



# Leading with Compassionate Care: Stories and Updates

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## Precision Medicine: Our Path to the Cure

Those with Parkinson's live with a wide variety of symptoms and a host of therapies to help manage them. Yet slowing down or stopping the disease at the cellular or molecular level remains paramount to curing the disease. At the Parkinson's Institute and Clinical Center, understanding complex genetic changes underlying movement disorders is helping our scientists design therapeutics that target them.

**We're positioned to deliver this personalized care, also known as precision medicine, by our brilliant team of doctors offering expertise in both medicine and science—doctors like Kristin Andruska MD, PhD.**

Dr. Andruska is a board-certified neurologist as well as a neurobiology researcher. "With a background in research and clinical medicine, I split my time between seeing patients in the clinic and helping run our clinical studies," Dr. Andruska says.

**"Dr. Andruska embraces our vision that the physician-patient relationship both informs, and is infused by, scientific discovery," shares Dr. Carolee Barlow, Chief Executive Officer. "Our physicians provide highly personalized, sophisticated care, but are equally focused on discovery and cure."**

Mutations in the genes *GBA* and *LRRK2* are currently under the microscope—both literally and figuratively—for Dr. Andruska and team.

The *GBA* mutation can cause abnormal aggregates of the protein alpha-synuclein. Dysfunctional alpha-synuclein is linked to Parkinson's. A clinical study, currently in phase 2, tests a treatment for those

with the *GBA* mutation that, "may protect the brain from Parkinson's by preventing that damaging accumulation of alpha-synuclein," reports Dr. Andruska.

*LRRK2* is one of the most widely known genetic contributors in the development of Parkinson's. In people with the *LRRK2* mutation, the protein is overactive. "We're working to bring a clinical study to the Institute that offers a *LRRK2* inhibitor-based treatment which would decrease the activity of *LRRK2*," shares Dr. Andruska. "Doing so may slow down or stop the disease."

Doctors with clinical expertise, like Dr. Andruska, help identify unique symptom complexes in patients with certain genetic risk factors. This allows the Institute to partner with the best of industry in nearby Silicon Valley and pursue the most promising therapies that may halt or even prevent Parkinson's.

**"The Institute is unique in its partnerships with science and technology," mentions Dr. Andruska. "Through these collaborations, we're able to offer patients therapies that are not available everywhere."**



**"It's exciting to work at an institution that has such a strong focus on clinical research because it's so important for patients and for the field. Patients come to us for excellent clinical care, but they also know we are staying at the forefront of research and clinical studies."**

— Dr. Kristin Andruska MD, PhD

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## From our CEO

Dear Institute family,

We're midway through the year and making so many exciting discoveries through our GI natural history study, genetic testing, and other clinical studies. Our science and patient care weave seamlessly together to offer breakthrough therapies and learnings for all those living with Parkinson's and other movement disorders.

The promise of our research extends far beyond our own walls to all suffering from Parkinson's across the globe (an estimated 7 to 10 million people according to the Parkinson's Foundation). More broadly, our progress impacts all those with movement-related disorders.

We simply couldn't have a better staff in place to lead the charge. Physicians like Dr. Kristin Andruska bring such a wealth of experience in the movement disorder space and together with other researchers and doctors, guide our patients in successfully managing their Parkinson's.

Thank you for fueling the important progress made on behalf of all those living with neurodegenerative diseases. Every day we move closer to a cure.



Carolee Barlow,  
MD, PhD  
*Chief Executive  
Officer*

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Technology also forges new opportunities for more comprehensive genetic testing, complementing our studies around *GBA* and *LRRK2*. The Institute's exciting partnership with the genetic diagnostic company CENTOGENE, "The Rare Disease Company," invites individual patients to test for 32 different genetic mutations linked to Parkinson's, including *GBA*, through a simple blood draw. Their physician receives the results within three months.

"As an Institute, we're excited that we can offer this more extensive genetic testing to our patients, especially at a highly reduced cost compared to what it would be on the open market," says Dr. Andruska. "As genetic technologies advance and become exponentially more powerful, we are able to sequence and characterize patients' genetic profiles quickly."

All of these promising advances in the Institute's precision medicine will guide the field of Parkinson's, and all related movement disorders, toward relevant cures. And closer to home, the lives of individual patients with Parkinson's will continue to be changed.

**"Part of being a physician-scientist is that you're always inspired and motivated by the people you take care of,"** Dr. Andruska shares. **"They inspire you to go out and translate basic science research into clinical medicine."** And that's exactly what our team spends their day accomplishing.

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## Danville d'Elegance Gala Event



The Danville d'Elegance Foundation is committed to 'Stop Parkinson's in its Tracks!' The Foundation hosts a weekend of events in September organized entirely by a dedicated team of volunteers who have been touched by Parkinson's. The

'jewel' of this fundraising crown, the annual gala, is an elegant affair delivering an evening of celebrity performances, great company, and delicious food and wine. **This year, the gala will be held on September 15, 2018 at the Blackhawk Museum in Danville, California, and all proceeds benefit the Parkinson's Institute and Clinical Center.** In attendance will be young Danville local, Colin Mullan, who has recently become connected to the Parkinson's Institute and Clinical Center by leveraging his successful car racing career to bring awareness to Parkinson's. Join him and others by attending the Danville d'Elegance annual gala to show your support for those with Parkinson's.

**For details visit [www.danville-delegance.org](http://www.danville-delegance.org)**

# Honoring Eva Nemeth

Eva Nemeth left a beautiful legacy through her support of the Institute and other non-profits

Eva Nemeth (1935–2018) lived with Parkinson's for the final eight years of her life and left a legacy marked by tenacity, empathy, and generosity. **As a patient at the Parkinson's Institute and Clinical Center, Eva's determination to rid the world of Parkinson's inspires us to push on for a cure of this terrible disease.**

As a young child living in Budapest through the horrors of World War II, Eva developed a deep and enduring character. When life restarted after the war ended, she met her future spouse Alex at a village dance; both were young teens. Alex and Eva made their life in the United States, settling first in Detroit, and then in California, as they forged their future with the grit and gratitude many immigrants possess.

The couple ultimately invested in a fig farm in Encinitas, CA and grew to love the nearby city of San Diego. Eva especially loved animals. Serendipitously, the world-famous San Diego Zoo was a close visit away. Alex grew and excelled as a successful real estate investor.

**Eva consistently demonstrated an empathy for those less fortunate, especially those living with disease.** Sadly, just years after Alex's death in 2010, Eva was diagnosed with Parkinson's. Her path inter-



sected with the Parkinson's Institute and Clinical Center as one of our patients and she developed a special place in her heart for helping doctors and researchers find cures for Parkinson's. **Under the care of our world-renowned physicians, Eva successfully managed the impact of her disease until her passing earlier this year.**

Eva's passion and empathy inspired the formation of The Alexander and Eva Nemeth Foundation, focused on benefiting healthcare, children, and animals. **The Institute is a recipient of the foundation's generous legacy grant,** bestowed to non-profit organizations to continue their good works in perpetuity and to expand

the legacy of Alexander and Eva Nemeth.

Eva's generous gift to the Institute provides necessary research equipment for our scientists, fulfilling her desire to help physician-scientists find a cure. **By passionately pursuing the cure, we aim to honor her legacy and all those who live bravely with Parkinson's.**

For more about The Alexander and Eva Nemeth Foundation, please visit [thenemethfoundation.org](http://thenemethfoundation.org).

*If you'd like to support Parkinson's patients through a gift to the Parkinson's Institute and Clinical Center, please contact the Development Team at 408-734-2800 or 408-542-5676.*

## Powerful Ways to Support the Institute

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 are 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**
- **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**
- **Include us in your will or estate plans**



# How and Why We Treat Parkinson's Differently

As the medical, economic and political ground shifts beneath us, the space between the patient and physician widens, further distancing research from the population they work to cure. Doctors, under pressure from insurance providers to maximize profitability, only have time to manage their patients. Scientists rarely interact with patients, leading to an academic echo chamber where incremental progress becomes the norm.

Our patient care and therapeutic science model disrupts this cycle of failure. As the only independent, non-profit Parkinson's clinic and research center in the world, we focus on the patient. Generous donors like you see to it. Your gifts allow our clinician-researchers the ability to engage with patients and their unique symptoms to gain insights that are driving us toward a cure.

This delicately balanced ecosystem between patient, physician and research makes us the leaders in the prevention, care, and cure for Parkinson's and related neurological movement disorders.

That's why we're asking for your help. We must continue to support physicians, so they can provide for a steady stream of patients while, at the same time, performing the critical research that will lead to a cure.

**The Parkinson's Institute and Clinical Center studies and treats Parkinson's differently.** Progressing toward a cure for this complex disease requires a reciprocal relationship: patient care informed by research and research guided by patient interactions. It also requires focused, philanthropic support committed to innovation.

**The Institute's pipeline for a cure starts with patient care.** This care powers the natural history studies, clinical trial medicine and the preclinical pipeline—each step that, when integrated back into patient treatment, will lead us to a cure.

**Patient-centered clinical care ensures patients aren't just shuffled through a system, but are accurately known down to their genetic level.** We go beyond the standard doctor-patient relationship. We are patient-focused to the point that we get to know each patient down to their genetic level, so we can build treatments and a potential cure from their individual genetic makeup.

**The GI Natural History study identifies biomarkers that could allow physicians to detect and even halt this disease before it reaches the brain.** Participants

**Part 1**  
Patient Centered Clinical Care

**Part 2**  
Natural History Studies

**Part 3**  
Clinical Trial Medicine  
& Preclinical Pipeline

**Part 4**  
CURES

swallow a "smart pill" which gathers data, like pressure and pH, that our researchers then use to determine what biomarkers Parkinson's patients share.

**Our clinical trial medicine orients around partnerships with industry leaders to provide access to safe, experimental therapies, personalized to benefit each patient.** Our deep understanding of the science of Parkinson's and related movement disorders makes us very effective at pursuing the most promising trials.

We're positioned to discover the cure for Parkinson's, but our model is in jeopardy because caring for people with a disease as complex as Parkinson's does not fit neatly into today's healthcare economics. It takes much more than an assembly line approach and a 15-minute consultation to provide appropriate and impactful care. **Financial support from families like yours ensures that no sacrifice is made and no corner is cut. Together, we shape the future of medicine for people living with multiple neurodegenerative diseases.**

**If you'd like to support Parkinson's patients through a gift to the Parkinson's Institute and Clinical Center, please contact the Development Team at 408-734-2800 or 408-542-5676. Thank you!**