As a person in Cancer Research, I never even considered Parkinson's (PD) as a possibility. Everyone in my family died of Cancer. But, there I was in 2009 getting a diagnosis of a chronic & progressive disease, a diagnosis that was devastating as much for me as my family. After a few years of denial, I knew I needed to do something & believed that my experience as both a patient and as someone in bio-medical research and care (at NIH, UCSF. Bristol-Myers & Sanofi/Genzyme) with strengths in data standards (CDISC, HL7) could be put to good use so that, in the future, others & their families, wouldn't have to suffer like mine. I am a big believer in the power of science. Science is an investment in the future & we need to make sure we have appropriate funding. There is no calling greater than helping people who can't care for themselves. We can't be satisfied that things are okay. We need major change in the way we do research and how patients and providers interact with the healthcare system. While recently there have been more attempts to share data, the data made available to others is often not in a form that is really useful, is stale, is restricted to a small community of researchers and/or it is very difficult and, at times, nearly impossible to combine that data with other data since existing data standards were not used. Furthermore, the current model of care & research is based on tools developed in the time of Guttenberg (1440). If we continue to adhere to this model, our understanding of clinical interventions and our ability to develop new treatments will continue to be limited. 21st Century medicine requires new organizational approaches that embrace our capacity to work digitally. As a patient, I find the lack of data sharing to be a travesty. PD patients need to demand change! We are making progress but way too slowly. This is a call to action. Data sharing, especially given no effective treatments to slow or stop progression, is critical. Science is a community, continually building on one another's ideas. In the era of electronic knowledge exchange, only when data sharing becomes the norm, can we derive its full benefits. Change is challenging, but change we must. What is true for any scientific inquiry is true for improving healthcare: the better the data, the more meaningful the results. The time is now for clinical care, research, and scientific discovery to be connected in a seamless continuum that speeds innovation and benefits patients.

Data Sharing: A Patient's Call to Action

		Where We Are Today		Where We Need to Be
Accuracy	•	Compromising copy-and-paste dependence	٠	Automated quality checks and verification
		and multiple data storage locations		requirements ensure that data is always
		perpetuate inaccurate, outdated data.		accurate and up to date.
Accessibility	•	Key clinical data live in multiple places and is	•	Mission critical data is central, succinct: one
		difficult to find.		click away.
	•	Data is silo-ed and cannot be shared with	•	Standardized and consistent data capture
		other systems for both care and research.		allows information to be transmitted across multiple platforms.
Efficiency	•	Data is entered and abstracted many times;	•	Data is entered correctly once and persists
		work is duplicated.		throughout the patient's care, only needing
	•	Cumbersome, time-consuming data entry		occasional updates.
		means less quality time with patients.	٠	One-click clinical notes and treatment
	٠	User interface hampers rather than facilitates		summaries
		clinical care and research workflow.	•	User-centered design supports workflow
				rather than hindering it.
Re-usability	•	After collection, data cannot be used in any	•	Captured data can inform care decisions and
		meaningful, clinically-relevant way.		drive clinical trials, registries, referrals, etc.
User	•	Unfriendly design and usage complexity lead	•	Intuitive and user-centered design boosts
Experience		to frustration, low compliance, and decreased		ease of use and completion rate.
		completion.	•	Information model facilitates a collaborative,
	•	Model of ownership does not support		"team science" approach to medicine.
		effective collaboration.		

"21st Century medicine requires new organizational approaches that embrace our capacity to work digitally." In practice that means:

Patients can:

- Have their key medical information and history accessible to any provider or researcher they choose, freeing them from the burden of requesting records and answering the same questions repeatedly;
- Patients automatic access to the appropriate resources (counseling and preventative services) based on their personal medical information;
- Participate in research more easily with greater access to ongoing trials and without the need to repeat tests and imaging;

Healthcare providers and researchers can:

- Securely and appropriately share high-quality, structured and standards-based data from the authoritative data source, including electronic patient reported outcomes, wearables, devices and more.
- Access and query large collections of high quality clinical data, annotated specimens and images, genetic testing results, and much more;
- Facilitate clinical trial and registry enrollment;
- Identify and isolate disease sub-groups, which can be used to validate biomarkers and risk models;
- Develop personalized, evidence-based innovations in the diagnosis and treatment of cancer and other diseases and allow continuous quality improvement.