

Albinism In Pakistan

Albinism in Pakistan is a common condition. However, it still remains an under the radar topic. There is a lack of data as no surveys have ever been carried out to calculate the prevalence of this disease thus the knowledge regarding albinism remains limited. Since, albinism is an autosomal recessive disorder, it is more common in areas where family marriages are common, like Pakistan.¹ Not only because of its treatment but also because of its social and financial consequences, oculocutaneous albinism is daunting. In such cases, the current pattern of consanguineous marriages, prevalent in this village, places more focus on the role and significance of marriage counseling.² Recently, researches have been carried out to find out the common mutated alleles in Pakistani population but still the work done is quite limited to reach a certain conclusion.³

Albinism and awareness

Awareness regarding albinism is very limited. Families of children with albinism have often felt that there was no support group dedicated to albinism where they can discuss their problems and get guidance from others with similar experience.⁴ We interviewed a father of 3-year old and he described his experience of seeing his daughter with albinism for the first time, as very confusing as he had no idea what this was. He said, it was only after his daughter that he actively started getting knowledge from various sources to understand albinism. He also mentioned that explaining the condition to his relatives was one of the hardest tasks. This shows that there is general lack of awareness regarding this condition.

Albinism and health

Affordability and quality of healthcare are two major barriers that people in Pakistan with albinism face. Primary and secondary healthcare hospitals lack trained staff and tertiary hospitals are too costly for majority of the population. Genetic counselling given to a parent at the time of the birth of their child is also very rare and thus new parents have no idea on how to deal with it, further adding to their worries. Risk of developing skin cancer is often not known to the families due to poor counselling and thus children with albinism often stay exposed to UV rays for prolonged duration and develop skin sores that could develop into skin cancer. Due to affordability issues, people with albinism don't use sunscreens on

regular basis. Health campaigns directed to address this issue and availability of sunscreens to those who can't afford can significantly prevent this complication.



Figure 1 children of a family of Dadu, interior Sindh, Pakistan.

Albinism and social aspects

“People staring whenever we go out, make us feel alienated”. “My daughter gets annoyed whenever she goes out and people stare at her and approach her, even if it’s in good faith”. Albinism is still a new disease for many and because of lack of understanding of the condition, people treat children with albinism as foreign. Such experiences induce anxiety and negatively impacts the child’s confidence. Many children avoid public gatherings just because of that and that leads to social isolation and depression when they approach teenage years. Due to their appearance, they are often bullied. Name-calling is the most common cause of bullying they face and thus they tend to skip school or not go to one at all. There are lots of myths directed at this condition which further provokes people to misbehave.

Albinism and Parenting

For many people with albinism, parents are the main support and often the only support they need. But not all parents are same. Due to society’s prevailing myths, some parents think that this is some sort of disability and thus keep their child in confinement. They make them dependent on themselves and in doing that compromise their education and freedom. The constant reminder of the condition and it’s limitations shatter child’s confidence. Lack of support group and proper counselling of new parents can help eradicate this problem as they can learn form other’s experience and implement habits of positive parenting.

Albinism and Education

At present, there are no special services provided to kids with albinism. At times, it becomes hard for them to copy work as they cant read the board clearly. Friends support is often what gets them through. Teachers aren’t provided with any special kind of training to deal with children with albinism. This leads to children dropping out or not going to school at all.

NOTE:

This article is based on the interviews taken by Pakistan albinism support group – PASG. It's a student run society and thus the information provided is very basic and doesn't have proper statistics included.

1. Shah SA, Saeed A, Irshad M, et al. Oculocutaneous Albinism in Pakistan: A Review. Published online 2018. doi:10.4172/1948-5956.1000552
2. Jah Samdani A, Khan Khoso B. *A Unique Albino Village of Bhatti Tribe in Rural Sindh, Pakistan, with Oculocutaneous Albinism Manifestations: An Epidemiological Study*. Vol 12. Iranian Society of Dermatology; 2009. Accessed January 17, 2021. http://iranjd.ir/article_101319.html
3. Gul H, Shah AH, Harripaul R, et al. Genetic studies of multiple consanguineous Pakistani families segregating oculocutaneous albinism identified novel and reported mutations. *Ann Hum Genet*. 2019;83(4):278-284. doi:10.1111/ahg.12307
4. Albinism and Pakistan – Safire Dreams. Accessed January 17, 2021. <https://sapphirical.wordpress.com/2010/05/22/albinism-and-pakistan/?unapproved=2233&moderation-hash=a5e1ae438eefb5e908fb75e1ae8581ef#comment-2233>

