



# Capital Area Parkinson's Society

Newsletter/February 2021

P.O. Box 27565, Austin, Texas 78755-2565

512-371-3373

capitalareaparkinsons.org

## A Word from Your President



Welcome to the month of Love, Groundhog Day and hopefully, the beginning of a "light at the end of the tunnel" vision out of the current COVID-19 pandemic as vaccinations become more accessible! My wish for each of you is that you will be able to receive those vaccinations soon! I am very excited to announce that the **MEMBERS ONLY** section that we have been working on is finally going to be launched in February! For those of you who have paid your CAPS membership dues, you will be receiving an e-mail from us inviting you to fill out a sign-up form that will ask for your user ID and password, so that you can access this new feature. We will be in a "testing" mode for these first few months and will, therefore, need your feedback. There will be several Zoom events listed on a special calendar, along with discounts and offerings. So remember, your **CAPS DUES ARE DUE!** And then, take advantage of this new set of benefits of your membership! CAPS support groups, monthly meetings, information and resources on the website, and the newsletter and general calendar will still be available to the public and to the CAPS community at large. **THANK YOU** for your support!

Take care, Ingrid

## Loving the Man—NOT Loving Parkinson's

Angela Robb, January 19, 2018

The way that my husband, Karl and I met was unconventional. It was 1995 and the Internet was just starting to make strides into people's homes. We met on a Saturday night—in a chatroom! It was a unique start for a unique union.

Karl and I spent the first few nights getting to know each other by playing *Twenty Questions* via instant message. Asking all types of questions about life, living, likes and dislikes, I remember trying to be creative and funny while making sure I spelled rapid replies, correctly. Karl made me laugh through his responses. I could tell he was smart, funny, inquisitive, and overall a happy person. All these qualities made me want to know more about him and meet him.

Our online conversation progressed to the phone—a dated hardline phone. When I wasn't working, we would spend what seemed to be hours talking to each other. One Sunday evening, maybe a week or so into our friendship, he revealed to me that he had Parkinson's disease.

### How Parkinson's Entered My Life

In a flash, my mind flew back to a memory of sitting in anatomy class, my senior year of high school, learning about the nervous system. My teacher spoke briefly about Parkinson's disease, detailing that it mostly affected older people and mentioning something about a tremor being the most notable symptom. I asked Karl how could it be that someone so young (at the time, Karl was 28) could have Parkinson's? He began to

relay to me his personal story of struggle in living with undiagnosed symptoms, visiting over nine doctors to find out what was wrong, and how he had self-misdiagnosed himself with a brain tumor!

Fast forward to today, twenty-two years later. When I introduce myself at Parkinson's events or support groups, I make sure to say that I met Karl after his diagnosis. I feel it is important for fellow care partners to know that my introduction to Parkinson's may be unlike theirs. Parkinson's did not enter my life via a shocking diagnosis in a doctor's office. Parkinson's entered my life because I love a wonderful human being who just happens to be living with this disease.

### Adapting to Life with Parkinson's

I wasn't about to give up a life with Karl because of Parkinson's. Does Parkinson's make life difficult sometimes? Absolutely! Parkinson's can be a total disrupter—wrecking plans to take a walk or a hike, enjoying a meal with friends, or changes plans for a vacation. But, here's where adaptation comes in, and turns Parkinson's into a teacher. Instead of taking a walk or a hike right now, we might drive around taking pictures at overlooks until the medication kicks in. We found that the friends who couldn't cope with the dyskinesias at dinner lead us to new friends who didn't mind the dyskinesias and

encouraged us to go out more. We modified our vacation plans to include off-times, and we found ways to make accessing vacation sights easier, such as taking cruises.

Do I have uncertainty about the future? Yes! But it's not primarily the Parkinson's that causes this uncertainty. Doesn't everybody have a sinking feeling sometimes when they think about the end of their life or their loved one's life? I do. What I do is not let the uncertainty rob me of this moment. I do all I can to make the most of this moment and realize that I love my life, I love my husband, and I'll do whatever it takes to make the most out of today—whatever it brings! ■

**\$20**

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Capital Area  
Parkinson's Society

**10% discount members only**

**Comfortable, wrinkle-free cotton, sizes S-XL, gray only. Order yours online today to support CAPS! Thank you.**

SAVE THE DATE

**Join CAPS with Amplify Austin on March 4th!**

For the third year in a row, CAPS has joined the "I Live Here, I Give Here" fundraising campaign as one of the local non-profits raising awareness and donations in the Amplify Austin on-line 24-hour fundraising event (March 4-5, 2021). Your gifts made to us on March 4 will be amplified—so please help us serve the growing needs of the Central Texas Parkinson's community! Here is the link:

<https://www.amplifyatx.org/organizations/capital-area-parkinson-s-society>

Please let your friends and family members know too! Thank you!!!

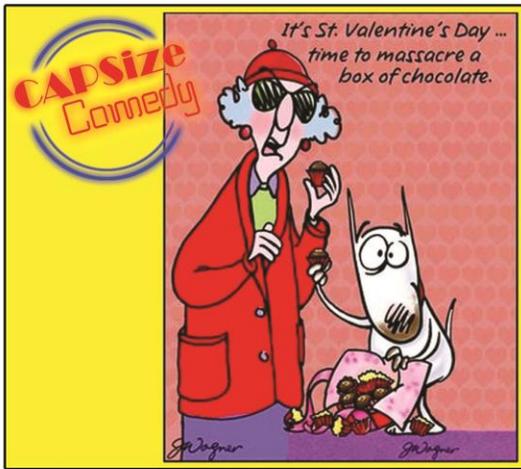
Amplify Austin

Meet Your CAPS Board of Directors

**Andrea Nobis**

Andrea Nobis, joined the Capitol Hospice team in 2019, bringing with her a wealth of knowledge and expertise. She has worked directly in the hospice field for 4 1/2 years and indirectly collaborating with hospice agencies for 17 years. Andrea earned her Masters of Social Work from SUNY Albany and began her career as an Executive Director and Regional Consultant of an assisted living community in Phoenix, Arizona. Ten years later, she relocated to North Carolina to start a family. After five years, Andrea moved to Austin and promptly joined the hospice team of the Capitol family where she is able to offer support to patients and their families.

Outside of work, Andrea enjoys spending time with her husband, Mike, and son, Jacob. As outdoor enthusiasts, they enjoy activities such as swimming, hiking, camping and trips to the beach.



**Virtual Area Outreach Support Groups**

(Contact CAPS office at 512-371-3373 for more information)

“Women” Care Partners – Tuesdays, Biweekly

Parkinson’s Care Partners – 1st Wednesday @ 11am

People for Parkinson’s, Men and Women – 3rd Thursday @ 3pm



**Area Outreach Support Groups - Temporarily On Hold**

- Burnet – 2nd Wednesday @ 2pm
- Deep Brain Stimulation (DBS) – 3rd Friday @ 2pm
- Baylor Scott & White/Lakeway – 1st Tuesday @ 2pm
- Parsons House – 2nd Wednesday @ 2pm

For more information, visit [www.capitalareaparkinsons.org](http://www.capitalareaparkinsons.org).

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**February Membership Meeting**

“LIVE”



with Dr. Tom Hill and Corinne Jones

**Virtual Meeting**

**Saturday  
 February  
 20th  
 2:00 p.m.**

Please join us for a “LIVE” Q&A with two of our very own board members: Dr. Tom Hill, a retired Neurology Specialist that has worked with Parkinson’s patients for over 20 years; and Corinne Jones, an assistant professor and a practicing speech-language pathologist at UT. They will answer questions regarding your Parkinson’s disease, your medications, your functional issues and the problems you haven’t even thought to ask your doctor about. Some focus will be on the non-dopamine issues and functional issues with gait, balance, cognition and depression.

Following the presentation, there will be a fun dance exercise recorded by Art Beat Dance Center. A link will be posted on the website. They also offer a free PD class—visit <https://www.artbeatdancecenter.com/schedule>.

