美国选美皇后和她“ 看不见 ”的疾病

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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。


纳米英语 www.nm3.cn

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是美国马里兰州曼彻斯特的一名22岁学生，参加过美国的选美大赛。起初，她看起来与其他选手似乎别无二致，但是其实Viatoria患有一种影响她结缔组织的罕见遗传症——艾勒斯 - 达洛斯 综合症

（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."

回想起第一场比赛，她说：“我从门口走进去，被那些华丽高傲的女人所包围。我看着我的爸爸问道‘我究竟在这里做什么？’……这是很滑稽的。”

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并不愿意暴露自己的情况。“直到我19岁离开学校的时候我都没有让别人知道我的病。”她说。“我宁愿让我的膝盖脱臼，都不愿有人从膝盖上看出我的病。”但后来她意识到坦白她的情况会使她更加有力量，并且让她能够帮助那些和他处在同样境遇的人。

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.

Victoria从小练习体操并且被他的教练说“太灵活了”，在她十岁发生的一次体操事故以后她开始担心似乎她真的有什么问题。她说：“我会受伤，这是不正常的事情而不是累积的结果。”

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.

EDS是非常难以诊断的，她花了三年时间看不同的专家，试图解决这个问题。最终她的家人找了一名遗传学家给她诊断在她十三岁的时候。

“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.

“这是奇怪的，因为虽然没有治疗，没有治愈，但是我们是欣喜若狂，因为我们终于知道了疾病的名字。”她说。

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.

随后他的母亲、兄弟和其他家庭成员发现他们也有轻微的EDS症状，很显然，Victoria的症状显然是遗传病。

"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.

“ 我的祖母得了EDS，在不知情的情况下活了70年。我妈妈得了EDS40年。 ” 她说：“ 没有人能在得知他们生了什么病的情况下可以活那么久。 ”

Over a two-year period from 2014, Victoria had to undergo 10 operations on her brain and spine.

在2014年起的两年时间里，维多利亚不得不在她的大脑和脊椎上接受10次手术。

Victoria’s EDS affects a lot of aspects of her body, including blood flow.She says she has to take 20-25 tablets every two hours. Some are for pain relief, but others are supplements to ensure her body keeps functioning correctly.

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EDS影响了她身体的很多方面，包括血流量，她说每两个小时她就必须服用20-25粒药片。有些是为了缓解疼痛，但其它的是补充一些确保她的身体保持正常运作的营养。

Despite the severity of her condition, Victoria finds herself often dismissed and discriminated against because of the invisible nature of her illness.

不论她的病情是否严重，维多利亚州发现自己经常被解雇和歧视，因为她的疾病的无形性。

At school she consistently struggled with teachers’ unwillingness to make accommodations. And she says she often gets shouted at in public for using a disability parking pass.

在学校她坚持违背老师的意愿去住宿。并且她说她经常在学校被叽骂因为用了残疾人停车通行证。

As part of her efforts to raise awareness and educate people, Victoria now performs a monologue about her condition at pageant competitions.She says she entered her first competition as part of a ’bucket list’ deal with a friend after an operatio.

在选美比赛中，作为她努力提高认知和教育人民的一部分，维多利亚现在在阐述她的状况。她说，她第一次参加比赛是因为这是一个与朋友一起制作的“ 遗愿清单 ”协议中的的一部分。

She won her first local title just months later and now holds Miss Frostburg - a local title within the Miss America Organization.

几个月后，她赢得了她的第一个地方头衔，现在被称为Frostburg小姐，这是美国小姐组织内的地方称号。

Through this platform she has been able to meet and support young EDS sufferers.

通过这个身份，她已经可以和年轻的EDS患者见面并且支持他们了。

“Its not always easy, sometimes you want to be normal - you don’t want to be that girl with those scars on stage,” she says.

她说：“ 这通常不是很简单的，有时你想做一个正常人，你不想做一个登上舞台还有那些恐惧的女孩 ”。

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

尽管Victoria只有22岁，她现在已经运行着她自己的非营利性EDS支持组织‘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 its a bold decision to make without a college degree - but if someone else wasn’t doing it, I would be that someone."

“ 我看到正在同疾病作斗争的人就会向他们口头推荐医生。我看到网络上有迫切的需要病人来奉献自己的生命作为实验去解决这个疾病。 ”她说。“ 我知道我很年轻并且这是一个大胆的决定在没有大学学位的情况下，但是如果没有人来做这件事，我就会去做 ”

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’."

她解释了她的网络组织的名称：“ 在医学院，医生在通过简单询问病症进行诊断时，会经常认为是常见的简单的疾病，‘ 当你听到蹄声时，想到的是马不是斑马。 ’ 同样，如果一个孩子流鼻涕或咳嗽，看起来像患有感冒，而不是罕见的癌症。但是这些罕见的事情确实会发生，通常被称为‘ 医学斑马 ’。所以我们说，‘ 想想斑马，因为斑马确实存在 ’。 ”

Despite her confidence now, its been a fraught journey to this point for Victoria.

尽管她现在很自信，但达到这一目标对Victoria来说还需要很远的路要走。

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