

United States House of Representatives

Committee on Energy and Commerce

Subcommittee on Health

Telehealth to Digital Medicine: How 21st Century Technology Can Benefit Patients

Testimony of Gary Chard

Delaware State Director

Parkinson's Action Network

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Good morning, Chairman Pitts, Ranking Member Pallone, and members of the Subcommittee, my name is Gary Chard and I am the DE State Director for the Parkinson's Action Network.

Thank you for the opportunity to speak before you regarding the role telehealth technology can play in the lives of Parkinson's disease (PD) patients in the 21st century. I recognize this is an information-gathering session. So, as a person with Parkinson's, please hear me with the voice of several million of my fellow persons with Parkinson's moving and shaking along with me.

I am a sixty-two year old vibrant and healthy resident of the State of Delaware. I was diagnosed with this insidious disease in the spring of 2008, when I was anticipating another 10 to 15 years of productive work life. I am a Financial Representative by practice, as well as a husband, father, grandfather, church and community member of whom much was expected. To say that many of the hopes and dreams of my family, community members, and clients were dashed

with the progression of PD in me is an understatement. I come to you today not to share how my role in personal and social life has been tangentially skewed, but rather to tell you how technology can revolutionize the treatment and care of people living with PD and how it has personally helped me.

Please hear me that the employment of telehealth technology is not limited to benefit only persons with Parkinson's or people in deep rural communities; but it is an asset that can provide safe, secure, and in-depth diagnostic and evaluative care to the immobile and infirm, bringing to them experts who may otherwise be inaccessible. I am a capable person who can still walk, drive, move about unaided generally, after living with the disease progression for the past six years but seek the wise council of neurologists and movement disorder specialists to understand the changes in cognition and mobility that are occurring and help me remain a contributing member of the various life communities in which I participate.

Parkinson's disease is a neurological disorder that stems from reduced dopamine production in the substantia nigra portion of the brain, leading to tremors in the limbs, slowness of movement, rigidity, and impaired balance and coordination. It also exhibits itself through cognitive changes such as confusion, forgetfulness, loss of thought pattern, and sleep disruptions. If my voice begins to fade this morning, please recognize it as a typical example of my PD. Parkinson's is a disease that impacts between 500,000 and 1.5 million Americans and has an economic burden of at least \$14.4 billion a year in the United States. The prevalence is

estimated to more than double by the year 2040.<sup>1</sup>

PD is an individual's disease affecting me similarly, but not the same, as it affects my brethren in diagnosis and in treatment. It is progressive and not accurately defined. There is no definitive medical diagnosis or clinical standard of care for those who are recognized as people with Parkinson's. Medications are available, but are only symptomatic and come with a set of side effects and will only work for a short number of years. There is no cure; merely, the promise of living at a reduced mental and physical speed while the surrounding world moves along normally. Many people with Parkinson's rely on neurologists and movement disorder specialists, who are few in number, overbooked with appointments from those in need, and usually affiliated with specific research university hospitals or located in urban centers that are difficult to access. In my case, living in Delaware, I have no movement disorder specialist in my state. Rather, I have to be lucky enough to find an appointment with one at University of Pennsylvania Hospital in Philadelphia or travel an hour or more to Johns Hopkins University Hospital in Baltimore.

With the advent of telehealth, my access to Dr. Ray Dorsey, my diagnosing specialist in Rochester, NY, or Dr. David Perlmutter, my neurological health coach in Naples, FL can be achieved with the use of existing and improving technology, thereby providing me with the counsel and tracking I rely on in a safe and comfortable environment, saving me and my family costs for care, travel, and productive time. With the use of a telehealth link established

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<sup>1</sup> Kowal, Stacy, MSc, et al. The current and projected economic burden of Parkinson's disease in the United States. *Movement Disorders*, 28, 311-318.

between Dr. Dorsey and the University of Delaware's Nurse Managed Health Care facility, I can now safely visit with Dr. Dorsey on a frequent basis consistent with my diagnosis at a medically-staffed local facility and receive his evaluation of my disease progression and recommendation for treatment. If his recommendation includes a change in medication, it is then sent to my primary care physician for prescription. Further, telehealth can be established via a Skype or FaceTime styled secure link with communications equipment present in most homes today.

Part of the invaluable experience of telehealth is the real-time visit with my specialists. As long as I am in a private environment, I feel that I can speak as candidly with my doctor as I can when face-to-face. The improvements of this technology serve to enhance and expedite the one-on-one interaction with a specialist, not detract from it. I can say that I don't feel as comfortable as I do with an office visit; but, in lieu of traveling long distances, waiting to be seen in an office, and experiencing the other logistics of planning for an office visit, telehealth technology serves to provide me with a doctor-patient consult that surpasses searching for and traveling to a specialist who may be a hundred miles or more away.

In establishing the telehealth link at the University of Delaware, issues of patient privacy, cross-state licensure, reimbursement, and the always-looming liability immediately came into play. It took the interaction of several legal and government channels months of negotiating before allowing Dr. Dorsey, from New York, to speak with me in a doctor-patient relationship in Delaware, leaving me without interaction with a medical specialist for more than eighteen months. Why? Because the legal, financial, and licensure channels are so convoluted that it

took that long to sort through the terms and conditions in order to allow this exercise to proceed.

For the Parkinson's community, telehealth has the potential to be an extremely useful tool in providing greater access to specialists, such as neurologists or movement disorder specialists. In order to provide the data needed to inform needed policy changes, Dr. Dorsey, in partnership with the National Parkinson Foundation (NPF), is currently executing a Patient Centered Outcomes Research Institute-funded study on the quality and effectiveness of treating people with Parkinson's via videoconferencing. Dr. Dorsey and NPF hope to build on previous smaller studies to prove that expert care is important for Parkinson's patients and that it can be delivered via "virtual house calls."

Similar studies have shown that telemedicine can reduce hospitalization and keep people living safely and independently for longer, which are major concerns for people with Parkinson's and their families.<sup>2</sup> In addition, a recent study found that while seeing a neurologist increases quality of life, 42% of people with Parkinson's are not seeing a neurologist for their care.<sup>3</sup> The study also found that seeing a neurologist leads to better clinical outcomes and may lead to a longer life for people living with Parkinson's.

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<sup>2</sup> Darkins, M.D., Adam, et al. "Care Coordination/Home Telehealth: The Systematic Implementation of Health Informatics, Home Telehealth, and Disease Management to Support the Care of Veteran Patients with Chronic Conditions." *Telemedicine and e-Health*. 14.10 (2008): 1118-26

<sup>3</sup> Willis, AW, et al. "Neurologist care in Parkinson disease: A utilization, outcomes, and survival study." *Neurology*. 77.9 (2011): 851-7.

In conclusion, for people with PD or other complex diseases, I believe telehealth is a present-day solution to address the serious issue of access to proper medical care. Through advocacy organizations such as the Parkinson's Action Network, I look forward to working with members of the Committee to find common sense solutions to the hurdles that face the utilization of telehealth in order to improve the quality of care for patients across the country.

Thank you again for allowing me to testify today and I would be happy to answer any questions.

## Summary

Gary Chard, Delaware State Director for the Parkinson's Action Network, is a 62 year old person living with Parkinson's disease (PD). PD is a progressive, neurological disorder that impacts between 500,000 to 1.5 million Americans. As PD affects each person slightly differently, many people rely on neurologists and movement disorder specialists to receive specialized treatment and care. Unfortunately, neurologists and movement disorder specialists are few in number and usually affiliated with specific research university hospitals or located in urban centers that are difficult to access.

As the state of Delaware does not have a movement disorder specialist, Gary accesses Dr. Ray Dorsey, a movement disorder specialist located in New York, to receive specialized care via telehealth in a safe and comfortable environment, saving him and his family costs for care, travel, and productive time. Telehealth can be established via a Skype or FaceTime styled secure link with communications equipment present in most homes today.

For the Parkinson's community or other complex diseases, telehealth has the potential to be an extremely useful tool in providing greater access to specialists, such as neurologists or movement disorder specialists. Data shows that access to PD specialists can reduce hospitalizations, keep people living safely and independently, and lead to better clinical outcomes.