



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Autumn 2015

Welcome to NOAH Ed U!

The National Organization for Albinism & Hypopigmentation (NOAH) presents this complimentary supplement, geared toward educators, based on its quarterly magazine, *Albinism InSight*. We encourage you to share this publication with other educators who work with children with albinism. To enter your school or email address to this distribution list, please contact info@albinism.org.

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Photo courtesy Erwin Photography

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!

Fair Share

By Rita A. Jackson, *Albinism InSight* Editor, NOAH Editorial Committee Chair



Want to know how people celebrated the first-ever International Albinism Awareness Day? Need some tips for back to school? How about some info on colleges and careers? All of that plus Family Camp, mini conference memories and more are waiting for you in this edition, but first, let's share our knowledge. The question for Autumn honors educators. **What was the most helpful thing a teacher did for you at school?**

People didn't understand how to help me, especially at school. My mother wrote long letters explaining the limitations, and teachers tried to make it easier for me. Most assigned me a seat at the front of the class and never included me in seat rotation, for which I was grateful.

When he noticed my classmates checking on me and passing their notebooks to me, one of my teachers granted me permission to take pictures of notes on the blackboard with my phone. There was a strict policy against using cellphones in school, but after that day, all my teachers allowed me to use my phone for notes. Anvita B. – Los Angeles, CA

It sounds old-fashioned now, but in 1975, my high school history teacher lectured from notes on an overhead projector. After the first class, he said he understood I had a visual impairment, but he wasn't sure how to help. He offered to lend me the transparencies so I could copy them but emphasized that it was up to me to ask for what I needed. This was the greatest lesson I ever got in self-advocacy. Mike M. – Chicago, IL

When I was in 2nd grade and my brother, who also has albinism, was in 4th, we were in a

multi-grade class. Mr. Baty made sure we could see the board and that no one picked on us. Due to his experience with us, he later began working for the state helping visually-impaired students. My brother and I weren't aware of this until we attended high school in another part of the state and learned that our IEP person would be Mr. Baty! Natalie O. – Priest River, ID

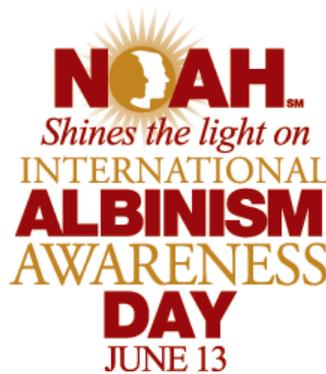
My 6th grade teacher assigned a classmate to dictate text on the blackboard to me. This made taking notes faster. In addition, I was no longer blocking the other students' view when I stood so close to copy notes. Karen K. – New York, NY

My favorite professor simply took an interest in how I see and what I needed. She was very understanding. Rachel R. – New Brighton, MN

Mrs. Kenyon, my 6th grade social studies teacher, devoted a summer to recording the 900+ page Western Civilization textbook onto tapes as a reading aid. Though not done specifically for me, the tapes provided an empowering path to knowledge that restored my self-esteem.

The school grouped students based on perceived ability. The announcement on the first day of school crushed and shamed me into silence. My vision landed me in Group 4, the lowest. I felt I was a 1, not a 4. The tapes helped me prove it.

They were a leveler and a leg up. I'd wear headphones and follow along in the text. Reduced reading stress enabled me to plow through text, ascending a ladder of accolades, while ignoring pleas to slow down. I finished



the book three months early, got the highest mark on the final test, and discovered a confidence-building model for tackling future reading tasks. Andrew L. — Portsmouth, NH

My daughter's teacher slipped her a note, sending her to the counselor's office during class when he noticed she had been crying. We later learned he had stepped into the hall and called the counselor to let her know that he was concerned that someone may have been unkind to Lexi. He wanted to give her an opportunity to talk with an adult and get help if she had been treated poorly. Misty W. — Yukon, OK

Every day, my science teacher asked how I was doing and if there was anything he could do for me. I felt special and knew he cared. He always gave me compliments, smiles and encouragement. Lexi W. — Yukon, OK, Age 13

My Orientation & Mobility teacher showed me an iPad app called Explain Everything. It allows me to take a picture of something, such as a math worksheet, and lets me "write" on it. I can put my answer in a text box and move it to my desired location. I can also draw shapes and lines to connect things. I can take a screenshot and email it to my teacher. This is CRAZY useful because I don't have to squint at a sheet of paper all the time. Tim L. — Loudon, NH, Age 11

The most harmful thing a teacher did turned out to be the most helpful. She seated me across the room from the blackboard. At Christmas, we were making cards for our parents. She printed the message on the board and told us to copy it then bring it to her for approval. I copied what I saw (with

my 20/200 vision) and confidently took it to my teacher. She took hold of my shoulders, shook me hard, and said something about not knowing when I was ever going to learn to write. This happened in front of all the other first graders. Crying and humiliated, I told my mother what had happened. She went back to the school with me and talked to the principal who then talked to the teacher. Throughout the rest of first grade and the rest of school, I was given the accommodations I needed. Janice K. — Terre Haute, IN



Lexi W., age 13

My teachers make sure I have seating near the smart board and chalkboard. I used to have a hard time asking for help because I didn't want people to treat me differently, but my teachers advocate for me and have empowered me to advocate for myself. Nicholas P. — Dublin, OH, Age 13

Teachers provided me with the notes they used to write on the blackboard. When I had the notes at the beginning of class, I could absorb the lesson more easily because I was not as concerned about making sure I wrote everything down correctly. Kathryn C. — Nesconset, NY

When I was in 9th grade, the typing teacher wanted me to take typing, but I had been typing since I was six years old and knew the touch system. My sight conservation / homeroom teacher, Mrs. Kersey, said she did not know how to type and would like to learn. I told her I could teach her the touch system in our classroom since we had two typewriters. We worked it out with the typing teacher that the lessons I gave Mrs. Kersey would be my grade. Mrs. Kersey was an excellent and hard-working student. Years later, Mrs. Kersey had

to write a report on all the junior high schools in Washington, D.C. If she had not learned to type, she would have had to write longhand.

Virginia C. – Springfield, VA, Age 76!

Several teachers printed hard copies of PowerPoint slides before class. Some college professors provided their PowerPoints for everyone in the class to download. It was much easier to follow along with a copy in front of me as opposed to peeking through a monocular and quickly typing a line of notes, hoping they don't advance to the next slide before I finished.

Alex C. – Dallas, TX

When we played "Around the World" with math flashcards, my elementary school teacher would always move closer to where I was standing. Since I couldn't see very far, my teacher was constantly on the move because I kept beating everyone. Yes, I know – I was awesome! Rodney I. – Orange, CA

My high school Government teacher, Mrs. Bradshaw, noticed I had trouble reading her notes on the white board, so she printed the notes for me. Juneall L. – Cape Girardeau, MO, Age 25

My 6th grade teacher allowed me to move around freely in the classroom. I was super grateful, because I didn't call extra attention to myself. My 4th grade teacher wrote my tests so I didn't have to go back and forth to the dry erase board. My math teacher read homework

answers out loud without me having to ask her to. My math teacher also helped me by asking after 10 math answers or so if I was OK. In elementary school, my super-cool vision teacher got my twin, Yasmine, and me a large computer screen, which helped bunches. It had

ZoomText. Gabriella S. – Queens, NY, Age 13

One teacher got a flat screen computer which helped me as well as my twin sister, Gabreilla, who also has albinism. It had a moving arm in the back so I could move around to see at different angles, and it had ZoomText which was a HUGE help. I did my homework on it and a program called Accelerated Reading. The other kids were jealous of my "big screen." Most of my teachers gave me extra time on tests, let me get closer to the board, and offered me large print, but this particular teacher was my biggest help. Yasmine S. – Queens, NY, Age 13

In 4th grade one of my favorite teachers, Mr. Mark McGowan, challenged me to use critical thinking, question authority, pursue excellence, overcome my disabilities, and never settle for "average and ordinary."

I was a "straight A" student. Now I am an African American woman with albinism who is also a Registered Nurse helping people overcome their challenges and giving them hope. Debra A. – Mountain View, CA

One of my teachers got me an iPad. I can take pictures with it, read with it, and connect to



Special - Madeleine W., age 7



the smart board with it. The iPad comes to every class, back and forth from my house and school, and I get to keep it over summer vacation. Bianca M. – Oyster Bay, NY, Age 12

My 3rd grade teacher recommended that I attend “Sight Saving” class. I was taught how to type, and tests were given to me in large print. Jimmy K. – Pahoia, HI

My school soccer coach listened to me and let me play at times and positions that best fit my abilities. Logan R. – Knoxville, TN, Age 15

I had some wonderful teachers and one of the benefits of going to a small school was that teachers knew about me before I was in their classes. I’ll always remember my 6th grade science teacher intervening with students who were teasing me. In 7th grade, my math class was in a portable building which had windows on one entire side. During my study period, I cleaned transparencies so she would use the overhead projector instead of the washed out chalkboard. It was a great trade-off! Kathi G. – Austin, TX

The most helpful thing a teacher did for me

was promoting friendship and anti-bullying. My 3rd grade teacher left an impact on my life because of her generosity and support. Now I am an advocate for anti-bullying and albinism. I visit elementary schools to share my experiences and explain my skin condition. The more knowledge and awareness, the less likely people are to stigmatize others. I know what it feels to be teased because of albinism. I don’t want any child to go through that. I have recently started a blog, www.albinismbeauty.wordpress.com, to discuss albinism. I am thankful for any teacher, friend or parent that stood up for me or anyone else who has been bullied. It has inspired me to spread positivity and let others know that no matter what complexion, you are beautiful. Alexis F. – Swedesboro, NJ, Age 17

So, dads and moms as well as adults, teens and kids with albinism, it’s time to share your InSight! Consider this question for Winter from Stacy H. of Thomaston, GA: **As it gets dark earlier, what do you do to stay safe whether driving or walking?** Submit your answers or questions for upcoming issues at ai@albinism.org.

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

Helping Kids Explain Albinism

By Aaron J. Byzak



Recently, our eight-year-old son, Adam, met another boy at the playground. After a few minutes the little boy turned to me and said, “Why does he wear that hat and sunglasses?” I asked Adam, “Do you want to tell him why?”

Without missing a beat Adam said, “I wear this hat and sunglasses because I am albino. That means that I have albinism, which means that my body doesn’t produce pigment like your body does, and I don’t see very well. My skin and hair are white.” He held out his hand to show the little boy. “See? So I wear long sleeved clothes, a hat and glasses to protect me from the sun.”

Hearing this never gets old. I couldn’t help but smile, and I did what any other parent would do — took a picture and posted the interaction on Facebook.

Here’s how we got to that moment.

When Adam was first diagnosed with albinism, my wife and I made a series of decisions.

Own It! We decided to embrace every aspect of his condition. We weren’t going to be offended by the term “albino” and would treat awkward glares or uncouth questions as an opportunity to educate, and we would empower our son to do the same.

It really comes down to a simple philosophy — own whatever it is that makes you different. Rather than righteous indignation, we respond with righteous information.

From the time Adam could talk, we drove home the message that if someone calls you an “albino,” even in a mean way, or asks why your skin is so white, or why your eyes move

so much, just say:

“Yes, I am albino, which means that I have a condition called albinism. That means that my body doesn’t produce pigment the way your body does which makes my hair and skin white and causes my vision to not be very good. It’s also why I wear this hat, glasses and long-sleeved clothes to protect me from the sun.”

Be Stylish! We resolved to be vigilant with sunscreen to avoid burns and to make sure that if Adam had to wear hats all the time, by gosh those hats would be incredibly stylish! Adam wears mostly fedoras and newsboy caps and is complimented daily on his great hat collection. You can get them pretty cheap at TJ Maxx, Ross Dress for Less or similar stores.

We also decided Adam would wear the coolest frames possible for his prescription glasses. He has to have stylish glasses to complement his stylish hats, right? Unlike the hats, cool frames cost a pretty penny.

As far as we were concerned, if Adam was going to have to face obstacles, he was going to look amazing doing it.

Speak Up! We’ve also stressed the importance of informing others about Adam’s visual impairment. This is important with both adults and children. If Adam can’t see, he needs to tell those around him so arrangements can be made for him to be fully engaged.

A great example is when kids play “catch me” or “tag.” Adam has learned to advocate for himself



by telling others about his visual limitations. Sometimes this works, but sometimes it doesn't. As parents, it's our responsibility to step in as necessary to make sure that changes are made so Adam can play and not feel left out or left behind.

Employing these tactics removes the mystery surrounding albinism. It educates people of all ages to the specifics of the condition, but does so in a way that anyone can remember the basics. It helps others understand how to adapt to allow full inclusion of those with disabilities.

This approach empowers Adam to not take offense at everything that may be said to him and to address ignorance (willful or otherwise)



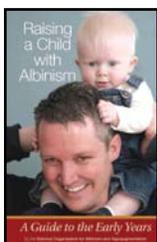
head-on through an engaging personality and insight into how we are all different and alike. It gives Adam the courage to advocate for himself so he can be fully included in activities. From our perspective, life is too short to feel offended all day long, and it's certainly too short to be left out. If you are different or need assistance, own it.

Practice for Success! We've seen Adam deploy his speech many times, often at school or on the playground, and it is wildly successful. Little kids are just curious. If you satisfy their thirst for information, the perceived differences in appearance or capability virtually disappear.

Back-to-School Resources for Parents & Educators

Did you know that NOAH offers two parent books? These unique resources cover areas of interest from professionals as well as members of the albinism community to support parents, the extended family, friends, educators and medical professionals...all who embrace and want to learn more about albinism.

Raising a Child with Albinism: A Guide to the Early Years is a comprehensive resource covering birth through preschool. Read practical advice and caring insights from parents and adults with albinism on topics such as:



- *An in-depth discussion about the types of albinism*
- *Ways to stimulate your child's vision*
- *Medical professionals, treatment options and accommodations*
- *The social aspects of albinism such as*

building self-esteem, developing good social skills, and making friends

Raising a Child with Albinism: A Guide to the School Years

explores topics through the research and knowledge of professionals as well as parents and adults with albinism including:



- *The IEP and ways to prepare for your team meeting*
- *Assessments you can request from the school district for your child*
- *The Expanded Core Curriculum and why it's important*
- *The role of an Orientation and Mobility Specialist*
- *Ways to support your child transitioning to high school, college and independent living*

Visit www.albinism.org/shop.

Inquire 2 Inspire: Careers in Our Community

By Kathi Garza, *Albinism InSight* Staff Writer



Some visually impaired students may begin career or vocational planning during middle school. It can be challenging to address this without knowing what supports may need to be in place or what obstacles might need to be addressed in a field, if any. Because my job is such a big part of who I am, I wondered how others in our community chose careers that resonate with them which led me to the inquiry:

As a person with albinism, how did you choose your career? What obstacles, if any, did you overcome, and what accommodations help you excel?

I always wanted to be a teacher. In high school, I played in the band, and I assisted younger students. I enjoyed picking up instruments with kids as they learned new skills. In college, I pursued a degree in Interdisciplinary Studies and became a certified elementary teacher.

As a classroom teacher, I compensated for my visual impairment by walking around the room to ensure students were on task. On the playground, I wore sunglasses and checked on students to make sure everyone was present. Identifying students was easy until they arrived the next day in different clothes. Fortunately I have a visual memory, so I rarely had trouble.

Eventually, I started graduate school, but I had no idea what I wanted to study. I rarely met with my vision teacher, and I hated being pulled from class because it drew negative attention from peers. I was SURE I would NEVER have any interest in choosing that career. However, when I met a mother who asked about my albinism, I prepared for a routine “public encounter.” After confirming I was from the university, she became emotional and said her three year old had albinism. She

was so happy to hear that I was working toward a college degree. For the first time, I felt I was helpful to someone who must have been in the same place my parents were years earlier. This experience solidified my choice for graduate school.

As a Teacher of the Visually Impaired in a residential setting with small groups, I don’t face many obstacles. I read and write reports, but screen magnification software helps me perform this task. I also pace myself to avoid eye strain. My school is accommodating when **I advocate for my needs**. When lighting is an issue, I work in a classroom where I can control the lighting.

Let’s turn it over to the community now to learn what other people with albinism have chosen for their careers and how they meet challenges to excel in their fields.

When I was six years old, I knew what I wanted to be — a nurse. My mother has always been my inspiration. From an early age, I couldn’t wait for her to come home so I could hear about the lives she saved, the hands she held, and how she was changing the world one patient at a time. I frequented “take your daughter to work day” where I had an opportunity to don surgical scrubs, tour an operating room, lie on the MRI table, and watch my mother artfully care for the sickest patients. I learned that nurses combine compassion, expert physical care and critical thinking to positively impact patient outcomes — and I wanted to be one of them!

Today, I am a pediatric acute care nurse practitioner on a 50-bed, inpatient, oncology unit at a large, urban, children’s hospital. I care for infants, children and adolescents with

cancer who are admitted to the hospital to receive chemotherapy. I love being a nurse in an advanced practice role. On a daily basis, I am the medical provider for up to 16 patients with different types of leukemia and solid tumors. My responsibilities include physical examinations, electronic documentation, prescribing medications as well as other therapies, and presenting in rounds with the inter-professional team. I am also responsible for performing procedures including lumbar punctures (spinal taps) and bone marrow aspirates / biopsies.

Being a nurse definitely has challenges, both visual and otherwise! I often feel I have to work harder to succeed than my colleagues. However, I find greater reward given the effort put into each successful day and each completed task. Currently, I do not use formal accommodations, although it can be challenging to perform some tasks both up close and at a distance. Instead, I wear glasses that contain magnification to successfully examine my patients, write notes in the computer, draw medications into a syringe, and perform procedures. I use a monocular to read and interpret vital signs from afar.

Experience taught me to **ask questions, stay positive, and speak up for myself** in the name of both patient safety and my own success. I hope others in the albinism community will follow in my footsteps and join an incredibly rewarding profession. Kristen D., MSN, RN, CPNP-AC, CPHON – Philadelphia, PA

I spent years working different retail jobs. Since stores want to keep costs down, making things accessible can be an uphill battle. Instead of spending money on accessible equipment, I was excused from the responsibilities of certain aspects of my job. For example, I didn't have to do Internet sales or cashier duty. I later developed joint issues that forced me to change careers.

After some soul searching, a career in

hospitality was an obvious choice. It's a job with plenty of career options, opportunities to meet interesting people, chances to travel or work around the world, offering great benefits, and since I've traveled for NOAH conferences, I know what I want when I travel and can relate to the needs of my guests.

I went back to school to study hospitality and landed a job with Marriott as a Guest Services Representative. I make and cancel hotel reservations, check people in and out, and ensure guests are comfortable. I use ZoomText on the computer, an 8x magnifier, and a video magnifier. My boss also gave me permission to adjust the lighting, and I use Metro Mobility — accessible transportation — to get to and from work. Betty C. – West St. Paul, MN

I became interested in computers and computer programming in elementary school during an after-school computer club. We did interesting things with computers such as making music. This creative aspect of producing programs and applications that people can use and interact with has kept me interested and excited about the field.

In college, I decided I wanted to work with computers. One of the obstacles I faced was learning to advocate for the right accommodations which would allow me to be successful. **Learning to communicate what I needed in the academic environment helped empower me to be resourceful in working with employers.**

Now, as a Hybrid Engineer, I build mobile applications for iPhones. I write, test and debug code on Windows-based computers, Macs and iPhones. I use an array of tools to make my job visually accessible. On Windows, I use ZoomText and the built-in magnifier. On Mac, the built-in accessibility options are able to meet my needs. For mobile devices, I use built-in accessibility options as well as a hand magnifier.

I've worked for different employers with

different levels of accommodations. I have found most employers will value you when you know what works for you and what you need to be successful. Sometimes this involves bringing in your own stuff. Matthew K. – Minneapolis, MN

I've worked as a Vocational Rehabilitation Counselor for over 10 years. For the last four years, I've had the honor to serve our nation's veterans as a rehab counselor at the second largest VA hospital in the country. Although most people think about state Vocational Rehabilitation (VR) when they hear the term "rehab," counselors can work in a variety of settings, including nonprofit, worker's compensation, independent living, healthcare and advocacy. My job is to support disabled veterans in achieving their employment and self-sufficiency goals. I serve people with a variety of disabilities including traumatic brain injury, mental illness, amputations, substance abuse, hearing loss and stroke. Working collaboratively with other medical and mental health professionals, I help each person to identify his or her unique strengths, needs, abilities and preferences related to employment. I communicate regularly with local employers to learn about how I can meet their hiring practices and to advocate for my veterans. I teach my vets how to self-advocate, develop problem-solving skills, and find a sense of empowerment as members of the disability community. I've been elated to see some of my patients transition from a point of hopelessness and despair to confidence and independence. Rehab counselors have extensive training in mental health counseling, medical and psychosocial aspects of disabilities, labor law and evaluation techniques.

I chose this career in a roundabout way. Although I had worked with state VR counselors since high school, I didn't aspire to have their jobs. As a student, I loved psychology and was drawn to the philosophy

of rehab counseling with its emphasis on empowerment, advocacy and recovery. By luck, I happened to meet extraordinary mentors who inspired and guided me.

The majority of my challenges have nothing to do with my vision. Those that do are usually easy to work around. I use screen magnification on my computer to keep up with documentation. **I occasionally explain my poor vision to my patients so they understand why I may not recognize them in the cafeteria** or why I hold things close to read them. I try to have this conversation in a way that it encourages them to think about how they'd have a conversation with a future employer or coworker when discussing their own needs related to their disability. Because I don't drive, I'm not able to transport my patients to interviews or appointments the way my colleagues do, but I can use my extensive knowledge of local transportation to teach my veterans independent travel strategies — and to show some of them that life doesn't have to end if you can no longer drive. Kelsey T., CRC, LCPC – Chicago, IL

I feel lucky that my vision allows me to typically read without aids. I grew up at a time when aids were not as available, so I didn't use them much. I sat in the front of the classroom and began using a monocular in college. Reading at near distances wasn't a challenge as long as I was able to get as close as I needed to the material.

I always liked science. I played with chemistry sets and entered college with an interest in research. I had some experience doing simple research projects in high school. I continued to do research in a lab and got a Ph.D. in biochemistry. However, I did encounter challenges. I remember having to thread a catheter into a vein in the liver and just could not do it. I was super frustrated and beat myself up over it. I eventually went to talk to my boss, and he said, "Bob, it's no problem. You do lots of other things really well." He

suggested I work with one of the technicians and agree that he would do the surgical aspects of the job, and I could do other things. The key has been that **I was willing to work hard, and if I received help with one thing, I would gladly do something else in exchange.**

For example, when I went to med school and as a physician, I faced difficulty with performing various procedures efficiently. I struggled with catheters and seeing things in the surgery rotation. I was up front about limitations but emphasized an interest in learning. I was able to accommodate for my visual limitations while learning new things with fellow residents. On a daily scale, I would offer to “work up” several patients, obtain their medical and physical histories, and chart the information in exchange for a resident completing a procedure for me. I would trade time in the ICU, which is a very procedure-oriented place for time in the ER.
Robert G., MD, Ph.D. – Boston, MA

As one who experienced teasing, rejection and unwanted attention due to my appearance, I have great compassion for those who struggle with “difference.” Fortunately, I have experienced few obstacles in my career as a consequence of my albinism, though I did have an interviewer ask if they make “special makeup” for people with albinism — a job I didn’t take. However, as a Caucasian woman, I wear considerable makeup, so now, although most people think I bleach my hair, they don’t know I have albinism.

I completed my Ph.D. at New York University on the social and emotional impact of albinism with a focus on experiences of social stigma. I am proud that *Albinism and Social Stigma: Results of a Nationwide Survey* represents the largest database on the social-emotional experiences of people with albinism in existence.

I have been a Clinical Social Worker for over 25 years and have worked equally in medical and psychiatric settings. I have a private

psychotherapy practice where I specialize in treatment of trauma. I am also a social work supervisor at Greater Baltimore Medical Center assisting medical patients with discharge planning needs.

The only real obstacle I deal with is at the hospital when I have to use a computer that doesn’t have the screen enlarged. Even reading glasses aren’t enough for the tiny print in the electronic medical record system!
Victoria Y., Ph.D., LCSW-C – Owings Mills, MD

I still do not know what I want to be when I “grow up.” However, I have acquired many skills and core competencies and I have contributed to business forums. I have maintained strong relationships that have helped to market myself.

I grew up in an era where albinism was a hindrance, but I adapted well without accommodation. For the past 17 years, I have worked in staffing and consulting services. My core competencies are in accounting and finance. I have participated in accounting management, consulting, sales, process improvement and strategic planning. I encourage people to always reinvent themselves. Never fall into a pattern of simply performing routine tasks. Embrace changes and sell your ideas. Success should never be a goal but a result of achieving goals for which you’ve given critical thought.
Peter C. – Newark, NJ

My mom suggested I look into occupational therapy because it is a versatile field. I think I rolled my eyes because what high school kid wants to be told to “research” anything? But I did, and it sounded interesting, so I pursued it.

After graduate school, I accepted my first job at a medium-sized hospital and quickly realized there would be some challenges because I had to read doctor’s handwriting, visually locate a chart at a cluttered nurse’s station, locate nurses from a distance, and maneuver multiple,

tiny, clear lines like IVs and oxygen. I also had doctors who were concerned about my nystagmus because that is often a sign of a serious medical condition. However, I worked there for over five years, and I built a good rapport with the staff. I learned to feel all the tiny lines to make sure none were tangled, and thankfully all the patient charts became computerized! Once people got to know me, they would tell me what I needed to do if I couldn't see something.

During my first job, the hospital replaced all the monitors with ones that were hard for me to see. My HR rep was very understanding. Unfortunately, the lady from the corporate office was not realistic with her suggestions, so I asked if they could leave one old monitor on each unit. She initially said no, but after a NOAH friend who is familiar with the ADA gave me some ideas, that solution was put in place. It was hard for me to formally ask for accommodations, but I tried to be as reasonable and economical as possible in my requests. Becca E., BS, MSOT, OTR/L – Bloomington, IL

For the last 17 years, my career has revolved around charitable grants — publicizing them as a web designer for foundations and as a grants administrator for a grant-making public charity, pursuing them as a fundraising professional, and helping organizations to find them as a trainer and blogger. My career path has been consistently guided by a love of working toward positive social change in the nonprofit sector.

My jobs have had a challenging visual component from a text and / or graphics perspective. I've relied on a large computer monitor using low screen resolution, a rapid refresh rate and large fonts. Since I need my monitor to be very close to my face, I keep it on the front edge of my desk and have a roll-out keyboard tray underneath to avoid excessive slouching or chronic wrist strain. I use a magnifying glass for reading anything

printed and a monocular for seeing materials presented at meetings.

Public presentations have become a critical component of my job. At first, I struggled since I have a hard time reading printed notes and seeing the content of my slides from more than a few inches away. My solution was to use the iPad tablet to enlarge my notes and slides. This workaround enabled me to present with comparable skill to my fully-sighted peers.

Although it took me nearly 20 years to get to my dream job, every previous job was a necessary step. The greatest lesson I've learned is that **no skill is ever wasted**. Once you've gotten enough experience under your belt, sometimes the perfect job finds you! Claire S. – New York, NY

I am a licensed cosmetologist, barber, esthetician and nail artist. After high school, I wasn't ready for a four-year college, so I chose a trade school.

Cutting hair is an up-close service, so my vision didn't cause problems. I use magnifiers when I need to read small print on bottles, and I am very conscious about having great lighting. However issues with depth perception have affected me. On a few occasions, I cut myself with shears, but with practice, I was able to remedy the problem and remain safe.

Helping people see their own beauty and knowing I can go anywhere and support myself are just a few reasons I love being a hairdresser. Marlaina M. – Kirkland, WA

It's clear that our community members have some wonderful stories centered on the diverse careers we have chosen. Now we need YOU to Inquire to Inspire. Send your questions with regard to issues faced by people in the albinism community to i2i@albinism.org.

Playing the Game with a Fair Ball

By Schroeder

Little League pitcher, Ryan Huizdos, who was featured in the Spring 2014 edition of *Albinism InSight* was thrust unexpectedly into the spotlight this summer.

According to his mother, Kelly, “Ryan has been playing baseball since he was four years old, and he’s played with the same Little League community for five years. An accommodation that has been extremely helpful to him is using a yellow baseball when he bats.”

Ryan, who is now 13 years old, was invited to play on a tournament team in June. His father, John, was told prior to the first round that the yellow balls were not authorized by the League and that they should never have been allowed. Kelly said, “Through the years, we have not had a single player, coach or umpire argue [about the use of yellow balls].”

An appeal to League authorities to allow the yellow baseballs during the tournament was denied in writing. However, at the last minute, a local official went against the League’s

decision and allowed Ryan to use them. Ryan’s team was eliminated from the tournament after losing their first two games.

But the story doesn’t end there.

A local TV news station ran a story a couple of days after the tournament highlighting the denied appeal but failed to mention the last-minute accommodation. After the appeal and following the TV story, Ryan and the Huizdos family became the center of a controversy they didn’t see coming.

The Huizdos family is weighing legal options to pursue a fair accommodation not only for Ryan but for other kids with albinism who may want to play Little League baseball in the future.

NOAH Executive Director, Mike McGowan, said, “NOAH provided contacts and relevant information to the Huizdos family following their request for assistance. NOAH will continue to provide information and support to the family and will keep the community informed.”



We are Beautiful!

By Victor Layton



What you choose to believe about yourself will determine how you truly see yourself. It took me almost half of my life to figure out this amazing truth. I started believing that I was beautiful, not ugly and unattractive as the people who teased me would have me believe.

I remember as far back as elementary school that I looked different from the rest of the kids. The older kids pointed at me and laughed, calling me “the ugly albino” and other hurtful names that sparked pain, embarrassment and shame deep down inside of me.

Unfortunately this would become an everyday occurrence in adolescence. My hair was a mix of white, yellow and gold. My skin was a pale, pinkish-white, and my eyes were dark brown. I am African American, and in my culture, I stand out like a white stain on a black suit. Often I was treated like a white stain by those who generally had darker skin and never let me forget that I looked different, and they didn’t like it, and they were not going to accept me as one of them.

Thank God for my mom and dad who did their best to lift my spirits and work on my self-esteem by telling me I was beautiful and normal, and I could do anything if I tried and didn’t give up. Unfortunately, I could not receive their empowerment because the minute I stepped out of my house, the haters were waiting. They never missed an opportunity to let me know that I was albino, that I looked different, that they couldn’t understand it, and they didn’t like it.

I remember junior high because it was the worst period of my life. I literally had a fight every day my first year, I was teased and called so many hurtful names that I almost forgot what my

parents named me! My mother became so frustrated with kids picking on me that she put me in Karate hoping it would raise my self-esteem and help me protect myself.

I started playing football, baseball and basketball. Baseball was my favorite, although I couldn’t see the ball very well. The white ball blended in with the sun’s rays until it was about an inch from my face, but I excelled at pitching. One time I was actually voted “pitcher of the year.”

Honestly, one of the things that made me such a good pitcher was that I had so much anger and pain inside of me. I threw the ball as hard as I could and loved the look on the faces of my opponents when I struck them out, and they had to walk back to their bench. Some were the same kids who taunted and teased me in school, telling me how much better they were than me. This was the first time I recognized I was worth something, and I could actually win at something. My perception of myself started to change a little. Other kids patted me on the back telling me how good I was. Kids wanted to be my friend and didn’t care that I was albino.

It was many years later when I had my eye-opening experience about being albino.

I had come a long way from the beat up and battered kid from junior high, I had many friends, I was a leader in my social group, and dated a variety of girls from different races. I had burst out of my shell and was feeling good about myself! I was the foundation of my family. I was seen as strong, protective, tough and outspoken. I appeared to have it all together on the outside, but on the inside I still had not accepted my albinism. I still could not stand to hear the word



albino. Every time someone said it, whether aimed at me or not, I crumbled on the inside. All I saw was “the ugly albino,” the name my haters branded me with so long ago.

One night changed the way I saw myself forever.

I was at a neighborhood party with a lot of my friends. Laughing and joking, we had formed a huge circle of 40 to 50 people, and somehow, I was right in the middle and having a good time. Then one of the guys who I’d known since we were kids turned to me and said in a loud voice, “What are you laughing at light bright? Why don’t you go home you UGLY ALBINO!” My whole world stopped. I stood there in shock hoping he did not just say that, but of course he had said, “THE WORD,” and everybody heard it.



But it was strange this time because all I heard was dead silence. No one was laughing at me. No one was adding to the most humiliating and embarrassing word I had ever heard. I was trying to catch my breath as my false self-esteem took off running, and left me feeling naked and alone.

To my amazement, walking toward me was a girl who I had never seen before. She grabbed my hand and screamed, “So what if he is albino? He’s cool, and I like him!” Then other voices started to join in and say the same in my defense.

I was in utter shock! No one outside of my family had ever stood up for me. As I lay in my bed that night, for the first time in my life I started realizing that maybe there was nothing wrong with being albino. It was actually cool. I realized that because most of those people believed that I had accepted who I was and appeared to be proud of being albino, they had accepted me too. I couldn’t believe that all the people in that circle thought I was actually proud to be albino. This new discovery had blown me away. So I started thinking, “What if I was really proud to be albino and not just faking it? What if I really believed in my heart that it was OK to be albino?”

Soon, I didn’t care who didn’t like me because of my albinism. It didn’t matter to me what the haters thought. I accepted being albino after that night. I started believing more and more in myself. I started believing that being albino was beautiful, and the more I believed that I was beautiful, the less effect the word albino had on me. I realized it was just a word. The reason it hurt so much in the past was because of what I believed. I had always seen myself through the eyes of my haters. I believed what the haters said about me.

Today I see myself as I am, I AM BEAUTIFUL. It is your choice to believe what you want about yourself. No one can take that from you! If you were born with albinism and you look different from most of the people around you, it’s OK. You don’t have to

be ashamed or embarrassed. Don’t believe what the haters say.

I will share with you what I did to build my real self-confidence. I say “real self-confidence” because I used to pretend to have self-confidence, but when faced by haters, I crumbled because I didn’t really believe in my heart that it was OK to be albino and that I was beautiful.

When I accepted being albino, I started telling myself every time I looked in a mirror that I was beautiful. I would say it three times out loud so I could hear myself. At first it sounded strange because I had never referred to myself as beautiful, but the more I said it, the more I believed it, and it became true to me. “Beauty is in the eye of the beholder” means you decide if you are beautiful. There is no one standard of beauty. It comes in different shapes, sizes, colors and from all around the world. Our differences are what make us even more beautiful. Socialize with people who accept you the way you are and see you the way you desire to be seen.

Whatever you choose to believe about yourself is who you are. I believe I AM BEAUTIFUL!



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



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