



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Autumn 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!

Helping Kids with Albinism in the Classroom

By Surabhi Kothari, *Albinism InSight* Staff Writer, New Delhi, India



It is said that home is the first school of any child and the mother is the first teacher. Gradually, when the time comes for the child to go to school, things are different, especially when it is a special child. Here, I've compiled some of the lessons I've learned as I prepared my daughter for school and prepared the school for my daughter in India.

As a parent of a child with a visual impairment, there are some things you may take into consideration such as the teacher-to-child ratio, the overall environment of the school and how comfortable it is for your child to get around. It is also important to make your child aware of the surroundings and places where she will be going most often, for instance the restroom or the cafeteria. In some countries, this may be referred to as Orientation and Mobility.

Be sure to talk to the teacher about albinism to foster an understanding of the situations and restrictions that might be faced by your child during the school hours. From here, it's the teacher's duty to help the child feel comfortable in the class and ensure the child has a healthy relationship with peer groups. In some countries there are specific laws to ensure that your child has the same access as the other children and any necessary accommodations.

Although the light hair and skin will make your child stand out, it is important for parents and the teachers to tell the child how he can view the situation more positively and how he can use his abilities more effectively.

Since vision is greatly affected in albinism, the font size of reading and writing material should be addressed. Some accommodation, which can be as simple as a hand magnifier or a reading stand, can help greatly. Using dark-lined paper and a felt-tipped pen or marker instead of a pencil may be a good idea. In higher grades, recorded materials and audio books can be helpful to reduce eye strain.

Glare can make reading white boards a challenge, so using a monocular can be helpful. Similarly, if there is a presentation, it can be configured to the child's own computer, tablet or a similar device so the child can have a closer look.

Field trips are fun for kids and your child should participate, but it is important that the people who are responsible for the kids are aware of your child's vision needs. For instance, they need to know that calling his name instead of pointing can be a good option because he might not see common hand gestures.

For the overall development of your child it is very important that she is not underestimated and that she is exposed to a wide variety of activities: playing an instrument, dancing or even participating in a sport.

Keep in mind that a child who is born with a limitation is unaware of what he is missing and doesn't know that he doesn't see as well as others. At the earliest stages, proper guidance and understanding play a crucial role in helping the child to bloom more beautifully, to develop more confidently, and to live a wonderful life.



**Mysha Kothari
and her friend**

New Ways to Read without Putting Your Nose in a Book

By Vidushi Kothari, *Albinism InSight* Staff Writer, New Delhi, India



On a daily basis, we have quick reads such as a restaurant menu, a bulletin board, a price tag or a text message. Then there are the more extensive materials such as textbooks, work reports or books to read for fun.

Even with a visual impairment, we are resourceful people so to extract the small bits of information we need, we enlist devices such as a handheld magnifier, a reading app or a camera on a tablet or phone. Nancy Lee, a member of our Editorial Team, shared her strategy. “Depending on the font size and lighting, I use reading glasses, a magnifier or my iPhone flashlight.” Cassandra Mendez has a different strategy. She said, “In public, when I have to read things quickly, I usually take a picture with the camera on my iPad and pinch to enlarge it. I hate conventional magnifiers and my iPad is like an all-in-one tool.”

For reading textbooks or reports with standard or small font, technology is making reading a piece of cake. Here’s what our members are using.

Bookshare works like a library membership. For a minimal fee, you have access to a large volume of books. Its app is called “**Read2go**,” and it’s extremely useful as it combines the visuals of the book with screen reading. Bookshare offers a wide selection of books including textbooks and it has fiction, nonfiction, bestsellers and more for leisure.

Audible is a website and app owned by Amazon that primarily sells audiobooks without their visual representations. It works well for leisure reading. The books are read by high-quality, human voices, not the synthetic text-to-speech types. Many Audible books are read by voiceover actors. As a result of the high quality, the books are expensive. Another downside is their collection is limited. But if you have a much-awaited book in mind that you would really enjoy listening to, the Audible version may be a good investment because it offers the highest quality of sound and voice that I have come across.

Blio is a third option that is somewhere between Audible and Bookshare. It has a wide collection of books which are visually represented and some have an audio option. The most useful feature is that it can read PDFs.

Furthermore, it can be used in combination with the voiceover feature on a smartphone or tablet. Voices may be purchased on Blio as well.

NaturalReader HD and **Voice Dream** are apps that can convert a PDF into text-to-speech. The text colors, backgrounds, fonts, reading speed, etc. are adjustable for both apps and highlights the word and sentence as it is being read. NaturalReader HD keeps the pictures and other visual representations intact. Voice Dream only preserves the text. However, Voice Dream



does allow annotations and bookmarks which NaturalReader HD does not.

The **Kindle** (Amazon), and **Nook** (Barnes and Noble), are tablets designed specifically for reading purposes. They are also available as apps. Their brightness is low, almost like paper, making them easier on the eyes than a regular tablet or smartphone. They may offer the largest variety of books for sale. Like Blio, the Kindle can also read PDFs. The background/text color, size, etc. may be altered on the Kindle. These devices may also be useful for reading the daily newspaper. Rachel Evans shared her experience with the Nook. “I love my Nook! I have the one without a backlight and eye fatigue is never a problem, even reading over 100 pages in a row. The app syncs to my iPhone, so I can read there as well.”

Mike McGowan shared his experience with reading. “I am hooked on the National Library Service. I have been listening to audiobooks for almost 20 years, first on cassette tapes and now digitally using a specialized player called a **Victor Read Stream**. I read books for recreation. Since the Stream is portable, I can read on trains, planes, on long car rides and on my daily walks.”

These are just a few examples of tools that are available and there are several projects underway that will further improve accessibility to printed material. Specific tools may not work for everyone, but since apps are inexpensive or have free downloads, they may be worth trying!

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)

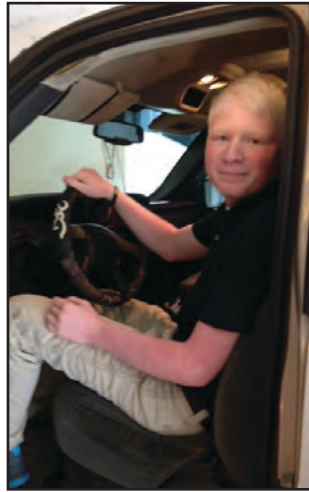
Cameron Can Drive!

By Nicole Barnum

“He won’t drive or ride a bike.” That’s what I said 16 years ago when my son, Cameron, at three months of age was diagnosed with albinism. The words still echo in my head like it was yesterday.

Fast forward to 2014, and my Cameron is now officially a licensed driver!

At the 2012 NOAH conference in St. Louis, we were given a referral to see Dr. Terrell McGinn, a low vision optometrist who helped us in obtaining the



right bioptic device for Cameron so he could drive.

Wow! Cameron completed the mandatory driver’s education and 30 hours behind-the-wheel training with the bioptic. Next he got his learner’s permit and eight months later, his license!

When I think back to his diagnosis and the emotions I felt, I’m even more proud to say that today, my son has ridden a bike since he was four years old, and Cameron **can** drive!

College Transition Tips from an Experienced High School Senior

By Cassandra Mendez, *Albinism InSight* Staff Writer



Whether you’re a soon-to-be middle schooler or the parent of a high school sophomore, your subconscious is probably already whispering about college. And if you’re like many people, the prospect is overwhelming! Words like “open house,” “financial aid,” “college majors,” “admissions” and “testing,” buzz noisily, without quite making sense. High school counselors urge you to make choices and apply, but you may be confused, not knowing where to begin.

Don’t despair! I’m on the road to college and have seen how confusing it can get. I definitely don’t know everything, but I’ve learned a lot and can try to give you a head start!

Decide what you’re looking for. Both location and personal preferences are important.

- Price Matters! Choose between public and

private institutions. Public universities in your home state can offer affordable in-state tuition, whereas private colleges and out-of-state public universities are usually more expensive. However, private colleges often provide more personal attention and a smaller student population.

- Size matters! Decide whether a small, close-knit campus or a large, diverse one is better for you – or perhaps a medium-sized one is just right? Will you be more comfortable in a school of 5,000 people or 50,000 people? Chances are, if you’re over- or underwhelmed by size, you won’t excel.

Location, location, location! What do you want your campus to be like?

- Rural areas may offer small colleges that might have the cozy feel you desire. Just make sure you can navigate easily!

- College towns are a nice compromise between city and rural life. Most college towns have little stores and restaurants on their perimeter and usually aren't far from a major city. Campuses typically have a bus system to access the nearby city.
- Cities may offer convenient public transit and most places are within walking or biking distance from campus. Decide whether you'd feel safe walking around or taking transit in an urban environment.

What's your future? If you don't know what you'd like to be, exploring your interests is a must. Sometimes, it may not be best to major in something you love because you might get bored. Find something that you enjoy and can see yourself doing for a long time. Think about combining your hobbies and career. For example, if you love music but also enjoy science, consider speech pathology which is the study and treatment of speech issues, with a music minor. If you're still unsure, that's okay! Most universities have programs for undecided students to gain exposure to all kinds of fields during your freshman year. These go by the names of "freshman exploration" or "exploratory studies." Often, these programs have special orientation sessions as well.

VISIT! VISIT! VISIT! Many people have the wrong idea of a college visit. Don't just settle for driving around a campus when you pass by. If you're going to live somewhere for 4+ years, you'll want to get to know the place! Go to the college's website, and look for a "Visit" or "Open House" link. Most colleges have specific days when you can get an in-depth campus tour, learn about your major and meet admissions staff. The best thing about campus tours is that they're student-led, so you can ask a real student about his or her likes and dislikes. I highly recommend these visits during your junior year of high school – before you apply. Try to go during the week so you can see student life in action – and who doesn't

love missing a day of school? Check out residence halls and the distance to where you'll be taking most classes for easy navigation. If you take Orientation and Mobility (O&M), see if your instructor can take you to a nearby college campus to practice navigation skills.

Learn about transportation. What transportation does the university offer? Larger universities often have off-campus bus systems, but also see what's available for on-campus transit. One of the universities I'm considering has an underground tunnel system that connects almost every building on campus, which is convenient during the winter. Many colleges also offer "Night Ride" which you can call past a certain time at night, and someone (often a police officer) will safely escort you to your residence hall. Night Ride is available to all students so don't hesitate to investigate. Many large campuses offer a HandiVan through The Office of Disability Services (ODS) that will take you door-to-door, regardless of what time it is. You'll only know if you ask!

ODS is your friend. The Office of Disability Services provides more than you might expect. The trick is knowing what you need. Lots of ODS offices have walk-in appointments, so see what they can do for you. It only takes about 20 minutes to discuss accommodations.

- **The big deal: Know your IEP / 504.** Every ODS I've visited has stressed that they want students to know what they need (sorry, parents, it's time to let us start flying solo). By high school, sit in on your IEP meetings. Use the first one to observe, but try to participate as much as you can. This will give you solid groundwork for self-advocacy, which colleges really want to see in every student, especially those with disabilities. College is when you begin to be self-sufficient, and this is the first step!
- Common ODS accommodations include:
 - Note takers

- Extended exam time in an isolated area with adapted technology
- Large-print or braille exams
- Alternative format (have profs email presentations / PDFs for iPad viewing)

Different universities offer varying accommodations, so it's best to meet with ODS and verify what they have. Don't be afraid to ask for accommodations. It's easier to determine an accommodation isn't needed and take it away rather than making the case for a new one.

- Bonus points: **registering with ODS often gets you priority perks!** Don't miss out on scheduling before the athletes and getting the residence hall and class times you want.
- Once you're accepted, update ODS and make your arrangements. When you decide on your college, make an official appointment before orientation and bring all documentation necessary for final arrangements.

In the meantime... Even if you're in middle school, it's never too early to prepare. Explore your interests and think about what you'd like to do. As a high school student:

- Get involved! Colleges love to see what you do outside of school. Start building a "non-academic resume" of all your extracurricular activities, volunteer work, community service, leadership opportunities, paid work and awards.
- Take your standardized tests early, like June after your sophomore year if you're in advanced/honors or AP classes. You don't have to send this one to any universities; just take it as a marker to see where you are. If you're not advanced, take it a few times during your junior year. Don't forget to talk to your guidance counselor or teacher of the visually impaired about ACT / SAT accommodations such as extra time and large print. They're worth it!
- Keep your grades up. This sounds obvious, but colleges are looking for

GPA in conjunction with test scores and extracurricular activities for a "well-rounded" student profile. Here's what they're looking for:

- Grades
- Test scores
- Class rank (if applicable)
- Admissions essay
- Recommendations or interview (if applicable)
- Work and extracurricular involvement (volunteering, demonstrating leadership)
- When applying for financial aid, go for the diversity scholarships. Even if you aren't ethnically diverse, colleges believe you're diverse by being YOU! Having albinism isn't so common, and that's what colleges love. Use this time to highlight the neat things only people with albinism can do, and BOOM! You're diverse!

Hopefully these points have given you some clarity on this multi-faceted decision. It definitely takes time, patience and a lot of persistence, but if you try hard enough, you'll go far. Admissions counselors are also willing to answer your questions, no matter how silly they may seem. It is their job, after all, so let them help you! Above all, dare to achieve and strive for excellence. It doesn't matter how smart you think you are, nothing great was ever accomplished without enthusiasm.

If you're hungry for more, check out these websites for some helpful pre-college resources:

- www.studentaid.ed.gov/prepare-for-college/checklists
- www.nextstopcollegewi.org/web/CAA/index.html
- www.shmoop.com/college/brag-sheet-resume-template.html

STEM: Perseverance is Key

By Arielle Lewis



One of the things I adore about NOAH is the ability to share stories. I hope this will serve as a resource for high school or undergraduate students who are interested in the Science, Technology, Engineering and Math (STEM) fields and want to work as a researcher.

As a visually-impaired student, it may be challenging to perform experiments in a grade school setting but rarely has it been a complete obstruction to my achieving the required scientific skills and knowledge. You should not eliminate STEM fields because of vision issues.

A story about science comes from my grade school experiences. I learned to adapt to the particular requirements of experiments and successfully learned scientific concepts. One memorable moment occurred in my fifth grade physical science class.

We were to perform an experiment on DC electrical circuits. I was partnered with a classmate who clearly did not fully understand the limitations of my vision. Coupled with small, thin wires, the experiments were very difficult for me to perform. I needed some way to demonstrate my knowledge and to find an accessible way to replicate the experiment from class. My father suggested that I redo the experiment with a larger battery and thicker copper wires. Those items would be easier to see. One trip to Home Depot and I had robust wires and batteries to complete the task! Once I got the approval from my teacher, I demonstrated the circuit experiment that we previewed at home. Unbeknownst to my teacher, my father or me, the battery had significant voltage and sufficient electric power to nearly cause a fire in the class!

Since I started working in a lab this summer, I searched several scholarly databases to find literature on how visually-impaired students work in labs. It has been established in many

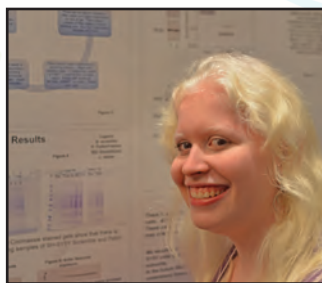
arenas that perseverance and a “can do” attitude is completely applicable and will contribute to success.

As I continue as a NET/work fellow, I adapt to situations in the lab. One of the main reasons I was accepted into NET/work was because I let the scientists know that I was capable of working in a research laboratory. Although I was strongly encouraged by my fellowship to only run a specific technique, I knew that I didn’t want to limit myself. Repetition of experiments (replication of data) is not only

important for confirming results, but also improves my technique and analysis over time. Taking time with reviewing the protocol is important for other scientists if they want to replicate the experiment, but it also serves to help figure out specific adaptations required to run the experiment successfully. There were

some situations where environments would change and I had to memorize the layout of an area (also achieved through repetition).

Be open to trying new things. Ask a lot of questions about procedures. Take notes. Everybody takes notes irrespective of visual acuity. You should consider an opportunity to work with a seasoned lab member and go through the procedures once and then try to complete them on your own (ask questions if you get lost). Be patient. Results don’t always come as quickly as you would like, and sometimes they may not come as you anticipated. In many ways, that’s the most fun: unraveling a newly-found puzzle. Feel comfortable and confident running these experiments and collecting data. Bottom line, you need to feel confident that you can complete the same protocol as a sighted person. Mistakes are fine, but make sure you note the error and document how it occurs. It’s simple!



NOAH's Nurse Emily

By Carol Gray

In 2002, at the age of 17, my daughter, Emily, attended her first NOAH conference. It was a life-changing event for her to make friends within the albinism community, to feel comfortable as a person with albinism, and to finally accept the use of visual aids in the classroom.

Emily graduated from college with a major in Film Studies. She stayed away from courses that captivated her interest such as biology and science, because she couldn't see written details on the blackboard. She began working for a company that created film trailers for movies; however she found working behind the scenes unsatisfying.

In 2007, NOAH sponsored one-day workshops in several cities around the country. When Emily saw a NOAH email asking for volunteers to organize the workshops, she realized that I would be a good fit, and asked me to volunteer.

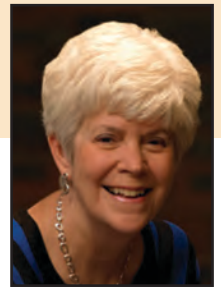
We didn't know that NOAH was about to change the course of Emily's life again!

At the workshop I organized at the Children's Hospital of Los Angeles, speakers demonstrated some of the latest technology for students. Emily saw the potential in a tiny closed-circuit, high-definition video camera attached to a laptop to allow her to zoom in on blackboard images and record them. The two optometrists, Dr. Bill Takeshita and Dr. Brett Nakatani, from the Center for the Partially Sighted, told her that she may qualify for a device from the California State Department of Rehabilitation. Armed with this new information and technology, Emily found herself back in the

classroom with the subjects that interested her. Her first course was in human anatomy and she spent her 25th birthday dissecting a cat. We may think that's gross, but she was mesmerized!

Emily made a daring decision to quit her job and go back to school to achieve her dream of becoming a registered nurse. She had doubts, especially if her low vision would hinder her dream, but NOAH member and nurse, Kristen Dalton, reassured her. Some lab classes were challenging, but Santa Monica College provided aids such as video displays linked to a microscope for microbiology. Before long, the teacher was using it to demonstrate for the entire class. Upon completion of these prerequisite classes, Emily was accepted at six nursing schools and selected UCLA's Masters Entry Clinical Nursing Program. It was an intense 22-month program, but Emily graduated with honors in June 2013. She has just completed her first year as a registered nurse at the same hospital where she was born.

NOAH, the friendships of its members, the knowledge shared, and the encouragement to succeed made the happy ending of this tale possible. Emily and I learned that when you volunteer for NOAH, you help others, but you might help yourself or your child in ways you never imaged.



©John Lewis



www.youtube.com/user/NOAHAlbinism



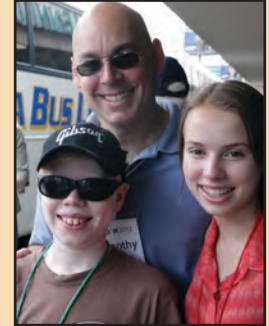
It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - *Brooke Jensen -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

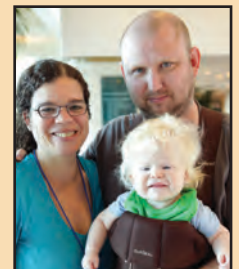
Here's an opportunity to talk with others who understand what you are going through as a parent of a child with albinism. Get the support you need to be a healthy, informed parent, and build connections in the albinism community – all in the comfort of your own home.

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



National Organization for Albinism and Hypopigmentation

PO Box 959, East Hampstead
NH 03826-0959 USA

Phone: 800-473-2310 • 603-887-2310

Toll-free fax: 800-648-2310

www.albinism.org • Email: info@albinism.org