

Parkinson Society Newfoundland & Labrador

the prattle

Summer 2020



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Shake, Rattle and Stroll 2020
COVID-19 and Parkinson's
New Parkinson's Research

Mark your 2020 Calendars

Sunday, September 20



Keep safe this year and have your own personal walk. It is easy and fun!

Do you still want to receive the Prattle?

For every edition of the Prattle, we mail out about 350 copies at cost of over \$2.00 in postage per copy.

It is possible that you are receiving a copy even though you no longer have a close connection to our Society.

If you enjoy reading it, we are very happy to keep sending you one. BUT - if it is just adding to the paper clutter in your house, please let us know and we will remove you from the mailing list.

Just call 1-800- 567-7020 or email parkinson@nf.aibn.com

If you would prefer to read it online, we also post digital versions of the current Prattles on our website: www.nlparkinson.ca

Membership Fees

Membership in Parkinson Society Newfoundland and Labrador is only \$5/year.

Membership entitles you and your care partner to attend all of our events and therapy classes free of charge.

You will also receive a copy of The Prattle.

Our Chapters may charge additional fees for some activities such as social events to recover costs associated with meals, room rentals, and entertainment.

To join our Society, please contact our office.

Cover Art: This month's cover is courtesy of Janet Knight-Grace. Janet always wanted to learn to paint and during her Covid isolation she decided it was a good time to start. After I saw several of her beautiful pieces online, I asked her if she would like to paint some tulips for us. She agreed and presented us with this wonderful original work. Congratulations Janet and thank you for supporting PSNL.

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.

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Executive Director: Derek Staubitzer

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Chairperson's Message

Dear Members –

2020 has been a Really! Tough! Year! And we've still got a ways to go. I know, from how challenging it has been for me personally, that it must have been a struggle for many of our members. I have no health or mobility issues and could fairly easily adapt to the "New Normal" of online work and social distancing that was required. Yet, I am still feeling completely rendered from the first seven months of this year. Your determination and strength always amazes and humbles me.

Without minimizing all of our valid and legitimate problems, I hereby encourage us all to channel the strength and resiliency of our beautiful province and "keep on keepin' on". I am trying (not always succeeding, but definitely trying) to focus on the positive. While others in the world are quarantined on Floor 29 of a highrise building in a large city somewhere, we are socially distanced amidst forests, rivers and the always refreshing Atlantic. While some places have seen increasing numbers of COVID deaths, we have flattened the curve and used the time to reunite with our loved ones.

We weren't able to have our AGM this year. It would have been where I thanked you for everything that you do to support the Society. When we need our members to rally for the Society, you do it without hesitation. You'll bake a cake, make a quilt, volunteer to sell tickets, or squeeze out a long list of donors for Shake Rattle and Stroll. Thank you for doing all of this so that we can help everyone who is living with Parkinson's in Newfoundland and Labrador.

Derek and the Board are working hard to take care of the Society and any members who may need some extra help during this difficult time. You just need to make sure that you can focus on taking care of yourself right now. If you need any help doing that – just let us know.

I encourage you to try our online therapy classes. Mindfully do something positive for your mental health. And when it's needed, grab a chocolate bar, throw on a sappy movie, and have a good cry (or is that just me?).

Take good care of yourselves.

Danielle

Executive Director's Message

Hi Everyone –

When I was writing the last Prattle, we had just emerged from "Snowmageddon". We were thinking "Ok...we got through that, the rest of the year should be a breeze." Who knew that we would be facing the largest global pandemic in over 100 years only a few weeks later. Overall, we have to be very thankful for our current situation. Thanks to sensible leadership decisions that relied on science and evidence and a public that accepted the burdens presented by the virus, our province is world-leader in combating COVID. We can only hope it stays that way!!

Things have changed so much in such a short time. It is like a huge "reset" button was pushed. Things that were a big deal only few months ago suddenly became insignificant. Who ever thought tax deadlines could be changed so easily? We are certainly witnessing history in a way few of us had ever imagined.

Through it all, your Society remained stable and open for business, albeit in a slightly modified format. I was working from home for several weeks when our building closed down and we had to move our therapy classes online on Facebook. These are fantastic classes – and you should be participating in them. Thanks to Renee, Sarah (and Mike), Hilary and Charlotte for making classes so much fun and beneficial for our members.

Given the situation, we really don't see it being safe to hold community walks for Shake, Rattle and Stroll in September. Therefore, this year, we would like everyone to undertake their own personal walk. It could be around your block, in your backyard, on a trail near your house or anywhere else that is special to you. You can even include your "bubble buddies" if you want. Just do it safely.

You can set-up your own personal online donation page from our website www.nlparkinson.ca. Instructions on how to do it are on Page 5. *It is very easy!* Then you can just send people the link to your page and you don't have to worry about meeting people or collecting money. It is the best and safest way for you to get donations this year. If you need any help – I am only a phone call or email away. With our Gala being canceled this year, we could really use your help to raise funds at Shake, Rattle and Stroll.

Keep safe everyone.

Derek

Sunday, September 20



It's time to start getting ready for *Shake, Rattle and Stroll* 2020!

A Sponsorship Form is included with this *Prattle*. If you need more forms, please contact the PSNL office and we'll send more out to you (you can also download it from our website).

Given the COVID situation, there will not be any community walks this year. So be creative and do your own personal walk. Walk in a special place that means something to you and tell everyone about it.

Once you have collected your pledges, 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!

ONLINE FUNDRAISING SITE IS BACK!

Our easy to use online donation system is ready and waiting for you.

ONLINE IS THE SAFEST AND BEST WAY TO GET SPONSORS THIS YEAR!

Just visit our website: WWW.NLPARKINSON.CA and once you are there, just click on the *Shake, Rattle and Stroll* logo. It will be in the middle of the banner along the top 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 and they will get their tax receipt immediately.

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 PSNL. 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!**

Going On.....

Pop-up Tulip Sale

For the past few years we have grown our own tulips to decorate the annual *Shake, Rattle and Roll Gala for Parkinson's*. With our Gala being canceled this year due to COVID, we needed a creative idea for all of the unused tulips.

When they bloomed in early June, we decided to have a "Pop-up Tulip Sale" to generate some donations.



For a donation of \$25 donors received a beautiful vase full of tulips. We sold them all and raised \$1000 for our programs and services.

PSNL Contributes \$10,000 to Develop a Parkinson's Registry

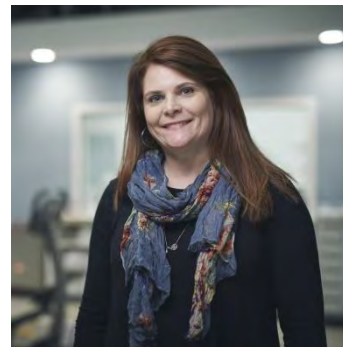
As part of PSNL's continued commitment to fund high quality Parkinson's disease research, we are making a \$10,000 contribution to a team from Memorial University to develop a Newfoundland and Labrador Parkinson's Disease Patient Registry. A disease registry is a database of people who share a specific condition

and having one will help increase research activity locally for the benefit of all people in our Province who are impacted by Parkinson's. One of the first planned uses of this registry will be to recruit participants for a clinical investigation of the impact of dietary supplementation on the progression of Parkinson's.

Dr. Kyna Squarey is an avid supporter of the registry's development. "A Parkinson's registry in Newfoundland and Labrador would be an extremely useful and important tool for clinical practice and research. There are countless applications and purposes for a registry, such as observing the course of disease; understanding variations in treatments and outcomes; examining care patterns including the appropriateness of care and any disparities in its delivery; and, to examine factors that influence prognosis and quality of life, to name just a few," she says.

Stay tuned for more information about this highly important project and how you can be part of it.

Beth Holloway Bursary Supports Speech Therapist Training



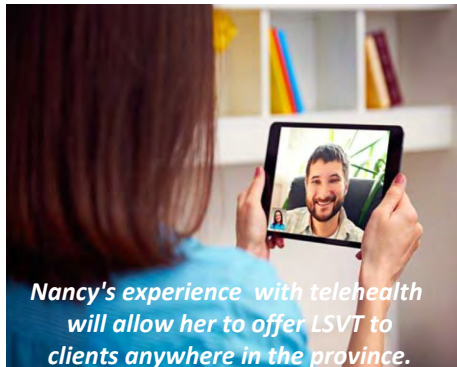
We are very pleased to announce that Nancy Shortall-Cura is the 2020 recipient of the *Beth Holloway Continuing Education Bursary for Healthcare Providers*.

With the help of this \$1,000 bursary, Nancy studied and received her certification in the research-based treatment protocol called the Lee Silverman Voice Treatment (LSVT Loud). This is considered the "Gold Standard" voice treatment for people with Parkinson's disease. LSVT Loud is an intensive and effective program that trains people with Parkinson's disease, who tend to speak at a very soft volume, to use and maintain a more normal loudness level.

In order to achieve the best results, it is recommended that LSVT treatment begin early. More details on LSVT can be found at: <https://www.lsvtglobal.com/LSVTloud>

Nancy is a graduate of Ohio University and holds a Master's Degree in Hearing and Speech Sciences. She is a licensed Speech-Language Pathologist with 27 years of experience working in the areas of medical & educational Speech-Language Pathology in both clinical and managerial roles. Over the past 27 years, Nancy has had the privilege of living in Venezuela, Argentina, and the USA and has provided speech and language services in those countries. In addition, she has taught English as a Second Language and Accent Reduction for second language learners of English. She has even picked up Spanish along the way!

She is now happily settled back in Newfoundland and is offering speech therapy services at the NL Balance & Dizziness Centre for patients with speech, language, and swallowing disorders including the LSVT Program.



Nancy's experience with telehealth will allow her to offer LSVT to clients anywhere in the province.

Nancy is accepting patients in the clinic and via telehealth for members anywhere in the province. She can be reached at 709-700-1474.

Wedding Celebration Raises Donations for Charities

When Michael Dawe and his wife Shaneen got married last summer, they wanted to do something special for two charities that were near and dear to them.

Michael's dad, Wayne, has been living with Parkinson's for many years and Shaneen's mom sadly passed away from Ovarian cancer a few years ago.



So, to get the bride and groom to kiss at the reception, guests were asked to make donations to PSNL and the Ovarian Cancer Society. As a result, Michael and Shaneen were able to donate \$800 to each charity. PSNL would like to thank Michael and Shaneen for this very generous gesture.

100% of donations like these go directly to our programs and services. If you know someone who is having a celebration of any kind, mention this idea to them. It is a very nice way for the celebrants to help out the charities that mean something to them.

PSNL Therapy Classes Move Online During COVID



When we were forced to suspend our world-class therapy classes in early March due to the COVID pandemic, we didn't want our members to miss out on all of the benefits of the classes. Thanks to the financial support of United Way Newfoundland and Labrador

and with the tremendous support of our class leaders, we were able to move our classes online using Facebook. We are currently offering exercise, dance and music therapy classes and we are hoping to add more. To join these classes, just visit our Facebook page at <https://www.facebook.com/ParkinsonSocietyNL>.

COVID-19 and Parkinson's

The last few months have been very challenging for everyone and unfortunately these challenges will most likely continue for the foreseeable future.

Managing your Parkinson's journey while worrying about the current pandemic can be increasingly stressful for you and your family.

While there are still more questions than answers, here are some basic questions and answers about navigating the COVID-19 pandemic while living with Parkinson's.

Is a person living with Parkinson's at a higher risk of contracting the virus?

No. People with Parkinson's do not have a higher risk of contracting the virus. However, people with Parkinson's may have a more severe reaction to the virus. This means that people living with Parkinson's may have a more challenging recovery if they get the disease. It is very important to try to avoid getting it.

How can I protect myself from getting the virus?

There are several things you can do to protect yourself.

Stay at home as much as you can. Wear a mask when you do go out and avoid unnecessary exposure to large crowds. Use the designated hours that some retailers have established for people with special needs and practice social distancing. This means you need to stay at least 6 feet away from other people.

Practice good hand washing technique. This means you should wash your hands with soap and warm water for at least 20 seconds by rubbing your palms together, tips of your fingers, including your thumbs, and the back of your hands. A good rule is to sing the happy birthday song twice.

Use hand sanitizer with at least 60% alcohol if soap and water are not available.

Eat healthy foods that strengthen your immune system, such as colourful fruits and vegetables.

Exercise to keep strong and get regular rest and good sleep.



What do I do if I or someone who lives with me develops symptoms of COVID-19?

If you or someone who lives with you develops symptoms such as fever, cough, and/or shortness of breath, isolate yourself immediately. If you live with other people, stay in one area of your house that is separate from the rest of the people in your household. If possible, have a designated bathroom for yourself. Separate your eating utensils.

Call your healthcare provider so they can determine if you need to be tested for the virus or not. Do not just show up in your doctor's office without notification. Your advance warning will help protect the members of the health team and other patients from the virus, and prepare in advance an isolation room for you. If your symptoms become more severe, such as increased shortness of breath, call the nearest emergency department.

Should I go to my doctor's appointments?

The short answer is YES. You should not allow your health to decline during this period by avoiding your medical care.

However, if you are going for a routine follow-up or prescription refill, it may be best to check if your health provider offers telephone services – most practices are. This is safer for you. Specialist appointments may require an office visit and will require that you take precautions such as wearing a mask. A telephone conversation with your specialist may determine if an office visit is really necessary.

Do not ignore changes in your health because of this situation!!

What medications can I take if I develop symptoms of cough or fever?

If you develop signs and symptoms of cough and/or fever, you can take over-the-counter medications such as Tylenol.

Take no more than 3000 mg of Tylenol (six extra-strength tablets) per 24 hours. However, if you have any liver disease, make sure you take no more than 2000 mg (four extra-strength tablets) per 24 hours.

If you are taking any MAO-B inhibitors for Parkinson's such as Azilect (rasagiline), Eldepryl (selegiline), or Xadago (safinamide), avoid medications with "DM" on the label (dextromethorphan) which is commonly given with cough medications.

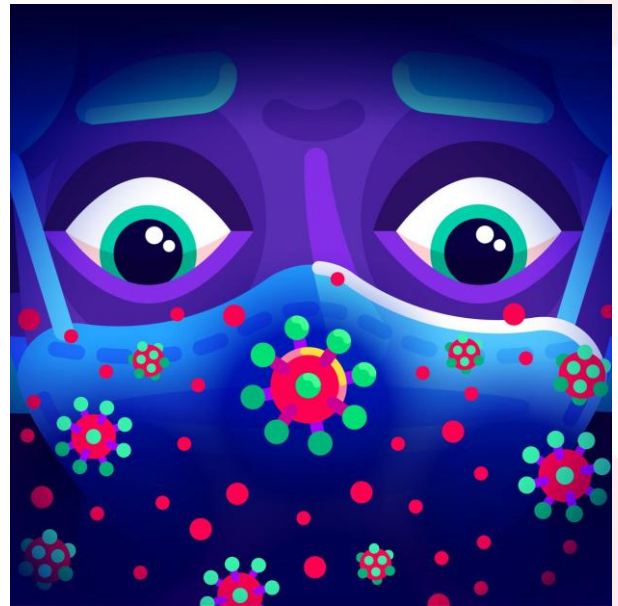
While there is still no definitive clinical research for avoiding Advil or Motrin (ibuprofen) at this time, some medical practitioners (supported by early research) are warning against taking it for COVID-19 symptoms as it may impact your immune response to the virus.



Can I still exercise?

You definitely should continue to exercise. PSNL is offering free exercise classes online on Facebook that you can do at home.

If you do not have any symptoms, you can walk outside, provided you maintain a social distance of at least 6 feet.



I am feeling anxious and isolated. What can I do to feel less nervous and socially isolated while maintaining safety?

First, it is perfectly okay for you to feel anxious under the circumstances. While there are so many things we cannot control right now, we do have things that we can. We can control our emotions and how we feel and react to situations. We can acknowledge our feelings and put in place systems that can potentially help us to overcome negative thoughts.

We can do this by writing in a journal, practicing meditation or calling family or friends. You can join online groups that you have similar interests with and share your ideas. You can join online support groups. You can write emails or actual letters to friends and loved ones or you can utilize FaceTime, Skype or any virtual apps to stay connected. You can check out things you are curious about and learn to do them. You can take online courses to learn new skills.

And, remember we are always here to help you!



Ole Geezer: Informative Parkinson's Humour

By: Robert Emberley

Up a Creek.....

A little while ago, I woke in the middle of the night with a sciatica type pain in my back and a terrible headache. I had been doing a lot of (Ok, I'll admit it - too many!!) balance exercises on my bike earlier in the day and I also forgot to have a nice drink of water before I went to bed to keep my brain hydrated during the night.

Unable to sleep, my mind wandered to an adventure that I could undertake.

I had always wanted to take my old canoe to an upper section of the Waterford River that I had never traveled. While the river really isn't too canoe friendly, I have been on parts of it before and I could see a section of it from Topsail Road that I had never explored. It looked fairly gentle and welcoming.

The decision was made. I was going to do it!



A few days later, I made it to a spot where I could park and unload my canoe close to the river. At the time of my trip, the volume of water where I was unloading was at an average of just two feet deep by about ten feet wide, flowing at a smooth but rapid pace. A little further up, the river widens into a meandering flood plain about an eighth of a mile wide. That was my goal.

I was hoping for a fairly easy ride up the river doing the "Canadian" solo-style paddle against the current. I slipped my old friend into the water and assumed the solo position.

Unfortunately, my old friend did not respond very well. The current was stronger than I suspected and a strong breeze played havoc with the raised bow. I expected the six foot reeds to baffle the wind but they didn't. Each turn in the meandering river became a real challenge.



Quite suddenly, the river changed and it was now a series of channels only a few feet wide and eight feet deep and rushing through the reeds. Trying to turn a seventeen by three foot canoe around a hairpin turn took everything I had in me. The wind would toss the bow in one direction and the current would take the keel in another. Then the hull would go aground on the mass of reeds. I had never been in these types of conditions before, but years of working with my canoe had taught me how to handle the unknown.

I would allow the current to take me back a few feet so that I could redirect the bow. With an explosion of paddling I would start to move forward, going from side to side to counter wind and current.



At another turn, even though the river was six feet deep, I had to grasp the six foot reeds on both sides to pull my grounded hull over surface weeds. Turn after turn I faced this. I didn't know the river, but I knew my canoe and how she would respond. I didn't realize that I had gone through an intense two hours of paddling until I reached a point where I could no longer go upstream due to the rocks and low water.



Turning around with a defiant smile of satisfaction, coming back down was a breeze with the wind and current at my back. As I looked down at the bottom of the river I could see that the reeds were twelve feet tall - six below and six above. If I had gotten really tangled in them on the way up - I would be calling for a water rescue and would have been on the evening news - "Old Geezer Gets Stuck Up A River!"



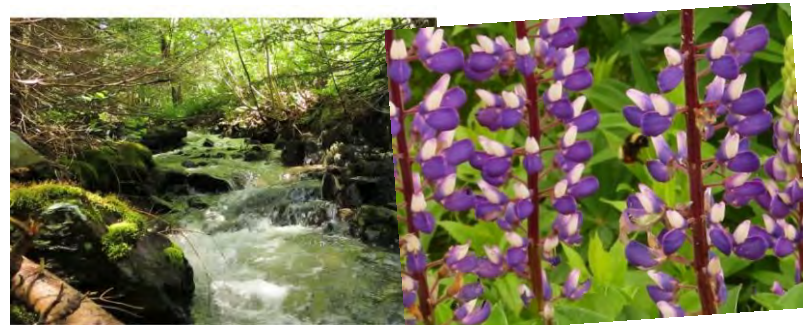
It took me thirty minutes to get back to the car. I was totally exhausted! I had to get help to load the canoe. It took me days to recover, but I survived and I am stronger because of it.

While this was my journey, you know it well too. I have lived with Parkinson's for many years now. It is a very challenging river. But my body is my canoe - I know it well and try my best to look after it. Exercise is key to keeping my muscles strong and my mind sharp. However, I don't know what's around the next corner in the river....my future. I am letting my past be my teacher. The reeds will not stop me without a fight. It may require a few steps backwards occasionally in order to fight forward, but I am very determined to go up this creek with my paddle firmly in my own hands.

Robert

During the COVID isolation, Robert spent a lot of time exploring in the woods near his house.

Here are some of his favorite pictures which he posted to a Facebook Group he helps to moderate called Parkinson's Place of Positivity and Peace.



Personal Parkinson's Experiences

COVID Chaos – but Fear Not!

By Wayne Dawe

“So, first of all, let me assert my firm belief that the only thing we have to fear is fear itself...”

These are the words of President F.D. Roosevelt during his inaugural address of 1933. This line has been quoted by many people ever since and it may mean a lot of things to a lot of people. Fear can be paralyzing for some people. In many cases it can make things worse, or it may motivate some people to work harder.

I was born in St John's and was one of four children. While going through the stages of childhood I had to be taken to the Janeway Hospital from time to time. I remember the fear welling up in me when I had to go to there. I always had a feeling that this was going to be the end of the line for me...lights out....no returning. Once when I had to go there, before I left, I remember hugging all of my siblings as if I would never see them again!

During my work life, I had to get a grip on my fears because sometimes I feared that I was not performing to the expectations of my supervisors. This fear prompted me to work harder and complete my tasks on time and on track.

I always believed that being a blood donor was a way I could give the gift of life to someone needing a transfusion. I knew I wanted to do it but the fear of the needle and having the nurse digging to try and find a good vein filled me with terror! However, I managed to talk myself into the fact that it would benefit someone else even if I had to pretend I was a tough guy! I have given blood for over 40 years now – but I admit it still fills me with a bit of fear every time!

In 2004 I was diagnosed with Parkinson's. This was the biggest health challenge I have ever had to face and to say it filled me with fear is an understatement. I feared the future, I feared for my family, my deterioration of

health and what was eventually coming down the road. As the weeks and months passed, I found the only way I could face this challenge and my fears was to surrender my life's ultimate journey over to God. Every day is a new challenge, but this strategy has helped me accept the hand I have been dealt.

Then along comes 2020 and some scary challenges that nobody saw coming. A massive blizzard in January shut our city down for a week. It was a time of great anxiety - but we managed to get through it. Then the most frightening thing of all: in March, a global pandemic spread quickly and fiercely all over the world, hitting our province with a sudden punishment. The new Coronavirus pounced with no respect for race, gender, rich, poor, young or old.



This virus filled us with fear, and my wife and I did like people everywhere...we locked ourselves in our house!

The fear and chaos that accompanied this situation could have been paralyzing but we knew we were not alone in facing it. We would “hold fast” and listen to and follow the advice of experts.

This greatly helped to reduce our fear and anxiety.

Whenever I find myself gripped with fear for whatever reason, I make sure I talk to somebody! I play music and sing along. The Parkinson's Society sponsors Exercise Classes and Music Therapy sessions online. I find these sessions immensely helpful and they help clear my mind of needless clutter. Prior to the COVID restrictions, I attended Yoga Classes which were also sponsored by the Parkinson's Society. These sessions were very relaxing, and I still use the breathing techniques I learned there.

These simple measures allow me to get focused and to face whatever challenge I have with peace and strength. I hope all of you find your source of strength to conquer any fears you may have and enjoy your life one day at a time!

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

BRAIN TEASERS

Stuck inside?

Try these brain teasers to keep your mind sharp!

The Stroop Test

This neuropsychological test was designed to test cognitive processing.

Going from left to right, top to bottom, say out loud the COLOUR you see in every word (*NOT* the word itself).

How fast can you go?

RED	BLUE	ORANGE	YELLOW	PINK
YELLOW	GREEN	WHITE	RED	BLUE
WHITE	ORANGE	PINK	GREEN	WHITE
BLUE	RED	GREEN	ORANGE	YELLOW

Riddle Me This

A man stands on one side of a river, his dog on the other. The man calls out to his dog and the dog crosses the river without getting wet and without using a bridge or a boat. How did his dog do it? (*Answer on Page 15*)

Attention and Working Memory

→ *Test your speed with these quick brain teasers - they're harder than they look!*

- Say the days of the week backwards, and then in alphabetical order
- Say the months of the year in alphabetical order
- Name two objects for every letter in your name. Work your way up to five objects, using different objects each time
- Calculate the sum of your date of birth: dd + mm + yyyy
 - Do the same with your partner's or best friend's birth date - extra points for knowing the date offhand!

Walter's Surfing for a Cure....

Health Canada Approves Kynmobi Sublingual Film to Treat Off Episodes

Kynmobi (apomorphine hydrochloride) soluble film has been approved by Health Canada as an on-demand treatment for off episodes in people with Parkinson's disease, its developer Sunovion, announced in June. Sunovion now is working to make Kynmobi available in pharmacies across Canada as soon as possible.

Kynmobi (previously known as APL-130277) is an apomorphine film that is placed under-the-tongue (sublingual therapy) when patients start experiencing an off episode — periods when symptoms reappear as a therapy wears off.

The treatment, which was approved for the same indication by the U.S. Food and Drug Administration in May, may be used up to five times a day. Once in the bloodstream, apomorphine can cross the blood-brain barrier — a semipermeable membrane that protects the brain from the external environment — and mimic the effects of dopamine in the brain. This counteracts the loss of dopamine-producing neurons in the brain, a hallmark of Parkinson's disease.

Kynmobi's effectiveness, safety and tolerability was evaluated in a Phase 3 clinical trial that compared the oral medication to placebo as an on-demand treatment for off periods.

The trial included patients who had at least two hours of total off periods per day, including predictable morning off episodes, despite being responsive to levodopa treatment. In an initial open-label phase, all participants were given increasing doses of Kynmobi (10–35 mg) until an optimal dose was found.

Patients were then assigned randomly to either Kynmobi or placebo, and could take the medication up to five

times a day for 12 weeks. The trial's main goal was improvements in motor symptoms — defined as changes on the Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS) Part III — from before dosing to 30 minutes after dosing at week 12.



Data showed that patients who received Kynmobi experienced a reduction of 7.6 points in their MDS-UPDRS scores compared to those taking placebo at week 12 of the trial.

The first clinical improvements were seen as early as 15 minutes after dosing, and persisted for up to 90 minutes. More patients given Kynmobi achieved full control of their motor symptoms (31%) — a full “on” response — within 30 minutes at week 12, compared with 14% of those given a placebo.

“The Health Canada approval of KYNMOBI provides healthcare providers and people living with Parkinson's disease with a novel treatment option that allows a quick and reliable transition from OFF to ON so they can more easily function in their daily lives,” said Antony Loebel, MD, president and CEO at Sunovion.

Kynmobi was generally well-tolerated, with most treatment-related side effects being mild to moderate. The most common side effects were nausea, sleepiness, and dizziness. One person with known cardiac risk factors who was treated with Kynmobi died due to heart failure.

“The unpredictable and frequent nature of OFF episodes, which can occur despite people taking their oral maintenance medications as prescribed, makes this a particularly challenging and burdensome facet of Parkinson's disease,” said Anthony E. Lang, MD, professor at the University of Toronto and Jack Clark Chair for Parkinson's Disease Research, and director of the Edmond J. Safra Program in Parkinson's disease at Toronto Western Hospital.

Kynmobi “is a welcome on-demand treatment that physicians can offer patients to help rapidly improve their PD OFF episodes,” he said.

Source: <https://parkinsonsnewstoday.com/2020/06/17/health-canada-approves-kynmobi-sublingual-film-to-treat-off-episodes/>



One-time Treatment Generates New Neurons, Eliminates Parkinson's Disease in mice

Kyoto Xiang-Dong Fu, PhD, says he has never been more excited about something in his entire career. He has long studied the basic biology of RNA, a genetic cousin of DNA, and the proteins that bind it. But a single discovery has launched Fu into a completely new field: neuroscience.

For decades, Fu and his team at University of California San Diego School of Medicine studied a protein called PTB, which is well known for binding RNA and influencing which genes are turned "on" or "off" in a cell. To study the role of a protein like PTB, scientists often manipulate cells to reduce the amount of that protein, and then watch to see what happens.

Several years ago, a postdoctoral researcher working in Fu's lab was taking that approach, using a technique called siRNA to silence the PTB gene in connective tissue cells known as fibroblasts. But it's a tedious process that needs to be performed over and over. He got tired of it and convinced Fu they should use a different technique to create a stable cell line that's permanently lacking PTB. At first, the postdoc complained about that too, because it made the cells grow so slowly.

But then he noticed something odd after a couple of weeks -- there were very few fibroblasts left. Almost the whole dish was instead filled with neurons.

In this serendipitous way, the team discovered that inhibiting or deleting just a single gene, the gene that encodes PTB, transforms several types of mouse cells directly into neurons.

More recently, Fu and Hao Qian, PhD, another postdoctoral researcher in his lab, took the finding a big step forward, applying it in what could one day be a new therapeutic approach for Parkinson's disease and other neurodegenerative diseases. Just a single treatment to inhibit PTB in mice converted native astrocytes, star-shaped support cells of the brain, into neurons that produce the neurotransmitter dopamine. As a result, the mice's Parkinson's disease symptoms disappeared.

The study was published June 24, 2020 in Nature.

"Researchers around the world have tried many ways to generate neurons in the lab, using stem cells and other means, so we can study them better, as well as to use them to replace lost neurons in neurodegenerative diseases," said Fu, who is a Distinguished Professor in the Department of Cellular and Molecular Medicine at UC San Diego School of Medicine. "The fact that we could produce so many neurons in such a relatively easy way came as a big surprise."

The treatment works like this: The researchers developed a noninfectious virus that carries an antisense oligonucleotide sequence -- an artificial piece of DNA designed to specifically bind the RNA coding for PTB, thus degrading it, preventing it from being translated into a functional protein and stimulating neuron development.

The researchers administered the PTB antisense oligonucleotide treatment directly to the mouse's midbrain, which is responsible for regulating motor control and reward behaviors, and the part of the brain that typically loses dopamine-producing neurons in Parkinson's disease. A control group of mice received mock treatment with an empty virus or an irrelevant antisense sequence.

In the treated mice, a small subset of astrocytes converted to neurons, increasing the number of neurons by approximately 30 percent. Dopamine levels were restored to a level comparable to that in normal mice. What's more, the neurons grew and sent their processes into other parts of brain. There was no change in the control mice.

By two different measures of limb movement and response, the treated mice returned to normal within three months after a single treatment, and remained completely free from symptoms of Parkinson's disease for the rest of their lives. In contrast, the control mice showed no improvement.

"I was stunned at what I saw," said study co-author William Mobley, MD, PhD, Distinguished Professor of Neurosciences at UC San Diego School of Medicine. "This whole new strategy for treating neurodegeneration gives hope that it may be possible to help even those with advanced disease."

Source:

<https://www.sciencedaily.com/releases/2020/06/200625102540.htm>

Parkinson's Exercise News

Sedentary behavior is linked to poorer attention spans in people with mild to moderate Parkinson's – reinforcing the value of exercise among patients.

A study entitled “Sedentary Time is Associated with Worse Attention in Parkinson’s Disease,” was recently published in the *Journal of Movement Disorders*.

Cognitive problems, such as deficits in memory, impulse control and attention, are known symptoms of Parkinson’s. Various studies have shown that moderate to vigorous activity can ease these disease symptoms. But prior studies have not characterized how sedentary behavior associates with cognitive difficulties.

Researchers at the University of Pittsburgh used armband accelerometers and neuropsychological tests to obtain objective and subjective measures of physical activity in 17 people with mild-to-moderate Parkinson’s, all on stable medication and between the ages of 50 and 80 (average age, 65).



Participants’ physical activity was measured for seven to 10 days using the Sensewear Pro armband, which uses an algorithm to collect information on the number of calories burned, as well as sleep quality and states of activity (such as walking, driving, or sitting).

Cognitive skills were measured using the Parkinson’s Disease-Cognitive Rating Scale (PD-CRS), which assesses memory, working memory, verbal fluency, and attention.

Participants also completed a computerized task-switching program to measure cognitive flexibility. This consisted of being shown a single number — one to nine, excluding five — surrounded by either a circle or a square. When surrounded by a circle, they were asked to indicate whether the number was odd or even. When a square, they had to tell whether the number was greater or lesser than five.

Tests using this task were given repeatedly, with each being either identical to or different from a previous test. The difference in reaction time between identical and differing tests (task-switching) provided a measure of a person’s cognitive flexibility. Of all the cognitive skills measured, sedentary behavior associated only with poorer attention scores.

Physical activity has shown benefits in overall cognition, including the areas of task-switching, memory, and attention. If sedentary behavior was simply the opposite of physical activity, the investigators wrote, all those cognitive areas should be expected to decline.

The fact that sedentary behavior appeared to affect attention alone suggests this relationship is different. “These results suggest that, relative to other aspects of cognition, sedentary behavior may be independently related to attention over and above MVPA [moderate-to-vigorous activity] in individuals” with Parkinson’s, the team wrote.

Possible reasons for this finding include the study’s small size, and the fact that the 17 people taking part were “very inactive,” although without motor symptoms or comorbidities that “precluded their ability to exercise,” the team added. Still, sedentary behavior was seen to predict attention deficits independent of mild-to-moderate exercise in this study, and merits future studies that focus not only on increasing physical activity but also on the potential contribution of reducing sedentary time.

“In short,” the researchers concluded, “this pilot study points to the need to further study the consequences of sedentary behavior in individuals living with Parkinson’s.”

Source: <https://parkinsonsnewstoday.com/2020/06/23/sedentary-behavior-linked-poorer-attention-small-pilot-parkinsons-study/>

Nutrition Corner

Healthy Blueberry Crisp

Healthy Blueberry Crisp is a quick and easy summer dessert, with juicy blueberries, a hint of cardamom and a crunchy, grain-free topping. It's naturally gluten-free, vegan and refined sugar-free, and it requires just nine ingredients with five minutes prep time!

INGREDIENTS

For the Blueberry Filling:

4 cups fresh blueberries
1/4 cup maple syrup
1 tablespoon tapioca flour
1/2 teaspoon cardamom

For the Crisp Topping:

1 cup buckwheat flakes
1/4 cup almond flour
1/4 cup unsweetened coconut,
flaked or shredded
1/4 teaspoon kosher salt
1/4 cup maple syrup
1/4 cup natural almond butter,
room temperature

INSTRUCTIONS

1. Pre-heat oven to 375°F and grease a 10-inch baking dish, pie plate or cast iron skillet (see note).
2. To prepare the filling, add the blueberries to a large bowl, along with the maple syrup, tapioca flour and cardamom. Stir until well combined. Pour into the bottom of the prepared dish and set aside.
3. For the crisp topping, add the buckwheat flakes, almond flour, coconut and salt to a large bowl and stir until combined. Add in the maple syrup and almond butter, and mix with a fork or your fingers until a wet and crumbly mixture forms.
4. Scatter the buckwheat mixture over the blueberries and press down slightly on the topping.
5. Bake for 28-30 minutes, or until the topping is golden brown and the blueberries are bubbling around the edges.
6. Serve warm with ice cream. Store any leftovers in an airtight container in the refrigerator and enjoy within 4-5 days.



Some tips for making Healthy Blueberry Crisp

You can make this recipe in a 10-inch cast iron skillet, pie plate or casserole dish. If you use a smaller dish or skillet, your blueberry and crisp layers will be thicker, so you may need to bake them for a few extra minutes.

Fresh blueberries are best, but you can also use frozen. Just make sure to de-frost them first, drain them of any water and then pat them dry with a paper towel.

If you can't find buckwheat flakes, you can use an equal amount of rolled oats. The crisp won't be grain-free, but if you use certified gluten-free oats, the crisp will still be gluten-free.

Bring the almond butter to room temperature to help it mix into the buckwheat mixture easily. You can also microwave it for 20-30 seconds to soften it.

If you make this Blueberry Crisp, the folks at Crumb Top Baking would love to hear about it!

Take a photo and post it to Facebook, Twitter or Instagram by tagging @crumtopbaking.

Recipes for the Nutrition Corner are provided compliments of www.crumtopbaking.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.

Caregiver's Corner

By Jane Macdonald

If you are living with someone who has Parkinson's disease you know that you both are living with the disease and the challenges it can bring. These challenges will change over time and are usually long term. Caregiving for someone with a chronic illness has been described as a "marathon, not a sprint". How do we look after ourselves as we face these challenges? Here are a few things for us to consider.

How is my own health? Do I go for regular health screenings? How am I sleeping? Am I able to include some regular exercise in my day? Am I eating healthy meals? Do I get a chance to socialize with friends and family? What gives me strength (such as spirituality)? How are my coping skills (with stress)?

Caregiving is most often a very positive and rewarding experience, but it is important to acknowledge that it can be stressful. As a caregiver we may feel many negative emotions like anger, anxiety, fear, guilt and frustration. And we may be exhausted.



Sometimes we forget that for us to continue to provide support to our partner over the long term we need to look after ourselves.

Sometimes we think we can do it all alone. Sometimes we don't ask for help when we need it. Family, friends and neighbours may say "let me know if you need help." Be sure to take them up on their offer and let them know how they can be a support. People will

gladly step up to help us if we are specific in what we need. Most people want to help, but don't know how.

It may help us cope if we are able to connect with another caregiver. Sometimes a friendly phone call or getting together for a coffee meet-up can lift our spirits. Sharing experiences may help us overcome feelings we have of isolation and loneliness. We may also be able to share ideas and information about what community and online resources are available.

If you have ideas as to how Parkinson Society NL can better support caregivers please let us know.

Words of Advice from Care Partners

"Learn to laugh at life and laugh at yourself as a caregiver. Humour is a must."

"When frustrated, take three deep breaths and say to yourself 'this too shall pass.'"

"Treat yourself with self-care. It is a monthly bill you need to pay on time."

"Ask for help when you want it, before you need it."

"Remember what you learned in kindergarten."

"Lord, give me patience, and give it to me now!"

"Listen! Patience! Love!"

"Get out once a week. Do something that makes you happy."

"Listen, meditate and communicate."

"Yoga, friends, naps, nature, good food and wine! All help!"

"Don't overthink before you act. Meditate 1-2 times a day."

"Make time for yourself. Join support groups. Socialize with others in the same situation."

"Don't take everything personally."

"Caregiving has no guide book. Just do what works!"

In Memoriam

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

Yvonne Clarke	Robert Combden
Dennis Brothers	Marietta Burton
Robert Rumsey	Jim Piercey
Herman Crewe	Lloyd Sheppard
Harold Miller	William Vail
Roberta Feaver	Myrtle Burry
Diane Garland	Ross Churchill
Lorraine Crummey	Dorothy Goulding
Terence Evans	Izola Yetman
Cecil Pelley	Claude Elgar
Alexandria Olufunola Beckley	

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



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!

Visit us on Facebook:
[@ParkinsonSocietyNL](https://www.facebook.com/ParkinsonSocietyNL)

And follow us on Twitter:
[@Parkinsons_NL](https://twitter.com/Parkinsons_NL)



Sunday, September 20
Visit www.nlparkinson.ca to register