

Taking his aim at CMD

By: Phil Gianficaro The Intelligencer

Alex Van Hook is a high school junior with congenital muscular dystrophy.

And he's deaf.

And he has a rare eye disorder.

And over his 17 years of life he's accomplished more things to make shivers run up and down the spine than most of us could ever dream of.

Have you ever stared into the mouth of an active volcano? He has. Have you ever piloted an airplane glider? He has.

Have you ever participated in a half marathon?

He will.

So although he has faced daily challenges since birth that make climbing the Matterhorn in bare feet a breeze, save your pity for someone who needs it.

Alex Van Hook is enjoying life far too much to slow down and listen.

On May 2 in Long Branch, N.J., Van Hook will kick his afflictions in the gut yet another time as he uses his electric powered wheelchair in a half marathon, determined to raise money and awareness for Cure CMD, a nonprofit organization whose mission is to find a cure for the group of genetic-mutated diseases that cause muscle weakness at birth or within the first two years of childhood.

"Since the half marathon will be 13.1 miles long, it will be quite a challenge for me," the 17-year-old from Upper Black Eddy said. "I also love speed and the wind blowing in my face and the environment whirring past me. I especially love to race, so I decided to join the half marathon.

"I'll be helping the CMD community. I really want to help Cure CMD because I have CMD, so I would do anything to help discover a cure. I'm not just thinking about curing myself but also about curing other people who have a similar diagnosis."

This kid that CMD cannot stop has already helped raise \$15,000 through race pledges. His goal is \$20,000.

Go ahead. Bet against him.

"Alex is a very positive person," said his father, Greg, who will ride a bicycle beside his son's wheelchair while his wife, Susan, walks the race. "He's rarely complained about CMD. Oh, there have been a few times he's asked questions like, 'Why did God give me CMD?' Basically we tell him God had nothing to do with it; it's a genetic mutation.

"Alex is a good self-advocate. He understands people see him differently and probably underestimate him. But he stubbornly does not allow people to underestimate him. I mean, he's going to be in a half marathon. How can you underestimate him knowing that?"

Perhaps the most amazing aspect of Van Hook - in a wheelchair but not taking it sitting down - is that his parents aren't the least bit amazed.

"When Alex was an infant, he couldn't crawl," Susan Van Hook said. "So we made him a scooter board to lie on to experience crawling. He's deaf, so he learned sign language. He's traveled to Hawaii. He is a big reader and loves video games. He plays power wheelchair hockey. So when he wanted to do the half marathon, no, we weren't surprised at all."

Seventeen years ago, Greg and Susan Van Hook's little boy was born with the inability to crawl, walk or hear.

Today he attends the Marie H. Katzenbach School for the Deaf in West Trenton, about an hour drive from his home. He stays in a dorm at school one night a week, helping him transition for the day sometime in the fall of 2011 when he'll fly off to college to study law, anthropology, history, technology or any number of his interests.

"Lots of young people we know have dreams of careers and lives," Susan Van Hook said. "As parents of kids like Alex, it's up to us to help provide them opportunities everyone else is afforded. Alex can do anything and everything he wants to do."

Which presents a giant problem for his parents:

Keeping up.

To make a race pledge, contact Susan Van Hook at www.sklar72@epix.net. For information on CMD, go to www.curecmd.org.

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