



Living for Today, An Inspiration for Tomorrow

By Melissa Combs, Public Relations

Living with a genetic condition that has no treatment or cure is devastating and can be debilitating for most. Sprinting with friends across the park, hammering up a mountain on a bike and charging down a ski run are pleasures children who have ataxia-telangiectasia (A-T) do not take for granted.

A-T is a rare, inherited disorder that most notably causes degeneration in the part of the brain responsible for motor movements and speech, causing muscular spasms, unsteady gait and slurred speech. Complications also include cancer, which occurs in about 20 percent of A-T patients due to a weakened immune system.

One in 40,000 children are diagnosed each year. Appearing normal at birth, the first signs of A-T usually appear during the second year of life. Feeling a strong "motherly instinct," Diana Rau sensed something was wrong with her son, Tim.

"We noticed something wasn't right with Tim since he was two," she said. "He had little to no energy, didn't have muscle recall, so we were constantly retraining his muscles, he needed extra snacks, two wetsuits in the pool..."

The first signs of A-T are a lack of balance and slurred speech caused by ataxia, which means a lack of muscle control. After a series of misdiagnoses by previous doctors, Julie Parsons, MD, neurologist at The Children's Hospital and assistant professor of pediatrics, child neurology residency program director at University of Colorado Denver, diagnosed Tim in 2003.

"Dr. Parsons was wonderful and found Tim's disease during the first round of tests," said Rau.



Top: In 2003 Tim climbed Mt. Antero with kids who were training to compete on the U.S. Ski Team. Tim walked the 3,000 ft. from the camp and ascended the mountain with the aid of his parents, Diana and Charlie Rau, and the encouragement of his friends.

Left: Ceremonial start of the Iditarod on March 3, 2007. Tim's wish to participate in the Iditarod was granted by Make-A-Wish Foundation. He rode in the sled with Jeff King, 2006 Iditarod winner.

Right: Tim rode his snowbike in March 2008 as part of the Aspen Winter Games presented by the Shining Stars Foundation of Colorado. Tim learned how to ride a snowbike this year with National Sports Center for the Disabled at Winter Park, Colo.

Tim started physical therapy shortly after his diagnosis to help retrain his muscle patterns and build a strong body to enable him to stay active. Today Tim is 16, 6'3" and weighs 178 lbs. He says Children's always encouraged him to "go do it." And, he did.

From learning how to ride a snowbike to climbing a fourteener (or 14er), Tim pushes himself.

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"My success stemmed from keeping active," he said. "Whatever doesn't kill you makes you stronger."

Tim's parents figured out how to support his desire to stay active, such as restricting the steering on Tim's four wheeler to reduce the effects of his tremors, working with him to learn how to ride a snowbike, riding tandem with his dad in bike events (Tim is the youngest finisher ever in the Winter Park Hill Climb) and much more.

"Tim's biggest passion and his primary motivation for staying strong is riding the snowmobile," said Tim's dad, Charlie. "It takes muscle to steer and move even a small snowmobile, and the steering is already so stiff that his tremors don't affect it."

"Despite the fact that Tim can no longer walk because of his balance issues, he has done the Iditarod as a Make a Wish recipient, has rafted the Grand Canyon, has climbed a fourteener and is all around exceptional thanks to his parents," explained Dr. Parsons.

Not only does Tim excel in physical activities, he is an independent A-B student. The school system he is part of is dedicated to helping him succeed by making available big button instruments, scribes, scooters and machines to help him read books.

"Tim is an inspiration to all kids at school," said Diana. "They say, 'If Tim can do it, I can do it.'"

Tim Rau is someone who lives for today and will continue to inspire us all for many tomorrows.

You can connect with Tim through his Web site: www.timothyrau.com.