



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Winter 2016

Welcome to NOAH Ed U!

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

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of Albinism InSight*

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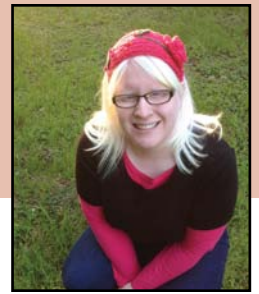


Does the family of your student with albinism know about NOAH?

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

Santa's Most "VI Friendly" Finds

By Kathi Garza



The holiday season is upon us! As a parent, I have been eagerly scouring through store flyers and online sales to find the most engaging items for my young toddler. However, as a parent with albinism, I also try to find things that will be easy for me to use as we play and create together. I have noticed that I tend to purchase books that are easy for me to read to him, and I often pick toys and puzzles that I can interact with, without obstructing his view or ability to engage. Although my son doesn't have albinism, he is exposed to many "vi friendly" items in his bookshelf and toy bins.

So, what ARE the best items to consider when shopping for the young child with albinism? Let's explore some things to consider when shopping, and at the end of the article, I'll provide some examples of items that are very engaging, accessible, and even educational.

Things to Consider

COLOR

You might notice that your young child is drawn to things of bright color. This is because they are easy to see. Toys with bright colors will encourage your child to move through their environment to seek out the toy. For older toddlers and preschoolers, brightly colored toys will also be easier to find in the toy box or on the shelf. Books with brightly colored covers will also stand out from the rest.



CONTRAST

Contrast has many definitions, depending on the context. For our purpose, contrast is used to describe how parts of the item stand out from itself or the environment. Toys with higher contrast are typically better for children with

visual impairments. Picture a car-launching racetrack.

Sounds like tons of fun! If the cars are the same color as the track, it might be difficult for the young child to watch the car as it speeds down the loops of the track. To improve contrast, choose cars that are of different colors than the track itself. For a play kitchen, knobs that stand out on doors or play appliances will also help your child. When you're having a hard time remembering contrast, think of the time you stepped on that light-colored Lego in the carpet. If it had been bright yellow, or hot pink, you probably would have seen it in time to save your foot!

Pictures in books can also be difficult to see due to contrast. Sometimes, the pictures are illustrated in a watercolor style. There are no clean, crisp lines. The color hues might also blend into one another. This can make identifying what is happening in the picture difficult. The text itself in the book might also be low contrast. I've seen some really fun books where there might be orange or red words on a brown or black page. It can be really challenging to decipher the letters in these instances.

With the right contrast, toys and books can be easier to find on the shelves. I use contrast to my advantage in my toddler's bedroom and playroom. He has a white shelf with cubbies. I purchased brightly colored bins, which are where we store different categories of toys. This helps me find things that I am looking for rather quickly, and it makes cleaning up much easier, too!

CLUTTER

Remember *Where's Waldo*? That is the epitome

of visual clutter. I personally enjoy those types of “I Spy” games in books, but sometimes, it can be challenging. On a simpler scale, when thinking of the young child with albinism, books and puzzles can be difficult due to the amount of clutter in the illustrations. I prefer books with simple illustrations that contain only a few objects or pictures on a page. I also like when the text is kept separate from the images so that it stands out. For puzzles, I choose the wooden kind with chunky pieces that aren’t too close together. Clutter can also impact your child’s ability to find things that he/she wants to play with in the room. Having bins that are labeled with pictures of the types of toys that go inside might be helpful. If you are playing with your child, you might also encourage him/her to put something away before choosing something else to minimize clutter in the play area.

SIZE

You all might have thought this should be first on the list of things to consider. It is a common misconception that for a child with low vision, bigger is better. Size is a good thing to consider when shopping for new playthings, but it looks different for everyone. I don’t like giant books because I often have to move my head to scan the pages. Smaller books with larger text and pictures work best for me and might be best for your child, too. Puzzles with larger pieces are best for young children with visual impairments because there is a higher success rate when putting the pieces in the correct slots. Coloring and activity books with large, bold-lined images are also helpful to have around. Larger balls and vehicle toys will be easy to find once the child has kicked, thrown, or pushed them out of reach, and larger beads are easier to thread.

Shopping Suggestions

- **Melissa and Doug** – This brand offers great

toys, but what I love most are the puzzles and educational shape-sorter or bead toys. They have great contrast with brightly colored pieces against wooden backgrounds, and the size of the pieces is always appropriate for little hands and for children who are developing fine motor skills. We love the Caterpillar Gear Bug, the Basic Skills Board, and the Geometric Stacker.

- **Balls** – A simple search on Amazon will yield some amazing balls. You can find balls with bells, textures, or ones that light up.
- **Blocks** – Many companies make large foam blocks that are a little safer than the wooden ones for younger toddlers. I like that they are also brightly colored. You might also like the Wonderworld Rainbow sound blocks that have transparent colored sides and items inside that rattle when shaken.
- **Musical Instruments** – Make some noise! Melissa and Doug have some great sets, but you can also do a search for rhythm band instruments to find a wide variety.



- **Books** – The Baby’s First Library series is my absolute favorite. It has large pictures outlined with thick black lines. The images are on a solid background. The text also stands out and is very simple. My son has developed his language from reading these books. His two favorites are “Animals” and “Numbers.” Karen Katz is another author we collect. The illustrations in these books are more detailed but still meet my standards for high contrast, size, and minimal clutter. The text is large and typically done with bold lines. We also love peeking under all of the flaps!
- **All Things Wheels** – Fisher Price and V-Tech make some great cars, buses, and tractors in a variety of sizes. The people that come with them are chunky and easy to keep up with. Some of the vehicles also

play music or talk when pushed forward. This helps the young child with albinism locate the toy once it has gone out of reach or sight.

Color, contrast, clutter, and size are all things to consider when purchasing new playthings

for young children with visual impairments. The addition of light and sound to toys has broadened the choices for accessible toys. I hope you all feel a bit more empowered to confidently navigate those long holiday lists. Happy shopping!

LEARNING & EDUCATION

Learning Sign Language with Low Vision

By Anna Reid

Have you ever wanted to learn American Sign Language (ASL)? Did you think you couldn't, or did you try, and find it was hard because of your vision? I tried to take a sign language class a few years ago and was quickly discouraged. I sat next to the teacher, and could mostly see what she was doing. However, I struggled to see some hand shapes and I completely missed the signed questions and comments of my classmates.

I gave up on that class and tried to learn ASL online. But videos can be hard to see, and honestly, videos can't take the place of real conversation for anyone learning any language.

That might have been the end of my mission to learn ASL. But I got lucky, because a friend put me in touch with a blind sign language interpreter. Say what? Blind people can learn ASL, and can even work as professional ASL interpreters? They can interpret a "visual" language? Yes, they can!

The key to the puzzle, I learned, is to understand that ASL is not only a visual language. It is also kinesthetic. It is produced through physical gestures, so it can be read through physical touch. There are a number

of ways to do this. One of the most common today is "tactile ASL" (TASL), which involves lightly placing your hands on the hands of the person who is signing. Some deaf-blind people use this technique. With practice, a person can communicate in TASL as effectively and efficiently as with visual ASL.

Here's how it works in practice, for a low vision person like myself.

In a classroom or other space where sign language is the mode of communication, I use the accommodation of an interpreter. I say "interpreter," but in fact what's happening is not interpretation from one language to another. I depend on a "deaf interpreter" (DI), which means a deaf individual who is a skilled signer and is trained to facilitate communication in sign language environments. Different people use the services of DIs in different ways. In my case, I sit directly in front of my DI, knee-to-knee with her so I can clearly see her hands and face.

My vision is 20/200. If the visual conditions are optimal (e.g., if the lighting is good, if



the person who is signing has a shirt color that contrasts with their hands, etc.), and if I am sitting close to the signer, I can see ASL. About half the time, I just use my eyes. The other half, I use TASL. I place my hands on the hands of my interpreter, and use this kinesthetic feedback to supplement what my eyes can see.

The main job of my DI is to watch the signed communications in the room, and reproduce them for me at close range. Whether it's the teacher who is talking or another student, the DI copies the communication exactly, including facial expression, speed, and exact signs that are used. This gives me full access to the content of the class.

In addition to relaying all of the signed communications in a room, my DI describes what's happening.

She gives me visual context. For example, when someone speaks

up with a signed comment, the DI tells me the name of the speaker and conveys his or her body language. If the teacher pauses in the middle of a lecture, the DI tells me why. Perhaps the teacher is fiddling with the slide projector, or is looking for a resource online, or is communicating with someone who just walked in the room. My DI tells me all of this. She also tells me what someone is referencing



when they point to a poster on the wall. She can even sign to me what the teacher is writing on the board, if this is easier (which it sometimes is) than me squinting through my telescope.

Classroom “aids” and “paras” are wonderful, but just to be clear, that's not what I'm talking about here. My interpreter is strictly responsible for funneling the visual information in the room into the few square feet of space between us.

All of this adds up to a remarkable experience. With the right set up, I sometimes feel more accommodated in a signing classroom than I've felt in my entire life. In a silent room,

where all cues and communications are visual, I have full access and opportunity to participate.

I went through school just fine without knowing the exact

expressions on my classmates' faces. But let me tell you: it's fun to know these details.

Learning how to accommodate my vision in a sign language class has blown open my understanding of what's possible. It's also gotten me thinking about the advantages of cross-disability collaboration. It has also allowed me to continue studying the beautiful, complex, language of ASL.



NOAH SchoolKit



WonderBaby.org Announces Favorite Apps



WonderBaby.org teamed up with Paths to Literacy to create this list of recommended iPad apps for children who are blind or visually impaired. They've categorized them by apps great for stimulating the use of vision, honing fine **motor skills** or teaching **cause & effect**, great **communication** apps, apps that tell **stories**, and one app that is really nice for calming down and **relaxation**.

Vision

- Tap-N-See Zoo
- My Talking Picture Board
- iLoveFireworks
- Doodle Kids
- Infant Zoo Lite
- Fluidity HD
- Art of Glow

Motor/Cause & Effect

- Baby Finger HD
- Bebot
- Cause & Effect Sensory Light Box

Communication

- Talking Tom Cat
- Sounding Board
- Answers YesNo

Relaxation

- Pocket Pond

Stories

- Tickle Finger in the Jungle
- Dr. Seuss's ABC

Accessibility

- Ballyland Magic App

To find out more on these apps visit www.wonderbaby.org.

Teen Spotlight



www.albinism.org/teenspotlight

Where Is This Bus Headed?

NOAH Looks to the Future with Latest Strategic Plan

By Mike McGowan, NOAH Executive Director



In 2016, NOAH had its largest conference ever, the introduction of the SchoolKit, a new albinism resource library on the website, and a record number of contacts with newly diagnosed children with albinism. With this impressive record of service to the albinism community, one might ask, where is NOAH headed from here?

A strategic planning team consisting of board members and staff met in Philadelphia in June to chart a course to the future. This meeting, facilitated by an outside consultant, was the latest in a series of strategic planning sessions conducted throughout NOAH's history. Past strategic plans led NOAH to make significant steps to grow the organization including the hiring of Lori Aubrey in 1999. The goal of the strategic planning committee was to imagine and articulate NOAH's immediate future and to set compelling – but realistic – organizational priorities and programmatic goals for the next planning horizon.

A strong consensus on NOAH's mission, vision, and organizational values was arrived at quickly during the strategic planning process. Team members agreed that the type, mix, and volume of services that NOAH provides is appropriate and meets constituent needs. While the team shared a common view of the organization's strengths, they realistically concluded that the current operating model (personal heroics, over-extended staff and volunteers) is not sustainable.

In many ways, NOAH gives the appearance of a large organization with a significant staff. During a recent conversation, a person with albinism expressed surprise to hear that NOAH is run primarily by volunteers and a small part-time staff. Today, NOAH manages over a dozen programs and is consistently revising and expanding information sources in a variety of media including in print, on the website, and through a strong social media presence.



NOAH's Strategic Planning Team in Philadelphia

As the strategic planning project evolved, it became increasingly evident that what NOAH most needed at this time was not a new strategic plan. It was found that NOAH would benefit more from a refresh of its current strategic plan focused on unfinished organizational and capacity goals. The 2010 plan included five strategic goals that, if accomplished, would position NOAH to be a self-sustaining, not-for-profit. A number of goals were developed by the team with the expectation that they could be accomplished by the end of 2018.

It was determined that NOAH must have reliable and diverse funding sources. These funding sources must include individual donors, grassroots events, major donors, corporate sponsorship and foundation support. Increased funding is needed to ensure that NOAH can sustain existing programs. NOAH staff is currently operating above the capacity required to maintain programs and services. This situation is clearly not sustainable. It is at risk of breaking down.

In addition to the urgent need to expand capacity, the team determined that NOAH also needs to perform organizational development tasks to build the infrastructure. Job descriptions, procedures, organizational charts, and project calendars are some of the elements that must be in place for NOAH to be ready for future growth. Without excess capacity, NOAH will need to do fewer events temporarily and defer new initiatives to make the time to build the organizational infrastructure.

Over the course of the strategic planning process, the team discussed ways for NOAH to better interact with the albinism community to address some of unfinished work of the 2010 plan. Little progress has been made on the strategic goal to establish, create, and support

an organizational structure that will maximize engagement of members at the local level.

The team considered a number of factors while grappling with the question of how to best serve the albinism community locally. Chapter activities have been inconsistent throughout NOAH's history. Few local chapters have been operated steadily over the years. Thought was also given to the emergence of social media and the effects that it may have on connecting the albinism community. A key goal of the strategic plan is to build a volunteer network to connect and engage the albinism community locally. This reset will likely involve reviving the local contact model and a coordinated use of social media.

It has been very difficult to expand financial support through member dues. Paid memberships in NOAH have remained flat since 2000 while contacts with individuals and families with albinism have grown steadily and participation in the national conference doubled over the same time frame. Membership dues as a percentage of NOAH income have dropped steadily over the past ten years. A goal of the strategic plan is for NOAH to move away from the membership model by focusing on new ways to obtain financial support from the community.

To make progress towards the goal of a self-sustaining not-for-profit, it is necessary to expand operational capacity, to develop a culture of philanthropy to support NOAH and to ensure strong local connections. With focused leadership, committed supporters, and an engaged community these goals are possible. We are headed towards a better connected, better supported, and more effective NOAH.

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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