



WISCONSIN PARKINSON

MAGAZINE ISSUE NO. 109 | 2022

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Our Mission and Focus
on the Future

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Charlie Dupont: A Man of
HOPE and Positivity

In this Issue



On the cover

Tulips have long been recognized as the symbol for Parkinson's disease. On April 11, 2005, the red tulip was launched as the international symbol of Parkinson's during the 9th World Parkinson's

Disease Day Conference in Luxembourg. This spring flower is a symbol of hope for those living with Parkinson's. A Dutch horticulturist, J.W.S. Van der Wereld, who had Parkinson's disease developed the original tulip – a glowing cardinal red, with a small feathered white edge and pale-yellow anthers. He named the flower after James Parkinson, the doctor who first described the disease.

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Parkinson's Awareness Month

April is Parkinson Awareness Month. It is the time of year WPA expands our messaging and outreach to increase awareness about the disease, its symptoms, and the resources that are available to help make life better for people living with Parkinson's, their care partners, family, and friends. Our goal is to engage as many people as possible to be advocates for this cause. Here are a few suggestions of how you can help build awareness about Parkinson's disease this month:

- Share WPA's information with someone who has Parkinson's
- Post WPA information on your social platforms
- Invite family and friends to join WPA's mailing list
- Ask your employer about matching funds for donations to WPA
- Invite friends and family to participate in upcoming events
- Support our sponsors and friends who are hosting fundraising events
- Hold your own fundraising event
- Share your own PD story – we'd love to hear from you!

Letter from the *Executive Director*

As you receive this edition, spring has officially arrived, at least on the calendar, and each week the energy of the new season seems to increase – temperatures are warmer, the sun feels brighter, the birds are singing louder, and our spirits soaring a little higher. Our gardens are also springing to life, and we look forward to the tulips blooming, our favorite flower and the symbol for Parkinson’s disease. To me, spring is the season of hope, and all of these activities of nature encourage us to be optimistic. It’s also personally rewarding for me to be part of Wisconsin Parkinson Association, an organization where hope is one of the cornerstones of fulfilling our mission, along with support, resources, and community. In this publication we’ll be focusing on how WPA brings those four pillars to life...and how together we are making a difference in the people living with Parkinson’s disease and their families.

April is Parkinson’s Awareness Month, a very important month to all of us. This month gives us the perfect opportunity and platform to share information about available resources, raise awareness about the disease and find new ways to collaborate and build community. This month also marks five months of being in the Executive Director role and I can tell you that I am more passionate than ever about the work that we do here at WPA. I have been meeting partner agencies, local and national representatives, community members, people with Parkinson’s, caregivers, medical staff, business leaders... anyone who I can talk to about how we can work together and collaborate to maximize resources. We know that it’s important to have a ready community of support, hope, and resources

available when you or someone you love receives that initial diagnosis “you have Parkinson’s”, and throughout living with the disease. Wisconsin Parkinson Association is here for you.

I am excited to tell you that our organization is currently engaged in a strategic planning process that will help us set both short and long-term goals for WPA. As an organization, we are looking at everything through a fresh lens with the intent to build upon existing offerings and deepen our impact. WPA knows that there are many needs to be addressed and our goal is to leverage our resources and the community to continue to provide support and hope for those affected by Parkinson’s disease in our communities.

In this month of building awareness for a disease that affects each of us personally in many different ways, I continue to be inspired by your stories. Please continue to reach out and connect with me and the team. We look forward to partnering with each of you as we move ahead on this journey to make WPA shine even brighter.

Forward
together,
Kelly



Kelly Cieslak, Executive Director
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Our Mission and Focus on the Future



WISCONSIN
PARKINSON
ASSOCIATION

PROVIDING HOPE, COMMUNITY, SUPPORT, AND RESOURCES
FOR PEOPLE WITH PARKINSON'S AND THEIR LOVED ONES.

Spring 2022 is a busy time at Wisconsin Parkinson Association! It is the season we recognize Parkinson's Awareness month and take time to reflect on the many programs and services that WPA provides for the men and women affected by PD – those who have the disease and their families and friends who support them in their care. As a team we are really reflecting on the core pillars of our mission: Hope, Resources, Community and Support and diving into how those elements come to life in the work that happens through our organization. The stories in this issue illustrate how the WPA mission positively impacts real people. We are inspired by their resiliency and willingness to share and help others through sharing their experiences.

Wisconsin Parkinson Association is fortunate to have dedicated and impassioned leadership and board members in our Executive Director, Kelly Cieslak, and the Executive Committee of the Board with President, Rob McDonald, Vice President, Angela Pecoraro, Secretary, Ron Mohorek and Treasurer, Ginger Wooster along with the entire Board of Directors. Both Rob and Angela have been WPA board members and have recently started their new terms in these executive board positions. WPA is continuously looking to strengthen and enhance our mission impact, and one of the ways we will do that is through engaging in a strategic planning process this spring.

Give a Gift of Hope! WPA Needs You!

Wisconsin Parkinson Association needs your help

Did you know that over 1 million people in the United States have Parkinson's? And more than 20,000 people in Wisconsin live with the disease.

At WPA, our mission is to provide resources, support, community, and yes, hope for those with Parkinson's and their families. WPA does that through educational webinars, living well programs, symposium, support groups, exercise and movement classes, advocacy, resources, and information for individuals who are newly diagnosed as well as those who have had long-term PD.

The need for WPA's programs and services continues to grow. Your financial contribution is crucial to ensuring these needed resources are available for individuals impacted by Parkinson's disease. Please give generously – give a gift of hope for a brighter future. It's only because of generous donors like you that we can make a powerful impact in the lives of those we serve.

Donating is easy!
Simply scan the QR code
with your smart phone to
make a donation today!



OR if you prefer, you can mail your
donation to the address below.



WISCONSIN
PARKINSON
ASSOCIATION

Give a Gift of Hope

Help us help those with Parkinson disease!

Print:
Name _____
Address _____
City _____
State _____ Zip _____

WPA is an organization that gives in the form of
programs and services so that
people with PD can live their best life.

Please accept my gift of:

- \$50
- \$100
- \$500
- \$1,000
- \$5,000
- \$ _____

Make checks payable to: Wisconsin Parkinson Association

Mail to: WPA, 16655 W. Bluemound Road, Suite 330, Brookfield, WI 53005

Please charge my: MC _____ Visa _____ Discover _____ AmEx _____

Card # _____ Exp. Date _____

Name on card _____ CVV _____

Email _____

Phone _____

WPA Spring 2022 Magazine

Charlie Dupont: *A Man of HOPE and Positivity*



Charlie & Jeanne Dupont

Sometimes in life we have an “Aha” moment, an instant when a universal truth or realization suddenly becomes completely apparent to us. Charlie Dupont recalls just such a moment.

He had gotten a flyer in the mail that discussed several early signs of Parkinson’s disease. As he read the flyer he realized that he had 5 of the 10 symptoms and that in all likelihood, he had Parkinson’s.

About 9 months earlier, Charlie and his wife Jeanne were walking from their car to the Fiserv Forum to attend a Bucks game. “I remember that we were lagging well behind some other fans who started walking from the same spot we did.”

“My handwriting had gotten smaller and somewhat illegible. When I took notes at a work meeting I often struggled to decipher what it was that I had written”.

A few days later Jeanne commented that he wasn’t swinging his arms when he walked. “I wasn’t trying not to swing my arms”, that’s just what happened. Several days later they received the flyer.

Charlie saw his family doctor who recommended that he see a neurologist. Charlie’s wife is an RN

at Aurora and knew of a very qualified neurologist and movement disorder specialist, Dr. Taylor Finseth, who confirmed Charlie’s “self-diagnosis of Parkinson’s disease. Dr Finseth also gave him some great advice.

“ I never thought my life was over or thought why me. What would be the point? ”

He encouraged Charlie, only 62 at the time, to start exercising immediately to help stave off the effects of PD. Charlie took that advice to heart, and within 2 months was attending a Big and Loud class that is designed to help combat the impact of PD on speech. It was during this class that Charlie learned about Rock Steady boxing. Soon thereafter, Charlie enrolled in a Rock Steady program at Fastback Physical Therapy in New Berlin.



Left to Right: Granddaughter Greta Ford, Son-in-Law Madison Ford, Daughter Alicia Ford, Granddaughter Penelope Ford, Charlie and Jeanne Dupont.

Continued on page 13...

Music Groupie Turned Concert Promoter Honors His Mentor



Left to Right: Kim McLean, Shana Morrison, Jamie Fox, Peter Jest, Jen Chapin, Stephen Crump.



Left to Right: Kelly Cieslak, WPA Executive Director; Harriet Mandelman; Steve Mandelman, Peter's Friend, Mentor and Honored Guest; Peter Jest, Concert Promoter, Jen Chapin.

Peter Jest has never forgotten the moment when concert promoter Steve Mandelman invited him to his office in 1982.

"I was a big music groupie in high school, but could not play an instrument," said Jest. "I bought and resold concert tickets in high school so I knew what shows sold and how well they sold. In fact I kept track of the concerts' gross sales and ads in a book. I called Steve in May of 1982 just as I was graduating high school and he was interested in looking at it."

Jest recalled getting paid to work shows like Van Halen and Diana Ross before Steve left the industry later that year. "That solidified that I wanted to be in the music business as a concert promoter," Jest said. "We have been friends ever since."

Mandelman has been battling Parkinson's Disease for years. When the idea arose to hold a fundraiser concert series for Parkinson's, Jest, who is Shank Hall and Alternative Concert Group's founder, jumped at the opportunity to honor his mentor.

Jest worked with singers Jen Chapin and Shana

Morrison to perform concerts at Milwaukee's Shank Hall, The Grand Oshkosh and Madison's Barrymore Theatre early in March to benefit the Wisconsin Parkinson Association.

Chapin, who is the daughter of the late Harry Chapin, and Morrison, whose father is Van Morrison, had never met or performed back to back in a concert. Both have released multiple, critically-acclaimed albums of their own music (10 for Chapin, five for Morrison).

"Without Steve inviting me to his house after I called him, there would be no Alternative Concert Group or Shank Hall," Jest says.

"When Steve was afflicted with Parkinson's, I wanted to do what I could. The sooner we find a cure, the better. Steve promoted many shows with Harry Chapin, so in his honor I wanted to present these shows, featuring Jen and a favorite of mine, Shana Morrison."

The concert series was a huge success, raising \$10,000 for the Wisconsin Parkinson Association.

"It was really fun to see Steve and his family connect with Jen Chapin, as Harry meant so much to Steve," Jest said.

“What Can You Do?”

The Resourcefulness of a Caregiver

Even though Gordon has been gone nearly five years, his daughter Kristine Johnson is still very much connected to him by the memories she has of caring for him during his Parkinson journey. Through that experience she discovered a passion for being a caregiver that didn't end with her father's passing, but in fact has grown because she understands both the gift and the challenge of managing that role. Kristine is very inspired to share what she has learned in hopes it helps others who are walking in her shoes.

Kristine found herself in the caregiver role for both her parents, first for her mother who had many medical issues that needed care and attention. And, soon after her mother passed, her father Gordon started exhibiting symptoms such as a shuffled walk, and then he developed a UTI that hospitalized him with intense symptoms. What doctors' thought might be Lewy Body, ultimately was diagnosed as Parkinson's Disease.

Kristine describes this period as a “quick front row seat” to the disease. Gordon's PD had a very fast onset and progressed rapidly. In the two years that Gordon lived with PD there

were many challenges to address, including the distance that Kristine had to travel to care for him (he lived in La Crosse, she lived in the greater Milwaukee area). Gordon wanted to retain his independence, Kristine worried about his safety and health when she was back home with her family. Life activities that we take for granted suddenly become difficult and Kristine would watch her father struggle with trying to complete simple tasks.



Kristine has a social work background, which gives her more preparation than most of us to handle life challenges, and yet she felt totally unprepared, assisting her father as he lived with Parkinson's disease. It was literally living day-to-day trying to figure out what care routines to put in place for her dad. She recalls it was like “putting out fires every day.” There was also a whole grieving process that was playing out during this

time as well, both for Kristine as she watched the changes take place in

her father, and for him as he lost the ability to do things for himself.

At some point during this intense journey, Kristine had that “aha” moment. Maybe the focus didn't have to be on what was lost or being diminished, instead she turned the question around and

started asking herself “what can we do?” And, to her father, when he focused on what he couldn’t do, Kristine would ask him, “if you can’t do that, what can you do?” She also realized she needed to “be a daughter, not a caregiver.” Sometimes

Sometimes the simple act of just being with someone is the greatest gift we can give them. Kristine found this to be one of the things she cherished most – sitting, even if it was in silence, with her dad, letting him know that she was there with him.

the simple act of just being with someone is the greatest gift we can give them. Kristine found this to be one of the things she cherished most – sitting, even if it was in silence, with her dad, letting him know that she was there with him. “It was really an honor to be with him at this time in his life,” said Kristine.

She showed me pictures of her father as a young man, standing tall and proud in his police officer uniform and recalls that he was always the strong, resourceful head of the family. Another favorite photo that reminds Kristine of her dad is of a small hand-held barbell with weights that Gordon kept by his chair. He would lift them regularly to maintain strength in his arms. It is a symbol to



her of her dad’s unwavering perseverance in the face of Parkinson’s disease.

Throughout this journey Kristine discovered the paradox of caregiving – it was overwhelming, and it was beautiful; it could be frustrating but also a time of complete compassion. Kristine said, “I look back on that experience as an honor.” As Kristine moves forward, she carries a purpose and desire to be there for other caregivers. She encourages caregivers to be resourceful and reframe the mindset when what used to be possible no longer is, to instead ask “what can you do?” The answer to that question can lead you to some amazing ways to support your loved one with Parkinson’s. That perspective made all the difference for Kristine and Gordon.

Where Do You Start

When You Get the Diagnosis?

"You have Parkinson's." Shock, disbelief, fear... just a few of the emotions that begin to course through your mind when you hear those words. Once you process those words, what happens next? How do you know where to start with finding the support and resources you need to live with Parkinson disease?

In our digital world, our phones and tablets become our research library – isn't the starting point often "Let's Google it"? When you begin to do your own research on PD, remember you are going to find a lot of information online...and not only helpful information, but also a lot of confusing, frightening, and even incorrect information. It's important to look for reputable sources and filter out those that may be promising quick remedies or are trying to sell you something. So, how do you determine if the organization is a trustworthy resource? Go to the organization's website. How are they presenting the information? Is the organization looking out for your best interest in sharing data and helpful resources, or are they more interested in promoting or selling something?

Wisconsin Parkinson Association is a trusted resource. As a state-wide non-profit that has

been in existence for 38 years, our mission has always been about serving people with Parkinson's and their families by providing resources, community, support, and hope. We have information, offer support, are able to connect you to PD resources throughout your Parkinson journey as well as providing insight and perspective for family members and caregivers. Other reliable sources for information include the National Institute of Health (NIH), and national level Parkinson organizations. These sources can provide additional guidance and resources to help you navigate your diagnosis and living with Parkinson's. You may also receive information from your doctor on some of these websites, which can also help you validate which resources are worth exploring.

It's normal that you may experience the stages of grief: Denial, Anger, Bargaining, Depression, and finally Acceptance after your diagnosis. Remember, Parkinson disease is not fatal or life ending, and you can live a very long and fulfilling life as you understand more about PD, its progression, and how to stay active and healthy.

After you have done some initial research about the disease, how do you build your Parkinson care team? Getting connected with a movement





disorder specialist, who is a neurologist with additional training in Parkinson's disease and other movement disorders, is an important early step.

This type of doctor typically has extensive knowledge of

Parkinson's therapies and ongoing research. Within your health care team, you may also meet other professionals, such as nurse practitioners, nurses, physical therapists, or other skilled care providers who will play an important role in your journey.

The advice many people living with Parkinson's share is that it is important to get connected to a community of support. For example, support groups and exercise programs that focus on Parkinson's can help you move beyond the fear and learn successful ways to manage your diagnosis. They are great resources that connect you with others who are experiencing the same things as you. Support groups are not just for the person living with Parkinson's, many groups include care-partners as well. Many of the support groups will bring in external speakers on current topics of interest around Parkinson related care or activity, as well as provide opportunities for open dialogue about your symptoms and concerns. Support groups provide valuable educational resources and emotional support.



Receiving a diagnosis, whether expected or unexpected is certainly life-altering. Wisconsin Parkinson Association wants to be there to provide resources and support to help you live your best life.

As you start your journey living with Parkinson's having a triad of support: your Parkinson's care team (medical team); a good support network (support groups, exercise groups); and trusted knowledge and resources (connection to Wisconsin Parkinson Association, and other related organizations) will give you the best way forward to live your best life for the rest of your life. Information about the resources available to you can be found on the Wisconsin Parkinson Association website at www.wiparkinson.org.



Game Changer: *Staying Active is Key Managing Parkinson's*



Rich and Sue Petersohn love the ocean...the waves crashing, the sand under their feet. Rich grew up on the East coast and enjoys trips to the Atlantic.

One day, about four years ago, while walking on the beach to observe the sunrise, Sue had difficulty navigating the soft sand. She had been a semi-

professional skater most of her adult life, and usually Rich was the one who had a hard time keeping up with her.

But this day was different. While harder sand was a bit easier for Sue to navigate, both look back on that day as an early sign that something was up. Sue had started a bit of trembling, too, that at first was brushed off as mild anxiety. When friends started to notice more tremors, it was time to see a neurologist. The diagnosis was not only devastating; it caused a lot of fear in Sue, a retired teacher and active outdoors person.

That day at the beach was a beautiful day in August. By October and November of that same year, Sue couldn't get out of the car easily. "One day I remember after being diagnosed, I

wanted to ride my bike," Sue recalled. "I was a nervous wreck to ride." She was later was sharing this with a friend who has Parkinson's.

"You have no business being on that bike," the friend said. "Your sense of balance isn't what it was." So Rich and Sue bought an adult three-wheel bike, so she could continue exercising and remain mobile.

'Don't' be a victim. Be an advocate,' said Rich. 'WPA really cares. Get involved.'

"With Parkinson's, you have to be mobile," Rich added. "You must do everything you can possibly do. Otherwise the repercussions are horrific."

Rich and Sue are staunch advocates for the Wisconsin Parkinsons Association (WPA) because the organization connects them with resources and exercise classes to keep Sue moving.

"The last thing you want to do is get out of a chair. It sounds awful," said Sue, who did synchronized swimming well into her 60s. "You have to override that in your head."

With Parkinson's, you have to move. We are stiff. Our joints are stiff. When I would walk, it's like a

tin soldier. It doesn't hurt. It just isn't smooth. By the time I'm done with a class, I feel wonderful."

Sue attends exercise classes five times a week, and Rich is right by her side. He physically benefits from it as well. WPA connected them with supportive places such as Fastback and Rock Steady Boxing.

The classes focus on balance, cardio, strength, eye-hand coordination, and exaggeration of movements, such as swinging arms. Patients have to exaggerate to compensate, they said. "We've learned so much," Rich added.

Rich recalled being in the WPA office and seeing a beautiful hand-carved Indian sculpture that another Parkinson's patient had carved for WPA's director at the time.



"When they are doing something with their hands, the symptoms seem to go away," Rich said. "It's a matter of being engaged that is so important." WPA keeps people engaged and finds support groups for patients. "We wouldn't know about Fastback without WPA being instrumental in building the community and helping patients."



The Petersohn's have so much to live for. At age 76 and with three children and thirteen grandchildren, they are not about to wilt away. They want to get back to kayaking and canoeing this spring, and Rich is continuing to advocate for easier lake access for people with disabilities.

"Don't be a victim. Be an advocate," said Rich. "WPA really cares. Get involved."

Exercise Corner

Find an exercise class in your area or virtually at wiparkinson.org.

Exercise has been proven to be one of the best ways to slow “the progression of Parkinson’s disease. Wisconsin Parkinson Association encourages people with Parkinson’s to participate in the exercise and movement classes that take place throughout the state and online. We are fortunate to have instructors who are passionate about the importance of exercise.

Our instructors come from backgrounds that include education and training in physical therapy, dance, fitness, and overall wellness. Spring is a good time to start a new exercise routine. Challenge yourself to find a class that you enjoy and develop a habit of health. Check out our website for details on our exercise classes...and, here is an opportunity to meet our instructors.



ELLEN DOVRE
Chippewa Falls



JOY CHOCHRON
Watertown



KATE MANN
Fond du Lac



LUCY SCOTT
Stevens Point



MARY WOOD
Cudahy



MICHELLE JENNS
Kiel

IMPORTANT WPA DATES

Mark your calendars for these upcoming events that benefit Wisconsin Parkinson Association. We are grateful to all the volunteers and staff who make these events possible and create opportunities to build community and spread awareness about PD.

April 23	Mini-golf outing – Sponsored by Matt and Megan Puthoff in memory of Tim Puthoff with all proceeds going to Wisconsin Parkinson Association. Golfing at Gastrau’s Golf Center with Awards Banquet at the Bottle Milwaukee. To register contact Matt Putthoff at mputhoff13@gmail.com
April 23	Dopamine Dash - Event by Touchmark on West Prospect Retirement Community to benefit Wisconsin Parkinson Association. Join us for a dash around Touchmark! Enjoy walking, dancing, boxing, and more on an outdoor course as we raise awareness of the vital role dopamine plays in keeping us on the move. Registration is \$10, and all proceeds go to the Wisconsin Parkinson Association. Please call 920-666-2503 or visit www.Tchmrk.co/DopamineDash2022 to register by April 15 to ensure your complimentary T-shirt.
April 27	Tulips for PD with the Friends of Boerner Botanical Garden (Details coming soon!)
July 6	Milwaukee Milkmen Baseball Game – WPA is the Featured Non-profit Organization (Details coming soon!)
Sept. 13	WPA Golf Outing – The Dick and Dee Schumann Memorial WPA Golf Outing WPA’s annual golf outing this year is named in memory of Dick Schumann and his wife Dee, long-time friends, and supporters of WPA. (Details coming soon!)

...continued from page 6.

Charlie is retired and Jeanne is still working. He is independent and hasn't made any changes to his daily life, except he doesn't get up on the second story of his house anymore. "My balance isn't quite what it used to be".

Charlie is a proponent of being as informed as you can about what you're dealing with. He spoke of somebody who told him she cried every day about her diagnosis. Not Charlie.

"I never thought my life was over or thought why me. What would be the point?" Within about 6 weeks of his diagnosis Charlie and Jeanne attended a WPA symposium at The Wisconsin Center.

To the newly diagnosed Charlie says, "Get involved in exercise programs as soon as you can, find a Big and Loud class. There are therapists

that can show you so much to build a good foundation for your exercising".

But Charlie is concerned about what he sees as an information gap that exists because some newly diagnosed aren't made aware of the resources that are available to them like Rock Steady Boxing, Big and Loud, and the many services provided by the Wisconsin Parkinson's Association.

In order to help fill that gap Charlie has taken his involvement with Parkinson's education a step further, recently joining the WPA board.

Michael J Fox said, "Acceptance doesn't mean resignation; it means understanding that something is what it is and that there's got to be a way through it". Charlie Dupont, in words and actions, lends credence to that philosophy.

The Dick and Dee Schumann Memorial WPA Golf Outing

This 11th annual golf outing is our signature event and it's an event not to miss! Held at The Legend at Merrill Hills course, the day includes lunch, golf, silent and live auctions, and dinner. This year's event will honor a special friend of WPA – the late Dick Schumann who passed away earlier this year. Dick filled many roles for WPA including board member, advisor, mentor, financial contributor, and community supporter. His dedication was first and foremost to his wife Dee, who lived with Parkinson's for many years before she passed away. Dick's care and compassion for her led him to be an advocate in a broader sense for others through the Wisconsin Parkinson Association for over 30 years. He will be remembered for the leadership and vision he had for WPA and its role in serving people with Parkinson's and their families. He knew firsthand the importance that education, support and hope plays in living with this disease. WPA can truly say that Dick Schumann was instrumental in making this organization a long-standing resource for the Parkinson community in the state of Wisconsin.



Would you like to receive Wisconsin Parkinson Magazine?

If you do not receive *Wisconsin Parkinson Magazine* quarterly, join our mailing list at wiparkinson.org. You will receive this magazine, as well as periodic information about educational events, support & exercise groups, and other resources in your area. This magazine is funded by your donations. Your support helps those living with Parkinson disease by allowing us to enhance and expand our services to you and your families. For more information, visit wiparkinson.org.

Wisconsin Parkinson Association provides hope, community, support, and resources for people with Parkinson's and their loves ones.



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