Physicist rides bike to raise money for rare disease

By Deborah Tracy
Uintah Basin Standard

Last week seemed to be the time for bike-riders out for a cause to be crossing the Basin. On Thursday, Greg Crawford passed through Vernal and Roosevelt on his way to the LC Ranch near Altamont.

This dean of the College of Science from the University of Notre Dame is biking from Boston to Pebble Beach, Calif., a distance of 3,250 miles, to raise awareness and funds for research to find a cure for a fatal disease that primarily strikes children.

The disease that has Crawford riding in Niemann-Pick Type C, which prevents the body from effectively processing cholesterol. It is a genetic disease that primarily affects children before or during adolescence who slowly begin to lose function.

Researchers have identified the cause and made significant progress towards a treatment for this rare disease but there is still no cure as yet.

Notre Dame has made working on this disease a passionate priority.

By riding, Crawford said he can help raise awareness by contacting different media along the way, as well as by talking to people and having yet others follow his trek on his blog and website.

Crawford said his reason for making these treks - this is the third and longest to date - is because the disease struck the Notre Dame faculty in a big way. Former two-time championship Notre Dame football coach Ara Parseghian had three grandchildren with the disease who eventually succumbed to it.

The college put an emphasis on Niemann-Pick Type C, with scientific researchers working to find a cure. "I'm a physicist by training, and I wanted to do something," he said, noting his research skills didn't apply to this field. "I've combined the biking as one way to raise awareness and funds for those that have the skills set to do that work."

He said he has had kids come along and ask him why he is riding. He explains, and sometimes they come back with their parents in tow and a handful of change. "It all adds up in the end," he said.

The Destination Cycle van and riders that accompany Crawford as he pedals the Road to Discovery are alone to be sure he is safe. In a previous trek, families affected by Niemann-Pick Type C signed the van, and seeing those messages as he rides are an inspiration for Crawford.

While he said the ride often presents challenges, such as riding uphill or with crosswinds, he admits his mind often turns to the fact those challenges are nothing compared to the challenges faced by families who have a terminal child that often doesn't live past 12 or 13, some of that time confined to a wheelchair.

The plan is for Crawford to roll into Pebble Beach Resort on June 22 in time for the Pebble Beach Classic, a golf tournament that also raises funds for the disease. Crawford said the area around LC Ranch were "gorgeous" and was one of the more remote legs of his trek, the last three-quarters of a mile on the hot, dusty dirt and rock-strewn road particularly challenging. The temperature was pushing 100 degrees as he rolled into the ranch.

To follow the rest of Crawford's trip or to make a donation to the cause, visit his daily blog at www.roadtodiscovery.nd.edu.

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