

YOUTH NEWS

Getting the message out



My name's Adam. I am 17 years old and I have severe haemophilia A. Why do I raise awareness? To get a positive message out about bleeding disorders.

Adam spoke to HFA about raising awareness about haemophilia in his local community and school and why he does it. His mum Donna had a bit to say as well!

Haemophilia is rare. **Paint the Town Red** has been a great way for Adam and his family (his dad Grant, his mum Donna, his big sister Emma) to help his community and school understand haemophilia and get the right messages about it. And that includes busting myths about what Adam can and can't do.

Donna started the **Paint the Town Red** event as a cup-cake stall during Haemophilia Awareness Week in the main street of Adam's town 14 years ago. Adam had been diagnosed with severe haemophilia A at one week old after having an intracranial bleed inside his skull at birth and Donna was determined that there would be support and understanding for him in his local community. 'We wanted our local community to know about Adam so if in the future anything happened, people would have knowledge of the condition,' she explained. 'It's a case of being seen and heard.'



Our local community knows a lot now about bleeding disorders.

Photo: Donna and Adam in 2014



Adam's story

Adam has been involved in Paint the Town Red and raising awareness at school and in the community since he was a small boy. He talked about his experiences.

How has raising awareness made a difference for you?

'It has been easier on one hand at school as my peers, teachers and other parents understand more about haemophilia.

'However, some of my friends thought they were the experts and at times tried to limit what I could do, thinking they were helping. They soon got the message from me that wasn't the case.

'I find it easier to now talk about haemophilia and what I have to do to treat myself. Our local community knows a lot now about bleeding disorders.'

Why do you both think it is important for teenagers to raise awareness about haemophilia?

'There are a few reasons.

'To help younger kids going through what I went through and to see it's not that bad. To make sure other kids look after their bodies and not be ashamed of having a bleeding disorder. To be role models.'

Do you have any suggestions about awareness raising for other young people with haemophilia and their families?

'Just do whatever you feel comfortable doing - it's your choice. The more people that raise awareness, the more it helps get the message out.'



To help younger kids going through what I went through and to see it's not that bad.

Photo: Adam 10 years ago

What are you up to these days – at school and with your friends?

'This year at school I am doing VCAL, which means I go to TAFE one day per week and have a job placement one day too. I want to be a motor mechanic and specialise in diesel mechanics so I can work on the bigger machinery like trucks and tractors.

'Outside of school I like fishing, gaming and non-competitive basketball with my mates.'

Read more

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