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Looking Ahead to 2023

As we head into the new year with a surge of new energy and excitement and we continue to grow as a foundation, helping more families across the state of South Dakota, raising awareness, becoming advocates, and providing more resources, education and support we can also look back at where we started knowing that through it all the mission to improve the quality of life for those touched by Parkinson's has not shifted and remains strong. We have come together in more ways than one and it's through this sense of community and partnership that we can reflect back on our successes and reach for even bigger goals in our future.

It can be challenging to come back even stronger than before after facing so many obstacles and unknowns and that's exactly what SDPF did. We faced challenges during the past few years head-on and worked together to find ways overcome. So yes, it's exciting to see just how far we've come and how we continue to grow. Just to reflect on some of the past year's successes...

SDPF made the exciting announcement back in 2022 that we would be implementing not just one, but two Parkinson's Awareness Conferences and even better yet both of these events would be free for all individuals and families that wanted to attend. The SF conference had its largest audience to date which also meant that come 2023 we would be searching for a new venue. And the very first RC conference held in October 2022 brought in close to 100 guests and some amazing presenters and has now made its way onto our annual calendar.

The Step Big Walk for Parkinson's was filled with many firsts. It was the first time in several years to host this event at a new location at Pasley Park in Sioux Falls. It was also the first time we had over 20 teams participate with over 500 individuals registered. And it was the first time the event raised over \$60K.

One of the biggest projects the foundation worked on through 2022 was the SDPF Newly Diagnosed folder. The design process for our vision began and content for the project came to life after many years of planning and discussions. Once completed in the upcoming year we will be able to distribute across the state to all major health systems and care facilities with the hope in mind to make sure that every individual that is diagnosed with Parkinson's receives one of these folders.



From the Doctor: Is Timing Everything?

Jerome 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 PD meds as often as every 2.5 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.

Care Partner Monthly Meetup with Connie Carpenter Phinney

Dates: 1st Tuesday of the month
Time: 1 pm

If you could use some extra support as a care partner, please consider joining the Davis Phinney Care Partner Monthly Meetup. During these one-hour sessions, Connie Carpenter Phinney and Davis Phinney Foundation Ambassadors and care partners Pat Donahoo and Gail Gitin discuss the concerns, challenges, and questions that many Parkinson's care partners have today.

Connie has been a care partner to her husband and Davis Phinney founder since his diagnosis 20 years ago. Pat is a care partner to his wife Cidney and Gail was a long-time care partner to her husband Gene before his passing. Together they have a wealth of knowledge and experience to share, but even more so, as fellow Parkinson's care partners, they "get" you in a way very few people do. So, come with your questions or come just to be in the presence of others who are traveling a similar path. If you need support and are eager to find additional ways to connect with others through meaningful conversations, you're going to love this hour each month with Connie, Pat, and Gail.

To register simply visit the Davis Phinney website at:

<https://davisphinneyfoundation.org/event/parkinsons-care-partner-meetup/>

Some topics that have been discussed during these monthly meet ups include:

- Intentions for the new year – the importance of rest & recovery
- Setting up your physical and mental environment for success
- Holiday stressors
- Gratitude in everyday living
- Open communication
- Planning for the future

These meetings are intended for the care partner and is a place to come together, ask questions and learn from one another.

Avera Parkinson's Community Exercise Program

Exercise is a vital component of managing symptoms related to Parkinson's. Avera offers Parkinson's-specific group exercise classes, with an emphasis on PWR! (Parkinson's Wellness Recovery) Moves, cardiovascular training, stretching, balance and agility, multi-tasking and functional strengthening. The multi-dimensional components of class aim to provide improvements in overall health, functional mobility, and social support. Classes also encompass a collaborative approach between the patient's therapists and our class instructor.

Here are some comments from current participants:

"Group Parkinson's Exercise Class is very important to me. I need the motivation to exercise, and the group does just that. Plus, I have many friends who understand what I am going through and we help each other."

"Intensity – that is what group exercise classes bring. I can exercise at home or with exercise CDs or You Tube offerings – but I find it's difficult to really challenge myself to do the intensity that really benefits me!"

"I began to attend later than the other participants had already started. It was an easy group to be assimilated into. We are so fortunate to work with such energetic people."

We would love to see you.

If you are interested in learning more or participating, please contact Jo Sannes, at (605)-504-2332.

Location: Avera Human Performance Center (6800 S. Louise Ave Sioux Falls, 57108)

Time: Monday – Thursday mornings



Step Big Walk for Parkinson's: Walking into 2023

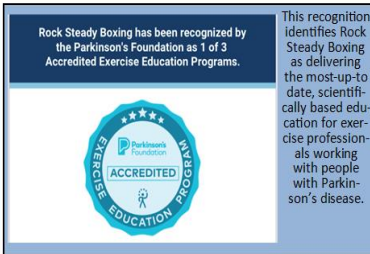
SDPF is eagerly planning the 2023 Step Big Walk for Parkinson's in hopes that it will be better than ever! With a team captain kickoff event, an updated online registration format, and a brand new location, the event is sure to be our best yet. We will host the in-person walk event but will also continue to maintain the virtual option as we want to continue to bring in new walk participants from across the state and surrounding areas. The past couple of years it's been so much fun seeing participants from California, Florida, Colorado and in other areas of South Dakota all come together to walk for our loved ones touched by Parkinson's disease. The new event date and location will be announced very soon so stay tuned and it's never too early to start putting your own friends and family team together.

Planning a walk fundraiser takes the talent and time of an entire team of individuals, working together to create an impactful and fun event. We need you! If you're interested in joining the walk planning committee, please contact Julie at info@sdparkinson.org. Committee meetings are held once a month for about one hour, starting mid-January 2023 up until the walk and shortly after to discuss the event's success. Events like this would not happen without the amazing help from all our wonderful volunteers. It's because of people like you this event continues to grow and reach new numbers every year.



Rock Steady Boxing Brings the Fun Factor to Exercise

Exercising is not always the most fun! Pushing yourself, getting sweaty, getting out of breath...but that's just what people with Parkinson's need to do! More and more research studies are touting the benefits of intense exercise in helping to slow down the progression of Parkinson's.



Rock Steady Boxing has recently been cited by the national Parkinson Foundation as 1 of 3 accredited exercise programs. This recognition identifies RSB as delivering the most-up-to-date, scientifically based education for professionals working with people with Parkinson's disease.

Parkinson's can be a lonely disease and many people don't want to go out socially. But when our fighters come into our RSB gym and put on their gloves – and start hitting our heavy and speed bags – many apprehensions vanish and an “I'm kind of a badass” swagger takes its place.

Rock Steady Boxing at The Inn on Westport has been helping people with Parkinson's fight back for almost six years. “Our boxing classes are fighting back against the symptoms of Parkinson's in all the drills and exercises we incorporate into class,” said Program Director, Lisa Howard. “From the quick footwork and agility drills we do, speed bag work strengthening upper back and shoulders, and intense cardio workouts on the heavy bags – each station is designed to address Parkinson's symptoms,” she added.

Our classes have become informal support groups as our boxers report the comradery as one of the things that keep them coming back. Add to that the “fun factor” mixed in – you have a winning combination.

Classes incorporate fun games, great music and even some balloon volleyball warm-ups into the curriculum. Despite the intense workouts going on – laughter is always in the air. Every six months fighters are re-assessed and across the board results taut the benefits of the program as balance scores improve, walking speeds get faster and leg strength gets stronger.

Here is what our fighters have to say:

“Steve is very committed to the Rock Steady Boxing program. His balance is very good and keeps improving all the time. Also, his neurologist is amazed at how strong his arms and legs are! This program keeps him moving and he is able to maintain his ability to walk, drive and take care of himself! We really appreciate all that Lisa does for him! She is a great coach!” Steve Stember (boxing since 2018)

“This class has stimulated me to be more aggressive with my daily routine. When I get done with the class I feel energetic and want to keep working, whether it's moving snow or other outdoor activities that I enjoy to do. My diabetic levels were at 6.7 and now are at 5.4 which I feel is a benefit of this program. I no longer have to take my diabetes medication. I would encourage everyone to do this program.”

Scott “Scoots” Quist. (boxing since April 2022)

Fighters are initially assessed to be placed in the most appropriate class for them. Potential fighters are encouraged to come observe a class and see if our program may be for you. Call Lisa at 605.362.1210 or email her at lisa.howard@innonwestport.org if you would like to learn more. You'll be glad you did.



ROCK STEADY
at
BOXING
THE INN ON WESTPORT



SDPF Recognizes National Family Caregiver Month

November was National Family Caregiver Month and during this time SDPF celebrated caregivers from across the state who have become amazing advocates for loved ones touched by Parkinson's disease.

During the month of November SDPF joined forces with Active Generations, along with several other professionals from local organizations to offer a one day event focused on the caregiver. The day was filled with speakers, exhibitors, lunch, break-out sessions, and fun gift baskets and door prizes. Everyone walked away with something and hopefully left that day feeling refreshed, inspired, and encouraged.

SDPF also reached out to those in the Parkinson's community to ask for special caregiver nominations. Individuals that received nominations were sent a little thank you gift from the foundation.

We wanted to share a couple of those nominations...

Harold and his wife Lorraine moved into the IOW this past summer. He brings Lorraine to her RSB classes 2x week and is an amazing cornerman for her. He motivates and encourages Lorraine and never harasses her to do anything out of her capabilities. You can see his love for her shine through each and every day. He is always there for her – but also takes time for himself and cultivates his love for wood-working by making toys for tots - wooden cars they send all over the world for children. Harold is an amazing example of a caregiver who stands by his loved ones side but also has learned to ask for help from others in his caregiving journey to take care of his lovely wife Lorraine. He is a shining example of a devoted husband. Thank you Harold for your example.

Don is always putting his wife first while trying to navigate his diagnosis of Parkinson's disease. We know it is so difficult for him to get the rest he needs, and to put himself first when he is such a devoted caregiver for his wife. Don, your valiant effort to be there for your wife does not go un-noticed! You are a truly devoted husband and we see all you do for Deliah. There are people who also care for you and want you to take time for yourself as well!



Director's Message

Janey Case, Executive Director



Happy New Year from my family to yours! I hope you and your family had a very blessed holiday season and took some time to relax and enjoy. It's hard to believe we've jumped right into 2023.

As we continue to take everything in stride, I'm looking forward to what we have planned for the coming year remaining hopeful that we will reach even more individuals and families touched by Parkinson's and continue to raise awareness across the state. Please take some time to look through the newsletter and read about all the wonderful things happening in the coming months.

There are several ways, outside of our newsletter, to stay updated with SDPF and I would encourage you to connect through the following online options:

- Website – www.southdakotaparkinson.org
- Facebook: listed under following names:
 1. South Dakota Parkinson Foundation
 2. Step Big Walk for Parkinson's
 3. SD Parkinson's Support Group
(private page with member request)

If online is not your preference, we will always have our quarterly newsletter distributed every January, April, July and October and it's completely free to be included on the mailing list.

So what's happening in 2023? Here's a quick glance at events and initiatives SDPF will be focused on:

- Petals for Parkinson's
- National Parkinson's Awareness Month
- SF Parkinson's Awareness Conference
- RC Parkinson's Awareness Conference
- SDPF Newly Diagnosed Folders
- SDPF Financial Assistance Program
- Parkinson's Annual Picnic
- Step Big Walk for Parkinson's
- National Family Caregiver Month

Thank you for your continued support and dedication. I feel fortunate to work for a foundation that demonstrates such passion and continues to educate, inspire, and encourage families touched by Parkinson's disease. We have so much to look forward to in 2023 and no matter the circumstances we are all in this TOGETHER!

EXECUTIVE BOARD

EDITOR

Janey Case

OFFICERS

Lisa Howard, *President*
Stephanie Meyers, *Vice President*
Noel Lais, *Treasurer*
Molly Keegan, *Secretary*

BOARD MEMBERS

Heidi Aderhold
Kris Ekstrum
Derek Simonsen

SDPF STAFF

Janey Case, *Executive Director*
Julie Nord-Eggebraaten,
Event Assistant

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 our foundation's mission and would like to become more involved in a variety of ways, we encourage you to consider serving on the SDPF board of directors. Currently, the SDPF board consists of seven volunteers from the Sioux Falls area. SDPF would like to continue our efforts in expansion across the entire state of South Dakota to have a full representation.

If you would like additional information or you have questions about this opportunity please contact the SDPF office. We would love to hear from you.

Thank You to All Our Donors

October 1st – December 31st, 2022

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

Bob Iverson
Marilyn Iverson

Sharon Kelley
Terry Kelley
Barbara Hegg
David & Bonnie Kiesow
Mike & Connie Ferrie
Kirk & Lori Kiesow
Roger & Judy Rae
Tom & Debra Graff
Robert & Diane Rieff
Gaylen & Shirley Backus
James & Lori Jones

Elaine Snyders
Luverne Community Foundation
Frank & Diane Newell
Lynn Larsen

IN HONOR OF

Don Vermundson
Avis Bergh



SDPF CHAPTER GIFTS

Gaylord & Mary Avery
Lynda Barley
Lowell & Paula Bartels
Dr. & Mrs. David Bartsch
Evelyn Blum
Curt & Nancy Cutler
Rosemary Draeger
Kristen Duerksen
Tim & Kristin Fox
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Randy & Mary Gross
Jennifer Hopf
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Robert & Diane Lien
David & Kathy Mah
Barbara McMurchie
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Lori Menke

Jim & Debbie Nixon
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Judy Olson
Tammy Pratt
Brian & Darla Slack
Barry & Carol Solomon
Richard & Marla Stoops
Carolyn Thomson
Becky Thorp
Alvin & Dorothy Vis
Mary Watson
Robert Webb
Marie Weisz
Benedictine Sisters
Rock Steady Boxers
Wellmark of South Dakota
Hy-Vee Operation Helpful Smile
Network for Good
Seed for Success Foundation
Sammons Financial Group
Sue Bastemeyer Memorial

Calendar of Events

January

Petals for Parkinson's Launch!

Dates: January 20th – March 31st

(all orders will be available before Easter 2023)

Orders: www.southdakotaparkinson.org



February

ADPA Educational Webinar: The Importance of Estate & Will Planning

Date: February 21st

Location: Online

Fee: Free & open to the public

Link: <https://www.apdaparkinson.org/events/parkinsons-educational-webinar-the-importance-of-estate-and-will-planning/>

March

Look for monthly educational webinars on the following PD websites:

- 1. Struthers Parkinson's Center:**
<https://www.healthpartners.com/care/specialty-centers/struthers-parkinsons-center/>
- 2. Michael J Fox Foundation:**
<https://www.michaeljfox.org/webinars>
- 3. Davis Phinney Foundation:**
<https://davisphinneyfoundation.org/>

April

SF Parkinson's Awareness Conference

Date: April 15th

Location: Active Generations

Time: 8 am – 3 pm

Fee: Free (*registration is required*)

****Stay tuned for more details to come!****

Community Support Groups

Aberdeen

2nd Monday (*every other month*)

1:00 pm

State Street Medical Square

Brookings

1st Thursday

1:30 pm

First Bank & Trust

Canton

3rd Tuesday

3:00 pm

Sanford Canton/Inwood

Huron

4th Wednesday

1:30 pm

HRMC Legacy Plaza

Luverne

1st Thursday

2:00 pm

Poplar Creek Care Center

Madison

2nd Sunday

3:00 pm

*Call for location

Mitchell

3rd Monday

2:00 pm

Avera Queen of Peace

Pierre

2nd Wednesday

12:00 pm

Countryside Hospice

Rapid City

2nd Saturday/1:00 pm

4th Monday/3:00 pm

SDSU Building

Sioux Falls

3rd Wednesday

1:00 pm

Edith Sanford Cancer Center

Sioux Falls (PD Caregivers)

Thursdays (*every other*)

11:00 am

Active Generations

SF (Family Caregivers)

Wednesdays

1:30 pm

Active Generations

Sioux Falls (Family Caregivers) Sioux Falls Women's

3rd Sunday

10:00 am

Gloria Dei Lutheran Church

2nd Thursday

1:15 pm

First Presbyterian

Viborg

3rd Wednesday

2:00 pm

Pioneer Memorial Hospital

Watertown

2nd Wednesday

2:00 pm

Edgewood Healthcare

Please contact your area support group facilitator each month for current meeting information. You can find a list of facilitators and phone numbers on the SDPF website at www.southdakotaparkinson.org.

Parkinson's Wellness Programs

The SD Parkinson Foundation can connect you with many wellness options for those managing Parkinson's disease. Exercise is a key component in slowing down the progression of the disease and SDPF can assist in finding an exercise regimen that best fits your needs. To learn more about specific programs or facility in your area please visit the SDPF website: www.southdakotaparkinson.org/wellness.

LSVT BIG & LOUD:

LSVT BIG & LOUD is a unique approach to physical and speech therapy designed specifically for people with Parkinson's disease or a neurological condition. Its success has lasted for up to at least two years after the therapy treatment.

PARKINSON WELLNESS RECOVERY:

The mission of PWR!4Life is to develop and implement worldwide access to cutting edge Parkinson disease-specific neuroplasticity-principled exercise programs that hold promise to slow disease progression, improve symptoms, restore function, and increase longevity and quality of life.

AQUATICS:

Aquatic therapy is exercise that can help delay the progression of Parkinson's symptoms and may be useful in reducing the severity of symptoms patients experience. Aquatic therapy helps patients maintain a greater quality of life and longer health while living with Parkinson's.

SPEAK OUT! & LOUD CROWD:

SPEAK OUT! & The LOUD Crowd is a clinically-proven speech therapy approach for individuals with Parkinson's. The program helps patients REGAIN and MAINTAIN their speaking abilities with a combination of education, individual speech therapy, daily home practice, group sessions, and regular re-assessments.

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ROCK STEADY BOXING:

Rock Steady Boxing enables individuals with Parkinson's disease to fight their disease by providing non-contact boxing style fitness programs that improve their quality of life and sense of efficacy and self-worth.

SDPF Financial Assistance Program

In support of the mission, the South Dakota Parkinson Foundation created a grant program to provide financial assistance for specific items, services, and programs that will aid in helping individuals, families, and support groups across the state of South Dakota.

Grants are available monthly and applications must be completed and returned to the foundation by the 1st of each month. All applications are kept confidential while being reviewed and applicants will be notified by the foundation. Applicants can apply for up to \$250 for assistance towards items and services such as walkers, exercise equipment or memberships, transportation assistance to/from doctor appointments or meetings, therapy tools, electronic devices, modifications to the home, just to name a few.

In 2022 grants were awarded for the following:

\$250 for home improvements

\$500 for PD voice & musical therapy

\$500 for Rock Steady Boxing in Watertown

\$250 for house cleaning services

\$500 for Rock Steady Boxing in SF

\$250 for Parkinson's therapy & exercise classes

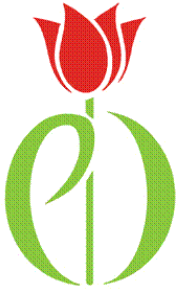
Testimonials:

"I am excited to receive a grant to help me attend the Loud Crowd! It will keep me motivated and it's always fun to participate in a group. I am very grateful."

"Thank you SDPF for the grant funding. I was diagnosed in 2018 with Parkinson's. I've needed modifications done to my home since my diagnosis, particularly my bathroom and the need for a high-rise toilet. This grant provided me with the funds have this installed and complete my bathroom modifications."

If you have additional questions please contact SDPF at 605.323.9779 or email at info@southdakotaparkinson.org.

Petals for Parkinson's



The red tulip has been associated with Parkinson's awareness since 1980 when a Dutch horticulturalist who had PD developed a red and white tulip and named it "Dr. James Parkinson." The European Parkinson's Disease Association (EPDA) uses a stylized red tulip based on the "Dr. James Parkinson" tulip as its logo. In April 2005, the red tulip was launched as the Worldwide Symbol of Parkinson's at the 9th World PD Day Conference in Luxembourg.

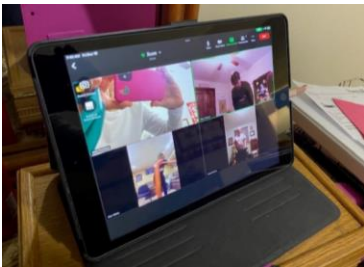
This stylized red tulip, with its distinctive leaves shaped like the letters "P" and "D", was designed by early-onset Parkinson's patient Karen Painter. Karen and her friend, Jean Burns, are behind the movement for it to become the nationally recognized symbol for Parkinson's disease awareness. The PD Tulip has inspired a grassroots movement combining efforts and resources to help find a cure in our lifetimes (*2017 Wilkins Parkinson's Foundation*).

April has been designated as Parkinson's Awareness Month, joining together to positively create a better understanding of Parkinson's disease and how we can better assist those living with the disease, their carepartners and family members. In conjunction with Parkinson's Awareness Month the SD Parkinson Foundation will be organizing for its sixth year, the Petals for Parkinson's fundraiser. We will be using the worldwide symbol (*the tulip*) to create awareness in our local and surrounding communities across SD.

Tulip sales will run January – March 31st. We are hoping to sell 400 potted tulip arrangements in the SF and surrounding areas with proceeds going to support the SD Parkinson Foundation. All tulips will be distributed before the 2023 Easter holiday.

Updates will continue to be posted on the SDPF Facebook page and through the SDPF website. A special thank you to Landscape Garden Centers for their continued dedication with this event. We truly appreciate the partnership over the years. We are excited to see all that is to come in 2023.

DIY (Do It Yourself) Zoom PD Exercise Classes



Most every Tuesday and Friday mornings at 7:30 am, you will find at least two women who have Parkinson's exercising via zoom. Mary Tidwell is usually the leader, but the rest (Glenda Halter, Cindy Jorgenson, Linda Martin, Mary Tranberg, and Kathy VanMaanen) feel free to make suggestions for the exercises and help lead if Tidwell isn't available. The group started during the Covid time, but they continue to meet to supplement the Avera classes held at the Human Performance Center in Sioux Falls two days a week.

The group uses the free 30-40 minutes zoom offering, usually set up by Tranberg. "It makes me a little more accountable to exercise more than just the twice a week classes," Tranberg said. "We know what we should be doing, but it's easy to slack off when you're by yourself."

Appointments and vacations get in the way, but the ladies join in as often as it works for them. Last winter Halter zoomed the regular Avera class from Florida, and Tranberg did the same a couple of times from Mexico. At times the DIY class has changed days depending on the availability of the group.

They do a variety of exercises using bands, weights, large dowels, etc. The basic PowerUp warmups are used, followed by various stretching and aerobic exercises. Ideas often come from the Parkinson's Foundation Fitness Friday YouTube videos. These videos are used frequently by the ladies when they want to exercise on their own. Another set of helpful videos are found under Power for Parkinson's. This is a perfect way to keep exercising and have that social time that is missing when you just follow a video.

Tidwell remarked, "Exercise for me can be downright boring and something I really don't look forward to. Our zoom group makes it much more tolerable and sometimes even fun! It keeps us exercising and holding each other and ourselves accountable.

Speaking with Intent Helps Speech in

Parkinson's

By Elizabeth K. Hanson, Ph.D., CCC-SLP

(elizabeth.hanson@usd.edu)

Department of Communication Sciences & Disorders

University of South Dakota

The saying “move it or lose it” makes sense when you read the research on Parkinson's disease and movement. We know that the reduced neurotransmitter – dopamine – in the brain of a person with Parkinson's leads to reduced movement in the muscles used for speaking and swallowing (as well as walking and other activities). One perplexing element of the condition is that the person who has it is not always aware of the changes in their speech, which may lead to delays in seeking speech therapy. But starting speech therapy early can help!

We don't think about the everyday act of speaking before we lose the ability to do it. Two speech treatments that have a growing body of evidence behind them is the SPEAK OUT!® and LOUD Crowd® treatment programs, developed by Samantha Elandary, M.A., CCC-SLP in Richardson, TX. This therapy approach is based on the Principles of Motor Learning and on the clinical research and expertise of Dr. Daniel Boone, a world-renowned researcher, educator, and speech-language pathologist.

SPEAK OUT!® therapy involves learning to turn speech – an automatic activity – into purposeful and intentional movement. The slogan is to “speak with intent” and it is learned during 8 – 12 speech therapy sessions with a trained speech-language pathologist (and sometimes their clinical graduate student). Practice at home is crucial to the success of the treatment and homework assignments are provided. Once speech goals are met, the patient “graduates” to the LOUD Crowd®, which is a weekly group session that provides a place to keep practicing intentional speaking with others in the program. LOUD Crowd® groups are also led by a speech-language pathologist (and sometimes their clinical graduate students) trained in the program.

The Communication Sciences & Disorders Department at the University of South Dakota was awarded a training grant from the Parkinson's Voice Project in 2021 and again in 2022. That means the professors who teach the graduate students in speech-language pathology are trained and certified providers of SPEAK OUT!® and LOUD Crowd® therapies and, moreover, the entire cohort of graduate students in the speech-language pathology program are trained to deliver this therapy! So far about 60 graduate students have been trained and the next cohort will begin their training in 2023.

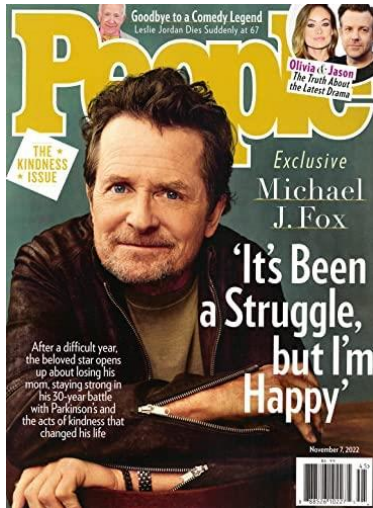
Because of this training grant the USD Speech-Language & Hearing Clinic is able to *offer the evaluation, individualized SPEAK OUT!® therapy, and LOUD Crowd® groups* to those with Parkinson's disease *in Sioux Falls, Vermillion, and across the state via telehealth!* This provides people with Parkinson's access to an evidence-based treatment while giving students unparalleled training experiences under the guidance of certified and licensed professionals. Together we work to combat the progression of Parkinson's disease to keep people talking!

For more information call the USD Speech-Language & Hearing Clinic at 605-658-3870 or email csd@usd.edu.

SPEAK
Live with Intent **OUT!**

The **LOUD**
Crowd®

People Magazine Exclusive Feature with Michael J. Fox



Michael J. Fox was recently featured in People magazine, talking about a difficult year with losing his mother, his 30-year journey with Parkinson's disease and how through it all he's remained hopeful and happy. It was a powerful read so here's a tiny bit into what he had to say.

People Magazine: Michael J. Fox 'When in Doubt, Just Be Kind' by Andrea Mandell, November 7, 2022 (The Kindness Issue)

Following a tough year of breaks and recovery, there's a mischievous glint in Fox's eye. The beloved star — famed for his optimism and tireless activism—who has helped raise more than a billion and a half dollars for Parkinson's research through his foundation since his 1991 diagnosis with the disease — will soon receive the Jean Hersholt Humanitarian Award, an honorary Oscar recognizing outstanding philanthropic efforts, at the Governors Awards on Nov. 19. But in the background, he has been quietly navigating another challenging chapter. His mother, Phyllis, died in September at the age of 92, and the past year has brought with it a cascade of frustrating new injuries.

The star has weathered difficult periods before. In a memoir two years ago, he chronicled what he called the worst year of his life, a period beginning in 2018 in which a risky spinal-cord surgery to remove a tumor was followed by a painful left-arm break. It ended with his recovery and an African safari with his wife, actress Tracy Pollan, and their four children: son Sam, 33; twin daughters Aquinnah and Schuyler, 27, and youngest daughter Esmé, 21.

But the past year brought new hurdles. "It got worse," Fox says matter-of-factly. "I broke my cheek, then my hand, then my shoulder, had a replacement shoulder put in and broke my [right] arm, then I broke my elbow. I'm 61 years old, and I'm feeling it a little bit more."

While Parkinson's affects Fox's movement, those around him say the injuries don't necessarily mean his disease is progressing any faster. He got an infection after surgery for his broken hand, and temporarily not being able to use the hand led to balance issues and falls. He admits the painful incidents put a dent in his sunny outlook. "I was never really a cranky guy, but I got very cranky and short with people," he says. "I try to nip it in the bud. I always think of these aides who work with me. And I often say to them, 'Whatever I say, just imagine I said "please" at the beginning and "thank you" at the end. Just take a second and absorb that I might have said that if I was more myself, but I didn't, so I apologize.' "

Fox also talked briefly about the power of positivity that he credits learning from his mother.

"My other lived a long, wonderful life. There was not a more revered woman. She was a sweet person. You knew you'd get a fair hearing. And she loved to laugh; she laughed like crazy." When he revealed his Parkinson's diagnosis to her, Phyllis was worried. "I started the foundation and was still doing TV and movies and raising a family," he says. "She asked me how I did it all, and I said, I just go forward. I'm not interested in taking inventory or ruing the thing not happening. My mother was like that too. She'd never add up the losses. She'd look at the gains."

To read the article in its entirety go to:

<https://people.com/tv/michael-j-fox-opens-up-about-painful-injuries-recovery-and-kind-acts-that-changed-his-life/>

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.

Thank You for Your Support!

As we wish 2022 farewell, all of us at the South Dakota Parkinson Foundation (SDPF) would like to thank you for your ongoing and generous support. Receiving a Parkinson's diagnosis can be overwhelming, riddled with questions. SDPF is here to be a light in your Parkinson's journey, letting you know you are not alone. Armed with information, SDPF connects individuals, their caregivers and family members to a robust network of service organizations helping to make more informed choices about your health and overall care.

The mission of SDPF is to improve the quality of life for all those touched by Parkinson's disease. Our focus centers around meeting you where you are at in your journey and bringing you the necessary resources and understanding your options when the timing is right. So thank you for being such an integral part of the South Dakota Parkinson Foundation's mission.

In the coming months whether you've made your own personal New Year's resolutions, or life goals, or just want to focus on the positive in your daily living here are some steps to help you along the way.

- ❖ Find someone to talk to
- ❖ Create healthy habits
- ❖ Keep active
- ❖ Find what brings you joy

"I was taught to strive not because there were any guarantees of success but because striving is in itself the only way to keep faith with life." ~Madeleine Albright

