



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Summer 2014

Welcome to NOAH Ed U!

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

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Does the family of your student with albinism know about NOAH?
Share this supplement with them so they can learn what NOAH has to offer!

From Educating my Classmates to *Scholastic Magazine*

By Elizabeth Armstrong

When I was in middle school, I was often bullied for looking different because many of the students did not understand my condition. They called me names and excluded me from groups and activities. I am in the ninth grade this year, and my life has changed for the better.

During my last year of middle school, I decided to educate my classmates about albinism. I thought that if they knew more about albinism, they would be more understanding toward me and others. I talked to several classes that were learning about Helen Keller. I brought my telescope, magnifier, Maxlupe and cane to explain their uses. Students put on simulators to walk around the room and tried to read regular sized print.

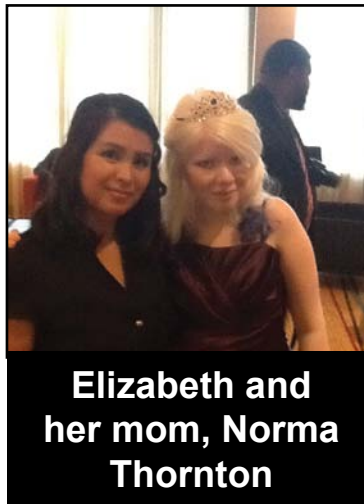
My teacher suggested that I submit an article to *Scholastic Magazine* for the section “Different Like You.” After several weeks of revisions, I decided my article was perfect, so we emailed it to the editor. Within a few days they accepted my article for publication and asked if I would like to be a student advisor and contribute ideas for future articles.

The editor, who lives in New York City, emailed us to explain the process of publication for articles. First, I answered questions she emailed to me. Later, she interviewed me for about two hours on the phone because the article was to be in an “as told by” format. *Scholastic Magazine* also

sent a photographer from Austin, TX to take pictures of me and my family. He took about 200 pictures. Some were of me using my cane and telescope and others were of me listening to music, writing poetry, and dancing!

When we received the digital version of the article, we were sad to see that the editor used the term “albino” more than once. We emailed the editor, and I explained that we liked the article, but I was offended by the use of the term “albino.” I explained that the term makes me feel as if I am a different species. We asked if there was any way she could fix that problem. The editor apologized sincerely and stated that the print copy was already out, but she would immediately change the digital copy online. She also started a blog on the Choices website apologizing for the misunderstanding and explaining why she changed the terminology.

After the article came out, I received an award from my school and the school board members. A lot of my classmates read the article, and I have noticed a big, positive change in the way I am treated on a daily basis. Reflecting on my first year of high school, I’ve had no problems with bullying and have made many friends. I plan to continue to talk to groups about albinism to help kids understand that just because you look different does not mean you should be treated differently.



**Elizabeth and
her mom, Norma
Thornton**



I Choose to Accept Myself as I Am

By Richard Brodesky

I believe that everyone has the right and the power to choose their own attitude about anything. Accordingly, everyone has the right and responsibility to change their attitude when new information becomes available through experiences of the senses, mind, body and especially the heart.

To be honest, being an albino was not an easy assignment in my family of origin or my hometown. My parents were ashamed of my appearance, my eye movements, my lack of athleticism, and my unique point of view which developed during my childhood.

I did not receive excellent vision care until I was 10 years old. To save my sight, which was presumed to be evaporating, I wore nearly opaque glasses. I spent many days walking into walls, missing fly balls in right field, and was told I couldn't perform many of the activities that sustain me today. Using tools and making art was just too visual for me, or so they thought.

Without sunscreen, playing outside was limited. I grimace at old pictures where I was tubby from lack of exercise. Even in black and white, you can see my sun-induced,



lobster-red skin.

I didn't know that I was an albino. What I did know was that I was living a life of frustration which often erupted in bursts of temper. Acting out in school and tussling with the other kids just added to my folks' shame and feelings of inadequacy.

As a youngster, I made a serious but understandable mistake.

I accepted the shame and derision that surrounded me. I let them into my inner life where they had a formative role. Now I can forgive myself because I was only a small boy living in a vacuum. I would also forgive any children who made similar inferences about themselves.

Through my behavior I was trying to say that

I wanted to be accepted as I was. I wanted the people around me to be sensitive to my needs. I wanted better vision care. I wanted to be attractive in a world that seemed to admire only "tall, dark and handsome" men.

The best decision I ever made was when I was in sixth grade. Harsh circumstances made me consider my life, and

I decided to choose a different attitude. In an ironic way, the civil rights movement helped

me. People in my town fretted about African Americans moving in. I needed to understand why they didn't want that to happen, yet they had problems with my whiteness. After struggling with this irony, I concluded that I would no longer accept anything negative or limiting about myself. I promised myself that I would have a better life, no matter what.

At the age of 11, my intent was laudable, but I had no idea how to take practical steps. I was fortunate because, in sheer frustration, my parents shipped me off to summer camp. I continued to have problems on the athletic field, but a remarkable counselor dressed me in long-sleeved shirts and taught me how to swim. The nature counselor was interested in teaching me wood lore. I loved the wood shop, and I mastered canoeing and rowing. The best times were hikes and canoe trips. Finally, I was with a new and more forgiving peer group.

I began to zoom. However, I would not have made any progress if I had not decided that I was worthy and deserving of a good life. Even if I couldn't catch a fly ball, I found activities I could embrace and which would give me joy, satisfaction and teach me new skills. I learned

that I could make a new kind of friend, a person with whom I shared a hobby or interest. Later on, this knowledge allowed me to be the new guy at work and to date attractive women.

Choosing to accept ourselves as we are is fundamental to having a rich life. Self-acceptance does not mean complacency, arrogance or conceit. On the contrary, it means that we see ourselves optimistically, honoring our gifts, and opening ourselves to our potential. We look into ourselves and see our talents and abilities. We scan the environment for people and experiences that will bring out the best in each of us. We use our minds, bodies and hearts to become better at being who we really are. We involve ourselves with life and learn from our experiences. We are not ashamed of ourselves, but we do respect adversity as a guide for improvement. On a daily basis, we work hard to remove false, negative views of ourselves and replace them with positive ones based on the authority of our own lives. And best of all, we do what we can to enable others to accomplish all of these things too.

NOAH at AER San Antonio

NOAH will be at AER International Conference, *Moving into the Future*, in San Antonio, TX

July 30 - August 3

Stop by Booth 106 to pick up materials you can share with your students and their families.



Inquire 2 Inspire: Fair Hair Care

By Kathi Garza, *Albinism InSight* Staff Writer



Summer vacation is in full swing, and it's time to slather on the sunscreen, grab the floppy hats, flaunt fashionable, but dark, sunglasses, and head out for an afternoon in the pool. Getting prepared before heading to the pool is something we all think to do, but what about after the pool? We remember to take care of our skin, but what about our beautiful hair? Let's dive into the deep end as we explore the following inquiry:

What can I do to keep chlorine from ruining my hair this summer?

Tip 1: Brittney B., a stylist with albinism in Round Rock, TX, suggested washing your hair with a clarifying shampoo right after a long swim. She also suggested using a moisturizing conditioner to keep the chemical damage to a minimum.

I have actually tried many clarifying shampoos. I am not a fan of blue / purple shampoo because if you aren't careful, you may end up with tinted roots or hair. I have used expensive clarifying shampoos which work well, but recently, I have seen more common brands carrying clarifying formulas for light or color-treated hair. Now I use these as a standard.

Tip 2: Brittney also suggested working some conditioner into your hair before getting into the pool. She explained that this helps to keep the chlorine from penetrating the hair.

Tip 3: Many salons and department stores carry special shampoos designed specifically to reverse the effects of chlorine. Two brands I saw most often were TriSwim and UltraSwim.

Tip 4: Tami, a stylist at my salon, suggested a tip which I thought was a little outside of the box, but here goes! To neutralize the green

from the chlorine, work a glob of tomato paste into your hair and leave it in for 30 minutes. (The tomato paste will neutralize the green from the chlorine.) After 30 minutes, resume your normal hair care ritual to remove the smell.

I was pretty skeptical about this, but a quick search online uncovered many who swear by this method. Other household items suggested on a variety of sites included a baking soda rub, lemon juice, vinegar or a vitamin C and water mixture. Go figure! Peanut butter removes gum and tomato removes chlorine!

Tip 5: If there's a big event coming up and you don't want to take any chances, put your hair up or wear a swim cap to keep it covered. This is probably the most obvious tip and may require planning ahead, but it's better to be safe than sorry!

If worse comes to worst, I learned the hard way that laundry detergent can strip just about anything out of my hair. When I tried an at-home dye at age 15, it didn't yield the results I was hoping for, but seven washes later, my hair was *almost* back to normal.

Now **SWIM ON** my fellow fair-haired friends! When you're sitting poolside, don't forget to inquire to inspire. Send your questions with regard to issues faced by individuals in the albinism community to i2i@albinism.org.

NOAH is Proud to Announce....

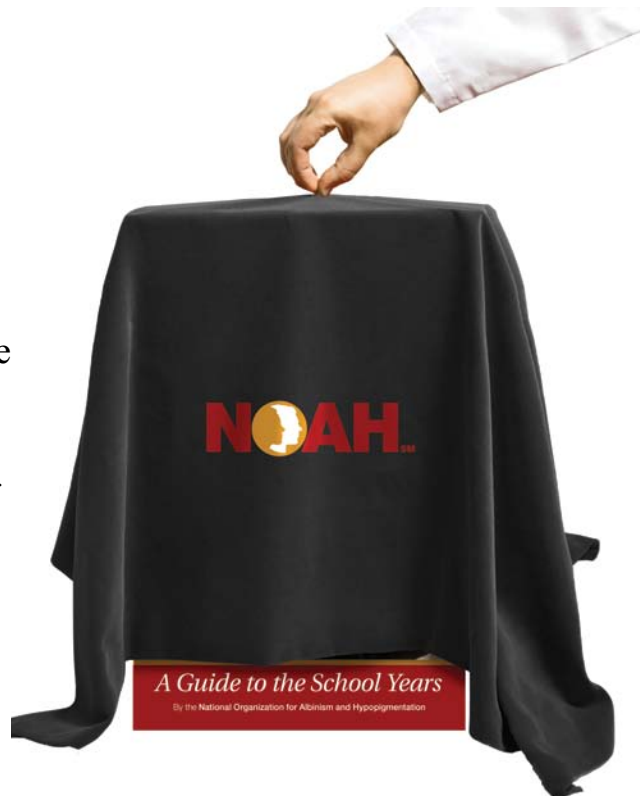
By Jill Gorman, Managing Editor, *Raising a Child with Albinism, A Guide to the School Years*



NOAH will be launching its next parent resource book at this year's conference in San Diego! NOAH's first parent book, *Raising a Child with Albinism, A Guide to the Early Years*, was published in 2008. Little did we know, this would be the catalyst for another book that would highlight and support the needs and issues of families in our community.

The second parent resource book, *Raising a Child with Albinism, A Guide to the School Years*, explores a wide variety of topics through the research and knowledge of professionals in their fields of study. Some of the topics presented include:

- What is an IEP, and how do you prepare for your team meeting?
- What assessments can you request for your child from the school district?
- Why is the Expanded Core Curriculum important?
- What is the role of an Orientation and Mobility Specialist?
- How can you support your child in their transition to high school and independent living?



Personal stories from members of our community are integrated throughout the book providing real-life personal perspectives to questions and situations often facing families in the albinism community.

- How do I explain what I see to others?
- What are my driving experiences with bioptics?
 - How do I deal with stares and unkind comments?
 - What sports can I play?

As NOAH began the journey of publishing a second parent book, the goal was to create a reference guide for parents - a book that parents would be able to share with their children as they grow and learn together. The hope is that this book will reach beyond our community as well to support our

extended family, friends, teachers, service providers, principals, pediatricians... all who embrace and want to learn more about albinism.

So, as you start preparing your summer reading list, don't forget to add *Raising a Child with Albinism, A Guide to the School Years*!

Online InSight: TED Talks

By Stacy Hoffman, *Albinism InSight* Staff Writer



TED started as an annual conference on the latest in technology, entertainment and design in Monterey, CA. In 2001, it became a nonprofit endeavor by The Sapling Foundation to share and spread cutting-edge ideas. The first TED videos were posted in June 2006 and by September of that year had over one million views.

I could get lost on **www.ted.com** or the TED talks site. There are hundreds of fascinating talks on all sorts of subjects, from scientific to social, by both self-proclaimed and recognized experts. The talks are short enough for the attention span of social media addicts and the speakers are interesting and smart enough for even the hipsters. Check out the following inspirational TED talks!

From Stigma to Supermodel by Rick Guidotti (18:16): If you haven't seen or heard Rick Guidotti's high-energy talk about how he came to partner with NOAH to show the world the beauty and spirit of people with albinism (PWAs), you need to go there now! His attitude is truly infectious and his photos are amazing.

I Got 99 Problems... Palsy is Just One by Maysoon Zayid (14:13): Maysoon deals with disability with style and wit. She has cerebral palsy but finds other problems in her life, like high heels and being from Jersey, more difficult to overcome. She is becoming the comic and actress she always wanted to be and personifying one of the most under-represented minority groups in the entertainment industry: people with disabilities.

Looking Past Limits by Caroline Casey (15:30): Caroline's life journey is remarkable. Her talk on how her parents first inspired her to ignore her limitations and how she eventually

learned when to ask for help gives the kind of encouragement all of us need. Spoiler alert! She's a PWA and didn't know it!

How I Named, Shamed and Jailed by Anas Aremeyaw Anas (12:46): This talk may not be suitable for all viewers. Anas is an undercover reporter in Ghana. He even wears a disguise for TED. He explains how and why he has risked his life to expose evil and corrupt men. He says, "When evil men destroy, good men must build." He has gone undercover to expose a professional gang of men who travel to villages to poison babies with disabilities and for the first time ever, he caught a trader in albino body parts on film. He also intentionally got himself thrown into prison to document the horrible conditions.

My Philosophy For A Happy Life by Sam Berns (12:44): Sam is 17 years old and has progeria, a rare disease that creates symptoms of premature aging like atherosclerosis, cardiovascular problems and musculoskeletal degeneration. He explains how and why he has a happy life and has lived his dream of marching and playing snare drum with his high school band despite weighing only 50 pounds. Sam's intentional can-do attitude will make you want to strike "can't" from your vocabulary.

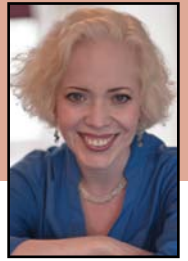


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www.facebook.com/NOAH.Albinism

Social Rejection and Physical Pain

By Victoria Young, Ph.D., LCSW-C



Social rejection hurts - literally. A number of studies conducted since the early 2000s have used functional Magnetic Resonance Imaging (fMRI) studies to demonstrate the connection between social rejection and the experience of physical pain. It allows a scan of actual brain activity and shows the blood flow in various regions of the brain in real time.

In the widely cited study, Eisenberger and her colleagues placed subjects in fMRI machines and had them participate in a virtual game. In the game, subjects were either included (a ball was thrown to them as often as to another virtual participant) or rejected (the ball was not thrown to them). Most participants in the “rejected” category showed brain activity in the anterior cingulate cortex (ACC) - a region of the brain which is also activated by physical pain. From their evidence, the authors assert that physical and social pain emerges from the same place in our brain and can be viewed as having similar roots.

From an evolutionary standpoint, a brain function that makes us physically hurt when we experience social rejection makes sense. Because we are a tribal species, we rely on social acceptance as a means of survival. Pain is a signal that our brain sends to our bodies to let us know that something is wrong. Thus, if social rejection did not “hurt,” survival would be compromised. A pain signal provides a clue that we need to change our behavior, or perhaps find a different group. It can help us to alter our behavior and shift our survival outcomes.

The experience of “social pain” can also have serious negative consequences. For example,

chronic experiences of social rejection can lead to a greater increase in aggression, anxiety and depression as well as long-term physical effects such as decreased sleep and dampened immune responses. It is also harder to “recover” from social rejection than physical pain. Chen and colleagues used imaging techniques to show that social pain can be “re-lived” in the memory in ways that physical pain cannot, thus allowing its effects to linger and become part of our “learned” experience of life.

As people with albinism, most of us have experienced social rejection in one form or another. The idea that social rejection can hurt physically is no mystery to most of us, although the fact that brain science supports this feeling is validating. It may also be useful for us to know that we aren’t the only ones who feel that way - we are ALL wired to feel awful in the face of rejection.

The “cure” for social rejection is its opposite, social acceptance. In fact, acceptance even by ONE other person can help mediate the effects of social rejection. Research on the impact of emotional connectedness has likewise demonstrated the profoundly healing effects of acceptance, both physically and psychically. Dan Siegel speaks extensively about the significance of social connectedness - both on an interpersonal and group level - in providing the neurochemical stimulus needed to heal the wounds of trauma, loss and yes, rejection. Our brains break us, but they also heal us. As such, the conscious act of forming, nurturing and deepening social connection is at the heart of both enduring and healing from the social

threats of non-connection that we experience in other contexts.

The bad news is that social rejection can be a fact of life. The good news is that we can work to counter its effects if we know how. Organizations such as NOAH can provide the springboard for many of us to find a sense of social acceptance and positive connection. The changing face of albinism - from scary pictures in medical books to Rick Guidotti's beautiful photographs of people with albinism from around the world, to the recent successes of supermodels with albinism - has helped to open many minds to the beauty and acceptability of albinism. Yet stereotypes - that ugly word that almost always precedes social rejection - still persist. We know that we cannot always rely on the world for social acceptance, but we can rely on each other. This is the type of tribal bond that heals!

If you'd like to know more, you can read:

Does rejection hurt? An fMRI study of social exclusion. *Science*, October 10, 2003.

Why does social exclusion hurt? The relationship between social and physical pain *Psychological Bulletin*, March, 2005.

Alone but feeling no pain: Effects of social exclusion on physical pain threshold, affective forecasting, and interpersonal empathy. *Journal of Personality and Social Psychology*, July 2006.

A little acceptance goes a long way: Applying Social Impact Theory to the rejection-aggression link. *Social Psychology and Personality Science*. April, 2010.

Imagined future social pain hurts more now than imagined future physical pain. *European Journal of Social Psychology*, April 2012.

The Neuroscience of Human Relationships: Attachment and the Developing Social Brain, 2006, the Dan Siegel chapter.

Educate! Advocate!

In the mall, at the grocery store, on the subway platform, sure you want to explain albinism but you've gotta run! Did you know that NOAH has free Albinism Information Cards? The size of a business card, they fit easily into a wallet, purse or back pocket.

- Leave some with your doctor for other patients with albinism.
- Take some to holiday gatherings to quickly spread information.
- Use them when you need a quick explanation of albinism or want to direct someone to NOAH.



To get your free cards:

Call: 800-473-2310 ~ Email: info@albinism.org



www.youtube.com/user/NOAHAlbinism



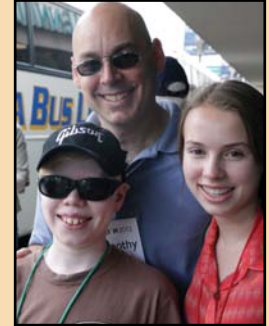
It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - *Brooke Jensen -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



NOAH's Parent Connections

IN PARTNERSHIP WITH LIGHTHOUSE GUILD INTERNATIONAL

To join one of our small group communities, please contact
Sheila Adamo at sadamo@albinism.org.



The calls provide a nice balance of sharing tips and stories, and interacting with guest speakers who provide valuable information. One speaker talked about ways we can help our preschooler inside and outside the classroom. We also gained insights from an adult with albinism into how our children see. He affirmed they can do anything!

Andrea Wade – Helotes, TX



The calls have been a really supportive experience. It's nice to hear the stories of other people going through a similar issue. The guest callers are informative and that gives me a head start on what to expect as my child grows. It's also a great outlet reminding me to nurture and take care of myself so I'm able to truly take care of my son.

Andrea Chadderdon - Chicago, IL

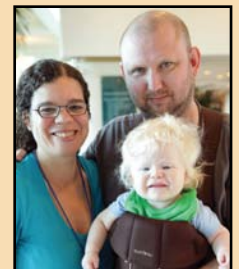
Here's an opportunity to talk with others who understand what you are going through as a parent of a child with albinism. Get the support you need to be a healthy, informed parent, and build connections in the albinism community – all in the comfort of your own home.

The teleconferences consist of a limited number of parents to provide a safe and comfortable environment for you to voice concerns, ask questions, and share your experiences. Two groups meet for one hour twice a month; one in the evenings and the other at midday. Both are facilitated by a licensed professional and feature presentations from professionals on raising children with albinism.

Thank you to the Lighthouse Guild International for the support which makes these teleconferences possible.



I appreciate the outlet to vent and share my experience of having two children with albinism. I feel very fortunate to be a part of this group. It has been amazing to have guests give insight to the various situations my children are faced with on a daily basis. — *Stacey Dolan - Bushkill, PA*



The HPS Network offers support groups in Spanish and English for parents of children with Hermansky-Pudlak Syndrome and another group for Chediak-Higashi Syndrome. Contact the HPS Network at 800-789-9477.

MEMBERSHIP



First three photos courtesy of Positive Exposure, Rick Guidotti

Photo courtesy of Ashley Montes

Mission

NOAH's mission is to act as a conduit for accurate and authoritative information about all aspects of living with albinism and to provide a place where people with albinism and their families, in the United States and Canada, can find acceptance, support and fellowship.

Information

NOAH is the world's most comprehensive source of information about albinism.

- A Quarterly Magazine
- Parent Books
- Webinars
- Website
- Information Bulletins

Support

- New Parent Program
- Biennial National Conference
- Family Camps
- Adult Weekends
- Regional Conferences
- Teleconference Series

**Join NOAH online
at www.albinism.org**



Photo courtesy of Whitney Harness, 2013



National Organization for Albinism and Hypopigmentation

PO Box 959, East Hampstead
NH 03826-0959 USA

Phone: 800-473-2310 • 603-887-2310

Toll-free fax: 800-648-2310

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