



BC Epilepsy Society

Exercise Benefits Given High Marks

Fall 2004
Newsletter

by Sylvia Blair

Thirty-six-year old Merrick Bartlett has generalized tonic-clonic and myoclonic seizures. She takes daily medication, but because many of her seizures seem to follow stressful situations, she wondered if exercising to reduce stress would help to reduce some of the seizures as well.

“Since I was frequently stressed and low in energy, I asked my neurologist if he thought exercise would be a good idea,” said Bartlett. “He was all for it. We did not really know if it would actually affect my seizures, but if nothing else, I would get back in shape.”

Bartlett started Jazzercise class, a dance-based aerobic fitness program. She loved it so much that she became an instructor. Bartlett said Jazzercise incorporates many of the new and popular fitness programs likes Pilates and yoga, providing variety in her workout.

Eventually, she became a franchise owner. She still teaches four to five times a week.

Better Attitude, More Confidence

“Although I don’t think exercise has helped to control my seizures or even lessen them, it has helped my mental attitude and confidence level. I know that despite epilepsy, I became a teacher to help others and now own my own business. My students look up to me. None of them have ever cared that I have epilepsy,” Bartlett said.

Now I feel like I can do anything. My doctor did put a few limits on me though, like no skiing, mountain climbing, or skydiving,” Bartlett said.

Physicians agree that many people with seizures find that exercise is good for them for a number of reasons. Exercise makes a person feel better about how he or she looks, and it fights depression. It keeps weight down and builds self-confidence.

Steven C. Schachter, MD, is a professor of neurology at Harvard Medical School and Director of Research, Department of Neurology at Beth Israel Deaconess Medical Center. Schachter said most people with epilepsy can exercise safely. “Most exercise experts recommend at least 20 minutes of aerobic activity three times a week,” said Schachter. “It is good for the heart, good for the mind, and for the bones.”

Check-Ups Still Needed

However, he cautioned that people with epilepsy should discuss their exercise routine with their doctor who can tailor their advice to the specifics of individuals’ situations. “Also, people with epilepsy should see their doctor periodically if they lose weight from exercising to make sure they are still taking the right amount of seizure medication,” he said. Are some forms of exercise better than others for people with epilepsy? Schachter said doctors recommend a recumbent bicycle or rowing machine instead of a stationary bike or

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treadmill for people with active seizures. Likewise, yoga may be better than free weights if a person's seizures are not under control.

"Some of my patients have had seizures in the setting of intense exercise," Schachter said. "That's why I recommend exercise in moderation. People with active seizures should stay away from forms of exercise that would put them or others at risk if they had a seizure."

People with epilepsy should see their doctors periodically if they lose weight from exercise to make sure they are still taking the right amount of seizure medication.

Looking for the Right Workout

Twenty-four year old Beate Wittich moved from Austria to San Antonio, Texas last year. To help her meet new people, she joined an aerobics class. She hoped getting active would also help reduce the stress that triggers her juvenile myoclonic seizures.

"It went fine for a while until for some reason, I developed anxiety in the class," said Wittich. "I got so sensitive to the music that was supposed to 'pump' people up. I quit the class, but did not give up exercise."

"I have to watch my stress level because it lowers my seizure threshold. So to relax now, I do yoga at home. It calms me down and gives me a good workout. I feel pretty safe in the afternoon when I do my exercise. My seizures mostly happen in the mornings," she said.

Never to Young to Start

Twenty-eight year old Missy Mattingly has had epilepsy since early childhood. She also has been an avid runner for as long as she can remember.

"I started running with my dad in local parks when I was six. The doctors told us that, in combination with daily medications, regular sleep, and good nutrition, exercise would help my epilepsy. That was true for a while. But then my seizures got worse. I continued running, always with someone biking next to me for safety," said Mattingly.

Then in 1994, Mattingly had brain surgery to remove scar tissue that was causing the seizures. It was successful. The seizures stopped, and she kept on running. In 1998, she competed in the Ironman Triathlon World Championships in Hawaii. Today she swims, bikes, and runs about 25 miles a week.

"I like keeping active. I've been a runner since I was a child. Running is an ingrained habit for me now," Mattingly said, adding that she and her husband now enjoy the sport together.

Exercise Safety Tips

Take frequent breaks. Stay cool. Save your greatest exertion for the coolest part of the day.

Review the risks carefully before taking up sports that could put you in danger if you were suddenly unaware of where you were or what you were doing.

Wearing a life vest is a good idea when you are on or close to water.

Swimming can be safe and fun for everyone, but avoid swimming alone.

Tell lifeguards and friends you swim with what kind of seizures you have, how to recognize them, and what to do if you have one. Make sure they swim well enough to help you.

Wear head protection when playing contact sports, or when there is an added risk of falling or of head injuries.



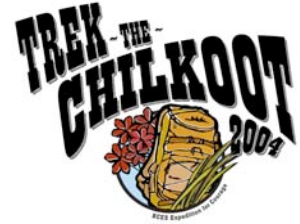
*Lisa Richardson, Anmore, BC
Ironman Triathlete*

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What a success! 16 committed trekkers raised a minimum of \$3,000 each in pledges and then packed their bags for a tough but exhilarating five days of hiking from Dyea, Alaska to Lake Bennett in northwest BC. The Trek followed the same route that eager gold rushers followed in the late 1800's.

Our top pledge collector was Dr. Mary Burke-Burgess who brought in over \$5,500. The pledges should total over \$52,000 when they all come in. We've decided that the funds raised by the trekkers will be used to support our services for women living with epilepsy.

Many thanks to Julie Burke for bringing the concept of a fund raising trek to the Society. She worked many hours on coordinating a variety of tasks, in addition to fund raising and training for her own participation. We're not sure what we'll do next year to try to match the success of this event, but we'll put our thinking caps on this fall and see what we come up with. Take a look at the Chilkoot Trek section of our web site (www.bcepilepsy.com) to see photos taken during the Trek.



Epilepsy specialist Dr. Kevin Farrell and fifteen-year old Shauna Leake, who is living with epilepsy, at the end of their five-day trek.

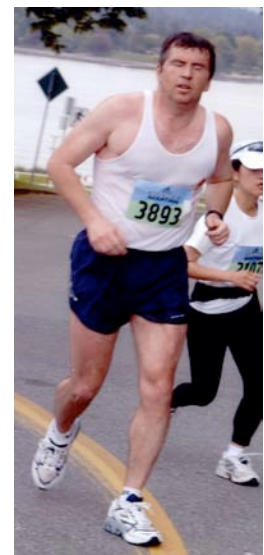
Marathon Results

This past spring, three British Columbians living with epilepsy successfully completed marathons. A marathon is contested over a distance of 26 miles, 385 yards.

Jean Haley traveled all the way to England to compete in the Flora London Marathon on April 8. Not only did she complete the Marathon, she collected almost \$700 in pledges from friends and family in support of our Society.

Lisa Richardson and Stephen Probyn completed the Adidas Vancouver Marathon on May 2nd. Lisa and Stephen are also valuable volunteers for the Society.

Congratulations, Jean, Lisa, and Stephen! If any of our readers who are living with epilepsy have participated in a sports or recreation activity, please let us know so that we can increase the number and variety of examples of people living active lifestyles.



Stephen Probyn

Kids at the Zajac Ranch



From August 2 to 7, a group of four kids living with epilepsy had the chance to attend the brand new Zajac Ranch at no cost to their family. Both the construction of the Ranch and the majority of camper fees were covered through the support of the Zajac Foundation. Our Society contributed a subsidy to eliminate any cost to the families. The Ranch is already planning for further expansion and construction to add facilities for next year.



Rebekah McGeer saddles up for rodeo days at the Zajac Ranch.

Children can participate in a variety of crafts and physical activities. If anyone is interested in having their child attend this fully accessible and medically supported Ranch next year, please contact our office for details.



Dog Walk Fund Raiser for Research

On Sunday, November 21, we're hosting our first annual dog walk for epilepsy research. The hour-long walk will start on the beaches of Jericho and Spanish Banks in Kitsilano and end up at the Aberthau Cultural Centre for a hot lunch.

Everyone is welcome, regardless of whether you come with a dog or not, and there will be treats for all dogs at the start. All of the funds raised will go towards epilepsy research. Please contact our office at 604-875-6704 to register.

Donate Your Shoppers Drug Mart Points



By donating some or all of your Shoppers Optimum Points to the BC Epilepsy Society, you'll help us purchase products and supplies we need from Shoppers Drug Mart.

To donate your Points, please go online to: www.shoppersdrugmart.ca/donate and browse the Shoppers Optimum section. Then click on "donate your points." Any number of points donated will be greatly appreciated.

This year we were fortunate to be given four scholarships to award to deserving BC post-secondary students living with epilepsy. Thank you Lundbeck!



Sage Kennedy (Lundbeck Canada), Erin Thompson, Ellie O'Day (BC Epilepsy Society), Jennifer Rose, Chris Lal, and Cassandra Strain

Erin Thompson of Langley is a basketball player currently attending Douglas College in the Dental Assistant program. Jennifer Rose of White Rock has applied to the University College of Kamloops. Along with her studies, she owns and operates a rabbitry. Chris Lal of Vancouver attends Langara College. His long-term goal is to be a counselor. Cassandra Strain of Richmond is a third year Social Work student at NVIT in Merritt. She's done lots of peer counseling and crisis line work. He volunteers as a support group facilitator for adults with epilepsy.



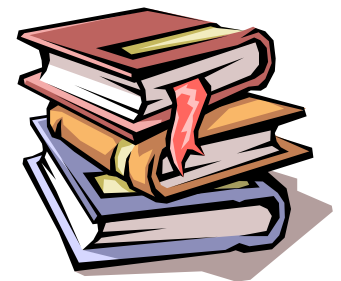
We were also lucky enough to have CTV air a great story about Chris and his scholarship. The story also mentioned a variety of issues facing people living with epilepsy. The four and a half minute news story can be found on our web site at www.bcepilepsy.com.

Hooray for Library Volunteers

Our Society office in Vancouver has a library of books, videos, and articles about epilepsy. They're available during office hours and can be borrowed by members.

Over the past year and a half, a succession of volunteer librarians have worked very diligently to upgrade and improve our library resources; cataloguing and categorizing all materials and creating a file of articles. We've added lots of new material this past year.

We're creating a complete list of available resources, with brief descriptions of each. This will be posted on our web site (www.bcepilepsy.com) in upcoming months. We are greatly indebted to our volunteers for all their efforts with this project: Yuko Sunami, Margaret Kwan, Soyun Kim, Richard Zhang, and Barbara Brown.



Partners in Teaching

Partners In Teaching is city-hopping...BC Epilepsy Society's newest program took a second trip to Kelowna in August. We went to the Okanagan Teachers' Summer Institute 2004 to deliver a professional development workshop. This was a great opportunity to take our program to teachers in the area and educate them about the impact of epilepsy on children.

Since last fall, we've hosted 31 workshops in 11 cities for people who work directly with students: from primary and middle school teachers, support staff, administrators, teachers' assistants, and para-educators to parents, and even classes of secondary students.

Audiences still rave about the workshops and our great volunteer facilitators. Paula from the South Vancouver Neighbourhood House says, "As a presenter, you were well informed, friendly, down-to-earth and responsive to questions and group needs." Staff at GF Strong said, "It was a well-prepared presentation. The facilitator has lots to offer and the volunteer was well informed and confident in his answers. We will recommend this to other daycares."



F.K. Morrow
Foundation



The valuable information that we offer educators has contributed to the growth of positive referrals to other educators and community groups. The ParaEducators' Network of British Columbia (PENBC) has asked, for the second year in a row, for volunteer facilitators to conduct a Partners In Teaching workshop at their annual conference. We will be connecting with paraeducators, partner groups, parents, teachers, administrators, and trustees to help them learn about epilepsy and become more seizure-aware.

With these successes in mind, we want to expand the program to serve public health nurses in BC by developing resource kits designed specifically for nurses. We have recruited a medical student volunteer who is analyzing our resources to determine which materials would be most appealing to nurses. We will ask a group of nurses what information they'd be interested in having, and the demographics of the people in their area to know what type of information would be the most popular. Once we've identified the necessary items and content, we'll be developing kit contents for use by nurses in schools and local communities.

The program continues to successfully educate people about epilepsy and seizures. We're effectively addressing the need for seizure awareness in the education system and community groups. Everyone who is part of the program has come together to educate families and educators and provide them with information that is comprehensible and easy to learn. For more details or to book a free 60 to 90 minute workshop, call our office at 604-875-6704.

Leadership Vancouver Completes Needs Assessment

Over the past four months a team of five volunteers from Leadership Vancouver conducted a needs assessment to help our Society find areas for improvement, provide guidance for strategic planning, and suggest elements of a responsive organization.

Four core needs emerged from a synthesis of the data from multiple sources:

Our Society needs to redefine its reach, including the scope of programs, to meet the primary needs of our clients in order to ensure the best use of resources.

We need to partner with other organizations.

We have to improve the public awareness of our Society.

We need to deliver programs and services that assist in improving quality of life for people living with epilepsy in BC.



We thank everyone who responded to surveys or participated in interviews. Your feedback has already been incorporated into the work of our strategic planning committee. Our goal is to have the 2005-2007 strategic plan adopted by November 2004.

Speaking of Epilepsy Lectures Available on Video

Once again our Society hosted a successful summer lecture series on a variety of topics. For those of you who weren't able to attend one or more of the lectures, you can now get a video copy of any of the lectures to review. The lecture topics included active living, medications, women living with epilepsy, what to do when your medications fail, and an "ask the neurologist" session. Each of the lectures was about two hours long and included a question and answer section.

There is no charge for videotapes for member except postage. Non-members can purchase any of the tapes for only \$10 each plus postage.

Annual General Meeting on April 21

Our AGM was held on April 21st and actually served as the culmination for a series of events that evening. Following a well-attended volunteer appreciation reception, we hosted a presentation on the Chilkootek Trek fund raiser, and then made presentations to our four Lundbeck Canada scholarship winners. This year's meeting was the best attended AGM in recent memory.

The AGM was highlighted by the adoption of our new constitution and bylaws. The bylaws provided for new terms of office for our Board members. Gavin McLeod, Gary Fechtmeyer, Gordon Cook, and Shiela Kent were elected to a two-year term of office. Julie Burke, Mike Rowlands, Dr. Kevin Farrell, and Dr. Lisa Bateman were elected to a one-year term. Special thanks go to departing Board members Billie Raptis, Ellie O'Day, and Leonard Zurkowski.

AGM

New Program and Communication Coordinator

We're pleased to announce the hiring of Elvira Balakshin as our new Program and Communications Coordinator. Elvira has been one of our Partners in Teaching volunteers and is living with epilepsy. She started the first week of August. Her email address is outreach@bcepilepsy.com.



Elvira Balakshin

Our Web Site

If you haven't been to our web site lately, have a look. We've updated the content considerably since it was launched in the spring. Our Professional Advisory Committee, a team of medical practitioners, continue to contribute significantly to the content for the site and we've had tremendous feedback by those who've used the site.

www.bcepilepsy.com

Mark Your Calendar

We offer opportunities for people living with epilepsy, their families, and friends to get better connected and strengthen their support networks.

Prince George: Brain Injury Group (1237 4th Ave.) Second Tuesday of the month 7-9 pm; Phone Jean: 250-562-3389

Courtenay Open Adult Group: Comox Valley Nursing Centre; third Monday of the month 7-9 pm; Phone Elaine: 250-338-1711

Chilliwack Open Adult Group Phone Richard 604-795-3089 for times and location.

Lower Mainland Adult Group: #120-535 West 10th Avenue, Vancouver.

First and Third Thursday every month 7-9 pm; Call for information at 604-875-6704.



Planned Giving

The Auckland Society

For the first time ever, we're offering the opportunity for people to make a financial commitment to the BC Epilepsy Society through their wills and estate planning.

We have prepared our first annual newsletter on planned giving, which is available for people to review with their families and financial planners. We have also placed more detailed text on our web site (www.bcepilepsy.com) that will help you understand the variety of gift planning options that you have in support of the Society.

Planned giving supporters of the BC Epilepsy Society become members of The Auckland Society, which is named for Society founder Dr. Norman Auckland and is our way of acknowledging a legacy of commitment.

Be a Part of Our Team

Help our membership grow! The more members we have, the more able we are to deliver needed programs and services. Anyone can join; whether you are living with epilepsy or not. One way for us to grow is to establish community-based volunteer chapters in different parts of the province. Please complete and return the attached membership/donation form if you would like to join our great team.



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Name: _____ Email: _____

Address: _____ City: _____

Province: _____ Postal Code: _____

\$25 Individual \$35 Family (includes children) \$50 Corporate \$5 Fixed Income

I am including a donation of \$ _____ Contact us if you prefer to donate monthly.

Cheque VISA Mastercard

Name on Card: _____

Card no.: _____ Expiry Date: _____

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