

Facts Regarding Children with Albinism for Physical Education and Recreation Professionals

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Albinism is a rare group of genetic disorders that causes the skin, hair and/or eyes to have little or no color, which causes the person to be sensitive to light. Albinism is also associated with low vision that isn't correctable with glasses or contacts. However, with a few accommodations, children with albinism have the potential to become successful, healthy members of society. Here are some issues and solutions you can use to help reach physical activity goals.

Sensitive to glare: Because the eyes of a child with albinism don't filter light, glare is problematic in gyms with shiny floors, sports in the snow and while in or around swimming pools.

Solution: Allow the use of sunglasses, tinted glasses or a brimmed cap outdoors and indoors when necessary.

Sensitive to sun/burns easily: Because a child with albinism has little or no pigment in his skin, the effects of the sun can be very harmful to skin and eyes.

Solution: Protect skin and eyes by:

- Dressing the child in long sleeves and pants, if possible apparel with built-in sun protection
- Having the child apply sunscreen at least 20 minutes before outdoor activities
- Adjusting PE uniforms to cover exposed skin
- Providing out-of-the-sunbreaks during outdoor activities such as a pop-up tent or beach umbrella

Vision lacks fine detail: Comparing a normally-sighted person's vision to that of a child with albinism is like comparing HDTV reception to a standard TV. You can see the big picture, but not fine details.

Solution: Make things easier for the child to see by:

- Assigning lockers at the end of a row to help students find theirs more easily
- Using large-print locks

- Adapting handouts so fewer items are on a page and increasing text size to 18 – 20 point font
- Avoiding colored paper on tests and handouts
- Using descriptive instructions for the small details of skills you are teaching
- Using brightly-colored pinnies, shirts or wristbands with bells for tag or cooperative games
- Using tactile maps made especially for sports to provide a whole-sport reference
- Using the student's name if instructions are only for that student, and using the names of other students so the student with low vision knows who is participating

Poor distance vision: Vision can't be corrected with glasses or contacts.

Solution: To help a child with albinism access information from a distance, ask the student what she can see, how far, how big and what colors work best. In addition, you can:

- Allow the child to get closer to targets, demonstrations, videos and projectiles
- Modify targets and balls so they are larger, brighter and have lots of contrast from background
- Use auditory targets and balls
- Use tethers, human guide method or other assisting methods for running and locomotion skills
- Use directional terms such as north, south, east and west, however some children with albinism have difficulty with right and left directions due to cross dominance, for example showing a preference for using the right hand, but having a dominant left eye
- Have a play-by-play action commentary or use descriptions when showing videos or doing visual demonstrations
- Use padding on poles or hazardous objects and ensure students are oriented to these hazards if equipment is hard to see in cases such as badminton or volleyball nets and poles

Social stigmatization and isolation: When a student's appearance and visual access is different from peers, extra care must be taken to ensure full participation.

Solution: You can help a student participate and provide an emotionally-safe environment by:

- Serving as a role model in your attention to social details of group work
- Using positive, person-first language
- Being mindful in placing the child with partners and in small groups
- Monitoring for bullying

Depth perception may be impaired: Poor binocular vision can cause children to have difficulty transitioning from one type of surface to another (cement to grass) and getting into the pool. Using steps, jumping and climbing down from a height, catching and batting a ball may be challenging due to impaired depth perception.

Solution: To assist with depth issues you can:

- Provide orientation to sport and activity areas
- Use neon-colored duct tape at transition places such as first steps, use rope under tape and indoor/outdoor carpet runners
- Use gym mats under jumping areas and provide verbal cues for entry into the pool
- Keep activity areas free of materials or equipment on the floor
- Use bright, colorful equipment such as neon yellow balls, flaming orange targets as well as using bright white with a contrast color
- Teaching all of the skills of a sport or game even if the full-sided team game is not achievable
- Emphasize individual sports such as track, swimming, tandem biking, stationary biking, elliptical treadmill and weight machines

A Special Note about Medical Issues with Rare Forms of Albinism

Hermansky-Pudlack Syndrome (HPS) includes a blood clotting disorder, respiratory disorder and possible large intestine and kidney disorder. Chediak-Higashi Syndrome (CHS) is an extremely rare form of albinism that is accompanied by problems in the immune and nervous systems. A child with these issues requires activity leaders to check with medical professionals on various activities. Contact sports and goalball may be contraindicated.

Reference: *Raising a child with albinism: A guide to the school years.* East Hampstead, NH: The National Organization for Albinism and Hypopigmentation, Appendix C, 314-316.