

# Hand in Hand: Patient Services and Research

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**Rather than competing for resources, patient services and research work together to achieve the ultimate mission of finding cures.**

The most critical role that disease-specific organizations can play when it comes to accelerating the search for cures is to bring patients to the table. In order to advance the science of our diseases, it is essential that we not only have the ability to find patients, but also to connect with them in a meaningful way and provide value throughout the journey of their disease.

This might sound counterintuitive. After all, many of us who started research foundations did so in order to bring researchers to the table—to get them interested in diseases they might not otherwise be incentivized to study. That is where my journey began. But what I've learned along the way is that patient services and research are inextricably linked. Rather than competing for

resources, they work hand in hand towards achieving the ultimate mission of finding cures.

This has been a game-changing revelation. Let me tell you why.

My journey—from student to patient, patient to researcher, and researcher to advocate—began in much the same way as many of yours. I came to this work through a personal battle with disease, in my case, chordoma—a rare type of cancer that occurs in the bones of the skull and spine.

I was a freshman in college when I received my diagnosis, and the statistics I read scared me. Treatment options were limited, and research efforts unfocused and underfunded. I knew I couldn't wait for things to change on their own.

In the nine years since, the science of chordoma has come a long way, and so have I. I started out tackling chordoma in a university lab. Initially this felt like a fight for my life—which it was—but, eventually, I became captivated by the science, and my curiosity took over. I saw powerful new technologies unraveling the mysteries of other diseases and enabling the development of extraordinary targeted therapies, and I became determined to bring those advances to chordoma. However, while in the lab, I saw first-hand the very practical challenges faced by researchers in this field that stood in the way of this dream—insufficient funding; scarcity of tissue, cell lines, and animal models needed for experiments; and isolation from others studying the disease.

It became clear that the field needed an organization to lead the charge in overcoming those hurdles and driving forward the search for a cure. It would need to be an organization that could unite physicians, researchers, drug companies, and patients, while balancing the needs of all of these critical stakeholders. Every disease, I realized, needs a quarterback to help research move forward as efficiently as possible and coordinate the work of everyone involved. And that is what we set out to do in forming the Chordoma Foundation.

From the beginning, we had a two-pronged mission: to lead the search for a cure and to improve the lives of those affected by chordoma. While patient services have always been an essential component of our mission, we initially viewed it as distinct from research, and even, at times, in competition for resources. In the foundation's early years, as we focused on jumpstarting the



nascent field of chordoma research and laying the groundwork for developing new therapies—from developing new models, to testing drugs in those models, to identifying therapeutic targets—we operated our patient services and research activities along separate work streams.

It was not until the foundation reached the point of helping to initiate our first clinical trial in 2013 that the connection between these two parts of our mission truly became clear. Within a week of notifying the chordoma patient community about the Phase I trial, it was completely filled and had a waiting list. This was a surprise to the investigators and company involved, and later provided confidence to invest in a Phase II trial. What we realized through this experience was that our ability to quickly enroll this promising trial was tied directly to the trust we had built with the patient community and the value we provided to them over time.

Since then, as we've worked with companies and investigators to plan and initiate subsequent trials, I have learned that the ability to bring patients to clinical trials is

of paramount importance to their success, particularly in a rare disease like chordoma. It is a well-known conundrum that many trials never finish for lack of accrual. And I'm sure countless more well-justified trials for rare diseases never start due to aversion to the risk of poor accrual. Thus, our ability to deliver new therapies to patients is reliant on our ability to facilitate their participation in clinical research. And that requires relationships and trust built over time through providing value in ways not necessarily having anything to do with research: disseminating reliable information about the disease, serving as a trusted guide to help navigate the complexities of treatment, offering emotional support, and creating a sense of community with patients around the world.

Once I came to understand and appreciate this relationship, I began to view patient services for what they are—not independent or ancillary to research, but an essential complement to research and an essential component of a comprehensive research strategy. Alone, each has its value, but together they are synergistic in the fight against disease.