joint Centre for Bioethics at the University of Toronto. I tried to link the history of the discipline of bioethics to the history of changes in healthcare and stressed that we could from that put the ethical issues about the patient experience front and centre on their agenda.