Characteristics of Albinism  
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March 17, 2008

Remember Marcus  
In Unit 2 you were introduced to Marcus, the third child and first son for his parents. His skin and hair color did not match the rest of the family, so his parents were immediately alerted to something being different about his birth. Their pediatrician informed them that Marcus had albinism and sent them home with some information about that condition as well as contact information for the local school district’s Early Start Program. Marcus had some trouble learning to read in school due both to his eye condition and to a slight learning disability. At this time he is succeeding academically in tenth grade and hoping to make the varsity basketball team as a junior.

Albinism is a condition which can affect vision, hair color and skin color. People and animals who have this condition were referred to as “albinos” in the past. This term has been used for many characters in books or movies who are in some way freaky. People who have albinism are rightfully tired of being referred to simply by the name of their eye and skin condition. In the current fashion of putting the person first when we refer to people who have disabilities, many people prefer to be referred to as someone who has albinism rather than as an albino.

There are several types of albinism. Types one and two affect the eyes and the skin and hair. They are called oculocutaneous albinism. People who have type one have very pale skin and very light hair. Their visual impairments tend to be moderate to severe. People who have type two oculocutaneous albinism have more color in their skin and hair and have less severe visual impairment. The third type of albinism is called ocular albinism, and it affects only the eyes.

The lack of pigmentation in the eye causes atypical development of the optic nerve. People who have albinism are also near-sighted, so their vision can be corrected to some degree with eyeglasses. They are also extremely sensitive to light and glare, since they have little pigment in their retinas. This extreme photosensitivity impairs their acuity in addition to the near-sightedness. Sunshades and hats with brims are helpful, but the vision cannot be corrected to 20/20. Even though many urban schools forbid students to wear hats on campus these days, students who have albinism need a “reasonable accommodation” that allows them to protect their eyes this way on the playground and in other brightly lit situations.

Nystagmus, which is a rapid, involuntary movement of the eyes, is also present in people who have albinism. The primary complaint of children who have nystagmus is that other kids are always asking them what’s wrong with their
eyes. The nystagmus itself does not blur their vision or make things look like they are constantly moving. The brain filters out the excess movement and image information coming from the eyes and allows people who have albinism to understand whether things are still or moving.

Most people who have nystagmus discover that by holding their heads at a certain tilt and looking from a certain angle they can find a spot where the nystagmus slows or stops. Some people use this spot for looking closely at details, such as when they are reading or looking at pictures. This spot is called the “nul spot.” It is important to allow students who have nystagmus to hold their heads in the position they find best for their vision even if the position is not the ideal posture expected of fully-sighted children.

Strabismus is another involuntary movement of the eyes which may accompany albinism. It may be present in only one eye, and is sometimes referred to as a “wandering” eye. Strabismus prevents people who have it from using both eyes at the same time, resulting in a reduction of depth perception. The brain suppresses the information from one of the eyes to avoid double vision.

Children who have albinism don’t have constant opportunities to learn incidentally by observing others visually as fully-sighted children do. There is a lot of information they are not picking up that their sighted peers are learning just by watching those around them. That is why systematic teaching needs to cover many concepts for orientation in space and activities such as cleaning, cooking and personal care. All of the areas that need special attention both at home and at school will be covered during this course.

People who have albinism may need special accommodations for academic work. Having print information enlarged will be helpful to many of them. Having a good contrast between the symbols or letters on a page and the background will help. Using glasses and/or a magnifier may be adequate to make print large enough for sustained reading, especially in the lower grades when reading material is in large print. As the print size becomes smaller in the higher grades, some students who have albinism will continue to prefer reading without low vision devices, but some may need higher magnification from reading glasses or an optical magnifier. Some may even prefer to use electronic magnification for reading and math. The teacher of visually impaired students will be able to determine the best reading method through assessment.

In summary, there are several accommodations that are helpful for students who have albinism:

- Protect the student from glare;
- Encourage use of sunshades and a hat with a brim for brightly lit situations;
• Facilitate preferential seating as recommended by the teacher of visually impaired students;
• Provide enlarged materials as recommended by the teacher of visually impaired students;
• Reduce glare by making sure light sources come from behind or from the side;
• Move computer screens or CCTV monitors away from light sources to reduce glare;
• Allow close viewing;
• Describe activities that are happening beyond the student’s ability to see clearly, as in school assembly programs;
• Encourage hands-on experience whenever possible.

References
