

Iddy And Hamiyar Ally

Before we introduce our latest Inspirational children, we must first explain a little about their medical condition so you can understand a little of the bravery of these young people.

Xeroderma Pigmentosum, XP, is a rare skin condition. Children are born with normal looking skin but lack the ability to repair damage from day-to-day sun exposure. It is passed on genetically. As a result, within a few years, skin (especially the face, arms and legs – ie the sun exposed areas) begins first to freckle and then harden in pre-malignant spots until finally it develops cancerous ulcers and lumps. This entire process can happen before a child is even 5 years old. These children are sometimes called Midnight children as the only truly safe for them is under the cover of darkness.

Tanzania is located very close to the equator where the sun is at its strongest. Obviously, children cannot easily live their lives in the dark and so we often see very young patients with extremely advanced disease – huge unresectable tumours on their little faces, or in their eyes or mouth or scalp. These tumours are very distressing and painful.

Iddy is 11 years old and has Xeroderma pigmentosum. He has been living with it his whole life. His big sister Hamiyar has the same condition, and although she is older she has less advanced disease. This is thanks largely her Muslim upbringing. She has been wearing a hijab from a young age which has minimized her skins' sun exposure. Despite this, she has already been treated for a small resectable skin cancer which was thankfully fully removed.

Iddi was not so lucky when he presented to us a few months ago with a malignant ulcer on his scalp that was already too big to remove. In an effort to shrink it he was initiated on chemotherapy. He comes to MNH every 2 weeks for treatment. Although the ulcer must be painful – Iddi never complains.

Many children with this condition are excluded from society as their faces can be very damaged – but not Iddi or Hamiyar!! Their mum insisted they attend school covering their skin as best as she can. And both children are bright and funny and very smart.

TLM supplies all children with this condition with a range of supports including factor 50 sunscreen; specially designed TLM XP sun hats; and tablets and cream to reduce pre-malignant lesions.

But our efforts only slow the inevitable horrific process – all children with XP in Tanzania die of their disease before adulthood. But it doesn't have to be this way. With the right protection we could save ALL these children.

We are really hoping that someone reading this message may have the skills we need – are you an ENGINEER or a FASHION DESIGNER or a SKIN SPECIALIST?? (Ideally, we need all 3!!) We need to design a suit and a mask for these children – both must be 100% sun protective and yet lightweight and fun enough so that children will wear them. They must come in very small sizes as we must protect these children from infancy.



There are many more children with XP that need not to be forgotten and need not suffer and with your help, TLM may be able to do more than simply slow this horrible disease – we could remove the threat entirely – no sun-exposure – no problem. CAN YOU HELP US??