

Diet, Discipline, New Drug Therapy Help Tame Rare Genetic Disorder

(NAPSA)—When you meet 23year-old Tampa native Ryan Cates, you'd probably never guess he has been battling a rare genetic disorder since birth.

A graduate student at the University of South Florida who's working toward his master's degree in Chemical Engineering, Ryan ran his first half marathon this year. He completed his first triathlon in October 2007 and plans to train for another one once his academic life quiets down. He's also an avid scuba diver.

"I've been scuba diving since I was 12 and go whenever I get the opportunity."

But Ryan's life was almost derailed by a metabolic disease called Phenylketonuria, or PKU. People with PKU can't metabolize an essential amino acid called phenylalanine (Phe), which is found in most foods. The buildup of Phe in the blood can be toxic to the brain, causing severe cognitive complications including mood swings, IQ loss, slower thinking, concentration problems and even mental retardation.

Patients with PKU must learn to manage their Phe levels through a strict low-Phe diet, and some may be able to take a daily medicine. As a youngster, Ryan's parents worked to keep his Phe levels in line, but as he got older, the pressures of being a teenager caused him to slip.

"My parents kept me on a strict low-protein diet when I was younger. They didn't want me to experience any side effects of uncontrolled Phe levels," Ryan said.

The Quest To Be "Normal"

At the age of 15, he says, Ryan went off the diet after transferring to a boarding school.



Ryan Cates, 23, once struggled to manage PKU, a genetic disorder, but today is reaching his full potential by taking charge of his disease.

"I wanted to be a normal kid. Bringing in these weird diet foods and formulas wasn't going to help me in that regard."

Soon Ryan began to struggle as elevated Phe levels impacted several aspects of his life. He experienced mood swings and lashed out at friends.

"I was emotional all the time," he says. "Those who were closest to me caught the brunt of my emotional outbursts."

Although Ryan's schoolwork was affected, he did well enough to advance to college, but there, faced with much more rigorous academic challenges, Ryan noticed that continued exposure to high levels of Phe was having a drastic impact on his analytical and problem-solving skills.

"The classes were harder, and I needed to function better," he says.

To step up to the challenge,

Ryan made a lifestyle change—he returned to treatment.

Ryan went back on the low-Phe diet. Interested in his treatment options, Ryan talked to his nutritionist about a medicine that can help lower Phe levels in some people with PKU. He enrolled in a clinical trial for the PKU medicine in 2007 and responded well. The medicine has since been approved by the FDA. Once his Phe levels were managed, Ryan was able to regain control of his life.

Reaching His Full Potential

"Managing my Phe levels made a huge impact on me. I could really feel the difference when my levels were stabilized."

With his Phe levels properly managed, Ryan has excelled, receiving several scholarships, including the prestigious Guthrie Scholarship.

Becoming more active in the student community, Ryan now plays a role in student organizations. He volunteers at the local science museum and has become committed to helping the science community.

"I really wanted to see what my major could offer me, and now I finally have the ability to do so."

Through it all, Ryan says his struggles with PKU have taught him valuable lessons that can help anyone stay active and healthy. Even if PKU patients stray from controlling their Phe levels, like Ryan, it's never too late to return to treatment.

"PKU is a blessing in disguise. It makes you aware of everything that you put into your body," he says. "Managing your Phe levels is so important. It gives you the opportunity to reach your full potential."

To learn more about PKU, please visit www.pku.com.