

Myeloma Canada Patient Advisory Council (PAC) 2021 Year in Review

The Patient Advisory Council is a team of highly capable, dedicated, and very collaborative members from across Canada, representing four regions of our country: Atlantic Canada, Québec, Ontario, and Western Canada. We are all myeloma patients. We care deeply about the Canadian myeloma community, and how Myeloma Canada can best serve the needs of our community.

For most of 2021, the PAC included the following members:



Glenn Hussey
Chair



Susan Mclean
Vice Chair
Western Canada



Phil Harbridge
Western Canada



Rinat Avitzur
Ontario



Tanya Zigomanis
Ontario



Manon Veilleux
Quebec



David McConkey*
Atlantic Canada

* David McConkey resigned from the PAC in August. A new Atlantic Canada representative will be named soon.

2021 Year in Review

In 2015, the Myeloma Canada Board of Directors created the PAC. The primary purpose of the Council was, and still is, to function as an advisory to the Myeloma Canada Board of Directors on matters important to patients, caregivers, and support groups, while providing the patient perspective on national and regional issues. The PAC also works closely with the Myeloma Canada professional team to provide advice and feedback, from a patient point of view, and provides support for numerous Myeloma Canada activities.

Highlights of PAC initiatives and activities in 2021 include:

- Created and submitted reports to the Board of Directors for each Board meeting that summarized recent and planned activities of the PAC. These reports also included comments and recommendations on matters important to patients, caregivers, and support groups, and provided the patient perspective on national and regional issues;
- Revised and updated the PAC terms of Reference;
- Held a Blue Sky Meeting to focus on the PAC role and activities. Results were provided to the Myeloma Canada professional team. (Top 5 initiatives were: continuing support to Support Group Leader Summits; expansion of Myeloma Awareness Day; increased support to Support Group Leaders; increased support in the area of Covid-19; and an increased focus on education and social perspectives for patients and caregivers);
- Built relationships with support group leaders in each region of Canada, regularly meeting through conference and Zoom calls;
- Ensured specific concerns, needs, and/or suggestions from all regions of Canada are heard;
- Provided suggestions for Myeloma Canada's response to COVID-19, offering advice for myeloma patients and their families;
- Advocated for third doses of COVID vaccines for immunocompromised patients, and for a shortened timeline between doses (as per manufacturer's recommended guidelines);
- Provided advice and feedback on various documents including:
 - the Declaration of Personal Health Data Rights in Canada;
 - the Guidelines to Establish Proclamations, the templates and the sample Proclamations for Myeloma Awareness Month;
 - the Myeloma Canada Advocacy Handbook.
- Helped in planning, and presented an update on the PAC, at the Support Group Leaders Virtual Summit;
- Held an orientation for the two new PAC representatives from Ontario;
- participated, as observers, in the Myeloma Education sessions entitled "Identifying Best Practices in the Diagnosis and Management of Myeloma";
- Most members of the PAC participated in other Myeloma Canada initiatives and committees, and had leadership roles in the Multiple Myeloma Marches;
- Continually improving some PAC internal practices, to enhance our effectiveness.

Looking Forward to 2022

Plans for 2022 include the following:

- Continue to provide advice to the Myeloma Canada Board;
- Advice and assistance to the Myeloma Canada professional team, on activities, plans, specific initiatives, and questions (with a focus on embedding the patient voice in all Myeloma Canada activities);
- Ongoing advice, support and advocacy with respect to COVID-19 and immunocompromised patients;
- Provision of support to new fundraising activities/events such as the Myeloma Canada Ride;
- Participation/support to Myeloma Awareness Month activities;
- Further build relationships with support group leaders, and others in Canadian myeloma community;
- Possibly other activities, initiatives, or needs, not currently known.

PAC Membership Changes in 2021

Rinat Avitzur and Tanya Zigomanis joined the PAC in February as the new PAC representatives for Ontario. Susan McLean also assumed the role of Vice Chair in February for a one-year period.

In the 3rd Quarter, David McConkey, PAC's Atlantic Canada representative, resigned from the committee. A process to name a new PAC representative for Atlantic Canada has been undertaken and a new PAC representative for Atlantic Canada is expected to be named soon.

The PAC thanks David McConkey for his much-valued contributions to the PAC, Myeloma Canada, and the Canadian myeloma community.

In closing, we would like to remind you to feel free to contact any PAC member at any time. We represent you and your voice, and are here for you:

- Glenn Hussey, Chair, helene-glenn@rogers.com
- Susan McLean, Vice Chair, representing Western Canada, mclean@shaw.ca
- Phil Harbridge, representing Western Canada, pharbridge@telus.net
- Rinat Avitzur, representing Ontario, rinatavitzur@hotmail.com
- Tanya Zigomanis, representing Ontario, tzigomanis@gmail.com
- Manon Veilleux – representing Québec, veilleux.manon@videotron.ca
- Atlantic Canada, currently vacant.

We wish everyone the best of health in 2022!
