



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Winter 2015

Welcome to NOAH Ed U!

The National Organization for Albinism & Hypopigmentation (NOAH) presents this complimentary supplement, geared toward educators, based on its quarterly magazine, *Albinism InSight*. We encourage you to share this publication with other educators who work with children with albinism. To enter your school or email address to this distribution list, please contact info@albinism.org.

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Photo courtesy Positive Exposure

Does the family of your student with albinism know about NOAH?

Share this supplement with them so they can learn what NOAH has to offer!

Preparation Tips for IEP Meetings

By Anne L. Corn, Ed.D., Research Professor (Volunteer), Department of Ophthalmology, University of Cincinnati



When an Individualized Education Program (IEP) is written well, it is a blueprint for special education services for your child for one year. These are a few tips to help you work with school personnel to obtain the best blueprint possible. Remember, the IEP team should function as a team. Although an IEP may be drafted before the meeting, it can be changed as the meeting progresses. Parental input is part of the IEP process and assures compliance with the Individuals with Disabilities Education Act (IDEA). In addition, if you believe your child is ready and should attend his or her own IEP meeting, this is also allowed under IDEA.

All goals and objectives should be based on assessed education needs. As a parent, the results of assessments should be explained to you. Recommendations and objectives that are written should be derived from what takes place during each assessment. Remember the “I” in IEP stands for “individualized” and objectives should reflect your child’s individual needs.

At times, a parent will be asked to help determine priorities for instruction. For example, while a child may have received assessments in each area of the nine areas of the Expanded Core Curriculum for Students with Visual Impairments, not all of the areas are of importance for each academic year. Parents may indicate that they think instructional time should be focused on specific areas, such as orientation and mobility and compensatory skills.

Be prepared to offer objectives that are important to you and your family.

When looking at or developing objectives, consider whether the objectives, as a whole, will take a year to complete. To give your signature for objectives that may be reached within a few months leaves a good part of the year without objectives. Objectives should include three parts:

- The given portion — what the teacher will be doing or presenting to your child
- The behavior or learning that takes place — this must be observable
- The criteria — the measure which will be used to determine whether a child accomplishes the objective

While teacher observations may be appropriate for some objectives, most objectives should be written so a teacher can show you why your child has or has not accomplished the objective.

After all of the goals and objectives are determined, add together how many direct hours of instruction will be needed for your child to accomplish each objective. As a parent, you might ask, “You know my child and you know how long a similar objective has taken to teach other students, how many hours of instruction do you think it will take for my child to accomplish this objective?” Once all the hours are totaled, that number of hours of instructional time should be allocated to your child. If that number of hours is not offered for the professionals needed, you may ask how school administrators can adjust schedules so your child will receive the instructional time needed.

In addition to instructional hours, administrative hours should be allocated for



each professional who provides instruction for your child. These hours may include time for:

- A teacher to prepare materials for your child for the general education classroom
- Direct instructional time within or outside the general education classroom
- Ordering books and materials
- Consultation with other professionals and with you
- Travel if the professional is an itinerant teacher

While parents generally do not receive information about the total number of hours assigned for each child, you may want to be certain that administrative hours are considered “in addition” to hours for direct instruction.

Add onto your child’s IEP any optical or electronic devices that your child is using. Once a device is on an IEP, a school becomes responsible for providing and maintaining the device.

Instruction in the use of the device will also be provided by a Teacher of the Visually Impaired (TVI), Certified Orientation and Mobility Specialists (COMS) and / or assistive technology specialists.

Include on the IEP any accommodations your

child uses, such as the use of optical devices on tests, preferential seating, extra time on tests and so forth.

Although IEPs are written with the hopes that they are a blueprint for a year, parents have the right to call for a new IEP meeting at any time.

Eligibility for special education services for children with visual impairments may be found on your state’s Department of Education website. A child with a visual impairment who is doing well academically should not be denied services. Information about your child’s eye condition, along with how the visual impairment impacts learning should be considered. Should a child be placed on a 504 Plan, (which originates from the Rehabilitation Act of 1973), a school system may still provide the services of a TVI, a COMS and other professionals based on your child’s education needs.



Whether your child is enrolled in general education classes, a special education program or a specialized school, resources are available for you. Visit the website for the Texas School for the Blind and Visually Impaired, www.tsbvi.edu as well as the NOAH website, www.albinism.org.

For Kids, For Adults, AFB eLearning Rocks!

AFB eLearning Center
American Foundation for the Blind

The eLearning Center is accessible by those who use assistive technology and allows learning 24 / 7. Courses are crafted and delivered by qualified practitioners and subject-matter experts. Visit <http://elearn.afb.org> to view over 40 webinars from preschool to senior living such as:

- Developing Friendships: A Preschool Priority
- Adapted PE for Students with Visual Impairments
- iPad in the Classroom Webinar Series
- Learning to Listen Webinar Series
- Bioptic Driving for People with Low Vision
- Teaching iPhone and iPad Basics to Seniors

Inquire 2 Inspire: To Be, Or Not to Be... A Driver

By Kathi Garza, *Albinism InSight* Staff Writer



As an adult with albinism, one of the first questions I am usually asked by parents who have received a diagnosis for their children is whether or not I drive with low vision. My heart sinks because I know my reply is not the answer they want to hear. I believe people ask out of hope for their children's futures because they cannot imagine how a person can exist without driving. While a license is one ticket to independence, in reality, it is not the only way to lead a successful and fulfilling life.

For this edition, I decided to explore the inquiry: **"Do you drive?"** I interviewed drivers and non-drivers in our community for insights into their choices. Drivers discussed legal requirements, restrictions and challenges. Non-drivers discussed reasons they don't drive and how they overcome challenges. Both sides also shared advice for parents and people who are facing this very personal decision.

I grew up in a small town in Texas, and I was always told that I didn't see well enough to drive. I have never pursued the process because I came to understand that driving is a very personal choice that carries great responsibility. I typically fall asleep during car rides or close my eyes because of the bright light. That is definitely not a best practice for driving!

One of the biggest challenges to not driving is the inability to go where I want whenever I want. My ability to cope with this comes and goes depending on

the situation. In my family, my husband does most of the driving. We work together, so it is convenient. We take our infant to his nanny, pick him up together, and attend appointments as a team. When our schedules do not align, I take a bus, a cab or carpool with a friend or coworker.

My advice to parents is to help your children consider this decision carefully. Listen to their wishes and acknowledge their feelings. Empower them to make a responsible decision and to consider all of their options. To young adults who have chosen not to drive, be confident in your decision and know that your

choice does not define you or the life you will lead.

Let's see what others in the community said about their experiences as drivers or non-drivers.

I've had my license for 21 years, and in Texas, the minimum requirement to obtain my license was an acuity of 20 / 70 with best correction. While I do not have any legal restrictions, I prefer not to drive at night or when it is raining. I also drive in familiar areas close to home and avoid downtown because of greater vehicular and pedestrian traffic.

I am challenged by the sun, by reading street names and other signs, and by seeing the color of the traffic lights. My GPS helps me with street names, and I look for traffic cues as I approach intersections so I know what to



do. I also worry that I won't see unexpected objects in the road quickly enough to avoid them.

Driving safely is always about being aware of what's going on around you and being prepared to react. I learned that although I have poor vision, I must look farther away than my comfort level to be prepared for what is ahead. I find driving in reverse very difficult. In parking lots, I look for spaces that I can pull straight out of without backing up. I also have a backup camera on my car, which is helpful at times when I don't have a choice.

My advice is to practice as much as you can in as many different conditions as possible. Understand that driving is stressful, especially in the beginning. Be patient, as it will take you longer to get comfortable and gain confidence than your fully sighted peers. If you decide you're not ready to drive yet, that's OK, too. I was in my 30s when I got my license because I wasn't comfortable before then. Happy motoring! Nancy L. — North Richland Hills, TX

I was a driver for about 10 years, but I do not drive anymore because I moved to a state that does not allow people to drive with low vision. I did not have any legal restrictions on my license, but I chose not to drive at sunset because it was too challenging to see while the sun was in my face. One of my biggest challenges was that many people did not trust my eyesight enough to feel comfortable getting into the car with me.

Although it's challenging, I rely on public transit or the generosity of others to get where I need to go. This sometimes means that I get to work very early or run a little late depending on transportation. My advice to parents is to understand that driving is a very personal choice involving great responsibility, and at

times, stress. To young adults, recognize your limitations. It's fine not to drive, and if you change your mind, it is never too late to learn!
Betty C. — West St. Paul, MN

I have been driving for 17 years. I tested for my first driver's license in Massachusetts where the requirements were 20 / 70 best corrected for a daytime license. One could test separately for night driving privileges.

Four years later, we moved to New Hampshire, and I had to transfer my license. New Hampshire required 20 / 40 with best correction in one eye. This meant I had to get a bioptic, and I am required to wear corrective lenses to drive.

At times, I take a longer route to avoid driving into the sun. I am also very careful about driving during winter weather. I'm

actually very comfortable driving in the snow, but I slow down to allow myself extra reaction time. Although some people can handle driving after a drink or two, I know that I cannot, and I have too much at stake to put myself at risk. Sometimes I find it challenging to locate new destinations. I typically ask for physical landmarks to help guide me, and I allow plenty of time to drive around the block a few times looking for the correct house.

My advice is to consult with a driving instructor who is certified in adaptive driving. Although it might be an additional expense, this type of support can help you prepare to pass the driving test since the rules of the road can be quite different than what is tested. When I first started, I was terrified, but I was determined to decide for myself whether or not I could safely drive. Driving is a privilege, and it's a HUGE responsibility. Getting my license opened a lot of doors, but if I hadn't been able to drive, I would still have a good life. Be safe!
Lee L. — Loudon, NH



Lee L.

With best correction, my visual acuity is 20 / 200. This is below the minimum requirements of 20 / 180 in California where I'm from, and 20 / 70 in Texas where I live now. One of the biggest challenges is lack of flexibility. Although I'm fortunate to live in a city with better-than-average public transportation, my daily schedule and arrival time to specific events revolve around transit schedules. A doctor's office that's 18 minutes by car takes two hours and three busses. The airport is 30 minutes away by car, but it takes nearly an hour and a half to reach by train. I travel by busses, trains and the occasional half mile walk to get to my destination. Uber and Lyft are options and, while pricey, they're great for getting to places where public transportation doesn't go.

My advice to parents is to be patient! Self-driving cars are far from being science fiction. Multiple companies are working on the technology, and testing has yielded promising results. Although we have miles to go and obstacles to overcome, the concept and technology are moving in the right direction. As a non-driver, I remind myself to look on the bright side. Owning and maintaining a vehicle is expensive! Would the expense and burden of owning a car be worth the added flexibility? I'm sure people living in small towns are all screaming, "YES!" but living in a big city, I'm content to take the train. Alex C. — Richardson, TX

I have been a driver for 12 years in Illinois, and I am required to use a bioptic. Driving candidates are required to read 20 / 40 through the telescope of their bioptic and 20 / 100 through the regular lens with a full field for viewing. The legal restrictions on my license indicate that I wear my bioptics when I drive, have both outside mirrors, and only drive in daytime hours during the first year. After a year, I was eligible to test for my night license, but I

waited several years to pursue that. A new law allows night drivers to drive four years before repeating their night test if they have not been involved in any accidents.

Driving on the interstate is challenging because I don't feel as though I see well enough to



respond to traffic and obstacles in time. It is challenging for me to drive when the sun is low and in my eyes, so I plan my activities around these times. Since I am a morning person, I am able to drive when there are fewer people on the road. I work in healthcare and must be present regardless of the weather, whether I feel comfortable driving or not. During these times, I often ride with a generous coworker to ensure I am safe. I also have had to

advocate for myself and not give in to pressure to "drive just this one time" because I know what I feel is safe for me, and I do not want to chance hurting anyone or losing my license.

It can be heartbreaking to watch your friends get their licenses and hear well-meaning adults ask when you will get yours. I know driving is a privilege and, unlike my friends, I fought hard because I am strong and courageous. Despite the importance our society places on driving, especially in towns with limited public transit, you are no less if you do not drive; just as you are no less if you don't drive everywhere or in every situation or didn't get your license the day you turned 16. Becca, E. — Bloomington, IL

What amazing insights and perspective these people brought to the issue of driving! I hope these stories help you to open a dialog about driving, and I hope you have gained an appreciation for the journey one must go on before deciding whether or not to drive with low vision.

Now we need YOU to Inquire to Inspire. Send your questions with regard to issues faced by individuals in the albinism community to i2i@albinism.org.

How to Become Driving Ready!

By Chuck Huss, COMS, Driver Rehabilitation Specialist



As children with albinism approach their mid-teens, independence, autonomy and driving invariably come to the forefront. Basic pedestrian travel skills and key areas of conceptual development are needed to become driving ready and enhance the likelihood of success for the future operation of a motor vehicle.

The skill sets include the abilities of prospective driver candidates to:

- Take in, remember and follow route or task instructions
- Travel to and return from a destination
- Detect, analyze and cross intersections with stop signs as well as traffic lights
- Detect, identify and react in time to critical objects or conditions in the travel environment

The definition of critical objects or conditions is anything which can be predicted to cause a traveler to change walking speed and / or path of travel. This includes pathway characteristics, other road users and traffic control devices.

The first two skill sets can be introduced and reinforced by family members and teachers as early as pre-school. Use familiar indoor and outdoor settings at home or school. The last two usually involve the services of a professional Certified Orientation and Mobility Specialist (COMS) as your child approaches the teen years.

Let's look at some tasks that can be used to develop driver-readiness skills in young candidates.

Take in, remember and follow instructions: Parents might ask their child to take a recipe

to the neighbor next door, or to drop a few letters into the corner mailbox. They may monitor these travel-related tasks closely when children are younger then may allow more distance in travel tasks as the child grows older and becomes more trustworthy.

Key concepts for the child to understand:

- Position: in front of, alongside of, behind
- Body turns
- Time of day
- Laterality: left or right
- The difference between a reverse route and an alternate route



Travel and return from a

destination: Parents may grant a child's request to participate in a sleepover at a friend's house that's a block walking distance from their home. After approval and an exchange of telephone calls between parents, your child will likely gather a favorite toy or pillow and set out, then return on foot (as both sets of parents watch from the front door).

Similar types of short-in-duration travel tasks can be introduced and reinforced in controlled school settings. For example, a teacher may ask your child to take the daily attendance list to the principal's office.

Eventually, as children climb the educational ladder, they will be required to change classes independently as part of their daily routine. By this time, distant functional vision skills including keeping their head facing ahead vs. downward, moving their eyes laterally and leaving an adequate distance from students ahead in order to avoid collision during class

change, can also be encouraged and reinforced.

Key concepts for routes within a short distance from your home might include:

- The meaning of street markers: Road signs that tell the name of the street you are walking along or signs that show you have arrived at the corner of an intersection
- Route shapes: Mentally mapping out a travel route and its reverse or alternate route back to the original starting point via interpretation of verbal directions given by the instructor
- Basic compass directions
- Address numbering system: Odd numbered addresses on one side of the street, even numbered addresses on the opposite side
- Basic math: Understanding the distance to travel — from 10th Street to 6th Street is a distance of four blocks

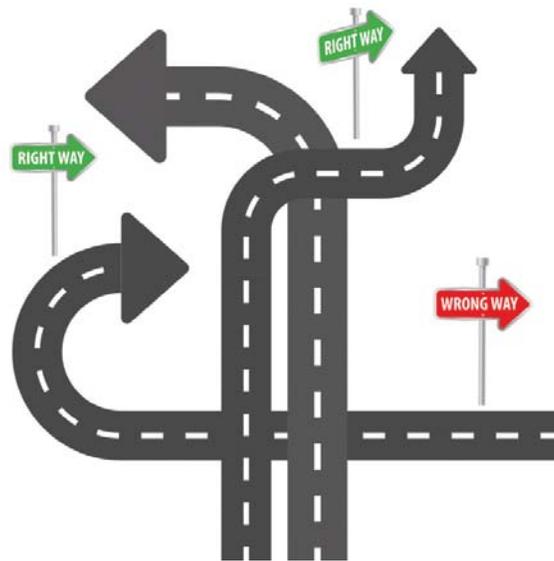
As your child grows older, routes will likely expand beyond the area of your home. As part of the middle through high school Individualized Education Program (IEP) goals, a COMS can address a sampling of outdoor travel tasks.

Detect, identify and react in time to critical objects or conditions in one's environment:

Under the direction and watchful eye of a mobility instructor, your child may be asked to walk multi-block, multi-directional routes (from point A to point B and back) and may be asked to make a business transaction or purchase as part of their Orientation and Mobility (O&M) lesson. This can be undertaken within residential or small metropolitan settings. These travel experiences will provide exposure to sidewalks of varying

types, widths and gradients, driveways (with parked vehicles that a child may have to maneuver around), alleys, curb cuts, and fixed hazards such as telephone poles, trees, fire hydrants, sloped lawns, fences, hedges, building fronts that interfere with their path of travel or hide other road users.

Place special emphasis on encouraging or reinforcing where and how your child should look and position themselves in their walking space (forward scan, eye scanning, staying to the right side of your walking path), avoiding contact with stationary or moving hazards to enhance their personal safety, effectiveness and self-confidence.



Key concepts include block distance and sun clues, such as where sun rays contact their body relative to basic body planes and compass directions.

The ability of children to gain experience in the use of functional visual acuities and functional visual fields is discussed in *Foundations of Orientation and Mobility*. For example, while gaining on-foot travel experience, an O&M instructor might ask

your child to look as far ahead as possible and indicate when the presence of a form is first detectable (awareness acuity), or to attempt to identify an object (identification acuity) or to move forward closer to a comfortable viewing distance, where they are able to provide sure identification of the form (sure acuity or preferred viewing distance).

Similarly, an O&M instructor may want to measure your child's functional field of view (the extent of a student's binocular visual field) by telling the student to:

- Stand still, keep the head and eyes still, look straight ahead at a distant target

and describe it to the highest, lowest and farthest boundaries to the left and right (static visual field)

- Move forward keeping the head and eyes still and looking directly at an object, and describe it to the highest, lowest and farthest boundaries to the left and right (dynamic visual field)
- Walk forward, moving the head and eyes as they would normally and observe the student's scanning patterns (preferred visual field)

Static and dynamic functional field measurements tell you about the potential area of visual field available to a student; while preferred visual field tells a trained observer what the student is actually using given a dynamic situation with no restrictions on how or where to look. The latter provides the best estimate of the student's use of potential visual field. Keep in mind that future driving tasks are primarily a functional visual field task.

Detect, analyze and cross intersections with stop signs as well as traffic lights: As your child becomes more confident with travel around your home, O&M can expand your child's exposure to stop sign and traffic light



street crossings. Types of street crossings might include variable traffic control (1-4 stop signs), standard and Automated Pedestrian Signal (APS) traffic lights, traffic flow (two-way vs. one-way), standard transverse (crosswalk, stop line), and longitudinal pavement markings (yellow vs. white, dash vs. solid).

Street crossing lessons include detecting corner curb surfaces, determining the shape and traffic flow at intersections (i.e. search and identification of road signs and pavement markings), alignment techniques (to increase one's safety and visibility to traffic), applicable scanning patterns prior to and during street crossings, and yielding procedures.

Concepts include:

- Sound cues (detection, differentiation and localization)
- Parallel vs. perpendicular traffic and sounds
- Turn right or left on red laws

Remember children cannot feel at ease and comfortable behind the wheel of an automobile if they haven't developed good pedestrian safety skills.

Welcome Back to Earth from Space Camp

By Dan Oates, NOAH Board of Directors

Photos courtesy of Space Camp



Another year is over and all of the trainees have “rocketed” back home from the 26th Space Camp for Interested Visually Impaired Students (SCIVIS). This year, 199 students from 23 states, as well as Australia, England, Ecuador, St. Lucia, Greece, Ireland, and three provinces of Canada attended.

NOAH scholarship winners Seth Berglund of Iowa and William Hedlund of Washington also joined the crew. William was the proud winner of The Right Stuff award for the Advanced Academy program.

Many of the foreign country trainees were scholarship winners from the Lighthouse for the Blind — St. Louis. The Lighthouse sponsors students with unique cultural backgrounds to add to the diversity of the program.

Another award winner was new NOAH member, Jamie Crosser of West Virginia. Jamie was the recipient of the Golden Arrow Award!

Would you like to reach for the stars? We'll blast off for the next SCIVIS, September 24 - 29, 2016, at the U.S. Space & Rocket Center in Huntsville, AL.



Searching Earth for those who want to Explore Space

Space Camp for Interested Visually Impaired Students (SCIVIS) is searching the world for blind and visually impaired students to attend Space Camp, September 24 - 29, 2016. For the last two years, the Lighthouse for the Blind, St. Louis has funded tuition and travel scholarships for students who are blind or have low vision, who have unique cultural identities, and who live outside the U.S. We are hopeful that funding will be available for this year's program as well. If you are interested in applying for this program, please email Dan Oates at scivis@atlanticbb.net. For more information, visit www.tsbvi.edu/space and www.spacecamp.com.

From Trials to Triumph

By Alexis Foster, age 17



There were many days I sat at lunch tables alone, cried myself to sleep, and despised my reflection in the mirror. The pain I experienced was a result of the bullying I endured throughout middle school. I frequently faced ridicule from my peers and was labeled “the albino girl.” No one was able to accept my pale skin and shaky eyes. My self-esteem was significantly low, and I resented my skin condition. My family attempted to boost my confidence, but I was unable to embrace my identity.

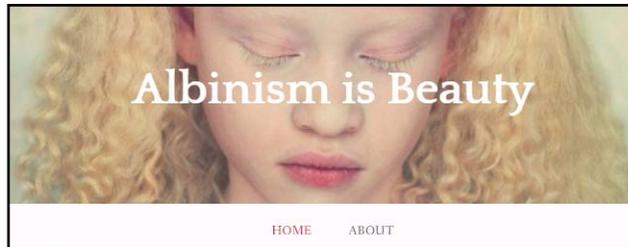
One day, I decided I was tired of being depressed. I wanted to be confident and unbothered by opinions. By blocking out all negativity and relying on my faith, I was able to build a stronger self-image. I experimented with makeup and began to admire my unique features. I never thought I would say this, but I am grateful for the trouble I faced as a child. It has molded me into the strong individual I am today.

This past year, I decided I wanted to spread awareness about albinism as well as anti-bullying. Many people are misinformed on

both of these topics, and I strongly believe the spread of knowledge decreases the occurrence of prejudice. Last spring, I visited my elementary school and spoke to students about bullying. I passed out anti-bullying bracelets and shared my story. I was empowered by this experience and hope to continue advocating. I also started a blog. I discuss topics related to albinism and emphasize the beauty that exists in all of us. Offering words of encouragement has made a difference in the lives of my viewers and has allowed me to continue growing. This is only the start of my journey of

spreading awareness and ridding the world of ignorance. My dream is to become a journalist and impact a larger audience.

Regardless of what society says, albinism is beautiful. For the longest time I sought approval from my peers. Now I realize the only way to be genuinely confident is to find beauty from within. It is OK to be different, so there is no need to strive to be like everyone else. You define beYOUty. Visit my blog at www.albinismbeauty.wordpress.com.



Caroline Educates First Graders

By Sarah Venn



Soon after our daughter Caroline was born, we found ourselves answering questions regarding her hair color, nystagmus and fair complexion. We figured this was our opportunity to educate others regarding her albinism. However, as she grew older and began school, we were curious as to how she would answer these questions on her own.

Within the initial week of school as a first grader, Caroline received comments and questions related to her albinism. On her own, she decided to write a book about her albinism and share it with the class. She wrote the book herself, and together, we picked out a few pictures to include.

I set up a day and time with her teacher, and together, Caroline and I educated her class about albinism. Caroline demonstrated how she uses her magnifier, monocular, book stand and iPad. We let the class explore her magnifier and monocular and ended the discussion by giving everyone a pair of sunglasses to take home. The students had wonderful questions and were interactive during the entire discussion. I gave a copy of Caroline's book to her teacher. She kept it in a place for the

students to read. I also left a magnifier and monocular for the children to use.

Caroline's teacher said that this was one of the most amazing experiences she's had during her teaching career. She also mentioned that the afternoon after Caroline's presentation, during a video showing, they all wanted to sit closest

to the computer! They had an "almost immediate reaction" of realizing they could help Caroline, and they encouraged her to be the closest one to the computer!

We are so proud of Caroline for taking the initiative to educate her classmates. Knowledge is power! Here is what she wrote in her book.

My name is Caroline Venn, and I was born with albinism. Albinism means that I don't

have pigment. Pigment means that you have tan or brown skin and your hair has a color like brown or black. I have blue eyes and white skin and white hair.

I have to wear a hat, sunglasses and sunscreen to protect me from the sun. I have to wear sunscreen because I have pale skin and it gets burnt easily. The sunscreen blocks the sun from my skin when I am outside.



My sunglasses protect my eyes from the sun because the sun is really bright for me. My hat blocks the sun like a shade.

My eyes do not work like everybody else's eyes. I have to get close to things to see them better. I have to sit next to the teachers and the Smart Board so I can see better.

My eyes wiggle back and forth. That is called nystagmus. My eyes can't stop wiggling back and forth.

My eyes wiggle more when I am nervous, scared or tired.

I wear glasses to help my eyes focus on what I am looking at. I have bifocals in my glasses. My bifocals make the words bigger when I read.

I have an Elsa bag. It holds all my tools. My monocular helps me see things far away like at community meetings or animals at the zoo.

My magnifier helps me see

things up close like a crossword puzzle or small pictures in a book.



I have an iPad. I sometimes use it when my other tools don't help me enough. I can read books on the iPad.

Sometimes I need help finding my friends like on the playground and in the lunch room. It is hard for me to see you far away. I can't see you waving at me far away. It is better if you tell me your name and walk

up to me. In the lunchroom, I might follow you to the trashcan because it is hard to see where it is. It is hard to see you on the playground. I like it when we meet at a certain place on the playground so I can find you easily.

I can do the same things you do. I dance. I ride a two wheeler, and I read. I like to read chapter books. I like when people ask me questions about my albinism. You can ask me questions any time you want.



Educate! Advocate!

In the mall, at the grocery store, on the subway platform, sure you want to explain albinism but you've gotta run! Did you know that NOAH has free Albinism Information Cards? The size of a business card, they fit easily into a wallet, purse or back pocket.

- Leave some with your doctor for other patients with albinism.
- Take some to holiday gatherings to quickly spread information.
- Use them when you need a quick explanation of albinism or want to direct someone to NOAH.



To get your free cards:

Call: 800-473-2310

Email: info@albinism.org

What is your HPS IQ?

- ✓ Did you know that all people who have HPS have albinism, but not all people with albinism have HPS?
- ✓ Did you know that cases of HPS have been documented in 40 countries on six continents?
- ✓ Did you know that 85% of people with albinism from Puerto Rico have some type of HPS?
- ✓ Did you know that in addition to low vision and reduced pigment, HPS involves other medical issues?

If you or your child has any of the following symptoms, consider being screened for HPS:

- easy bruising
- frequent nose bleeds
- bowel trouble
- breathing difficulties

Someone with HPS may have only one or more of these symptoms. The only way to know for sure is to be tested.

Contact the HPS Network for information on testing for HPS.

HPS Network
One South Road
Oyster Bay, New York 11771-1905
info@hpsnetwork.org ~ www.hpsnetwork.org
516-922-4022 ~ 800-789-9HPS (9477)

SAVE THE DATE



Albinism *Family Day*

March 12, 2016
**Maryland School
for the Blind**
3501 Taylor Ave
Baltimore, MD 21236
*(In partnership with
Maryland School
for the Blind)*

SAVE THE DATE

NOAH *Family Weekend*

April 16-17, 2016

Camp Metoche

42193 Santa Ana River Rd
Angelus Oaks, CA 92305



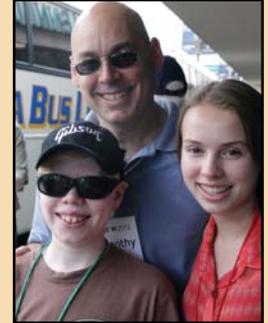


It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - Brooke Jensen - Fort Drum, NY



NOAH's Parent Connections

IN PARTNERSHIP WITH LIGHTHOUSE GUILD INTERNATIONAL



To join one of our small group communities, please contact Sheila Adamo at sadamo@albinism.org.

The calls provide a nice balance of sharing tips and stories, and interacting with guest speakers who provide valuable information. One speaker talked about ways we can help our preschooler inside and outside the classroom. We also gained insights from an adult with albinism into how our children see. He affirmed they can do anything!

Andrea Wade – Helotes, TX



The calls have been a really supportive experience. It's nice to hear the stories of other people going through a similar issue. The guest callers are informative and that gives me a head start on what to expect as my child grows. It's also a great outlet reminding me to nurture and take care of myself so I'm able to truly take care of my son.

Andrea Chadderdon - Chicago, IL

Here's an opportunity to talk with others who understand what you are going through as a parent of a child with albinism. Get the support you need to be a healthy, informed parent, and build connections in the albinism community – all in the comfort of your own home.

The teleconferences consist of a limited number of parents to provide a safe and comfortable environment for you to voice concerns, ask questions, and share your experiences. Two groups meet for one hour twice a month; one in the evenings and the other at midday. Both are facilitated by a licensed professional and feature presentations from professionals on raising children with albinism.

Thank you to the Lighthouse Guild International for the support which makes these teleconferences possible.



I appreciate the outlet to vent and share my experience of having two children with albinism. I feel very fortunate to be a part of this group. It has been amazing to have guests give insight to the various situations my children are faced with on a daily basis. — Stacey Dolan - Bushkill, PA



The HPS Network offers support groups in Spanish and English for parents of children with Hermansky-Pudlak Syndrome and another group for Chediak-Higashi Syndrome. Contact the HPS Network at 800-789-9477.

MEMBERSHIP



First three photos courtesy of Positive Exposure, Rick Guidotti

Photo courtesy of Ashley Montes

Mission

NOAH's mission is to act as a conduit for accurate and authoritative information about all aspects of living with albinism and to provide a place where people with albinism and their families, in the United States and Canada, can find acceptance, support and fellowship.

Information

NOAH is the world's most comprehensive source of information about albinism.

- A Quarterly Magazine
- Parent Books
- Webinars
- Website
- Information Bulletins

Support

- New Parent Program
- Biennial National Conference
- Family Camps
- Adult Weekends
- Regional Conferences
- Teleconference Series

**Join NOAH online
at www.albinism.org**



Photo courtesy of Whitney Harness, 2013



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