



# BC Epilepsy Society

ANNUAL REPORT

2015

# OUR MISSION

To empower, educate and support British Columbians living with epilepsy and their families, and support research to make their lives easier.

# NEW EXECUTIVE DIRECTOR

The BC Epilepsy Society is pleased to welcome Lori Eisenhour as our new Executive Director.

Lori comes to the Society as a seasoned, value-based leader with a unique background of medical, non-profit and operational expertise spanning public and private healthcare organizations. Lori is deeply committed to healthcare advocacy both professionally and personally.

She believes that advocacy, education and leadership is everyone's business and is passionate about facilitating and co-creating environments that inspire a shared vision, engage the heart, and enable action through collaboration and strengthening others. She also has the experience of being a parent of a child with a rare epilepsy.

# MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

2015 marked a year of proactive and purposeful change and development for BC Epilepsy Society. The Society made significant investment in strategic alignment and organizational development, probing new pathways to organizational relevance and financial stability while remaining true to our guiding mission and values.

## **Programs and Services**

In service of reducing stigma and improving community awareness for people and families living with epilepsy, our Partners In Teaching program delivered 66 FREE workshops to diverse audiences such as: teachers, students, child care providers, disability support workers and others. The program increased 29% in scale in 2015 and is growing. The PIT program continues to be well received and shaped by the community we serve.

This is our eleventh year of service and partnership with the neurology team at BC Children's Hospital. The Society donates time from our service staff to assist families in finding the appropriate community supports required to meet their individual needs. We are proud to have assisted over 2000 families on their journey with epilepsy.

We also provide direct funding to support the epilepsy clinic fellow which greatly impacts service levels and bandwidth of the department.

# MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

We have completed a full year of inaugural service with the Epilepsy Clinic at Vancouver General Hospital. Our staff provides a community presence and offers information on Society services, programs and resources to adult patients living with epilepsy.

The Society also funds a part time psychology service in the VGH epilepsy clinic. Dr. Mark Weinberg, the epilepsy clinic psychologist, provides an essential service that helps patients and families navigate the psychosocial aspects of living with an epilepsy diagnosis.

In November we hosted a Family Education Day about Epilepsy. With the cooperation of local experts we provided much needed information about genetics, mental health, mindfulness and epilepsy, online healthcare information, and cognitive implications of epilepsy. Delivered in this full-day workshop format also provided families a chance to connect, share experiences, and strengthen our community.

We are pleased to have awarded four \$2000 post-secondary scholarships to deserving students living with epilepsy. The Society has a long standing tradition of assisting young people achieve their academic goals. We have awarded 64 scholarships since 2007.

We remain partnered with Kids Up Front and through this program are able to offer families living with epilepsy the opportunity to access sports and entertainment events at no charge.

# MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

BC Epilepsy Society maintains and curates an extensive library of information about many topics relevant to people living with epilepsy. The library includes hardcopy materials which can be borrowed, digital assets to be downloaded and a expansive variety of information sheets. We have provided multi-language translations for many of our resources.

We are also proud to say that we were able to subsidize 13 families to enable their children to attend epilepsy safe and accessible camps.

Our in-house monthly support group continues to be an active and vibrant community of peer-led, wonderfully kind people helping each other find what they need on their journey. Our peer group has expanded to a second online group to allow a viable option for people that cannot access the in-house group due to geography, health or costs. The online group has been amazingly successful in its inaugural year and continues to grow.

We are pleased to say that we just completed our eighth year of delivering relevant and salient content via our monthly e-newsletter with a circulation of over 2000 constituents.

# MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

## **Research**

The Society remains actively engaged and committed to the with epilepsy research community. In 2015 we became partners in a national initiative to present research and findings on rare epilepsies across physician groups in Canada in the format of a Rare Epilepsy Grand Rounds series.

The Society is proud to continue support of Dr. Stuart Cain, a neuroscientist working in the Centre for Brain Health at the University of British Columbia. We are providing support for this project from July 2014 to June 2016 to characterize and establish a novel mouse model of Sudden Unexpected Death in Epilepsy (SUDEP). Since few models exist for SUDEP this research will benefit scientists and clinicians investigating the underlying mechanisms and promote the evaluation of new therapies to prevent it.

We also provide support to many local epilepsy researchers by acting as community support partners in the research grant process.

## **Governance**

We are pleased to welcome Dr. Linda Huh from BCCH neurology department and Dr. Islam Hassan from VGH neuropsychiatry to our professional advisory committee (PAC). Members of the PAC include local research, medical and social service epilepsy experts that come together in service of BC Epilepsy Society's mission and goals and act as subject expert governance to all that we do.

# MESSAGE FROM THE CHAIR AND EXECUTIVE DIRECTOR

## **In Appreciation**

BC Epilepsy Society is deeply grateful for the unrelenting and deeply rooted commitment of our constituents, Board of Director's, PAC members, Donors and Staff, Jasdeep Lachar, Chris Lal and Marlyn Chow for all that you do to improve the medical and social landscape for people and families living with epilepsy.

In particular we would also like to acknowledge the past contributions of:

Dr. Tiffany Townsend, thank you for a decade of service, not only have you contributed deeply to the medical content and culture of BC Epilepsy Society, but also to the BC patients and families living with epilepsy. Good luck with your new adventures in the Maritimes.

Cyrus Irani and Cindy Devlin, thank you for your long-term service on our Board of Directors. The Society appreciates all of your efforts in dedication to our mission.

Elvira Balakshin and Kathryn Clark, Your contributions and passion for the people living with epilepsy has significantly shaped the Society's programs. Thank you.

A very special thank you to our financial donors for their generous and thoughtful contributions.

# STAFF

Lori Eisenhaur, MA  
**Executive Director**

Marlyn Chow, RSW  
**Support Services Coordinator**

Jasdeep (Jas) Lachar  
**Community Development Coordinator**

Janice Bulger  
**Bookkeeper**

Chris Lal  
**Epilepsy Peer Support Lead**

# BOARD MEMBERS

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Trevor Young, MBA

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Linda Huh,

**Professional Advisory Committee Co-Chair**

Stuart Cain, Phd

**Professional Advisory Committee Co-Chair**

# PROFESSIONAL ADVISORY COMMITTEE

Linda Huh, MD, FRCPC

**Co-Chair**

Stuart Cain, Phd

**Co-Chair**

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