

Parkinson Society Newfoundland & Labrador

the prattle

Summer 2019



INSIDE:

Shake, Rattle & Stroll

Anne Rutherford Awards

Latest Parkinson's Science

Mark your 2019 Calendars

Sunday, September 22



Organize a Walk in your town!
We will help you. It is easy and fun!

Glee Club: Music for Health & Wellness

This program is designed to address health issues including, but not limited to: **Parkinson's, Alzheimer's, brain injury, COPD, hypertension & mental illness.**



Participants will...

- Learn fun vocal warm-ups & breathing techniques
- Sing a wide variety of both familiar & new repertoire
- Engage in rhythm activities such as drumming & hand chimes
- Feel supported by compassionate & skilled facilitators
- Make new social connections

Location: Take Note Music School, 1076 Topsail Road, Mount Pearl

Time: Mondays 1:15pm - 2:15pm **Dates:** July 8th - August 12th, 2019

Cost: 6 Week Rate - \$30, or Drop In Rate - \$10 (taxes incl.)

Ages: 18+ (Spouses, family members & care partners are encouraged to attend.)

Facilitated by: Renee White, MTA, certified neurologic music therapist
Chrissie Byrne, B.Mus., B.Mus.Ed., M.Ed., Music Specialist with NLESD

No Prior Music Experience Needed!

Please call or visit our website to register:

(709)763-4121 www.rwmt.musicteachershelper.com

Can't make it to us?

Find out how we can bring this program to you or your facility!

New Neurology Clinic



Dr. Kyna Squarey

Dr. Kyna Squarey, Movement Disorders Specialist and General Neurologist, has moved her clinic to the NL Balance and Dizziness Centre, 60 Elizabeth Ave, St. John's.

Referrals for new appointments may be faxed by your doctor to Dr. Squarey's clinic at 709-700-1474.



Mission Statement

Parkinson Society Newfoundland & Labrador is the provincial voice of people living with Parkinson's in Newfoundland and Labrador. Our mission is to ease the burden and find a cure through research, education, advocacy and support services which we offer directly to our Members.

Provincial Board of Directors

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Cynthia Cave: Western NL	cindycave@outlook.com	(640-9538)
Marie Mackey: Central NL	jmackey@nl.rogers.com	(489-5330)
Jane Macdonald: St. John's	janemacdonald@nf.sympatico.ca	(754-2657)

For all other areas, please
call the Provincial Office.

Provincial Office
136 Crosbie Road, Suite 305
St. John's, NL
A1B 3K3

T: 709-754-4428 or 1-800-567-7020

parkinson@nf.aibn.com

www.nlparkinson.ca

Charitable Registration No. 82783 8053 RR0001

Executive Director: Derek Staubitzer

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Executive Director's Message

Hi Everyone –

Another summer is upon us and we are busier than ever at the Society.

The number of phone calls, emails, newsletter sign-ups and social media inquiries has really increased recently and we are sending out more information packages than ever before. We are very happy to be able to help these members when they need advice, information and reassurance.

We continued to expand our exercise classes this spring, with a new program starting in Corner Brook. Big thanks to our new Western Chapter Chair, Cynthia Cave, for getting that program going. The Western Chapter will also start holding regular monthly meetings again in the fall. So, if you live in the area, please contact Cynthia (640-9538) and she'll give you all of the details.

I would like to recognize and thank some of the major contributors who are helping us make our exercise programs a success:

*Department of Children, Seniors and Social Development,
Community Healthy Living Fund - \$10,000*

United Way Newfoundland and Labrador - \$10,000

Ron Cadigan Foundation - \$4,000

Kittiwake Dance Theatre - \$1,350

Western Health Coalition - \$500

This financial support, along with our other fund-raising efforts, allows us to keep the exercise programs free for members and care-givers. They are really great classes – get out there and join one of them!

Speaking of fund-raising, ***Shake, Rattle and Stroll*** will be held on Sunday, September 22nd this year. As in previous years, we would like to have walks in as many locations as possible this year – not only to raise funds, but also to raise awareness about Parkinson's disease.

Holding a walk is fun and easy! You can make it as big or as small as you want. If you are interested in hosting one, just give me a call and we can chat about it.

The sponsorship forms for ***Shake, Rattle and Stroll*** are inside. As you see your friends and family over the summer, have the form handy and don't be shy about asking them for a donation. We also have a new online platform this year. It is very easy to set-up your own donation link. That way friends and family who are living away can easily make donations to you. Details on how to set it up can be found inside on Page 11.

You may have noticed that we have been experimenting with broadcasting some of our events live on Facebook. It has proven to be very successful so far. If you go to our Facebook page (@ParkinsonSocietyNL) you can still view the videos of these events. For example, our recent AGM and Meta Sellars Lecture are there. Our plan is to do more of this, including broadcasting some of our exercise classes. That way you will be able to join in from the comfort and convenience of your own home. If you are interested in being advised of our live events – send me an email and I'll add you to our invite list for them.

As you go through the Prattle, you will see the Facebook icon at the end of some of the articles. This means that there is video on our Facebook page that relates to that story.



Finally, I want to wish "Good Luck" to Charlotte Fowlow. Charlotte has been our summer intern for the last two years, but she has been involved with us as a volunteer for much longer than that. This fall, she is going to the University of Toronto to start a degree in Occupational Therapy. Charlotte, on behalf of everyone at PSQL, thank you so much for your caring and outstanding service to our members. We look forward to working with you again when you come home!

Have a great summer everyone! If you ever need me for anything, just call or email – I am here for you.

Derek

**5th Annual
Shake, Rattle and Roll Gala for Parkinson's**
**This year's event raised over \$60,000 to
support our programs and services.**



Photos by John Evoy Photography

**Thank you to everyone who donated
prizes and desserts for the event.**

Going On.....

PSNL AGM

Parkinson Society NL held our Annual General Meeting (AGM) on Saturday, June 8. PSNL Chairperson Danielle Somerton along with members of the Executive and representatives from the Chapters spoke to the audience about their activities during 2018. It was another great year for the Society with the expansion of our exercise programs.



PSNL Chairperson, Danielle Somerton, addresses members at the 2019 AGM.

A special part of this year's AGM was the presentation of the Anne Rutherford Memorial Awards.

This Award serves as a memorial to Anne, one of the founding members of Parkinson Society Newfoundland and Labrador. The recipients of this award epitomize Anne's determination in promoting an awareness of Parkinson's and her dedication to improving the lives of people with Parkinson's and their families.

This year's very worthy recipients are:

Wayne Dawe and Marion Counsel – St. John's

Dave and Mona Lee – St. John's

Dave Wells and Joan Sheppard-Wells – St. John's

Robert and Carolyn Emberley – St. John's

Patricia and Dennis Brothers – Grand Falls-Windsor

All of these folks have been long time members of PSNL and have selflessly given a tremendous amount of their time and energy to help others who are on the Parkinson's journey.



Dave & Mona Lee, Marion Counsel & Wayne Dawe, and Joan Sheppard-Wells & David Wells accept their Anne Rutherford Memorial Awards. Missing are Robert & Carolyn Emberley and Patricia & Dennis Brothers.

PSNL would like to thank and congratulate these members and for their overwhelming commitment and support.

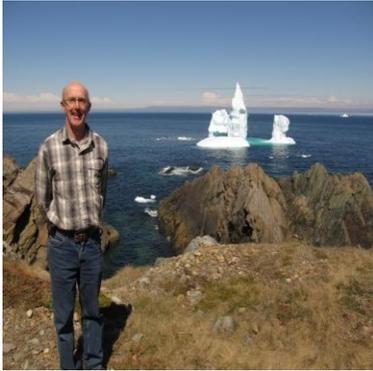
As a lasting tribute to Anne and all of the Award Winners throughout the years, a Memorial Bench will be installed in Bowring Park to recognize their contributions to PSNL. 

PSNL Donates \$10,000 to MUN to support Parkinson's Research

As part of PSNL's continued commitment to fund high quality PD research, the Society made a \$10,000 research contribution to Dr. Brian Staveley at Memorial University's Department of Biology. Dr. Staveley is researching the genetic elements of PD and delivered the annual Meta Sellars Lecture about his research at our recent AGM. 



PSNL Vice-Chair, Jane Macdonald, and Executive Director Derek Staubitzer present Dr. Brian Staveley and his research team a cheque for \$10,000 to support PD research.



Ole Geezer: Informative Parkinson's Humour

By Robert Emberley

Just a Glow-Worm

I have read a bit about Sir Winston Churchill over the years, and it turns out that he and I have something in common. He was an average humble guy who felt that life had put him in a strange place. He accepted his given role and played his part in saving the world from tyranny. He put it into context with this statement: "We are all worms, but I believe that I am a glow-worm".

My glow-worm role is to convince all of you that exercise is good for you!

Our granddaughter was just born in Lethbridge Alberta. My wife laid down the law, "We were going to Lethbridge for three weeks!" Now I love my wife, daughter and grandchildren, but I feared that Lethbridge had no support for anyone my age with Parkinson's.

Over the previous four years while visiting, I had gone down to their local Parkinson's office only to find that there was nothing going on at the moment. I am used to Parkinson's activities five or six times per week!

I was desperate and went on a "Google hunt". I found a link to the University of Lethbridge. A Dr. Jon Doan was doing research on Parkinson's and exercise. I sent him a note telling him of my many exercise activities, and asked him if he could use a test subject for the next three weeks. I could not believe it when Dr. Doan replied and then invited me to come along to their Parkinson's boxing group, who meet three times each week! Yahoo! I was excited and couldn't wait to get there.

The group there is typical to our class: same range of ages and abilities, a friendly boxing coach and great professional helpers from their School of Kinesiology.

Though it is called a "boxing group" there are aspects of other exercise disciplines. I saw some yoga, pilates, dance, voice, and the social side of it was great. I was welcomed with open arms and they even waived the entrance fee for me. They were VERY excited when they found out that our exercise programs were all free for our members and caregivers!



Jon, Chris, Hank, Lele, Robin, Dennis and the rest of the Lethbridge group, I want to thank you from the bottom of my heart for your friendship.

I guess my role in life this past month was to be the one to connect the dots between our groups. Dr. Doan, thank you so much! If you ever need a few subjects for your research, down here we have Jim, Thelma, Dave, Dianne, Brooks, Keith, Jane, Fred and a bunch of other "glow-worms" who would love to help you out.

Robert

Robert sent a draft of his article out to Dr. Doan and this was his response.

No 'Old Geezer' sighted in Alberta!

There are the young, and then there are the young at heart. When the Old Geezer first contacted me about opportunities for people living with Parkinson's disease in Lethbridge Alberta, I knew I was dealing with the second case – that initial message was full of vitality, a spark I knew was representative of a real exercise advocate that I had to meet.

Why? Because I take research ideas and encouragement and energy from people who are excited about exercise as management for PD. I always have. My experience is that the people living with PD have great ideas and examples of activities that really work for them, and probably for others – therapists and researchers just need to find ways to make them sustainable and enjoyable. Those same people living with PD also have a genuine desire to participate in making things better. The Old Geezer has all that, in spades and so much so that he was quickly dubbed the 'Young at Heart' Geezer during our fun exercise mornings together. Can't wait for your next visit.

Dr. Jon Doan

Nice Connection Robert! We have asked Dr. Doan to write an article about his research for a future Prattle.

St. John's Paddy's Day Party

Members attending the St. John's Chapter Paddy's Day Party were treated to a very special presentation of Marion Counsel's *Red Island - Resettlement Girl* show.



Based on her early years living on Red Island in Placentia Bay, Marion and her friends, Helen Murphy and Barbara O'Keefe, have been performing the show to sold-out audiences throughout the province for over a year now. 



Research has shown that dancing can be very beneficial for people living with Parkinson's. Charlotte showed the energetic group some of the dance exercises that they can try at home to improve their balance and keep themselves strong and flexible.



Charlotte was also the coordinator of Canada's National Ballet School's *Sharing Dance Day* in St. John's this year. This annual event encourages people from all walks of life to enjoy an afternoon of dancing in a public location. Each year there is a new choreography that participants learn to perform. Charlotte taught the piece to members of our Dancing for Life with PD class along with some residents of St. Patrick's Mercy Home. 



Marion also made and donated this beautiful hooked rug which we will display on our speaker podiums at PSNL events.

Dance Comes to the Gander Exercise Class

Our exercise class in Gander had a visit from Charlotte Fowlow, one of our Dancing for Life with PD instructors.



This year's Sharing Dance Day was held at the St. John's Community Market on July 6th.

Personal Parkinson's Experiences

The Bucket List!

By Wayne Dawe

What is on your "Bucket List"?

Do you even have one?

Basically, I worked all of my life. When I wasn't working, I was (and remain) very involved in my community and my church, and I played sports and coached my son.

I followed the seasons: summer - I picked berries and went fishing; winter: I shoveled snow!

However, there was always an underlying "Bucket List" that was percolating.

For example....I would find myself thinking: "I would like to go to Ireland some day" but I had no definite plans!

I would watch the Tely Ten Road Race each year and I would say to myself that next year I would definitely be part of it.

I longed to go on a salmon fishing trip to a big river.

And, I always said I would like to do something really outside my comfort level like Zip-Lining.

The fact that I have Parkinson's must now be considered when I am making plans. The question I have pondered is even though I may be physically able to do something today, will Parkinson's prevent me from doing it in a month?? In a year??

If I don't do it now, will the progression of Parkinson's force me to cross that event off my Bucket List before I accomplish it? My Bucket List became my "Do It Now" list.

So - where am I with Parkinson and my "Bucket List"?

Well, I have been to Ireland for a two-week holiday.

I have completed The Tely Ten twice and lived to tell about it!

I have been on several fantastic salmon fishing trips. There is nothing like the thrill of catching a salmon, bringing it home and having a gorgeous salmon dinner with family and friends. Especially the bragging rights!

I have even been Zip-Lining in Petty Harbour and survived to celebrate at Chafe's Landing with a big feed of fish and chips!!

The fact that I accomplished these things since I have been diagnosed with Parkinson's gives me an even greater sense of accomplishment!



Wayne Zip-Lining in Petty Harbour in 2017

I like to follow the adage of "strike when the iron is hot!"

Or as my mother-in-law would say "lie down when you're dead!"

Parkinson's has changed my life, but it has made me live with a new realization and that is.... we only have today!

When I review my new "Bucket List", I must consider the "Parkinson's Factor" but it doesn't stop me.

There are no promises or guarantees in this world.

I encourage all of you to get out and work on your bucket list TODAY!

Wayne

Wayne lives in St. John's and is an active member of the Parkinson's Community. He may be reached at: (709) 722-2310 or email: wpd@bellaliant.net

Life Stories of our Members

On September 21, 1999, Joan Sheppard-Wells was caught in a massive earthquake while living in Taiwan. The earthquake killed 2,400 people and destroyed over 50,000 buildings. This is Part Four of Joan's incredible story of survival. In the previous segments, the earthquake had happened and Joan was trapped hanging upside down in her apartment building with a severe gash on left arm. A rescuer had spotted her in the darkness earlier but couldn't reach her. He had just returned with some extra help to try to get her out.

With the emerging daylight, I could see why the rescuer couldn't have gotten closer to me than he did a couple of hours earlier. There were large pieces of fallen concrete and bricks from the walls and ceiling and a bunch of heavy furniture between where I was and the windows.

The three rescuers did not appear to be professionals, but they worked very hard for the next hour and a half to dig me out of my sudden prison. Several walls had to be demolished so they could open a pathway to reach me. When they finally got close to me, there were still many pieces of furniture, bricks, and large pieces of concrete all around me that they had to carefully remove so that they could fully get me out.

I kept thinking and praying – “Ok, I have come this far, I am going to make it out of this soon.”

Just before the last bit of debris was being removed from around my feet, another fairly substantial tremor hit. By this time, I was so tired that I didn't panic. I was beyond that point.



But, panicked looks were very evident on the faces of my rescuers.

Just about then, in the silence that followed the after-shock, I thought I heard a faint tapping noise from below us. However, with all of the chaos that quickly ensued again and lack of language ability to tell the men what I thought I had heard, nothing was said. I still wonder if it had been someone else who was trapped and if that person was ever rescued.

Finally, I was free from the debris and the men moved me into a more upright position in our cramped quarters. A

rope was lowered through the windows, which was now the ceiling, and moved within my grasp. I was thinking that if I could just hold onto that rope it would help the rescuers get me out - but when I tried, I just had no strength left. Despite the gash in my arm and hanging upside for several hours, I still felt no pain. The men made a seat-like design with the



rope and sat me on it. One of the men took off his jacket and placed it under me like a cushion. They tied some more rope around me so that I wouldn't fall out.

They shouted up towards the opening and I slowly started to emerge from the building.

Very slowly I was moved up through an opening and out. Eventually, I could see that several excavators had been set-up as make-shift cranes to pull out people like me. Once out, I was carefully moved to a “cherry picker” hoist, where I was finally able to sit properly, yoga style, while I was lowered down. I had to be lifted off the hoist and placed on the ground because I had no feelings in my feet and ankles. A man from one of the Christian Churches in Taiwan who also lived in the building saw me and serenely said “You'll be all right now.”

As he said that, I look back over my shoulder and saw the devastation. My building was on its side and other buildings had fallen over onto it. Some of the lower floors had collapsed entirely. However, I still hadn't completely realized the full impact of the earthquake.

Someone appearing to be a journalist took my picture. Even though the sun was shining brightly as if to auger in some better times, I remember thinking, “I wonder if he wants me to smile?” because I couldn't.

While I was waiting for an ambulance, I spoke to someone and asked him to call my husband David in Canada to tell him that I was still alive. I had emailed David every day, at least once, and he would have certainly heard about the earthquake by now. I later found out that the man was a Buddhist Priest who had done exactly as I had asked him.

Some time later, an ambulance arrived, and I was lifted onto a stretcher. I was taken to a small hospital called the Tong Shih Farmer's Hospital. They had set-up a triage unit and I was put on the floor in the lobby along with hundreds of others. I was free and with other people but I felt very much alone and perhaps even more scared as the scope of what had happened became clear.

To be continued....

Sunday, September 22



It's time to start getting ready for *Shake, Rattle and Stroll 2019!*

A Sponsorship Form is included with this *Prattle*. If you need more, please contact the PSQL office and we'll send more out to you (you can also download it from our website). The sponsor sheets will work the same as previous years: get pledges, collect the money and bring the sheets and the money with you to your walk site. If you don't go to a walk, you can send the sheets and a cheque or money order for the money you have collected to our office – *please* do not send cash!

NEW ONLINE FUNDRAISING TOOL FOR YOU!

We have a much better online donation system this year. You can register as an individual walker or create a team. It is really easy. Just visit our website: WWW.NLPARKINSON.CA and once you are there, just click on the ***Shake, Rattle and Stroll*** logo. It will be right in the middle of the screen – you won't be able to miss it.

Once you click on that logo, you will be taken to our ***Shake, Rattle and Stroll*** online donation page. There you will see the easy instructions that will lead you through creating an individual or team account. Once you have created your account, send out the link to your friends and family and they will be able to donate to you from anywhere in the world.

We will have an email template for you to use to send out to your friends and family asking for donations. If you want it, just email our office (parkinson@nf.aibn.com) and we'll send it to you.

We will also have messages available for Facebook and other social media. Just ask us if you want them!

One other important point – do not direct people to "SuperWalk" if they want to contribute to you. Any funds donated to "SuperWalk" will not be contributed to PSQL. They will remain with Parkinson Canada.

If you have any questions at all – please call or email us.

Thanks so much for participating in ***Shake, Rattle and Stroll***.

Keep safe and have fun!!

Walter's Surfing for a Cure....

MS Medicine Copaxone May Have Benefits in Parkinson's Disease, Mouse Study Finds

A Treatment with Copaxone (glatiramer acetate), an FDA-approved medicine for multiple sclerosis, can restore motor function and biochemical markers in a mouse model of Parkinson's disease, according to a recent study.

The findings, "Glatiramer Acetate Reverses Motor Dysfunction and the Decrease in 9 Tyrosine Hydroxylase Levels in a Mouse Model of Parkinson's Disease," were published in Neuroscience.

"Glatiramer acetate (GA, also known as Copaxone), which is currently an FDA approved drug used in the treatment for multiple sclerosis, has been shown to directly dampen the pro-inflammatory response within the brain, in both mouse models of multiple sclerosis and Huntington's disease," the researchers wrote.



Scientists set out to examine the therapeutic potential of Copaxone, an immunomodulatory drug, in the treatment of Parkinson's disease.

In doing so, researchers used a mouse model of induced-Parkinson's disease, in which the disorder was triggered by treating animals with MPTP, a neurotoxin that induces brain inflammation, loss of dopaminergic neurons, and motor impairments, as seen in patients with the disorder. Treatment with Copaxone after the onset of the disease reversed gait (walking) and grip impairments in MPTP-treated mice.

Investigators believe this was due to the remarkable recovery in the levels of tyrosine hydroxylase (TH), one of the enzymes that is responsible for the production of dopamine in the striatum (a region of the brain involved in motor coordination) following treatment with Copaxone.

In addition, researchers found the number of TH-positive neurons in the substantia nigra increased slightly, albeit non-significantly, in animals treated with Copaxone, compared to those treated with a vehicle solution (control) after MPTP induction.

This was also associated with an increase in the levels of brain-derived neurotrophic factor (BDNF) — a protein whose main function is to protect dopaminergic neurons — and a decrease in the levels of IBA1, a marker of glial cells' over-activation caused by brain inflammation. Glial cells, also known as microglia, are nerve cells that support and protect neurons.

Moreover, the levels of non-phosphorylated alpha-synuclein (syn-1), a protein directly involved in Parkinson's disease, in the midbrain and striatum dropped significantly after MPTP induction and gradually recovered to normal levels after treatment with Copaxone. The midbrain is the region that connects the spinal cord to the brain, and plays key roles in motor movement and auditory and visual processing.

"In this study, we show that GA [Copaxone] treatment results in restoration of motor impairments and recovery of the nigrostriatal pathway, (...) while dampening the microglia response and restoring BDNF levels," the researchers wrote.

"Of note, this study also tested GA after the full regimen of MPTP had been completed, a time point at which there is no further loss of TH within the striatum or substantia nigra, showing that GA is a potential neurorestorative agent that has significant translational value for patients with Parkinson's disease. To our knowledge, we are the first to test GA in a true restoration animal model of PD, resulting in recovery of the nigrostriatal pathway, leading the way for repurposing of this FDA approved drug," they added

Source: <https://parkinsonsnewstoday.com/2019/06/25/copaxone-benefits-parkinsons-disease-study/>

Man-made DNA Molecules May Help Prevent Parkinson's

Osaka University scientists have built short fragments of DNA that can stop the production of abnormal alpha-synuclein protein in the brain — which may advance the development of new therapies for the control and prevention of Parkinson's disease.

The study, “Amido-bridged nucleic acid (AmNA)-modified antisense oligonucleotides targeting α -synuclein as a novel therapy for Parkinson's disease,” was published in *Scientific Reports*.

“While there are a few drugs that treat the symptoms associated with PD [Parkinson's disease], there is no fundamental treatment to control the onset and progression of the disease,” Takuya Uehara, PhD, the study's lead author, said in a press release.

It is believed that gene therapy could someday be used to treat or halt Parkinson's. Potential therapeutic targets include genes associated with the disorder, such as the SNCA gene — the gene that codes for the alpha-synuclein protein. Mutations in SNCA lead to the production and accumulation of an abnormal, and harmful, form of the alpha-synuclein protein within brain cells of people with Parkinson's. As the disease progresses, neuronal toxic protein buildup increases, eventually leading to cellular death. That, in turn, leads to the disease-related motor and non-motor symptoms.

“The antisense oligonucleotide (ASO) is a potential gene therapy for targeting the SNCA gene. ASO-based therapies have already been approved for neuromuscular diseases including spinal muscular atrophy (SMA) and Duchenne muscular dystrophy,” the researchers said.

Japanese researchers now looked for ways to prevent the production of toxic alpha-synuclein, hoping to eliminate Parkinson's molecular trigger. To do so, they designed 50 small fragments of DNA that mirrored parts of the coding sequence of the SNCA gene messenger RNA (mRNA).

All genetic information contained within genes (DNA) is ultimately translated into proteins. However, several complex steps exist before a protein can be

produced: DNA is first transformed into mRNA, and eventually, into a protein.



The man-made DNA fragments, also known as amido-bridged nucleic acid-modified antisense oligonucleotides (AmNA-ASO), were stabilized with resilient cyclic amide structures (hence the term “amido-bridged”). Amide are compounds that confer structural rigidity.

In total, these 50 molecules covered around 80.7% of SNCA's mRNA. In doing so, engineered molecules were able to bind to their matching natural mRNA sequence, disabling it from being translated into a protein.

Using human embryonic kidney cells that naturally produce alpha-synuclein, scientists observed that several of these engineered molecules reduced SNCA mRNA levels. One of the constructs, specifically number 19, significantly decreased SNCA mRNA levels to 24.5% of the normal alpha-synuclein levels, “suggesting that AmNA-ASO [number] 19 is highly potent for targeting SNCA mRNA in human cultured cells,” the researchers said.

Importantly, this particular ASO was efficiently delivered into the brains of mice using an intracerebroventricular (a fluid-filled interconnected brain cavity) injection, without the aid of additional chemical carriers. The ASO was then mainly taken up by neurons and neuronal support cells.

Further testing, using a Parkinson's mouse model that had disease-characteristic motor impairment, revealed AmNA-ASO number 19 successfully reduced alpha-synuclein protein levels, and significantly eased symptom severity 27 days after administration.

The researchers concluded that reducing alpha-synuclein mRNA and corresponding protein levels via gene therapy seems to enhance Parkinson's-related motor manifestations in mice. This highlighted AmNA-ASO's potential as a novel therapy for this neurodegenerative disorder.

Source: <https://parkinsonsnewstoday.com/2019/06/17/man-made-dna-molecules-may-help-prevent-parkinsons-study-finds/>

COMMUNITY EXERCISE PROGRAMS

Weekly Exercise Classes

St. John's

TUESDAYS at 2:00pm
Pony Locale Studio
120 LeMarchant Road

Bay Roberts

TUESDAYS at 1:00pm
ProActive Physiotherapy
261 Conception Bay Highway

Grand Falls-Windsor

TUES & THURS 10:30am
ProActive Physiotherapy
105 Lincoln Rd, Unit 6

Gander

TUESDAYS at 2:00pm
St. Martin's Parish Hall
2 Lindbergh Road

Clareville

Call PSNL for day/time
Power Conditioning
57 Thompson Street

Corner Brook

WEDNESDAYS at 2:00pm
Saltos Gymnastics
1 Canada Games Drive

These classes focus on building and maintaining core strength, balance and flexibility.

Some Classes may have changed times and locations for the summer months. Please call our office to check before going a class.

Yoga Therapy

WEDNESDAYS at 1:30pm

Yoga Kula Co-op, Coaker's Meadow Plaza, 286 Torbay Road
Yoga therapy relaxation class with gentle exercise movements.

Boxing to Beat Parkinson's

WEDNESDAYS at 10:30am

Rock Athletics, 236 Park Avenue

Specialized exercise program using boxing techniques.

Dancing for Life with Parkinson's

THURSDAYS at 2:00pm

St. John's Arts and Culture Centre

A fun and interactive afternoon of dance therapy.

No previous dance experience is required.

Intensive Exercise Class

FRIDAYS at 2:00pm

Pony Locale Studio, 120 LeMarchant Road

Using Pilates techniques, this class is intended for members who are able to complete more strenuous activities as well as floor exercises.

Parkinson's Walking/Running Club

SUNDAYS at 2:00pm

Memorial University Field House

Come join us for an hour of social walking or running.

All of our Exercise Programs are FREE for people living with Parkinson's and their care-partners. Classes are 45-60mins long.

For more information, please contact us at:

1-800-567-7020 parkinson@nf.aibn.com www.nlparkinson.ca

Parkinson's Exercise News

A new review published in the *Journal of Parkinson's Disease* reports that Exercise has the potential to improve cognitive function.

While traditionally Parkinson's disease (PD) was regarded as a movement disorder, it is now known to be a heterogeneous multisystem disorder -- in recognition of the significant impact that non-motor symptoms have on the quality of life of individuals affected by PD. It is widely acknowledged that physical exercise improves motor symptoms such as tremor, gait disturbances, and postural instability. However, the effect of exercise on non-motor symptoms in PD, especially cognitive function, is less clear.



PSNL Members warm-up at a recent exercise class.

A comprehensive literature review was conducted by investigators from the Institute of Movement and Neurosciences, German Sport University, Cologne, Germany, and the VasoActive Research Group, School of Health and Sport Sciences, University of the Sunshine Coast, Queensland, Australia. The studies reviewed included investigations of the effects of coordination exercise, resistance exercise, and aerobic exercise on domain-specific cognitive function in patients with PD. "Physical exercise is generally associated with increased cognitive function in older adults, but the effects in individuals suffering from PD are not known," explained lead investigator Tim Stuckenschneider, MA.

The researchers identified relevant studies published before March 2018. There were 11 studies included with a combined total of over five hundred patients with PD with a disease severity from stages 1 to 4 on the Hoehn

& Yahr scale, which is used to describe the symptom progression of PD. In four studies, positive effects of exercise on cognition (memory, executive function, and global cognitive function) were shown with no negative effect of exercise on any cognitive domain. Furthermore, disease severity was generally improved by exercise interventions.



Exercises like our dancing and boxing classes may be particularly good for delaying the cognitive impacts of Parkinson's disease as they involve both aerobic activity and executive brain functioning.

The investigators concluded that all modes of exercise are associated with improved cognitive function in individuals with PD. Aerobic exercise tended to improve memory best, but different forms of exercises such as treadmill training or stationary bike training may have different effects, although both are considered aerobic exercise. Future studies are needed that directly compare the effects of different exercise modes, as the number of high-quality research projects is still limited." The potential of exercise to improve motor and non-motor symptoms is promising and may help to decelerate disease progression in individuals affected by PD," observed Stuckenschneider. "Exercise therapy needs to be, and often already is, an essential part of therapy in individuals with PD. However, it is mostly used to treat motor symptoms.

As part of a holistic therapy, the potential of exercise to maintain or improve non-motor symptoms such as cognitive function in individuals with PD needs to be acknowledged, and the most effective treatment options need to be defined. This will not only help practitioners to recommend specific exercise programs, but also ultimately improve the quality of life of the individual. Our work shows that 'exercise is medicine' and should routinely be recommended for people with PD to help combat both the physical and cognitive challenges of the disease."

Source: <https://www.sciencedaily.com/releases/2019/03/19>

Beth Holloway

Continuing Education Bursary for Healthcare Providers

In 2018, we announced a new education bursary which recognizes and honours the tremendous contributions that Beth Holloway has made to the Parkinson's community in Newfoundland and Labrador.

Awarded annually, the Beth Holloway Continuing Education Bursary for Healthcare Providers is made available so that healthcare professionals can further their education and professional practice with the latest treatment options for people living with Parkinson's in our province.

The first recipient of this bursary was Kathryn Bautista.

Here is Kathryn's story of how she used the funding.

My interest in physiotherapy for people living with Parkinson's disease began while attending physiotherapy school at the University of Toronto. Two clinicians from One Step Ahead Mobility, a clinic in Toronto that is well known for treating people with Parkinson's disease, did an afternoon workshop with our class. Contrary to other approaches we had been exposed to, which focused mainly on compensating for impairments, these clinicians focused on improvements in mobility through high intensity, repetitious practice. I became so intrigued that I signed up for their course in Rehabilitation in Parkinson's disease upon graduating. It was here that I first learned about the LSVT BIG Course and I had wanted to do the course ever since. With the generous support of Parkinson Society NL through the Beth Holloway Continuing Education Bursary, I have been able to further my education in treating patients with Parkinson's disease by travelling to New York last December to become certified in the LSVT BIG Treatment.

LSVT BIG is an exercise-based treatment delivered by a physiotherapist or occupational therapist to treat people living with Parkinson's disease or other Parkinsonian Disorders. It uses high intensity, high effort

exercise to promote changes in the brain to improve movement, and to override the hypokinesia (decreased movement) and bradykinesia (slow movement) that is associated with Parkinson's disease. The treatment is delivered over a four-week period, with four one-hour sessions a week. Though standardized in approach, the program is adapted to each individual's goals and abilities; the participant chooses activities or tasks that are meaningful to them to work on during the four weeks.



The main focus of the LSVT approach is making movements bigger. In people with Parkinson's disease, there is a difference in how an individual feels they are moving, and what the movement actually looks like. For example, a family member may notice that their loved

one is shuffling more when they walk, but the loved one may feel as if they are walking quite normally. By focusing on making bigger movements, the participant learns how much effort is needed to make normal sized movements during the program, and in their daily lives. Additionally, research has shown that when treatment focuses on big movements, other variables such as balance, speed, and reaction time also improve.

Being a certified LSVT Clinician has enhanced my ability to assess and treat people with Parkinson's disease, whether they are doing the LSVT BIG Program or not. It has been a rewarding and eye-opening experience to see the difference that physiotherapy can make to the quality of life of my patients living with Parkinson's disease; the treatment sessions tend to leave us both sweating and smiling. I am very grateful for the opportunities Parkinson Society NL has given me to further my education and enhance my practice, and I look forward to continuing to apply the techniques and strategies I have learned as I continue to build my practice at Wedgewood Physiotherapy.

Nutrition Corner

DAIRY-FREE SEAFOOD CHOWDER

With a smooth and creamy cashew base, this Dairy-Free Seafood Chowder is sure to satisfy your seafood chowder craving! It has chunks of potatoes, carrots and celery, along with a generous amount of scallops, salmon and shrimp, which all sit in a thick and savoury broth. One bowl makes a filling meal!

INGREDIENTS

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| 1 cup raw cashews | 4 fresh bay leaves (or 8 dried bay leaves) |
| 1 cup hot water | 1 tablespoon fresh thyme (or 1 teaspoon dried thyme) |
| 2 tablespoons extra virgin olive oil, divided | 1/2 + 1/4 teaspoon kosher salt, divided |
| 3 cloves garlic, minced or chopped | 1/4 + 1/8 teaspoon ground black pepper, divided |
| 1 medium-sized onion, chopped | 2 cups chopped/cubed salmon, uncooked |
| 2 cups chopped carrot | 2 cups shrimp, uncooked, peeled, deveined and tails removed |
| 1 cup chopped celery | 1 cup scallops, uncooked |
| 1–1/2 cups baby potatoes, halved | 1/4 teaspoon smoked paprika |
| 4 cups no-salt added chicken broth | 1/4 teaspoon garlic powder |

INSTRUCTIONS

1. In a glass jar or dish, add the cashews and hot water. Cover and let soak for 30 minutes. (Use this time to prep the other ingredients).
2. In a medium-sized pot or dutch oven, heat up one tablespoon of oil on medium-heat and add the garlic and onion. Reduce heat and sauté on low for 8-10 minutes. Add the carrots and celery and sauté for 5 minutes. Lastly, add the potatoes and sauté for another 5 minutes. During this process, stir the veggies frequently so they don't burn onto the bottom of the pot.
3. Add the broth, bay leaves, thyme, 1/2 teaspoon salt and 1/4 teaspoon pepper and stir to combine. Cover and bring to a boil. Reduce heat and let veggies cook for 10 minutes.
4. While the veggies are cooking, prepare the seafood. In a frying pan or cast iron skillet, heat up the remaining tablespoon of oil on medium-heat. Add in the salmon, shrimp and scallops and sprinkle on the smoked paprika, garlic powder and remaining salt and pepper. Reduce heat to low and cook for about 15 minutes, or until the seafood is cooked through.
5. While the seafood is cooking, add the cashews and water to a blender, and blend on high until smooth and creamy.
6. Once the veggies have cooked for 10 minutes, pour the cashew cream into the pot and stir until combined. Add in the cooked seafood and stir to combine. Cover and let simmer for 5 minutes.
7. Remove the bay leaves and serve immediately, or store in an airtight glass dish in the fridge and enjoy within 3 days.

Notes:

This recipe calls for no-salt added chicken broth. If you use regular or reduced-sodium broth, consider reducing the amount of salt you add to the recipe.



Recipes for the Nutrition Corner are provided compliments of www.crumbtopbaking.com

This locally based website offers healthy recipes for Clean Eats and Decadent Treats.

Please visit their website to see more great recipe ideas and amazing photos of the treats.



Beth's Five Bucks Worth

By Beth Holloway

PRIDE in the Name of Love

Big Deal. I'm a lesbian, or gay, or however you wish to identify me in these gay-friendlier times.

The bottom line is that I was born in a small town in rural Newfoundland just after the war. A very religious small town too. While all things relating to sex were changing fast around the world thanks to characters like Elvis, Marilyn and Twiggy, things were not changing at all in my home town for people like me. A teenager in small town NL in the 1960's never revealed their sexuality to anyone. No one! Not a soul! It would be social suicide. I learned that lesson the hard way. I mistakenly made my feelings known to one girl. She didn't handle it very well. She got so angry she almost outed me to the whole school. Maybe she did. I never had enough close friends who would report the content of the recess-time chatter to me. It hurt. It hurt big time. So it was into a closet for many years for me.

These were unhappy times. I was being bullied before I really knew what "bullying" was. People would call me a "Tomboy" as a common expression of "she's not like other girls who wear fancy dresses and go for rides in cars with boys." Lesbian wasn't a word that was used – I was a Lizzy or a Dyke. I was isolated and pretty much alone, suffering the negative looks and eye-rolling from the community elders every day.

Eventually, after moving away and starting my career as a teacher, the social barriers started to come down and I was able to emerge as a strong, independent gay woman. It was liberating and exhilarating. As a teacher, I even got to teach religious studies and sex education. Wasn't that ironic? I was there to help the students who needed the reassurances that weren't there for me when I needed them. I was making a difference in their lives.

Then, after 20 years of teaching, this idiotic disease Parkinson's comes along. It was a game-changer. In a matter of just a few years, my career was over and eventually a seven-year marriage also ended. I was much more emotionally stronger now though and kept going, determined not to go back to the dark places where I had been as a teenager.

A couple of years ago, I was faced with a big decision. A long-term care room at Pleasant View Towers was beckoning to me. Apart from the obvious concerns about that decision, I was very concerned about how a gay woman would be received in there. I remembered reading about a gay couple who had decided to move back to Toronto because they felt they would receive more understanding long-term care up-along.

That event, I learned later, spurred Eastern Health into tackling the long-term care concerns of the LGBTQ+ community and a working group was formed to explore diversity. A lot was accomplished in a short period of time and in 2015 Pleasant View Towers became the first long-term care facility in Newfoundland and Labrador to fly the PRIDE flag. After hearing about that from a friend, I felt much more comfortable about making this place my home.



When I moved in, I got active on an LGBTQ+ Committee right away. We plan the PRIDE week celebrations and we discuss issues relating to LGBTQ+ resources and rights in long term care facilities.

Our opinions and feelings are heard and acted on. I can't speak for all long-term homes around the province, but the management and staff at Pleasant View Towers have made major inroads into developing a welcoming culture of diversity and inclusion. For that, I want to thank them.

I might still end up in a closet from time-to-time now, but it is usually because of a wrong turn in a hallway and my scooter wheels getting stuck on the door frame. Yes...that does really happen!

In Memoriam

Donations to our Society have been gratefully received in memory of:

Elizabeth Warren	Harry Whitten
Stan Puddister	Suzanne Maynard
Ethel Fuller	Morgan Colbourne
Marion Green	Norma Scott
Gerri Dickenson	Margaret Tucker
Bea Howse	Bill Rees
Tom MacDonald	Donald Brake
Joshua Brushett	Pearl Wiseman
Robert McCarthy	Marjorie Hiscock
Walter Spurrell	Audrey Spurrell
Justin Blundon	Thomas Dandeno

PSNL extends our sincerest condolences to the families and friends of those loved ones honoured here.

Caring for the Care-Giver

Here are a few helpful suggestions to keep yourself strong as you support your loved one on the Parkinson's journey.

Take time for yourself. Make sure you have time to relax. If necessary, enlist the help of other family members or even hire someone to assist you in providing care.

Learn as much as you can about your loved one's disease. That way you'll understand what changes to expect in your loved one's behavior or symptoms and how you can best help when those changes occur.

Let your loved one participate. Don't try to do everything for your loved one. Allow him or her the time to complete daily activities on his or her own, such as dressing.

Set realistic goals for yourself and your loved one. Don't attempt to do everything. By setting attainable goals, you are setting everyone up for success rather than disappointment.

Do not put your life on hold. Continue to meet with friends, participate in hobbies or groups, and maintain a schedule as normal as possible. You will not only feel more energized, you will be less likely to feel resentful.

Have someone you can talk to. You are there to listen to and support your loved one, but you also need a support person. Talk openly and honestly with a friend or family member. If that's not possible, join a support group. Understanding that you are not alone and that someone else is in a similar situation helps you to feel nurtured.

We Appreciate your Financial Support!

There is a mantra that charities often use:
No Money, No Mission,
No Mission, No Money.

The reality is that we need to fundraise to continue to meet our mandate of helping people living with Parkinson's in Newfoundland and Labrador.

About 90% of our budget comes from donations and special events.

We appreciate the financial support we receive from you, our members, and your families and friends.

We run a very tight financial ship here at Parkinson Society Newfoundland and Labrador.

Your Board has given very clear direction that every dollar must be mission-focused on supporting our members in some way.

That is our commitment to you!

There are many ways to support us:

Honour Donations—to recognize someone who is living with Parkinson's or someone who has contributed to helping the Parkinson's community.

In Memoriam Donations—to honour the memory of someone who lived with Parkinson's.

Monthly Donor—we can process a monthly charge to your credit card.

Support our Events—Get your friends together and come to our events!

Please visit www.nlparkinson.ca to donate

All donations are eligible for a tax receipt.

Thank you!

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Sunday, September 22

Visit www.nlparkinson.ca to register

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PENNECON

