Inside Philanthropy

From Grassroots Beginnings, the Pediatric Cancer Research Foundation Now Funds Nationwide

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Some medical research grantmakers start with an enormous endowment from a billionaire founder. But others emerge from a group of ordinary people who see a need and want to make a difference — and then go on to fund important science. The Pediatric Cancer Research Foundation is one of them. It's a small, nonprofit grantmaker based in Orange County, California, created more than 40 years ago by a group of families united by their shared experience of one of the toughest imaginable challenges: childhood cancer.

Since its modest start, the PCRF has grown from backing a single local clinician and researcher to supporting pediatric cancer research across the country. Now, it's ready to make yet another leap in scope and funding, aiming to triple its size in the next five years.

Change-ups in the PCRF's leadership are underway. Longtime executive director Jeri Wilson, who led the organization for 12 years, will step into the newly created role of vice president of development, principal gifts. Meanwhile, Danielle Fragalla, a veteran of cancer-oriented nonprofits in California, will take over as chief executive officer.

About 400,000 children are diagnosed with cancer each year — there are more than a dozen types of pediatric cancers and numerous subtypes. In the U.S., more children die of pediatric cancer than from any other disease, second in fatalities only to accidents for kids aged five to 14, according to federal statistics.

Nevertheless, federal funding for pediatric cancer research is limited, and the relatively small number of childhood cancer patients leaves less incentive for big pharma to invest in this area. So while it's still not the largest cancer research funder out there, millions of additional dollars annually from philanthropic sources like the PCRF can make an important difference for the pediatric cancer research community.

Building a bigger footprint

The PCRF's beginnings were as grassroots as they come. In its earliest years, the organization supported a single cancer physician/researcher, Mitchell Cairo, then based at the Children's Hospital of Orange County and the University of California, Irvine. Cairo was treating kids from about a dozen families in the area. The families, learning firsthand about the pressing need for additional pediatric cancer research and funding, decided to do something about it. In 1982, they established the PCRF to raise money to support Cairo's research.

"We started off as a grassroots, committed group of friends and family that wanted to make a difference and make a bigger impact," Wilson said. For several years, the organization slowly expanded its support to a handful of additional researchers. "My main focus when I came on in 2011 was to raise more money to start funding different types of research and different types of cancers, at different institutions, and to build a bigger footprint so people didn't think of us as only an Orange County organization."

Since its formation, the PCRF has raised and invested more than $46 million in pediatric cancer research, backing key advances in both basic cancer science and treatment along the way. Like many philanthropic funders of medical research, the PCRF aims to support early, promising avenues of study, providing funding to help researchers gather the preliminary data necessary to attract larger grants from federal and other sources.

PCRF grants for emerging, early-career researchers are typically $60,000 for one year, an amount that can cover the salary of a newer researcher — and perhaps keep that scientist employed at a research institution. Grants for translational research — advancing basic science into potential treatments — range between $75,000 and $125,000 for two years. Basic science research grants are $150,000 for three years. For application reviews and recommendations, the PCRF turns to a scientific advisory board and external scientific reviewers.

Research supported by the PCRF has resulted in cures and treatments across the spectrum of pediatric cancer. That includes curing advanced mature B-NHL in children and adolescents and reducing their toxic exposure and length of therapy, a new CAR-T cell immunotherapy treatment, immunotherapy advances for osteosarcoma, development of diagnostic tests to determine which patients will respond to treatment for a type of juvenile myelomonocytic leukemia, and drug therapies for acute myeloid leukemia.

The PCRF is not a huge funder on an annual basis, providing about $3 million in grants in recent years, but its impact is amplified by virtue of the comparative scarcity of funding in the pediatric cancer field. To put that in a bit more perspective, about 4% of the NIH National Cancer Institute budget — which amounts to only about $250 million annually — goes to pediatric cancer research. Fortunately, though, pediatric cancer is relatively rare, with about 15 new cases per 100,000 per year — far less than the 400 per 100,000 for adult cancer. To be sure, some non-pediatric cancer research can apply to pediatric cancers as well, so that 4% statistic doesn't tell the whole story. But there are some important differences between pediatric and adult cancers, so dedicated pediatric research is indeed necessary.

What’s next for PCRF

The good news here is that the cancer death rate among children and adolescents has declined by more than half since 1970, according to the American Cancer Society. Research has made great strides to treat certain types, such as lymphoma, but for others, there exist no known treatments.

The improved survival rate, however, actually points to another important funding area that the PCRF wants to address. While more kids are cured these days, the diseases themselves, and frequently harsh chemotherapy, surgery and other treatments, often affect young patients for the rest of their lives. These impacts include mental health issues, memory loss, hearing loss, damage to the heart and other organs, fertility issues and more.

As noted above, the PCRF began as a grassroots initiative — it wasn't created with some massive, perpetual endowment. It has raised virtually all of its money from fundraising events and corporate support, as well as gifts from individuals who want to support the organization's grantmaking. Wilson and Fragalla are now looking to develop new fundraising mechanisms, including the generation of passive income, and collaboration with athletes and sports teams, among other methods.

"This next phase for us is really about expanding upon our work and garnering more funding so we can expand into additional research," said Fragalla, whose experience includes nonprofit fundraising and development positions at Children's Hospital of Orange County, American Heart Association and the multistate cancer treatment and research institution City of Hope.

"The PCRF has really laid the groundwork over the last 42 years to build trust with the scientific community across the nation," Fragalla said. "It was time to take a step back and ask how to grow us into a larger foundation, to invest more funding and drive larger outcomes.”