NOAH Ed U

CREATED WITH EDUCATORS IN MIND

Spring 2017

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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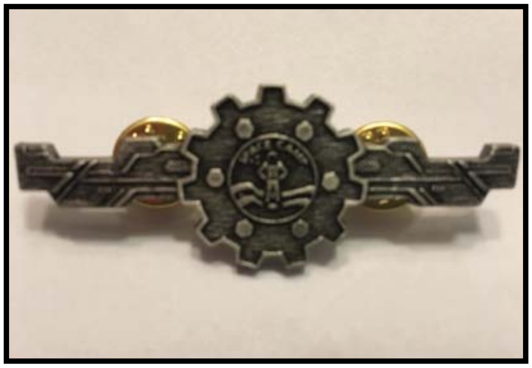
Does the family of your student with albinism know about NOAH?

Share this supplement with them so they can learn what NOAH has to offer!

Space Camp® and NOAH

By Dan Oates and Andrea Goodmon

Space Camp® was launched in 1982 to inspire and motivate young people from around the country to join the ranks of space pioneers who persevere to push the boundaries of human exploration. This immersive program still continues to challenge young people to dream of a future in space.



However, when Space Camp® first opened, little thought was given to special populations attending the program. It was a different time and the Education for All Handicapped Children Act (Public Law (PL) 94-142) was still in its infancy. As the popularity of Space Camp® grew, it was soon apparent that all children wanted to attend. In the late 1980's, a group of Special Education students petitioned Space Camp® to attend. It was granted and the barriers began to fall. The story is best told in the made-for-television movie, "A Smile As Big As the Moon".

In 1988, West Virginia Schools for the Deaf and the Blind received the first invitation to a camp for the deaf. Shortly thereafter, in 1990, twenty blind students launched toward Huntsville, Alabama, the home of Space Camp®. During that first trip, students with albinism attended. The program slowly grew and began attracting students from different states and even countries.

In 2016, its 27th year, 211 students from Australia, Belgium, Canada, Greece, Ireland, India, Israel, and South Africa were present. Thirty of those students had albinism! Since 1990, close to 4,000 students have attended from almost every U. S. state and Canadian province and over 20 countries.

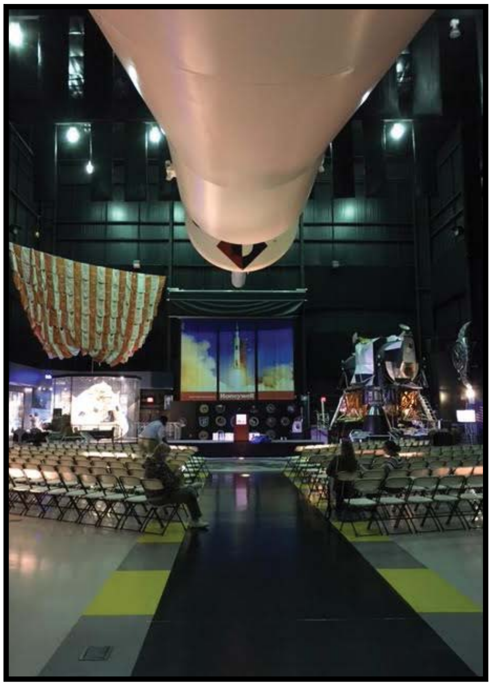
The program at Space Camp® consists of three choices: astronaut training, jet fighter pilot training or robotics. Students can choose which program they want. Space Camp® for Interested Visually Impaired Students (SCIVIS) takes place in late September. Students starting in the 4th grade can attend. During SCIVIS week, adaptations are provided for blind and visually impaired students. Those adaptations may include large print, braille, electronic magnification, an adapted schedule and equipment, and most importantly, socialization with your visually impaired peers. This has truly been the highlight of the program. Astronaut and jet fighter simulators are an integral part of the training for the week. The training ends with simulated space and aviation missions.

For the Advanced Academy program for college-bound 10th through 12th graders, scuba-diving and a high ropes course are included in the program. A one-hour college science credit from the University of Alabama in Huntsville (UAH) is given to those young astronauts completing the curriculum.

Students with albinism are a perfect fit for SCIVIS, as these Space Camp® alums can attest!

Connor

I really enjoyed Space Camp® . I especially loved the 1/6 gravity chair. It was so awesome feeling like you were on the moon. I also loved all the other simulators like the MMU simulator. The MMU is a jetpack for space. I also learned a lot about space history like the fact that the Gemini missions involved meeting in space. Did you know that in one of the Apollo missions when they were testing the Saturn V, NASA only gave them half the fuel they needed to prevent them from trying to go to the moon? I also loved being the flight engineer on the second simulated mission. I made stuff like rocket foam and slime! We went swimming at a lake in the Aviation Challenge area. We also had great food every day like biscuits, potato soup, mashed potatoes, spaghetti and lots more. I especially loved the biscuits and dinner rolls. I also really liked the 5DF chair, which was a simulator just like the MMU, except you don't control it. There was also the MAT which spun you every which way, while keeping your stomach in the center so you don't get dizzy. Space Camp® was an experience that I will never forget.



Finn

I had the best time of my life at Space Camp®. I met new friends, learned about space and the space missions. There were 3 other kids with albinism in my group.

Space Camp® was extraordinary. We had missions with different positions on the orbiter, space station and mission control. I was Shuttle Commander. I flew the orbiter. We also learned about the next mission to Mars. We went in a lot of simulators. One was called the MAT Multi Axis Trainer. The MAT simulates a disoriented roll in space. I loved it because it spun you everywhere, upside down and side-to-side.

The teachers were nice and very helpful. The program had large print and braille. They also had zoom features on the computers. It was awesome because there were no issues with seeing things. I love to fly and I thought it was cool that NASA worked with Boeing. The airport in Huntsville had an exhibit based on Boeing. It was interesting. I hope I have another opportunity to go back to Space Camp® and learn more with my friends. I will be in Space Academy next time.

Thomas

I am an 8th grader at Union Academy Charter School in Monroe, North Carolina. I received a scholarship to attend SCIVIS 2016 from NOAH and participated in the robotics program. This year was the first year it was offered at SCIVIS and I was the only trainee with albinism in robotics.

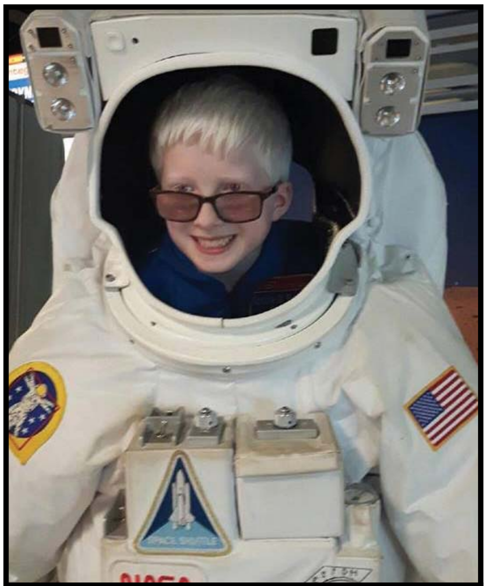
During the week, the robotics team had a focus word each day to help learn the terminology used in robotics. I spent time in the robotics lab learning about connections, motors and basics of how robots work. I would then build robots for the competition trying to make them multi-functional. Every robot had to have 3 functions. My team had to make underwater robots to complete challenges such as picking up rings and bringing them to the surface. We also practiced flight simulators using hand held controls and created an electronic project to take home.

On the last day before graduation, there was a final robotics challenge. I was the system analyst (aka computer guy). I was responsible for connecting the robots to wireless controls, tracking team balances and most importantly playing the music. The trainees and instructors custom made the programs for the challenge, which simulated repairing satellites and collecting samples from the moon. It was so much fun. I want to do it again. I recommend Space Camp® for anyone interested in engineering and robotics.

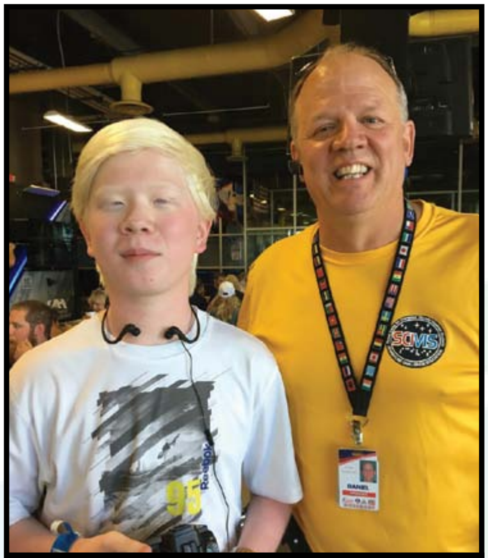
NOAH has been awarding full scholarships since 2013 and has committed to sending six more students for SCIVIS 2017. Mike McGowan, Executive Director, attended the program as an honored guest, studied the program, and realized the impact that it has on children. Look for more information on how to apply in the summer edition of *Albinism InSight*. Other scholarships are also available through the Delta Gamma International Sorority, St. Louis Lighthouse Vision Program and Northrup-Grumman Foundation. Visit **http://www.scivis.org** to apply.

Connor & Family

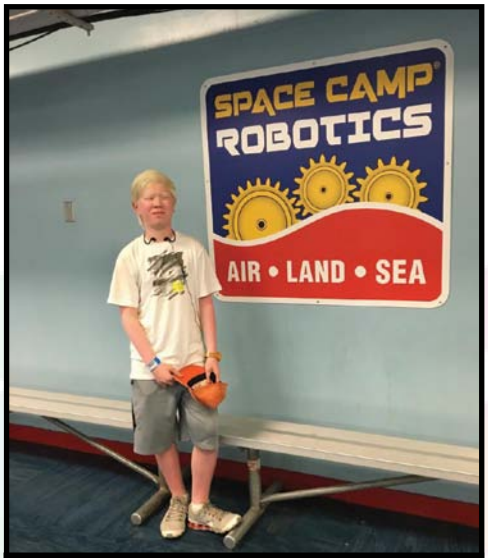
Finn



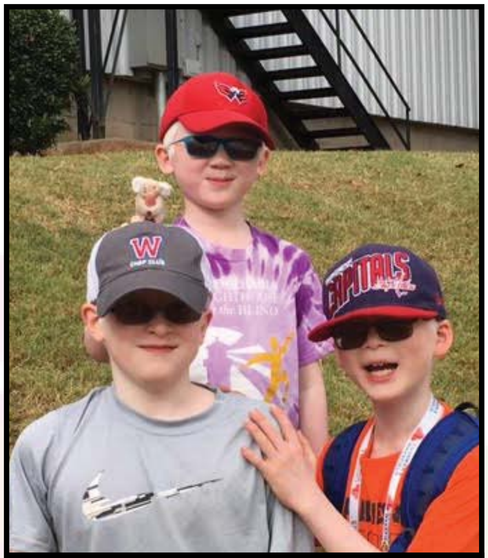
Connor



Thomas with Dan Oates



Thomas



Finn with NOAH friends!

To Disclose or Not to Disclose?

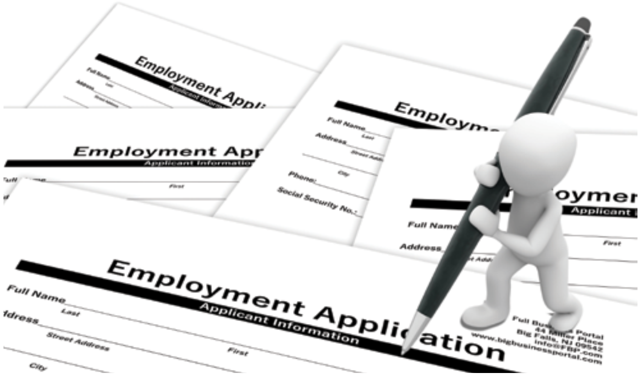
By Rachel Revennaugh

This year, I'm a senior undergraduate music and English major. I sent in my graduate school application the day before Thanksgiving. I am so excited that I finally submitted it after working on it for at least 20 hours and having to pay the grad school fee and taking the GRE. Before I sent it in, I spent hours meeting with career counseling services at my university working through my statements and interview questions.

One of my inquiries was whether I should mention my albinism or not. After all, before college I never told people about albinism. It has only been in college that I began identifying as having a disability. This is partly because my vision is miraculously quite good, even with the albinism. But just like everyone with albinism, I have visual challenges that affect my everyday life that I overcome.

I, therefore, asked the career counseling and disabilities offices if they had any suggestions.

Here are some important things to consider:

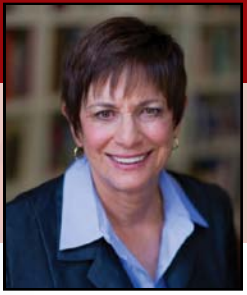


1. **What am I applying for?** I'm applying for school, not a job. The degree I'm seeking is a Master's of Music Therapy. The music therapy occupation is related to disability because many in the client population are receiving the therapy.
2. **How obvious is my disability?** People often do not know that I have albinism (instead, I'm getting used to the more-often reaction of surprise: "Oh, but your eyes aren't red. You must not have it very bad." Then I have to figure out a way to explain things). Mentioning it or not is completely my choice. It is possible that it might never come up, unless I choose to bring it up.
3. **How has albinism affected me?** I believe that I have matured by having experiences with albinism that many people without disorders have not experienced at my age. This includes things like surgeries and waiting for medical decisions. I have learned empathy through these experiences that I can relate to others, with and without disabilities. This has helped me be a better tutor at school. Through all of this, God has proven that He can bring good things out of potentially difficult circumstances. I want to go into music therapy because I want to help other people with disabilities. Therefore, having albinism can definitely be relevant to the conversation of why I decided to go into this field.

What was my decision? As you may have guessed, I decided to disclose my albinism. I even told my references that they could mention it. At least one of them thanked me for the permission because it has a lot to do with my activities on campus. I am definitely not saying that everyone should disclose having albinism. I also identify as having a disability, which not everyone who has albinism does. These are personal decisions that people must make themselves. I am just sharing my own perspective and hope that it can relate to some of your own goals and experiences.

Steps Toward Visual Independence

By Anne L. Corn, Ed.D.



You may have been told that your child's visual acuity (measure of how much detail a child can see on an eye chart under specific lighting conditions) isn't going to tell you the whole story about what your child is able to see at home, at school or on a playground. I have watched children in similar lighting situations with similar visual acuities use their vision in very different ways. As a teacher of children with visual impairments and later as a teacher of teachers, I have wondered why this is true. There are different theories about how lighting, color, size, location, distance and contrast help a child to see objects. I have also come to understand that aspects of a child's personality, motivations, social environment and emotional support also need to be considered. I offer this article to share how I've seen children move through steps toward becoming visually independent. For some children, this may be intuitive. However, for others, there may be challenges or barriers along the way.

Visual Reach

Think of a child's visual reach as what he sees when he opens his eyes (with standard glasses and / or contact lenses, if prescribed).

Many children with low vision are able to quickly learn about their environment and people, animals and objects within it. By contrast, others will benefit from instruction to use their visual reach to understand what is seen at various distances, to become aware of objects in their peripheral vision or to learn to use visual cues and interpret what is seen. A child's visual reach is sometimes referred to as unaided vision. This is because the child is not using a device to obtain more detail about what is seen.

At this stage, a child needs to: 1) know an object exists, by seeing the object with sufficient detail, or from a visual image that may not provide enough information to identify the object, or from a sound that indicates where an object is located, or from directions given as to where to look for the object, and 2) the child needs to learn how to interpret what is seen.

Extending Visual Reach

Extending visual reach refers to when a child takes an action and / or uses a device to better see that which is not accessible within her visual reach.

A typically sighted person may use a pair of binoculars to see a sporting event or a magnifier to pull threads in a sewing project. Some of the actions a child with low vision may do include: moving his head closer to an object, tilting his head to use a null point, altering his position to get more or less light on an object or using a low vision device to magnify an object.

At this stage, a child needs to: 1) understand that others see the object with more detail, 2) have a curiosity about an object, 3) have a need to know more information about an object and 4) know he has the skills and devices to gather more information about the object.

Visual Efficiency

Visual efficiency refers to how well a child uses his or her vision, sometimes referred to as functional vision.

A child may be able to use “less” detail vision and be able to function in a similar way to someone with a better visual acuity if he is efficient with his unaided vision and knows how to extend his visual reach. For example, a child may not see letters clearly but is able to use what he sees and be able to read. She may learn to use magnification and increase her reading speeds to grade level expectations. Visual efficiency, therefore, involves the extent to which a child is able to use vision in relation to clinical measures, such as the measure of visual acuity or contrast sensitivity.

Teachers of students with visual impairments and orientation and mobility specialists should be able assess and provide instruction for a child to use her visual reach, to extend her visual reach and to improve visual efficiency. Still, there is one more step to the process.

For visual efficiency, a child must be willing to develop the skills needed to improve her visual skills with or without a device.

Rick Guidotti, Positive Exposure

Visual Independence

The final concept that should be considered for a child with low vision is visual independence. This refers to the extent to which he uses his vision in daily life to receive information, to plan and / or to complete tasks, to create or appreciate beauty in his environment.

The extent to which a child becomes visually independent is based not only on how well the child understands what he sees, has the skills to extend his visual reach and how efficient he is with his vision. It also comes with choices for personal independence and the extent to which the child wishes to gain control over his visual needs.

Visually independent children use their vision in a comfortable and efficient manner for most tasks for which a visual approach is commonly used. Therefore, a child can be visually efficient but may or may not be visually independent. A visually independent child tends to be someone who wishes to do for himself, to make judgments based on visual information and past experiences and seeks new visual experiences. Visually independent children also tend to be thoughtful about when the use of vision is preferred and when a non-visual method is a better approach when participating in various activities.

When a child is increasing her visual independence she needs to have 1) a positive sense of self as a person with a vision impairment, 2) a willingness to let others see her taking an action or using a device, 3) a sense that she wants to be visually independent and 4) an understanding that there are times when using non-visual approaches or using assistance is a choice that may lead to completing a task more efficiently or comfortably.

To be totally visually independent is not, and should not be, the goal or the status that is valued. With an understanding of the consequences of wanting others to provide visual information, children’s choices need to be respected. I believe the goal should be focused on adults providing children with opportunities that enable those with low vision to use their gift of vision to the extent they are able to function comfortably and efficiently and to offer emotional support and encouragement for a child to do so. This is a philosophical decision for adults and one from which children will learn to gain control of their visual needs.

Adults are often faced with dilemmas of just how much to expect and how much to encourage visual independence. An example is a child who has learned how to efficiently use a handheld monocular or an electronic device to obtain information from a whiteboard and can do so at a speed that permits him to keep up with his classmates. However, he still prefers to let others give him their notes, his parents ask that a teacher provide notes on his desk or his teacher wants to make life easier for the student and is happy to provide the notes. The child learns how to accept help. However, what has he learned about gaining control of his visual needs?


Rick Guidotti, Positive Exposure

Similar dilemmas may occur within families. For example, each time a teen wants to cook, he brings the package over to a parent to read directions that are in small print. The parent may not wish to discourage cooking and it is easy to read aloud. The child receives the directions but doesn't learn to cook independently. The child may also not be expected to learn to cook because the parent is concerned about the child's safety in the kitchen, how to measure ingredients or how to read recipes.

There are children who choose to forgo receiving visual information or functioning independently, regardless of their visual abilities or skills in extending their visual reach or the level of visual efficiency they have obtained.

Based on my experience, hypothetical children are introduced with a description of how they first function without visual independence and then what can be changed.

TAYLER (age 4)

Assisted

A door opens to a preschool class. Four-year-old Tayler's mother is coming to pick him up from school. Just before dismissal, all the preschool children have free playtime. Tayler likes to play with the blocks to build houses and towers. The door opens each time a parent comes into the room to pick up a child. When Tayler's mother arrives, the teacher usually says aloud, "Tayler, your Mommy is here." Tayler starts putting the blocks into the box next to where he is playing. His mother comes to him.

Independent

After giving Tayler a handheld monocular, he is given instruction in how to locate and identify people using the device. When the classroom door opens, he checks to see who is entering. When his mother comes, he leaves his toys and goes to greet her, as do the other children in the class with their parents.

AUSTIN (age 8)

Assisted

Third graders in Austin's class are expected to come into their classroom and copy into their journal one to three sentences from the whiteboard. These sentences are a prompt for their journal entry. Each day Austin's teacher leaves a copy of the sentences in 20-point print on Austin's desk. While the other children are copying, she may also come to Austin's desk and speak the sentences to him as he writes them. Earlier in the year, he walked up to the whiteboard and tried to copy after the other children had finished. However, he didn't have enough time to write his journal entry. He also asked another child at his table to read it aloud, but his teacher thought the two boys were talking and he was scolded. He was too embarrassed to tell his teacher why they were talking. Austin really doesn't like the attention from the teacher taking care of him. However, he doesn't know of any other way to do the task.

Independent

Austin is given an iPad and shown how to use it to photograph the sentences on the board. Austin enlarges the image and is able to use the sentences to begin his journal entry. He usually begins writing before all of the other students start to write in their journals.

TONASHA (age 16)

Assisted

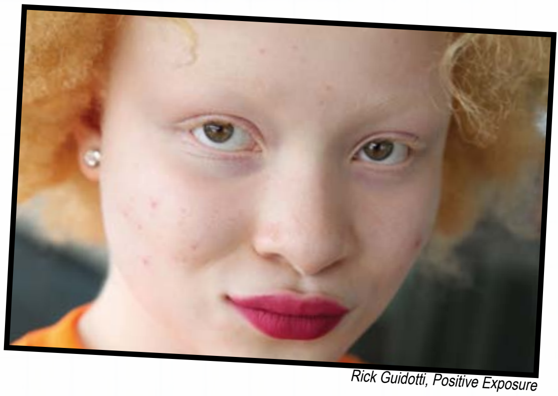
Tonasha is a 10th grade girl who goes shopping with her older and younger sisters. They are going to the mall for T-shirts to wear to each of their school events. Tonasha, in middle school, is looking for her school colors, maroon and gold. On previous trips, one of Tonasha's sisters would stay close to her and read each of the sizes and prices of clothing. Tonasha is accustomed to having others read for her, when she does not have large print provided to her. Tonasha is perfectly fine with her sister assisting with this task and taking care of her. She has never shopped by herself.

Independent

Tonasha is given a handheld magnifier and also shown how to use a smart phone to enlarge price tags, sizes of clothing and receipts. She finds she enjoys shopping with her sisters but enjoys being able to go off and find her sizes while her sisters find their sizes of clothes. They meet to compare how the clothes look on each of them before making purchases.

Rick Guidotti, Positive Exposure

Rick Guidotti, Positive Exposure



Rick Guidotti, Positive Exposure

Rick Guidotti, Positive Exposure

JONI (age 16)

Assisted

Joni takes the #102 bus from a bus stop where several busses stop along their routes. When each bus arrives, Joni gets up from the bench, goes to the open door of the bus and asks the driver if it is the correct bus. She wishes that the drivers of the #102 would just look for her and tell her when they arrive.

Independent

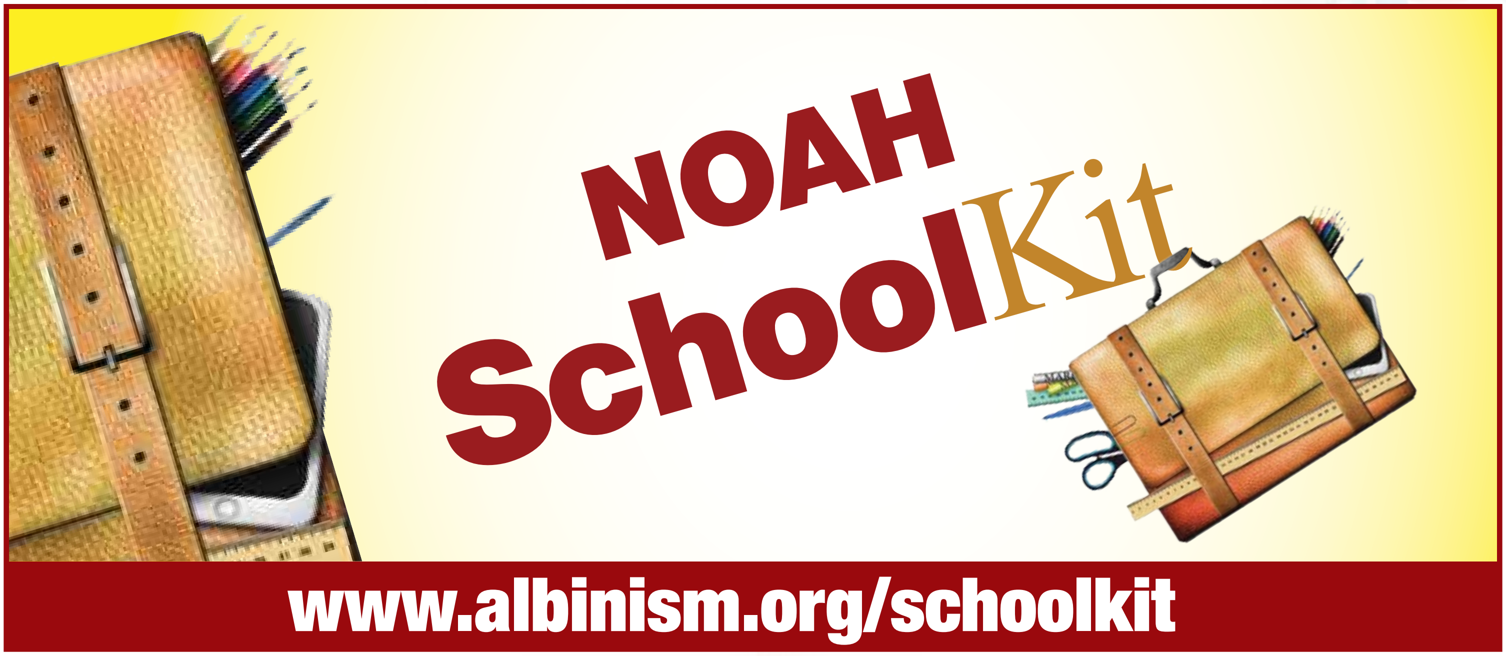
Joni is introduced to a handheld monocular and is given instruction on how to use it to identify busses as they approach the stop. This allows her to remain seated and to read her book. She only has to stop briefly to check busses. She is also discussing whether driving with a bioptic telescopic system would be feasible. However, she knows that first she must be able to use her monocular in public and to better develop her travel skills.

In summary, through instruction and low vision methods and devices, children with low vision can move toward becoming both visually efficient and visually independent. Some children will go through the steps toward visual independence with minimal assistance, while others will need adults to provide the methods and devices, as well as the support necessary to meet their potential. As adults they will decide the extent to which they wish to be visually independent.

When I see an IFSP, an IEP or a 504 Plan, I look for an assessment of visual skills and for visual independence goals for the child.

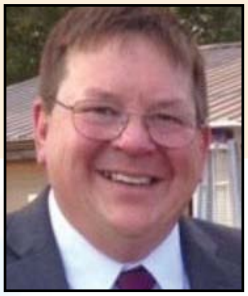
Here is some additional information that may be helpful:

- Medical evaluations (e.g., clinical low vision evaluations) are available through IDEA, if they will assist a child in improving functioning within special education.
- IDEA covers assessments, procurement, instruction, and maintenance of assistive technologies (e.g., optical and electronic devices).
- The Expanded Core Curriculum for Students with Visual Impairments (ECC) includes Sensory Development and is part of the instruction afforded to students with low vision by certified teachers of students with visual impairments (TVIs) and certified orientation and mobility specialists (COMS). The ECC has been adopted by many school districts and is required in some states.
- Visual skills may be taught within several curricula areas of the ECC, including but not limited to career education, social skills, daily living skills, orientation and mobility skills and sensory development.
- 504 Plans are based on anti-discrimination legislation. They can include both direct instruction and optical and electronic devices as needed.



Starting the IEP Process

By Joseph Sartorius



The various education processes in the local school district, state and even federal programs can be very overwhelming. IDEA (Individual with Disabilities Education Act), ADA (Americans with a Disability Act) and 504's (Section 504 of the Rehabilitation Act) are all legislative acts that will have an impact on your child through adulthood.

In reflecting on the advocacy, I found myself remembering how many times I have actually had conversations with parents, friends, and neighbors over the years. Of course, as educators we always want to be helpful and find ways to improve any situation for students. The most important step to helping a student [and their family] is to realize that to have success at any school, we must match the needs of the child with the resources that are available in order to challenge them academically and to provide the best learning opportunities.

When telling parents how to help their child, we always want to start with the teacher, principal and the counselor. Communication is key in any evaluation scenario. The parent and student need to meet with the teacher and principal to make them aware of their concern. However, the counselor is the person who will get the IEP process started. The counselor will collect data from the student's academic history. From that data, the team will decide on the severity of the need. If necessary, the school psychologist may also evaluate the child. The student will work through a set of interventions to help them before special education services are provided. This is based on the past history of data from the student's academic records.

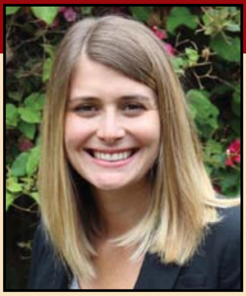
If the intervention is not successful, the student may move on to special service testing to determine a special education category outlined by each individual state, following the Federal IDEA. IDEA defines an IEP (Individual Educational Plan), which is a legal document developed by a team including but not limited to a general education teacher, a special education teacher, an administrator, parent, counselor and student, if appropriate. The team begins by reviewing data about the student and any medical information that may be pertinent to the student's ability to learn.

From all of the information gathered and reviewed, educational goals are developed which can be met within a year time frame. How these goals will be measured is also determined. A determination is made of the child's disability and placement. The next step is to develop accommodations. Common accommodations include: shortened assignments, repeating directions, highlighted text, outlines/teacher notes, verbal cues, word banks, note taker, extended time, manipulatives, preferential seating, computer access and use of a test center. Modifications are also reviewed and include changing the curriculum or expectations of the student's performance from that of the grade level. An example may be reducing the number of problems to be completed on a math assignment.

After reviewing existing data, the team will identify goals based on student needs, determine placement for the student and look at accommodations and modification. The last area to address is the number of minutes of service the child will receive by special education staff.

There is no 'cookie cutter' approach to any one situation. Learning about the whole student is necessary to place them appropriately for the optimal success. Any parent, who wonders if their child needs special services, needs to keep in mind that every child is different. Not every student gets straight A's and that doesn't mean they need special education support. Children may have learning issues that may require additional support to be successful. Every child is unique. Therefore, the process for helping them will also be unique.

ADVOCACY & AWARENESS



Young Professional with OCA Draws from Life Experiences to Help Others

By Emily Coring, Director of Development for The Vision of Children Foundation

"The diagnosis of albinism can be confusing for parents, and adjusting to life with the condition can be difficult for affected children," wrote Britanny Kronick in her September 2016 article published in *The Journal for Nurse Practitioners*. Her article focused on pediatric primary care management of children with oculocutaneous albinism 2 (OCA 2). However, she was also writing from her own experience.

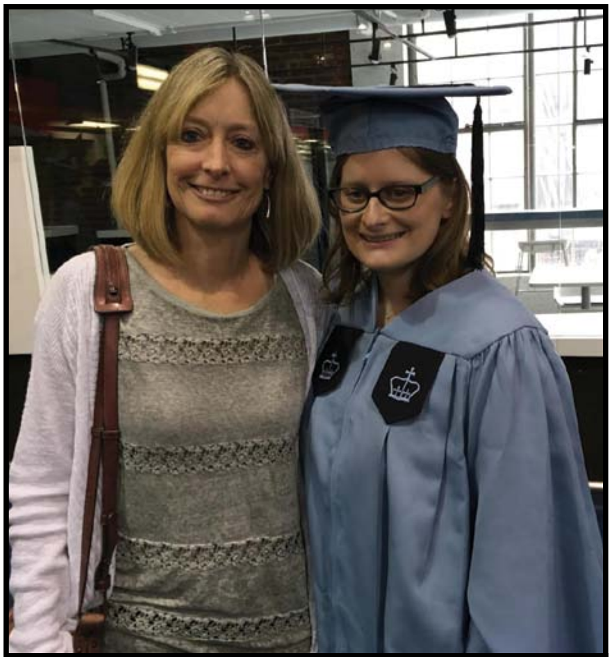
"I have albinism, OCA, and I've always wrestled with how it fit into my life," said Brittany, who holds an MSN degree and is the pediatric nurse practitioner at New Alternatives for Children, which provides services in support of birth, foster and adoptive families caring primarily for medically fragile children in New York City.

"As a teen I had extra angst," Brittany said. During her sophomore year, her eyes re-crossed (strabismus), and she felt isolated and angry that she had to deal with a problem that her peers didn't understand. "Adolescents may focus on potential future obstacles because of others' lack of understanding of their capabilities," she stated in her article. "Visual impairment can increase the risk of social exclusion or low community participation."

These experiences left an impression on Brittany and she decided she was uniquely qualified to do something about it. In her current role at New Alternatives for Children, she provides and manages the medical care for some of New York City's neediest children. She attributes her success in working with this group to her ability to treat each person with respect and let them know that they are not alone.

"I am the only one in my family who has albinism," Brittany said. "I have a supportive family, but while growing up they didn't quite understand what I could and couldn't do. As a result, I've been adjusting to life on my own."

She is now working on her doctorate in nursing practice from Columbia University.



Brittany, with her mom, after receiving her Master of Science, Pediatric Primary Care Nurse Practitioner degree, from Columbia University School of Nursing.

Brittany recalled milestones from her youth that reinforced her path of independence. She learned how to read books with regular size print, rather than enlarged print. She participated in gymnastics for 10 years and reached a competitive level. She also played on a baseball team. She said that she experienced the most frustration when doctors told her, “You can’t.”

“Just to limit someone because they have a condition seems pointless,” she says. “As a clinician, if I tell a parent that their child can’t do something, then they don’t push their children to their fullest potential. That doesn’t seem right.” She added, “I never felt pushed beyond a point of what I could do. I’ve always been motivated. Living with albinism is stressful, no matter what.”

Brittany is living proof that a condition like OCA does not have to define a person’s inabilities, but it can contribute positively to a person’s abilities.

For more information on The Vision of Children Foundation, please visit www.visionofchildren.org .

ANNOUNCEMENTS & GATHERINGS

NOAH and The Maryland School for the Blind Family Workshop

Albinism
Family Day

Saturday, April 22, 2017
10:00 a.m. – 3:00 p.m.
The Maryland School for the Blind

Come network with other students, individuals and families of children with albinism for a fun-filled day of adapted carnival and backyard games! Learn about updated information and resources through an information scavenger hunt with mentors from the albinism community and professionals in the vision field.

For more information please contact Ruth Ann Hynson, Director of Statewide Outreach Service at 410-444-5000, ext. 1726 or email her at **ruthh@mdschblind.org**.

Determined to Drive

By Christian Farley

My name is Christian Taylor Farley and I was born with albinism. I turn 17 in March. I love math, video games and sports. My favorites are NES, Namco, and Xbox Live games. I currently run the 55-meter dash, 300-meter and 600-meter races at my school indoor track meets. I enjoy running and exercising. I wear glasses to see and block out the glare from the sun as well as wear sun protective long sleeve shirts on the really hot days to prevent sunburns. I tried running with a hat but it blows off in the wind. I still love running no matter what the challenge.

As a teen with albinism, I feel unique and different because no one at my school looks like me. As a result, I kind of stand out in a crowd. No one in my school understands what it is like to be a person with albinism. I face many challenges, like fluorescent lights bothering my eyes, kids teasing me when I was in elementary school and not being able to see the boards at school.

My mom and I love reading the *Albinism InSight* magazine to learn more about albinism and to see people just like me. The NOAH organization has helped me to better understand albinism and to love myself. I am inspired by all of the stories that I read.

I recently went to the Department of Motor Vehicles to apply for my learner's permit. I had studied and I was ready to take the test. However, I was concerned about the vision test. Even with a brand new pair of glasses that I love with glare protection, the DMV clerk informed me that my script was not strong enough to pass the vision test. I found that the DMV clerk knew very little about albinism, since I see perfectly clear up close. I wish they had more knowledge in dealing with persons with albinism.

I would love to walk into a Department of Motor Vehicle Department and be welcomed by signs for people with albinism, or anyone who needs visual aids or support. I didn't know what to do or say at the DMV, but I felt a sense of urgency to find out the next steps to obtaining my driver's license.

Upon visiting my eye doctor, he stated that it would be a 50/50 chance that I could get my permit or license. He said that my eyeglasses improve my vision, but they do not determine if I can drive. My vision with albinism is short but clear, making me almost legally blind. This can be very discouraging, but I don't want to give up.

I would love to know if there are other teens out there that want their freedom to drive and if it is possible. I would love to hear your stories of how to be independent as a teen and future college student tackling the transportation needs in order to be independent.

Save the Date!

NOAH
FAMILY SUMMER CAMP
NEW HAMPSHIRE
July 15 – 19, 2017

NOAH FAMILY CAMP
FUN & FREEDOM

Create amazing memories **with a classic camping experience** designed for children with albinism and their siblings (seven and older).

NOAH Family Camp
Lions Camp Pride
154 Lions Camp Pride Way
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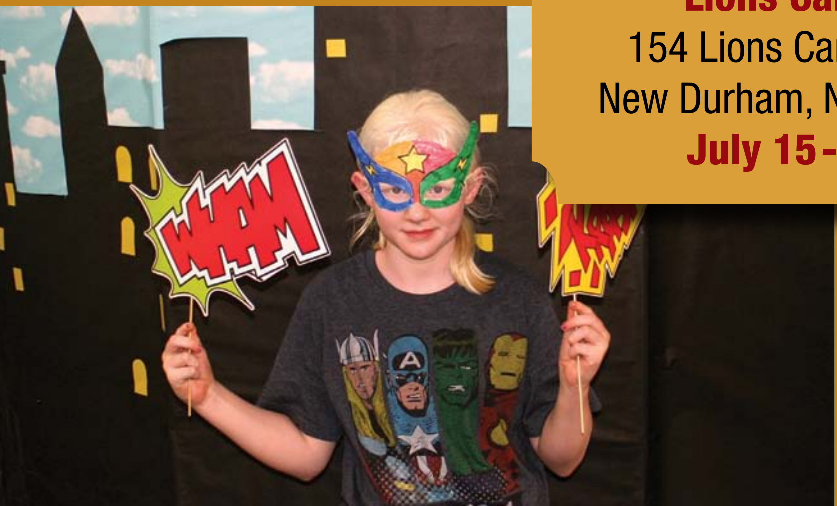
July 15-19, 2017



Announcing the 9th Annual
Michael J. McGowan
LEADERSHIP
SCHOLARSHIP AWARD


Lee-Anne, **2016**

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

Past Recipients


Nicole, **2009**


Silpa, **2010**


Diane, **2011**


Charles, **2012**


Tricia, **2013**


Arielle, **2014**


Cassandra, **2015**
Photo credit: David McMeans

Apply for **NOAH's 2017 McGowan Leadership Scholarship**
at **www.albinism.org/scholarship** and submit supporting materials **by May 1, 2017.**