Welcome to the Summer 2015 edition of the BC Epilepsy Society newsletter. This issue includes updates about BC Epilepsy Society programs and services, breaking news about epilepsy advocacy, research, and support services, as well as feature articles about epilepsy surgery in children by Dr. Anita Datta and personal experiences of epilepsy by Sita Gaia.

Why Consider Early Epilepsy Surgery?

by Dr. Anita Datta, a pediatric neurologist at BC Children's Hospital

Background

Various epilepsy surgery procedures can be used to cure or reduce seizure frequency. Most procedures are either designed to resect or disconnect the area of the brain where seizures originate or spread. Epilepsy surgery is a procedure that either removes or isolates the area of the brain where seizures originate. Epilepsy surgery can significantly improve seizure control in a carefully selected group of individuals. Seizure freedom can be as high as 70-80%, and a large percentage of patients can have a significant reduction in seizure frequency or disabling seizures following surgery. However, referral for evaluation often is delayed and occurs years later after numerous medications have been tried. Unfortunately, it often takes 20 years for a patient to be referred for evaluation for epilepsy surgery.

Worldwide, referral for epilepsy surgery is underutilized. Less than 1% of patients with treatment resistant epilepsy are referred for a surgical evaluation. Lack of knowledge by physicians of the benefits of surgery and appropriate surgical candidates, fear of complications, and the thought that people may outgrow the epilepsy at a later time are some of the reasons. Another reason could be due to physicians' perception of epilepsy surgery as a "last resort" procedure.

In British Columbia, 40,000 individuals have epilepsy. Approximately 30% have treatment resistant epilepsy. Therefore, 3000 to 5000 patients in our province could benefit from epilepsy surgery.

Natural history of epilepsy and response to medication

One of the main arguments for early epilepsy surgery is the observation that once seizures do not respond to treatment (treatment resistant), the chance of seizure freedom with further medication trials is small. One study looked at patients who had epilepsy for at least five years and at least one seizure per month. Of those who had tried less than five medications, in 24% seizures were controlled with expert treatment. In comparison, only 11% of those who had tried five or more medications became controlled (1). This is obviously dependent on the cause of seizures and the epilepsy syndrome. Children may have a higher response rate to medications. Also, the introduction of newer anti-seizure medications may slightly change these numbers. Resistance to medications may remit over time (at a rate of 4% per year among adults and a higher rate among children). However, seizure relapse is common, suggesting epilepsy can have a fluctuating course (2).

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7th Annual Cindy's Walk Fundraiser

On Sunday, June 28th the 7th Annual Cindy's Walk will bring people together to raise epilepsy awareness and funds for the BC Epilepsy Society. This walk was founded by Cindy Devlin, a board member of the BC Epilepsy Society.

The walk will kick off at John Lawson Park in West Vancouver at 10:00 am and continue along the West Vancouver Seawall for 5 km. Come out to see the beautiful scenery, smell the fresh ocean air, and support people with epilepsy.

Refreshments, socialization, music, and arts and crafts will follow the walk.

Registration is \$25 and children aged 12 and younger are free.

This event is wheelchair and transit accessible. There is free parking on site.

To register, please go to www.bcepilepsy.com, email info@bcepilepsy.com, or call our office at 604-875-6704. Participants are also encouraged to collect pledges in support of the programs, resources, and services of the Society. Pledge forms are also available online and at our office.

Volunteers are still needed to help on the day of the walk. For volunteer information please contact Marlyn Chow at info@bcepilepsy.com



Meet Our New Executive Director

The BC Epilepsy Society is pleased to welcome Lori Eisenhaur 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 severe epilepsy.

You can contact Lori at 604-875-6704 or at lori@bcepilepsy.com



Annual General Meeting Update

On March 26th, the BC Epilepsy Society hosted its Annual General Meeting (AGM) for the fiscal year ending December 31, 2014.

Board Chair, Cyrus Irani reported on the accomplishments of the Society throughout 2014. This included the growth and delivery of our programs and services across BC as well as the development of new resources.

Cyrus Irani, John Stiver, Tiffany Townsend, and Dan O'Brien were elected to two-year terms on the Board of Directors.

Society Treasurer, Dan O'Brien gave the Society's financial report and the 2014 audited statements were approved. Sidhu Straker & Associates were also approved as our auditors for the 2015 fiscal year.

More information can be found in our 2014 Annual General Report. This is available on our website or through our office.





To register
call 604-875-6704, email info@bcepilepsy.com
or go to www.bcepilepsy.com



Article continued from page one

"Surgery in children also aims to prevent the negative effects of seizures on brain development and to improve quality of life in the child and family" Kwan and Brodie reported that those who have many seizures before therapy or who have an inadequate response to initial treatment with anti-seizure medications are likely to have treatment resistant epilepsy. They found that 47% became seizure free with their first anti-seizure medication and 14% became seizure free during treatment with a second or third medication. Among patients who had no response to the first medication, the percentage that subsequently became seizure free was smaller (11%) when treatment failure was due to lack of efficacy than when it was due to intolerable side effects (41%) (3).

Consequences of uncontrolled seizures

The goals of epilepsy surgery are to decrease seizure frequency or to render patients seizure free sooner with better success than medical therapy. Surgery in children also aims to prevent the negative effects of seizures on brain development and to improve quality of life in the child and family. Better and earlier seizure control should reduce seizure associated morbidities.

Mortality

Uncontrolled frequent seizures are associated with an increased risk of death. Sudden unexplained death in epilepsy (SUDEP) rates are quoted to be the highest in surgical series patients with treatment resistant epilepsy compared with community prevalence samples (4). Lower mortality has been consistently observed among patients who are seizure free by surgery compared with both surgical patients who have persisting seizures and patients who were evaluated for but did have surgery.

Cognitive decline

Seizures can have a negative effect on brain development and learning especially in children. Good seizure control, even after years of treatment resistance, can have a beneficial impact on cognition (5).

With temporal lobe epilepsy, in cross-sectional studies memory is worse in patients with a longer duration and earlier age at onset of epilepsy (6). In one longitudinal study, surgery abolished or reversed the decline in memory function (7). In another study, 25-40% of treatment resistant patients showed decline on tests of confrontation and naming compared to friend or relative controls (8).

It also known that frequent seizures can lead to "pseudo-regression" where the seizures and medications impact sleep, energy, attention, mood, learning and interaction with the environment. This is thought to be reversible with better seizure control.

Effectiveness of epilepsy surgery

Evidence for the effectiveness of epilepsy surgery has been shown in one randomized controlled trial in temporal lobe epilepsy. 58% of surgically treated patients were seizure free at one year compared with 8% of medically treated patients (9). The resulting practice guideline by the American Academy of Neurology, the American Epilepsy Society and the American Association of Neurological Surgeons recommends that those with partial seizures who failed first-line anti-seizure medications should be referred to an epilepsy surgery center, and that those who meet the criteria for mesial temporal resection should be offered surgery. There is evidence for success of epilepsy surgery from other areas of the brain also.

The success rates of surgery are dependent on several factors, such as the presence or absence of a lesion, seizure etiology, area of seizure onset, concordance of other tests, etc.

Self-reported quality of life (QOL) studies consistently show improvements with postsurgical seizure control. The results are not so favorable when seizures persist (10,11).

Risks of epilepsy surgery

As is true for any surgery, brain surgery has risks. General risks of surgery include complication of anesthesia, bleeding and infection. A more serious infection, meningitis, can occur after brain surgery. This is an infection of the layers that cover the brain. Brain swelling can also occur and lead to headache and discomfort. The surgeon will often prescribe a medication to reduce the risk of swelling after surgery. Rarely, a vascular injury can occur intraoperatively and this can lead to a stroke. The risks are dependent on the area and extent of the resection. Investigations, such as cortical stimulation or mapping brain function, neuropsychological evaluation and functional MRI, can predict and determine the risks of neurological deficit prior to surgery. In one meta-analysis of temporal lobe resections, dysphasia or speech alteration occurred in 3%, weakness on one side of the body occurred in 2%, and large visual field defects occurred in 2%. Of these, half were permanent. Death was reported in 0.4% and was unrelated to surgery (12).

Declines in verbal memory and word finding are the most common cognitive side effects, occurring in up to 40% of patients with temporal lobe resections. However, these are often known with the pre-surgical work-up, and the risks versus benefits are discussed with the patient (13). Of note, memory decline has been associated with a decline in the quality of life when seizures persist (14).

Cognitive outcomes of epilepsy surgery

Early surgery may reduce cognitive morbidity by preventing progression associated with frequent seizures. Timing may be very important, as younger brains may have a greater capacity for plasticity or "rewiring" of function and therefore better recovery. Some believe that the long-term cognitive trajectory after surgery may be related more to progression of the underlying disease than to seizure control. Early surgery could be most beneficial if it could decrease or halt progression of the underlying disease.

There are not many studies comparing epilepsy surgery in adults and children. One study compared cognitive tests between groups of children and adults. Adults and children with a left sided resection showed expected mean declines in verbal memory at three months following surgery. By one year, the mean scores for children were no longer different from pre-surgical scores, but adult scores remained below their presurgical mean (15). This exemplifies the potential benefits of early surgery.

Conclusion

The evidence for performing surgery earlier is persuasive. It is known that late remissions with medical treatment are less likely. The data regarding the impact of uncontrolled seizures on morbidity, quality of life, mortality, and social and cognitive functions supports early surgery.

Also, the efficacy and safety of surgery have been established in patients. However, the optimum timing of surgery has not been fully determined. Treatment resistance and consideration for surgery does not develop at a uniform time in surgical candidates, and late remissions are still possible. Ultimately, the goal is to reduce seizure frequency, optimize quality of life, and reduce morbidity and mortality as soon as possible. Good prospective studies looking at standardized interventions and outcomes are necessary. However, evidence to date suggests benefits of early epilepsy surgery in appropriate candidates.

References for this article are available by request and on our website.

"Timing may be very important, as younger brains may have a greater capacity for plasticity or "rewiring" of function and therefore better recovery"

Purple Day: A Day for Epilepsy Awareness

Purple Day is an annual initiative dedicated to increasing awareness about epilepsy. On March 26th every year people around the world are encouraged to wear purple and host events in support of epilepsy awareness.

British Columbians hosted events throughout the province in order to help promote this day and understanding of epilepsy. These initiatives included presentations at schools, workplace events, and bake sales.

We distributed epilepsy awareness and educational materials throughout the province for a variety of events and community initiatives. We also gave interviews and background information for a variety of media sources.

During Purple Day an open house was held at the BC Epilepsy Society office. The office was decorated in purple and had purple themed snacks, crafts, and epilepsythemed board games and activities.

In the evening, we hosted our Annual General Meeting followed by our sold out lecture called *Cannabinoids and Epilepsy: The Science Behind the Hype*.

Vancouver landmarks such as BC Place, Science World, the Olympic Cauldron, Canada Place, and Rogers Arena were also lit up in purple in support of Purple Day.

Thank you to everyone who participated in Purple Day this year. Because of you we are able to help increase awareness and understanding of epilepsy. Whether you organized a school or workplace awareness day, wore a purple ribbon or purple clothing, or took the day as an opportunity to talk to a friend or co-worker about epilepsy, your actions make a difference. Now lets keep that awareness going every day of the year!

Cannabinoids Presentation Now Online

On March 26th the BC Epilepsy Society hosted the lecture *Cannabinoids and Epilepsy: The Science Behind the Hype*. To accommodate those who were not able to come, we have posted the presentation slides on our website. You can go to the Presentations webpage at www.bcepilepsy.com to view this and slides from other lectures that we have hosted.

Kids Up Front

BC Epilepsy Society is entering its fourth year of partnering with Kids Up Front. This is a charitable organization that provides tickets to arts, culture, recreation, and sports events for kids who otherwise would not have these opportunities.

The following organizations have hosted events that our members and their families have been able to enjoy free of charge: Vancouver Canucks, Vancouver Giants, Vancouver Whitecaps, BC Ballet, Vancouver Symphony, and the Vancouver Art Gallery.

Anyone can donate tickets to Kids Up Front, which in turn distributes them to partner agencies such as the BC Epilepsy Society to encourage family bonding and social opportunities.

Tickets from Kids Up Front are available for free to BC Epilepsy Society members. To get on the ticket notification list, please contact Marlyn Chow at info@bcepilepsy.com or 604-875-6704.







Dear Seizures...

The contributor of this feature article is Sita Gaia. Sita is a young woman from BC with epilepsy. She is also the author of the blog called *Life at Full Volume*. The goal of her blog is to teach about epilepsy and discuss the stigma and social issues that people with epilepsy may deal with. She loves owls, working out, deep meaningful conversations, and the sound of the rain. Below is a letter she wrote to her seizures along with the response.

Dear Seizures,

I just thought I should write you a letter about our relationship. Hey guess what? It's not working for me, and it never will work for me. I get it, you're more tame these days, which I totally appreciate. I don't like your temper, or when you go crazy on me. Can we try to keep consistency in your craziness?? That would be much, much, better. Because of you, I have to be extra careful today and miss my dance class. I have been looking forward to this class since well....a long time. Did you know seizures that if I went to a dance class and you decided to make an appearance I could hit my head, break a tooth, or sprain an ankle, just to name a few. Do you know how mean of you that is?? Causing injury on to people? That's not proper behavior. Get your s**t together and then maybe we can talk.

Sincerely,

Me

Dear Sita,

I apologize greatly for wreaking havoc on your life. It must be so frustrating. I wish I could control the amount of havoc that I wreak on to your life. When I went to the Neurological counter before you were born, they held up your precious little face and I was devastated that I would have to create such chaos on a woman who is so competent and capable.

Try to see me as coming in to your life as little hiccups; life isn't over sweetheart! If it were, I would march back up to that Neurological counter and demand a refund. I know you want to break up with me, but there are medications that can make us have a quasi-break up. I will always be there, but better controlled.

Hopefully they find a cure for this illness that wreaks chaos on not only you but 65 million people around the world. I wish I could have been the one who wrote "BlackBird" by the Beatles instead, but such is not so.

Please remember that people love you, despite me making life difficult, and the fact that you have to miss yoga class and dance class.

You are loved, despite my presence in your life.

Love,

Seizures xox

News Alerts

Below is a selection of recent news items of importance to people with epilepsy. We research this information to ensure that you stay up-to-date with developments in advocacy, research, political issues, and social services.

Rare Epilepsy Network (REN) Study

Do you or your loved one have a rare form of epilepsy? If so, there is a new initiative to help you. This is called the Rare Epilepsy Network (REN). This organization is registering people with rare types of epilepsy in order to conduct specialized research on how to improve the lives of people who have them. You can sign up to participate on their website at https://ren.rti.org

New Mandatory Drug Shortage Reporting Required in Canada

The federal government is now requiring manufacturers to publicly report current and anticipated drug shortages.

Health Minister Rona Ambrose made the announcement at Vancouver General Hospital. She said, "we know that drug shortages are a very complex global problem, but they have impacts that are felt right here in Canada...nobody feels these impacts more than patients and their families."

In the past 5 years, there has been supply disruptions in 16 out of 23 medications used for epilepsy in Canada.

Advanced Imaging and Seizure Detecting Machines Coming to Surrey Memorial Hospital

A new 3T MRI (magnetic resonance imaging) machine and a MEG (magnetoencephalography) machine are coming to Surrey Memorial Hospital. The MRI being installed is the most advanced model of MRI machines. It takes extremely detailed images of the brain. The MEG machine is used to find where seizure activity is coming from in the brain. Installation of the equipment is expected to be finished this year.

New Service Dog Guidelines in BC

BC has just adopted new guidelines for service dogs (including seizure awareness dogs). These new guidelines extend public access and tenancy rights for service dog owners, require a high training standard for certified dogs, and penalize trainers who falsely claim that they are certified.

For more information about service dogs for people with epilepsy, please refer to our Information Sheet titled Seizure Response Dogs at www.bcepilepsy.com/publications and resources/information sheets/aspx

World Health Organization Resolution About Epilepsy

The World Health Organization (WHO) has endorsed a landmark resolution urging Member States (including Canada) to improve care and treatment of people with epilepsy.

The resolution calls on the WHO Secretariat to lead and coordinate support to Member States to address the global burden of epilepsy so that people with epilepsy can receive timely treatment and can benefit from educational and occupational opportunities, free from stigma and discrimination.

You can read more news alerts on our website and on our Twitter feed, Facebook page, and e-newsletter. Go to www.bcepilepsy.com to sign up for our e-newsletter and for the links to our social media accounts.

Online Support Group

Would you like to learn about epilepsy as well as listen to others experiences and perhaps share your own?

You can do this at our online support group meetings.

This group discussion provides the opportunity to connect with other British Columbians who have been affected by epilepsy.

It's a place to gain confidential emotional support and to share information and resources. It also provides an opportunity to exchange practical solutions to the everyday challenges associated with epilepsy.

This group typically meets the first Monday of each month from 7:00 pm to 8:00 pm. The first 30 minutes are focused on discussions of a topic of interest and the next 30 minutes discuss common feelings and questions.

The group has focussed on the following topics in the past several months: health and fitness goals, epilepsy and family relationships, how to raise epilepsy awareness, where we see ourselves in 10 years, and how the initial diagnosis of epilepsy affected you.

The online chats are hosted on a secure password protected online forum (the forum and set-up is similar to Skype but without the pictures). Please note that you must preregister and sign a confidentiality agreement before attending an online support group meeting.

To register contact Jas Lachar at services@bcepilepsy.com or 604-875-6704.

Educating Teachers and Students: A Success Story

With the end of the school year quickly approaching, it's a great time to reflect upon the successes of our Partners in Teaching program throughout the 2014-2015 school year. Partners in Teaching is a school outreach program. It provides seizure awareness workshops and educational resources for teachers, school support workers, and students.

This year we've formed new partnerships with various organizations and different types of audiences. A particular notable achievement was our partnership with the 2015 Operation Med School conference. This is an event for high school students who plan to go into medical school. It consists of a day of workshops on a variety of scientific topics.

Over 160 students attended our workshop about epilepsy and how they can help people who have it. The feedback from them was very inspiring. Even though these students already had advanced scientific knowledge, the majority admitted that they knew almost nothing about epilepsy. After our presentations the students were very intrigued. In fact, there were several inquiries as to how they could specialize in epilepsy in their future medical careers.

Thank you to our donors and supporters that help us make the Partners in Teaching program so successful. This program spreads awareness about epilepsy throughout all age groups. This then helps to improve acceptance and compassion for people affected by epilepsy.

For more information about school outreach and seizure awareness workshops, please contact Elvira Balakshin at 604-875-6704 Ext. 11 or at outreach@bcepilepsy.com

Upcoming online support group meeting dates: July 6th August 10th September 14th



Post-Secondary Scholarships for People with Epilepsy

To help people with epilepsy further their education, the BC Epilepsy Society offers post-secondary scholarships to those who currently attend or plan to attend a post-secondary institution or employment training program. This year four scholarships of \$2,500 will be awarded.

Individuals who are BC residents, ages 16 and older, who are Canadian citizens or who have landed immigrant status, under a physicians' care for epilepsy, and have a current BC Epilepsy Society membership, are eligible.

The scholarships are awarded on the basis of educational commitment, volunteer work, and other achievements or interests. The grants can be applied to tuition, books, and/or related educational expenses.

Go to www.bcepilepsy.com to download the 2015 scholarship application form. The deadline to submit applications is June 30th, 2015.



Camp Subsidies

Camps are a great way for children with epilepsy to develop social and leadership skills, increase independence, and explore new activities.

The BC Epilepsy Society provides financial subsidies to help cover the costs of various camp programs. These are for children who need extra support due to medical needs and learning or physical disabilities.

The subsidies reimburse camp costs up to \$150 and are awarded on a first-come, first-served basis. Recipients must be a current member of the BC Epilepsy Society to be eligible.

Subsidies are provided for BC Easter Seals Camps, Eureka Camp, Zajac Ranch, and various adaptive day camps such as the ones offered by PosAbilities, Kids Matter, Summer Social, and various community centres. For a summer camp subsidy application form go to www.bcepilepsy.com, email info@bcepilepsy.com, or call 604-875-6704.



Fall Events from the BC Epilepsy Society

Epilepsy Webinar

September TBA 7:00 pm to 8:00 pm Topic TBA Online

Family Epilepsy Education Day Conference

Saturday, November TBA 8:30 am to 5:00 pm Chan Auditorium BC Children's Hospital Vancouver, BC

Shakin' Not Cured

A James Bond themed extravaganza gala fundraiser. Tuesday, November 10th 7:00 pm Location TBA



How You Can Help

As a non-profit, charitable organization, the BC Epilepsy Society relies on individuals like you to help us deliver our support and education programs.

There are a variety of ways that you can donate. Below are some options that may work for you. For more information please contact Lori Eisenhaur at 604-875-6704 or lori@bcepilepsy.com

In Celebration Gifts

Most people are familiar with the practice of making a charitable donation in memory of a friend or family member. These are often referred to "in memoriam" gifts.

On the other hand, most people don't know about the concept of "in celebration" gifts. When families host a celebration event like a baby shower, birthday, wedding, anniversary, or graduation, you can ask guests to make a donation to a charity rather than bringing a present.

The next time you have a special event in your family, please consider having gifts made as donations to the BC Epilepsy Society in recognition of that memorable event.

Monthly Giving Plans

We've heard from donors who feel that it's easier for them to make a series of monthly donations rather than a single donation each year. For example, \$50 each month may be easier to budget than \$500 once a year. You can choose any amount that fits your budget.

You can choose to have your monthly donations designated to support any of our great programs, resources, or research grants. You can use the form on the back of this newsletter to start your monthly donations or contact our office to sign-up.

Estate Planning and Bequests

Estate planning involves making plans for the transfer of your estate after death. Your estate is all the property that you own. It can include cash, clothes, jewelry, cars, houses, land, retirement, investment and savings accounts, etc.

A bequest - a gift given through a Will - is a popular way of making a future significant gift to charity while maintaining your present financial security. Your bequest to the BC Epilepsy Society can be made with a gift of cash, real estate, or securities.

You may also make a restricted bequest to be used for a particular purpose or program. For example, you may specify it be used to establish a named endowment fund. You can also designate your gift to support epilepsy research or a specific service or program.

Please contact our office to get our planned giving newsletter that you can review with your family and financial planner.



The BC Epilepsy Society was incorporated as a registered charity on August 17, 1959, under the leadership of pediatric neurologist Dr. Norman Auckland.

Dr. Auckland believed that an increased understanding of epilepsy, among those living with the disorder and their families, could help those living with epilepsy to help themselves.

The Society's programs and services today remain true to Dr. Auckland's original vision of support and education.

BOARD OF DIRECTORS

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Phone: 604-875-6704 Fax: 604-875-0617 info@bcepilepsy.com www.bcepilepsy.com

Show Your Support: Become a Member

You can help support the work of the BC Epilepsy Society by taking out a membership. Membership is \$10 for an individual or \$50 for an organization. You can also purchase a multi-year membership.

Membership benefits include free admission to our lecture series, loaning privileges from our resource library, access to free tickets for recreational events, eligibility for subsidies to accessible kids camps and post-secondary scholarships, voting privileges at our Annual General Meeting, and a yearly subscription to our newsletter.

The more members we have, the better able we are to deliver needed programs, resources, and services. Please complete and return the membership form below if you would like to join.

BC Epilepsy Society
newsletters are posted on
our website at
www.bcepilepsy.com in the
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