Combating Childhood Cancer

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In a region known for its many institutes of science and medicine, Beth Anne Baber believes the intellectual capital, business acumen and philanthropic potential in San Diego provide the ideal environment to support the growth of a new institute that focuses on pediatric cancer research, diagnosis and treatment.

Baber has a personal stake in advancing the cause of The Nicholas Conor Institute, which also has struck a responsive chord in the greater San Diego business community. Her son Conor was diagnosed and treated for neuroblastoma, a cancer that forms in nerve tissue, at Radys Children Hospital-San Diego at the age of 15 months. He received eight months of high-dose chemotherapy. Today, hes a 7-year-old cancer survivor who enjoys surfing every chance he gets.

A scientist at the Salk Institute for Biological Studies at the time of Conors treatment, Baber said her commitment to link academia and industry to find innovative approaches to pediatric cancer was prompted by her familys experience and led to the creation of the nonprofit, which she now oversees. The next step: launching a major donor campaign to fund the operations of the institute and support its ambitious goals.

With the assistance of many volunteers, Baber launched the institute in 2007. The Del Mar resident has tapped into the expertise of members of the local business community, who sit on the institutes board of directors, serve as unpaid business advisers and have partnered to advance research techniques and treatments in labs and research facilities.

Baber estimated that 100 high-quality board members and volunteers are "very connected to our mission," as evidenced by the supporters hailing from business and industry, academia and health care. Their early steps to help the institute gain visibility and win financial backing have been pivotal, said Baber, the institutes co-founder and chief executive officer.

Baber, who has a masters degree in business administration from the Rady School of Management at UC San Diego, said TNCI needs $15 million to advance to the next step, which would include serious efforts at developing tests for several rare childhood cancers and finding partners that could help in the areas of commercialization.

Individualized Therapies

And the institute seeks to do this in the most stripped-down way possible by partnering with existing biotech companies and research facilities to fulfill its greatest goal: finding individualized therapies that reduce the severity of side effects from cancer treatments and provide a better qualify of life for children.

"I think the vision here is to try and be as virtual as possible and at the same time advance the cause of childhood cancer treatment in a very meaningful way," said Baber, whose son Nicholas Conor Boddy is better known by his middle name.

When he was diagnosed with the disease, Baber and her husband, Michael Nicholas Boddy, a faculty member at The Scripps Research Institute, were asked to consider a bone marrow transplant on Conor. They decided on a less aggressive therapy: high-dose chemotherapy.

"As the parents of a child with cancer, we know all too well the gut-wrenching impact it can have," said Baber, who said children are given the same therapies as those provided to adults. While 25 percent of children receiving cancer therapy remain healthy, the other 75 percent are prone to second cancers, strokes and other health problems as a result of the toxic treatment regimens given to them when they were young.

One volunteer, Susan Cornelius, a business development adviser to the institute and the grandparent of a youngster who died of cancer, said current therapies are akin "to throwing the kitchen sink at children with cancer."

"Today, most cancer diagnosis and treatment is adult-centric," said Cornelius, who believes future cancer therapies for children could be less taxing and just as effective. Cornelius is the chief operations officer at Scientific Solutions, a San Diego physics and engineering consulting firm that helps clients create sensing devices for medical and homeland security applications.

She envisions the institute not as a stand-alone organization, but one that is characterized by its partnerships rather than an edifice.

One notable link with an existing company is the collaboration between TNCI and AltheaDx Inc., a San Diego company. The partnership will build upon Altheas existing diagnostic test for multiple pediatric tumor types, said Francois Ferre, the companys CEO. Ferre said the goal of the collaboration is to produce a single genetic panel from a single biopsy that will diagnose and guide treatment.

The institute will seek funding to help cover the development costs of the program.

Unusual Business Model

On the financing end, the blocks are starting to fall into place for TNCIs unique business model, a nonprofit 501(c) 3 research institute thats using an approach called hybrid venture philanthropy.

Martin Kleckner, institute co-founder, business adviser and principal of La Costa Group LLC, a Carlsbad firm that consults with clients on developing medical technology ventures, described the approach as one that encompasses the deployment of a blend of charitable funds and grants with venture and corporate development capital that industry partners already have. Kleckner, who has 15

years of experience working for medical device and life sciences companies, said TNCIs partners benefit by receiving licensing fees from the commercialization of intellectual property.

The institute is now engaged in a 30-month campaign using this model to raise the $15 million during a three-phase development process.

Kleckner said the organization hopes to get the ball rolling by a major donor campaign, writing successful grants and seeking the assistance of foundations.

The cost-sharing initiative with various partners helps spread the expense of developing diagnostic tools, treatments and research. From a drug development standpoint, "Its difficult for established companies to see the value of such a small market," said Baber, adding that about 13,000 rare pediatric cancers similar to what Conor had are diagnosed each year in the U.S.

Despite the small market, shes hopeful that the institutes collaborative model will ensure that individualized, kid-friendly therapies are developed and shared, as opposed to the ones now utilized, which are about 30 years old.

"This disease devastates children and families," said Baber. "Unfortunately, the drugs, research, treatment and funding that exist for kids pale in comparison with whats available for adult forms of cancer.

"Thankfully, our business partners realize the urgency to increase the odds of survival and the quality of the lives of our children, and to do that, we have to make an investment."

Supporting Institutes Mission

Several corporate supporters and nonprofits are associated with The Nicholas Conor Institute. The following is by no means a complete list. Many other individuals and businesses have provided support to the organization.

AltheaDx Inc.

Cesira Inc.

CollabRx Inc.

Childrens Rare Disease Network

CureSearch for Childrens Cancer

Gydle Inc.

The Law Offices of Jurgensen Villasenor

Life Technologies Corp.

In addition, The Nicholas Conor Institute board members represent organizations such as Keene Solutions, Psynomics Inc., Procopio Cory Hargreaves & Savitch, iChanneX Corp., Wolf Management Consultants and Catalyst Law Group.

SOURCE [1]

Links:
[1] http://www.sdbj.com/news/2010/nov/08/combating-childhood-cancer/