



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Summer 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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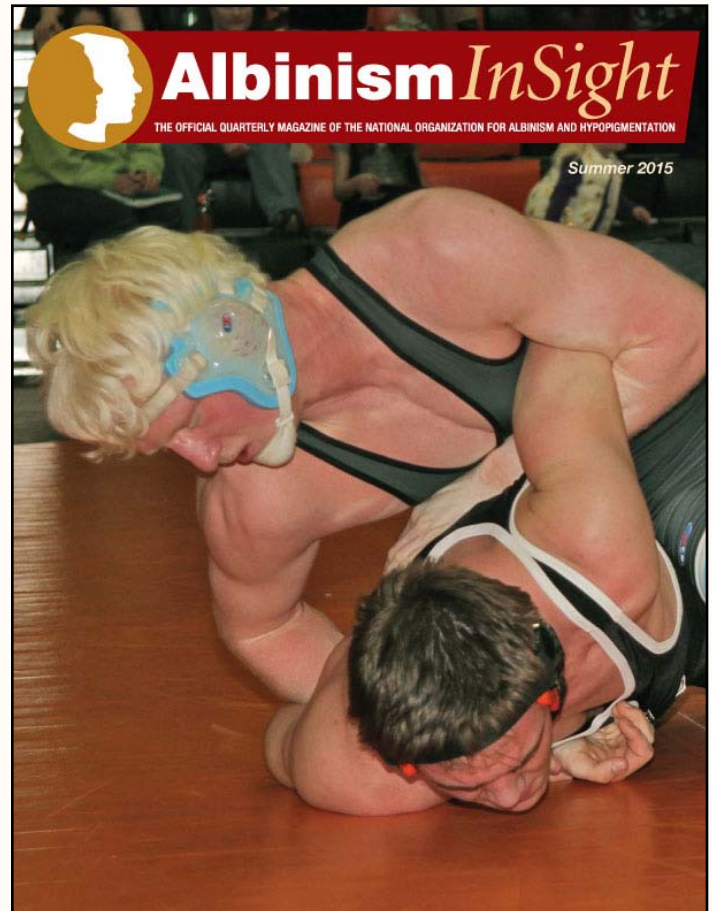


Photo courtesy Jim Pressler

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!

Teens and Young Adults: Bring *On Beauty* to Your School

By Stephanie Sunata



Would you like to open a forum to discuss differences in a positive way and to encourage your classmates to re-evaluate their concept of beauty? Here's your chance! Joanna Rudnick's education program brings her documentary, *On Beauty* to schools and sparks discussions about changing the way we see beauty. The documentary follows fashion photographer and Positive Exposure founder, Rick Guidotti, as he travels the world using his camera to challenge societal norms about beauty. The film features two young women including Jayne Waithera, a person with albinism who lives in East Africa where she constantly battles cultural prejudices and threats on her life.

The educational screening program is designed to bring the award-winning, 31-minute film and structured discussions to classrooms around the country. There is a discussion guide and lesson plan to help educators

teach students about genetics, bullying and self-esteem. The film and materials are appropriate for a variety of classes from middle school and up.

The *On Beauty* team just expanded the educational screenings program to include universities. The first university screening was at Long Island University, and was followed by the University of Washington. Each screening included a sneak peek of the film and a panel discussion with special guests such as Joanna Rudnick, Rick Guidotti and members of the albinism community.

Learn more about the film, get involved in the movement, and celebrate the spirit of difference. **To bring the film and educational materials to your school visit [http://](http://iambeauty.me/contact/request-a-screening)**

iambeauty.me/contact/request-a-screening or email info@iambeauty.me.



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

When the Sun Shines, Screen It!

By Vail Reese, M.D., Dermatologist



After a long winter, the arrival of spring and summer means more time spent doing outdoor activities. For those with fair skin, this means the potential for sun exposure. In an effort to avoid sunburns, wrinkles and eventual skin cancer, protection from ultraviolet radiation is paramount. Is this news to anyone reading *Albinism InSight*? Here are details about sunscreens that you may not know.


SPF is not the full story. SPF, or Sun Protection Factor, is a measure of the strength of a product's ingredients. Higher numbers correlate with better protection and a longer duration of outdoor benefit. But SPF only refers to shielding from one of the bands of sunlight, UVB. This range of light typically results in sunburns. Turns out, there is also UVA, the rays that cause tans in folks who are able to produce pigment. Even in those without albinism, the UVA range is also unhealthy, but products don't always protect against UVA wavelengths. **Seek out "Broad-Spectrum" creams that cover UVA and UVB.**

No sunscreen can work all day. Theoretically, the power of high SPFs (60, for example) should last twice as long as SPF 30. In reality, sweat and water combine to dilute even the stronger creams. It's best to **reapply lotions to any exposed areas at least every two hours.**

Sunscreen needs time to set in. Slapping on sunblock while running out the door, while better than nothing, is not ideal. After application, products need time to take effect. Just like a fine wine, sunscreen takes a little time. Typically, **waiting at least 15 minutes after rubbing the cream in should be sufficient for full protection.**

To spray or not to spray, that is the question. In aerosolized sprays, some of the material is lost in the air, so creams and lotions are more cost effective. Also, it is not clear whether inhaling the aerosol is safe. Finally, aerosol is typically flammable. There have been isolated reports of skin catching fire when these products were used near open flame. Better not to be part of the BBQ! While some enjoy the efficiency and ease of application in sprays, **I recommend rubbing the product onto the skin.**

Why does my skin get red and itchy when I apply certain sunscreens? For most people, sunblock rubs in easily, feeling like a moisturizer. Rarely, **certain ingredients can cause an allergic reaction.** To complicate this issue, some have an allergy only when that ingredient is exposed to the sun. If you develop a rash after sunscreen, apply cortisone creams until the inflammation subsides. **Make**



If you use a lotion that's an SPF 5 and a sunscreen that's SPF 20, are you getting the cumulative effect of SPF 25?

Nice try, but you can't add SPFs together to gain a higher SPF.

a note of the ingredients and find products without them.

What about the expiration date? Sunscreens in the U.S. are required to remain **stable for at least three years**. Used appropriately, most bottles should be used up well before that time. Just like taking a chance with old milk, the risk of using a cream that is not potent isn't worth the cost savings. **If you have a bottle past its expiration date, we recommend discarding it.**

But...Vitamin D! This is a topic in itself. Although Vitamin D can be helpful for bone development and levels of the vitamin can be activated by sun exposure, using a lower SPF screen in hopes of getting a boost of "D" is "D"-angerous! **Vitamin D supplements and**

eating foods high in D are the safe way to go.

Which sunscreen should I use? Within certain parameters, this is a personal decision. After going with a product with **at least SPF 30 that is also Broad Spectrum**, the options open up. There is no data to suggest a more expensive sunscreen works better than a bargain-basement balm. Creams tend to feel heavier than lotions and might play a role in facial acne. Gels may be more drying to the skin. Most importantly, find a product that feels good enough to use routinely. And don't forget your hat, sunglasses and sun protective swimsuits. The more effort you make, the more you put dermatologists like me out of business!

UV Rays and Your Eyes – Protection Isn't Just for Skin

By Rick Thompson, OD, FAAO, Reprint from Autumn 2007



"Protect yourself from ultraviolet (UV) radiation," is a mantra that we have heard for some time. My observation is that many people either overreact or underreact to this threat. Like many things, lack of understanding of UV light leads to inappropriate actions.

There are a few questions we may ask ourselves. What is UV light? What damage does it do? When is it a problem? What steps do I take to minimize the risks of damage? These questions are especially important to the albinism community since those with albinism lack pigment that offers needed protection. Let's look at the issue of UV radiation and the eyes.

What is UV light? Light that we use to see in our everyday life is made up of different wavelengths of electromagnetic radiation.

We can see these different wavelengths in a rainbow with violet, blue, green, yellow, orange and red, in that order. On either side of the rainbow there are wavelengths that the human eye cannot see.

Beyond red, the light we can't see is called infrared (IR) which has less energy than visible colors. IR rays do not generally pose a threat. Beyond violet, the light we cannot see is called ultraviolet. This is also called "black light" for the same reason – we cannot see it. However many insects and birds can see UV as color. UV has more energy than visible light. This extra energy is what causes tissue damage.

Modest amounts of UV light are unlikely to cause damage; however once the intensity is above a certain level, damage to tissue occurs.

What damage does UV light do?

If UV light has enough intensity, it will “cook” tissue. Skin damage results in sunburn and red blotches on the skin after overexposure. It is also well documented that damage can occur to the eyes. The good news is that these problems can be avoided if proper steps are taken to protect the eyes such as sunglasses, wide-brimmed hats, window tints and staying out of the sun during peak UV times of the day.

Both acute and chronic problems can be the result of UV overexposure to the eyes.

Acute problems tend to be brief but severe. These tend to be painful and usually resolve in a matter of days, but they may result in permanent damage including vision loss. Sunburn of the eyelids is probably the most common problem. Photokeratitis, which, in essence, is a sunburn to the cornea, is another condition one may get if proper protection is not worn. This is quite painful for one or two days but is temporary. Corneal dystrophies may result from repeated bouts of photokeratitis. Solar retinopathy (retinal burn) develops most commonly after looking at the sun during an eclipse.

Chronic eye problems arise slowly and range from being a nuisance to life-threatening from repeated overexposure to UV over a period of years. Tumors and cancer of the eyelids, conjunctiva and sclera are possible. Pterygium is a triangular flat growth that may slowly cover the nasal portion of the cornea. Pinguecula are common but have no effect on vision. Dry eyes are a common finding due to

the loss of cells that produce mucus and lipids that lubricate the eye. Those with dry eyes may experience dryness, burning, itchiness, tiredness and blur just to mention a few symptoms.

Cataracts (cloudy lens within the eye) are one of the more common long-term results of UV exposure. When caused by UV exposure, cataracts increase gradually over a period of many years. Today, the surgical techniques to remove the cataract are excellent, but the person with the cataract may have to live with gradually deteriorating vision for some time before surgery is indicated. In other words, there is more vision impairment

in addition to their already reduced vision. Nutrition, trauma and genetics are other factors that can cause cataracts.

In the typically-pigmented population, UV exposure is a risk factor in age-related macular degeneration. However, this condition does not seem to be found in people with albinism.

What steps do I take to minimize the risks of damage?

Time of Day: Peak exposure is typically found at midday. To figure midday, calculate the exact time midway between sunrise and sunset. For example, if sunrise is 7:00 AM and sunset is 7:00 PM, midday or peak UV is 1:00 PM. Planning outdoor activities for morning or evening is the most important measure for people with albinism to avoid sun damage to the eyes or skin.

Latitude: A person who can tolerate one hour of sun in Florida without burning can tolerate



two hours of sun in New Jersey under the same conditions.

Season: The greatest intensity of ultraviolet light occurs at the summer solstice, about June 22nd. May 1st has as much intensity as August 15th.

Altitude: Each 1,000-foot increase in altitude adds 4% to the intensity of the burning rays. The intensity of sunlight at 5,000 feet is about 20% greater than at sea level.

Weather: A bright day with a thin cloud cover has 60 to 80% of the UV rays present on a clear day. Clouds can cool giving a false impression there is little risk of sunburn.

Environment: Sand, water and especially snow reflect UV rays.

UV meters are available to measure UV rays. Handheld UV meters are relatively inexpensive and easy to use. You can actually measure UV in a variety of locations so you can determine the risk of burning for yourself under very specific circumstances. This eliminates much of the guesswork.

Understanding and using the “UV Index” is another major step in reducing one’s exposure to UV. The index was developed in 1992 by scientists at Environment Canada and with some modification has been adopted

by the World Health Organization (WHO). This is a very useful tool for assessing and understanding the risk of UV, especially for those with albinism. The index is a scale assessing the risk of danger for the average pigmented person: low (0-2), moderate (3-5), high (6-7), very high (8-10) and extreme (11+). Most media report the peak UV index during the day which is helpful, but hourly forecasts allow you to pinpoint the times when you can safely go outdoors. When plotted on a graph, hourly forecasts resemble a bell curve with the peak at midday.

A good example of hourly forecasts can be found at www.theweathernetwork.com.

If your favorite website or paper does not

have hourly forecasts, consider lobbying them to provide one.

People with albinism can avoid eye problems associated with overexposure to UV light by protecting the eyes with sunglasses (usually dark grey or brown tints), wide-brimmed hats, window tints, staying out of

the sun during peak UV times, and always remembering sunscreen for the skin. All of these steps will be worth it in the long term.

For more information about the sun and albinism, visit www.albinism.org, select “Learn” from the top navigation bar, and check out the Sun Protection information bulletin.



www.youtube.com/user/NOAHAlbinism

Working with the School District on Testing Accommodations

By Lee Laughlin



Standardized testing is nothing new, but with the arrival of the Common Core Curriculum, the administration of standardized testing has changed. Large print, once only available by special order, is now available with the click of a mouse. All rejoice! Well, sort of. Even though the tests are computerized, parents and teachers still need to be on top of the accommodations provided for their children. We have a great relationship with our school district, and our Individualized Education Program (IEP) teams have professionals who genuinely have our kids' best interests at heart and who respect my husband and me.

My son, Timmy, is in the 5th grade, and he had to write the Math, English and Language Arts components of the Smarter Balanced Tests in April. Starting in January, his teacher spent time reviewing what would be on the tests and what types of questions the students could expect. Two weeks before the test, students had the opportunity to take practice tests on the computer. I asked if I could help Timmy get

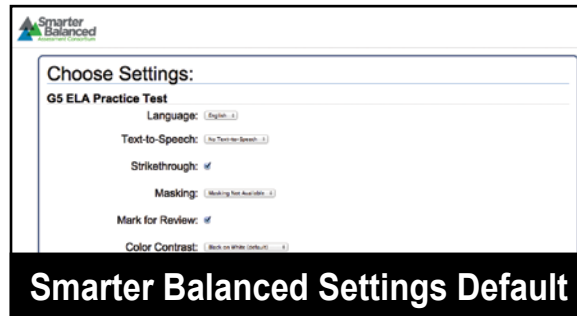
things formatted correctly and thankfully, his teacher

welcomed my assistance.

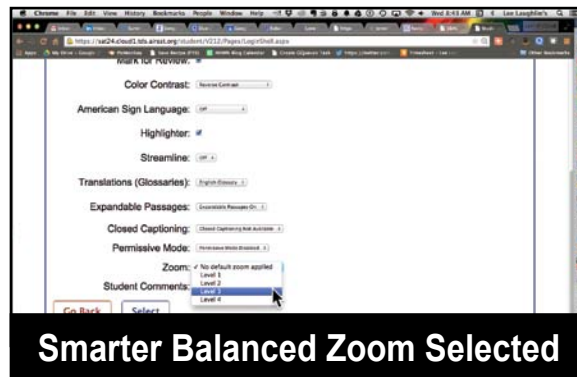
By sharing my experience I hope to help other parents create a supportive testing environment for their children. As I said, our IEP team is fantastic and the support they had in place met the specifications of the IEP, but ultimately, it didn't provide the best environment. There was no malicious intent, merely a lack of knowledge. When I pointed out the challenges of their plans the usual response was, "Oh, I didn't think of that."

All Computers are Not Created Equal

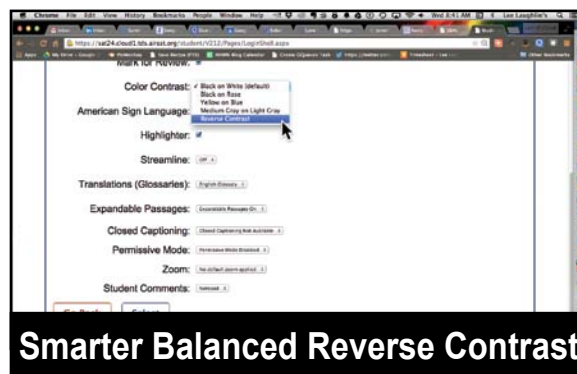
The original plan was for Timmy to take the test using a MacBook. However, I asked to use an alternative platform. While Timmy is most familiar with the Mac operating system, the test is Web based, so it doesn't matter whether he takes the test on a Mac, a Windows machine or a Chrome book. The 11-inch screen of the MacBook would have him hunched forward for the entire test. He could use a Chrome book like his peers,



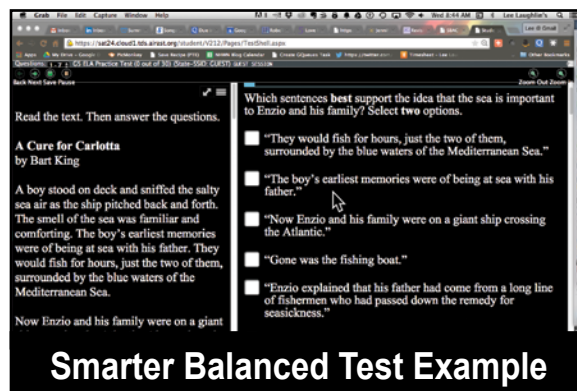
Smarter Balanced Settings Default



Smarter Balanced Zoom Selected



Smarter Balanced Reverse Contrast



Smarter Balanced Test Example

so I requested a larger monitor and a separate keyboard.

All Monitors are Not Created Equal

Testing was set to start on a Monday and the Friday before, an IT technician from the school district came to set up Timmy's monitor. The monitor that was provided was a low quality, 19-inch screen. I am not afraid to advocate for my child, so I asked the IT technician for a different monitor with better resolution. Ultimately, a 22-inch, sharper resolution monitor was located and set up for Timmy, and we spent time going through the accessibility settings. We changed the background to white text on a black background to meet his preference, enlarged the text, and spent time adjusting the angle of the monitor so the glare from the windows and the lights was minimized. We also made sure the text-to-speech feature was available for the test.

Advice for Parents

The tests themselves are controversial, and every parent needs to evaluate their options to make the best decision for their child. In some

states, these tests have high values attached to them for graduation requirements. As parents you need to make the effort so your child has a level playing field. I was glad I was able to be there because my son was comfortable enough to tell me when something was not working. The parent and the Teacher of the Visually Impaired should work with the child before the tests to ensure the right accommodations have been made and work for the child.

This is the first year these tests are being offered and there is still a lot of confusion and questions about how the tests function. In our district, the teachers, special education professionals and IT staff have been stretched to the maximum. However, without an ounce of malice, the staff thought they had Timmy squared away. I am glad I stepped in to verify the accommodations, and I encourage all parents to do the same.



School is Out – Education Plans are In!

As the school year comes to a close, remember to submit your education plan! Creating a Resource for Education (CARE) collects student education plans from early childhood intervention to the senior year of high school. We request IFSPs (for students three years and under), IEPs (for students three years to graduation), and 504 accommodation plans. The CARE team removes confidential information, extracts the content to a database, indexes the information by state and grade, and publishes the education plan and database at iep.albinism.org. This resource is free online to aid parents / caregivers in establishing their child's individual and unique education plan.

Our resource is only as good as the input we receive from participants, so please, before you file them away for the summer, consider sharing them with CARE.

Mail: NOAH, PO Box 959, East Hampstead, NH 03826-0959

Email: iep@albinism.org

In person: We will collect plans at NOAH's Family Camp

CARE IFSPs
IEPs
504s

Creating an Albinism Resource for Education

Albinism Minecraft Server Update

By Joey Adamo



The Albinism Minecraft Server is live! Launched at the end of 2014, it's a place where the albinism community can have fun and interact. So far we have about 20 users, and we'd like to have more.

The server is open to anyone with albinism and their families. There's no cost to join, but you do need the PC version of Minecraft if you

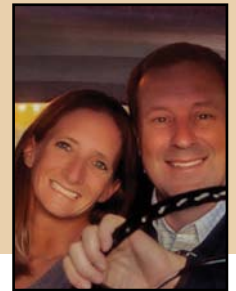
do not already own it (around \$30). After installing the PC version, you enter the server IP address **Noahminecraft.adamofam.com** in the "Add Server" screen in order to join.

We look forward to seeing you online soon!



Ready to Rumble? WrestleMania in the Albinism Community!

By Tammy McClure, Photos courtesy Jim Pressler



Reading the article in the Spring edition of *Albinism InSight* about the little boy who started wrestling brought tears to my eyes because it reminded me of my senior wrestler, Kevin. We wanted to share his story to help other parents and children with albinism.

When Kevin was diagnosed with albinism, many doctors, counselors and advisors doubted that he would ever drive, read or be able to succeed in school due to his vision. From a very young age, Kevin showed he was determined and physically strong. When he first started playing sports, he enjoyed playing but had a difficult time seeing the ball. He played football as a seven year old but couldn't make out the play or see the ball in the backfield. On one occasion, his little sister told him, "Kevin, just look around for a big brown thing and when you see it, that is the football." His dad told him to hit

anything that wasn't in a yellow jersey which resulted in three penalties on one play for late hits. On another play, the team lost 45 yards.

After the season was over, we asked him what he liked about football and his response was, "I just like hitting people." So we decided to try another sport, wrestling or boxing. We started him at the Alabama Wrestling Club (AWC) at the age of nine. The first day he was terrible and got pinned several times. The other wrestlers lined up to wrestle him because he was so easy to take down. We went home thinking boxing would be our next sport, but to our surprise, he told us that he loved wrestling and wanted to go back. For

almost nine years, Kevin has wrestled several times a week. He is known by everyone at the AWC as the kid who comes busting through the door, ready to wrestle anyone at any time.



**Alabama State
Wrestling
Champion, Kevin
McClure**



Wrestling was a better fit for Kevin than other sports because of his low vision, but it was not without challenges. He had difficulty seeing techniques in class. He wasn't the most coordinated kid either and could barely do the warm-up exercises correctly. Kevin spent hours practicing jumping jacks and jump rope at home. When he was wrestling, he had difficulty seeing the coach, the clock, the scoreboard and the referee. His dad would often be mat-side telling him the score and the amount of time left.

Kevin's first few tournaments as a 6th grader were anything but promising. But with a lot of hard work and determination, he eventually had success in middle school and ended up with a 110-7 overall record. He won Outstanding Wrestler in the metro tournament in 8th grade. He also won the USA Wrestling State Tournament in 7th and 8th grade and took 4th place in the Dixie National Tournament in Atlanta.

Kevin's mentor was Doug Blubaugh, an Olympic wrestler who won gold in 1960. Doug was a "tough as nails" fighter like Kevin and was also famous for his "coke bottle glasses." Doug couldn't wrestle in glasses so he wrestled nearly blind. He taught Kevin how to wrestle in close and even how to do some moves with his eyes closed. Doug said if your technique and

conditioning were right, it didn't matter who you wrestled or what the opponent did, you would win. Kevin took this to heart and rarely even looked at the brackets to see who he would be wrestling. He just showed up to do his best. If something didn't go as planned, he would go back to training and make corrections to his technique or learn something new. Sadly, we lost Doug in 2012, but we are frequently reminded of him through the techniques he taught Kevin and the picture Kevin has on his bedroom wall.

Kevin's successes continued in high school with a four-year record of 194-39. He qualified for the state championship every year, placed 2nd his sophomore year and 3rd in a very difficult weight class his junior year. He finally obtained his goal as State Champion with a 54-3 record under Coach Ryan Thompson during his senior year. He has also set lifetime and single season school records for the most wins, most pins, most points and fastest pin. He was elected the team's most outstanding wrestler his junior year and Captain of the team his senior year.

Kevin has had to work harder than normally-sighted people to excel in wrestling, but the sport has given him a lot. As a young child with low vision, nystagmus and white hair, kids often teased him, but Kevin quickly became known as a formidable wrestler. Instead of being teased about his vision or white hair, others looked to



Kevin for help when they were being teased. Wrestling gave him confidence to stand up for himself and for others. It has also given him an avenue to excel individually and to be part of a team and a community. Wrestling has become part of his identity. Almost all the other wrestlers and coaches in the state know Kevin, and he is truly part of the statewide wrestling community. After the state tournament this year, an opposing coach said it wouldn't be the same without Kevin around the mat next year.

Wrestling is a great sport because you get out of it what you put into it. Working hard and training well always pays off. Hard work, determination and passion for the sport yield results even if you

aren't the biggest or most gifted athlete. What Kevin lacked in vision and natural athletic ability, he more than made up for with his dedication, hard work, fearless attitude and competitive spirit.

He has put those qualities to work in other areas of his life as well. He has worked every summer with a local moving company where the crew leaders say he does the work of two people. He and his dad spend their spare time rebuilding his 1971 classic Ford truck. He will graduate with a 3.5 GPA and he scored a 31 on his ACT. He will attend Auburn in the fall to study Civil Engineering.

Have You Seen Our New Website?

The sleek new design offers some differences in accessing information, but the site remains the comprehensive source of accurate and authoritative information about albinism you've come to know and trust.

New technology allows the home page to deliver links to the latest events and news, so you'll want to come back often. Top and left navigation provides access to a variety of resources and information.

Top Tabs – Info about NOAH such as:

- Programs & Services
- Opportunities to Learn
- Opportunities to Connect
- Ways to Get Involved
- The NOAH Store

Left Tabs – Info specifically for:

- Adults with Albinism
- Parents
- Educators
- Doctors
- Students doing Research



We're still at
www.albinism.org
so come check it out, and
help us spread the word!



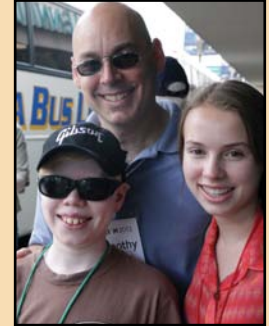
It's an opportunity for parents to share thoughts, ask questions, provide resources for each other, and describe the struggles and triumphs experienced by our children and ourselves. Because everyone already understands the condition, a deeper level of conversation can be reached. - *Brooke Jensen -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