

《美国选美皇后和她“看不见”的疾病》

导读:对于脊柱有25英寸疤痕的人来说，穿着泳装参加选美比赛也许真的不容易。



Victoria Graham, a 22-year-old student from Manchester in the US state of Maryland, had an untraditional journey into the glitzy world of US beauty pageants. She may look like any other contestant at first glance, but Victoria suffers from Ehlers-Danlos Syndrome (EDS) - a rare genetic condition that affects her connective tissues.

Victoria Graham??????????22?????????????????????????????????????Viatoria????????????????——??? -
 ??? ?????EDS?

Recalling her first competition, she says: "I walked into orientation in a neck-brace, surrounded by all of these gorgeous sky-tall women. I looked to my Dad and asked 'What in the world am I doing here?'... It was comical."

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Victoria wasn't always so open about her condition. "Until I left school at 19, I hid my illness from others," she says. "I would rather have my legs dislocate than someone see me in a knee brace." But she's since realised that speaking out makes her feel empowered - and enables her to help others in the same situation.

Victoria????????????“??19????????????????????”??“????????????????????????????????????”????????????????????????
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Victoria grew up practising gymnastics and was told she was "too flexible" by her coaches. She became aware something was really wrong after a gymnastics accident when she was 10. "I'd get injuries that weren't normal - things weren't adding up," she says.

[illegible]

EDS is notoriously difficult to diagnose, and she spent three years seeing different specialists, trying to pin down the problem. Eventually her family found a geneticist who gave her a diagnosis aged 13.

[illegible]

"It was weird because although there's no treatment and no cure, we were ecstatic because we finally had a name for what was going on," she says.

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It then became apparent that Victoria's condition was inherited - only then did her mother, brother and other family members find out they also had lesser forms of EDS.

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"My grandmother lived with EDS for nearly 70 years without knowing and my Mom had it 40 years. Nobody should have to live that long before finding out what's going on with them," she says.

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Despite being only 22, Victoria now runs her own non-profit EDS support group called 'The Zebra Network'.

Victoria's journey with EDS and the founding of 'The Zebra Network'.

"I was seeing people who were struggling - doctors were often recommended through word of mouth. I saw a dire need for a network of sufferers and for someone to dedicate their life to that," she says. "I know I'm young and it's a bold decision to make without a college degree - but if someone else wasn't doing it, I would be that someone."

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She explains the network's name: "In medical school, doctors are trained to think of the common thing when diagnosing through the phrase, 'When you hear hoofbeats, think of horses not zebras.' So if a kid has runny nose or a cough they most likely have a cold rather than a rare form of cancer. But those rare things do happen and are often called 'medical zebras'. So we say, 'Think zebras, because zebras do exist'."

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Despite her confidence now, it's been a fraught journey to this point for Victoria.

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