

# HOW YOU CAN HELP

Yasick shares multiple methods to support EDS

1. Follow the Ehlers-Danlos Syndrome support accounts on social media to find out about fundraising opportunities

[www.facebook.com/DEFYEDS](http://www.facebook.com/DEFYEDS)

Twitter: @DEFY\_EDS

2. Donate to Dr. Dietz

P.O. Box 3386  
West Chester, PA 19381

3. Participate in an event benefitting research of EDS

4. Donate online or scan below

[www.gofundme.com/DEFYEDS](http://www.gofundme.com/DEFYEDS)



Jonas Quirin **THE BUCS' BLADE**

**NUMBERS:** One in 50-200 thousand are diagnosed with vascular Ehlers-Danlos Syndrome. Seven members in Yasick's family have the disease.

## Senior Erin Yasick raises awareness of genetic disease affecting family **By Landon Hudson**

It was 2 a.m. when senior Erin Yasick saw her dad cry for the first time.

It was 2 a.m. when she was told to quickly put on socks and go downstairs. The rest of her family was already gathered, wide-eyed and pajama clad, more tears and heightened suspense.

Her parents took a deep breath as they shared that her uncle Steve passed away from vascular Ehlers-Danlos syndrome (vEDS).

She was seven-years-old and had never heard of the fatal disease before that morning.

EDS is a genetic disorder categorized into six different types depending on signs and symptoms. The vascular type is considered to be the most serious form due to the potential of organ and arterial ruptures. It is also on the rare end of the spectrum, only affecting one in 50-200 thousand people.

The untreatable disease involves tissue deterioration, which leads to fragile skin, joint hyper mobility and bruising.

The Yasick's current strategy is to raise awareness of the sickness and encourage people through social media to sign a digital petition to have a Michigan representative support the OPEN ACT (Orphan Product Extensions Now, Accelerating Cures & Treatments) which would fund a system where old drugs could be re-purposed in hopes to try and find possible treatment for an array of rare diseases.

The deadly diagnosis has been cycling through their family since before she

was born. Yasick lost her grandfather, three uncles and one cousin to vEDS.

The lifespan for people living with the illness tends to be shorter than average. According to Yasick, not one family member battling vEDS has lived past 50 years old.

"Losing someone you love provokes a lot of tears and stomach aches and sleepless nights," Yasick said. "Someone gets diagnosed and that's it. You know for a fact their time is limited and there's honestly nothing you can do about it. It's like a sick waiting game because you don't know when they'll be taken from you."

Yasick's seven-year-old cousin Stevie and 21-year-old cousin Emma were also born with vEDS.

"I honestly look up to Emma so much, it just makes me sick to my stomach when I truly acknowledge what she's battling," Yasick said.

There's a 50/50 chance Yasick's dad could also be living with it.

"It's really hard to deal with but we try not to dwell on it and we lean on each other when it's hard," Yasick said.

According to Doctor Harry "Hal" Dietz at Johns Hopkins University School of Medicine, who has specifically been studying vEDS for the past five years, there is no current cure. There are medicinal treatments to reduce heart rate and blood pressure to decrease stress on fragile blood vessels, and large doses of Vitamin C are recommended to support biomechanically weak tissue.

Dietz and a team of medical experts have been using mice models that show identical vascular features to someone diagnosed with vEDS. With this breakthrough, they are able to examine cellular events that often lead to aneurysms and blood vessel damage.

"This type of work is a marathon and not a sprint," Dietz said via email. "I hope and expect that we can make some progress over the next few years."

For right now, the Yasick's main focus is to spread awareness for the life-threatening disorder.

"The more people who know makes a huge difference and means the world to us," Yasick said.

In addition, people can donate and participate in fundraising opportunities where the proceeds go towards Dietz's research team.

"I don't need anyone to feel sorry for my family at all, but having people who are willing to donate out of the kindness of their heart or attend 5Ks or any of the fundraiser type stuff is awesome," Yasick said.

Despite the challenges the family faces, they don't lose sight of what's important.

"It's really important to make sure you cherish the people you care for because unfortunately life can be fragile," Yasick said. "We just live our lives as normally as possible and as well as we can. I wouldn't want to live my life acting like I know I'm going to die. I wouldn't want to be careful."