

AT2030
Case Study

Brenda's Story: Journey to Gain Mobility

Prepared by
Humanity & Inclusion

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Innovation
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Impact Stories

About AT2030

AT2030 tests 'what works' to improve access to life-changing Assistive Technology (AT) for all; investing £20m over 5 years to support solutions to scale. Led by Global Disability Innovation Hub and funded by UK aid, AT2030 will reach 9 million directly and 6 million more indirectly, driving a lifetime of potential. AT2030 is operational in 31 countries globally.

About Humanity & Inclusion

Humanity & Inclusion (HI) is an independent charity working in situations of poverty and exclusion, conflict and disaster. We work tirelessly alongside people with disabilities and vulnerable people to help meet their basic needs, improve their living conditions and promote respect for their dignity and fundamental rights.

In Uganda, HI operates in 13 districts and 8 refugee settlements. HI in Uganda is implementing a range of projects including functional rehabilitation, mental health and psycho-social support, inclusive health, inclusive education and livelihoods targeting refugee populations and Uganda communities. HI works in the Omugo refugee settlement in Arua District to deliver orthosis to refugees with disability with the 3D Printing through Emergency Tele Rehabilitation Access (3D PETRA) project.

HI was awarded a European Innovation Council Horizon Prize of one million euros in September 2020 for our ground-breaking work using technology and telemedicine for physical rehabilitation.

Transforming Lives through Innovative AT

Life in a refugee settlement can be so difficult and challenging. You can imagine how it is like to trek so many kilometres fleeing a conflict from your home country. You can also now imagine the challenges Persons with Disabilities go through 365 days a year. This is twice the suffering experienced by other people, in terms of accessing services, information, the discrimination that comes from being different. With the advent of the global pandemic, the impact been even devastating. Amidst these challenges, Persons Living with Disabilities in refugee settlements have not been left behind. With the innovative technologies and rehabilitation services offered by Humanity & Inclusion, so many lives of Persons Living with Disabilities have been greatly transformed.

Brenda's Story

10-year-old Brenda who lives with her mother in Ofua, Rhino Camp, Arua district in Uganda was born with hydrocephalus, a condition in which build-up fluid is stored in

the cavities deep within Brenda's brain. The extra fluid has put pressure on Brenda's brain which the mother felt would cause damage to her daughter's brain, as she narrates," My daughter's head has enlarged since she was born, she experiences headache, has cognitive difficulties, impaired vision and she has loss coordination and incontinence".



Brenda, a 10-year-old South Sudanese refugee, living in Rhino Camp, a refugee settlement, in Ofua, Uganda.

The AT2030 HI impact on his life

In 2019, Brenda was identified by community-based volunteers who referred her to HI field staff, a team comprising of a Physiotherapist and Psychosocial worker for assessment. Upon the physiotherapist observation, Brenda could not sit, stand and walk because of weight in her head. They also observed deformities of the right lower

limb. She could spend most of her day lying on a mat and was not in school because of her condition. Even when Brenda had undergone several surgeries to manage her condition, the physical and functional abilities had not improved.



Figure 1: Brenda undergoing physiotherapy sessions at the HI rehabilitation centre.

In an interview with the psychosocial worker, it was observed that the mother had lost hope in her child's future. She never thought her child would start school, because she never had any NGO in their settlement who could support her daughter and improve her condition. The physiotherapist and psychosocial worker

developed a comprehensive action plan with the

mother and family members on how to improve Brenda's condition physically and mentally. Which included Improving head control, joint range of motion in all limbs, training bladder control, strengthening exercises. The Psychosocial worker conducted counselling and psychoeducation to the family about the condition.

After a series of intervention, Brenda's condition started to improve progressively. She could now sit with minimal support, developed strength in the lower limb whereby if supported could stand. Her self-esteem improved as a result of psychosocial support and she became determined to start school. When she fully managed to sit, in 2020 prior to the outbreak of COVID-19, HI team provided her with a wheelchair to enable her access school.



Figure 2 Brenda undergoing physiotherapy sessions at the HI rehabilitation centre.

Because of the deformities on Brenda's lower limb, she could not fully weight bear through the lower limbs to enable her stand on her two feet. Later in 2020, Brenda was assessed and qualified for the 3D PETRA project financed by the AT2030 programme. This is an innovative Project by HI providing quality orthoses to correct deformities of the lower and upper limbs like the one Brenda to improve on general functional independence.

Brenda was scanned where a copy of her lower limb was taken and a pair of Ankle Foot Orthosis (AFO) meant to correct the deformity of her feet was printed. She was later fitted in December 2020 and currently using devices provided as a night splint. As Brenda continues with a series of physiotherapy sessions, her progress is inspiring. She is now able to sit independently, lift herself from sitting to standing while holding on parallel bars and use her upper limbs while spitted to do activities

like writing, washing utensils, helping the mother sort beans. With the orthosis, the deformity is correcting progressively. The Mother said, "I am so happy for the progress I so far observed on my daughter. My daughter has become more active and helps me wash dishes, sort beans, help herself too". The mother has become more supportive and engaged in her daughter's therapy sessions. Her and other family members continue to provide Brenda with all the necessary support to see her improve encouraging her to do her daily taught exercises.

HI's field team continues with follow up sessions of exercises and psychosocial support. We cannot wait to update you on Brenda's next journey to greatness because her dream is to become a doctor and help other children like her who have such difficulties.

Photo Credit: James Odinga - Physiotherapist