

Snippets May 2016



IN THIS ISSUE: SRABC NEWS AND VIEWS

- Art After Stroke 2016
- SRABC Board of Directors Update
- Branch Update News from SRABC's Branches

INSPIRATIONAL RECOVERIES

- Stroke Information & Resource Guide
- Greater Consideration to Sleep in Stroke Care
 - Resources for Anxiety
 - Making Healthy Choices App

Brain Plasticity

EVENTS

SexyVoices: A Burlesque Theatre Cabaret

CAREGIVER'S CORNER

- New Family Caregivers' Grapevine Newsletter is Out!
 - "Careliving" Guide
- Setting up a Family Caregiver Support Group in Your Community
 - Timing it Right: Stroke Family Support Program Guide
 - Post-stroke Checklist for Survivors and Caregivers

IN FOCUS: APHASIA IN THE MEDIA

- Mayo Clinic Researchers Uncover Clues to Apraxia of Speech
 - Speechless: a Documentary about Aphasia
 - I Sing to Speak: Therapy and Technology Meet
- What Goes Wrong in the Brain When Someone Can't Spell?

RESOURCES

- Share Awareness with Your Community
- Stages of Stroke Recovery and Why Recovery Can Stall

STUDIES

- Have you had a Stroke? Free Therapy is Available!
- Volunteers (honorarium paid) Wanted for Robotics Research
 - The Hyperbaric Oxygen Post Established Stroke Study

SRABC NEWS AND VIEWS

SRABC NEWS AND VIEWS

- Art After Stroke



• Join us on July 8th for an incredible art experience! SRABC will be hosting its first ever Art After Stroke, a fundraiser that will feature incredible work by stroke survivors in visual and performing arts to generate publicity and raise awareness. Art After Stroke will communicate a message of hope by showing the continued talent and potential of stroke survivors. It will showcase that people who have had a stroke are capable of producing fantastic works of art that can take your breath away.

Featuring the talents of:

- Manny Ravelo (artist)
- Dannielle Hayes (artist)
- Amy Stephen (piano player)
- Rosemarie Hurst (artist)
- Jacques Lalonde (performer)
- David Baker (composer)
- Duncan Holmes (artist)
- Jose Suganob Biodata (artist)
- Brock House/Kerrisdale Seniors Community Choir (performers)
- Jacques Lalonde (comedian)

Location: Roundhouse Community Arts Centre

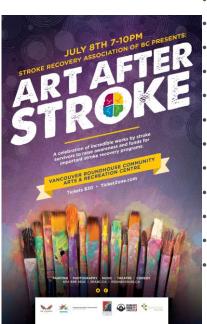
Date: Friday, July 8th, 2016 • Time: 7:00 pm – 10:00 pm

Tickets: \$30.00, available here (http://www.ticketzone.com/event/Art-after-

Stroke/305871)

THANK YOU TO OUR SPONSORS AND DONORS

- News1130 and host (and our event MC!) Tanya Fletcher
- Stroke Services BC A Rembrandt Sponsor!
- Andrew Kiss
- Edward Jones: Katrine Clark from Edward Jones Downtown Vancouver; Audrey McFarlane from Edward Jones Oak Bay, Victoria; Eric Liu, from Edward Jones Cambie Village, Vancouver; Abbie Green from Edward Jones, Dunbar, Vancouver; and Brian Moist from Edward Jones, Fraser Valley. They all got together and are now a Picasso sponsor!



- Physio Control
- Kate Linder
- Two Sparrows Media
- Derrick Higgins
- Cecilia Aisin-Gioro
- Vancouver TheatreSports
- Chef Aaron Zizek
- Mrs. Sarla Gadhia
- Form Body Lab
- Burke Billboards
- La Terrazza
- Tapestry at Wesbrook Village

• It's not too late to join in! If you are interested in helping or being part of this event please contact Genevieve Thompson at office@strokerecoerybc.ca

http://www.ticketzone.com/event/Art-after-Stroke/305871

Keep your eyes on our Facebook page for more updates!

https://www.facebook.com/events/428300690705522

SRABC Board of Directors Update



Stroke Recovery Association of British Columbia Collaboration with March of Dimes Canada

- The SRABC/MODC 'Affiliation and Collaboration Agreement' document is now signed by both parties and became active on April 1st 2016.
- Tim Readman presented an Introduction to SRABC Programs and Services at the Leadership in Volunteer Education (L.I.V.E) Conference which is MODC's annual three-day training and networking event for active members of March of Dimes Canada Stroke, including peer support chapters and associations, current and future volunteer leaders in stroke, and caregiver support groups.
- Tim also gave a presentation to senior management at MODC HQ in Toronto on SRABC. Brent Page presented key info on the Affiliation and Collaboration Agreement.
- Brent Page and Tim attend a series of meetings with management at MODC HQ April 11-14. The purpose was to orient Tim to MODC Operations and to discuss implementation of the affiliation and collaboration agreement.
- Brent and Tim are working with Chris Russell in the Transition Team to plan and manage the many steps required in the implementation of the affiliation and collaboration agreement.
- This is a big challenge as the net effect is a significant increase in workload for Tim, Brent and Genevieve.

Art After Stroke

We are continuing with planning for our Special Event to take place July 2016
entitled Art After Stroke. If you are interested in helping or being part of this event
please contact Genevieve Thompson at office@strokerecoerybc.ca

Heart and Stroke Foundation Canadian Partnership for Stroke Recovery

- SRABC has been invited by Cathy Campbell, Director, Communications at Heart and Stroke Foundation Canadian Partnership for Stroke Recovery to get involved in an important new project with the HSF Canadian Partnership for Stroke Recovery.
- The Partnership would like to commission a national survey and report on:
 - The unmet needs of stroke patients; and,
 - o What happens to people once they have been discharged from hospital?

They would like to set up a steering committee to begin to develop the objectives for this study, identify the target population, identify the potential uses for the data, and more. SRABC Executive Director, Tim Readman, has been asked to be join the steering committee that guides the development of the report. Last year, the Partnership commissioned a study on the prevalence of long-term stroke disability in Canada. The report led to the development of updated stroke disability numbers in Canada, new projections for the future, and resulted in a publication that garnered significant national media attention.



'Town Hall' Meeting Calls



Each 'Town Hall Meeting' call is hosted by a board member and the Executive Director who provide updates on want's happening at SRABC. Members are encouraged to ask questions and provide feedback.

These calls are scheduled for the **second Wednesday of every month at 4pm.**To dial in please call:

Toll Free: 1-866-279-1594 OR Local Calls: 604-484-1962 and enter Participant Code: 616230

Branch Update - News from SRABC's Branches Delta Stroke Recovery

Congratulations to Delta Stroke Recovery - we are proud to have you in the SRABC family!

The Delta Optimist featured an article about the twentieth anniversary of the Delta Stroke Recovery. Karel Ley started the group in 1996 and it has gone from a dozen members to over 70.

Delta Stroke Recovery relies entirely on community donations and volunteers to keep their plentitude of programs running. Weekly gatherings provide services such as speech and physical therapy, word games and memory puzzles, sessions for caregivers, and social lunches.

The sessions run from 11 a.m. until 2 p.m. every Tuesday at Tsawwassen United Church. For those who need it, the speech therapy portion begins at 10 a.m.

To celebrate an incredible twenty years, a volunteer appreciation dinner was held this past April.

For more information about Delta Stroke Recovery, call coordinator Dawn Sillett at 604-946-2731.

Click <u>here</u> to read the full Delta Optimist article and learn more about the Delta branch and their programs.



■Dawn Sillet, coordinator of over eleven years, receives a

bouquet from club president, Peter McTait.

Prince George Stroke Recovery

Luella Novak, coordinator of our Prince George branch sent us the following email and

photo:



We had a wonderful time last week honouring our volunteers for Volunteer Appreciation Week. Here's a photo of me with the team!

Thank you to our Prince George branch and their volunteers for all their hard work!

Chilliwack & Abbotsford Stroke Recovery Hosts A Successful Walk N' Roll Fundraiser

Chilliwack's Walk N' Roll event, which took place Saturday April 30th, has raised \$1989.15 to date with more to come!

Walk 'n' Roll is a 'go at your own pace' mall-walk and fundraising event for people of all abilities that has been run by our friends at March of Dimes Canada since 2009. The event allows stroke survivors, their caregivers, and supporters to get active and out in their communities, support and promote vital programs that contribute to their recovery, and improve their own health and fitness as a bonus.

Check out www.marchofdimes.ca/walknroll to learn about all the previous walks and their success!



INSPIRATIONAL RECOVERIES

National Youth Choir to Perform Stroke Survivor's Song



Here's a message from David Baker, songwriter and Maple Ridge Stroke Recovery:

The choir Unisong which is an all-star youth choir made up of choirs from all across Canada will be performing my "This Land is what I Am" at their Canada Day Celebration concert in Ottawa on July 1st, 2016.

You can hear the song on YouTube

You can also hear him perform live at Art After Stroke on July 8th, 2016. Three of his songs will also be performed by Brock House/Kerrisdale Community Choir.

Former SRABC Board Member Named Courage to Come Back Award Recipient

Christy Campbell, 41, of North Vancouver is the 2016 Courage To Come Back Award recipient in the Physical Rehabilitation category. Christy is a former SRABC Board member. The following is from the Courage To Come Back website's story about Christy:

Christy had it all: active healthy life; loving partner, rewarding career, happy home, and great friends. Then, in December, 2005, at the age of 31, she was devastated by a stroke. Unable to walk or talk or read, Christy's vocabulary was wiped out. She could not ask for help, type an email or say her own name. She lost every word but one and learned a new word "aphasia." Aphasia is a communication disorder best described as being dropped into an alien land where you can't speak the language and don't understand a single letter of the alphabet.

Give up? Not a chance. The one word she had was "yes." Christy was alive and with the

support of her husband and many friends and family took her life in an unexpected direction. At the time of her stroke, beyond short-term therapy BC's medical system had very limited resources for people

EVENTS

SexyVoices: A Burlesque Theatre Cabaret



In a creative and fun approach to breaking down the stigma of disability, award-winning professional theatre company Realwheels is presenting SexyVoices: A Burlesque Theatre Cabaret. This community based performance stars members of the disability community in a performance that explores sexual identity in a playful, and well, sexy way. Using storytelling and burlesque, SexyVoices is a celebration of everyone and everyBODY!

Directed by award-winning Rachel Peake with burlesque choreography by Jenny Magenta.

Location: Performance Centre

Date: May 12 – 14th

Time: 8pm

Tickets: Pay-what-you-can, suggested: \$20.00 (min. \$6) Purchase tickets here

For more information go www.realwheels.ca or call 604-322-7325

CAREGIVER'S CORNER

New Family Caregivers' Grapevine Newsletter is Out!

The Family Caregivers' Grapevine is a bi-monthly publication that promotes the importance of self-care and provides practical information to help with the caregiving role. Share an inspiring quote, a personal story, or useful tip with other caregivers. To read or download Grapevine go here. To contribute please contact Lindsay at lindsay.kwan@nscr.bc.ca or 604-982-3319.

If you're a caregiver in need of support, consider contacting the North Shore Community

Resources Caregiver Support Program. This group offers workshops, stress management strategies, telephone support, and educational resources. To register call 604-985-7138, email: karyn.davies@nscr.bc.ca or complete and return the registration form. They also run a blog, North Van Caregivers where you can find tips and inspiration.

"Careliving" Guide



The National Stroke Association has published a free online and printable guide for stroke caregivers is designed to help caregivers transition into their new and often difficult roles. The book focuses on both the practical and emotional elements of being a caregiver. It's purpose is to assist with developing a care plan by providing tips, resources, tools, and templates, with navigating new roles and relationships, and with how to prevent future strokes. Download the guide here.

Setting up a Family Caregiver Support Group in Your Community



Family Caregivers of British Columbia have released a handout on setting-up a Family Caregiver Support Group.

In this handout you'll find:

- •the benefits, goals and expectations of a family caregiver support group
- •establishing the focus of the group and group guidelines
- •important details to consider location, schedule, drop-in or closed group, facilitator
- •how to advertise your support group and recruit participants

You can download the document here.

Their website is at http://www.familycaregiversbc.ca/

On the last page of this newsletter you will find SAMPLE VOLUNTEER INTERVIEW QUESTIONS for recruiting a Family Caregiver Support Group.

Also be on the look out for new <u>webinars</u> from Family Caregivers of BC this month. These webinars feature medical professionals and caregivers discussing a range of topics around caregiving.

Timing it Right: Stroke Family Support Program Guide



After much research the Heart and Stroke Foundation put together a guide for stroke caregivers. Its goal is to help caregivers be better assisted and prepared for their important role in stroke recovery. After researching and talking to caregivers, the key areas of concern were identified and addressed, including:

- Needing to know what had just happened
- Needing to know what this meant for the health of their family member
- Needing to know how this would change their life

The guide walks you through all stages of recovery and provides an extensive list of resources throughout Canada.

You can download the Program Guide here:

http://www.heartandstroke.com/atf/cf/%7B99452D8B-E7F1-4BD6-A57D-B136CE6C95BF%7D/TIRSFSP_ProgramGuide_SSD.pdf

If you'd like us to mail you a copy please contact the SRABC Provincial Office.

Post-stroke Checklist for Survivors and Caregivers

The National Stroke Association (USA) has developed a companion checklist for stroke survivors and caregivers. The Post-stroke Checklist for Survivors and Caregivers can help you address challenges you might forget during an appointment and issues you might not know are related to your stroke or that are embarrassing to bring up. Go here to download it.

IN FOCUS: APHASIA IN THE MEDIA

Mayo Clinic Researchers Uncover Clues to Apraxia of Speech



According to the Mayo Clinic, the term "apraxia of speech" (AOS) was coined by Frederick L. Darley, Ph.D. in 1969. The term was used to an acquired motor speech disorder characterized by an inability to produce sounds correctly. Since then AOS has been widely associated with stroke, and thus sudden onset. As such, progressive apraxia of speech occurring in neurodegenerative disease has largely been ignored and typically subsumed under aphasia, leading to misdiagnoses.

This past February, two researchers at the Mayo Clinic presented "My Words Come Out Wrong:

When Thought and Language Are Disconnected from Speech" at the American Association for the Advancement of Science annual meeting in Washington. D.C. Keith Josephs, M.D., a neurologist, and Joseph R. Duffy, Ph.D., a speech pathologist, study the breakdown of spoken communication due to strokes and neurodegenerative diseases in an attempt to have aphasia, apraxia, and other associated symptoms understood as distinct from one another.

Aphasia occurs when there is damage to the left hemisphere of the brain, resulting in impaired understanding and expression of language, as well as reading and writing.

Apraxia is when the language centre of the brain is still functioning, but a person has trouble saying what he or she wants to say correctly and consistently. To quote Dr. Josephs, "Patients with apraxia of speech may ultimately become mute because they can't produce sounds. Yet they can communicate by typing or writing... [t]he patient who is aphasic has problems finding words or structuring sentences correctly, which affects both spoken and written forms of communication. These patients can't rely on typing or writing to communicate."

For original sources and further information, go **here** and **here**.

Speechless: a Documentary about Aphasia

SPJECHLJSS

[the documentary]

This in development 56 minute documentary about aphasia follows the lives of three stroke survivors. The film accompanies Ed, Tinna and Lance on their quest for happiness and illustrates the importance of human communication and the social consequences of its loss. Funds are still being raised to finish it. You can view the trailer and donate on their website, www.speechlessdoc.org

I Sing to Speak: Therapy and Technology Meet



"I Sing to speak" is a collaboration between Dr. Liz Barnes, Clinical Director at WIRED Cornwall and Musical Director Mr. Greg Woods. Using Melodic Intonation Therapy over Skype the goal is to bridge distance in order to help cure aphasia. With a great track record, they receive requests for help from around the world including the USA, Canada, Switzerland, and of course the many regions that make up Great Britain. Musical Intonation Therapy is a technique that uses musical minor thirds and tapping therapies to motivate the musical brain to recover speech, often lost after a stroke or trauma to left hand temporal lobes.

With the accompaniment of their book "Sing your way to Health" and a supportive friend or family member the twenty week program is tailored to each client and includes an assessment. For more information visit http://www.isingtospeak.com/

What Goes Wrong in the Brain When Someone Can't Spell?

By studying the brains of stroke survivors, researchers at Johns Hopkins University have identified the distinct parts of the brain that control spelling. Their research could lead to better therapies for spelling recovery.

For the full story please go here:http://www.strokesmart.org/Spelling-Study

RESOURCES

Share Awareness with Your Community

National Stroke Association (USA) has prepared some educational materials that you can download.

They have created four different ready-to-use presentations to meet your needs.

- **Explaining Stroke 101**: Learn the basic information about strokes, risk factors, symptoms and what you can do to protect yourself.
- Act FAST: Stroke is an emergency. Know the signs of a stroke and act FAST.
- **Stroke And Long Term Disability**: There is hope after stroke. Learn how to manage long-term disability related to stroke.
- Stroke Prevention And Risk Factors: Up to 80% of strokes are preventable.
 Learn about controllable and uncontrollable risk factors for stroke. Download presentations here.

Stages of Stroke Recovery and Why Recovery Can Stall

The Canadian Partnership for Stroke Recovery has recently produced a new video that looks at the stages of stroke recovery and why recovery can stall. It offers encouragement to people experiencing slowdowns and provides advice on how to keep recovery on track. The video includes interviews with Drs. Mark Bayley, Janice Eng and Dale Corbett and stroke patient advocate Carole Laurin. Also discussed is the CPSR's plan to conduct a clinical trial focused on reopening the recovery window after stroke.

View the video on our YouTube channel here.

STUDIES

Have you had a Stroke? - Free Therapy is Available!





You may be eligible for a research study. We are evaluating the benefits of a rehabilitation program delivered online.

Therapy will take place in your home approximately twice a week for one hour and last for about 8 weeks.

Before and after the therapy you will be tested to see if the therapy helps you. Financial compensation will be provided for study participation.

Eligible persons:

- · Have had a stroke at least 3 months ago
- · Have a computer with web camera
- Are able to identify at least three things you want to/need to do in your daily life but are having trouble with
- Are 18 years of age or older

Participation is CONFIDENTIAL

For more information, please contact:

Study coordinator, 416-785-2500 ext. 3377, email:ybar@research.baycrest.org
Research funded by Heart and Stroke Foundation Canadian Partnership for Stroke
Recovery and approved by the Baycrest Research Ethics Board.

Volunteers (honorarium paid) Wanted for Robotics Research

You will receive an honorarium to offset your expenses and taking part in research is voluntary.

RECOVERING ARM FUNCTIONS THROUGH A MIND-CONTROLLED ROBOT

Eligibility

- 1. Had a stroke more than 6 months ago
- 2. Able to communicate and follow instructions from others
- 3. Able to move your shoulder (minimal)
- 4. Currently not enrolled in other research or rehabilitation programs
- 5. Willing to come to SFU (Burnaby or Surrey)

Study

- 1. During the experiment, you will wear
- a) A cap that can record your brain activities and
- b) A robotic for the elbow/hand.
- 2. You will use mental / imaginations to move the robot to aid you grasping, pick up, place, etc.

Where do I go?

Simon Fraser University (Room 10857, Applied Science Building, Burnaby)

OR

Surrey (14568 104A Avenue, Surrey)

Please contact Bubblepreet Randhawa, Tel:778-782-9098;

Email:bubblepreet_randhawa@sfu.ca for more information

The Hyperbaric Oxygen Post Established Stroke Study



You're invited to participate in our research study about Ischemic Stroke and Hyperbaric Oxygen.

Vancouver General Hospital's Hyperbaric Unit is conducting the study called 'The

Hyperbaric Oxygen Post Established Stroke Study'.

About you:

- 1. Are you between the ages of 19 and 85?
- 2. Have you had one ischemic stroke 6 months to 3 years ago?

If so, we want to hear from you!

This study involves multiple visits over 2 years. You will be offered a small amount of money to assist with the travel costs of coming to Vancouver General Hospital for treatment and subsequent visits.

Interested? Want more information?

Call: Research Coordinator: Janice Andrade (Tel) 604-875-4111 ext. 68469

SAMPLE Volunteer Interview Questions
Family Caregiver Support Group Facilitator

Name: Date:

- 1. What attracted you to this volunteer position? Why would you like to volunteer with the [insert name of organization]?
- 2. Why do you want to be a support group facilitator?
- 3. Have you done volunteer work before? Where? How did it work out?
- 4. What do you know about our family caregiver support groups? Format? Self-help model?
- 5. Tell me about your experience with family caregiving.
- 6. Tell me about your experience with support group facilitation or with attending a support group.
- 7. What skills do you bring to this position?

- 8. What do you think would be your biggest challenges with this position?
- 9. Availability?
- 10. Two references for me to check?
- 11. Available for training?
- 12. Any questions for me? Anything else you think I need to know that I haven't asked you?

END NOTES

Facebook and Twitter

SRABC is on Facebook at: https://www.facebook.com/StrokeRecoveryBC and Twitter at: https://twitter.com/StrokeRecovBC

- Snippets is published on the 10th day of each month by Stroke Recovery Association of BC
- Snippets contains SRABC news and information and stroke recovery resources for stroke survivors and caregivers
- Snippets is for our Branch Coordinators to assist them in their work with people whose lives have been affected by stroke
- Snippets can also be useful for people recovering from a stroke, their caregivers, their friends, family and supporters
- We welcome your comments and feedback about Snippets
- If you know anyone who will find Snippets useful please forward it to them
 or ask them to add their name to our mailing list by sending an email to
 office@strokerecoverybc.ca
- All past issues of Snippets are available on the SRABC website at: http://strokerecoverybc.ca/snippets-2013/

follow on Twitter | friend on Facebook | forward to a friend

Copyright © 2016 Stroke Recovery Association of BC, All rights reserved.

MailChimp.

We send out the snippets newsletter to all of our Coordinators to keep everyone connected.

Our mailing address is:

Stroke Recovery Association of BC 301 - 1212 West Broadway Vancouver, British Columbia (BC) V6H 3V1

Add us to your address book

unsubscribe from this list | update subscription preferences