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Parents face hard road raising funds to fight cancer

By Michael Doyle - mdoyle@mcclatchydc.com

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WASHINGTON – Virginia firefighter Alec Oughton lost his child and gained a cause, which is no deal at all.

Neuroblastoma had gripped his daughter, Grace. She was 3, and he was desperate. So one year ago Saturday, Oughton and six other fathers finished a Sacramento-to-East Coast bicycle ride intended to help fight the rare cancer that affects young children. The 3,700-mile ride proved successful.

"I don't believe this happened for a reason. It's a random disease," Oughton said. "I don't think it's part of a celestial plan, or anything like that, but I do believe we can make something come from it."

Last year's cross-country ride raised about \$300,000 and drew helpful attention. The fire department in Olathe, Kan., donated \$500.

Fire engines in other communities began escorting the riders. Camera crews tracked their progress through Salt Lake City, Kansas City and Lexington, Ky.

In time, bolstered by other fundraising efforts, a total of \$370,000 was donated in Grace Oughton's name to the Memorial Sloan-Kettering Cancer Center in New York. It was a beautiful tribute, but not a cure.

Grace Oughton died Oct. 29, 2007, one month after her father returned home. Marissa Jean Monroe, a 2-year-old Michigan resident and daughter of another cross-country rider, died in June.

Now, Alec Oughton and his wife, Crystal, are still trying to translate pain into action through the Grace Oughton Cancer Foundation, which raises money for researchers and families. They have big plans for the foundation, based in suburban Richmond, Va., where Alec Oughton is a lieutenant and paramedic with the Henrico County Division of Fire.

Oughton and his allies raised \$7,000 on a recent two-day bicycle ride through rural Virginia. They are trying the popular 5K route, with an Oct. 11 run in Fredericksburg, 50 miles south of Washington.

While they cultivate life-saving ambitions, the Oughtons face startup challenges familiar to other parents. There's paperwork to complete, motivation to sustain and competition to

confront.

"Often, after a child dies, parents want to turn the compassion they experienced into help for others," noted Robyn Raphael, a foundation president and resident of Roseville. "This was our case. However, I will caution that this is not an easy road, as sustaining family memorials and foundations is a very long commitment."

At least four other national foundations focus on neuroblastoma, according to records filed with the nonprofit Foundation Center. Three of these, like the Oughtons', were begun by grieving parents.

In June 1997, Robyn Raphael's 5-year-old son Keaton was diagnosed with neuroblastoma. Roughly 650 U.S. children are diagnosed annually with the cancer that strikes the sympathetic nervous system.

The initial symptoms are vague: fatigue, loss of appetite or an inexplicable black eye. Detection often comes too late.

Keaton Raphael endured a bone-marrow transplant, aggressive chemotherapy and radiation treatment before he died in February 1998.

Since then, the Raphael family has administered the Keaton Raphael Memorial for Neuroblastoma, a foundation that last year donated \$183,000 to related causes. These included University of California research and direct assistance to stricken families.

"Like the Oughtons, we built this from the ground up," Raphael said.

In a similar vein, the Evan T.J. Dunbar Neuroblastoma Foundation, based in Louisville, Ky., was established by the parents of a 6-year-old boy who died in 2001. Last year, according to public records, the foundation contributed more than \$429,000 to beneficiaries, including the Children's Hospital of Los Angeles and the University of South Florida Foundation.

"I have seen from our own efforts it takes planning, a solid board of directors and a development plan to fulfill your goals," Raphael said.

The parental foundations must navigate a crowded field. At least 276 national foundations with the word "cancer" in their title have registered with the Internal Revenue Service, according to Foundation Center records. Some of the most vital foundations fighting cancer don't have the word in their title. The Lance Armstrong Foundation, for instance, handed out nearly \$13 million in cancer-fighting efforts in 2006.

Inevitably, there is a learning curve.

Oughton, a 35-year-old Lancaster, Pa., native, lacked public-relations experience when he initiated his cross-country venture in the company of riders such as Air Force investigator Kevin Sims of Valrico, Fla. A media-savvy friend of his sister's began advising the riders: Seek bigger cities. The riders redrew their route to include bigger markets and more dangerous roads. For a time, breaking all the rules of conventional bicycling, they rode on Interstate 80 out of Salt Lake City.

The ride succeeded. That was last year. The question now is: What next?

"A lot of this," Oughton said, "is trial by fire."

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