

Patient Entrepreneurs to Drive Health Care Innovation for Kidney Disease

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Introduction

In January 2009, I was in San Francisco at the annual JP Morgan Healthcare Conference—a conference I had been attending for 10 years and looked forward to each winter. I was representing Johnson & Johnson, the large health care and consumer product company, as the Vice President of Metabolic Strategy and Business Development. Every day, I was meeting with life sciences companies that were combatting metabolic disease and its complications using the latest technology, sprinkled with back-to-back meetings with key opinion leaders and executives in the field, to try to absorb as much as possible about the evolving environment. This conference is a tough one. My schedule included daily meetings from very early morning to late in the evening mixed in with lunches, receptions, and dinners. Everyone in my field is there during those critical 5 days in January. I was eager to show my management and team how I could bring back key learnings and potential business opportunities.

Although I had a lot to accomplish, my body was not cooperating. I was tired beyond words. My skin was dull, even greyish; my eyes were swollen as were my feet, and I had difficulties sleeping. Something was wrong and had been for a while. However, being the “Viking” that I am (thanks to my Swedish upbringing), I had been ignoring pain and suffering to avoid what felt like complaining. Even more, I was in denial. On the third morning of the conference, I had a breakfast meeting with my friend Howie, a hedge fund manager and trained nephrologist. He actually told me, “You look awful,” and I remember thinking, “Thanks for that!” But Howie continued, “You look like your kidneys are failing. What is your creatinine level?” Because my doctor had actually emailed me my latest laboratory results, I pulled up my data and reviewed it with him. After reviewing my laboratory results together, Howie did not mince words. He concluded, “Karin, you need a kidney transplant.” Looking back, I realize that I was very lucky to have had that breakfast meeting with Howie that day.

My kidneys were failing due to severe nephropathy from long-term type 1 diabetes. I was diagnosed almost exactly 20 years before this morning in San Francisco, as a 16 year old at the height of her tennis career. The first 10 years with type 1 diabetes, I managed my disease perfectly. My hemoglobin A1c was between

4% and 6%, and I managed to both graduate from medical school and obtain a PhD in molecular medicine during those years. However, when I moved to the United States to conduct my postdoctorate studies at the Joslin Diabetes Center, Harvard Medical School, I was tired of the constant monitoring and the feeling of never, ever having a break from this horrible disease. Over the next 7 years, I took on a number of high-intensity jobs on Wall Street and in the world of biotechnology, all while hiding my disease. I allowed my glucose levels to be slightly elevated to avoid “going low” in awkward situations at work or socially. Although suboptimal medically, in this state, it was easier (to me) to be competitive and avoid looks of pity and differential treatment. Here I was, an expert in diabetic complications, and I lived my life exactly the opposite of what I knew had been proven to reduce late-stage complications.

Although this experience launched a very challenging period for me, it was the beginning of my journey to better health. It helped trigger the inspiration that would create the concept of patient entrepreneurship.

Patient Entrepreneurs

Not to be confused with the meaning of patience, “Patient Entrepreneurs” are people living with or closely related to someone with a chronic disease who became inspired to create products and solutions that may help them or others in the management of their disease. Patient Entrepreneurs do not sit back and wait for something to come along. They pioneer innovation to bring solutions to market, because they have personal experience with this chronic disease and know more is needed now.

In early 2014, 5 years after that critical morning in San Francisco, I finally launched a company together with my two cofounders, Dr. Steve Squinto and Riccardo Braglia. I was ready for the challenge and could not wait for the opportunity to make a difference in people’s lives on my own terms. After my kidney and pancreas transplants, I had identified two areas of improvement within myself. I decided that it was important to address these areas more globally. First, as someone who never connected with anyone with type 1 diabetes and actually hid it for almost 20 years, I realized that there must be better ways to learn from patients like myself. I was not looking just for

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communities of patients but for one-to-one connections through a so-called “buddy” system, where individuals are matched with someone with whom they can relate. Second, I realized that patients’ insights and their own solutions to reduce disease burden were an untapped source of innovation. We had identified a need to bridge patient communities with industry and created a way for the lived experience to be leveraged by drug and device developers, which the marketing and advertising industry has understood for years. In research and development and importantly, in the origination of new ideas and concepts, patients, the ultimate user, had not previously been identified as drivers of innovation.

We created the Patient Entrepreneur Circle in 2015, which features people who have made their disease the center of their career or even their sole career. They identify an issue in their lives caused by the disease, and then, they address that issue by creating a product or an entire company. That passion inspires me, and I know that it inspires others just as much.

This strategy of highlighting Patient Entrepreneurs works across different chronic disease categories. We partnered with Novo Nordisk, a global leader in diabetes, in 2016 and 2017; with Helsinn, a global leader in cancer, in 2018 and 2019; with UnitedHealth Group, a global leader in several areas including inflammatory bowel disease, in 2018, and a new area to be announced this year; and with Celgene, a global leader in multiple sclerosis, in 2019. We source and screen applicants who are innovative entrepreneurs who are passionate about improving lives for themselves and others. Finalists participate in innovation summits, where they network with each other, compete for a cash prize, connect with health care executives, and above all, find ways to further their products to eventually reach and help as many as possible.

Some examples of these remarkable Patient Entrepreneurs include a young man from Sweden who understood that many with diabetes sometimes forget when and how much insulin they had dosed. As someone with type 1 diabetes for many years, he was fed up with the additional task of memorizing and risking over- or underdosing, and therefore, he developed a connected cap to the insulin pen that records the dose and the time automatically. Another young man from New York City realized, on diagnosis with Crohn’s disease, that he would never be able to enjoy raw veggies again, because the roughage was too harsh for his gastrointestinal system. He created a nutritious and safe powder in a simple package that, when mixed with water, becomes a delicious shake. Now, customers with and without Crohn’s disease alike tell him that they count on his products as a nutritious veggie option! A third example is a woman who, when her father passed away due to cancer, decided to study science and create better diagnostics to avoid having people die due to late discovery and broad treatments. Her company is now running multiple clinical trials across Europe.

In kidney disease, there are examples of individuals who are making a difference. Broadly, there is a need for better and earlier diagnostics, more adherence to antihypertensives and diabetes medications, improved access to nutritious yet delicious meals, education and encouragement to stay on target, and finally, improvement of the transplant process. KidneyX and the collaboration between the

Department of Veterans Affairs and the American Society of Nephrology leading to an innovation summit are two great examples of initiatives to spur innovation, and in the latter, the patient perspective is central. Through a collaborative effort, even a patient entrepreneur track, we would gain not only insights but also, solutions that are even more patient-centric and already vetted by the end user.

Of course, not everyone can become an entrepreneur, but everyone can help someone—and that one-to-one connection (*e.g.*, what Howie did for me) is another important aspect of our company. Patients need patients, and we are working fervently to build the ability to connect patients one on one now. Together, the entrepreneurs and the patients with insights who are representative of a larger group can influence large companies. Lastly, patients need to advocate for progress—no one does that better than someone who is living with the disease and those who support those patients.

Conclusions

I have a very special passion for kidney disease. I trained as an MD and PhD in diabetes research with a focus on diabetes complications, spent my career in identifying and developing products for this population, and have gone through the very serious consequences that occur with kidney failure. I was quite fortunate to receive a successful kidney transplant from my father at a fantastic hospital, but this option is not commonly available. People are still suffering the horrible symptoms of kidney disease, they still need to be dialyzed several times a week, and so many die while on the waiting list for kidney transplants. I truly believe that one of the next areas for us at Lyfebulb is kidney disease. We are actively seeking a partner so that we may together identify new solutions to help the field and empower people who inspire others to live better.

I have come far from that breakfast in San Francisco almost 10 years ago. This year, I became a mother, and I realize more than ever how important medical science is to all of us, including my daughter’s future. I cannot go back to being affected by ESKD—I have someone else to live for now. Giving patients the voice through an organization like ours can shift vulnerability to strength.

Above all, I want to showcase individuals who, like myself, are not accepting of the role of a passive patient but are willing to take on the challenge of changing the future for themselves and others living with chronic disease. We believe that many of today’s answers in CKD can be found by asking and encouraging those who are closest to the disease. We welcome the opportunity to partner with innovators in this space.

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Disclosures

K.H. is the Chief Executive Officer and founder of Lyfebulb. Lyfebulb is a chronic disease–focused patient empowerment platform that connects patients, industry (manufacturers and payers), and investors to support user-driven innovation and reduce the burden of chronic disease. Lyfebulb promotes a

healthy, take-charge lifestyle for those affected by chronic disease. Grounded with its strong foundation in diabetes, the company has expanded disease states covered to cancer, inflammatory bowel disease, and now, multiple sclerosis (<https://lyfebulb.com/>).

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