



Leading with Compassionate Care: *Stories and Updates*

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Music legend explains life with Parkinson's

San Francisco's KTVU recently conducted a video interview at Linda Ronstadt's home as a feature in their segment "Bay Area People." In her gracious and witty manner, she shared parts of her experience living with Parkinson's, which are highlighted in the article below. If you'd like to watch the full five minute interview, or see an additional video highlighting the Institute, visit the archives of www.ktvu.com/community.

Most people know Linda Ronstadt for her 45-year singing career. She won Grammys for hits like "I Can't Help It (If I'm Still in Love With You)" and "Hasten Down the Wind" in addition to garnering countless other awards in her genres. She was inducted into the Rock and Roll Hall of Fame in 2014.

At the time of her memoir's release in 2013, what most people didn't know was that Ronstadt had just been diagnosed with Parkinson's.

Looking back on the diagnosis now, Linda shares that it came as quite a shock at first. It's a sentiment common among those who are told their symptoms and pain relate back to this disease.

Linda thought when she retired she would explore the world, getting a break from the chaotic life of a professional musician. However, her Parkinson's keeps her a bit closer to

her home in the Bay Area. Most tragically, it took away her wonderful ability to sing.

"There are thousands of vibrations a second that happen in a female voice when you sing, and what you can't do with Parkinson's is repetitive motion," Linda explains. "Thousands of vibrations a second is a lot of repetitive motion."



Linda shares her life from a different stage now.

Photo Credit: KTVU video interview

Despite the loss of her ability to sing, Linda found new hobbies; she is an avid reader and enjoys her outdoor garden, also relying on lifelong friends to keep her spirits lifted. "It's humbling to be able to do stuff and then suddenly not be able to do it. I have a lot more sympathy for people that are disabled," she shares.

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From our CEO

Dear Parkinson's Institute family,

Your Parkinson's Institute and Clinical Center continues to zero in on areas that might effect the most change for patients, their families, and the future of Parkinson's. That's why we exist.

And that's why over the past several months, I've been working in Washington to introduce and move legislation that would provide innovative pharmaceutical industry leaders with seven years of market exclusivity for neuro-protectants developed to halt disease progression and ultimately, cure Parkinson's and other central nervous system disorders. You can read more about it on page 4 of this newsletter.

Collaborating with Washington, DC-based colleagues to aggressively describe the urgency of this legislation has been inspiring. Many staff and Members understand the need for front-end financial support to be appropriately protected, consistent with other diseases.

The patients we serve daily at the Institute are never far from my mind. Neither are people like you, who support the Institute with financial gifts, support a family member or friend with Parkinson's, and perhaps even live with Parkinson's personally.

Here's to successful advancement of new, catalytic investments toward life-saving treatments and the cure for Parkinson's. I'm grateful for your part in the story.



Carrolee Barlow,
MD, PhD
Chief Executive Officer

Music legend explains life with Parkinson's

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Linda participates in fundraisers and other events where she occupies a much different platform than the music stage but is able to share her experience with Parkinson's.

“Parkinson's is so much a part of my life now, but I didn't even remotely think that could happen.”

– Linda Ronstadt

“Ordinarily I would have sung concerts to raise money, but I can't do that anymore,” Linda says.

“I always think you give your gift, whatever that is. When there's a chance to help people understand what it's like to have Parkinson's, I'm happy to do it.”

We admire the bravery and resolve of countless patients like Linda we serve at the Parkinson's Institute in the face of a difficult disease. And we cannot offer the world-class care or research we provide without people like you who, in Linda's words, ‘give your gift, whatever that is.’

Please consider making a donation to the Parkinson's Institute and Clinical Center, and remember that any gift made through 12/31 will triple in impact thanks to a generous matching gift. Thank you!

Your gift TRIPLES in impact this fall

We are so grateful to a generous supporter of the Parkinson's Institute and Clinical Center for providing a significant gift this fall. **Through December 31st, all gifts you make will be TRIPLED dollar-for-dollar, up to \$500,000,** to provide the highest level of compassionate care for each individual we treat suffering from Parkinson's. Additionally, your gift will work to advance critical research, establish better treatments, and unlock cures for this disease.

Volunteer Spotlight:

High Schooler Shivani Seshan

Still in high school, Shivani Seshan already identifies in herself a heightened interest in diseases and biology. When she heard that the Parkinson's Institute and Clinical Center was looking for volunteers for the annual Battle of the Bay walk, she decided to join the team as a high school sophomore for a few hours a week. That was last November.

"I always enjoyed the work that I got to do on the development team because it was an hour of my day not thinking about the stress of school," Shivani shares. "Even if it was something monotonous, it was fun." Leading up to the walk, she helped stamp envelopes and organize sponsors. Then an opportunity opened up to help in the laboratory.

In the lab, Shivani started applying what she was learning in her AP biology class to real-life research during her volunteer shift right after school. Her voice grows even more enthusiastic as she talks about her experience working with Dr. Schuele. "It was the first time I was in a traditional lab setting, so I was constantly surprised at all the different machines that were in the lab," she explains. "It was a crazy experience for me because it is the thing that I want to do in the future and I got to experience it a little while there." Shivani considers it an honor to have worked with Dr. Schuele, who makes so many advances in research concerning Parkinson's. It's really the entire team at the Institute she admires. "They are



"I remember the first time I stepped into the lab at the Parkinson's Institute, I thought—YES—I want to do this again," Shivani recalls. "It made me like biology more."

really nice to work with, really smart, they know what they're doing...it's really cool," she says. "I'm kind of at a loss for words when I watch them do their thing."

When asked why she remains passionate about volunteering at the Institute a year later, giving up every Friday afternoon while juggling junior year coursework and extracurriculars, her comments get personal. "I see my grandparents and friend's grandparents with deteriorating health. I see more

and more issues in our world today, and I think it should be getting better, not worse. So if a group of people are motivated to help out more people, then at least one life will be saved."

She found that group of motivated, compassionate people at the Parkinson's Institute and Clinical Center. This fall, she's volunteering in the clinical department. Her aspirations for the future include attending a college in California for biomedical engineering or biochemical engineering with hopes of creating future technology to advance research and expedite cures for diseases. In light of these significant goals and the potential to reach them, she considers every function performed at the Institute worthwhile.

"Even if it's just sending out letters so we can help fund the Parkinson's Institute, that is helping someone," she says. "It's an indirect way, but it's doing something. That's what has been motivating me for the past year."

We're grateful for the individuals who give time and energy to volunteer at the Institute. We're also grateful for all who choose to help fund the compassionate care and cutting-edge research that takes place here every day. **If you'd like to make a donation, please use the included reply device or go online.**

To find out more about how to volunteer at the Parkinson's Institute and Clinical Center, please call (408) 734-2800.

Spotlight on neuro-protectants

(and why we're talking to Congress about them)



these types of drugs are critical to helping patients manage their Parkinson's symptoms—and even reverse them. The problem is that investment in central nervous system disorders lags behind cancer and rare diseases. Our conviction remains that this area too can advance if development investment can be adequately protected.

Our goal is to educate legislatures on the rising system-wide economic burden of Parkinson's, most notably for the families themselves. We also explain the unique, lengthy clinical testing time for neuro-protectants, which

The Parkinson's Institute and Clinical Center leads the way in identifying the most significant opportunities to advance the treatment and cure for Parkinson's. That's why right now, Dr. Barlow and a host of other partners have been meeting with staff and members of Congress to sponsor a critical federal legislative effort concerning neuro-protectants.

You may not be very familiar with neuro-protectants or their relation to Parkinson's, so here's a brief explanation courtesy of a University of Missouri study done in 2017: "Neuro-protectants preserve neuronal structure and/or function, and offer potential treatment to slow disease progression and ultimately, cure central nervous system disorders and Parkinson's disease." Essentially,

averages 9.3 years (vs. a strong contingent of other therapeutic categories which range just 4-7 years). And we're helping legislators understand the estimated doubling of Parkinson's diagnoses in the coming decades—including 15% under the age of 40 with decades of career and family-raising ahead.

In light of these factors, we are rallying for seven years of market exclusivity for neuro-protectants which can motivate developers (pharmaceutical companies) to focus on research and development spanning multiple neuro-degenerative diseases.

If we accomplish this, it will reinvigorate the field and begin reversing trends that, up until now, keep critical Parkinson's solutions on the sidelines.

Giving can take many shapes

Both the level of compassionate care our patients receive daily, as well as the world-class research we perform, are unique to the Parkinson's Institute and Clinical Center and only made possible through your support. We want you to know about the variety of ways you can give to the Institute.

- Write a check or use your credit card today (remember your gift will be tripled!)
- Give a gift from your Donor Advised Fund or Family Foundation
- Give a gift of stock or other appreciated assets
- Have your gift matched by your employer – then BOTH of your gifts will be tripled!
- Include us in your will or estate plans, and let us know so we can make sure your gift is tripled