

# **UPCOMING EVENTS**

# YOUNG ONSET PARKINSON'S DISEASE, 4 WEEK SERIES

This series will provide emotional and educational support to people who have been diagnosed with Parkinson's under 50 years of age. It will explore topics on:

- Understanding Parkinson's and its Symptoms | Sharon Yardley, RN
- · Adjusting to a Diagnosis | Elaine Book, SW
- What to Expect with Disease Progression | Dr. Silke Cresswell, Neurologist
- Living well with Parkinson's | Matt Sacheli, PhD Candidate

Date:	Every Tuesday in February beginning February 2, 2016
Time:	7:00 pm - 8:30 pm
Location:	Delivered via webinar. An internet connection is required.
Cost:	Free of charge.
Registration:	Contact Myriame Lépine Lyons at <u>mlepinelyons@parkinson.bc.ca</u> , 604 662 3240 or 1 800 668 3330

#### **REGIONAL CONFERENCE NANAIMO**

Parkinson's is a journey with different stages and associated challenges. Our regional conferences provide attendees the opportunity to learn from experts and connect with others who have been affected by Parkinson's disease.

Presentations and speakers at this conference will include:

- Parkinson's Overview | Dr. Martin McKeown
- · The Neurological Effects of Exercise in Parkinson's Disease | Matthew Sacheli
- Nutrition and You | Elietha Bocskei, MSc, RD
- The Benefits of Mindful Living | Cindy Fisher, RCC
- Get Moving | Doug Pickard

Date:Saturday, February 20, 2016Time:10:00 am - 4:00 pm (registration opens at 9:30 am)Location:Vancouver Island Conference Centre, Mt. Benson Ballroom D | 101 Gordon St, Nanaimo (map)Cost:Member \$30.00 | Member (Pair) \$50.00; Non-Member \$40.00 | Non-Member (Pair) \$70.00Registration:http://www.parkinson.bc.ca/nanaimo-conference-2016

#### COMMUNICATION AND SWALLOW WORKSHOP COQUITLAM\*

This full day workshop will focus on the communication and swallowing challenges faced by people with Parkinson's (PwP). The interactive and participatory format will allow attendees to practise treatment techniques and gain insight from a registered speech-language pathologist. This workshop is open to those already experiencing communication & swallowing challenges, as well as those who wish to be proactive in their treatment. A catered lunch will be provided.

Date:	Friday, March 18, 2016
Time:	9:00 am – 4:00 pm (registration opens at 8:30 am)
Location:	Poirier Sport & Leisure Complex   633 Poirier Street, Coquitlam (map)
Cost:	Member \$40.00   Member (Pair) \$70.00; Non-Member \$50.00   Non-Member (Pair) \$90.00
Facilitator:	Sherri K. Zelazny, MA RSLP
Registration:	http://www.parkinson.bc.ca/Coquitlam-Communication-Swallow

\* To ensure the best learning experience, a minimum of 25 participants will be required 7 days prior to the event date. Please be advised that if these numbers are not met, we will be unable to proceed with the workshop and all registrants will receive a full refund.



#### FREE WORKSHOPS FROM FAMILY CAREGIVERS OF BRITISH COLUMBIA

Not in my Family: Working with family caregivers to reduce elder abuse Seniors Come Share Society | 15008 – 26th Avenue, Surrey March 3, 2016 – 1:00pm to 3:30pm Registration: 604 531 9400 ext 202

Not in my Family: Working with family caregivers to reduce elder abuse Hillside Seniors Health Centre | 1454 Hillside Avenue, Victoria March 7, 2016 – 1:30pm to 3:30pm Registration: 250 370 5641 & press '2' or email <u>wellnesscentreregistration@viha.ca</u>

#### STEP BY STEP

Starting Monday April 11, 2016 PSBC is bringing back the Step by Step program! Step by Step is a 12-week walking program aimed at incrementally improving the number of average daily steps taken. The first week will determine each walker's baseline, and then each week they will be encouraged to increase their steps based on a personal goal. While participants are encouraged to walk and track their own steps, a community group leader will organize a weekly walk allowing walkers to meet, socialize and help support one another.

Interested in becoming a community group leader? As a team leader you would be responsible for organizing a weekly walk, selecting walking locations and motivating your team! Interested? Contact Caroline <u>cwiggins@parkinson.bc.ca</u> or 1-800-668-3330.

The goal of this program is to help motivate people to become physically fit to combat the symptoms of Parkinson's disease. We hope to encourage people to continue a regular exercise routine following the program.

#### **BRAIN HEALTH FAIR**

Save the date - Friday, April 15th, 2016 at the Vancouver Convention Centre, Vancouver, BC, Canada

The Brain Health Fair is a free, daylong event connecting hundreds of neurology patients, families, and caregivers affected by a brain disease, as well as students interested in brain science and the general public interested in brain health. The program is designed and executed by neurologists, with local and national experts, who are on hand to answer questions about the wonders of the brain and the latest research advances.

For more information, please visit: http://patients.aan.com/go/activities/brainhealthfair

#### THE VICTORY SUMMIT<sup>® BY</sup> BY DAVIS PHINNEY FOUNDATION

Save the date - Saturday, April 30th, 2016 at Sheraton Vancouver Airport Hotel.

The Victory Summit® Parkinson's symposium is a free national educational event of information and inspiration, featuring dynamic presentations from leading movement disorder neurologists and therapists from across Canada and the US. It's an upbeat, fast-paced event of community and connection, filled with laughter and conversation. You will leave feeling motivated and armed with tools to help you be more involved in your own treatment and to improve your quality of life. As one attendee said, "I left this event with the knowledge and hope of how to live well with my Parkinson's."

Registration available soon.

# SONGSHINE INSTRUCTOR TRAINING

In partnership with PSBC, SongShine Foundation is offering an Instructor Training, May 12-14 2016 (2.5 days). Participants will be trained to teach an integrated voice strengthening method for those with Parkinson's. The method combines singing, drama therapy techniques, creative expression, improvisation, imagination, and speech. Additional components include breath support, physical awareness, and relaxation, all designed for reviving the speaking voice. SongShine Foundation is seeking those with experience and/or education in voice, music education, choral music, speech pathology, music or drama therapy, theater arts, or arts in healthcare.

More information on the SongShine method, SongShine classes, and learning about their passion for restoring voices can be found at their website <u>www.SongShineforParkinsons.org</u>.

To find out about the Instructor Training in May 2016 contact Myriame, Education & Support Services Coordinator, <u>mlepinelyons@parkinson.bc.ca</u> | 1-800-668-3330.

# ANNUAL GENERAL MEETING

Save the date! On Saturday, June 11, 2016, PSBC will hold its Annual General Meeting featuring keynote speaker Dr. J. Eric Ahlskog, PhD, MD of the Mayo Clinic, Minnesota.

## WORLD PARKINSON CONGRESS

Date:September 20 - September 23, 2016Location:Oregon Convention Center | 777 NE Martin Luther King Jr Blvd, Portland, OR

Will you be joining us in Portland for the WPC 2016 and have an interest in music, voice and Parkinson's disease? <u>Learn</u> more about the secret project with Marimba Artist and Choir Director Judi Spencer!

**Parkinson Society British Columbia's WPC Scholarship Program:** We are proud to offer scholarships to those with financial limitations that may prevent them from attending the 2016 World Parkinson Congress. In providing these scholarships, our hope is to increase the diversity of leadership in BC's Parkinson's community. For more information, please visit: <u>http://www.parkinson.bc.ca/PSBC-WPC-Scholarship-Program</u>



For a listing of all upcoming events, visit our events calendar.

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## CHRONIC DISEASE SELF-MANAGEMENT PROGRAM OFFERED THROUGH SELF-MANAGEMENT BC

The Chronic Disease Self-Management Program is a six-week workshop that helps people with chronic conditions to better manage their symptoms and their daily lives. The workshop provides information and teaches practical skills. It gives people the confidence and motivation they need to manage the challenges of living with chronic health conditions.

For more information, visit: http://www.selfmanagementbc.ca/chronicdiseaseprogram

## STAY HEALTHY THIS WINTER! FACTS ABOUT INFLUENZA (THE FLU)

HealthLinkBC released a helpful fact sheet on preventing the spread of influenza as well as information on when to see a health care provider. Get the <u>fact sheet</u>.

#### GOVERNMENT OF CANADA INCREASES DURATION OF EMPLOYMENT INSURANCE FOR COMPASSIONATE CARE

Effective January 3, 2016, the enhanced benefit, announced in 2015, allows claimants to collect up to 26 weeks of benefits, up from the current 6 weeks. Further, the period during which benefits can be taken is expanded to 52 weeks (up from 26 weeks). Benefits can be shared between family members.

Eligibility for compassionate care benefits remains the same, including the requirement for a medical certificate signed by a doctor attesting to the family member's condition. For more information, read the press release issued by the <u>Government of Canada</u>.

#### UPDATE ON THE REQUIP CLASS ACTION LAWSUIT

The tentative Settlement Agreement will be considered by the Ontario Superior court at a motion on May 3rd, 2016. The proposed settlement will provide compensation to known class members with valid claims and those with valid claims who identify themselves and apply to part of the settlement on before February 12th, 2016. Further details of the settlement are available by visiting <u>http://www.thomsonrogers.com</u>.

#### FEATURED BOOKS FROM OUR LENDING LIBRARY

- 1. The Healing Power of Sound: Recovery from Life-Threatening Illness Using Sound, Voice, and Music. Mitchell L. Gaynor, M.D. 1999. The author presents his sound-based techniques for self-healing. Discusses techniques that anyone can use, whether faced with a life-threatening disease or simply seeking relief from the stresses of daily life. The book includes twelve exercises, including breathing, meditation, and the use of pure vocal sound to resolve tension, release emotion, and spur on the healing process.
- Swallow Safety: How Swallowing Problems Threaten the Elderly and Other A Caregivers Guide to Recognition, Treatment, and Prevention. Roya Sayadi & Joel Herskowitz. 2010. This book will be your guide to recognizing and dealing with swallowing problems before they become life-threatening. Four copies available.
- 3. New Diagnosis Day Videos. If you missed our New Diagnosis Day in fall 2015, videos of the four presentations are available in our lending library on DVD.

# **RESEARCH STUDIES**

- 1. The effects of exercise on Parkinson's disease: A new research interest of Pacific Parkinson's Research Centre (PPRC). The investigators are recruiting patients with PD, between the ages of 40-80, who are interested in participating in research on exercise [more info].
- Brain Research Studies at the PPRC. PPRC is looking for healthy men between the ages of 19 & 85 and healthy women between the ages of 30 and 85 who are interested in participating in research using P.E.T. (Positron Emission Tomography) brain scanning [more info].
- 3. Advance Care Planning for End of Life Care for Patients with Parkinson's Disease [more info].

# **DISCUSSION TOPIC: COMMUNICATION & SWALLOWING DIFFICULTIES**

#### **COMMUNICATION DIFFICULTIES**

Many people with Parkinson's disease (PD) will experience problems with their voice. The most common communication disorder is hypokinetic dysarthria, a speech disorder that causes rigidity and slowness of the systems of communication including breathing, swallowing, voice and speech.

Problems with communication can result in social isolation and difficulty communicating your needs to your health care providers and caregivers. Listeners may have increased difficulty hearing you and may be asking you repeatedly to speak up.

#### SYMPTOMS THAT MAY INDICATE HYPOKINETIC DYSARTHRIA

In the same way that PD can cause slowness, rigidity, tremor, and difficulty with initiation of movement, it can also affect your breathing, your voice and your speech. You may experience one or more of the following symptoms:

- Reduced volume, even when you think you are speaking loudly
- Hoarse voice quality
- Monotone in conversation
- Imprecise articulation
- Vocal tremor
- Change in rate of speech

#### **EVALUTATION AND TREATMENT**

Evaluation and treatment of hypokinetic dysarthria is performed by a Speech Language Pathologist (SLP). You may also need to meet with an Ear, Nose and Throat Specialist. In British Columbia, local hospitals, rehabilitation centres and movement disorder clinics employ SLPs to provide both inpatient and outpatient services. In addition, many SLPs have private practices. The CSHHPBC website will help you locate a SLP in specific geographic areas [http://www.cshhpbc.org/docs/directorybycity.pdf]. You can also contact the College at 604-568-1568. BC Association of Speech/Language Pathologists and Audiologists (BCASLPA), the provincial Speech and Hearing Association, also has a Find a Profession-al resource [http://www.bcaslpa.ca/public/find-a-professional/].

The Lee Silverman Voice Treatment® for PD is an evidence based treatment for voice disorders. It is an intensive and unique speech therapy specifically designed for the communication problems experienced by people with PD.

Discuss your communication difficulties with your physician and request a referral to a Speech Language Pathologist. To find a SLP trained in LSVT® LOUD near you, contact PSBC at 1-800-668-3330 or visit the LSVT® Global website at www.lsvtglobal.com.

#### **SELF HELP FOR A STRONGER VOICE**

- · Make sure you have your listener's attention before speaking.
- Maintain eye contact with your listener.
- Avoid speaking in the presence of distracting background noise.
- You may need to speak slower. Make sure every word is clear.
- Swallow before speaking to clear any pooled saliva.
- Try to speak louder than you are used to speaking.
- Begin speaking with a topic phrase, such as, "I would like to talk about..."
- Try to plan important conversations during a time when you are feeling your best.

#### **SWALLOWING DIFFICULTIES**

Half of all people with Parkinson's disease (PD) develop difficulty swallowing. It is more common with advanced Parkinson's but may also appear in the early stages. When difficulty swallowing makes it less pleasurable to eat and drink, quality of life can be affected. In addition, difficulty swallowing can result in food, liquid or saliva entering the lungs, a process called aspiration. Repeated episodes of aspiration can lead to aspiration pneumonia, a condition that is a primary cause of death for people with PD.

## CAUSES AND SYMPTOMS OF SWALLOWING PROBLEMS IN PARKINSON'S

The swallowing system is dependent on specific and coordinated movement of the swallowing mechanism. In the same way that PD can cause you to experience slowness, rigidity, tremor, and difficulty with initiation of movement, it can also affect the phases of swallowing. Phases of swallowing include the oral phase (bolus preparation/chewing), the pharyngeal (moving food down through the throat), and the esophageal (movement of food to the stomach). You may experience one or more of the following symptoms:

- Choking
- · Coughing or throat clearing during meals
- · Difficulty moving food or liquid from the front of the mouth to be swallowed
- Loss of liquid or food from the mouth
- Drooling
- Slowed chewing
- Increased time required to eat a meal
- Feeling food or liquid sticking in the throat
- Increased difficulty swallowing pills
- Weakened cough or changes in voice

#### **HIGH RISK SWALLOWING CONCERN – SILENT ASPIRATION**

Silent aspiration occurs when food or liquid (including your own saliva) enter the lungs WITHOUT any outward signs or symptoms such as coughing. Silent aspiration can occur secondary to problems associated with the swallowing mechanism such as decreased sensation, slowed motor function, general weakness, decreased coordination, and weak or absent cough. Symptoms of silent aspiration can include, but are not limited to: wet sounding voice especially with eating, absence of coughing or throat clearing, chest congestion, fever, and pneumonia.

#### **EVALUATION AND TREATMENT**

Swallowing difficulty should be evaluated and treated by an experienced Speech Language Pathologist. You would benefit from participation in a videofluoroscopic swallowing study (a video x-ray that examines all phases of swallowing). This study will help the swallowing specialist create a safe swallowing program specific to the concerns with your swallowing. Swallowing treatment plans are highly individual and should be created specifically for you following evaluation.

Discuss any eating and swallowing difficulties with your physician and request a referral for evaluation and treatment of your swallowing symptoms.

#### **SELF-HELP FOR SWALLOWING**

- Eat in an environment free from distraction.
- Always eat sitting upright at 90 degrees.
- Remain upright for at least 45 minutes after eating.
- To avoid the effects of fatigue, try to eat 5 small meals instead of 3 large meals.
- Chew thoroughly. Discuss any changes to your teeth or dentures with your dentist.
- · Alternate liquids and solids. Do not wash down food.
- Eat when you are at your best.
- · Do not ignore symptoms of a swallowing disorder.

Source: Sherri Zelazny, Certified Speech Language Pathologist, Director, Parkinson Society British Columbia Board of Directors

# CAREPARTNER'S CORNER

#### NON-VERBAL COMMUNICATION: BODY LANGUAGE

Not all communication takes place with speech and words. People also communicate with each other by their body language and gestures. Facial masking, or lack of facial expression that is common in those with PD, is a result of rigidity and reduced range of movement in the muscles of the face. Some friends and family members report that the listener who displays no facial expression does not seem interested in their conversation. Facial expressions, as well as other nonverbal gestures, contribute to and enhance the communication process. We can use facial expressions, head movements, hand and arm gestures, and body posture and body position to clarify or add to what we are saying.

Using body language in communication can be a special challenge to PwP because of facial masking, slowness of body movements and rigidity of muscles. Practice body language and gestures and then make a point of using them when you are talking.

Practice and remember the following:

- Eye contact is probably the most important type of non-spoken communication. Always make eye contact when you are talking. Making eye contact shows that you are interested in communicating and in the listener.
- **Practice exaggerating facial expressions**. What does the face feel and look like when expressing emotions such as happiness, sadness, worry or concern? Practice these facial expressions: raise the eyebrows, wrinkle the forehead, open the eyes widely, squint the eyes, smile broadly, purse the lips. Use these movements of facial muscles when talking.
- Keep the lips closed when listening. Having lips closed indicates concentration and attention.
- Use body posture to show feelings when talking. Leaning slightly forward in the chair shows interest; leaning back in the chair may show a state of relaxation and comfort. Leaning back and breaking eye contact can show a lack of interest in communicating or that the communication should stop.
- Use gestures to add to the spoken message. Shrug the shoulders, clasp the hands, turn the head, raise the arms

Simply **pointing** to what is being talked about can be an effective way to add to the spoken message.

