Some years ago walking into a church parking lot in St. George, UT, I saw four little children running from a car to the church building where I was going. I promptly opened the door for them and one by one they got into the building as fast as they could. I then noticed something unusual, three of the children wore cloaks attached to a hat, and their clothing covered them completely from head to toe. Their attire included gloves, a very uncommon item of clothing for a hot Saint George summer. As soon as I closed the door behind them, they removed their covers and ran into the classrooms looking for their friends. Later that morning the oldest child, Paris, a cute little girl, looked at me, provided a cryptic explanation for their attire, “We have allergies to the sun”, and walked away, without additional details.

That is how I incidentally met the Feltners, a middle class family in Utah with five children, with three of them diagnosed with a rare and hereditary syndrome called Xeroderma pigmentosum (XP). XP is an inherited condition characterized by an extreme hypersensitivity to ultraviolet (UV) rays from sunlight produced by a genetic defect in the normal repair of DNA. The surface of the body being the most exposed to the sun suffers the manifestations of this defect in DNA repair through extensive damage of the exposed skin and other areas of the body such as the eyes. The skin damage of XP is not trivial and can lead to an early onset of skin cancer and blindness. XP is not limited to the exposed parts of the body and can in addition include other abnormalities such as approximately 20% of people with XP may also develop progressive neurological disease. Luckily, XP is a very rare disorder and in the USA, there are only around 250 people with documented XP. The devastating results of this rare disease are malignant forms of skin cancer (e.g. melanomas), which cause the death of most of the children affected with this syndrome during the first decade of their lives.

The main purpose for the documentary is to educate people about this rare condition and to create an awareness of the problems faced by XP patients. I would also like the documentary to be a wakeup call to young researchers and to supporters so that solutions for these young people could be a focus of attention at some level. I would also like to be able to keep this documentary as an ongoing process and be able in the future to add more details and chapters to it so that there will be more information and data through this very easily accessible form of documentation.

My goal is to ease the path for these children and many others like them and if possible be part of the chain that will help them obtain the attention and support they deserve. XP is not a uniquely American problem. Around the world, more children are suffering the consequences of this rare condition when it is untreated or misdiagnosed which is likely the case in most resource-constrained countries where there is lack of awareness and resources to help these children. Finally, as Payton pledge in the interview, “I wish the researchers could find the cure for XP that I can go to any hospital and get a shot that will be awesome if they could”.

“UNDER THE CLOAK OF PENUMBRA”
Candelaria Atalaya (Jeff Metcalf)
Department of English
UNDER THE CLOAK OF PENUMBRA

Directed by: Candelaria Atalaya
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