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## The LINK Newsletter

*Keeping Leaders and Coaches Informed*

Volume 11 - Issue 6, December 2014

### Office News

#### **Happy holidays to all of our volunteers!**

The Ladner Office staff would like to wish all of our volunteers a safe and happy holiday season and all the best for 2015! Whatever you happen to be celebrating, we hope you have a Merry Christmas, Happy Hanukkah or Happy Kwanzaa. We would like to take this opportunity to express our thanks to all of our volunteers. The program would simply not exist without your efforts.



## **Lawson Foundation Diabetes Coach Study trains first group of coaches**

The study entitled "The Role and Effectiveness of Diabetes Coaches in British Columbia" is getting underway since ethical approval has been granted. Funded by the Lawson Foundation, this randomized controlled trial will match a group of 150 Fraser Health Diabetes Education Centre clients to coaches, and compare this group to 150 clients who receive usual care. The first training was held in Langley for a group of 16 talented volunteers. This three-day training prepared coaches to provide telephone support for six-months to a person living with type 2 diabetes. Training was conducted by Patrick McGowan, Program Director of Self-Management BC, and Siobhan Whalley, Diabetes Patient Care Coordinator, FHA Primary Health Care. The diabetes educators at the Fraser Health Diabetes Health Centres will start informing their patients about the opportunity to participate in the study starting in January. A second weekend training is being organized for February 2015. If you are interested in becoming trained as a diabetes coach, please contact Suzanne at 604-940-8973 or email [dhcoach@uvic.ca](mailto:dhcoach@uvic.ca)



## **Chronic Pain Self-Management Program revision**

Stanford University recently announced that the new CPSMP manual and book should be available by April or May 2015. One bit of good news is a new pain self-management book, which is a combination of Living a Healthy life and the current pain manual. The pain exercise CD will be part of the book. Look for more information from your Coordinator in the Spring.

## **Webinar on the Chronic Pain Self-Management Program**

Dr. Sandra LeFort gave a webinar presentation for the Canadian Institute for the Relief of Pain and Disability on November 20. The session briefly outlined the process and content of the CPSMP as well as the theory on which it is based. The dissemination and uptake of the program across Canada, the United States and Denmark was discussed. Recent research findings from Denmark were presented. As well, updates to the program expected in early 2015 were reviewed. A few minutes were devoted to a description of the new Chronic Angina Self-Management Program. As you may or may not know, Dr. LeFort is a professor at the School of Nursing at Memorial University in St.

John's, Newfoundland. She developed the CPSMP in 1996 as part of her PhD work at McGill University. Presenting with her was Nicolaj Holm Faber, Chief Consultant with the Danish Committee for Health Education in Copenhagen, Denmark. He was trained in the CPSMP in Toronto in 2010 and brought the program to Denmark.

This webinar is recorded and available on the CIRPD [website](#). Please feel free to pass this information on to anyone who is interested in the research behind the CPSMP, especially health professionals who are not familiar with the program.



*Dr. Sandra LeFort*

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## Volunteer Profile

### **Heather Shana Burke - Online CDSMP Facilitator**

My introduction to the Chronic Disease Self-Management Program was in 2000, after being diagnosed with Ulcerative Colitis and Rheumatoid Arthritis, which caused me to go on long term medical leave from my employment. In the supportive and interactive environment, I learned the needed tools to manage, to the best of my ability, my chronic pain and resulting challenging emotions. I soon realized that these skills were beneficial in all life areas. Achieving a

task, in small steps, made the world of difference, as I could celebrate success along the way. I always remember getting through a dental appointment, minute by minute, when the freezing didn't work. Without the program, I would never have succeeded.

Wanting to share this invaluable information with others, I became a leader of the CDSMP , CPSMP and DSMP in the community. As time passed, I was diagnosed with additional health conditions. My pain increased and I was often ill, which made volunteering in the community difficult. I was thrilled to then train for the online CDSMP and have since co-facilitated 11 workshops. It has been ideal for me, as I'm able to respond to participants and take breaks when needed. Witnessing the growth and transformations of the participants, in the short six week period, is amazing , exciting and incredibly rewarding.

Facilitating these workshops has helped me to hone my self-management skills, as well as to grow in self confidence, self esteem and interpersonal skills. The mentors and co-facilitators are wonderful and very supportive. My total involvement in the CDSMP has dramatically changed my life for the better. It's so empowering to be able to manage my conditions, as opposed to them controlling my life. To pass this on to others, well, it always warms my heart and I feel ten feet tall. I must admit that I've two very helpful co-facilitators at home named Flocon and Mickey Velvet. They are my bunnies and when I'm feeling stressed and or in pain one of them sits on my lap as I type. My fur babies are a fantastic help in my pain management.

I'm so grateful to all those involved in the CDSMP programs and it's an honour to be part of them.



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## Tips for Leaders

### **Patient Activation Measure (PAM) questionnaires**

PAM questionnaires will no longer be distributed to workshops that start in the months of January, June, July, or December. The decision was made based on the number of PAMs that have already been collected. Leaders, please ensure to follow the directions for the PAMs in your workshop when they are included in your box of supplies. If you have any questions, please do not hesitate to contact your coordinator or the office at toll-free 1-866-902-3767 or 604-940-1273.

### **Let your participants know about the Active Choices Program**

Just a reminder to let participants know about the opportunity to

partake in the University of Victoria's Active Choices program. The end of a six-session workshop is an ideal time for participants to join, especially those who have physical activity action plans. The program pairs individuals with a telephone coach who offers support via personal phone calls to track goals and progress for physical activity. The coach provides encouragement in creating a personal activity plan that works for each person. Coaches are waiting and ready to take participants so please encourage people to contact Angela at 604-522-1492 or toll-free 1-877-522-1492 or email [angela.activechoices@shaw.ca](mailto:angela.activechoices@shaw.ca). Active Choices coaches, do not forget to remind your clients about all of the self-management programs available through Self-Management BC.



## **Self-Management BC website - have you checked it out?**

Just a reminder to take the time to check out the Self-Management BC website. You can find information on all the available workshops in BC and also see how many available spots are left. Also, giving out the website link is a good way to promote the programs. Currently, about half of our participants are registering online. We are able to track the number of hits on the website. In the three month period of July to September 2014, we had 28,481 page views and 7,329 sessions (individuals logging on to the website). In the new year, we will be

'freshening up' the website with new photos and reviewing content.



## Shipping questions? Do not hesitate to call

Just another reminder to please read through the directions on returning the supplies with Purolator. Please take the time at the conclusion of your sixth session to pack the box and have Purolator come and pick it up. We appreciate the prompt return of any unused items, along with the attendance sheet. If you have any questions about shipping, please do not hesitate to contact the general office toll-free line at 1-866-902-3767. A staff member is answering calls from 9 am to 5 pm Monday to Friday. We are here to help you! Here is the process again:

- Place all the items (including attendance sheet and questionnaires) in the box.
- Put folded return address sheets into the self-sticking plastic envelopes, seal securely, and put on chart tube and box.
- Call Purolator at 1-888-744-7123 and give them the UVIC account number (4060636), number of items for pick up and the full address, including postal code of where to pick up the materials, along with the UVIC Ladner Office address of 4907 Chisholm Street, Delta, BC V4K 2K6.



## Keep those testimonials coming

If you have testimonials from your workshop participants, please remember to forward them to your coordinator. These testimonials are very powerful for promoting the program. **Leaders are also encouraged to send in their testimonials - how has leading a self-management program impacted your life?**



If you have a workshop challenge you would like to address, please send in your questions to [slynch@uvic.ca](mailto:slynch@uvic.ca).

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## Testimonials

### Interior Health leader

During my participation in the CPSMP, with two incredibly intuitive leaders, there was a lady who was non-responsive, weepy, and totally feeling hopeless. She was unable to make action plans. Finally, she made a half-hearted commitment to a small task. Each week the

actions planned became greater and her demeanor became cheery. Later, she confided to me that the program had saved her life as she had contemplated ending life due to hopelessness. What an inspiration she was...a testimony of what the program can achieve in the lives of people.

## **Vancouver Coastal Health leader**

Imagine waking up one morning with a high fever and cold sweats. Imagine going from hospital to hospital and test after test. Imagine being told that you may have cancer or something worse. And, finally, imagine being diagnosed with lupus at the age of 14. That's my tale. Lupus took me on a long journey of depression, low self-esteem, and an internal fight for acceptance. Why me? That was the question I asked myself over and over. Accepting lupus was my biggest challenge. Massive doses of steroids dramatically altered my physical appearance. My face was corrugated with acne and facial hair, my cheeks were puffed like a pumpkin, and my body was completely carved with deep stretch marks.

Although physical changes are inevitable, frankly, the steroids created a gross caricature of me. High school was certainly not easy; I was shunned and ridiculed by many classmates. One brazen girl compared me to a porcupine fish. During this protracted period of time, my only desire was to be accepted as "normal." This is not an uncommon feeling as Katharine Gerould, an American author, has said and I quote "the only glory most of us have to hope for is the glory of being normal."

Lupus also impacted my energy level. I was constantly tired; I couldn't engage in normal teenage activities like biking and football, and to make matters worse, I faced many complications because of my illness. I had frequent flare-ups, muscle and joint pain, and organ involvements which perpetuated my feelings of anger, frustration, and depression.

In due course, I realized that some intervention was necessary to better cope with my illness. At university, a professor introduced me to self-management programs as a way to take responsibility for my health, so in 2007 I received training in facilitating the Chronic Disease Self-Management Program. I figured this way I could combine my desire to learn about self-management strategies with my passion to help others in similar circumstances.

Immediately, the program resonated with me because it was delivered by two experienced and caring volunteers whom themselves had a chronic condition. I felt they could relate to me and understand me. Being among a small group of participants also had a powerful impact. I began to realize that I wasn't alone in this struggle. In fact, I noticed that some participants had even more debilitating conditions than me and still were happy and driven in making a positive change to their health. The participants became part of my support system through my struggles and triumphs.

The program offered me a myriad of other benefits. It really seemed tailor-made for my challenges. In the first session of the program, I was introduced to the simple art of making effective action plans – something so beneficial and yet so overlooked. Each session, I was encouraged to make a simple goal that was specific, desirable, achievable, and timely. The positive results combined with the encouragement from the participants and facilitators built up my confidence level. If an action plan wasn't successful, I learned how to problem-solve around it to make it successful in the future. Slowly I realized that with the proper action plan and pacing, I was able to maintain a productive and enjoyable lifestyle.

I also learned about the importance of the mind and body connection and how some of my difficult emotions such as anger, frustration, and depression can feed on each other and contribute to other symptoms

that I had experienced such as fatigue, stress, and anxiety which can ultimately result in frequent flare-ups and complications. Thus, I learned to use different tools to help break this vicious symptom cycle.

To deal with my difficult emotions, I learned about positive thinking, guided imagery, relaxation and breathing techniques, and communication skills. For fatigue and stress, I learned about pacing – balancing activity and rest and creating a fitness program which consisted of flexibility, aerobic, and strengthening exercises. For weight management, in addition to the fitness program, I learned about healthy eating and began to make small, gradual changes in the way I ate. Lastly, I learned how to work effectively with my doctors to manage lupus. I started keeping a health journal and recorded my symptoms, concerns, and questions to share with my doctors. I kept track of my medications and lab results. During visits, I started asking questions about my diagnosis, tests, and medications. These simple actions helped me to become more proactive in my own health. I felt empowered.

In closing, because of the self-management program, I had higher self-efficacy in my ability to manage lupus; some of my symptoms were reduced or eliminated altogether, and for the symptoms that still persisted, I had learned tools to manage them. Having gone through the challenges and difficulties of lupus, the program also made me realize that I had something to share with others. Thus since 2007, I have been a volunteer for the self-management programs, helping others self-manage their chronic conditions. If you have a chronic condition or care for someone with a chronic condition, I highly encourage you to attend one of the many workshops organized by Self-Management BC throughout the province. It certainly changed my life, and I am positive it will change yours as well!

## Quotes

*Never think that what you have to offer is insignificant. There is always someone out there that needs what you have to give.*

*Be a fountain, not a drain.*

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Please send your suggestions and feedback to [slynch@uvic.ca](mailto:slynch@uvic.ca)



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