



# NOAH Ed U

CREATED WITH EDUCATORS IN MIND



**Spring 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](mailto:info@albinism.org).

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*Photo courtesy of Karen Mackay*

**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!**

# International Albinism Awareness Day: Making the World a Better Place

By Schroeder

On November 18, 2014, the United Nations' General Assembly adopted a resolution establishing June 13th as International Albinism Awareness Day. This historic resolution firmly fixes albinism advocacy at a global level. Adoption of the resolution was the latest result of the vigorous efforts of the organization, Under the Same Sun (UTSS). UTSS founder and president, Peter Ash, spearheaded political efforts in the U.N. to address discrimination against people with albinism, particularly in Africa.

NOAH was invited to participate in a U.N. "side event" on November 19th to celebrate the adoption of the International Albinism Awareness Day resolution. A side event is a meeting held at the U.N. On very short notice, NYC Metro NOAH chapter president, Angi Keung, rallied over 20 area members to attend

the memorable event.

The event was hosted by the U.N. Somali delegation. Ambassador of the Mission of Somalia to the U.N., Geneva, Yusuf Mohamed Ismail Bari-Bari, led the effort to pass the resolution. His Excellency Bari-Bari made opening and closing remarks at the event, which included sharing a story of his audience with Pope Francis at which he informed the Pontiff of the atrocities committed against people with albinism in Africa.

Representatives from the U.N. delegations from Italy, Israel, Canada and the United States attended the event each making brief statements in support of the resolution. A representative from UNICEF and the U.N. Special Representative for Violence against Children attended and spoke in appreciation of the resolution.



**Peter Ash of UTSS**





A series of invited individuals made statements regarding the significance of the resolution. Peter Ash led the presentations with a deeply personal account of his efforts to advocate for the albinism community. Then NOAH Executive Director, Mike McGowan, introduced Angi Keung who eloquently described the significance of the resolution to the albinism community in the United States. Read her speech on page 8. Garth Mullins, creator



**NOAH Executive Director, Mike McGowan, shakes hands with the Somali diplomat**

of *The Imaginary Albino*, a multiple award-winning documentary, and artist, Yrneh Gabon, of the *Visibly Invisible* exhibit on albinism at the California African American Museum, also spoke.

When the floor opened to those in attendance, eight-year-old NOAH member, Andy Fass, climbed up on his chair, leaned into a microphone, and said, “Thank you for making this world a better place.”

## Albinism 101 at My Children's School

By Meredith West, NOAH Editorial Committee

During “Friday Share,” the weekly school-wide assembly at my children’s school, I began my presentation by saying that in our family we talk about and celebrate differences a lot! Because recognizing these differences are what make us special, unique and interesting. I was inspired and emboldened by several presenters at the 2014 NOAH Conference so I requested the opportunity to speak to the student body at Tyler and Dixon’s school about albinism and Dixon’s unique abilities and challenges.

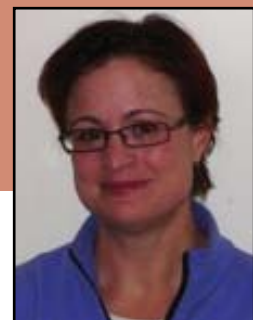
I was allotted 10 minutes to speak which struck me as not enough time to introduce Dixon’s genetic and vision differences, but it worked out

great. Members of the NOAH Albinism Facebook page offered helpful advice on what to present.

I also showed parts of the YouTube video, *What Can I See*, created by Snowysnowflake 21 for illustration. I ended my presentation with a key piece of advice from the Facebook group members – I asked the students to say their names when they greeted Dixon in the hallways, playground, etc.

After my presentation, several teachers invited me into their classrooms to talk more and answer questions. I had not been nervous during the presentation,

but I was as I entered the first classroom. Thoughts ran through my mind about whether



**Dixon and Tyler**

the kids and teachers would understand the information I presented. Would they care? And most importantly, how would they react and respond to Dixon?

As it turned out, there was no need to worry. Both the kids and teachers were overflowing with interesting, intelligent and compassionate questions. They all wanted to know how Dixon

got albinism. Is it linked to other conditions? Is this why he wears his sunglasses inside? Where do you go to learn about albinism? In each class, I ran out of time long before the kids ran out of questions. The most rewarding moment was on Monday when I picked up the boys from school. Several kids yelled “Good-bye” to Dixon and added their names!

## Free and Fearless: An Introduction to Cane Exploration

By Cassandra Mendez, *Albinism InSight* Staff Writer



I remember the day my mom taught me to make cherry Jell-O. You would’ve thought I got a new bicycle by the way I reacted, but I was fascinated. I loved the feeling of getting to do something all on my own (with supervision, of course). After that, I made boxed brownies, boxed macaroni and cheese, and eventually, a hard-boiled egg. Now, I make hard-boiled eggs at least twice a week, but it’s never been nearly as exciting as when I learned.

**Why was it so thrilling? Because I felt independent!**

Everyone values independence to some degree. We like feeling “in control” of our lives. People with visual impairments tend to either embrace independence or completely shy away,

depending on their personalities. While not driving is frustrating, we often find ways around it, such as walking, biking or taking transit. One silver lining is that we get to sleep while someone else drives.

When going out on our own, we often appreciate well-intentioned help, but sometimes, we’d rather make our own mistakes, like going into the wrong restroom. Those of us independents find means to comfortably navigate unfamiliar territory, whether by technology or the old, reliable tool, the white cane.

The white cane is a very useful and versatile tool for those willing to use it. Not only does it give “feedback” on the ground texture and drop-offs, it also grants security, both literally (like street





crossings) and figuratively (self-confidence). I love to use my white cane in unfamiliar territory because it validates asking for directions or explains if I trip.

My Orientation and Mobility (O&M) instructor, Ms. Hallie Greenfield, provided thoughts on cane usage:

#### **Assessing readiness:**

Depending on a child's personality, he may or may not be ready for a cane at age three or four. Ms. Greenfield said to consult an O&M instructor if you are interested in cane training for your child, and they will assess readiness. Young children usually begin with a "pre-cane" (an object children drag to get used to moving a cane, such as a PVC pipe or a rolling toy). Older children usually go straight to a mobility cane and are trained with an instructor.

**Introducing canes:** Cane training usually begins in a familiar, indoor environment where the user can focus on technique. Children who should use a cane but are resistant can use Ambutech's new Hi-Lite canes, or use stickers or key chains to make the tool more appealing. Although younger children typically receive large rolling tips to make gliding effortless, older children can decide if they would rather tap or drag, and how much sound "feedback" they want. If you like tapping, the ceramic tip is my favorite because it's small, light and gives excellent feedback.

**Using canes:** As you've noticed, every facet of cane usage depends on your personality. While using canes depends largely on vision, it also depends on willingness. Some people choose to use canes wherever they go, while others

use it at street crossings only. I prefer taking it to unfamiliar areas and new cities – especially at night. As Ms. Greenfield said, "A cane is only a valuable tool if it's used."

Some parents may be apprehensive about cane training. The most common reason is that canes symbolize acceptance of a visual impairment, which is often difficult for parents to acknowledge. However, cane training can be a "stepping stone" for guide dog training. Ms. Greenfield summarized that, ultimately, "The cane is a wonderful tool for independence for people where it's an appropriate fit."

If you are interested in training for your child, get in touch with your school's Teacher of the Visually Impaired (TVI), or ask your O&M instructor. Adults can consult their state's services

for the visually impaired that can provide complimentary mobility services for enrolled, qualifying members. Owning a cane can help you receive other special services with minimal testing, such as regional paratransit or discounted rates for people with disabilities. The choice is yours, but if independent travel is your aim, then go explore, free and fearless.



*Photos in this article courtesy of David McMeans*

# Redefining Accommodations

By Kyle Bergam



As an Information Technology professional with ocular albinism, my definition of accommodation has revolved around technology. My visual disability presents challenges, but it also gives me the opportunity to think creatively. Most of my work consists of listening to my clients and designing technology solutions to address deficiencies, so being resourceful works to my advantage. Before I address my recent shift in definition, I'd like to share solutions I've found while thinking of accommodations from a technology viewpoint.

**Reading:** One of my biggest challenges at work is that I have to read a lot and type a lot. Since pain and fatigue impact how much and how long I can read, I use Kurzweil K3000 which converts scanned images to text and text to speech. I also use Firefly on an iPad. Kurzweil K3000 works well when the materials I need are not available through Kindle or iTunes.

Due to my visual impairment, my posture is horrible! Even though I touch-type, I lean forward to see the monitor. To meet my needs, I use a 55" monitor and change my computer settings to a lower resolution until I hit my target screen magnification. To compensate for my hunched posture, I use an ergonomics Kinesis keyboard, a Microsoft ergonomic mouse and a Herman Miller Aeron chair.

**Presentations:** I worked at Microsoft as a top 10 presenter speaking at global conferences. One of the silliest challenges was that I couldn't see the presenter's clock. Sticking my face into a watch or raising my

phone to check the time would have sent the wrong message to the audience, so I purchased a Tissot Silen-T watch which vibrates to indicate the correct hour and minutes.

**Meetings & Performances:** When I'm participating in a meeting or enjoying a performance, I use a monocular or a Jordy which is a video camera with TV screens that sit in front of my eyes. Unfortunately, the Jordy is no longer available for purchase.

**Light Sensitivity:** To best address the light sensitivity issue which many of us experience, I use a hat, tinted lenses and filters. These are similar to the filters welders use.

**Navigation:** To stay safe, I use a white cane with a wheel. I also enlist my smartphone sidekick to tell me where I am and to provide directions to where I want to go.

I also use my iPhone 6 Plus to take pictures and magnify things to see them better. The iPhone 6 Plus is large enough that I can comfortably manage my email and social media presence.

**My definition of accommodation changed recently from technology to imagination and communication.**



I went back to school for radio broadcasting. A totally blind person and I applied for the program, but he was not admitted. Although there are several blind or legally blind people in broadcasting, they couldn't envision a totally blind person working in radio. I began to realize that imagination and communication were going to be

key elements to my success.

During the admissions process I worked closely with the Disability Student Services Team to arrange accommodations. When I started classes, it was clear that it was up to me to work with each instructor to accommodate myself. At the end of the semester, the level of communication I had with each instructor directly correlated to my mark in the course. Great communication resulted in an A, but bad communications resulted in a D.

Communication was critical in shared problem solving with my instructors. Equally important was my instructor's ability to "imagine" that I could find a way to do my studies.

In my journey, I've encountered obstacles and so far, there haven't been many things I've not been able to tackle because I've made an effort to see challenges as opportunities. In redefining my definition of accommodations, technology is still an important factor, but I've learned that communication and imagination are vital.



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

## Danny Meets his Match

By Erin Carrington

When Danny was born, the nurses loved calling him "surfer dude" because of his very blond hair. My husband, Jason, and I couldn't wait until we could share our love of sports with him and our older daughter, Claire. We both played baseball and softball into adulthood and were excited about T-ball.

At his one-week appointment, the pediatrician said she thought he had albinism, and the next week, we had a confirmation from an ophthalmologist. So many thoughts ran through our minds such as, "Will he be



bullied?" and "Will he be able to play sports?"

We were lucky to find NOAH right away! We talked to others including Pam McGonigle who was from our area. She helped ease our concerns. We decided we would make sure his physical and emotional needs were met, and we'd help him tell us about his needs as he grew.

At four, Danny was old enough to play T-ball. He was excited to play, so we got him a glove, sunscreen, a hat, prescription sunglasses and began practicing! Jason stood near him on the field to guide him.



Unfortunately, his photophobia, bright Saturday mornings and small T-balls rolling on the ground were not a good mix. He had fun seeing his friends, but as the season continued, it became a fight to get him to go. T-ball wasn't a success, but flag football season was just around the corner! We hoped the evening hours and the physical aspect of the sport would help.

Jason became a coach of the eager four year olds who were just learning. Danny loved the activities and playing with his friends. In a scrimmage against another town's team, Danny sacked the quarterback on the first play by pulling off his flags! It was fun seeing him succeed!

Jason was excited to try one more sport – wrestling. He wrestled as a teenager and thought this would be the sport for Danny. In fact, the United Association of Blind Athletes (USABA) considers wrestling to be one of the easiest sports to modify for blind and visually-impaired athletes. He started researching clubs, and after the first meeting, Jason contacted the



coaches to explain Danny's visual impairment. The coaches were very supportive. They researched the visual accommodations in wrestling, which is really only one adaptation. The competitors must be in contact when in standing position, which is how most wrestling matches begin. They touch fingertips with one hand up and one hand down.

Again, Jason's participation in practices was important. He was there to put Danny's glasses on and move him closer when the head coach was teaching and took off his glasses and helped him with the moves. Now, all of the coaches help. When Jason was sick, they moved Danny so he could see better and helped with his glasses!

Coaches try to set up matches so beginners win some and lose some. We went to the first meet, and I couldn't believe how nervous I felt! There were so many people, so many mats, so many children in singlets and headgear! What if he lost? What if he cried?

Danny had two matches that day. The referees and coaches made sure he started each match

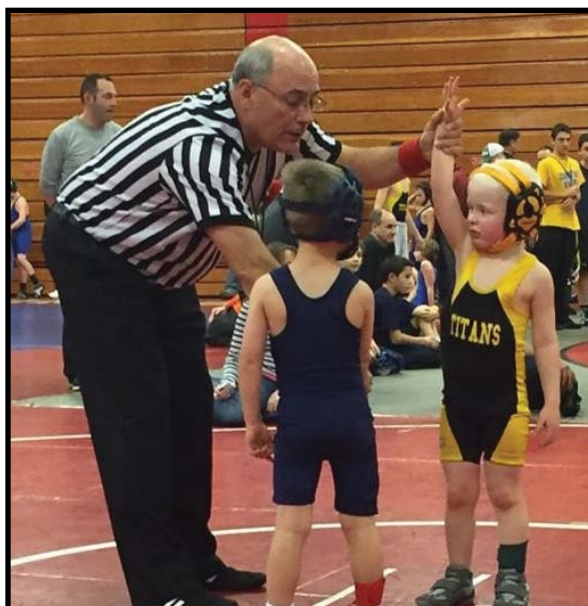


Adapted start



following the USABA guidelines. Danny won both matches! Since then, Danny has experienced some losses and wins, but it is not a fight to take him to practice or go to meets! Also, many people have asked about albinism and the accommodations. It has been an easy way to educate more people.

Our family would encourage you to try sports with your little ones. Make



sure they are interested and excited to go! Encourage them to learn responsibility and perseverance by not quitting right away. Get involved with the athletic leagues by educating them about albinism and help coach if you are able. Most of all, make sure everyone has fun!

To learn more about sports adaptations, visit [www.usaba.org](http://www.usaba.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)

# 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.

# JUST FOR YOU, A NOAH SIX



More fun than going to the gym  
and healthier than drinking soda,  
**celebrate 2015** by joining your  
friends in the albinism community  
at any of **six events** from  
**coast to coast.**



## MINI CONFERENCES: PARTICIPATE & LEARN

Join us in cities across the country to feel the power of the albinism community as we share common experience, interact and learn together. Watch your inboxes and mailboxes for details.

### TX - May 2, 2015

Texas School for the  
Blind and Visually Impaired  
1100 W. 45th St.  
Austin, TX 78756

### CA - May 16, 2015

Ed Roberts Campus  
3075 Adeline St.  
Berkeley, CA 94703

### WI - August 1, 2015

Medical College of Wisconsin  
8701 Watertown Plank Road  
Milwaukee, WI 53226

## NOAH FAMILY CAMP

Create amazing memories with a classic camping experience for you and your siblings ages seven and older. Choose from two options.

### Southern California Family Camp

#### CA - June 17-21, 2015

Camp Metoche  
42193 Santa Ana River Rd.  
Angelus Oaks, CA 92305



Photo courtesy of Positive Exposure, Rick Guidotti





# PACK OF EVENTS FOR 2015!

## PAH SUMMER CAMP

SAVE  
THE DATES!



### PA: FUN & FREEDOM

Experiences designed for children with albinism and  
great locations:

#### New Hampshire Family Camp

**NH - July 7-11, 2015**

Lions Camp Pride  
154 Lions Camp Pride Way  
New Durham, NH 03855



Philadelphia, PA

## Adults with Albinism Weekend

### ADULT WEEKEND: SIGHTSEEING & SOCIALIZING

Explore historic Philadelphia and enjoy the fellowship of the albinism community in September! This unique event is tailored specifically to adults with albinism including discussion groups, educational presentations, sightseeing and lots of social time. The camaraderie at these events can be life-affirming, life-changing and long lasting.

**PA - September 11-13, 2015**

Courtyard by Marriott  
Philadelphia Downtown  
21 N. Juniper Street  
Philadelphia, PA 19107

*\$169 per night plus approx. 15.5% tax*





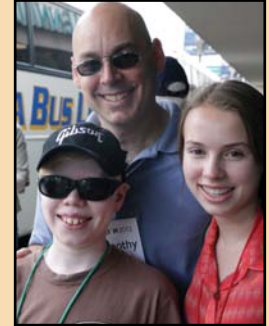
It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - *Brooke Jensen -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

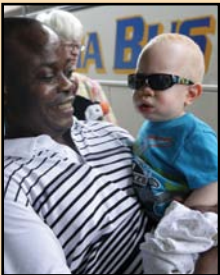


The calls have been a really supportive experience. It's nice to hear the stories of other people going through a similar issue. The guest callers are informative and that gives me a head start on what to expect as my child grows. It's also a great outlet reminding me to nurture and take care of myself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

*Andrea Chadderdon - Chicago, IL*

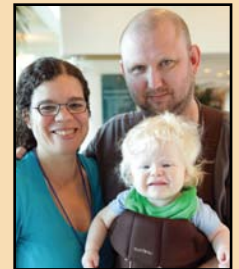
Here's an opportunity to talk with others who understand what you are going through as a parent of a child with albinism. Get the support you need to be a healthy, informed parent, and build connections in the albinism community – all in the comfort of your own home.

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



**National Organization for Albinism and Hypopigmentation**

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