Newsletter

July, August, September

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# **Step Big Walk for Parkinson's**

**Step Big Walk for Parkinson's** is almost here! Excitement and anticipation are in the air. This is going to be another fabulous day full of movement, hope, companionship, food and lots of fun! Gather your friends, family and coworkers and join us on **Saturday, August 24**<sup>th</sup> at the **Sioux Falls Canaries Baseball Stadium** where participants will have the opportunity for a unique experience to walk the baseball field and around the entire stadium.

Step Big is an annual fundraiser for the South Dakota Parkinson Foundation and all donations remain within the state of SD and to go towards providing continued services and programs. One survey ranked South Dakota second in the nation in prevalence of Parkinson's disease and the number of individuals diagnosed with Parkinson's disease continues to be on the rise. We need your help to continue to move forward in our mission to improve the quality of life for those touched by Parkinson's disease.

This is the perfect time to remember and honor parents, siblings, grandparents, friends, neighbors and community members that continue to cope with the complications of Parkinson's disease. Make a difference in their lives by showing your support and starting a Step Big Walk team, raising funds for the walk and celebrating time with family and friends from local and surrounding communities. Getting started is super easy with the new Eventbrite registration process that has been included on the SDPF website.

Would you like to start a team, register as an individual, donate to a participant, or volunteer at the walk...learn how to become involved today:

- ❖ Visit the SDPF website at <u>www.southdakotaparkinson.org</u>
  - Click on EVENTS tab
  - O Click on WALK EVENT (this will bring you to the Step Big main page)
  - Click on REGISTER NOW (blue box)
- Call the SDPF office at 605.271.6113
- Send an email to sdpfevent@outlook.com

Walk registration is **\$30/person** (12 years and under are free). Those that register by **July 31**st will receive a Step Big Walk participant t-shirt at the event.

Step Big Walk Goals

**TOTAL:** \$41,000

Teams: 20 Walkers: 400



# From the Doctor: Is Timing Everything?

Jerome W Freeman, MD Sanford Clinic Neurology



The phrase "timing is everything" has been used in many contexts. It might apply to the optimal time to propose marriage, ask the boss for a raise, or risk an investment. The phrase is less commonly associated with an individual's prescription medications.

Indeed, when discussing medications, it is more common to ask "how much" than to inquire about "when" a dose should be taken. For many types of medication -- heart pills, antibiotics, cholesterol drugs -- the timing of a dose can vary without causing adverse consequences.

Timing can be much more crucial for the person with Parkinson's disease. All too often, there are frustrating, and sometimes embarrassing, consequences when a scheduled dose is delayed. Many people with Parkinson's know precisely when their meds are exerting peak benefit and when the effects of a dose start to wane. The "on/off" phenomenon of Parkinson's can seem like a veritable roller coaster of influences that dictate a person's physical abilities from one minute to the next.

As the physician and patient work together to determine the best dosage schedule, an increase in the amount of medication per dose is often not the answer. Indeed, if an individual is experiencing a "wearing off" effect before the next scheduled dose, a mere increase in the amount of medication may cause peak level dyskinesias that are still followed by disconcerting "off" times.

By decreasing the time between each dose of medication, a patient can often maintain a more consistent level of Parkinson's medication. Large peaks and valleys of medication effect can be avoided. The correct interval between doses must be individually determined. With mild Parkinson's symptoms, a patient might get by taking meds every 4 or 5 hours. But as the disease progresses, it may be best to decrease the dosage interval. Sometimes compulsively taking Parkinson's meds as often as every 2 1/2 to 3 hours works best.

To maintain optimal functioning, many persons with PD do indeed discover that "timing is everything". Broad strokes of good intention may be sufficient for some medical conditions. But for Parkinson's, close attention to dosage times can be crucial.



# President's Message

Tony Mau, SDPF



As we transition from spring to summer...wait a minute, did we get a spring season this year? I think we can all relate to the feeling that we recently trudged through eight long weeks of winter to the Amazonian

rain season (our new spring) to summer being almost to the halfway mark, but that's all part of the experience when residing in the wonderful state of South Dakota.

Like most of you, I could use a little sunshine to brighten the skies and overall spirits. The South Dakota Parkinson Foundation received a little sunshine earlier in the year. Riley Conklin, former SDPF board member, agreed to act as our new Event Coordinator. He hit the ground running with the early planning stages for the Step Big Walk for Parkinson's event, the Petals for Parkinson's fundraiser and the annual Parkinson's Awareness Conference. Luckily, for him and us, Janey Case, SDPF Executive Director, and an awesome team of volunteers helped to assemble our best attended conference to date. If you missed it, make sure to mark it on your calendar for 2020. It usually falls on the 2<sup>nd</sup> or 3<sup>rd</sup> Saturday in April, in conjunction with Parkinson's Awareness Month.

For those of you that haven't heard, we started a project called Petals for Parkinson's last year. Thanks to Landscape Garden Centers for their drive, dedication and benevolence, SDPF was able to raise needed funds to help support the resources across the state of South Dakota.

The next big event on the radar is the Step Big Walk for Parkinson's. We are coming off a banner year, so we'll need your help to continue setting records to spread awareness. So, assemble your team, hold a few fundraisers and strap on your shoes. We will see you on August 24th @ 8:00am.

Thanks to you, WE are making a difference!

# Rock Steady Boxing Brings Fun & Fitness to Those Battling Parkinson's

Step in the boxing gym at Rock Steady Boxing at The Inn on Westport and one of the first things you may notice are the many smiles you see on the faces of boxers. You'd never know that this is a group of people with Parkinson's disease. No one in this gym is feeling sorry for themselves or having a pity party as they fight back against their diagnoses.

"Our Rock Steady Boxing program is maybe first a support group and then a fitness class!" said Program Director and Coach Lisa Howard. "It's been amazing to see the fighting spirit and comradery of the group that's developed in the past two years of holding classes.

## Our boxers probably say it best:

"I love going to class – we have such a fun group. There are laughs. There is sharing of information related to PD. Our coach has a keen sense of humor and shows compassion for us all. Molly Liberko, boxer since November '17.

"The social aspect is very important – my fellow boxers make me laugh. The comradery helps me know I'm not alone – and helps so much." Roger Van Maaanen, boxer since June '17.

"The social aspect is probably just as important as the physical part. It helps to know that most everyone has ups and downs at different times, and we can all relate to each other and what we're feeling. It helps the motivation to keep going." Greg Hemmingson, boxer since July '18.

The Rock Steady Boxing method of exercise is proving to be effective in fighting back against this disease. This fitness class provides encouragement by inspiring maximum effort, speed, strength, balance and flexibility. Boxing works by moving your body in all planes of motion while continuously changing the routine as your progress through the workout. RSB classes have proven that anyone, at any level of Parkinson's, can actually lessen their symptoms and that a regular intense exercise program can lead to a healthier, happier life.

With almost 50 boxers, Rock Steady Boxing at the Inn on Westport has different level classes to help anyone at any level that has been diagnosed with Parkinson's. Our youngest boxer is in his 40's and we have several boxers in their 80's. Kent Kluver moved from Rock Rapids to live at The Inn on Westport and takes advantage of the classes. When he first started, coaches were unable to finish his balance assessment because he was such a high risk for falls. Fast forward a year later and he is now standing straighter, walking better and faster, is much stronger and is enjoying his daily life much better. His balance test jumped up 15 points and where before he could barely lift his legs – he is now do the "running man" drill in class – fast feet and punching the heavy bag with gusto! Kent had this to say about his RSB classes. "I enjoy working out hard enough to break a sweat and breathe heavily. It makes me feel good. The results have been great – I hardly ever fall down anymore!"

Do you or someone you love have Parkinson's? If so, start fighting back today – come watch a class and learn now Rock Steady Boxing can help you! For more information contact program director, Lisa Howard at lisa.howard@innonwestport.org or 362-1210.



Rock Steady Boxing is also looking for individuals who would like to **volunteer** in class as a **Cornerman** for those that do not have a spouse or family member to help them.

"It's a very rewarding experience! You are helping someone and you get to work out as well!" said Coach Lisa.

# **Step Big Walk for Parkinson's: Team Townsend**

How do I start a team and reach my fundraising goals? Fundraising can be intimidating and overwhelming and finding ways to be creative and fun can prove to be a challenge. We strive to make the Step Big Walk for Parkinson's not just a fundraiser, but an event where we can gather together as family, friends and coworkers to support those affected by the disease.

At the SD Parkinson's Foundation we want to help you build your team and reach your fundraising goals so we asked Ray Townsend, one of our top fundraisers, to offer some insight and advice on how he has become so successful throughout the past few years. Here's what Ray had to say...

How do you share your story & the importance of the Parkinson Foundation with others? Email tends to be my communication method of choice (that's the IT nerd thing coming through).

In terms of the walk, I try to send multiple emails prior to the walk - to provide multiple opportunities to say yes! I also send at least one, usually two, follow-up emails after the walk. I try to keep all of them short and to the point (*people are busy*).

I send the first email inviting them to join Team Townsend about six weeks before the event. I thank them for their past financial and/or moral support. I include information about the walk and remind people that 100% of their donation is used to help local SD families impacted by Parkinson's. I also usually include some brief but interesting facts about Parkinson's. And, since these are all people I have a personal connection with, I will include an update of my status if the email isn't getting too long. I'll then send a reminder email about two weeks before the event and a final reminder a few days before the event.

About a week or two after the event I send a thank you to all donors and walkers. In my opinion this email is the most important one! There are a lot of worthy causes in need of financial support and volunteer help to pick from. The fact that these folks chose to join Team Townsend and support the SD Parkinson Foundation means a lot to me. I include a reminder to those that have company matching to please do what is required to make the match happen.





# Who do you recruit for your team?

I stick to people I have a personal connection with. Mostly that's family, friends, and former coworkers.

# How do you set your team fundraising goal?

I simply look at what we raised last year, adjust it for inflation and add a small percentage.

# What materials do you provide your team for fundraising?

Nothing, other than keeping them informed. Last year I did offer that if we met our goal my wife would make cookies for all Team Townsend members that came to the walk. (It would have been a better move if I'd asked her first, but when she found out about it she just smiled and shook her head and then came through with the goods!)

# What is your favorite part about the walk?

Making new connections...connections with team members; connections with other individuals impacted by Parkinson's disease; connections to information on treatment and support options; connections with care providers such as Avera Therapy & Rock Steady Boxing and the SD Parkinson Foundation.

# **Step Big Walk Incentives!**

Who doesn't like a little friendly competition? We have big goals to reach for this year's walk and we need your help...help in spreading the word, creating teams, and fundraising efforts!

The South Dakota Parkinson Foundation wants to provide as much support & encouragement to you these next couple months so here are some fun incentives to keep you and your team motivated.

- #1 The <u>FIRST</u> team to raise \$2,500 will win a Family Summer Fun themed basket!
- #2 The FIRST participant to raise \$1,000 (as an individual) will win a Step Big Basket!
- #3 The <u>FIRST</u> team to register 10 members and raise \$1,000 will win a Team Celebration Basket!
- #4 If your team holds a fundraiser we want to see it...post a picture on the Step Big Walk Facebook page and you will win a Step Big tumbler and gift card!

  (will be presented to the Team Captain)

\*\*\*Remember to **LIKE & FOLLOW** the Step Big Walk for Parkinson's Facebook page to stay current with walk updates. Teams can share stories and fundraising tips with one another to help us all work together in reaching our 2019 goals.\*\*\*



# **Director's Message**

Janey Case, Executive Director



Summer is here and August is fast approaching and I've been receiving emails and phone calls inquiring about the upcoming Step Big Walk registration/donation process. It's exciting to know that so many have marked the date on their calendars and have started forming walk teams and setting team fundraising

goals! So I wanted to give you a brief overview of the changes that have been made and how to get started. I hope you will find the new registration process easy to navigate and helpful in preparing for this year's walk. Together we can make this the best year yet!

The Step Big Walk for Parkinson's will be held on Saturday, August 24<sup>th</sup> at the Sioux Falls Canaries Baseball Stadium and to register online through EventBrite you have two options:

- 1. Register as an individual
- 2. Join a Group (team)

To Register Online Follow These Steps:
Step #1: Go to www.southdakotparkinson.org

Step #2: Click on the EVENTS tab and scroll down to WALK EVENT

Step #3: Once here click on "REGISTER NOW"

**Step #4:** Fill out all the contact information and then go to complete the process by paying the registration fee (\$30 per person/12 years & under are free)

# Additional Step Big Walk Website Updates:

- You can now add all team/family members under one registration
- You can add all children under one registration
- You can pay the registration fee for everybody at once instead of one at a time
- You can add a personal donation in addition to your registration fee during the payment process
- Letter templates have been added...simply copy/paste in an email and send to all your friends/family to help you reach your goal

We look forward to having you join us for a day supporting all those touched by Parkinson's!

#### **EXECUTIVE BOARD**

**EDITOR**Janey Case

#### **OFFICERS**

Tony Mau, *President*Stephanie Myers, *Vice President*Noel Lais, *Treasurer*Jaclyn Schaap, *Secretary* 

#### **BOARD MEMBERS**

Kelly Woldt Lorri Halverson Meldon & Linda Kroeger Molly Keegan Teagan Molden Lisa Howard Paul DeJong

#### **SDPF STAFF**

Janey Case, Executive Director Riley Conklin, Event Coordinator

#### LOCAL OFFICE

South Dakota Parkinson Foundation (SDPF)

1000 N West Ave, Ste. 220 Sioux Falls, SD 57104 605.271.6113

www.southdakotaparkinson.org

#### **BOARD OF DIRECTORS:**

If you have a strong passion for the SDPF mission and would like to become more involved, we encourage you to consider serving on the board of directors. Currently, the SDPF board of directors consists of 12 volunteers. The SD Parkinson Foundation would like to expand the board to consist of members both within the SF area and outside communities across the state of South Dakota.

If you would like more information about this opportunity within the board of directors please contact the SDPF office at 605,271,6113

# Thank You to All Our Donors April 1<sup>st</sup> – June 30<sup>th</sup>, 2019

Gifts to the South Dakota Parkinson Foundation support educational programs and services across the state. Thank you to all who support the SDPF mission by giving generously throughout the year.

At the time of the gift, the donor receives notification and SDPF sends a special acknowledgement letter to the family upon request. SDPF has made every effort to ensure accuracy of this information. If you notice an error or omission, please notify the office and corrections will be made.

## IN MEMORY OF

Jim Flannery Craig & Patricia Lloyd

Redetta Jensen
Dr. Jerome & Mary Freeman

Thomas Probst Ken Reuter



RSB: Painting for Parkinson's
The Inn on Westport
James & Mary Waddell
William & Donna Devick
Wells Fargo Support Campaign



# **SD Parkinson's Awareness Conference**

This year, the annual SD Parkinson's Awareness Conference convened April 13<sup>th</sup>, 2019 at the Sioux Falls Hilton Garden Inn with just over 155 attendees. Throughout the day we had entertainment, enlightenment and inspiration supplemented by the opportunity to interact with peers from across the state and surrounding areas, as well as, to network with agencies and organizations offering services specific to the needs of those dealing with Parkinson's disease.

Presentations were given by Rose Wichmann and Joan Hlas with Struthers Parkinson's Center, Dr. Andrew Ridder with Avera Medical Group Neurology, Jayna Voss with Legacy Law Firm and several breakout sessions with Avera Therapy and Rock Steady Boxing. The SD Parkinson's Awareness Conference ended the day with a wonderful Parkinson's Panel of individuals who shared about their Parkinson's journey and answered a variety of audience questions.

The SD Parkinson Foundation would like to extend a very sincere thank you to all attendees & exhibitors who provided the purpose for this event, to the sponsors who made this event possible and to the volunteers who made everything come together on a very successful day!





# Calendar of Events

# **July**

## **Parkinson's Annual Picnic**

Date: Wednesday, July 17<sup>th</sup> Location: The Inn on Westport Time: 1:00 pm – 2:30 pm

Date: Wednesday, July 24<sup>th</sup> Location: Edith Cancer Center Time: 6:30 pm – 8:00 pm

\*\*\*To RSVP please call 605.271.6113\*\*\*

All are welcome to attend!!!

# **August**

# Step Big Walk for Parkinson's

Date: Saturday, August 24<sup>th</sup>

Location: SF Canaries Baseball Stadium
Time: 8 am Registration (enter through main gates)

9 am Walk Begins!

Fee: \$30 Per Person (12 & under free)

\*\*\*Register by July 30<sup>th</sup> to guarantee a Step Big Walk participant t-shirt\*\*\*

\*\*\*To register please go to SDPF website\*\*\*
www.southdakotaparkinson.org\*\*\*

# **September**

# **Living Well with PD Weekend Retreat**

Dates: September 20<sup>th</sup> – 22<sup>nd</sup>

Location: Abbey of the Hills Retreat Center,

Milbank, SD

Register: June 10<sup>th</sup> – September 6<sup>th</sup> Information Contact: 605.322.5150

# **November**

# **Caregiver Celebration Night!**

Date: TBD Location: TBD

Time: 6:00 pm - 8:00 pm

\*\*\*Stay tuned for more details to come in the coming months. \*\*\*

This annual event is held to celebrate all our amazing and wonderful caregivers in the Parkinson's community!

# **Community Support Groups**

#### **Aberdeen**

2<sup>nd</sup> Thursday 1:30 pm

Parkside Retirement

#### Luverne

3<sup>rd</sup> Thursday 1:00 pm

St. John Lutheran Church

#### Sioux Falls

3<sup>rd</sup> Wednesday 1:00 pm Edith Sanford Cancer Center

### Sioux Falls

3<sup>rd</sup> Thursday 3:00 pm

Touchmark At All Saints

#### Watertown

2<sup>nd</sup> Wednesday 2:00 pm Jenkins Living Center

# **Brookings**

1st Thursday 1:30 pm

First Bank & Trust

#### **Madison**

2<sup>nd</sup> Thursday 7:00 pm St. John Lutheran Church

#### Sioux Falls

4<sup>th</sup> Wednesday 6:30 pm Edith Sanford Cancer Center

### Sioux Falls

1<sup>st</sup> Monday 5:30 pm

**Edgewood Prairie Crossings** 

#### Yankton

2<sup>nd</sup> Tuesday 6:00 pm

Professional Office Pavillion

# Canton

2<sup>nd</sup> Wednesday 3:00 pm

Sanford Canton/Inwood

### Mitchell

3<sup>rd</sup> Monday 2:00 pm

Avera Queen of Peace

#### Sioux Falls

Tues/Thurs 2:30 pm Avera Therapy

#### Vermillion

1st Wednesday 11:30 am Sanford Vermillion

# Huron

4<sup>th</sup> Wednesday 1:30 pm

HRMC Legacy Plaza

# Rapid City

2<sup>nd</sup> Saturday 1:00 pm

WestHills Village

# Sioux Falls

2<sup>nd</sup> Thursday (Women)

9:30 am

Avera Therapy Clinic

#### **Viborg**

2<sup>nd</sup> Tuesday 2:00 pm

Pioneer Memorial

\*\*\*To view the SDPF newsletter online please visit the website: www.southdakotaparkinson.org\*\*\*

# From the Pharmacist: New Levodopa Inhalation Powder

Kylie A. Brooks, *PharmD Candidate 2019 Emily J. Van Klompenburg, PharmD, BCACP* 

Patients with Parkinson's disease (PD) symptoms fluctuate between ON episodes when symptoms are controlled and OFF episodes when symptoms return. Sometimes taking medication to help control PD symptoms is not enough as OFF episodes can occur and cause disruption in daily living. OFF episodes can effect a patient's mobility, activities of daily living, emotional health, cognition, communication, and bodily comfort. In a survey conducted by the Michael J. Fox Foundation, 64% of patients reported experiencing two or more hours of daily OFF time.

Levodopa has been the longstanding medication in the treatment of Parkinson's since its development in the late 1960s.<sup>2</sup> Previously, levodopa has always been administered in combination with carbidopa to help enhance the absorption of levodopa centrally (within the brain) and prevent premature conversion to dopamine in the periphery (outside the brain), resulting in a smaller dose of levodopa required and less potential for nausea.<sup>2</sup>

Recently, the Food and Drug Administration (FDA) approved an inhalation powder of levodopa called Inbrija® for the intermittent treatment of OFF episodes, or the return of Parkinson's symptoms, in combination with oral carbidopa-levodopa.³ During clinical trials, it was found that Inbrija® had a significant improvement in motor functions during OFF periods starting 10 to 30 minutes after a dose was administered. The average number of doses administered during clinical trials was two doses per day.³

This new dosage form of levodopa comes as a reusable inhaler with blister packed capsules, each 42 mg, to be placed in the inhaler and punctured within the inhaler immediately prior to being inhaled.<sup>3</sup> The recommended dose of Inbrija® is oral inhalation of the contents of two capsules, 84 mg total dose, as needed up to 5 times a day.<sup>3</sup> Some of the common adverse effects reported with Inbrija® are cough, upper respiratory tract infections, nausea, and sputum discoloration with more severe adverse effects including low blood pressure, falling asleep during normal daily activities, and hallucinations.<sup>3</sup> Prior to Inbrija®, available dosage forms of carbidopa-levodopa included extended release and immediate release tablets, extended release capsules, orally disintegrating tablets (ODT), and oral suspension.<sup>4</sup>

#### References:

- OFF Limits. Sunovion Pharmaceuticals INC. Marlborough, MA. Available at https://www.offlimitspd.com/physical-emotional impact.html. Accessed 3.28.19
- Parkinson's Foundation. Levodopa. Available at https://www.parkinson.org/UnderstandingParkinsons/Treatment/Pr escription-Medications/Levodopa. Accessed 3.28.19.
- Package Inert: Inbrija (levodopa inhalation powder). Acorda Therapeutics. Ardsley, NY. Available at https://www.inbrija.com/prescribinginformation.pdf?webSyncID=d3 9801b8-9900-4040-51e02bb8ed3698b4&sessionGUID=12d62695a772-8ea2-62b6-8cb09a6b5885. Accessed 3.28.19.
- 4. Lexicomp.LexiDrugs:Carbidopa-Levodopa.Accessed 3.28.19.

# New Parkinson's Therapy Program Now at Avera

Tina Jacobsen, M.A.CCC-SLP Avera Therapy

90% of people with Parkinson's are at risk of developing a weak voice that can lead to serious speech and swallowing difficulties. Intensive speech therapy is beneficial, but people with Parkinson's require continuous vocal exercise in order to maintain their vocal strength. Avera Therapy is pleased to offer a two-part speech therapy program to help individuals with Parkinson's regain and maintain effective communication: SPEAK OUT!® followed by The LOUD Crowd®.



The first part of the therapy is the SPEAK OUT!® program. This consists of individual speech therapy sessions which include a series of speech, voice and cognitive exercises. The primary goal of SPEAK OUT! is to strengthen the muscles used for speaking and swallowing. It places emphasis on speaking with intent and converting speech from an automatic function to an intentional act. Together, patients and their speech-language pathologist work through a series of speech, voice, and cognitive exercises outlined in a SPEAK OUT!® Workbook. Upon completion of SPEAK OUT!®, patients transition to The LOUD Crowd®.



This maintenance program consists of weekly group sessions led by a speech-language pathologist. The SPEAK OUT!® exercises are performed, and group members provide support, encouragement, and accountability to one another. Participation in The LOUD Crowd®, along with daily home practice and sixmonth re-evaluations, has been shown to help patients maintain their communication skills throughout the progression of Parkinson's.

For more information or to schedule a speech evaluation, contact Avera Therapy at 605-322-5150.



# **LSVT BIG & LOUD**

Want to learn more about LSVT BIG & LOUD? There are several facilities across the state of South Dakota that has certified clinicians. We encourage you to reach out to a facility in your local area.

**ABERDEEN, SD:** 

Avera St. Luke's Hospital

305 S State Street 605.622.5772 **CANTON, SD:** 

Sanford Canton/Inwood

400 N Hiawatha Drive 605.764.1480

**HURON, SD:** 

**Huron Regional Medical Center** 

172 4th Street SE 605.352.6253 MITCHELL, SD:

**Integrated Therapy Services** 

501 W Havens 605.753.5400 **RAPID CITY, SD:** 

RC Regional Rehabilitation Institute Avera Outpatient Therapy

2908 5th Street 605.755.1408 **VERMILLION, SD:** Sanford Vermillion

20 S Plum 605.677.3590

**WATERTOWN, SD:** Jenkins Living Center

215 S Maple Street 605.886.5777

**BERESFORD, SD:** 

**Bethesda Nursing Home** 

606 W Cedar Street 605.760.5066 **CUSTER, SD:** 

**Custer Regional Hospital** 

Montgomery Street 605.673.2229 **LUVERNE, MN:** 

Prairie Rehabilitation 106. N Cedar Street

507.449.2003 PARKER, SD:

Parker Medical Clinic

100 E Sanborn Street 605.760.5066

SIOUX FALLS, SD:

1325 S Cliff Avenue 605.322.5150 **VIBORG, SD:** 

**Pioneer Outpatient Center** 

315 N Washington Street 605.760.5066

YANKTON. SD:

**Avera Sacred Heart Hospital** 

501 Summit 605.668.8268 **BROOKINGS, SD:** 

**Brookings Health Systems** 

300 22<sup>nd</sup> Avenue 605.696.8821 **FORT MEADE, SD:** 

Black Hills VA Healthcare System

113 Comanche Road

605.347.7000 MILLER, SD:

**Avera Hand County Hospital** 

300 W 5th Street 605.853.0350 PIERRE, SD:

Avera St. Mary's Hospital

801 E Sioux Avenue 605.224.3162

SIOUX FALLS, SD:

**Sanford Outpatient Center** 1210 W 18th Street, LL01

605.328.1860

**WATERTOWN, SD:** 

Big Stone Therapies, Inc.

Eight 5th Street SE 605.995.6044

# How to Be the Best Patient

Article By: Brain&Life (April/May 2019 Issue) Neurology for Everyday Living www.brainandlife.org





Your relationship with your neurologist is a two-way street. Chad Hoyle, MD, associate professor of neurology at Ohio State University in Columbus, recommends these strategies to improve it.

- Come prepared. To make the most of your appointment, have a list ready of your main concerns and questions. This will help you and your doctor stay focused.
- Bring a buddy. A friend can take notes and help you remember your doctor's advice and, if necessary, remind you of what you wanted to talk about in the first place.
- Be transparent. Tell your doctor about any new symptoms or changes in your health. Be open and specific, so your neurologist can recommend the best treatment plan.
- **Discuss medications.** Your doctor should have a detailed list of what you take, including prescription and over-the-counter medications as well as herbs, supplements, vitamins, and any alternativetherapy treatments. He or she can then assess the potential for harmful interactions between medications and whether you're taking them in the safest and most effective way. Tell your physician about any side effects or other concerns, such as costs, that may interfere with your taking your drugs. Be sure to take medications as prescribed; not doing so could lead to adverse outcomes or ineffective management of your condition.
- Request clarity. If your doctor's suggestions are unclear, ask him or her to repeat them or provide instructions in writing.

# LIVING WELL WITH PARKINSON'S DISEASE: NEW APPROACHES

3RD ANNUAL RETREAT ABBEY OF THE HILLS NEAR MILBANK, SD SEPTEMBER 20-22, 2019

# **KEYNOTE SPEAKERS**



- <u>Dr. Andrew Ridder graduated from University of South Dakota's</u>
   School of Medicine and completed a neurology residency in 2016
   and movement disorder fellowship in 2018 at University of Michigan
- He specializes in the treatment of movement disorders with special focus in Parkinson's Disease, parkinsonism syndromes, tremors, ataxia, and dystonia.



- <u>Jennifer Bazan-Wigle</u>, PT, DPT, graduated as a doctor of physical therapy from Nova Southeastern University in Ft. Lauderdale, FL. in 2010.
- Provides physical therapy services focusing on patients with an emphasis in neurological involvement including Parkinson's disease.
- She is a full time PWR! Expert at the PWR! Gym in Tucson, AZ.



- <u>Denise Borass</u>, CNP, graduated from Augustana College with a degree in nursing and from SDSU with a Masters in Nursing/Family Nurse Practitioner.
- Has practiced with Avera Medical Group Neurology since 2005.
- Neuromodulation Navigator (DBS, Duopa pumps, VNS)



Registration available June 10 - September 6, 2019
Please call 605-322-5150 for more information.







# **Summer Travel Tips**

Tony Mau, SDPF Board President



Summers are often the ideal time for family caregivers to take their senior loved ones on vacation, to reunions or on group outings with family and friends. Travel can be physically and emotionally stressful at any age, so planning ahead will help ensure older adults stay safe and comfortable on the trip.

"Many seniors eagerly look forward to summer traveling, but also can feel overwhelmed and nervous about getting to their destination and enjoying their stay," explains Tony Mau, owner of Right at Home in Sioux Falls. "With a few pretrip action steps, older adults can relax and enjoy their time away without incident."

Mau recommends the following summer travel tips to assist senior adults whether driving, flying, taking a train or riding a bus.

- About a month before traveling be sure the senior consults with his/her doctor to discuss
  any special health needs, refill prescriptions to last through the trip and update any necessary
  vaccinations. If the older adult has a chronic medical condition, ask the doctor to write an
  overview of the loved one's medical history and provide medication instructions in case of
  emergency treatment away from home.
- Know your elderly loved one's physical limitations. Make sure the senior gets plenty of rest before and during travel. In the excitement of the journey, it's easy to overdo and pack in too many activities each day. Take frequent breaks.
- Make use of travel resources. When purchasing tickets or detailing an itinerary for the trip, plan
  ahead for accommodations and any dietary, mobility or medical needs. Even if your older loved
  one does not usually require mobility assistance, walking longer distances in airports or train or
  bus terminals can quickly exhaust seniors. Also, check whether restrooms are easily accessible
  and consider aisle seats for easier maneuverability. Contact airlines, rental car companies and
  hotels about your senior's special needs and allowing assistive medical equipment including
  oxygen tanks.
- Pack for the worst-case scenario. Keep all of the senior's prescription medications with you at
  all times. It may be tempting to carry only the pills your loved one will need for traveling and to
  store the rest in a checked bag, but travel delays or scheduling issues are common.
- Ensure the senior carries essentials. During the journey to your destination and when traveling about each day, be sure the older adult keeps a bag with the following handy: water bottle, medications, snacks, sunglasses, sunscreen, sweater/jacket and proper identification.
- **Verify phone numbers** with relatives and friends, and update emergency contact information in your cellphone, in case you need to reach relatives.
- **Dress for comfort.** In warmer weather, be sure the senior wears lightweight clothing in light colors to reduce overheating. Loose, comfortable clothing is best for traveling seniors to help with optimal circulation. If the elderly loved one is at risk for blood clots when sitting for long periods, ask if his/her doctor recommends wearing compression stockings while traveling.
- Avoid direct sun and too much heat. Seniors are particularly vulnerable to heat stroke and heat exhaustion. Be sure your older loved one stays hydrated and wears sunscreen and a hat.
- Visit tourist sites, public places and restaurants during non-peak times. Crowded, noisy surroundings can be difficult for seniors' hearing and mobility.
- Let travel apps guide you. The plethora of travel apps for smartphones can point out directions, keep track of trip expenses, and provide weather information and much more.

When planning a trip, include your loved one in the planning from the beginning so he/she can communicate personal needs and travel interests and feels included. If your senior may need more assistance than you will be able to provide, consider hiring a caregiver to travel with you. Senior care companies like **Right at Home**, **www.RAHSESD.com** can offer senior care travel services.



South Dakota Parkinson Foundation 1000 N West Ave, Suite 220 Sioux Falls, SD 57104 www.southdakotaparkinson.org PRSRT STD US POSTAGE PAID SIOUX FALLS, SD PERMIT NO. 1234

 $The South \ Dakota \ Parkinson \ Foundation \ a \ non-profit, voluntary \ alliance, is \ dedicated \ to \ improving \ the \ lives \ of \ those \ affected \ by \ Parkinson's \ disease, through \ fundraising, \ community \ building, \ advocacy \ and \ increasing \ public \ awareness.$ 

Recipe For: Parkinson's Annual Picnic  From the kitchen of: the South Dakota Parkinson Foundation and the Sanford Parkinson Support Groups
Ingredients: support group members  SDPF community  family
friends valet parking
catered lunch, no charge  Memorial Service  Friend Award
Mix all thoroughly on Wednesday, July 17, 2019,
Westport Ave, Sioux Falls, SD). Bake with the warmth of community for an afternoon of fun.  RSVP: info@southdakotaparkinson.org or 605-271-6113.
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