

BOARD OF DIRECTORS

Henry Seo, *Chair*Michelle Elliott
Stephanie Kaes
Ilene Sussman

Dear Fellow Canadian VHLers,

I am taking this opportunity to introduce myself as the new Chair of the Canadian VHL Alliance. By trade, I am a clinical social worker, but my interest in VHL is personal. In 1985, I was diagnosed with VHL and, since that time have had numerous medical treatments due to brain and kidney involvement.

The Canadian VHL Family Alliance was created in 1998 by Tania Durand. The reins of leadership were passed to Jill Shields and Sue Lamb in 2001. These 3 dedicated women worked hard to create educational programs including a 2005 National Meeting in Whistler and a 2006 International Symposium in Ontario. Over \$100,000 has been raised to support VHL research. We applaud and thank them for their incredible effort.

This past fall, Jill and Sue decided it was time for new leadership as a first step for reinvigorating the Canadian VHL Alliance. I am happy to announce my fellow Board members, elected in October 2013 meeting:

- Henry Seo, Chair: Toronto, ON; <u>Canada@vhl.org</u>; 647-272-4747
- Michelle Elliott, Director: North Saanich, BC; Canada-bc@vhl.org; 250-655-9166
- Stephanie Kaes, Director: White Rock, BC; Stephanie@vhl.org; 604-536-1862
- Ilene Sussman, Director: Boston, MA; Director@vhl.org; 800-767-4845 x4

In addition, we have a number of people who have stepped forward to act as Chapter Leaders. These people are here to help you, whether you are a patient, family member, friend, donor, researcher, or healthcare professional. They can answer your questions, point you in the right direction, or be a listening ear. Their contact information can be found at www.vhl.org/canada.

While we are a new Board, we bring a lot of energy. We have already updated our website (www.vhl.org/canada) and are working with the International VHL Alliance housed in Boston, MA to expand our programmatic efforts including education, support, and outreach. In addition, we have initiated conversations to create the first VHL Clinical Care Centre in Canada! We also will be joining the United States as they launch their new landmark project: Cancer in Our Genes International Patient Database.

As we move forward, strengthening the already existing infrastructure, we want to hear from you. How can we better support you and meet your needs?

We also hope that you will help us raise the funds needed to perform the essential research in our Quest for a Cure! Giving is simple! Just go to www.vhl.org/canada to donate online, or send a check to The Canadian VHL Alliance, c/o H. Seo, 49 Hook Ave, Toronto, ON M6P 1T3). We thank you in advance for your generosity. Together we can make a difference and offer a brighter future to those with VHL.

Best regards,

Henry Seo, MSW, RSW Chair, Canadian VHL Alliance

canada@vhl.org

