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The Ugandan Treatment Gap – Peter Nangalu

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> *"I'm working so hard to prove to everyone that having haemophilia is not a failure. It's not being a failure. I know that and I believe it."*

Many people in the haemophilia community are aware of the disparity in access to healthcare and resources between developed and economically developing countries. In Uganda, for example, it is estimated that only four out of every 100 people with haemophilia are diagnosed. Access to effective treatments is severely limited, and care for people with haemophilia is available only from Mulago Hospital in the capital, Kampala. Prophylactic factor replacement is not an option, and humanitarian aid donations have allowed for on-demand factor treatment only in recent years. According to the World Federation of Hemophilia, per capita use of factor VIII in Uganda is around 350 times lower than in the UK [1]. Speaking with Peter Nangalu reveals what that treatment gap means for people living with haemophilia.

Peter is 23 years old. Despite having severe haemophilia, he is studying computer science at Kampala University. It is an impressive achievement to have got so far: many people born with haemophilia in Uganda do not survive into adulthood. The resilience and strength Peter has shown throughout his life is truly remarkable.

Problems started for Peter at age two, when he suspects an attack of malaria marked the first manifestations of haemophilia.

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Peter Nangalu is 23 years old and lives with severe haemophilia A. He is currently studying computer science in Uganda's capital, Kampala.

> *"I was hurt by a serious... let me call it malaria fever. I don't know whether I'd call it haemophilia, but it affected me because it broke my every joint. Someone who used to walk, run, I went back to childhood, to someone who can't even lift his own hand. I stayed in bed for over two years, when I could do nothing."*

He was eventually able to get about again, but joint damage had left him with poor mobility and bleeds kept recurring:

> *"At the age of four years, God helped me and I started to walk again. But my legs were so weak and by that time I was crippled because of the*

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> *long time I'd spent in bed. Every time I got a cut, I could bleed for a long [time]. But because we were in a village... there is only one hospital and a few health centres with no medication to help me, I just stayed in that situation and I kept on suffering. It was very terrible. I sometimes don't feel like talking about it because it makes me sad."*

These challenges made access to school even more difficult than it already was. Many families in Uganda cannot afford to pay for transport to a school, but Peter's mother was determined that his difficulties would not stand in the way of an education.

> *"...they took me to school, but still my legs were so weak and we didn't have any transport to use... so my Mum would carry me on her back and take me to school. And at the time when I had to go back, she did the same thing to pick me up from school, on her back."*

With time, Peter felt an improvement in his mobility and started to walk again – but without a medical diagnosis confirming haemophilia and no access to treatment, this was short-lived.

> *"As time went on, God helped me and I gained energy in my legs and I started to walk by myself. But when I was in Primary 7, I again had an accident. When I had this accident it totally injured my knees and I could no longer walk again."*

After three months in bed, Peter returned to school.

Growing up with unrecognised and untreated haemophilia had a major and often traumatic impact on the first two decades of Peter's life, and he gained a good education against the odds. He is passionate about sharing story in the hope that people will understand more about haemophilia. He is pictured here at community event organised by the Haemophilia Foundation of Uganda in Kampala

> *"I remember they gave me crutches to use when I was going to school. It was my first time using crutches and my hands were so weak, but I managed – because we didn't have money to buy a wheelchair. I managed. I sat for my exams and I managed to pass."*

Academic success brought a new challenge. The high school was even further from home and the journey was too far for Peter to make on crutches. There was only one option.

> *"During high school I was on the crutches... because the school was far away from where we used to stay, every morning I would go along the road and sit there to wait for someone I could plead to take me to school – every day I'd do the same thing. I'd do the same thing from school to home, just to beg for someone to take me back home."*

Peter's fellow students were now of an age where they could see he was different, and he was at risk of being stigmatised due to his physical disability. His parents, desperate to find a solution to their son's suffering, consulted people in their village.

> *"I didn't know I had haemophilia. I was in a village where there is no medication, there is no treatment, no hospitals. Where I come from, they used to call it witchcraft. I remember they even advised my parents to offer some sacrifices for the Gods to remove that curse – they used to call it a curse. But we didn't use that. We didn't follow their advice."*

Peter's family knew that he wasn't cursed, but they still had no answers. Continuing his education was a priority; however, he was now a target for bullying.

> *"They used to abuse me at school, they'd call me funny names, every kind of name. But I just knew to commit to school and I followed that. I had a few friends. Some of them were afraid to be with me because of the situation I had; they used to see me as a curse. But there were still a few who were ready to be with me."*

Another severe bleed forced Peter back to bed for many more months, precipitating a very dark period when he began to doubt whether the struggle was worthwhile.

Peter did not receive a formal diagnosis of haemophilia until age 21, when he came to the attention of the Haemophilia Foundation of Uganda. He is now an active volunteer with the Foundation, frequently attending events to raise awareness about haemophilia

> *"I remember when I was in Senior 3, again I had an accident that injured my knee and it took me to bed again for some good months. Sometimes I thought that maybe to die was the solution, because at that time I could see no future."*

Those closest to Peter rallied round and helped him to carry on.

> *"…the people I had used to advise me… encouraged me that this is not the end, it's not the end and I'm not a curse, I'm not a curse. Those words kept me to the goal I had to finish my studies and I finished my high school."*

By now, Peter had seen many doctors from hospitals across the country, and at last he came to the attention of the Haemophilia Foundation of Uganda. Recognising his symptoms, they directed him to the haematology unit at Mulago Hospital. After a childhood living with repeated internal bleeds and joint damage that had made him a wheelchair user, Peter was formally diagnosed with severe haemophilia. He could now be treated with replacement clotting factor.

> *"…I was 21 years. Imagine: you have spent 21 years without haemophilia medication… Since last year, there has been a very big change since I started using the medication, because I'd reached the stage of using a wheelchair. My legs were weak and it was so painful to walk. It was so painful [to use] some crutches, but in time I [decided] I no longer needed them because the nicknames were too much, when everyone saw me as someone who was useless."*

Factor replacement has transformed Peter's life. He finds recalling the trauma of growing up with unrecognised and untreated haemophilia an extremely painful experience – but he is passionate about sharing his story and hopeful that others will learn from it. The strength he gained through his emotional and physical struggles has made him a powerful advocate for the haemophilia community in Uganda, volunteering his time to speak at awareness-raising events. He is now looking towards a future where he can help raise awareness about haemophilia and reduce the stigma still attached to it.

> *"I'm very sure that I'll finish my education and I will help even those who used to abuse me. I'm working so hard to prove to everyone that having haemophilia is not a failure. It's not being a failure. I know that and I believe it… because I'm improving I can now spend some good weeks without having any pain – which I didn't have. I'm so pleased. I'm so pleased to be part of this organisation."*

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