



# NOAH Ed U

CREATED WITH EDUCATORS IN MIND



**Winter 2014**

## Welcome to NOAH Ed U!

The National Organization of 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](mailto:info@albinism.org).

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*Photo courtesy of Justin Dingwall, Shaw Media*

**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!**

# Fair Share

By Rita A. Jackson, *Albinism InSight* Editor, NOAH Editorial Committee Chair

I hope you're enjoying all of the winter celebrations! In this issue, you'll find some great winter pictures as well as perspectives from pre-teens to retirees. There's a little something for everyone, but first, let's look at the responses to the Fair Share question which evolved from one of the conference sessions: **How do you deal with negative comments in public?**

It depends on the situation. I usually ignore negative comments; however I look in their direction so they know I heard what was said. If I feel I can correct the person without starting a fight, I might try to start a conversation. Betty C. — West Saint Paul, MN

Although my nine-year-old daughter is albino, we haven't had any negative comments in public, just rude stares. We say, "Hi," answer any questions they have, and give them the NOAH website address. We tell the little kids that Nah'Airra is famous! She is a Barbie with beautiful blonde hair. And to make it fun, she swings her hair when she leaves. Taschica F. — Smyrna, DE



Nah'Airra

When we encounter negative comments or stares, I take the opportunity to educate and advocate for people with albinism (PWA). My goal is to help people understand the term "albinism" and that PWA look different but are just as normal as everyone else. I use the NOAH info cards as a great way to end the "teachable moment." *See the ad at the end of*

*this article to learn how to get NOAH information cards.*  
Tikia K. — Park Forest, IL



I think it's interesting to hear negative comments because it lets me know what's on people's minds. I deal with it by trying to educate people, but it's not always about albinism. Charles T. — Owings Mills, MD

As the mom of two boys with albinism, I've had my share of strangers staring, pointing and whispering. When my oldest son was a baby, I used to react with anger, and then go home and cry.

As he grew, I developed an understanding that most people were not being intentionally cruel. Their behavior was due to ignorance about albinism. From that moment on, I decided to educate people. I always greet the negativity with a smile, and then I spend two minutes explaining albinism. I am matter-of-fact and brief. I say the same thing every time to teach the boys how to respond as well. "The boys have albinism. It is a genetic condition that results in a lack of pigment. That's why their hair is white. Isn't it beautiful? We call it their rock star hair." I have never had a person react with more negativity. Quite the contrary, this approach had sparked lots of lovely and meaningful conversations.

The decision my husband and I made to teach the boys about albinism, pigment and what it means to be legally blind was a game changer. It took away the mystery and empowered them with knowledge. They are only four and six years old, but they have started telling people about albinism themselves. In fact, for the last year, they have told everyone they have magic powers, just like Elsa!

Tarsha B. — Burlington, MA

Many times, I ignore negative comments, but as a young girl, I used to fight back or shout insults. At times, I would sulk and say things like, "I also did not want to be the way I am." None of this brought me any peace or self-confidence. Instead, I would wallow in my misery or seek solace from my mom.

Now, I ignore them and CHOOSE not to hear. Hearing has levels, and of course you hear with your ears, BUT do not take these comments to heart. I have learned not to concentrate on these comments because I view such people as being myopic or shallow-minded. I enjoy my life, including being able to drive a car in the crazy traffic of a developing country with almost no traffic rules. Many marvel at this feat, but I have done it for five years!

Olive N. — Kampala, Uganda

I am an 8th grade student making all A's. Although I have faced many hardships, I still live my life the best I can. I still get called names and taunted, but I just smile because I know my albinism is just one of the many traits that makes me unique.

Alexis C. — Villa Rica, GA

I think dealing with comments depends on how you portray yourself. If you are comfortable and confident, if you like yourself, then you come across more positive, and it is hard to knock you down.

If you let a bully get to you, then they thrive and do it again and again. Their friends also thrive on what they see their leader doing.

My parents always told me that I was better than they were because I didn't have to try to make them look bad. I learned that people are bullies because they feel threatened. They don't know how to deal with someone who is different. I also learned that my friends hung out with me because they like me.

Here's a situation where I took control of a negative comment. I was walking down the

street, and four people were coming toward me. "Hey, Whitey, you look like a ghost!" Without missing a beat I replied, "Hey what about Cotton Top, Casper, Pale Face, Santa and you forgot Four Eyes." The bully stood quietly and his friends looked at him like he was the idiot. I realized my parents were right. I **was** better than he was.

Scott G. — Kitchener, ON, Canada

So, dads and moms as well as adults, teens and kids with albinism, it's time to share your InSight! The question for the Spring edition comes from Alex C. of Dallas, TX: **How did you discover NOAH?** Submit your answers or questions for upcoming issues at [ai@albinism.org](mailto:ai@albinism.org).

## 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](mailto:info@albinism.org)



## Thando Hopa: Choosing Pretty

By Antonia Opiah, Founder of un-ruly.com, Article reprinted with permission

“...I don’t know what the number of people with albinism in Turkey is, but I could tell that this was the very first time that he saw a Black woman who looks white. And he argued with me. He argued with me. **He said: I’m telling you, you are white. And I said: No, I’m not; I’m black.** And he said: Listen, I promise you; you are white. And I said: No, my father is Xhosa. My mother is Sotho. So, I am definitely Black. And he said: Are you sure you’re not adopted? And I said: I promise you I’m not adopted. So we just had a continuous exchange. And when (this is why I say I identify with black people, because I was wearing a hat) I took off my hat, he saw my hair and then it dawned on him that this is possible. And he touched my hair. And he felt it and I said: See, this is not white people’s hair. And I think that’s the only time he actually understood.”

Thando Hopa told me this story when I asked her if she’d ever been mistaken for white. At only 25 years old, this public prosecutor and part-time model already demonstrates a precocious collectedness and understanding of people and a thorough understanding of herself.

I spoke to Thando because I’ve been thinking a lot about being “**confident despite.**” Confident despite not getting the little affirmations we seem to need to feel valuable in our communities—a pat on the back from the boss, a compliment from an acquaintance, a wink from a cute guy. There’s a sector of popular thought that tells us that we should just be able to be confident and love ourselves despite what



*Photos by Justin Dingwall, Shaw Media*



anyone says and not need any validation. But that directive is a tall order and very few of the messages touting self-love and celebration are coupled with how exactly we do that. But in exploring Black identity alongside confidence, I stumbled upon Thando's story. Thando shares that an unyielding support system and an opportunity to explore her beauty in a way she never considered were integral in her feeling secure about her appearance. Her story is not one of being confident despite being different; it's one of understanding difference in a larger unifying context as well as tuning into our innate ability to decide who we are.

Early in my conversation with Thando, I noticed how at ease she was about speaking about living with albinism, an inherited condition where a person is unable to produce coloring of the skin, hair and eyes.

"My parents raised me to feel comfortable about being who I was and made me open to even talking about it. Because we were in a situation where—even though my parents were quite liberal (and I suppose they had to be because they had a child who was different)—but a lot of people around us weren't as liberal and they needed me to be vocal and unashamed in order for me to educate anybody who never quite understood the condition. So from a young age I was very vocal about it and I never shied away from it."

Naturally, Thando's childhood had its challenges, especially in South Africa where having albinism often means living with superstitions and stigmas that isolate you. "I was teased, called names, people didn't want

to touch me," Thando recounted. "And as a child, you don't quite know how to articulate what is going on in your head or how to reason it out in a mature way. So you begin resenting the way you look." Luckily, her parents relentlessly tried to instill as much confidence in her as possible, despite outside forces counteracting their efforts. "If it weren't for my parents, I don't know how I would have turned out. They really fortified every aspect of my character."

It's very easy to feel beautiful at home or when you're around friends or family because they can see you for everything that you are. But how does that self-assurance carry over when you leave the safety net of loved ones and the outside world not only fails to see you but negates all the wonderful things you were told? To get some perspective on this, **I asked Thando what exactly her parents did that had such a lasting impact.**

"Basically, it was affirmations and you know what, repetition has far more power than people would like to give it credit for. My father would tell me all the time how beautiful I was. He would tell me I was the most beautiful girl in the world. And I would cry and tell him that I didn't believe him. And he said, 'I don't care if you don't believe me. But I'm telling you, I've seen a lot of little girls and I've never seen a little girl that's more beautiful than you.' And my mother, on the other hand, she was more practical. She would make me look like the prettiest thing. She would put all sorts of ribbons on me as a child and she would make sure she meticulously took care of my skin.



*Justin Dingwall, Shaw Media*



“...I really made strong efforts not to believe them because I thought those are my parents and of course they think I’m beautiful. But as time went on, they shaped my psychology. Then being beautiful stopped being something where I had to hear it from somebody else. It was a decision I had to make. I had to decide that from now onwards I would be beautiful. It got to a point where they had said it so much and made so much effort around it that as I grew older, it became a decision that I made. So, if somebody tells me that I’m not beautiful. It’s quite fine. Because it’s a decision I made for myself, therefore I don’t need them to tell me anymore. Not like then when what [people] said affected me and affected my confidence.”

One wouldn’t expect it, but modeling also played a role in shaping Thando’s view of herself. Thando had previously been scouted as a model, but it wasn’t until fashion designer, Gert-Johan Coetzee, approached her did she decide to go down that path. She explained that Coetzee wanted to help redefine beauty and she wanted to be part of that effort. As she delved into the fashion world, she found, at times, photographers wanted to photograph her completely natural, with no make-up on at all, which at first made Thando uncomfortable, as she would normally color in her eyebrows and eyelashes. But one of the first times she saw photos of herself with a “purely clean look,” it hit her:

“I think it was a moment of enlightenment... and perhaps it was because by the time this enlightenment came, it came at a point in my life when I was ready for it. I might not have explored the avenue of how confident I was [without make-up] and this was one of the ways I had been given the opportunity to explore it. But had this happened maybe five years ago, I would probably not have had the

same reaction because I was deeply conscious of everything and nothing felt right.”

Now, it seems, that quite a lot is right for Thando. She’s not fazed by stares, which she says happens every 15 minutes, so it’s useless to be bothered by them. And she welcomes conversations about albinism (although they happen rarely) as she sees them as opportunities to remedy uninformed thinking. She also sees her difference as the thing that unites her with everyone else.



*Justin Dingwall, Shaw Media*

“The reason why **[another shade of normal]** is sort of a saying that you continually see used is not because being different is a bad thing it’s because everybody is different just like everybody else. ...I might be different, but I’m different just like you and that actually makes us all normal because we are all different... [if you] confine me in a space where you make me loathe my being, then I have to articulate things in a way where you understand that I am just like you, different just like you.”

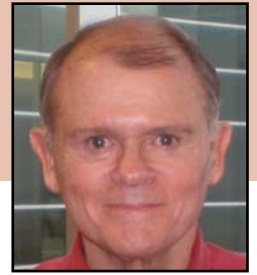
As if our conversation hadn’t already been full of TONS of insight and words of wisdom, I asked Thando what advice she would give to anyone struggling with any kind of difference, to which she responded:

“I’ve said this before and I only repeat it because I believe it as an absolute truth. **It is extremely important for you to define who you are...** I’m also growing in my own advice because I’m trying to define myself in every aspect of my life and it’s not easy. But when you get to that point, when you get to a point where you have thoroughly defined who you are, then people have no option but to yield to the definition that you have of yourself. So that is honestly the most sincere advice that I can give from my experience.”



# Visual System Differences in Albinism

By Donnell J. Creel, John A. Moran Eye Center



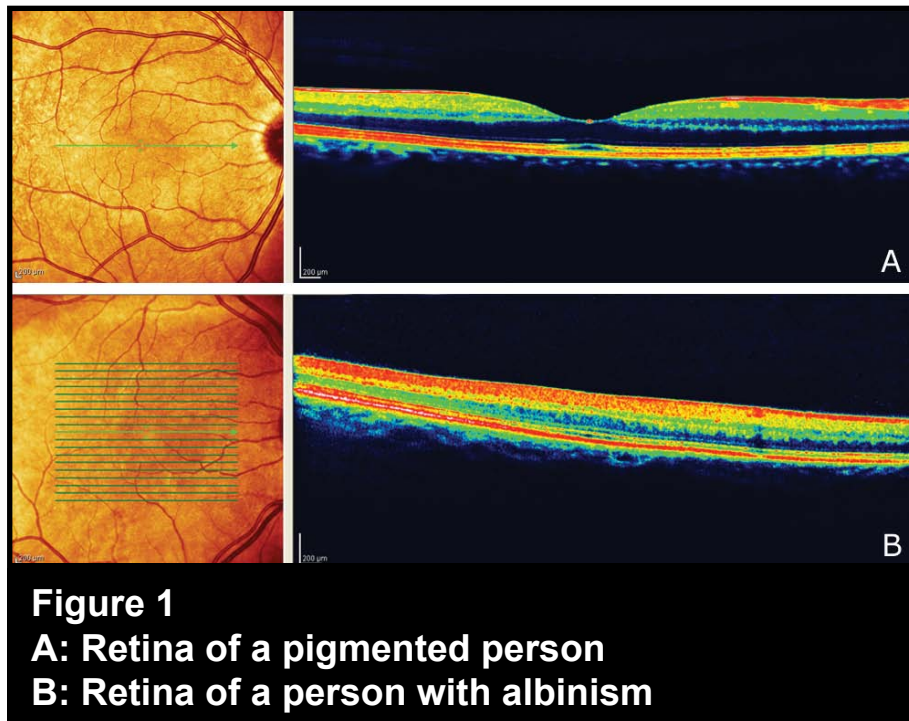
Nearly all people with albinism have problems with vision. One problem is that an eye without pigment to block light, other than the light entering the pupil, will experience excessive glare.

The number one problem for most is poor acuity, often to the extent that visual acuity does not meet minimum requirements for a driver's license. The underlying cause of poor acuity is the focal point in the eye which is underdeveloped. At the back of the eye, there is

a thin layer, about one millimeter thick, called the retina. Images entering the eye project onto the retina where cells identify shapes and colors sending this information to be further processed in the brain.

The point at the center of the retina where one focuses small images is called the fovea. In an eye with pigment, this focal point, the fovea, is a V-shaped depression in the retina which enhances and sharpens images. In an eye with little or no pigment, the V-shaped depression, fovea, is not formed. Using optical coherence tomography, Figure 1 shows the cross section of the inside of the eye where the slice through the retina is located. In (A), you can see a pigmented person's retina with a foveal depression. In (B), you can see the retina from

a person with albinism with no fovea. The consequence of not having a fovea is that images are not sharp.



**Figure 1**

**A: Retina of a pigmented person**

**B: Retina of a person with albinism**

After processing in the retina, the information is sent into the brain via approximately one million optic fibers called retinal ganglion cells which comprise each optic nerve. Each optic nerve is only the size of a pencil. About two inches behind the bridge of your nose is a crossing

point where the optic nerves from each eye meet. This crossing point is called the chiasm, which means cross or crossing point. In human eyes with pigment, approximately half of the optic fibers cross to the opposite side of the brain and a little less than half remain on the same side of the brain. In an eye with reduced pigment, almost all optic fibers cross to the opposite side of the brain and few fibers remain on the same side of the brain. This is true of all albino mammals whether humans, mice, rabbits, mink, even Siamese cats and white tigers.

The consequence of excessive proportion of optic fibers crossing at the optic chiasm is that this disrupts the organization of the processing centers for vision in the brain including

stereovision (i.e., depth perception). The unusual distribution from each eye also affects brain centers that keep one's eye straight. The consequence is that many mammals with albinism, including human beings, Siamese cats and white tigers have misalignment of their eyes with an eye that looks inward or outward instead of straight ahead.

Pigment is also present in the inner ear. The consequence of reduced pigment in the inner ear is greater susceptibility to noise damage.

Humans with albinism do not recover as quickly to a normal hearing threshold if exposed to loud noise.

For more information and history of this area of research, including diagrams and photos, please visit the website Webvision, Part XI or search for the word "webvision" on the Internet. On the Webvision home page scroll down to the Table of Contents on the right to Part XI where you can access a chapter on albinism.

## Let's Move Toward a Better IDEA

By Anne L. Corn, Ed. D., University of Cincinnati, Professor Emerita, Vanderbilt University



I taught braille to teachers of students with visual impairments from 1976 to 2008 and was the lead researcher on the Alphabetic Braille, Contracted Braille Study from 2002 to 2008. Although I support the use of braille for children for whom braille is the most beneficial learning medium, I am concerned about the language used in the Individuals with Disabilities Education Act (IDEA). As an educator, it is my steadfast belief that a child with albinism must have the opportunity to learn to use the most effective learning medium whether it is braille, print or a combination of both, known as "dual media."

### Background

The current language in IDEA leads one to infer that braille is the "default" learning media. It requires that a child who has a visual impairment receive instruction in braille and the use of braille unless the IEP team determines that it

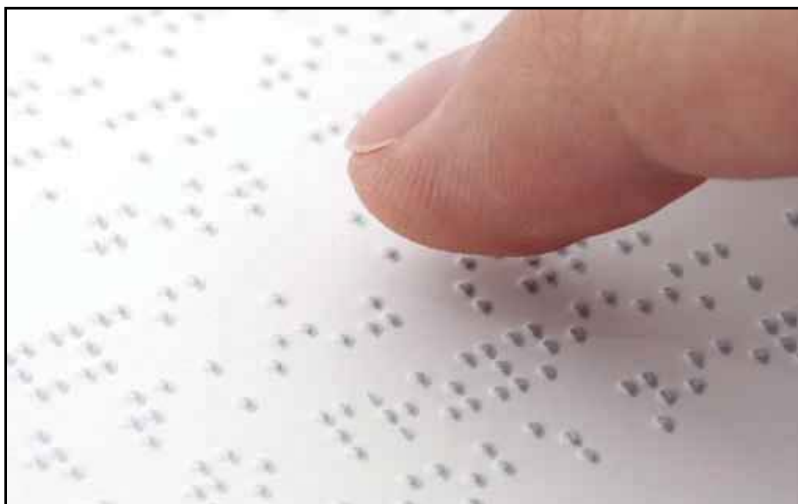
is not appropriate for the child. They must make their decision based on the child at the time of assessment and must also determine if braille might be needed at some time in the future. This discussion about braille instruction must be revisited at each annual IEP meeting.

### The Issues

There is no stipulation in IDEA regarding how a school should make the determinations. There is no assurance that a child will receive a clinical low vision evaluation to determine if she may benefit from optical and / or electronic devices before conducting a Learning Media

Assessment (LMA).

The LMA may be administered with standard-sized print or by not permitting a child who has prescribed optical devices to use them during the assessment. For example, if a child has a stable condition





with a visual acuity of 20/100 and can read comfortably and efficiently with a hand magnifier or a portable video magnifier, he may be required to learn and use braille. He may be able to use a handheld monocular telescope to see a whiteboard but not given the opportunity to have one prescribed without a clinical low vision evaluation.

Additionally, unless a child is known to be losing vision that will lead to total blindness, an educator cannot adequately determine whether braille will or will not be needed in the future.

Parents have reported that funding has been used as an issue in their children receiving clinical low vision evaluations. Schools that hire audiologists, physical therapists and other related service providers can be reluctant to use local funds to hire a clinical low vision specialist for children with low vision. Parents have reported that clinical low vision evaluations haven't been part of the discussions during IEP meetings for their child. And, LMAs for children with low vision, whether they will use print or a dual media approach, should be based not only on whether optical and electronic devices may be beneficial, but also include information about the child's reading rate and reading stamina at various times during the day.

### **The Value of IDEA**

While braille has become the default learning media, IDEA does ensure that the provider of special education makes decisions based on the following principles (examples are added for children with albinism). When requesting low vision services from a school district, parents may refer to five tenets of IDEA:

- **Access to the general education curriculum:** Children should have access to the library books, standard texts,

whiteboards, microscopes, plays in the auditorium and so forth.

- **Assistive technologies:** All children receiving special education receive assessments for assistive technologies, the devices and instruction in their use.
- **Least restrictive environment:** Local schools provide supports for a child so she may be educated with her peers without disabilities. For some children, a specialized school may be their least restrictive learning environment.
- **Accommodations:** This may include the use of an assistive device, extended time for assignments or tests, change in lighting, and so forth.
- **Medical evaluations:** If a medical evaluation may improve functioning in special education, clinical low vision evaluations are conducted by ophthalmologists or optometrists with a specialty in low vision.



### **IDEA Needs Parity**

While the U.S. Office of Special Education and Rehabilitative Services strives to have evidence-based instruction for children, no data supports having braille as a default reading media. In 2013, U.S. Commissioner of Education, Arne Duncan, ignored studies that show benefits of students' use of prescribed optical devices and

instead emphasized the language of IDEA in a letter to schools.

Although the date has not been set, when Congress reauthorizes IDEA, we need the language of the law changed to show "parity." This means the language for braille instruction would remain the same as it is today, however two additional parts would be added; one for children who will be print readers and one for

children who will learn and use dual media.

As far back as the 1970s, I saw children receive devices without being given instruction on how to use them. Not surprisingly, those devices were not used. In my recent experience, I know of children who have not been allowed to use their prescribed optical devices during assessments, who have been denied dual media, and who have not received a clinical low vision evaluation or the devices that have been prescribed. Clear language must be a part of the next reauthorization of IDEA.

### **Professionals Agree**

In 2013, the American Association for Education and Rehabilitation of the Blind and Visually Impaired adopted a position paper, *Literacy Media Decisions for Students with Visual Impairments* which includes all three parts for braille, print and dual media. Also in 2013, the American Academy of Ophthalmology revised its *Preferred Practice Pattern: Rehabilitation* to provide guidance to ophthalmologists regarding the needs of children with low vision. This document states the importance of the three

parts of low vision services: clinical low vision evaluation, the provision of prescribed devices, and instruction in their use. In 2014, *Position Paper on Clinical Low vision Evaluation and Treatment of Students with Visual Impairments for Parents, Educators and Other Professionals*, also became available through the American Academy of Optometry with a similar statement.

### **Get Involved!**

I hope you will share these proposed changes to IDEA with more people. It is vitally important to involve parents and families of children with low vision as well as adults who have low vision. We need advocacy from you and from professionals in education and medicine to help our legislators understand what is at stake.

Helen Keller's teacher, Anne Sullivan Macy, had low vision. In 1924, when she was shown a pair of telescopic lenses, she wrote, "I never knew there was so much in the world to see." By getting involved, we will give our children with low vision every chance to see their world.

## **Inquire 2 Inspire: Practical Participation in the IEP**

By Kathi Garza, *Albinism InSight* Staff Writer



As we prepare for the spring semester at school, many parents and educators will begin planning for upcoming Individualized Education Plan (IEP) meetings. Did the mere mention of IEP make the hair on your neck stand up? Did you start to shiver in your shoes? In this edition, I2I explores a common inquiry regarding parent participation in the IEP. Read on to learn how parents in our community have been involved in the process and how professionals in the field encourage them to be practical participants.

I always felt my position as a team member was unique because I served as a Teacher of the Visually Impaired (TVI) and classroom teacher simultaneously. I loved seeing the child as a whole, looking at each academic area while addressing Expanded Core Curriculum (ECC) areas and needs related to visual impairments. Part of our paperwork included a document entitled "Parent Considerations to the IEP." In just a few short questions, parents were encouraged to discuss the strengths and challenges for their child and desired goals for



the upcoming year. Receiving this document allowed me to address parent concerns and anticipate points of contention related to goal development. Having the input beforehand allowed me to address expectations prior to the meeting under neutral conditions.

Now, let's hear from some other parents and professionals regarding their experiences with the IEP process.

Some parents find it confusing to understand the IEP process and their role on the team. When developing an IEP, the first consideration must be the evaluation. As teachers, we know that a good evaluation leads to a good IEP. Your input into the evaluation is invaluable because students exhibit different behaviors across settings. Request the evaluation before the meeting so your questions and concerns can be addressed.

As an Orientation and Mobility (O&M) Specialist, I've used a variety of methods to foster a stronger relationship with parents. I want the parent to trust me with their child and will go out of my way to show them I have their child's best interest at heart. I try to meet face-to-face on a regular basis, and I like to have them observe a lesson, or I have it videotaped and schedule a home visit to show both parent and child the lesson. Meeting the parent and child somewhere in the community is also a great opportunity to show off the student's abilities or discuss issues. – Marjie W.

A great way for parents to get involved is to learn about the special education system and what quality services look like for your child. You can do this by joining parent groups, such as your local chapter of the National Association of Parents of Children with Visual Impairments (NAPVI). You can also attend Special Education 101 training offered in your school district or education service center. Knowing about your child's disability and the supports and services available to help her access the general education curriculum

will give you the information you need to meaningfully participate in the IEP process.

– Amanda F.

You are your child's greatest advocate, so it's important for you to stay involved in the IEP process! As a parent of a child with albinism and a TVI, I think there are two important points to keep in mind.

First, you are a part of the team, so your voice is as important as each voice around that table. Be inquisitive and stay upbeat to set a productive tone. Team implies that you are working together, so assume that you will be treated with respect, and work with everyone to make the best decisions for your child.

Second, do your research. If you think your child needs a specific accommodation, low vision aid or piece of technology, make sure you are able to explain why. For example, just wanting a device does not mean that the district has to provide one. Explaining how the device will allow your child access to materials that he is not currently able to access will entice the district to listen carefully and take the consideration seriously.

– Gianna G.

Bring a friend whose only job is to take notes. I was happy that someone I trusted was documenting the overwhelming amount of information being presented so I could concentrate on the discussions. In some places, you have to submit a written request to receive the assessment reports before the IEP rather than getting them for the first time at the meeting. Check with your school to stay updated on policies. It is invaluable to read them before the meeting instead of struggling to process them in the moment. – Meredith W.

I stay involved by asking to meet with some of the team members individually prior to the IEP meeting to discuss their goals as well as ours. This is helpful since the "big" meeting

can sometimes feel overwhelming. It's nice for everyone to put a face to the name. – Ripple M.

Throughout the school year, we check in with our son's service providers via email or a face-to-face meeting to review goal progress. We also ask service providers to share things we can do at home to support the goals they are working on at school. Feedback from our son is also important, and we often ask if there is anything that he needs help with or if there is a lesson that he finds helpful and would like to continue.

A few weeks prior to the IEP meeting we meet with each service provider and the classroom teacher to discuss the next year's proposed goals. At that time, we share goals that we would like to focus on during the IEP meeting and discuss edits to proposed goals. We also meet with the case manager prior to the IEP meeting to discuss the meeting's agenda. At this time, we share our parent report, review goals we have been working on at home, parent concerns, and any vision changes we may have noticed. – Jill G.

I have developed a great relationship with my son's TVI over the last eight years. Additionally, his Gifted and Talented teacher has worked with him for three years. Between the three of us, we rally other teachers to get involved throughout the year so when it is time for his IEP, nothing is a surprise. Last year, my son not only attended the meeting, but he also had a say during the planning process. It was very exciting for us all. – Patti Z.

I always request that the proposed goals, service times and accommodations one week in advance so I have time to ask questions and request changes. I also bring a picture of my daughter to annual meetings. I place it on the table and remind the team that we are discussing this child, not "fixing" a situation on paper. Every year, the team gets excited to see

the newest picture, especially last year when she wore a shirt saying, "I am the 'I' in IEP!"

When asked if I have any concerns, I always start with positives for each person working with my daughter, even when I have to stretch to find them. I feel this step is critical and will empower them to continue to do their best for her. I extend this throughout the year by sending emails to her team members thanking them for investing in my daughter's success. I feel it helps to keep everyone motivated.

Lastly, I ensure that we address educational implications for her future so I can stay ahead of the curve. In the end, I am her only advocate, and I take that job very seriously! I choose to educate myself to the fullest so I can be prepared to attend meetings. This drive led me to become a TVI. I try to give her the tools to advocate for herself, and when I get a call about what's best for her, I empower teachers to ask my daughter, since ultimately, the decisions affect her. – Summer G.

And lastly, the best advice ever! Take doughnuts! They make everyone warm and fuzzy and feel cared for, and they keep them wanting to please you! – Mindy H.

Thanks to everyone for such great advice! Although there are many statements on social media regarding the stress of IEP meetings or expressing disappointment with instructional team members, it's important to keep things in perspective. Remember, the ultimate goal for everyone is to serve the child. I hope this article has inspired you to get involved with your child's IEP in a practical and productive way.

Now it's YOUR turn to inquire to inspire. Send your questions with regard to issues faced by individuals in the albinism community to [i2i@albinism.org](mailto:i2i@albinism.org).



# CARE

IFSPs

IEPs

504s

*Creating an Albinism Resource for Education*

NOAH's CARE program collects education plans from early childhood intervention through high school:

- IFSPs for students three and under
- IEP for students age three to graduation
- 504 accommodation plans

Personal information is removed then the content is indexed by state and grade at [iep.albinism.org](http://iep.albinism.org). This free resource aids in establishing a child's Individualized Education Plan. Our resource is only as good as the input we receive so please, consider sharing with CARE.

## Helping Kids Hit the Slopes

By Kelly Rodden

My husband, Brendan, is a big skier and used to be a ski instructor. When we found out I was pregnant, he couldn't wait to teach our child to ski. But when our son, Bryan, was diagnosed with albinism, we didn't know what he would be able to do.

The consistent message we found through NOAH was to let kids try anything and everything. So, Bryan put on his first pair of skis at the age of three. He cried the entire time, so we decided to try again in a couple of years. The next two times Bryan got on skis, we enrolled him in adaptive ski schools. We opted to enroll Bryan in these classes because they have specialized equipment and more experience teaching visually-impaired children how to ski. Both times he was in ski school, he had two instructors with him. They were very positive experiences, and he had lots of fun. With adaptive or any ski school, one can



choose half- or whole-day instruction.

Bryan had this to say about his skiing experience. "When I was about to ski, I was nervous because I was afraid of falling. When I went skiing, it was lots of fun. My favorite part was going fast. The guides taught me how to ski, and they were very nice. When I skied, I had no problems seeing my guides."

The guides used ski tip connectors to keep the tips of his skis together preventing his legs from spreading and going into a split. With the tips on, you either snow plow (used to slow down) or go straight. The guides also attached leashes to his skis to prevent him from going too fast, and they wore special ski bibs so Bryan could see them easily. After another couple of times in adaptive ski school, he will be ready to ski confidently without the use of aids!





# SCIVIS Puts Kids in Space

By Dan Oates, NOAH Board of Directors



This year, Space Camp for Interested Visually Impaired Students (SCIVIS) celebrated its 25th anniversary. SCIVIS is a yearly gathering of blind and visually-impaired students from all over the world. The event is normally held the last full week of September. Many of the chaperones, students and parents said that it was the best year ever. I have to agree!

This was the first year we had over 200 students. It was a wonderful mix of students who came from 24 states in the U.S., three Canadian provinces, two Australian states, Israel, Ireland, Trinidad & Tobago, St. Lucia, Greece, New Zealand as well as international students living in the United States from China, Egypt and Nepal. This diversity was made possible by a grant from the St. Louis Lighthouse for the Blind.

NOAH sponsored six students so they could at-

tend the program: Elizabeth Armstrong from Tyler, TX; Xander Ayala from Brentwood, TN; Will Christophersen from Vienna, VA; William Hedlund from Kent, WA; Shane Huking from Plain City, UT and Darin Tomaszewski from Ringgold, GA.

The week, filled with space simulations, teamwork, leadership challenges and making new friends, ended with a beautiful graduation ceremony held under the Saturn V rocket in the Davidson Center in Huntsville, AL. All of the original founders of SCIVIS were in attendance: Ralph Brewer, retired superintendent of the Tennessee School for the Blind and principal of the West Virginia School for the Blind; Max Carpenter, retired superintendent of the West Virginia Schools for the Deaf and the Blind; and Edward O. Buckbee, retired director







**Will C.**



**Shane H.**



**Darin T.**



**William H.**

of the U. S. Space & Rocket Center and founder of Space Camp. These men were responsible for the first group of students traveling from West Virginia to Alabama in 1990 to participate in the first program for the blind and visually impaired. Also in attendance for graduation was Keller Johnson-Thompson, who is the great,

great niece of Helen Keller. She delivered a short graduation address to the trainees and congratulated them on the accomplishments.

To learn more about Space Camp for Interested Visually Impaired Students, visit [www.tsbvi.edu/space](http://www.tsbvi.edu/space).



[www.youtube.com/user/NOAHAlbinism](http://www.youtube.com/user/NOAHAlbinism)



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[www.facebook.com/NOAH.Albinism](http://www.facebook.com/NOAH.Albinism)

## 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](mailto:info@hpsnetwork.org) ~ [www.hpsnetwork.org](http://www.hpsnetwork.org)  
516-922-4022 ~ 800-789-9HPS (9477)



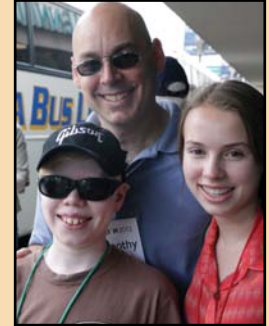
It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - *Brooke Jensen -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

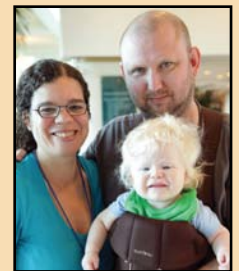
Here's an opportunity to talk with others who understand what you are going through as a parent of a child with albinism. Get the support you need to be a healthy, informed parent, and build connections in the albinism community – all in the comfort of your own home.

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](http://www.albinism.org)**



Photo courtesy of Whitney Harness, 2013



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