Life’s short, make the most of it

Michiel Vandeweert

Michiel Vandeweert is 19 years old. At the age of five, he was diagnosed with Progeria. (An aging disease with a mutation in the LMNA gene which causes cells to malfunction.) As a result, he remains small and doesn’t grow any hair. He was born just like a normal baby. But after a few months, his parents noticed there was something wrong with his development physically.

Worldwide, there are only 144 kids with Progeria, and their average age is 12. So as he likes to put it, he’s 7 years and overtime. Life with progeria wasn’t always easy.

In primary school, kids called him “alien”. And one day when he was only six years old, a boy walked up to him and said he would die when he is 12 years old. So he went home crying.

That’s when his Mum explained everything to him. That he would always remain small, that he wouldn’t grow any hair, that he wouldn’t be as strong as his friends, and that he would die at a young age.

In 2006, when he was 8 years old, his sister, Emma, was born. To his parents’ relief, the doctors told them Emma was perfectly healthy. Two weeks later though, Emma fell ill. And his Dad, who started to get worried, insisted on a blood test. He still remembers very well how they went into a very small room together with the doctor to learn about the test results. Emma turned out to have progeria too. And his Mum broke into tears. Michiel sat on her lap and said to her, “Mom, why are you crying? It’s not that bad. Now Emma can experience all the fun things that I got to do thanks to progeria, such as the reunions and meeting all the nice people I got to know.” And he didn’t even mention the fact that she didn’t have to wait in line at amusement parks. “And that’s eactly who I am.”

Despite him and his sister’s disease, he looks on the bright side of life and try to live each day to its fullest. People often ask him where he finds the strength to keep going.

Actually, there are three things that keep him ticking. (those things which he would like to share with everyone)

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First, his family and friends.

His Mum and Dad always made sure that he had the best life he could get. In fact, if there was one reason that he managed to accept his disease is because his parents raised him in a positive way. And they always encouraged him to experience his life as much as he could in his short life. Whether it was going to a festival, throwing a party or doing a TED talk.

Furthermore, he is blessed with amazing friends, who supports him through thick and thin. Last year, when his friends and him graduated from high school, they gave him a book. Right on the front was a photograph of him and the title saying, "**More than a Legend**". On the inside, photos of all kinds of fun things he and his friend did together. And it made him realize again ***"how much these goofballs mean to me"***.

The second important element in my life are challenges.

And one of those challenges are **sports**. He used to play football. But he had to quit because he wasn't big anymore, and he wasn't strong enough. His Dad used to compare him to Stuart Little, the mouse. He said, "One day, one of your friends will kick the ball so hard, that you will be stuck to it and fly straight into the goal with it". "At least I would have scored a goal!"

But anyway, he had to quit.

Fortunately, he came across snowboarding. After his first snowboarding experience, he immediately bought his own snowboard and went on a skiing holiday together with his Dad. And this was amazing. Four days, nothing but snowboarding. And the best thing bout snowboarding: flying past all those big people and leaving them wondering how this little kid could be so good. Then in two weeks, he is going on another skiing holiday. And he is really looking forward to it.

Then at a reunion in Denmark, I was introduced to go-karting. The adrenaline that go-karting gave him was amazing. He even went racing with the Dads, and he got fifth out of eight. Not too bad for a 15 year old, who was only one metre and 25 centimeters tall. When he came home, he immediately started go-karting at a club in his neighborhood. And they saw how much he enjoyed it and they gave him his own cart and his own suit.

But go-karting was just a step towards an even bigger goal – getting his driving licence. So when he turned 17, his father challenged him. He said "If you pass your theoretical exam before we leave on holiday, we will pay for your car." So the day before they went on holiday, he went for his theoretical exam. And guess what? He passed! A year later, on the day that he turned 18, he couldn't wait. He went for his practical exam. And guess what?! "I passed again!"

"And yes, I got my car!"

He has been driving for almost 2 years now and it's amazing. Not being dependent on anyone and he could go wherever he wanted, whenever he wanted.

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But apart from family and friends and taking up challenges, there is one more thing that brightens up his day. And that's moments like this one: Moments in which he can talk about life with progeria. By talking about his disease, he wants to make people aware of its consequences. As such, he hopes he can make a difference for his sister, Emma, the other 142 progeria kids, and the whole Progeria community. **"It's for these guys that I do it!"**

"But also, I hope I can make a difference for you." We all have a bad day now and then and sometimes life can be bluntly unfair. But hey **with a nice family, some great friends, and some exciting challenges, you can come a long way already**. So don't complain about the things you are not capable of, but **show the world what you are capable of**.

Because life's too short. Make the most of it.

"Oh and never forget to take a smart phone with you, so you can **capture the beautiful moments (just like this one)."**

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