

Materials for the Educational Team

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Purpose

- This section includes documents that can be presented to members of the educational team as helpful tools for working with your child.
- Ideally, these documents would be compiled into a packet so that the team members may refer to them as needed throughout the year.
- Refer to the instructions in each document for additional information.

Albinism Terminology

Oculocutaneous Albinism (OCA): Oculocutaneous (pronounced ock-you-low-kew-TAIN-ee-us) Albinism is an inherited genetic condition characterized by the lack of or diminished pigment in the hair, skin, and eyes. Implications of this condition include eye and skin sensitivities to light and visual impairment.

Ocular Albinism (OA): Ocular Albinism is an inherited genetic condition, diagnosed predominantly in males, characterized by the lack of pigment in the eyes. Implications of this condition include eye sensitivities to light and visual impairment.

Hermansky Pudlak Syndrome (HPS): Hermansky-Pudlak Syndrome is a type of albinism which includes a bleeding tendency and lung disease. HPS may also include inflammatory bowel disease or kidney disease. The severity of these problems varies much from person to person, and the condition can be difficult to diagnose with traditional blood tests

Chediak Higashi Syndrome: Chediak Higashi Syndrome is a type of albinism in which the immune system is affected. Illnesses and infections are common from infancy and can be severe. Issues also arise with blood clotting and severe bleeding.

Melanin: Melanin is pigment found in a group of cells called melanocytes in most organisms. In albinism, the production of melanin is impaired or completely lacking.

Nystagmus: Nystagmus is an involuntary movement of the eyes in either a vertical, horizontal, pendular, or circular pattern caused by a problem with the visual pathway from the eye to the brain. As a result, both eyes are unable to hold steady on objects being viewed. Nystagmus may be accompanied by unusual head positions and head nodding in an attempt to compensate for the condition. Nystagmus appears more prominent as students focus visually on a target.

Null Point: A null point refers to the point in which a student has positioned his/her head to greatly reduce or eliminate nystagmus.

Strabismus: Strabismus is a misalignment of the eyes caused by a muscle imbalance. The eyes deviate upward, downward, inward, or outward simultaneously or independently of each other.

Photophobia: Photophobia is an abnormal discomfort or sensitivity to light and glare. Individuals with albinism experience photophobia because the lack of pigment in the iris does not allow the eyes to filter out light.

Refractive Error: Refractive errors are vision problems that happen when the shape of the eye keeps you from focusing well. The cause could be the length of the eyeball (longer or shorter), changes in the shape of the cornea, or aging of the lens. This could

manifest in a student being nearsighted or farsighted. Students with albinism sometimes experience refractive errors in addition to the impaired vision associated with albinism, but this is not always the case, thus, not all students with albinism will be prescribed or benefit from glasses.

Foveal Hypoplasia: The retina, the surface inside the eye that receives light, does not develop normally before birth and in infancy.

Optic Nerve Misrouting: The nerve signals from the retina to the brain do not follow the usual nerve routes.

Optical Devices: An optical device is a tool used by a student with low vision to improve access to a given near or distance tasks. These devices are typically prescribed by a Low Vision Specialist, and some examples include hand-held magnifiers, monoculars (telescopes), and/or video magnifiers.

Scotoma: A scotoma refers to a partial loss of vision in an area of the eye where otherwise normal vision exists. It is also known as a blindspot.

Possible Accommodations for the Student

With a Visual Impairment

By Chrissy Cowan TSBVI Outreach Dept.

General

- Your VI teacher should give you a copy of the Functional Vision Evaluation and Learning Media Assessment with detailed information about how your particular student uses his/her vision.
- Students with low vision should be encouraged to use their eyes to the maximum. Vision is not diminished by use.
- A student with albinism will be sensitive to the light and will sometimes require an adjustment period of about 10 minutes when he or she comes in from being in the sun.
- Allow the student to adjust his/her work to a position that he/she is most comfortable with.
- Familiarize yourself with your student's print needs as specified in the LMA or IEP. Use regular print when appropriate and large print when specified. Reminder: decimal points (for instance, when used in math) in any size can be difficult to read in any size font.
- Colored paper and font size make a difference. Sans serif fonts are harder to read.
- Whenever an assignment refers to a picture (as in math workbooks) allow the student to look at the picture in a regular print book. The large print process distorts pictures.

Reading the Blackboard / Smartboards

- Seat student near the board (within 3 to 5 feet) and in a central location, but within a group of students.
- Verbalize as you write on board.
- If possible, provide a copy of what you have written on the board to the student.
- Have another student with good handwriting copy off the board. The visually impaired student can then take a photo of the other student's notes. Allow student to use a telescope supplied by the vision teacher (if this is done the student will probably need to be seated back away from the board to increase his/her visual field).
- A clean board makes for better contrast and is easier to read. Certain color markers provide better visibility for the student to read. Consult with student and TVI.

Overhead Projectors / Video

- Seat student close to the screen.
- Provide student with your overhead projector sheet or master copy so he or she can read and/or copy from it.

- Use a dark (preferably black) Vis-à-vis pen on the overhead sheet
- Discuss movies thoroughly afterwards to make sure the student understands major concepts presented
- A darkened room provides more contrast
- Move the projector closer to the screen to produce a smaller, more distinct image
- Make a good photo copy of your master
- Do not use red ink
- When projected, please ensure that your tests are completely legible. Ask the student to read parts of the test to you privately to be sure he or she can see all parts of the test
- Give the student a little extra time if needed to read projected notes / video on the board

Illumination

- Light intensity can be regulated by adjusting distance from the window or light source
- Artificial lights should be used whenever brightness levels become low in any part of the room.
- Avoid glares on working surfaces (a piece of dark colored paper taped to the entire desk surface diminishes glare off the desk)

Seating

- Avoid having students work in their own shadows or facing the light
- Students may need to change their seats whenever they desire more or less light

Contrast

- Dry erase boards used with dark markers offer better contrast
- Soft lead pencils and felt-tipped pens with black ink are recommended for use on matte, white and tinted paper
- Good contrast and white space between lines of print offer the best viewing comfort for lengthy reading assignments
- Avoid using red/orange/yellow on Smartboards

Tests

- Tests should be dark and clear
- If there is a time element, please remember that a person with low vision will frequently be a slower reader than a person with normal sight of the same intelligence. His or her eyes may tire much faster, so tests in the afternoon can be particularly difficult to read
- On timed drills allow at least double the time for a student with low vision. Ideally they should be untimed
- If the student is comfortable performing orally, tests could be given orally by another person who fills in the blanks. Please be careful here, as some people are not auditory performers, and it is a misconception that all blind and low vision students can perform better auditorally.

Physical Education/Recess

- Check with TVI to see if there are any restrictions of activity or on visual fields
- Ball Sports: practice catching, kicking, and batting with students to check whether or not he/she can see the ball in time to catch, kick, or bat
- Use audible goals and/or balls (available from TVI) or use a radio as a goal locator (as in basketball)

Mobility and Orientation

- Allow student to explore your classroom during the first week and whenever you make any major changes
- Show student where his or her desk is, where materials are located, papers turned in, etc.
- Point out the restrooms, water fountains, library, office, cafeteria, gym, and bus stops
- Contact O&M specialist for detailed information

Educational Considerations

Eye Condition Albinism	Effects On Vision	Educational Considerations
<p>Total or partial absence of pigment, causing abnormal optic nerve development</p> <p>Lenses and tinted lenses may be prescribed.</p>	<p>Decreased acuity</p> <p>Photophobia</p> <p>Increased sensitivity to glare</p> <p>High refractive error</p> <p>Astigmatism</p> <p>Central scotomas</p> <p>Nystagmus</p> <p>Eye muscle imbalance</p> <p>Eye fatigue with close or detailed work</p> <p>Reduced depth perception</p>	<p>Magnification (e.g., hand-held magnifier, electronic magnifier, screen enlargement software, monocular / telescope, etc.)</p> <p>Close viewing</p> <p>High contrast materials</p> <p>May need to use sunglasses, visors, or hats outdoors and indoors as well</p> <p>Lighting from behind</p> <p>Reduced glare</p> <p>Line markers, templates, placeholders</p> <p>Frequent breaks</p> <p>Prosthetic, iris occluding contact lenses</p>

IEP Summary

How to Use this Document:

- It is not recommended that you simply photocopy the IEP. Often times, this information is quite lengthy.
- Highlight or point out the most important information. (See below for suggestions.)
- This information may be summarized verbally and presented in a brief handout. Best practice is to share this information in writing for future reference.

Share information about:

1. Goals and objectives
2. Accommodations/modification page
3. Special education service delivery (amount of service for VI and other related/special education services as applicable)
4. Special information related statewide assessment
5. Recommendations from FVA* / LMA* and O&M* evaluation

NOAH Project Notation: The CARE Project (**C**reating an **A**lbinism **R**esource for **E**ducation) provides parents of school-aged children with albinism, educators and other professionals with resources and information to assist them in formulating a child with albinism's education document. For more information on the CARE Project visit: www.albinism.org/CARE.

*List of acronyms found in section **V. Resources: List of Acronyms**

Student Involvement

The documents in the Student Involvement Portfolio can be used in their entirety or individually, and are an important step in the development of student self-advocacy. The intent is that the student creates a packet of information related to albinism and its implication on visual access to be shared with teachers. This can be done independently or with support from a parent or TVI.

The portfolio can be in any media format. Some examples include a 3-ring binder, a multimedia slideshow, a simple folder, or a collection of electronic documents linked to a shared location.

Sample Ideas: (See **Section V** for templates.)

- Ability Statement
- Letter of Introduction
- Student Portfolio
- Technology I Find Useful
- Video
- Picture Collage
- Class Presentation

Once student has completed work samples for this topic, they may be presented to the educational team with other items in this section.

Facts Regarding Children with Albinism for Physical Education and Recreation Professionals

By Monica Lepore, Ed.D., Certified Adapted Physical Educator
& Maria Lepore-Stevens, M.A., COMS, Certified Adapted Physical Educator

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.

Fact Sheet for Substitute Teachers

CONFIDENTIAL

Student Name: _____

Seat Location: _____

Pull-out schedule: (Student pulled out of class)

Monday	Tuesday	Wednesday	Thursday	Friday

Push-in schedule: (Service providers visit the classroom)

Monday	Tuesday	Wednesday	Thursday	Friday

Notations (*specific to your student, such as*):

- Glasses do not correct vision.
- Allowed to wear hat and sunglasses in class.
- Allowed to move location in class to be closer to board or item being used for teaching lesson (i.e. map, science materials) as long as safety of student and others is not compromised.
- Allowed to move closer to stage for assemblies.
- May or may not use optical devices to access instructional materials.
- May require materials in larger print for access.