

# NOAH SchoolKit



A kit designed to guide parents and general education teachers in supporting students with albinism in the classroom.

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A NOAH Program  
In Collaboration with  
TSBVI Teachers

# Introduction

## **What is the NOAH SchoolKit?**

The following pages provide information and resources to guide parents in supporting general education teachers when a student with albinism will be placed in their classroom during the upcoming school year. The kit is divided into sections with instructions and suggestions on how to use the information within it. Sections include informational sheets for teachers, documents to help guide conversations between parents and educators, and templates for student involvement in conversations and advocacy.

## **Who is the kit intended for?**

This kit is intended to be used by students and families when communicating needs to general education teachers. The Teacher of the Visually Impaired (TVI) may or may not be involved in this exchange of information depending on appropriateness and availability.

## **Why is this important?**

A few points of relevance are listed below and serve as the foundation for why this resource was developed.

- In many cases, students with albinism are able to access the general education curriculum with few accommodations and modifications which are outlined in the Individualized Education Plan (IEP).
- Although students likely receive services from a Teacher of the Visually Impaired (TVI), service delivery times may vary, and often times, responsibility for ensuring that modifications and accommodations are carried out daily falls on the general education teacher.
- Many teacher credential programs spend little time on the special education student population. Classes often focus on higher incidence disabilities leaving many general education teachers unaware of the implications for students with albinism in their classroom.
- Empowering parents to facilitate communication with general education teachers with or without the TVI opens a dialogue between the two most important people to a student's education. Leading by example can translate into student empowerment and self-advocacy later in life.

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# Sharing General Information with Educators

## Items in this section:

- What is Albinism?
- What Do You See?
- What Do You Call Me?
- Albinism Terminology

## Purpose

- Use the following information to support conversations about albinism with the general education teacher prior to the first day of school.
- Encourage an open dialogue between parent and teacher/student about any physical, social, or emotional issues pertaining to the diagnosis.
- Refer to the documents if/when the general education teacher has questions.
- Provide a resource list for any inquiries that require more attention or in the event that educators want to seek additional information.

# What Is Albinism?

**Albinism** is an inherited genetic condition that reduces the amount of melanin pigment formed in the **skin, hair and/or eyes**. Albinism occurs in all racial and ethnic groups throughout the world. In the U.S., approximately one in 18,000 to 20,000 people has some type of albinism. In other parts of the world, the occurrence can be as high as one in 3,000. Most children with albinism are born to parents whose hair and eye color are typical for their ethnic backgrounds.

A common myth is that people with albinism have red eyes. Although lighting conditions can allow the blood vessels at the back of the eye to be seen, which can cause the eyes to look reddish or violet, most people with albinism have blue eyes, and some have hazel or brown eyes. There are different types of albinism and the amount of pigment in the eyes varies. However, vision problems are associated with all types of albinism.

## Vision Considerations

People with albinism have vision problems that are not correctable with eyeglasses, and many have low vision. It's the abnormal development of the retina and abnormal patterns of nerve connections between the eye and the brain that cause vision problems. The presence of these eye problems defines the diagnosis of albinism.

The degree of impairment varies with the different types of albinism. Although people with albinism may be considered "legally blind" with a corrected visual acuity of 20/200 or worse, most learn to use their

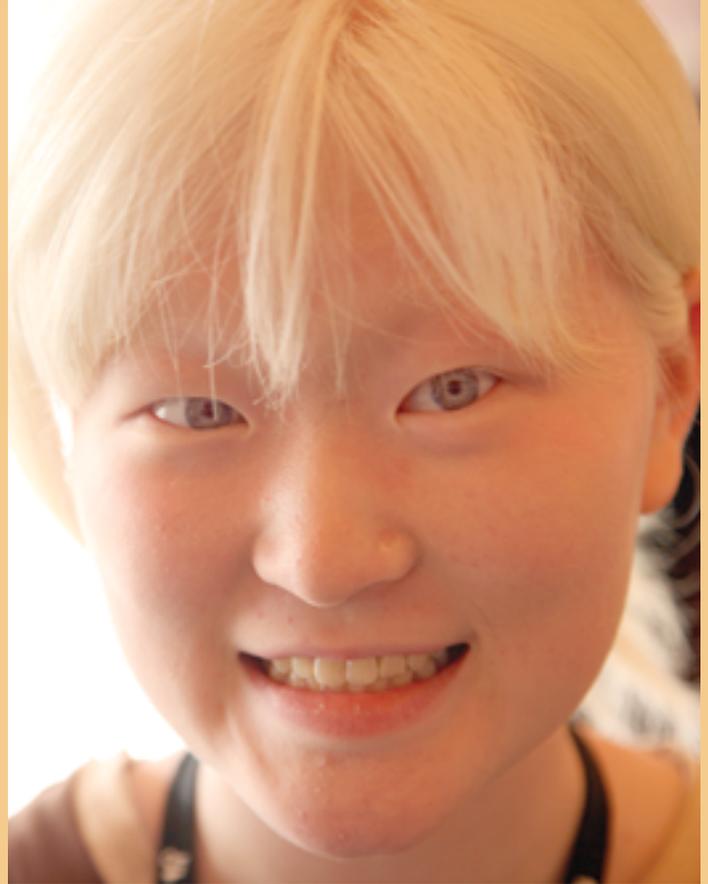


Photo courtesy of Positive Exposure, Rick Guidotti

vision in a variety of ways and are able to perform innumerable activities such as reading, riding a bike or fishing. Some have sufficient vision to drive a car.

## Dermatological Considerations

Because most people with albinism have fair complexions, it's important to avoid sun damage to the skin and eyes by taking precautions such as wearing sunscreen or sunblock, hats, sunglasses and sun-protective clothing.

## Types of Albinism

While most people with albinism have very light skin and hair, levels of pigmentation can vary depending on one's type of albinism. Oculocutaneous (pronounced ock-you-low-kew-TAIN-ee-us) albinism (OCA) involves the eyes, hair and skin. Ocular albinism (OA), which is much less



Photo courtesy of Positive Exposure, Rick Guidotti

common, involves only the eyes, while skin and hair may appear similar or slightly lighter than that of other family members.

Over the years, researchers have used various systems for classifying oculocutaneous albinism. In general, these systems contrasted types of albinism having almost no pigmentation with types having slight pigmentation. In less pigmented types of albinism, hair and skin are cream-colored and vision is often in the range of 20/200. In types with slight pigmentation, hair appears more yellow or has a reddish tinge and vision may be better.

DNA tests can determine the precise type of albinism. Research on albinism genes is ongoing. **To date as many as seven forms of oculocutaneous albinism are now recognized – OCA1, OCA2, OCA3, OCA4, OCA5, OCA6 and OCA7.** Some are further divided into subtypes.

- **OCA1**, or tyrosinase-related albinism, results from a genetic defect in an enzyme called tyrosinase. This enzyme helps the body to change the amino acid, tyrosine, into pigment. (An amino acid is a “building block” of protein.) There are two subtypes of OCA1. In OCA1A, the enzyme is inactive and no melanin is produced, leading to white hair and very light skin. In OCA1B, the enzyme is minimally active and a small amount of melanin is produced, leading to hair that may darken to blond, yellow/orange or even light brown, as well as slightly more pigment in the skin.



Photo courtesy of Positive Exposure, Rick Guidotti

- **OCA2**, or P gene albinism, results from a genetic defect in the P protein that helps the tyrosinase enzyme to function. People with OCA2 make a minimal amount of melanin pigment and can have hair color ranging from very light blond to brown.
- **OCA3** is rarely described and results from a genetic defect in TYRP1, a protein related to tyrosinase. People with OCA3 can have substantial pigment.
- **OCA4** results from a genetic defect in the SLC45A2 protein that helps the tyrosinase enzyme to function. People with OCA4 make a minimal amount of melanin pigment similar to people with OCA2.
- **OCA5–7** were recognized in humans in 2012 and 2013. They have reported mutations on three additional causative genes. As gene testing becomes available, and more people with these types of albinism are identified, the complete range of physical manifestations will be recognized, and may overlap with other known types of OCA. Currently, these types of albinism are considered to be uncommon.

Researchers have also identified several other genes that result in albinism with other features. One group includes at least 10 genes leading to **Hermansky-Pudlak Syndrome** (HPS). In addition to albinism, HPS is associated with bleeding problems and bruising. Some forms are also associated with lung and bowel disease. HPS is a less common form of albinism but should be suspected if a person with albinism shows unusual bruising or bleeding or if

a genetic test for a type of OCA produces inconclusive results.

Other albinism-related syndromes include **Chediak-Higashi Syndrome** and **Griscelli Syndrome**.



Photo courtesy of Positive Exposure, Rick Guidotti

### Genetics of Albinism

The genes for OCA are located on “autosomal” chromosomes. Autosomes are the 22 pairs of chromosomes that contain genes for our general body characteristics, compared to the one pair of sex chromosomes. We normally have two copies of these chromosomes and the many genes on them – one inherited from our father, the other inherited from our mother. For a recessive trait (like most types of albinism) to occur, both of the person’s chromosomes must carry that trait. That means that most

types of albinism result from inheriting an albinism trait from both the mother and the father who often have typical pigmentation. In this case, the mother and father are considered to be carriers of the albinism trait because they each carry a recessive gene for the condition but do not manifest the condition themselves. When both parents carry the albinism gene (and neither parent has albinism) there is a one in four chance at each pregnancy that the baby will be born with albinism. This type of inheritance is called “autosomal recessive” inheritance.



Photo courtesy of Positive Exposure, Rick Guidotti

with OA1 are males. Parents should be suspicious if a female child is said to have ocular albinism. While possible if the mother is a carrier of ocular albinism and the father has ocular albinism, it is extremely rare.

For couples who have not had a child with albinism, there is no simple test to determine whether a person carries a gene for albinism. Researchers have analyzed the DNA of many people with albinism and found the changes that cause albinism, but these changes are not always in exactly the same place, even for a given type of albinism. Moreover, many of the tests do not find all possible changes. Therefore, the tests for the albinism gene may be inconclusive. If parents have had a child with albinism previously, and if that affected child has had a confirmed diagnosis by DNA analysis, there is a way to test in subsequent pregnancies to see if the fetus has albinism. The test uses either amniocentesis (placing a needle into the uterus to draw off fluid) or chorionic villous sampling (CVS). Cells in the fluid are examined to see if they have an albinism gene from each parent.



Photo courtesy of Positive Exposure, Rick Guidotti

**Ocular albinism (OA1)** is caused by a change in the GPR143 gene that plays a signaling role that is especially important to pigmentation in the eye. OA1 follows a simpler pattern of inheritance because the gene for OA1 is on the X chromosome. Females have two copies of the X chromosome while males have only one copy (and a Y chromosome that makes them male). To have ocular albinism, a male only needs to inherit one changed copy of the gene for ocular albinism from his carrier mother. Therefore almost all of the people

For specific information and genetic testing, seek the advice of a qualified geneticist or genetic counselor. The American College of Medical Genetics and the National Society of Genetic Counselors maintain a referral list. Those considering prenatal testing should be made aware that people with albinism usually adapt quite well to their disabilities and lead very fulfilling lives.

### Vision Rehabilitation

Eye problems in albinism result from the abnormal development of the eye because of a lack of pigment and often include:

- **Nystagmus:** Regular horizontal back and forth movement of the eyes
- **Strabismus:** Muscle imbalance of the eyes, “crossed eyes” (esotropia), “lazy eye” or an eye that deviates out (exotropia)
- **Photophobia:** Sensitivity to bright light and glare
- **Refractive Error:** People with albinism may be either farsighted or nearsighted and usually have astigmatism
- **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

The iris, the colored area in the center of the eye, has very little or no pigment to screen out stray light coming into the eye. Light normally enters the eye only through the pupil, the dark opening in

the center of the iris, but in albinism light can pass through the iris as well.

For the most part, treatment consists of visual rehabilitation. Surgery to correct strabismus may improve the appearance of the eyes. However, since surgery will not correct the misrouting of nerves from the eyes to the brain, surgery will not improve eyesight or fine binocular vision. In the case of esotropia or “crossed eyes,” surgery may help vision by expanding the visual field (the area that the eyes can see while looking at one point). Surgical intervention is also available to minimize nystagmus.

People with albinism are sensitive to glare, but they do not prefer to be in the dark, and they need light to see just like anyone else. Sunglasses or tinted contact



Photo courtesy of Positive Exposure, Rick Guidotti

lenses may help outdoors. Indoors, it is important to place lights for reading or close work over a shoulder rather than in front.

Various optical aids are helpful to people with albinism, and the choice of an optical aid depends on how a person uses his or her eyes in jobs, hobbies or other usual activities. Some people do well using bifocals which have a strong



Photo courtesy of Positive Exposure, Rick Guidotti

reading lens, prescription reading glasses or contact lenses. Others use handheld magnifiers or special small telescopes, and some prefer to use screen magnification products on computers.

Some people with albinism use bioptics, glasses which have small telescopes mounted on, in or behind their regular lenses so that one can look through either the regular lens or the telescope. Some states allow the use of bioptic telescopes for driving.

Optometrists or ophthalmologists who are experienced in working with low vision patients can recommend various

optical aids. Clinics should provide instruction in their use. The American Foundation for the Blind maintains a directory of low vision clinics. In Canada, support is available from the Canadian National Institute for the Blind.

### Medical Problems

In the United States, most people with albinism live normal life spans and have the same types of general medical problems as the rest of the population. The lives of people with Hermansky-Pudlak Syndrome can be shortened by lung disease or other medical problems.

In tropical countries, people with albinism who do not have access to adequate skin protection may develop life-threatening skin cancers. If they use appropriate skin protection, such as



Photo courtesy of Positive Exposure, Rick Guidotti



Photo courtesy of Positive Exposure, Rick Guidotti

sunscreens rated 20 SPF or higher and opaque clothing, people with albinism can enjoy outdoor activities even in summer.

### Social Considerations

People with albinism are at risk of isolation because the condition is often misunderstood. Social stigmatization can occur, especially within communities of color, where the race or paternity of a person with albinism may be questioned. Families and schools must make an effort to include children with albinism in group activities. Contact with others with albinism or who have albinism in their families or communities is most helpful. NOAH can provide the names of contacts in many regions of the country.

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# What Do You See?

## An Adult with Albinism Describes What He Sees

by Matt Bailey

Normally-sighted people often ask those of us with albinism, “What do you see?” Parents of children with albinism are especially interested in the answer. Here you’ll find a brief explanation of how a person with albinism “sees.”

### Banishing the Blurry Misconception

There is often a misconception that our vision is blurry. Many people are baffled to learn that it’s not.

When normally-sighted people experience vision problems, it is because the lens in front of the eye doesn’t focus the image clearly onto the back of the eye causing blurriness. Near-sightedness, far-sightedness and astigmatism are “out of focus” problems. Glasses and contacts correct these problems by reshaping the light entering the eye so that images are focused correctly onto the back of the eye. This is similar to the way you would turn the focus knob to correct a blurry image when using binoculars.

Although blurriness isn’t associated with the major vision issue related to albinism, we may be affected by the same “out of focus” problems as normally-sighted people. If near-sightedness, far-sightedness and astigmatism aren’t addressed, our vision could become blurry. That’s why it can be important for young children and even babies with albinism to wear glasses. In many children, the use of their vision and their eyes develop more fully when images entering the eye are focused correctly.



Photo courtesy of Positive Exposure, Rick Guidotti

### Clear, but not Hi-Def

Understanding the concept of resolution will help clarify the problems in the back of the eye that albinism causes but glasses cannot fix. All pictures are made up of dots, with each dot capturing a different color and brightness level. The pictures in magazines and newspapers, the pictures on TV and on social media, as well as the pictures taken by digital and film cameras are composed of a bunch of dots. You see more details in a picture that has more dots.

## Cross section of the human eye

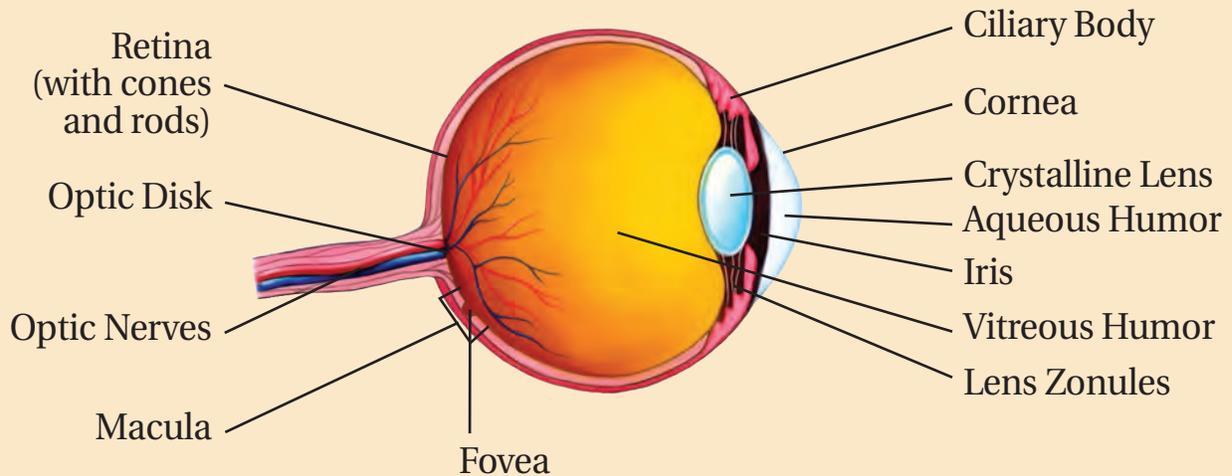


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The picture on the back of the human eye is also made up of dots, millions and millions of them in fact. They're the "cones" and "rods" on the retina in the back of the eye. The primary reason people with albinism can't see as well as normally-sighted people is because we have fewer cones in the fovea which is within the macula. In other words, we have fewer "dots" to make up the picture we see. The cones in particular are the "dots" that people use to see details, such as printed letters and numbers or the details of people's faces.

Nystagmus (the back and forth movement of the eyes) as well as the lack of pigment in the iris and the retina are also contributing factors to our reduced vision, although to a lesser degree.

The easiest way to understand how the lack of cones affects the vision of people with albinism is to turn on your television. If you have upgraded to a High Definition Television (HDTV), you have experienced an upgrade in the "visual acuity" of your television. That's because a high-definition



Photo courtesy of Positive Exposure, Rick Guidotti

## Older TV (left) vs. High-Definition TV (right)



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television signal contains five times the visual information. The picture on an old-fashioned TV is made up of five times fewer dots therefore each dot covers a larger portion of the total picture so you can't see as many fine details. When TV manufacturers tout a television's resolution with terms such as "1080p," they're telling you how many "dots" the picture on their TV screen has.

To experience the difference in low visual acuity and normal visual acuity, watch a program in High Definition (HD) on your HDTV. Then, go to an old TV and watch the same program on the standard definition TV. (Alternatively, many cable and satellite TV companies offer both a HD and a Standard Definition (SD) version of the same channel. Simply switch between the HD and SD channel.) Notice how the standard definition image on the old TV isn't blurry. It simply lacks the fine detail of the image on the HDTV. You can still recognize faces, but you'll see more details in HD than on the old TV. You can still follow the action of sports on the old TV, but you won't see the

individual blades of grass on the field the way you can on a HDTV.

Another trick to see how reduced resolution does not make a picture blurry is to watch a video online with a service such as YouTube that allows you to select the quality of the video image. First, watch the video with the highest resolution or quality setting, such as 1080p. Then, switch to a lower resolution or quality setting designed for slower Internet connections, such as 480p. The difference between how those of us with albinism see and normally-sighted people see is a lot like the difference between the low resolution video versus the high resolution video: Neither is blurry, however, we can't quite make out some of the finer details that normally-sighted people see.

Just like that low resolution video or the program on your old-fashioned TV, we often don't need to see the details we're missing to fully understand and participate in the world we see.

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# What Do You Call Me?

For many people the term “albino” brings to mind images of a person or animal with a pale complexion and pink eyes. The term “albinism,” by contrast, is less commonplace or recognizable to people who may not know a person with the condition. We all know that words can be powerful, so how do you say that someone is an albino without being disrespectful?

## Words Can Hurt or Heal

In the albinism community, opinions vary on the use of the word albino. While some find it extraordinarily offensive, others feel the label carries neutral or even empowering connotations. Many people with albinism agree that their feelings depend on the context or intent in which the word is used. The term can be derogatory when said mockingly or with malice, or it can be used innocently by someone who means no offense or is just curious.

Some people with albinism grew up in families or communities that used the word albino often and learned at an early age that there was no shame or negativity in referring to themselves as such. Others may have found that they were only called albino when they were being teased. Some describe their negative association with the word as being as offensive as a racial slur.

Some children and adults with albinism may use the term albino proudly and may feel empowered by “taking back” a once offensive word. By showing the world that they are comfortable calling themselves a word they once found hurtful or derogatory, the word “albino” loses all the power and shock value that it once claimed. By taking personal ownership of one’s condition,



Photo courtesy of Positive Exposure, Rick Guidotti

many people with albinism find that words like albino can no longer hurt them. Of course this is a very personal decision, and not all people with albinism feel comfortable using or hearing the term.

## Put the Person First

Although there are many people with albinism who are at peace with the term albino, when dealing with any condition, it is best to put the person first. For instance, say, “a person with albinism” rather than “an albino” or “an albino person.” The rationale for this person-centered language is to do just that: put the person ahead of the condition. When a person is referred to as an albino, he or she is essentially being reduced to and defined by nothing more than their condition. It’s as though the world looks at that person and sees only the condition of albinism. In this way, it can feel like a dehumanizing label.



Photo courtesy of Positive Exposure, Rick Guidotti

To most in the albinism community, the term “person with albinism” will always be a kinder, gentler, less shocking term. Regardless of the context, the word albino can sometimes be an ugly, jolting word to many, especially when heard unexpectedly. If you’re ever unsure, just ask. In a world of political correctness run rampant, you shouldn’t feel the need to tiptoe around the obvious. Every person with albinism will have personal experiences and opinions about the label. As one NOAH member said, “I may be an albino, but above all else, I am a person. I just happen to have the condition of albinism.”

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# 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.

# Sharing Educational Information with Educators

## Items in this section:

- Role of Instructional Team Members
  - Services Provided by the TVI
  - Services Provided by the COM
- IEP Summary Document
- Technology Devices
- Educational Considerations
- Special Procedures and Considerations
- Expanded Core Curriculum (ECC) Flyer
- Parent/Teacher Conversation Bank

## Purpose

- Use the following information to support conversations with the general education teacher prior to the first day of school.
- Review these documents and highlight the information within them that is applicable to the student. (Example: Not all students will use each piece of technology.)
- Encourage an open dialogue between parent and teacher/student using the conversation bank.

## Role of Instructional Team Members

The instructional team working with your child may consist of several staff members offering individualized services in specific areas. Below is a list of possible team members and a description of the role each person plays on the team. You might find it helpful to identify members specific to your child so the general education teacher knows who will serve your child and the different capacities with which he/she will do so.

**Teacher of the Visually Impaired (TVI):** The role of the TVI is to assess, provide instruction to students with visual impairments in the areas of the Expanded Core Curriculum (ECC), and collaborate with the instructional team. See attached “Services Provided by the TVI” and the “ECC Flyer”.

**Certified Orientation and Mobility Specialist (COMS):** The role of the COMS is to assess, provide instruction to students with visual impairments, and collaborate with the instructional team. The focus of instruction is in the use of their senses for the purpose of orienting oneself in an environment and in the safe movement from one place to another. See attached “Services Provided by the COMS.”

**Occupational Therapist (OT):** The role of the OT is to support students in gaining access to the general education curriculum and to their learning environments. Students who qualify for OT services have undergone an evaluation identifying deficits in the areas of fine motor, visual motor, self-regulation and sensory responses, and/or self-help skills. Services are often provided in the student’s learning environment and during naturally occurring routines to ensure meaningful practice opportunities for the student, but in some cases, individual or group sessions may be necessary. The OT may consult with general education teachers about how the classroom environment can be modified to improve student attention and the ability to complete tasks successfully.

**Physical Therapist (PT):** The role of the PT is to prepare students for further education, employment, and independent living by addressing assessed needs in the areas of motor development and the student’s participation in everyday routines and activities which are part of the educational program. The PT performs therapeutic interventions focusing on functional mobility and safe, efficient access and participation in activities and routines in the natural learning environment, but in some cases, individual or group sessions may be necessary. The PT may also collaborate with the student and team to make appropriate recommendations or modifications regarding equipment, such as leg braces, walkers, or wheelchairs.

**Paraprofessional:** The paraprofessional, sometimes referred to as a Teacher’s Assistant (TA) or Educational Assistant (EA) may be assigned to work with a student through the day in a variety of educational settings. Under the direction of certified teachers and related service providers, the paraprofessional supports implementation of

goals and objectives outlined in the student's IEP. The paraprofessional must take great care to provide adequate services while encouraging peer relationships within the classroom.

**Speech & Language Pathologist (SLP):** The role of the SLP is to work with school children who have communication problems that affect their participation in classroom activities, social interaction, literacy, or learning. Communication disorders can involve the areas of language, articulation, voice, or fluency (i.e. stuttering). SLPs can also work with students who have difficulty with swallowing. Students who qualify may receive services in individual or group therapy sessions, or by having the SLP act as a consultant in the classroom. Teachers or parents with concerns about a student's communication development can meet with the SLP and request a screening.

**Resource Specialist:** The role of the Resource Specialist is to provide services, instruction and support as needed for students who are identified through the IEP process. Services may be provided in the classroom or outside of the classroom in a group setting or one-on-one situation. The Resource Specialist may also provide support, consultation and informational materials to parents and educational staff, such as the classroom teacher, to support the assessed educational needs of the student.

## **Services Provided by Teachers of Students with Visual Impairments (TVI)**

Assessment (includes reports and IEP paperwork)

- Functional Vision Assessment
- Learning Media Assessment
- Assessment in all areas of the expanded core curriculum (ECC)
- 

Direct instruction with students

- Individual
- Group
- Co-teach

Collaboration (indirect instruction)

- Observe student in variety of settings
- Diagnostic teaching
- Support to school staff and families
- Collect data/evaluate

Share information (consult)

- Implication of vision loss on assessment
- Implications of vision loss for education
- Implications of vision loss on family/community life
- With eye medical professionals, especially low vision clinics

TVI is responsible for coordinating and procuring the low vision tools for the classroom

Manage materials

- Create/modify
- Obtain
- Maintain

Case management/service coordination

Attend meetings

- IEP / ARD meetings
- Transdisciplinary team
- Other district VI staff meetings (collaboration, transition and professional development)

Supervise VI paraprofessionals

Provide professional development on the topic of visual impairments in schools and classes

## **Services Provided by Certified Orientation and Mobility Specialists (COMS)**

Assessment (includes reports and IEP paperwork)

- Orientation and Mobility Assessment
- Assessment in the expanded core curriculum (ECC)

Direct instruction with students

- Individual
- Group
- Co-teach

Collaboration (indirect instruction)

- Observe student in variety of settings
- Diagnostic teaching
- Support to school staff and families
- Collect data/evaluate

Share information (consult)

- With educational team and family concerning implications of vision loss on orientation and mobility in home, school, and community
- With educational team and family concerning implications of vision loss for accommodations to student travel strategies
- With eye medical professionals, especially low vision clinics

Manage materials

- Create/modify
- Obtain
- Maintain

Attend meetings

- IEP/ARD meetings
- Transdisciplinary team
- Other district O&M staff meetings (collaboration, transition and professional development)
- 

Provide professional development on the topic of orientation and mobility in schools and classes

# 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](http://www.albinism.org/CARE).

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

## Technology I Find Useful

**Monocular or telescope:** I use this for reading and copying from the board, watching assemblies, looking at things that are more than 8 feet away from me (e.g., a ball game, signs across the road, overhead menus).

**Magnifier:** for reading smaller print on school handouts, in textbooks, on food packages, etc.

**Reading glasses:** are for reading longer sections of text where my hands are free to hold the material. These may be called microscope glasses or high ADD glasses.

**Audio App for Smartphones, Tablets, MP3 Player:** This app allows me to listen to audible textbooks that I get from the Learning Ally.

**JAWS:** software installed on a computer to help access websites (this program will read out what is on the monitor).

**ZoomText:** software installed on a computer to enlarge print on the monitor.

**TI Graphing Calculator ViewScreen Enlargement Solution:** This enlarges the readout on my graphing calculator.

**Portable video magnifier:** This can hook up to a laptop. It swivels to view the board, or I can use it with books and other print materials.

**Tablet:** This can enlarge materials, take a snapshot of something at a distance and then enlarge it, and/or load auditory books.

## Educational Considerations

<b>Eye Condition Albinism</b>	<b>Effects On Vision</b>	<b>Educational Considerations</b>
<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>

# Special Procedures and Considerations

## (Playground, Gym, Field Trips, Sun Safety, Fire Drills)

### Emergency Situations & Drills:

- Discuss each scenario with your classroom teacher to understand school procedures.
- Choose a partner from the class to support your student during emergency situations using guide technique.
- Walk the routes in advance for fire drills and school evacuations rather than relying on verbal instructions alone.
- Include a sun hat and sunscreen in classroom/schoolwide emergency kit.

### Playground:

- Tour the playground in its entirety, pointing out in which direction the student's classroom, restrooms, school office and lunch room are located.
- When touring the school grounds at the beginning of the school year, request that your student has an opportunity to play on the play structure by himself or herself to become familiar with the structure's layout.
- When the school year starts, support the student in a conversation with friends about where they might meet up or "hang out" during recess times.
- Watch for signs that the student is lost or unable to find friends to interact with during playground time.
- Consider additional points in the "Facts Regarding Children with Albinism for Physical Education and Recreation Professionals" document.
- Look for potential points of low visibility such as metal poles or door openings; work with the TVI and team members to make accommodations such as using neon duct tape to create a visual aid for areas of low contrast.

### Gym:

- Inform the classroom teacher that special considerations should be made for sun safety and visual needs regarding participation in PE classes.
- Provide copies of the document, "Facts Regarding Children with Albinism for Physical Education and Recreation Professionals" to the physical education teachers working with your student.

### Field Trips:

- When making field trip reservations, encourage your classroom teacher to inform the destination that there is a student with a visual impairment in the group.
  - This may allow the group to be seated towards the front of a large auditorium. The classroom teacher can also request a seat in the front of the audience seating for your student and a classroom friend in addition to the TVI/chaperone.

- If the destination limits the number of chaperones, this information could allow for an additional adult in the group, i.e. paraprofessional or parent of the student with a visual impairment.
  - NOTE: IEP Accommodation – An accommodation can be written into your student’s IEP that states one of the student’s parents / guardians be invited to all field trips to assist with visual needs.
- Consider additional points in the “Facts Regarding Children with Albinism for Physical Education and Recreation Professionals” document.

**Sun Safety:**

- Discuss school policies regarding safe use and storage of sunscreen.
  - Allow time in the event that student must travel to the nurse or other location to apply sunscreen.
  - Plan for communicating when sunscreen needs to be replenished.
  - Inform staff as to the appropriate application intervals for your student.
- Request that there be a consistent storage area in the classroom for hats, sunglasses, and sunscreen. This allows for independent access to sun protection items throughout the day for the student.
  - Keep an extra hat and pair of sunglasses at school in case of loss or damage.

**Additional Considerations:**

- Always keep an extra set of eyeglasses, sunglasses and extra hat in your student’s backpack.
- Have your student or classroom teacher send home empty sunscreen bottles from school as a cue that more sunscreen is needed in the school supply basket.

# ECC Flyer

## What is the Expanded Core Curriculum?

*Developed by the Texas School for the Blind and Visually Impaired*

The term **expanded core curriculum** (ECC) is used to define concepts and skills that often require specialized instruction with students who are blind or visually impaired in order to compensate for decreased opportunities to learn incidentally by observing others. In addition to the general education core curriculum that all students are taught, students with visual impairments, starting at birth, also need instruction in the ECC. The ECC areas include (A) needs that result from the visual impairment that enable the student “to be involved in and make progress in the general education curriculum; and (B) other educational needs that result from the child’s disability” as required by IDEA (34 CFR 300.320 (a)(2)(A)(B)). Texas Education Code (TEC) 30.002(c)(5) and (e)(5) require the flexibility of school districts to make arrangements for services to occur “beyond regular school hours to ensure the student learns the skills and receives the instruction” in the ECC.

**With the passage of Senate Bill 39 in 2013 (Texas 83<sup>rd</sup> Legislative Session), evaluation in all areas of the ECC is required for students with visual impairments. Priority needs must be identified by the IEP team and instruction provided in these areas.**

### Nine Areas of the ECC

#### Assistive Technology

Assistive technology is an umbrella term that includes assistive and adaptive tools as well as instructional services that can enhance communication, access, and learning. It can include electronic equipment such as switches, mobile devices, and portable notetakers; computer access such as magnification software, screen readers, and keyboarding; and low-tech devices such as an abacus, a braille, Active Learning materials (e.g., Little Room®), and optical devices.

#### Career Education

Career education will provide students with visual impairments of all ages the opportunity to learn through hands-on experiences about jobs that they may not

otherwise be aware of without the ability to observe people working. They also learn work-related skills such as assuming responsibility, punctuality, and staying on task. Career education provides opportunities for students to explore and discover strengths and interests and plan for transition to adult life.

### **Compensatory Skills**

Compensatory skills include skills necessary for accessing the core curriculum including concept development; communication modes; organization and study skills; access to print materials; and the use of braille/Nemeth, tactile graphics, object and/or tactile symbols, sign language, and audio materials.

### **Independent Living Skills**

Independent living skills include the tasks and functions people perform in daily life to increase their independence and contribute to the family structure. These skills include personal hygiene, eating skills, food preparation, time and money management, clothing care, and household tasks. People with vision typically learn such daily routines through observation, whereas individuals with visual impairments often need systematic instruction and frequent practice in these daily tasks.

### **Orientation and Mobility (O&M)**

O&M instruction enables students of all ages and motor abilities to be oriented to their surroundings and to move as independently and safely as possible. Students learn about themselves and their environments, including home, school, and community. O&M lessons incorporate skills ranging from basic body image, spatial relationships, and purposeful movement to cane usage, travel in the community, and use of public transportation. Having O&M skills enables students to acquire independence to the greatest extent possible, based on their individual needs and abilities.

### **Recreation and Leisure**

Being unable to observe others reduces awareness of recreation and leisure options. Instruction in recreation and leisure skills will ensure that students with visual impairments will have opportunities to explore, experience, and choose physical and leisure-time activities, both organized and individual, that they enjoy. This instruction should focus on the development of life-long skills.

### **Self-Determination**

Self-determination includes choice-making, decision-making, problem solving, personal advocacy, assertiveness, and goal setting. Students with visual impairments often have fewer opportunities to develop and practice the specific skills that lead to self-determination. Students who know and value who they are and who have self-determination skills become effective advocates for themselves and therefore have more control over their lives.

## **Sensory Efficiency**

Sensory efficiency includes instruction in the use of vision, hearing, touch, smell, and taste. It also addresses the development of the proprioceptive, kinesthetic, and vestibular systems. Learning to use their senses efficiently, including the use of optical devices, will enable students with visual impairments to access and participate in activities in school, home, and community environments.

## **Social Interaction Skills**

Social interaction skills include awareness of body language, gestures, facial expressions, and personal space. Instruction also includes learning about interpersonal relationships, self-control, and human sexuality. Almost all social skills are learned by visually observing other people. Instruction in social interaction skills in school, work, and recreational settings is crucial. Having appropriate social skills can often mean the difference between social isolation and a fulfilling life as an adult.

*For additional information on the ECC, refer to:*

- <http://www.afb.org/info/programs-and-services/professional-development/teachers/expanded-core-curriculum/ecc-resources/12345>
- <http://www.perkins.org/resources/scout/education/expanded-core-curriculum.html>
- <http://www.familyconnect.org/parentsites.aspx?FolderID=23&TopicID=382>
- <http://www.tsbvi.edu/recc/>
- [www.tsbvi.edu/attachments/EducatingStudentswithVIGuidelinesandStandards.pdf](http://www.tsbvi.edu/attachments/EducatingStudentswithVIGuidelinesandStandards.pdf)

# Parent / Teacher Conversation Bank

## Parent to Teacher Questions

1. Do you have any experience in teaching a student with a visual impairment?
2. Have you seen any information on my child? Is there anything I need to clarify?
3. Has my child's Teacher of the Visually Impaired (TVI) and/or Certified Orientation and Mobility Specialist (COMS) contacted you yet?
4. Glare and reflective light is uncomfortable for my child. Can we find the best place for him/her to sit so that glare is reduced, but he / she can still access the parts of the room where the most instruction will take place?
5. Will my child be expected to perform tasks on a computer? If so, the TVI can provide support for accessing these tasks.
6. What are some typical near and distance tasks students will be expected to perform in different subject areas?
7. Sometimes my child will act like he/she sees what you are doing when this is not the case. I find that checking for understanding is helpful.
8. What is the best time/way for my child to communicate visual needs or difficulties?
9. What is the best time/way for me to contact you to share information?

## **Teacher to Parent Questions**

1. Who is your child's Teacher of the Visually Impaired (TVI) and Certified Orientation and Mobility Specialist (COMS)?
2. What are some things, both close up and far away, that your child can see easily?
3. What are some things, both close up and far away, that your child has difficulty seeing?
4. What are some things your child likes to do and does well?
5. Where is the best place for your child to sit?
6. Does your child use optical devices independently? Which ones?
7. What is your child's visual stamina like? Are there times of the day when his/her eyes are especially tired?
8. What are some signs that your child is struggling visually?
9. Is your child comfortable traveling independently in different parts of the school?
10. What are some things I should know about outdoor / sports equipment and safety for your child?
11. What precautions does your child use in the sun? Does he/she do this independently, or do they need reminders and / or support?
12. What are some signs that your child might be struggling socially?
13. How can I help classmates to understand albinism and your child's visual needs?
14. What are the biggest educational concerns for your child?
15. What is the best time / way for me to contact you to share information?

# Materials for the Educational Team

## Items in this section:

- Albinism Terminology
- Possible Accommodations
- Educational Considerations
- IEP Summary
- Student Involvement
- Facts Regarding Children with Albinism for Physical Education and Recreation Professionals
- Fact Sheet for Substitute Teachers

## 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

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5. Recommendations from FVA\* / LMA\* and O&M\* evaluation

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\*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.

# Sharing Information on Continuation of Skills in the Home & Community

## Items in this section:

- ECC – Applications
- Attention to Extra Curricular Activities

## Purpose

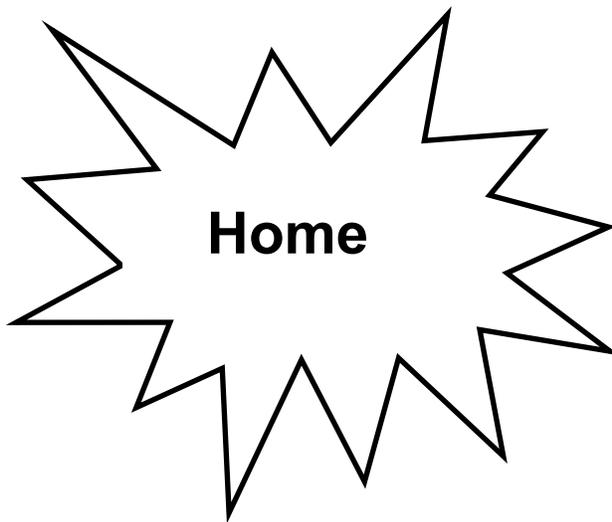
- This section is written to guide parents and families in supporting the development of ECC skills in the home and community.
- Each graphic organizer that follows suggests tasks that focus on ECC skills in a given location. These are just a few ideas. The possibilities are endless.
- The collection of vignettes in this section offers insight into which activities children with albinism across the country participate in outside of school.

**Assistive Technology**

- Use optical device to read recipes
- Use computer to complete a homework assignment
- Use an electronic tablet to read books/complete a research paper

**Career Education**

- Go to see where a parent works
- Observe service people working in the home (plumber, electrician, construction, etc.)
- Watch as work is done on a car at home
- Manage an allowance

**Recreation and Leisure**

- Play board games/parlor games
- Play electronic games on computer/tablet
- Play in the yard with friends
- Host/attend a sleep-over with a friend
- Attend concert/sporting event with family/friends

**Independent Living**

- Complete chores
- Wash dishes and put them away
- Sort silverware
- Set the table
- Feed a pet
- Fix a snack/meal
- Clean a room/closet

**Orientation and Mobility**

- Walk/bike to a friend's house independently
- Take the dog for a walk
- Get the newspaper/mail from the curb

**Sensory Efficiency**

- Identify sounds of carts, cash registers, food in containers
- Locate specified areas based on sounds or smells
- Identify produce based on visual or tactile characteristics

**Orientation and Mobility**

- Direction concepts (left, right, top, bottom)
- Read & navigate a store map
- Learn about store section names and layout

**Self-Determination**

- Make choices regarding food items
- Identify store staff
- Request assistance in locating an item
- Problem solve how much of an item to purchase or best value

**Grocery Store****Daily Living Skills**

- Creation and use of a grocery list
- Read and interpret food labels
- Budget and pay for items
- Seek out a personal shopper

**Assistive Technology**

- Use optical devices to read aisle numbers and content
- Use optical devices to read food labels
- Use tablet or smartphone to make lists and calculate estimated cost

**Career Education**

- Explore materials used in a vocational trade (e.g., electrical, plumbing)
- Visit with a store manager about qualifications for working in different departments (e.g., Garden Center)

**Recreation and Leisure**

- Choose a Do-It-Yourself home improvement project
- Choose an item that you can make for gifts or to sell such as birdhouses or decorative boxes

**Sensory Efficiency**

- Examine texture and design details in products such as carpet and tile
- Use a near device to read instructions printed on the package for operating a tool or installing a product (e.g., light timer)

**Hardware Store****Self-Determination**

- Talk with a store manager about in-store classes and accommodations that may be needed
- Identify an adult who can help you learn about tools and develop skills described here; write out an apprentice contract

**Independent Living Skills**

- Talk with a parent or a neighbor about assisting in-home repair tasks
- Watch online videos for completing simple home maintenance projects and practice with adult supervision

# Resources

## Items in this section:

- Parent To-Do List
- Things Parents Can Ask For
- List of Acronyms
- Top 10 Tips for Optical Device Use
- Observation Guidelines
- Tips from Parents
- Website Resources
- Student Involvement Documents
  - Letter of Introduction
  - Contents for a Student Portfolio
  - Ability Statement

## Purpose

- These final items have been included to support parents as they advocate for their children's success in the general education classroom.
- As with any information, consider that these are suggestions and guidelines, not essentials. Not all students function the same and need the same supports to be successful.

# Parent To-Do List

## **Before School Starts:**

- Locate map of school on school website/Request school map
- Request to tour the school campus
- Connect with classroom teacher to meet and review classroom set-up (Bring tools to class and locate an area to store them within the classroom)
- Plan a time with classroom teacher to set up student's desk prior to first day of school
- Confirm large print texts have been delivered
- Provide student information to classroom teacher

## **After Start of School – 2 weeks:**

- Meet with each service provider to review IEP goals
- Confirm that staff is aware of student needs (ex: lunch supervisors know that student can wear sunglasses / hat in lunch room)
- Provide extra sunscreen, hat, sunglasses, cane... to school nurse or classroom teacher for emergency events

## **After Start of School – 1 month:**

- Request observation of classroom set-up by TVI
- Request observation of PE, Music, other extracurricular class set-up by TVI and O&M

## **One Month Prior to State Testing:**

- Learn about the state testing schedule at your child's school.
- Collaborate with your child's TVI / Case Manager to ensure that all testing materials have been received and online testing settings have been confirmed.

## Things Parents Can Ask For

The following is a list of accommodations and/or modifications that may be included in the IEP for the student with albinism in the general education classroom. All children with albinism experience varying degrees of visual functioning, regardless of acuity. Some items on this list may not be applicable or may offer too much support for your child, hindering the development of independence across environments. **Please view this as a list of suggestions, not requirements for attaining success in educational programming.**

- Shades on windows / Classroom lighting adjustments
- Communication Journal for notations between parents/guardians and service providers/classroom teacher
- Parent/Guardian participation in field trips
- Training on technology and tools
- Technology Assessment from an outside organization such as a school for the blind
- Orientation and Mobility Assessment
- Extended time for tests
- Periodic observations of classes by yourself or service providers (ex: TVI observing computer lab, O&M observing sport practice or PE class)
- In-service with classmates
- Access to electronic books, electronic book services such as Bookshare and BARD; Large print books
- Slant board, dark pencils, dark lined paper
- Preferential assigned seating in class and during assemblies
- Breaks between assignments for eye fatigue
- Lighting adjustments
- Resource binder in class – duplicates of information displayed in the classroom
- Testing accommodations
- Hard copy of classroom notes
- Request that concrete manipulatives be used when concepts might be difficult to see on paper even when enlarged, i.e. bills and coins, clock, measurements/rulers.

## List of Acronyms

An acronym is a word that is formed from the first letters of multiple words. The use of acronyms is common in many fields, including special education. Acronyms change often and families should feel comfortable asking for explanation of terms they are not familiar with.

504 – Section 504 of the Rehabilitation Act of 1973

AAR – Academic Achievement Record

ADA – Americans with Disabilities Act of 1990

AEIS- Academic Excellence Indicator System

AEP – Alternative Education Program

AI – Auditory Impairment

ARD – Admission, Review, and Dismissal

AT – Assistive Technology

AU – Autism

BIP - Behavior Intervention Plan

CATE – Career and Technology Education

CFR – Code of Federal Regulations

CF – Child Find

COMS – Certified Orientation and Mobility Specialist

DARS – Texas Department of Assistive & Rehabilitative Services

DB – Deaf-Blind

DPH – Due Process Hearing

EI – Early Childhood Intervention

ED – Emotional Disturbance

EIS – Early Intervening Services

ELL – English Language Learner

ESC – Education Service Center

ESY – Extended School Year Services

FAPE – Free Appropriate Public Education

FBA – Functional Behavioral Assessment

FERPA – Family Educational Rights & Privacy Act

FIE – Full and Individual Evaluation

FVA – Functional Vision Assessment

GED – General Educational Development Certificate

GC – General Curriculum

IDEA – Individuals with Disabilities Education Act of 2004

IDEA-B – IDEA program for children with disabilities 3-21

IDEA-C – IDEA program for children with disabilities 0-2

IEE – Independent Educational Evaluation

IEP – Individualized Education Program

IFSP – Individual Family Service Plan

IN – Intellectual Disability

LD – Learning Disability

LEA – Local Education Agency

LEP – Limited English Proficient

LMA – Learning Media Assessment

LRE – Least Restrictive Environment

MD – Multiple Disabilities

MOU – Memorandum of Understanding

OHI – Other Health Impairment

OI – Orthopedic Impairment

O&M – Orientation & Mobility

OSEP- Office of Special Education Programs, U.S. Department of Education

OSERS – Office of Special Education & Rehabilitative Services

PACER – Parent Advocacy Coalition for Educational Rights

PBM – Performance-Based Monitoring

PBIS - Positive Behavioral Interventions & Support

PEIMS – Public Education Information Management System

PPCD – Preschool Program for Children with Disabilities

PTI – Parent Training and Information Center

REED – Review of Existing Evaluation Data

RTI – Response-to-Intervention

RPTE – Reading Proficiency Tests in English

SBEC – State Board for Educator Certification

SBOE – State Board of Education

SDAA – State-Developed Alternative Assessment

SHARS – Student Health & Related Services

SI – Speech or Language Impairment

SSA – Shared Services Arrangement

TBI – Traumatic Brain Injury

TSBVI – Texas School for the Blind & Visually Impaired

TVI – Teacher of the Visually Impaired or Teacher of Students with Visual Impairments

USDE – United States Department of Education

VI – Visual impairment

# Top 10 Tips for Optical Device Use

By Cynthia Bachofer TSBVI Outreach

**This page gives a quick summary of some ideas for helping your child improve skills with optical devices (magnifiers, telescopes, glasses.) A couple of the items that follow apply to all devices. Most of the items refer to either a near (magnifier, glasses) or a distance (telescope) device. A book titled *Looking to Learn: Promoting Literacy for Students with Low Vision* (Frances Mary D'Andrea) gives good ideas for activities at home and at school to build skills.**

Optical devices are carefully designed tools that work best when matched to the specific needs and vision of your child. A low vision specialist, an eye doctor trained in low vision, should be consulted to recommend the best tools. This medical professional focuses on individual goals and functioning in everyday tasks.

The teacher of students with visual impairments (TVI) and/or the Orientation and Mobility specialist (O&M) who works with your child can give more information on topics such as techniques for focusing, outdoor use, or comfortable positions for device use. Your child may also have an IEP goal written on learning to use optical devices.

1. An optical device makes objects look larger so things are easier to see. This means that you can help your child focus the device. Your child may “re-set focus” slightly but you can help by checking that the view is not blurry. These devices are made of inexpensive materials (metal or plastic and a clear lens) but they need to be taken care of to last and work well.
2. Setting focus takes a little practice but quickly becomes second nature for the device user. Turn the middle section (the barrel) of the telescope to set focus. The “closed” or shortest position of the telescope is the best starting point. Turn the barrel slowly *while* looking through the scope. As the barrel becomes longer or is more “open,” the user is able to see things that are just beyond arm’s reach. Test this to see how it works.
3. Matching the tool your child uses to his or her level of vision is very important. The device your child receives is a specific power or strength, for example 3x for 3 times magnification. The ideal formula is having the widest field of view through the lens with *just enough* power for comfortable viewing. Too much power can be a problem and make using the tool frustrating.
4. An optical device is versatile but one tool is not able to do all tasks. The 4x or 6x telescope may work well in a classroom (15’ viewing distance.) In an outdoor setting, your child may need an 8x for reading signs across the street (40’ viewing distance).

5. Getting the telescope lens as close to the eye as possible is the big goal. Most scopes have a soft rubbery end that is the eye piece cup. It helps to block out glare and to direct eye gaze. Some users prefer to keep their glasses on while using the telescope and others prefer to take off their glasses so that they gain the widest field of view through the lens. This is a personal choice for each user.
6. Two styles of magnifiers are common—a stand type that stays flat on the page (e.g., a dome magnifier) and a handheld that is lifted off the page. A stand is built to always be in focus when it's flat on the page. This type is good for young students who are exploring the page. The best viewing position of a handheld magnifier has space between the page and the lens and the lens and the eye. This is the work distance. The magnifier is not working at its best if it is flat on the page or held against the user's eye.
7. Reading a page of print with a magnifier or reading glasses (sometimes called microscope lenses) takes practice, concentration, and stamina—like an athlete learning the skill of handling a ball. Fluent readers stay on a line of print and move to the next line smoothly. Some students use their finger or a line guide (a ruler-sized piece of paper) to mark the line. Once the eye and brain have practiced reading with a magnifier, the line guide is used less and less.
8. Learning to use a tool can be hard work. Sometimes, people stare when they see someone using a device and this can be awkward. Help your child develop skills with the device and feel good about using it by practicing at home or away from others. Start with high interest items such as finding a favorite cartoon character on the TV at a 10 foot distance with a telescope or reading the bright advertisements in a store's weekly ad with a magnifier.
9. Your child will build skill if adults help with practice and encourage regular use. Your child can use the telescope to read signs or traffic signals when you are doing errands. Your child can read information on food packages to you during kitchen time while cooking or washing dishes. Look for times each week that you expect and need your child to use devices to find information for you.
10. An optical device is as important as house keys or a cell phone. This tool gives access to what is valuable and important. Each tool should have a carrying case when being used away from home and a specific place to be kept at home so the user always knows where it is when needed. Your child can show others (e.g. siblings, neighbors) how it works, but this tool is like an extension of his or her eyes. Being able to grab it quickly and knowing that it is ready to use are first steps to success with devices.

# Observation Guidelines

## For use by the Teacher of Students with Visual Impairments

*The following are guidelines for observing students with visual impairments in classroom situations. The purpose of this observation is to monitor the student's functioning in the classroom, and determine the focus for VI services, including instruction.*

### Evaluating Classroom Functions

#### **Organization:**

- Materials
- Furniture
- Extra work space
- Walkways
- Desk layouts
- Maps
- Placement of educational *prompts* (e.g., alphabet, number line, colors, periodic chart of elements)
- Class rules
- Placement of chalkboards / smartboards
- Overhead screen

#### **Discipline:**

- Are rules clearly posted?
- Does the teacher have a system of discipline?
- Does the teacher follow the system with all students, particularly the VI student?
- Are students respectful of the system?

#### **Classroom (group) behaviors:**

- Are students on-task?
- Can most keep up?
- Are more than just a few *fooling around* when they shouldn't be?
- Do students get up to turn in papers, get materials, and go to the bathroom?
- Do they wait for cues from the teacher to move from one activity to another or do they do so independently?
- Are most attentive during the teacher's presentations?
- Is the activity in the room constructive?

### Evaluating an Activity

- Does the teacher present or introduce lessons or is there an established routine that is more auto-tutorial?
- Are tangible objects used to demonstrate concepts where applicable?
- Does everyone need to follow along in a book?

- Do students have to read aloud?
- Does the activity involve a concept, which is very visual in nature (e.g., adding with carrying)?
- Are visual materials used (e.g., maps, charts, diagrams)?
- Is the chalkboard or overhead screen used frequently?
- Do students use a dictionary?
- Is the pace fast, slow, or medium?
- What do students do when the activity is completed?
- How many handouts are used and what is their quality?
- Are materials enlarged or brailled for an activity if needed?

### **Observing Student Functioning**

- Is the student on task?
- Does student look in teacher's general direction?
- Is student able to get out materials on time?
- Is student using low vision devices, or other necessary devices?
- Is student attending?
- In what condition is the student's desk?
- Does the student know how to access the educational *prompts* posted around the room?
- Is the student organized?
- Can the student maintain the pace of the lesson presented?
- Does the student get up to get his own materials?
- Do other students help the student in any way?
- Could the student be acting more independently?
- Does the student raise a hand to participate and ask questions?
- Does the student interrupt appropriately?
- Does the student have any distracting mannerisms?
- Does the student use time wisely?
- What does the student do when work is finished?
- Does the student interact appropriately with peers in the room, on the playground, in the cafeteria?
- How does the student get around?
- How does the student go through the cafeteria line and to the table?
- What is the student's eating skills?
- Does the student's appearance blend with the group?
- Does the student have friends?
- What does the student do during free time and on the playground?
- Does the student speak before the class, such as in show and tell?

- If the student fails to complete his seatwork, is it due to lack of understanding, poor work habits, or inability to keep up with the pace?
- How does the general quality of the student's work compare to peers?
- Does the student talk too much to neighbors?
- Are the student's materials placed so as to be accessible to him?
- Are games, toys, and materials available for the student to use in interactive play during free time?
- Are lighting and desk location appropriate?
- Are any of the student's materials or equipment inconveniencing another student?
- Can the student fully operate any equipment given to him?
- Is a system in place for the student to correct malfunctioning equipment?
- Can the student manage equipment and materials through class changes?
- How does the student ask for and accept assistance from peers and others.
- How do peers relate to the student; how is he treated?
- Is the student displaying age-appropriate skills?

### **Observing Teacher Behaviors**

- Does the teacher move about the room or remain fairly stationary?
- Does the teacher's voice carry well?
- Are chalkboards, overhead screen, and charts used frequently? Does the teacher read aloud what is written down?
- Will a student teacher be taking the class?
- How does the teacher handle misbehavior and off-task behavior?
- Does the teacher check for understanding and how is this done with the VI student?
- If brailled materials are to be handed out, is the teacher organized enough to have the materials ready?
- Can the teacher communicate her concerns and observations of the VI student during a conference (beware the teacher who always reports that "everything's just fine")?

## **Tips FOR Parents FROM Parents**

**Published in Albinism Insight (Autumn 2013), “Inquire to inspire: School Days”**

- Contact teachers before the first day of school and share the webinar link called “How We See”. Don’t forget to include not only the classroom teachers, but also the PE teacher, the music teacher and the media center teacher.
- Reinforce with my student that they must be their own advocate.
- Meet with the group of teachers including the TVI and share the information on albinism, descriptions of visual aids, stereotypes, how our student sees and signs of struggling or eye fatigue.
- Visit each classroom to discuss lighting and seating and where information will be presented so our student knows where to focus her attention.
- Establish routines for storing and retrieving school supplies, sunglasses, devices and sunscreen so my student will likely reach for them.
- Explain IEP jargon to the teachers and create an open line of positive communication for questions and concerns.
- Teach our student to be open about albinism. Teach our student definitions for nystagmus, photophobia, retina and pigment and their relation to albinism.
- Role-play to ensure our student can give a real answer, a “flip” answer, and a vague answer as needed. This is especially helpful in social situations and if the class has a substitute who may not know your student.
- Explore the room noting the location of things like Kleenex, the pencil sharpener, assignment trays, hall passes and cubbies.
- Especially in upper grades – middle and high school – walk to all of the rooms in order to familiarize and memorize the route for classes.
- In college, speak with each professor on the first day of class and request notes in advance. Also register with the Disability Resource Center to receive testing accommodations.

- When I can I try to volunteer for school activities. It gives me the opportunity to build relationships with the teachers. During these times of an active classroom or assembly, the teacher may think of questions to ask you about how they can support your child during certain classroom/school activities.
- Work with your IEP team to include consultation time for your TVI to work with the classroom teachers, especially at the beginning of the year. This consultation time can be used to review classroom accommodations and support the classroom teachers with questions they may have about their student's needs.

## Website Resources

Following is a list of suggested resources for parents, educators, doctors and students. This list is not intended to be a complete list or an endorsement of any specific commercial provider but is offered as an informational starting point.

### General Information and Support

#### **The National Organization for Albinism and Hypopigmentation (NOAH)**

P.O. Box 959

East Hampstead, NH 03826-0959

800-473-2310

Website: [www.albinism.org](http://www.albinism.org)

Email: [info@albinism.org](mailto:info@albinism.org)

A support and advocacy group for people with albinism and for parents whose children have albinism

#### **The Texas School for the Blind and Visually Impaired**

1100 West 45th Street

Austin, TX 78756

Phone: 800-872-5273

Website: [www.tsbvi.edu](http://www.tsbvi.edu)

The special education school for students who have a visual impairment is a statewide resource to parents of these children as well as the professionals who serve them, and the website offers a wide range of information and resources on education issues, technology, curriculum and publications

#### **American Foundation for the Blind**

2 Penn Plaza, Suite 1102

New York, NY 10121

Phone: 212-502-7600

Website: [www.afb.org](http://www.afb.org)

Email: [afbinfo@afb.net](mailto:afbinfo@afb.net)

A national nonprofit that expands possibilities for people with vision loss such as broader access to technology; elevated quality of information and tools for the professionals who serve people with vision loss; and promoting independent and healthy living for people with vision loss by providing relevant and timely resources

#### **HPS Network Inc.**

One South Road

Oyster Bay, NY 11771-1905

Phone: 800-789-9HPS

Website: [www.hpsnetwork.org](http://www.hpsnetwork.org)

Email: [info@hpsnetwork.org](mailto:info@hpsnetwork.org)

Provides support and information for people and families dealing with Hermansky-Pudlak Syndrome and related disorders such as Chediak-Higashi Syndrome

**Lighthouse Guild**

15 West 65th Street

New York, NY 10023

Phone: 800-284-4422

Website: [www.lighthouseguild.org](http://www.lighthouseguild.org)

Email: [info@lighthouseguild.org](mailto:info@lighthouseguild.org)

Provides vision and rehabilitation services to the visually impaired, offers clinical services, education, research and advocacy for people with low vision and blindness

**National Federation of the Blind**

200 East Wells Street (at Jernigan Place)

Baltimore, MD 21230

Phone: 410-659-9314

Website: [www.nfb.org](http://www.nfb.org)

Works to improve blind people's lives through advocacy, education, research, technology and programs encouraging independence and self-confidence

**Government Resources, Early Intervention and Education Information****American Council of the Blind**

2200 Wilson Blvd.

Suite 650

Arlington, VA 22201-3354

Phone: 800-424-8666; 202-467-5081

Website: [www.acb.org](http://www.acb.org)

Email: [info@acb.org](mailto:info@acb.org)

Provides support and information for parents of children who are blind or visually impaired, holds an annual conference, and publishes a newsletter

**Division on Visual Impairment, Council for Exceptional Children (DVI/CEC)**

Website: <http://community.cec.sped.org/DVI/home/>

Advance the education of individuals with visual impairments and promotes related educational, scientific and charitable purposes, assists and supports The Council for Exceptional Children (CEC)

**U. S. Department of Education**

Website: <http://idea.ed.gov>

A "one-stop shop" for resources related to IDEA and its implementing regulations

## **Books and Publications**

### **American Foundation for the Blind**

2 Penn Plaza, Suite 1102

New York, NY 10121

Phone: 212-502-7600

Website: [www.afb.org](http://www.afb.org)

Email: [afbinfo@afb.net](mailto:afbinfo@afb.net)

Publishes a variety of books on visual impairments, including *A Parent's Guide to Special Education for Children with Visual Impairments*

### **American Printing House for the Blind, Inc.**

1839 Frankfort Avenue

P.O. Box 6085

Louisville, KY 40206-0085

Phone: 800-223-1839; 502-895-2405

Website: [www.aph.org](http://www.aph.org)

Email: [info@aph.org](mailto:info@aph.org)

Manufactures educational aids for blind and visually impaired persons, has an educational research program, sells books in braille, large print, disk and cassette and offers a database for locating textbooks and other materials in accessible media

### **Bookshare**

480 South California Avenue

Palo Alto, CA 94306

Phone: 650-352-0198

Website: [www.bookshare.org](http://www.bookshare.org)

An accessible online library making the world of print accessible to people with disabilities

### **Learning Ally**

20 Roszel Road

Princeton, NJ 08540

Phone: 800-221-4792

Website: [www.learningally.org](http://www.learningally.org)

Email: [bvidialogue@LearningAlly.org](mailto:bvidialogue@LearningAlly.org)

Produces accessible educational materials for students with visual impairments with titles available in every subject area and grade level from kindergarten through graduate studies

## **National Library Service for the Blind and Physically Handicapped: The Library of Congress**

Phone: 800-424-8567; 202-707-5100

Website: [www.loc.gov/nls](http://www.loc.gov/nls)

Email: [nls@loc.gov](mailto:nls@loc.gov)

A free library program of braille and audio material circulated to eligible borrowers - an excellent resource for audio books for school-age children

## **Adaptive Sports and Camps**

### **Adaptive Sports Association**

P.O. Box 1884

Durango, CO 81302

Phone: 970-259-0374

Winter Program Office: 970-385-2163

Website: [www.asadurango.com](http://www.asadurango.com)

Email: [info@asadurango.com](mailto:info@asadurango.com)

Supports and transforms the lives of students who have physical and cognitive challenges through sports and recreation activities

### **Adaptive Sports Foundation**

P.O. Box 266

100 Silverman Way

Windham, NY 12496

Phone: 518-734-5070

Website: [www.adaptivesportsfoundation.org](http://www.adaptivesportsfoundation.org)

Email: [info@adaptivesportsfoundation.org](mailto:info@adaptivesportsfoundation.org)

Offers both winter and summer sports clinics to a wide range of special needs children and adults

### **Camp Abilities PA@WCU**

West Chester University of Pennsylvania

Phone: 610-436-2516

Website: [www.campabilitiespa.org](http://www.campabilitiespa.org)

Email: [campabilitiespa@gmail.com](mailto:campabilitiespa@gmail.com)

A developmental sports camp for children ages 7-17 who are blind or have low vision - search the Web for other Camp Abilities locations

**Higher Ground Sun Valley (HG)**

P.O. Box 6791

Ketchum, ID 83340

Phone: 208-726-9298

Website: [www.highergroundsv.org](http://www.highergroundsv.org)

Email: [info@HigherGroundSV.org](mailto:info@HigherGroundSV.org)

A nonprofit organization focused on enriching the lives of people with recreational activities and sports that works with 80 of the top adaptive sports programs in the country to provide high-quality adaptive sports programs that are safe, fun and have measurable outcomes

**The National Beep Baseball Association**

Phone: 866-400-4551

Website: [www.nbba.org](http://www.nbba.org)

Email: [secretary@nbba.org](mailto:secretary@nbba.org)

Provides information about beep baseball including registered teams and equipment for beep baseball

**Space Camp for Interested Visually Impaired Students (SCIVIS)**

Dan Oates - SCIVIS

190 Armstrong Street

Romney, WV 26757-1407

Phone: 304-851-5680

Website: [www.tsbvi.edu/space](http://www.tsbvi.edu/space)

Email: [scivis@atlanticbb.net](mailto:scivis@atlanticbb.net)

A week-long camp conducted by Teachers of the Visually Impaired where children can experience what it's like to train as an astronaut and prepare for a mission at the U.S. Space and Rocket Center in Alabama

**United States Association of Blind Athletes**

1 Olympic Plaza

Colorado Springs, CO 80909

Phone: 719-866-3224

Website: [www.usaba.org](http://www.usaba.org)

A member of the United States Olympic Committee, USABA offers training in a variety of sports for blind and low vision athletes

# Student Involvement Document

## Ability Statement

My name is \_\_\_\_\_

Three things I can see well are:

- 1.
- 2.
- 3.

Three things I cannot see well are:

- 1.
- 2.
- 3.

Three things that I do well independently are:

- 1.
- 2.
- 3.

Three things I need assistance with are:

- 1.
- 2.
- 3.

Three things that I use to help me finish tasks where I use my eyes a lot:

- 1.
- 2.
- 3.

# Student Involvement Document

## Letter of Introduction

Dear teachers,

Hello, my name is \_\_\_\_\_. I will be in your classes this coming school year. I am writing this letter to introduce myself and to inform you that I am a student with a visual impairment. My etiology (diagnosis) is called \_\_\_\_\_. A brief description of this condition is:

\_\_\_\_\_

\_\_\_\_\_. I will need some accommodations in your class, and have developed this notebook to help explain my eye condition and my preferences for materials. These accommodations will help me be successful in your class.

Sincerely,

# **Student Involvement Document**

## **Contents for a Student Portfolio**

### **Letter of Introduction**

Who you are, what your diagnosis is (be brief), and what accommodations you will need in classes.

### **Etiology (Diagnosis)**

Include information on your diagnosis. It is OK to get this from the internet. Be brief.

### **Challenges**

This should be a listing of the kinds of things you find difficult to do with your vision. Be sure to include things that occur outside of the classroom, such as mobility, daily living skills, observation skills, recreation.

### **Preferences for Print**

Use a computer to make a page that includes examples of font style, print size, and line spacing that you prefer.

### **Examples of Good Print**

Put copies of handouts you have received in the past that are easier for you to read. Try including handouts depicting good quality copy, high contrast images, and are free of visual clutter rather than documents that have simply been enlarged.

### **Examples of Difficult Print**

Put copies of handouts you have received in the past that are difficult for you to read. On each, put a Post-It note that states what makes it hard to read. (example: print too faded or blotchy, format is difficult)

### **Technology I Find Useful**

List the technology you use for vision, plus a brief description of what you use it for.

### **Resources**

This section could include people your teachers could contact for more information, additional information on your diagnosis, and agencies you work with.