

NOAH Ed U

Spring 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.

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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!

Self-Advocacy Starts Young

By Arielle Lewis



I wish to share some “secrets to success” as a person living with albinism. I feel people within the albinism community give me significant credit for my own success. However, support from my friends, teachers, birth family members and fellow NOAH “family” members all contributed to making me a successful student and independent young adult. For that, I am sincerely thankful for all of the help and guidance afforded me by so many people.

To those who know me, it should come as no surprise that I am an achiever determined to defeat or maneuver around any obstacle in the path to my goal. It also should be clear that such a personality trait has nothing to do directly with albinism; however, albinism does place me, occasionally, in situations that require affirmative and direct action. This is a cultivated skill as well as an ability and has little to do with my degree of pigment.

Realizing your potential and self-advocacy are two important ingredients to achieving success. While it is clear that individual achievement is, at least in part, self-motivated, I consider my academic success largely shaped by an extraordinary teacher, Ms. Julie Martin. Without her help as my vision teacher (TVI) and her continuing support as a friend and role model, outcomes may have been different. Her “no nonsense,” blunt approach was based on her experience with students with visual impairment, a sincere desire to see me succeed, and an identification of such potential in me. In her own way, she pushed me to do things in

elementary school, which laid the foundation of my activities today. She crystallized the critical importance of going up and requesting clearly what I needed to accomplish a task. Thanks in part to her efforts, I make sure my professors know who I am and are familiar with my needs from the very beginning of the semester. This allows me to maximize my own success in the classroom and not be limited by visual problems. For a person living with albinism, speaking up is one of the most important tools I have learned to use to navigate the world, particularly because few people are aware of our special needs.

Acceptance of albinism as part of your life is an important step. At the risk of being cliché, you only have one life, so live it to the fullest, irrespective of albinism. Denying albinism or visual impairment will not serve you well. The other side of the coin is to remember that knowing your limitations is an important component of achieving success, and this reflects in the “real world.” For example, while I know I’m not going to be a fighter pilot anytime soon, I presume that such a realization would be true for essentially the entire population with albinism.

Being able to speak up and explain to teachers, professors and bosses what I need in order to accomplish a task is a key step to achieving self-advocacy. It might take some practice and will not necessarily happen overnight. You can start by asking a friend or family member to help you explain your specific needs. For

example, at the beginning of every school year, my TVI made me write emails to my teachers to explain my condition and what accommodations I required. I can safely say that I am willing to discuss my limitations

because of these letters. Here's a copy of the document as I transitioned from second to third grade. I hope that these points are helpful in bringing you closer to your personal goals!

Dear Teachers,

My name is Arielle Lewis. My favorite subjects are math and science. I have a twin sister named Sarah that goes to this school too. I have three dogs. They are pugs. They bark when strangers come. I feed them, give them water, and play with them.

I use some special tools at school and at home to help me see better. I use writing paper with dark lines. I use a telescope to see far away, like the chalkboard or the clock. I use my telescope for "spotting" just a few words. If I read too many words with my telescope, I might get a headache. If there is too much on the board to read with my telescope, I need to sit at a table very close to the board. Sometimes it is easier if I have a desk copy of what is on the board.

I also use a jewel magnifier. I use it to read books and worksheets. I have a closed circuit television (CCTV) that I can use to read and write. I mostly use a CCTV at home, but I'll be using my CCTV at school more than I used to. I have large print textbooks, and I need all my work in large print, unless I am using my CCTV.

My eye problem is albinism. I have light hair and skin, and blue eyes. Sometimes the light is too strong for my eyes. I put on sunglasses and a cap. I'll always wear my sunglasses and cap outside. Please give me a desk with my back to the window. I also have nystagmus, which means that sometimes my eyes move from side to side.

Every two years, I go to a big meeting called NOAH. It's a meeting for people with albinism. I went to this meeting with my family this summer. I went to this meeting when I was little, too.

I have a vision teacher who works with me. We work outside of class for 2 hours each week, and 1 hour in the classroom.

I hope I have a good year in third grade.

Your student,
Arielle Lewis

Finding Your Way When It's Hard to Find It

By Cassandra Mendez, *Albinism InSight* Staff Writer



You've met a really interesting guy who has invited you to a party at his house. When he gives you the address, he asks if you're familiar with the area. To impress him, you nod "yes" enthusiastically.

Yet panic slowly sets in as you realize you have poor navigation skills, and there's no way you'll find that house. After failed attempts on MapQuest, Google Maps and Apple Maps, you consider texting your colleague to tell him you have sudden family plans.

Orientation and mobility (O&M) training provides easy and applicable tips for navigating virtually anywhere. Whether it's going to a friend's party, exploring your future college campus, or learning how to use a cane, mobility can show you how to go so you can avoid the sad fate of missing the delicious chips and dip at the party.

First, try to be a little less proud. I know, you want to look good, but you'll look even worse walking into your new friend's creepy neighbor's house.

Second, know what to ask. After you get the address, consider these questions.

- What does the house look like? Does it have trees out front? Three rocking chairs

on the porch? Is it neon purple, or is it Victorian?

- Are there landmarks or distinctive structures, such as a church or gazebo, nearby?
- Is it on the corner or in the middle of the block?
- What are the closest intersecting streets? This helps you know where to turn.
- How do I know when I've passed it? The answer typically comes in the format, "If you're at (street name, landmark), you've gone too far."

You don't have to ask all of these questions, but this basic list could give you a foothold to grasp what the house is like. I know what you may be thinking: why don't you just use a GPS? While a GPS is great, for legal reasons, they aren't accurate enough to tell you exactly where to stop. As older models become out-of-date, they become even less reliable and might tell you the store you're looking for is the cornfield to your left. So try not to rely solely on your navigation devices when you go out.

Enjoy the chips and dip as you find the house, while renewing your self-confidence. This lesson is brought to you by training in Orientation and Mobility, which is available in most public school districts and highly recommended by yours truly. Along with navigation skills, you can sharpen (or learn) cane skills, which is especially helpful for new places and large city travel. Give it a go, and see where you go!



iPad Apps for K through College

By Penny Bernard, NOAH Editorial Committee



As a mother of an adult daughter with albinism, it's interesting to see the variety of applications that can help students with visual impairments. As I started my research, I realized I had to search by grade level.

Kindergarten

- Decide Now! www.adigitalkindergarten.com - incorporating spinners and dice, this application is used for reading, writing and math games. It's free!
- Screen Chomp! – Geared toward kids with low vision, it's a recordable whiteboard and can be found on “interactive whiteboards.”
- Preschool University has ABC Magic series, Pocket Phonics Lite and LiveBinder which includes links for iPad usage and games for beginners to advanced users. These are not free, but they are great apps for little ones.

Middle School

There are many applications for middle school students with low vision, but each student must individually assess how useful the apps are to them. I read many comments from users who found certain apps useful but another user didn't share the same experience. My deduction is that you and your student must analyze the needs, technology and price to choose what works best for you.

College

I followed the link to the Adaptive Technology Center for New Jersey Colleges at the College of New Jersey and found these links:

- Screen magnification (2x-36x) – This application runs simultaneously with the computer's operating system and other apps. It is offered under the names, MAGIC, ZoomText, Magnifier (Microsoft) and Zoom (Mac OS X).
- Screen readers – This app reads everything on the screen aloud. It can be found as Narrator (Microsoft) and Voiceover (Mac OS X).
- Digital book readers – These are portable CD/MP3 players that read DAISY compatible audio books.
- Scan/read systems – This reads printed text aloud after it has been scanned into the computer. Great for textbook pages, handouts and tests.
- Braille translation software converts text to braille.



Writing this article has been a very rewarding and informational experience. I hope you will find an app that interests you as well.

Paralympics Pride

By Judy Cunningham, NOAH Editorial Committee



“Live Like a Champion” has been how Jaclyn Smith lives her life. Born with albinism into a very athletic family, she faced the challenges and isolation of her condition. At the age of 11, she attended Camp Helen Keller in Farmingdale, NY and finally felt a connection with her visual limitations by meeting kids who were like her. Since then, she has participated in many sports but found her passion when she joined the rowing team in high school.

After attending the United States Association of Blind Athletes (USABA) Development Camp for adaptive rowing in 2013, her coaches recommend her for the National Paralympics

Team. Last summer, she was selected for summer training and moved to Boston. From her bow seat position, Jaclyn helped her team win 4th place in the Para-Rowing World Championships in South Korea. Needless to say, Jaclyn’s future goal is to row in the Paralympics Games in Rio de Janeiro, in 2016.

In addition to college classes and studying, Jaclyn trains for over 20 hours a week. This powerful athlete has brought honor to the sport of rowing. She has made not only herself proud, but also her family, teammates, and now, NOAH! You are a true champion Jaclyn, inside and out.



Jaclyn and family



Jaclyn mentally prepares for her final race in South Korea



Jaclyn and her pairs partner, Danielle Palmaccio



NOAH's 15th National Conference

By Schroeder

Every day that we stand strong against the slings and arrows of rudeness, every day that we overcome visual challenges, every day that we advocate for our children, every day that we get up and try again, we live like champions! Whether you're a first-timer or an old-timer, come celebrate your inner champion at the 15th NOAH National Conference in San Diego, July 10 - 13. Although the details and registration materials will be available in late March, here's a preview of what's in store.

Special Events

- NOAH is proud to present its second parent book, *Raising a Child with Albinism: A Guide to the School Years*.
- NOAH has the honor of hosting the induction ceremony for Pam McGonigle into the United States Association of Blind Athletes Hall of Fame. The albinism community will help celebrate the lifetime achievement of one of our own, a four-time Paralympian and medalist.
- NOAH will premiere Rick Guidotti's latest work to champion the battle against the stigma of difference, a short video on albinism to be included in a groundbreaking project entitled, FRAME (Faces Redefining the Art of Medical Education).

And that's just the first night! There's lots more!

Pre-conference Activities

- Adults with albinism outing
- A workshop for moms

Educational Sessions

- Keynote session on exciting new albinism research
- Keynote session on the struggle to access the visual environment for visually impaired students by Dr. Anne Corn
- Panels and discussion groups covering a wide variety of topics
- Experts address topics of interest to the albinism community including:
 - Low vision driving
 - Assistive technology
 - Orientation and mobility
 - Update on the Africa crisis
 - Sports and recreation

Children's Programs

- Expert care for preschool children
- Fun activities for elementary-aged kids
- Field trips and time to hang out for teens and tweens

Social Functions

- Thursday evening reception
- Optional Friday evening trips and tours
- Saturday evening dance party and dessert reception

- Sunday morning hot breakfast
- Gatherings for special interest groups such as:
 - Adoptive parents
 - International attendees



- Couples who both have albinism
- Spanish-speaking attendees
- The Golden Family Facebook group

Making the Conference More Affordable

So, you want to go to NOAH's national conference in San Diego, but your budget is tight, and you might not be able to afford it. Well, here's some good news! NOAH has prepared a funding information kit which includes a list of local community service groups and social service agencies who might be interested in helping you fund your trip!

Start early!

Time is your greatest ally when searching for funding sources. Many agencies and organizations have set disbursement schedules,

or a series of steps that must be completed during the application process. Get started early so you won't be scrambling to complete forms or trying to gather information at the last minute.

The funding information kit is full of information such as suggestions for who to ask, what to ask, and even has a sample letter of application for funding assistance. Get started today! Contact info@albinism.org to get your copy of the kit.



www.youtube.com/user/NOAHAlbinism



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Teen Talk: Conference Prep Tips from a Two-Timer

By Cassandra Mendez, *Albinism InSight* Staff Writer



As you eagerly anticipate school to end, summer to start, and NOAH's 15th National Conference in San Diego, here are some tips to help you plan. If you put the "pro" in "procrastination" when it comes to packing, don't worry, that's not the kind of planning I am referring to. Getting mentally ready and making plans for what to do beforehand is crucial for your enjoyment when the time comes.

I have only been to two conferences, but I am ready to share my knowledge to help you have the best experience. Keep these things in mind as you mull over the possibilities!

Bring a camera. It doesn't matter how expensive or cheap the camera is. Having a camera to capture that moment when you and your friends accidentally walk into the men's room will be a priceless memory.

Don't forget the sunscreen (and sunburn gel) and sunglasses. First of all, wear sunscreen. Someone always ends up pink, or bright red. I recommend buying several travel-sized sunscreens and having them in every bag you plan to carry around. More people get burned than you think!

Introverts: Plan some personal recharging time. There will be a lot of people and you'll most likely end up meeting a large percentage

of them, but don't worry: we don't bite. Just plan for some downtime.

Extroverts: Use this time to socialize. You can go to the pool, converse with people, or explore the city.

Set aside some extra cash.

You never know when you'll need this. During NOAH's Teen Conference, we usually set out to see the city we're visiting. Whether you'd like to buy a souvenir button for your collection or go on a spontaneous Build-A-Bear excursion with two of your new friends with 10 minutes left of lunch (I've done it!), you'll want to be able to pay for it.

Finally, just relax! Feel free to express yourself however you want. A lot of people with gorgeous snow-white hair highlight it with crazy colors. Don't be self-conscious. These are people just like you! Don't

freak out if you spill someone's drink. Odds are they'll just crack up. Everyone will mostly look the same so don't worry if you get mistaken for someone else or if you incorrectly tug at someone's arm. Feel free to tell anecdotes about encounters with ignorant people, your new tanning lotion, or painful sunburns – we'll understand you.

When the conference details are published, get excited! I know I will be.



Back Row: Rebekah, Andrew, Katherine
Front Row: Cassandra, Lauren, Kaitlin S.



Cassandra, Natalie, Rebekah, Kaitlyn O.



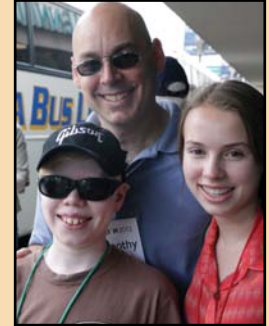
It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - *Brooke Jensen -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

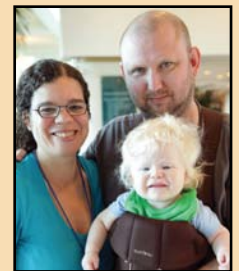
Here's an opportunity to talk with others who understand what you are going through as a parent of a child with albinism. Get the support you need to be a healthy, informed parent, and build connections in the albinism community – all in the comfort of your own home.

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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