



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Autumn 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.

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of Albinism InSight*

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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!

LEARNING & EDUCATION

Introducing the NOAH SchoolKit

By Kathi Garza & Jill Gorman



Like over one thousand other people, we sat in anticipation of the opening reception of NOAHCon2016. The room was buzzing with camaraderie and the NOAH magic that we all crave. Our anticipation was much like that of the other attendees, but also a little different. In a matter of moments, we would venture to the stage to address the audience and introduce the NOAH SchoolKit officially, for the first time. We had two minutes to share, and all we could think about was how could we possibly sum up the last three years of work and excitement in just two minutes? We would like to take this opportunity to briefly discuss the SchoolKit and its purpose.

The SchoolKit is a compilation of information and resources to guide parents in supporting general education teachers when a student with albinism is placed in their classroom for the upcoming school year. This kit is intended to be used by students and families when communicating needs to general education teachers. In many cases, students with albinism are able to access the general education curriculum with a few accommodations and

modifications that are outlined in the Individualized Education Plan (IEP). Although students likely receive services from a Teacher of the Visually Impaired (TVI), service delivery times may vary, and often responsibility for ensuring that modifications and accommodations are carried out daily falls on the general education teacher. Empowering parents to facilitate communication with general education teachers, with or without the TVI, opens a dialogue between the two most important people in a student's education. Leading by example can translate into student empowerment and self-advocacy later in life.

Whether your student is starting kindergarten or high school, with every new school year there comes a time when families find themselves educating school staff about albinism and your student's specific needs. Here are the Top 10 SchoolKit Resources we think you will find helpful when advocating for your student while providing support to your student's instructional team:



NOAH SchoolKit



Top 10 SchoolKit Resources

10. Albinism Terminology List at your fingertips that covers definitions for OCA and OA, as well as terms such as nystagmus and null point.
9. Summary of instructional team roles and the services they provide.
8. List of Safety and Emergency considerations for the instructional team to take into account on the playground, during field trips, and in preparation for events such as fire drills.
7. A fact sheet to share with physical education teachers that outlines solutions to possible concerns that may arise during physical education class.
6. Suggested questions to review with the classroom teacher at the beginning of the school year concerning several topics such as classroom set-up, student accommodations, and your student's instructional team.
5. Tips for parents from parents.
4. Checklist of "to-do's" for parents when preparing for the new school year.
3. A list of possible accommodations to be discussed with the instructional team based on your student's classroom and instructional needs.
2. What is the Expanded Core Curriculum and how can the development of ECC skills be supported beyond the classroom?
1. Suggestions on how to empower your student by involving him/her in the process of educating the instructional team.

This SchoolKit Top 10 List is just a small sample of the many resources and informational tools compiled by educational experts and parents. We are very excited to launch the SchoolKit and to provide some support to families while navigating your student's educational journey!

To view the SchoolKit visit **www.albinism.org/SchoolKit**.

International Albinism Awareness Day

On December 18, 2014, the General Assembly of the United Nations adopted a resolution proclaiming June 13th as International Albinism Awareness Day. Albinism has continued to be misunderstood throughout the world with many erroneous beliefs leading to many forms of stigma and discrimination. Social observance of this special day is intended to bring awareness, encourage education and ultimately inspire acceptance and inclusion.



"The 2030 Sustainable Development Agenda pledges to leave no one behind. That includes people with albinism. The cycle of attacks, discrimination and poverty must be broken."

BAN KI-MOON UN Secretary-General

Here is just one way that NOAH members commemorated this special day in 2016.

Brave Fourth Grader Opens Up to His Class About Albinism

By Dina Pinelli

To celebrate International Albinism Awareness Day, students at the Connetquot School District's Edith L. Slocum Elementary School learned about albinism from David Avila, a 4th grade student. Avila has albinism and is legally



4th grade student Daniel Avila (center), wearing sunglasses and a police hat with his classmates

blind. This is a common combination because both are affected by the lack of melanin.

Avila and his vision teacher prepared an interactive PowerPoint presentation to teach more than 20 students in the 4th

grade class about albinism. This included how to prevent sun damage to skin if you have albinism, characteristics of a person with albinism and how to celebrate differences rather than bullying people because of how they look. Ms. Pinelli's class also wore "crazy hats" during the presentation, symbolizing

the need for people with albinism to protect themselves from the sun.

The purpose of this event was to increase awareness about this uncommon genetic disorder and to promote anti-bullying in schools.

Rideshare Revolution

By Alex Carrillo



While taxis have been the standard way of getting around for a long time, there are new players in town. Uber, and its close competitor Lyft, are two companies that provide a service called ridesharing. With these companies, normal (background-checked) people give rides in their personal vehicles. It's like becoming your own taxi service.

Requesting a ride

Both apps may have a multitude of vehicle types depending on your location. They offer the basics to carpooling, SUVs, luxury vehicles, and even helicopters. Each vehicle type carries its own rate and availability. Once you have selected a vehicle type and ensured that your location is pinpointed correctly, simply request a ride.

Upon having a driver accept your request, you will be provided with

their vehicle's license plate number, make, model, and sometimes color. You'll also see your driver's name, photograph, location on a map, and the approximate time they will reach you.

Identifying your driver

By far one of the most difficult parts of these services for people with a visual impairment is identifying their driver. Identifying taxis is easy. They're usually yellow, say "taxi" or "cab" on the side, and sometimes have a top light. Meanwhile, an Uber or Lyft is just a normal car in a sea of other normal cars. It's like when your parents picked you up from school.

What I like to do is request a ride from an area that doesn't receive a lot of vehicle traffic, like a residential neighborhood or closed storefront. Therefore, if a vehicle is pulling up to me



Lyft information screen - after a request has been made but before a driver is assigned.

and the app is telling me my driver is near, it's probably them. However, for those not wanting to leave things up to chance, both apps let you contact your driver via phone call or text message.

You can communicate to your driver what you look like/are wearing and request that they do something to aid you in identifying them when they arrive. This could include: calling your name, honking, stepping out of their vehicle, flashing their emergency lights, etc. In my experience, drivers are very accommodating to these kinds of requests — especially because you both benefit from identifying each other quickly.

Calculating your fare

Your fare is calculated based on a per-minute and/or per-mile fixed rate, plus any additional fees, based on the vehicle type. All of the details can be found in the app before

a ride is requested, with both apps offering fare estimates. Metrics are tracked by the app on the driver's phone, similar to a meter in a taxi. At the end of your ride, the total is automatically charged to your payment

method, and you can go on your way. Riders and drivers can rate each other from one to five stars, with five stars meaning that the ride was uneventful.

Overall, Uber and Lyft are a wonderful alternative in places where taxis are not reliable or even available. They are also a great supplement to public transportation. They allow you to go places that it may not serve or to get around after it has stopped. I use it frequently to get home from concerts. While it can be expensive to use these services on a regular basis, they are very resourceful in a pinch. They are an excellent tool to increase the independence of people with albinism.



2016 McGowan Leadership Scholarship Recipient Lee-Anne Thompson

Established by the NOAH Board of Directors in 2008, the Michael J. McGowan Leadership Scholarship has sought to recognize leadership and empower young people with albinism. They believe in nurturing the passion and focus of the next generation of leaders and celebrating their contribution to the albinism

community. This year's McGowan Leadership Scholarship was presented to Lee-Anne Thompson at NOAHCon2016.

Lee-Anne and her family have been involved with NOAH since before she can remember... literally. At nine months old, she attended her first conference in Philadelphia and has been a

devoted advocate and role model ever since.

Lee-Anne has demonstrated a strong commitment to service and leadership through fundraising and public education. Since 2007, she has been an active member of a fraternal youth organization called the International Order of the Rainbow for Girls, utilizing opportunities within this organization to educate her peers about albinism and to support NOAH through local fundraising events. Lee-Anne eventually rose to the ranks of Worthy Advisor, the highest station attainable in her local Chapter. Lee-Anne has also served as an administrative volunteer at her local low vision clinic, where colleagues and supervisors have praised her work ethic, compassion and dedication. Here, she has also utilized opportunities to promote NOAH, to educate others about albinism and to ensure the highest level of accessibility and sensitivity to patients with low vision in the clinic.

In an effort to raise awareness about albinism at home and abroad, Lee-Anne has confidently shared her story via such media outlets as The Weather Channel and TLC. She has presented at local and international conferences, including co-facilitating age-appropriate educational programs for children

at the past three NOAH national conferences. Lee-Anne has noted how these experiences teaching children with albinism about their condition has empowered them to be their own best advocate. Lee-Anne also served as the first secretary for NOAH Canada in 2011.

“I wouldn’t know a life without NOAH,” Lee-Anne said. “I have received so much encouragement and support from the NOAH community. Now I’m at a turning point, where I hope to pay it forward so that those in the albinism community can have access to the same resources that I’ve had throughout my life.”



Lee-Anne is currently attending the University of Waterloo in Waterloo, Ontario, where she is majoring in Social Development Studies with a specialization in social work. After completing her bachelor’s degree next spring, Lee-Anne aspires to pursue a master’s degree in social work in the hopes of finding a career path where she can help others to fulfill their potential. “I hope I can continue to embody

the leadership qualities to teach and help others the way that so many of my mentors within the NOAH community have been able to do for me,” she said.

Thank You from CARE

By Judi Duffey

Thank you to everyone who stopped by the CARE table at the NOAH conference. Because of you, we now have more IFSPs, IEPs and 504s to share with our albinism community.

The CARE Project, also known as Create Albinism Resource for Education, is a program that seeks to provide parents and educators with resource information that will aid them in formulating their child's or student's educational plan.

By continuing to submit your IFSPs, IEPs and 504s at www.albinism.org/care, you will help other parents benefit from your experience. All documents will be scrubbed of personal information before they are released.

If personalized educational plans are new to

you or you are planning ahead to see examples of accommodations, devices and objectives

that are being used in upper grades, NOAH has a proven resource for you. Through the PARENT page on the NOAH website, a database of actual documents is available for viewing and downloading. Documents in the database can be viewed

by document type, state, age, grade and visual acuity.

All children with albinism have different personal developmental needs. After viewing the material provided by CARE, parents can broaden their understanding of educational plans which will assist them in establishing their child's unique IFSP, IEP or 504.



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

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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