



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Spring 2016

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.

Inside this Issue

From the Winter edition of Albinism InSight

- Driver Readiness with Low Vision Aids
- My Story as a DMV Edge Case
- Let's Take a Walk (CARE Project)
- New for YOU in 2016



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!

Driver Readiness with Low Vision Aids

By Chuck Huss, COMS, Driver Rehabilitation Specialist



How can parents, teachers or vision rehabilitation professionals further contribute to making their child or student with low vision more driver ready? One way is to introduce them to prescription hand-held or head-borne distant optical low vision devices. Such hand-held monocular telescopes and their head-borne (bioptic lens system) counterparts come in a variety of styles, shape, sizes, and powers of magnification (see photos or illustrations below).

The first step to obtaining a device is to contact an optometrist or ophthalmologist who practices clinical low vision and arrange a comprehensive clinical low vision examination, including visual field testing, for your child or student. This examination should take place before dispensing such devices on loan or final prescription.

Some states such as Tennessee, West Virginia and Missouri provide clinical low vision services for children or school-age students through public or privately funded programs like the Children's Vision Rehabilitation Project. Other states may simply work through recommendations made by your students' assigned Teachers for the Visually Impaired (TVI), Specialty Counselors for the Blind, or other Individualized Education Plan (IEP) or Individualized Plan for Employment (IPE) member referral source.

As part of multi-disciplinary low vision service programs, where available, it is suggested that parents or teachers also seek out the hands-on type ancillary services and expertise of a certified low vision therapist (CLVT) and/or certified orientation and mobility specialist (C.O.M.S.). They can help ensure that your

child or student is willing to and capable of using either type of device in real world conditions (school, outdoor travel activities, etc.) before final prescription.

The additional evaluation or assessment services provided by the above mentioned professionals may include:

- An overview of preliminary functional tasks, i.e., learning how to hold, position, focus (at different distances), cleaning, and scanning with the device;
- A review of common limitations of distant telescopic optical devices (i.e. the nearness illusion, restricted field of view, movement of magnified field of view in opposite direction to head turn, swimming or blurring effect due to too quick movement with either type of device, etc.);
- Affording student an opportunity to practice using the device(s) under naturalistic conditions as well as observed training or reinforcement sessions with a CLVT or C.O.M.S.;
- Formulation of a progress report and sharing of findings with low vision clinical sources;
- Final prescription and dispensation of device(s).

Once a decision is made as to which device(s) works best, a purchase order is formulated and approved by the funding source; the device(s) is ordered; and they are later dispensed to child or student with follow-up training provided by a CLVT or C.O.M.S. as needed.

A sampling of indoor tasks that your child or student may find interesting, and that can increase driver readiness, are as follows:



bioptic lens system

- Telling the time on a distant wall clock in the hallway;
- Finding a new classroom by detecting the room number and teacher's name on the classroom entrance door or on a nearby wall surface, from a distance;
- Detecting or locating an exit sign leading to a stairwell or actual exit door(s);
- Detecting and deciphering the actions or movements of other students or a faculty speaker on stage during a play, skit, or presentation;
- Reading their name off a banner or list of winners for a spelling bee or other contest.



handheld monocular

Outdoors students can become very creative by using their device to:

- View at greater distances and appreciate the distant landscape or objects or forms in the landscape;
- Locate street markers from the opposite side of an intersection;
- Identify an address, or the building front of a business or home dwelling, from the sidewalk on either side of the street;
- Identify the name and number of an approaching city bus from a designated bus stop;
- Spot a landmark while traveling on a city bus, before asking the bus driver to begin slowing and pulling off to the side of the road for his/her departure;
- Detect and identify product signs from middle to distant viewing ranges along aisles in a typical grocery or department store;

- Detect and recognize someone who is waving from a distance in a shopping mall.

In essence, what is being enhanced during the above indoor and outdoor tasks is a child's or student's ability to expand their distance viewing and critical object awareness skills, which are prerequisite for future operation of a motor vehicle.

Learning to use hand-held distant monocular low vision devices is fairly simple and straightforward. In contrast, head-borne devices such as prescription bioptic lens systems are used mostly hands free, and are much quicker for both

extended viewing tasks (when positioned stationary or as a passenger in a vehicle) and for short-term vertical spotting viewing tasks, which often take only fractions of a second during activities involving movement (such as walking, riding a bicycle, operating a moving vehicle of some sort, etc.).

With both types of devices, instructional time centers on better understanding and adjusting to optical limitations.



Monocular Accessories

finger ring

hand grip

As your child or student becomes more proficient with basic distance viewing, critical object or condition awareness and basic distance low vision aid skills on foot, similar types of skills can be introduced and reinforced in the car under what is commonly referred to as "commentary drive" or "passenger-in-car" types of conditions. This will be the main topic of an article that will appear in the Summer Issue of *Albinism InSight*.

My Story as a DMV Edge Case: How to Battle Bureaucracy and Win

By Hannah Birch, ProPublica



When I showed up with paperwork for my low-vision condition, the DMV was totally baffled. Here's how I walked them through an edge case and how you can use the strategies yourself.

"I don't know what this is," she said, sliding the form back to me. "I'm not a doctor."

Thank you, I thought. I realize that. You work at the Department of Motor Vehicles.

I was at a New York DMV office and the form — an MV-80L — is what people with low vision need to submit in order to get a driver's license. You take the form to your eye doctor, who evaluates whether you're safe to drive. If the answer is "yes", the doctor fills out the form, you mail it to the Medical Review Unit in Albany, and then you go get your license.

I have an eye condition called oculocutaneous albinism, which affected how my eyes developed. My retinas — they're at the back of your eye, helping you see detail — were late to the party. Think of having underdeveloped retinas like using a camera phone from the early aughts: You can see general shapes pretty well, but there just aren't enough pixels to see small details, like text that's far away.

Albinism includes other issues that affect things like depth perception and light sensitivity. Basically, I trip and squint a lot. My mom tells me it's cute. And I'm guaranteed to fail that eye test at the DMV every time.

But even though I can't read those tiny little letters on the sheet of paper they hold up, doctors in three states now have concluded my

vision is good enough for me to safely drive. The doctors fill out paperwork for me and then I steel myself to make it through a situation that feels designed to make me fail: walking DMV employees through an edge case.

The Americans with Disabilities Act outlaws discrimination against, you know, people with disabilities. But government workers can still make it difficult for you to get what you're qualified for under the law.



That's where the woman refusing my form at the DMV comes in, and where I can offer advice about your fundamental rights.

Know As Much As You Can in Advance

Understand as much of the process from start to finish as you can so you're able to tell if someone is bluffing or, more likely, uninformed.

A New York DMV spokesperson told me that employees are trained on how to handle documents for people with disabilities. When I asked her why no one seemed to recognize my paperwork, she told me my MV-80L isn't something an employee would encounter often since it's intended for another office, the Medical Review Unit. Ideally, the employee would still be able to help me out. But that wasn't the case for me.

Even though I've gone through this process in two other places before, every state handles low-vision drivers differently. So whenever I get a license in a new state, I have to learn a new system. That's the next step.

Figure Out As Much As You Can Quickly

If the system is new to you, observation of what's right in front of you might not be that

helpful. The MV-80L, for instance, is currently missing information about how the approval process works. After receiving your paperwork, the Medical Review Unit sends a letter back to you for you to take to the DMV. I know this now, but I didn't when I started this process. So I crossed my fingers and mailed the form, having no idea what was going to happen.

(The DMV spokesperson later told me they're adding language to the form that walks people through the process.)

In the absence of knowing the next steps, a phone call did the trick for me. After a DMV employee told me my form wasn't for the DMV, I asked her to call the Medical Review Unit for clarification on what to do. She refused. So I called them myself.

Luckily I was connected with someone who explained to me how the process is supposed to work. Anyone who's an expert in the system you're battling is an obvious power-up in these situations. Look for them wherever you can, and bear in mind that they might not be part of the organization you're dealing with.

Use Keywords

This is important. While my Medical Review Unit guy was talking to me on the phone, I was taking notes. I latched onto keywords he let slip — the names of computer systems the DMV would use to look up my records, the date they received my paperwork, and the letter codes of the restrictions they would place on my license.

After I got off the phone, I used these keywords in conversations with DMV workers who otherwise wouldn't have known what I was talking about. I slipped in terms they were familiar with, as if I regularly used them, too. It worked. They stopped arguing and did as I asked. Take away the ambiguity and people lose their ability to hedge with an "I don't know."

Speak Directly and Stand Your Ground

At one point, the DMV employee I was talking to called over her supervisor. "Why are you

refusing to take the eye test?" the supervisor asked me, hands on her hips, like I was being argumentative. (Having an MV-80L precluded me from taking the test at the DMV. I knew this. They didn't seem to.) "Because I have a low-vision condition and someone with a medical degree is better qualified to evaluate my case than you are," I replied, without sass but also without smiling or apologizing.

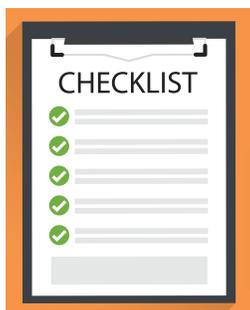
I talked with design expert Derek Featherstone — he founded a design company specializing in accessibility — about the balance between being open to dialogue and being defensive. "There's this sliding scale and you're always somewhere in between, and there's an appropriate mix for each situation. And I think that changes depending on the situation and how people are reacting."

Bottom line: Don't get pushed around. As much as you can, know what you are and aren't obligated to do in a given situation. Be open to talking something through, but don't get bullied into unnecessary hassles.

Follow Up With the People Who Helped You Out

After some tactful maneuvering, I was eventually able to walk out the door with a driver's license in hand. Then I immediately called the guy in the Medical Review Unit office and gave him my heartfelt thanks. He responded with warmth and good grace.

That became the conversation I remembered at the end of it all. I added it to my collection of "wait 'til you hear what happened to me at the DMV" stories. And it affirmed for me how, for all the times dumb systems thwart smart people, sometimes smart people can win. If you or someone you know has low vision and wants to know more about getting a driver's license in New York, or if you're interested in talking more about accessibility and design, email me at hannah.birch@propublica.org.



Let's Take a Walk

By Judi Duffey & Deborah Kitchin

“Do you know where we are going?”, Hannah asked her mother. “Yes,” said her mom taking her hand, “I have been there before. I will show you.”

Walking down the educational document road

is new for some of us. There is new verbiage to be learned, new technologies to be discovered, and new ways of navigating obstacles on the path. Some of us have been on the road for a while but a bend in the road has taken us in a new direction and we now need navigational help again. The National Organization for Albinism and Hypopigmentation (NOAH) can be a great resource for you as you journey down the educational document road with your children.

A well thought out educational document with appropriate goals and accommodations can give your child the help they need to progress academically. Create Albinism Resource for Education (CARE) is a program that aims to provide parents with resource information that will aid them in formulating their child's IEPs, IFSPs and 504s.

The Individualized Education Program (IEP) is a written statement of an educational program designed to meet a child's individual needs and is typically reviewed annually. Children under the age of three can have an Individual Family Service Plan (IFSP), which is a plan for special services for children with developmental delays. The 504 Plan is also an educational plan option that gives students with disabilities individualized help.

The CARE Project, found on the NOAH website in the PARENT section under the link Programs and Services, provides an online database of actual educational documents through 12th grade that are available for

viewing and downloading in either PDF (Adobe) or XLS (Excel) formats. Documents within the database can be viewed by document type, state, age, grade and visual acuity.



**CARE Team Leads
Judi & Debbie**

“I found it a great resource when we were preparing her first IEP” is what South Carolina mom Sarah said when asked about the CARE Project. Six-year-old Caroline was going to have her first IEP and Sarah was thankful to be able to look at a variety of formats and the different accommodations they outlined.

Each child with albinism is unique in their visual acuity and developmental needs, therefore each educational plan should be specific to that child. The CARE Project provides information that can assist parents and other professionals in ideas for individual goals and accommodations.

If you are the parent of an older child, you have already walked down the educational document road and have an advantage. Will you share your wisdom and insight with others who need it? Only you can understand the impact of having a solid educational plan and help those who are just few steps behind you. The greater the scope of the database, the greater the resource for the albinism community.

You can help parents benefit from your experience by submitting a copy of your child's IEP, IFSP or 504 Plan to the CARE Project. All documents will be scrubbed of personal information before they are released. The NOAH CARE Project page has all the information you need to submit copies of your child's educational documents.

If you are taking your first steps down this unfamiliar road, rest assured you do not have

to walk alone. NOAH has a proven resource for you in the CARE Project. With information and ideas gleaned from genuine documents,

you too can create a strong and impactful educational plan for your child.

CARE for you, CARE for our Community

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

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

The content is indexed by state and grade, so you can use this free resource to help establish your child's Individualized Education Plan.

You can also help the albinism community. Personal information is removed so your privacy is protected. Our resource is only as good as the input we receive, so please consider sharing with CARE.

Visit www.albinism.org/care for more information.

CARE IFSPs
IEPs
504s

Creating an Albinism Resource for Education

New for YOU in 2016

NOAH's 16th National Conference in Pittsburgh includes five exciting brand new features.

Conference Webpage – www.albinism.org/NOAHCon2016

Get the latest and most complete conference information online whenever you want. Detailed information about the host hotel, fees and deadlines, the conference program, optional activities and conference news will be kept up to date as the conference nears. The page will include an extensive list of area amenities to make it easy for you to find everything from food to pharmacies. Maps and transportation information have all you need to know to get to the conference and how to get around while you are there.

One-Woman (With Albinism) Cabaret Show

“Thank You for the Music”

Featuring Marleena Barber

Friday July 15, 2016 9:00 PM

Marleena Barber is an active performer, educator and disability advocate. Her one-woman cabaret show, Thank You for the Music, tells the story about her life growing up with albinism and how music played a vital role in the journey to believing



in herself. The show is an inspiring piece that reaches out to all ages encouraging audiences, through a variety of different musical styles, to live their dreams despite any challenges they may face. Marleena directs Braille Institute's award-winning Johnny Mercer Children's choir---a choir composed entirely of blind and visually impaired students. As a visually impaired individual, Marleena strives to be a role model of independence and determination, demonstrating to her students, and her audiences, that with hard work dreams can come true.

Pre-conference Low Vision Driving Workshop

Driving with Low Vision and Bioptics: A Multi-Disciplinary Perspective will take place on Thursday, July 14, 2016 from 8:30 am to 4:30 pm before the NOAH conference. Low vision driving guru Chuck Huss and a group of experts will talk on a comprehensive series of topics to help attendees understand the process.

This new workshop is meant for those with low vision seriously considering obtaining a driver's license. Parents or spouses who might offer direct or indirect related services or emotional support are also encouraged to attend.

Please note that this workshop will require an additional registration fee. See www.albinism.org/LVDriving for details.

Self Defense Program

1Touch™ is a groundbreaking self-defense program created to address the specific needs of the blind and visually impaired. It teaches vital self-defense skills such as threat recognition, threat analysis and appropriate response. NOAH will host three half day sessions during the conference in which participants will learn practical and effective self-defense through hands-on training and an



easy to follow methodology. Space is limited so be sure to sign up as part of your NOAH conference registration.

Documentary Screening – *On Beauty*

From Emmy-nominated filmmaker Joanna Rudnick (*In the Family*) and Chicago's Kartemquin Films comes a story about challenging norms and redefining beauty. *On Beauty* follows fashion photographer Rick Guidotti, who left the fashion world when he grew frustrated with having to work within the restrictive parameters of the industry's standard of beauty. After a chance encounter with a young woman who has albinism, Rick re-focused his lens on those too often relegated to the shadows to change the way we see and experience beauty.



On Beauty is a story about recognizing and appreciating the beauty of difference. At the center of *On Beauty* are two of Rick's photo subjects - Sarah and Jayne. Sarah lives in upstate New York and left public school for homeschooling after being bullied so harshly for the Sturge-Weber birthmark on her face and brain. Jayne lives in Eastern Africa where witch doctors hunt people with albinism to sell their body parts and the society is blind to their unique health and safety needs. Rick, Sarah, Jayne and the other vibrant people highlighted in *On Beauty* prove that people with genetic conditions are more than what is in medical textbooks and beauty is more than what is in magazines.



Driving with Low Vision and Bioptics:

A Multi-Disciplinary Perspective

One-Day Pre Conference Workshop
Thursday, July 14, 8:30 AM – 4:30 PM
Wyndham Grand Pittsburgh Downtown
600 Commonwealth Place
Pittsburgh, PA 15222

Obtaining a driver's license that requires the use of a bioptic lens system involves the cooperation and services of a multi-disciplinary team of professionals. This workshop will provide an overview of:



- the preliminary clinical low vision exam;
- process of evaluating, fitting, and prescribing a bioptic;
- pre-driver readiness; behind-the-wheel training or re-training; current bioptic driving related research;
- advocacy tips for legislative change;
- ample time for addressing those questions or concerns that arise concerning low vision driving issues.

This workshop is intended for low vision individuals who are considering exploring the driving privilege. Professionals, parents or spouses who might offer direct or indirect related services or emotional support are also encouraged to attend.



Looking through a carrier lens of a bioptic



Looking through the telescope of a bioptic

Photos courtesy of Susan Patterson

Topics & Presenters:

- The Clinical Low Vision Examination, Paul Freeman, O.D. FAAO
- Fitting, Evaluation & Prescription of Bioptics, Cheryl Reed, O. D.
- Pre-Driver Readiness Skills, Chuck Huss, C.O.M.S., DRS
- Behind-The-Wheel Training, Kathleen Miller, OTR/L, CDRS
- Bioptic Driving Research, Cynthia Owsley, Ph. D., MSPH
- Consumer Advocacy, Matt Bailey
- Panel Discussion / Questions & Answers

Fee: \$90 per person (includes lunch)
Register on-line only by June 16, 2016, at:
www.albinism.org/LVDriving. We are not able to accommodate on-site registrations.

Hotel Reservations: Group Room Rate
Wed. July 11 – Sunday, July 17. \$140 per night
(plus tax and fees) single / double / triple /
quad. Reserve NOAH rates online at:
<https://aws.passkey.com/g/34681122>
or call **877-999-3223** to book with NOAH.



**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

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

NOAHSM

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

Announcing the 8th Annual
Michael J. McGowan
LEADERSHIP
SCHOLARSHIP AWARD

Photo credit: David McMeans



Eligible candidates for this year's \$3,000 award must be:

- A **NOAH** member with albinism residing in the **U.S.** or **Canada**
- Enrolled in an **undergraduate** program at an institution of higher education in the **U.S.** or **Canada**
- A person exhibiting **outstanding dedication and leadership qualities**

Apply for **NOAH's 2016 McGowan Leadership Scholarship**
at www.albinism.org/scholarship and
submit supporting materials **by May 1, 2016.**

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)



www.youtube.com/user/NOAHAlbinism

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



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.