

Creating from Necessity: The Value of Patient Invention By GRETA FRIAR

From the outside, it may be difficult to understand the extraordinary drive many patients have to improve their quality of life through their own ideas and innovations. These range from simple, inexpensive aids to more complex devices and systems.

Attending a forum on this topic held this past spring at Harvard Medical School, George Gondo, director of research and grants for the Amputee Coalition, spoke about a quadruple amputee who invented a simple solution that helped him take a shower independently, something that most people take for granted. This patient's simple invention involved securing a frilled suction cup to his shower wall, which he used to lather shampoo by rubbing his head against the surface. Gondo said that patients must be innovative to solve the challenges they confront in their daily lives: "It's amazing to see the problem-solving skills that come out of necessity," he said.

The creative solutions that patients devise to address their unmet needs were the topic of the day at Harvard Catalyst's first meeting on patient innovation, "Maximizing the Value of Patient Invention," which took place on April 24. Sponsored by the organization's Reactor program, approximately 100 invited attendees contributed to a wide-ranging discussion on how patient inventors might collaborate with academic researchers to improve on promising ideas and co-create new products.

Leaders and board members from 13 disease-specific patient foundations attended, in addition to academic investigators from Harvard University, Massachusetts Institute of Technology, Boston University, University of Massachusetts, and Northeastern University. Presentations by innovators and leaders of disease foundations were followed by a collaborative discussion on how a platform might be created that would allow Harvard Catalyst to support collaboration between patient inventors and the academic community to develop and disseminate patient-initiated inventions.

Eva Guinan, MD, a professor at Harvard Medical School and the faculty director of Harvard Catalyst's Reactor Program, opened the event by welcoming all of the participants, a group that included doctors, researchers, entrepreneurs, patient advocates, and patient inventors. Pedro Oliveira, a professor at the Católica Lisbon School of Business & Economics and the founder of Patient Innovation, an open platform for sharing patient problems and solutions, presented the insightful keynote address.

Polly Dawkins, the executive director of the Davis Phinney Foundation for Parkinson's, discussed inventions created by members of the foundation's patient and caregiver community. "There are solutions out there ready to go," Dawkins said.

Then she asked a question that would recur during the day's discussion: "How do we find what's out there so we don't waste time reinventing?"

Gondo, in his talk on inventors among the amputee community, emphasized the importance of empowering patients as problem solvers. He said that the Amputee Coalition's goal is to give people who have been marginalized or pigeonholed the confidence to be self-advocates. Both Gondo and Dawkins stated that the opportunity for patients to feel proactive in their own care was vital – and that organizations recognizing patients as collaborators throughout the invention process was beneficial for patient communities and organizations alike.

Andrew Berlin, a distinguished member of the technical staff at Draper Labs and a cancer survivor, provided a perspective as a patient innovator. He spoke about how his experiences with invasive and faulty biopsy technology made him increasingly frustrated with the state of the field, inspiring him to design an enhanced biopsy probe that can minimize failures that typically result from having insufficient samples.

Berlin also talked about how he collaborated with a doctor at Stanford University to apply the work he was performing at Draper on satellite image enhancement to medical software after the doctor shared that it was "exactly what he needed for PET imaging." With his unique skills, Berlin has helped develop several sophisticated medical technologies, but patient inventions need not be technically complex to impact patient care.

Jack Armitage, the executive director of the Scleroderma Foundation New England, discussed a range of symptoms common to patients with scleroderma, an autoimmune condition that results in scarring and hardening of the skin and other organs. Patients have invented solutions for the plethora of symptoms they struggle with, from swallowing issues to problems breathing to finger flexibility. His request to the scleroderma patient community for ideas that would improve their day-to-day function yielded suggestions such as "a small pocket container (for example, chapstick) that would have a tacky substance that I could use to help me to turn the pages in the newspaper or a book" and "a glove that has a rubber fingertip. Maybe we could suggest user friendly colors and smaller sizes." The broad scope of ideas demonstrated another recurring theme of the day: solutions to problems that may seem minor to medical personnel can have significant positive effects on patients' confidence and quality of life.

The gap for some patients between identifying a problem – and a possible solution – and creating, and then marketing a high-quality invention is an important space Harvard Catalyst might help bridge by bringing patients and researchers together. To determine how the organization might best facilitate collaboration among researchers, entrepreneurs, and patients with product prototypes or ideas, Guinan led a 90-minute open discussion to close out the event.

The productive discussion saw participation from a number of the event's attendees, including Harvard University Professor George Whitesides, the ALS Association's executive vice president of strategy, Calaneet Balas, MIT Little Devices lab director Jose Gomez-Marquez, and many more. Participants identified numerous practical challenges to turning a one-off homemade patient invention into a distributable product. The discussion also focused on how researchers and companies must learn to treat patients as key stakeholders and collaborators from the early stages of designing solutions. From issues around how organizations can convince patient inventors to trust them with their intellectual property to finding funding mechanisms that fit the market size and research and development needs of a given invention, the hurdles to improving the patient invention pipeline are many.

In spite of these challenges, the event attendees left the event optimistic. Participants described problems that they had tackled while soliciting and developing patient solutions, and advised Harvard Catalyst staff on the successes – and challenges they've witnessed while working in this emerging area. At the conclusion of a day of networking, participants appeared eager to take what they had learned and the connections they had made back to their respective communities to continue much-needed dialogues among patients, inventors, and the professionals who serve them.