LIGHT UP

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Meera & L.B. Deshpande Centre for
Sight Enhancement

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Rehabilitation of
Blind and Visually Impaired

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Better late than never

When Mr Modavath Saida Naik came to LVPEI's Vision Rehabilitation Centres at the age of 18, in March 2000, he had just completed his schooling in a special school for the blind. Although he had good residual vision, he had never learned how to make the most of it because of the lack of low vision services and proper educational guidance.

Modavath Naik, born to consanguineous parents, was from Guntur district in Andhra Pradesh. At the Rehabilitation Centres, he was diagnosed to have oculocutaneous albinism, a condition that is characterised by lack of sufficient pigmentation in the retina, and resultant low vision. His hair and skin too lacked pigmentation. He had grown up with the stigma of this different appearance. His psychosocial trauma was compounded by the fact that he had lost his father when he was just three years old.

At the Vision Rehabilitation Centres, we found that he had difficulty reading the chalkboard and normal-print college textbooks. He could not engage in outdoor activities because of his extreme sensitivity to bright light; his skin developed a rash when exposed to the sun. The rehabilitation team studied his needs and prescribed a variety of intervention that would enhance his quality of life. His best corrected visual acuity was 3/15 in the better eye, and this was improved to 3/4 with the use of a handheld telescope, which allowed him to do board work independently. His near vision, which was N12, was improved to N8 with the use of a spectacles device (+6.50), and as a consequence he could read his college books. The rehabilitation team trained him in the use of these devices, and provided additional counseling that would help him deal with the psychosocial issues he faced. Tinted gray sunglasses were prescribed, he was advised to wear a cap to help deal with the daytime glare, and he was asked to see a dermatologist for advice on skin care.

During the follow up visit we found that his personality had undergone a change; his new-found confidence had taken him through the graduation course successfully. Financial constraints prevented him from going on to fulfil his ambition of doing an MBA, and in the certainty that he had the ability to support his family, he is now actively seeking a job.

Albinism

Albinism is a set of inherited disorders that result from the body's inability to produce melanin pigment. Melanin is dark the pigment that protects our tissues from ultraviolet radiation. The formation melanin in the body is a multi-step process that may be affected by genes on six different chromosomes. Due to the many genetic variations causing this condition many different forms of albinism may occur. The most severe form of albinism presents with little or no pigmentation of the skin, hair and eyes.

Naik was a typical case of albinism. It presents itself in individuals with white / platinum hair, pink skin and often a pinkish eye color. Other forms of albinism may affect only the eyes. These individuals will present with many of the eye and vision problems related to albinism, but have normal skin and hair pigmentation.

Implication of Albinism

At our centre we have treated persons of all ages with albinism and the way it manifests itself is a discuss below.

Reduced Vision & Macular/ Foveal Hypoplasia: Patients with albinism have reduced visual acuity primarily from an underdevelopment of the center of the retina. The macula is where the best vision is located and it contains a very sensitive area called the foveal pit. In albinism the pit fails to develop and causes mild to moderate reduction of central vision.

Photophobia: Melanin absorbs stray light and protects our eyes and skin from ultraviolet light. It coats most of the internal layer of the eye allowing light to enter only through the pupil, while the pigment in the retina normally absorbs stray light. In albinism, failure of the eye to develop pigmentation results in extreme light sensitivity. Thus the patient may not only have too much light entering the eye, but also have no way to handle the excess stray light once it enters.

Sunburn: Patients with albinism are face the risk of severe sunburn. Children must be taught to protect their skin. Sunscreens and adequate clothing are essential. Sun may pass through clothing, especially wet clothing, and burn the skin. Increased risk of sunburn occurs at higher altitudes, and may occur at lower latitudes around reflective surroundings such as sand and water.

Nystagmus: In congenital forms of vision loss it is common for patients to have nystagmus. Nystagmus is an involuntary rhythmic oscillation of the eyes. It is often the first sign that parents recognize when an infant has vision loss. Nystagmus can occur in many forms and can lead to a decrease in vision just from the rhythmic movement.

The Null Position - Unusual Head and/or Eye Position: Patients may also show a tilt or turning of their head or eyes to where they achieve their best vision. This is called the null position. It is crucial that family and teachers allow a child with albinism to tilt or turn their head or eyes to the position that lets them see the best. When bifocals are prescribed, the low vision specialist must select the type and position that works with the patient's null position.

Fluctuating Vision: A patient's nystagmus often fluctuates when under stress or when tired. As the nystagmus increases, the vision may blur further. Children with nystagmus may not do well with timed tests as they may be under stress. Even covering one eye may cause a change in the vision of the viewing eye due to an increase in Strabismus (Crossing or turning out):

The loss of binocular vision is common in albinism, and this results in reduced depth perception.

Stable Condition: Albinism is a stable condition. In fact, some patients show slight improvement in visual acuity by the time, they are young adults. This may be related to increased pigmentation or a better control of the nystagmus.

Systemic Issues: Albinism has been linked in rare cases with systemic diseases, the most common of which is Hermansky-Pudlak Syndrome (HPS). HPS occurs throughout the world, but is most commonly associated with patients of Puerto Rican descent. Abnormalities of the granules in the blood platelets cause a bleeding disorder and an accumulation of a chemical called ceroid. Lung and gastrointestinal problems such as colitis may develop including the inability to fully expand the lungs.

Emotional Aspects: Patients with albinism must deal with the emotional trauma of appearing different. Pink skin and eyes, white or platinum hair, unusual head or eye null positions, thick eyewear and the need to hold reading material very close unfortunately cause these patients to stand out more. Adding to the problem, Hollywood has frequently exploited albinism in movies picturing "albinos" as evil or sinister characters.

Low Vision Care for Albinism

Patients with albinism are excellent candidates for low vision care. Albinism is a mild to moderate, stable central vision loss. These patients have excellent residual side vision. Simple magnification, correction of refractive errors, light and glare control and use of adaptive aids may all benefit albinism patients.

Filters & Sun Protection: Tints, selective filters and hats may aid the albinism patient. The low vision specialist must consider the need for adequate filters both inside and out. Sunlight may be 100 times brighter than inside light. Filters for general wear are usually not adequate for outside wear. Some patients may benefit from Transitions Xtra lenses that darken in the sun. Additionally, adequate education on the use of sunscreens, hats and clothing is necessary for all albinism patients.

Refractive Error: Albinism usually results in significant amounts of farsightedness or near sightedness combined with astigmatism. Most albinism patients require prescription eyewear. Refracting the nystagmus patient requires special techniques to reduce stress and avoid increasing the nystagmus. Children with albinism should be carefully refracted by the low vision specialist at an early age.

Close Reading Distance: With a mild to moderate loss of visual acuity, an albino child may need to holding materials closer. Parents and teachers often worry about the close distance, but the child should be allowed to read at the most comfortable viewing distance where they see the best. Most albinism patients benefit from bifocals to reduce the strain of focusing at such a close distance. Bifocals should be considered in all school age children with albinism.

Reading Vision: At an early age bifocals may help patients with albinism by reducing fatigue and eye strain caused by the close working distance. Magnifiers, strong reading glasses and closed circuit television systems may be helpful.

Contact Lenses: Contact lenses can be used to correct the refractive error (myopia, farsightedness and astigmatism) of an albinism patient and in some cases an improvement in visual acuity is obtained. Contact lenses have been shown to aid some patients with nystagmus. One theory is that the tactile feedback of feeling the contact lenses on the eyes may lead to better control of the movement and allow the patient better vision. Another benefit of contact lenses is that they move with the eyes and provide better image quality.

Low Vision Devices

There are different low vision devices to help improve the lives of people with albinism. To get the most from a low vision device, it's important to see and understand what the device can and cannot do. Since different devices help with different tasks, the person with low vision will likely choose a mix of different devices to accomplish all of his or her goals. Tasks, goals, and technology change over time, therefore, a person who uses low vision devices should re-evaluate the choices.

Glasses

Glasses cannot fix low vision, but they do ensure that the person's eyes see the clearest image possible and can easily focus at close distances. Even as babies, people with albinism instinctively hold things closer to their eyes to see them better. Up until the age of five or six, this technique sufficiently compensates for low vision because books for young children already feature large print. Looking closely at objects does not hurt a child's eyes in any way. However, it is important for babies and young children with albinism to wear glasses to correct refractive error if they are near sighted, far sighted, or have astigmatism.

Near vision devices

Reading glasses and hand-held and stand magnifiers are near vision devices that help people with albinism read, look at pictures, diagrams, and maps, and accomplish other tasks that require seeing small details up close.

Reading glasses help the user focus on text or other objects while holding the object close to the user's eyes. Reading glasses allow the widest field of view for reading compared to other devices. Hand-held and stand magnifiers enlarge close-up images, allowing the user to see small print and images at greater distances from the user's eyes.

Distance vision devices

Telescopes can help people with low vision improve their distance vision. Distance vision includes seeing a chalkboard in a classroom, a sporting event. Telescopes are differentiated from one another by their magnification power and the

field of view. Typical magnification powers for low vision telescopes range from 2x to 4x. When a person with 20/100 vision uses a 4x telescope, that person theoretically sees an image 4 times bigger than normal and, therefore, sees the same details as a person with 20/25 vision. In general, the greater the magnification power of a telescope, the more fine detail the person with low vision will see using the telescope. However, as magnifying power increases, the field of view, or the size of the area enlarged by the telescope, generally decreases.

Hand-held telescope: One of the most common low vision device is the hand-held telescope, also called a monocular. Hand-held telescopes come in a wide variety of sizes, magnification powers and prices. Hand-held telescopes work best to quickly view a distant object, or to perform tasks such as reading a sign or locating an object. Clip-on telescopes allow the user to slip the telescope over his or her glasses for hands-free use. The clip on telescope works well for the person who needs to use the telescope for extended time periods, such as for watching TV, a movie, or a live stage performance. The user can remove the clip on the telescope and use it as a hand-held telescope for quick viewing tasks.

Electronic devices: When traditional optical low vision devices don't help a person accomplish a task, electronic aids might help. Closed Circuit Television (CCTV) systems help people who need greater magnification than reading glasses and magnifiers. CCTV systems also allow the user to adjust the size, brightness, and contrast of the magnified image to best match the user's vision. The user can even read white letters on a black background to decrease glare. CCTV systems are expensive and far less portable than other near vision aids. Newer CCTV designs, however, are now smaller, more versatile, more portable, and less expensive.

Contrast enhancement devices: For people with albinism, bigger isn't always better. Increasing the contrast of text is often more effective than increasing the size of text. Black felt-tipped pens and dark lined paper can make writing easier for some people with low vision. Bright-colored chalk can also help students with albinism. Writing guides, which are templates with open areas where one writes, can help people write in straight lines, or with tasks like write checks. Colored filters can make it easier to see certain colors. For example, a yellow filter can make light blue letters appear darker and easier to read. Lighting plays a major role in how well a person with low vision sees. Experimenting with different types and brightness of light, as well as the location of the light, can make tasks a lot easier. Keep in mind that too much light and too little light can both cause problems.

Low Vision Awareness Program

February 21 to 23, 2003
September 26 to 28, 2003

Short term fellowship program in Low Vision Care

Three month program for ophthalmologists and optometrists commencing January 1, May 1 and September 1, 2003.

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You can help the Vision Rehabilitation Centres of the L.V. Prasad Eye Institute discover basic causes and treatment strategies for eye disease through research, restore vision to an indigent patient and help expand the frontiers of ophthalmology through your tax deductible contribution to the Hyderabad Eye Institute or the Hyderabad Eye Research Foundation.

(Donations above Rs. 250/- are exempted under Section 80G of Income Tax Act, 1961 for Hyderabad Eye Institute and 35(i) (ii) for Hyderabad Eye Research Foundation). For more information, please contact :

You Can Make A Difference

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