



Tuberous Sclerosis Alliance

Adults with TSC

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Because rare diseases
really aren't that rare.

#IAMTSC



Kate Maciulewicz-Gass is all about goals and challenges. For the 32-year-old, there is no other way.

Her story starts when doctors discovered tumors on her heart shortly after birth. She was sent her to a children's hospital in Buffalo, New York. She had her first open-heart surgery at 4 weeks of age; her second, at 8 weeks. TSC was never mentioned.

Kate had what she called a "normal childhood." She had some seizures during her younger years. Medicine was able to control them and she was later weaned. The family moved to Texas when Kate was 7. Kate says she received "no special treatment from my parents... I went on to be a kid." Her school career was typical: she was in mainstream classes, had some difficulty with math and science, but her grades were good thanks to her effort and extra tutoring. Band life was huge: "In Texas, that's a really big deal, like football, Friday Night Lights." Kate also discovered a new passion: fitness and health. She set her sights on becoming a lifeguard. It was her first job at 16. It taught her a lot about leadership.

College was next. While Kate had good grades, she struggled with standardized tests. As such, many colleges wouldn't accept her because of her SAT score. Her persistence with admissions staff at the local public university got her in and she majored in kinesiology and minored in health promotions. She continued to work as a lifeguard. Kate finished college in 3 ½ years. Now Kate had her sights set on a master's degree and she wanted to "grow up." So off to San Antonio she went to continue her studies in sport and exercise psychology. Her thesis was on eating disorders and high school track and field female athletes. While in the master's program, Kate became a fitness instructor and running coach for the university's faculty and staff members training for a half marathon.

At a conference, Kate would discover new next adventure: Attaining her Ph.D. and moving to Canada to attend the University of Saskatchewan. Her study: Endurance athletes and body image. Kate had to learn everything from how to drive in snow to understanding a new banking system. Life went on: Kate got involved with a local rowing team and started learning of dragon-boat racing sport. She was teaching. She was collecting data for her dissertation. It was during this time that her mother died of a heart attack. She graduated and finished her dissertation back in Texas. She would start her business, found a nonprofit for breast-cancer survivors and marry her husband, whom she met while on the dragon-boat team.

In 2016, she would face her new challenge: Learning she had TSC. She went to see a gastroenterologist because of heartburn she experienced after running. An ultrasound revealed tumors on the kidneys. She went to cancer, but in talks with her father, wondered if it might be related to something else. A Google search led her to TSC. She and her husband found the Houston clinic. It was discovered that the tumors were close to hemorrhaging. She was put on Afinitor. Kate also mentioned to doctors that she experienced fatigue and breathing problems. The pulmonologist initially thought LAM but testing instead found a missing pulmonary valve, most likely removed during one of her surgeries as a newborn. Kate would undergo her third open-heart surgery in November 2017.

The biggest takeaways for Kate during her TSC journey: Support, understanding, perseverance, and physical and mental health. Kate says that when you are facing adversity like TSC, it's important to stay positive and not give up. She is a firm believer of having a purpose in life and using the gifts and strength within us "to serve other people" and "to be the best version of yourself."

"I hope my story inspires you and to go after your dreams and not let TSC define you. It's a part of you but it is not your identity. We get to wake up every day and decide who we are and who we want to be."

In the Spotlight



THE 2018 WORLD CONFERENCE

The World Conference is fast approaching! This year's host city is Dallas, Texas. July 26-29, 2018. For more information, go to <http://www.tsalliance.org/2018-world-tsc-conference>.

Benefits to attending:

The latest TSC diagnosis, treatment and research information.

Assistance on educational, transitional, financial and emotional challenges of TSC

The opportunity to meet hundreds of other families and individuals with TSC

Access to a wide range of service providers, and Q&A sessions with physician experts.

READ THIS BLOG

Rylee Grandia is a young adult living with TSC. She is a TS Alliance Junior Representative who is speaking up about her experiences living with TSC and how she is using her diagnosis to help others. You can access her blog at <https://thelifeofrytsc.blogspot.com>