



NOAH Ed U

CREATED WITH EDUCATORS IN MIND



Summer 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!

Book Review: A Blind Guide to Stinkville

By Kathi Garza



Young adult fiction has always been one of my favorite genres of literature. I am captivated by an author's ability to connect with adolescents through the pages of a story, and when the opportunity to read a book where the main character had albinism arose, I was eager to get started. After downloading "A Blind Guide to Stinkville" by Beth Vrabel to my device, I immediately began scrolling through the pages. I found that I could not stop reading and I couldn't read fast enough to keep up with my desire to find out what happened next in the story. At times I made myself stop and close my eyes for a second to savor the story because as I read chapter after chapter I knew the end was nearing and, I could already tell that once the book was over I'd experience that feeling of wanting more (like when you have that last bite of ice cream on a hot day). "A Blind Guide to Stinkville" follows Alice, a 12-year-old girl with albinism, as she tries to make the stinky paper mill town of Sinkville, South Carolina, feel more like a home.

For Alice, life had been great right up until her family moved from their happy home in Seattle, Washington, to a small mill town called Sinkville in South Carolina. Everyone back home knew about Alice and her albinism. She used a magnifier to read books, wore sunscreen and hats, and occasionally used her cane to avoid bumping into things in new environments. Leaving her life and best friend behind was bad enough, but moving to a small paper mill town that smelled bad enough to be dubbed "Stinkville" by the residents made life

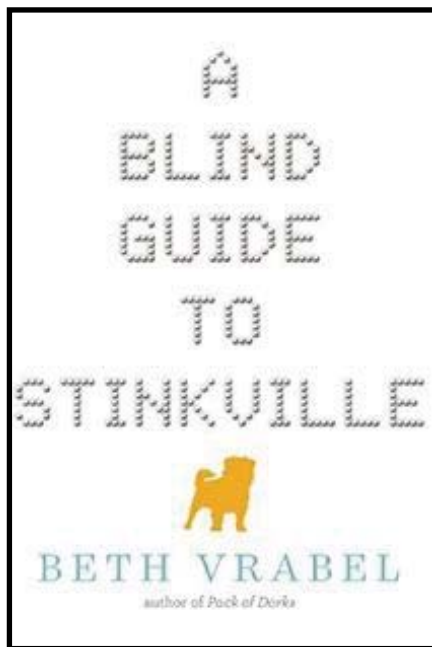
much more difficult for Alice.

What made things worse for her was that she didn't know anyone and couldn't get around on her own causing her parents to look into schools for the blind. With her mom battling depression, her father immersed in a new job, and her brother dealing with his own feelings about the move, Alice becomes determined to show her family that she is independent and capable and can face her visual impairment head on!

At the library, where Alice ventures each day to take refuge from her home, she learns about the Sinkville Success Stories essay contest. Although no one thinks that the "new girl" could possibly find out all of the juicy stories in the town, Alice immerses herself into the task while making many friends along the way. Throughout her journey, Alice gains confidence and empowerment as she faces adversity in a new place while trying to cling to her old life and keep her family from tearing apart at the seams.

Having moved to a new town at the start of high school, I could definitely identify with Alice's feelings. As I clung to my old friends, they embraced new opportunities and seemed to move on without me. I was put into a new environment where I had to learn to advocate

for myself all over again, and while this wasn't so difficult in the academic sense, advocating and explaining in the social sense was extremely difficult. The author handled this delicate situation quite beautifully in the



way she documented common perceptions and misconceptions about those with visual impairments and in the language she gave Alice to communicate about her needs both to the audience and to the other characters in the book. I found the analogies and descriptions of visual abilities to be realistic and believable in most instances.

Beth Vrabel tackled so many topics within the pages of this book. Depression, learning disabilities, and visual impairment were just a few. The lives of the characters were

so intertwined and complex that at times I almost forgot that the main character had albinism. This struck me as very profound in that I believe this book speaks to a variety of audiences and is valuable to those in and out of the albinism community. “A Blind Guide to Stinkville” is definitely a coming of age story. Each character, no matter the role, grows and develops their sense of accepting change as the story progresses. If you’re looking for a great summer read, I highly recommend this book. I’m looking forward to the sequel!

Apply for USABA Scholarships before July 31

Through the generosity of I C You Foundation and Paralympian Markeith Price, and Arthur E. and Helen Copeland, the USABA offers two scholarship opportunities annually to college students enrolled in two or four-year colleges or universities. Deadline to apply for the 2016-2017 academic year is July 31. To learn more about the scholarships and eligibility visit www.usaba.org or contact Kevin Brousard at kbrousard@usaba.org with questions or completed applications.



Goalball's Life-Changing Impact

By Amanda Weldon, U.S. Association of Blind Athletes (USABA)

Images courtesy USABA

Marybai Huking of Plain City, Utah, and Donté Mickens of Delray Beach, Florida, both had different ideas of where life would take them. “I grew up really enjoying basketball,” explained Donté, a member of the U.S. Men’s National Goalball Team. “But it’s something I knew would be impossible for me to continue at the competitive level.” After being introduced to goalball at the Florida School for the Deaf and the Blind, Donté played on the school-sponsored team throughout middle and high school, leading his team to three consecutive National Youth Championship titles. He later joined the National Team in

2003 and became a two-time Paralympian, securing bronze with his team at the 2004 Athens Games and placing fourth at the 2008 Beijing Games.

After being a competitive figure skater, Marybai, member of the Women’s National Goalball Team, was also introduced to goalball at a younger age by her teacher for the visually impaired (TVI). After attending a few practices, Marybai was convinced goalball was not for her. “I came from a background of wearing makeup and dresses,” said Huking. “Then I was diving on a dirty



gym floor. It just didn't seem ideal." But after being pushed by her mom, she went to the Utah Goalball Tournament, which changed her mind completely. "It wasn't until I got to the tournament that I fell in love with the sport," said Marybai. "Up to this point I didn't really have any girls to look up to with visual impairments, and I was still coming into being confident in myself and my visual impairment." She became so inspired by these girls and the Utah youth team that she began attending camps soon after and made the youth team the following year.

"Goalball is something that helped me come to terms with my blindness and understand that it will only be a disability if I let it," Marybai said. She explains how it provided her the confidence and understanding that she is capable of anything, crediting goalball for her participation in track, cross country and other sports, as well as her position as editor in chief of her high school yearbook. "I didn't need to limit myself because I am blind or because I have albinism," she said. "You can be successful in every aspect of your life if you are willing to put in the work. That is one of the main things goalball has taught me." Marybai currently trains in Utah as part of the U.S. Women's Goalball Team. They are managed by the U.S. Association of Blind

Athletes whose mission is to enhance the lives of people who are blind and visually impaired by providing the opportunity for participation in sports and physical activity. Although USABA is involved in numerous sports, it is the official national governing body for the sport of goalball and offers opportunities from the grassroots levels all the way to the Paralympic level where Marybai currently trains.



Donté Mickens



After moving to Portland to attend Portland State University and train with the Women's National Team, Marybai moved back to Utah in January to start classes in the fall at the University of Utah because of the importance she places on balance in all aspects of her life. "It is really important to find that balance between sports, friends and family, and I believe I was not able to find it in Portland," she says. But how does Marybai

find that balance? "It's driven by passion," she explains. "Your passion for the sport is important, but you have to carry that passion into your academics as well and realize that you can be successful in both as long as you are willing to work for it." Marybai remembers traveling almost 30 percent of her senior year for goalball but was still able to achieve her goals and become ranked first in her class with a GPA of 4.0. "This is completely possible but

it takes a lot of work,” she describes. “It all has to be driven by passion and must come from a place where you want to be successful and you are willing to put in that effort to do so.”

When asked what Marybai’s advice would be to NOAH readers interested or currently competing in sports while continuing their education, she explains that you should “not be afraid to lean on other people for support. Any big dream, whether it is athletic, academic or artistic, takes a lot out of you, and you shouldn’t be afraid to lean on those around you. They are more than willing to help,” she says. “I think that is how I was able to get where I am now, because of the support I have around me.”

Donté also knows what hard work and dedication can achieve. In addition to being a member of the U.S. Men’s National Goalball Team, in 2012 he completed his Master’s at

Florida State University in Management, Risk Management and Insurance. Prior to this, he completed a Bachelor’s degree in Risk Management/Insurance in 2006 and Bachelor’s in Finance in 2003. In addition to completing

his schooling, Donté works as an insurance and financial consultant in Boca Raton, FL. With his experience in higher education as well as being an elite athlete, Donté knows firsthand about balancing school, work, and training and just how important they are to one’s life. He is a seamless example of what can be achieved when you have dedication in every avenue of life.

Editor’s Note:
Goalball is just one of 22 different

sports that will be featured in the Rio 2016 Paralympic Games, September 7 – 18, 2016. Coverage being provided by NBC and USOC. For detailed viewing information visit www.paralympic.org/watch-rio-2016.



Marybai Huking



Pre-Driver Readiness Skills for Novice Bioptic Lens Users

By Chuck Huss, COMS, Driver Rehabilitation Specialist

Photos courtesy Dr. Cindy Bachofer, TSBVI



Becoming driving ready takes place over increments of time, along with learning, experience and maturity. Parents, teachers and rehabilitation professionals were first advised of the importance of early introduction and reinforcement of basic survival (on-foot) low vision orientation and mobility skills with their son, daughter or student during the formative years (as alluded to in *How to Become Driving Ready*, Albinism InSight, Winter 2015). Then light was shed on the early dispensation and practice using both hand-held monocular telescopes as well as head-borne bioptic lens systems by such novice potential driving candidates in a variety of indoor and outdoor environments (as described in *Driver Readiness with Low Vision Aids*, Albinism InSight, Spring 2016)

As such individuals reach their early to middle teen years, the introduction and reinforcement of what is oftentimes referred to as “commentary type” (passenger-in-car) pre-driver readiness skills is next in line. During such skill development, mom, dad or instructor will become the designated driver, while their son, daughter or student assumes a front right seat passenger in-car position.

The objective behind these active passenger-in-car type outdoor routes of travel is to teach the novice driver not only where and how to look, and the distance to maintain behind other motorists in front of their vehicle (referred to commonly as **distance viewing skills**), but also what is important to look for and comment on

(referred to as **critical objects or conditions**) while using their head-borne prescription bioptic lens system.

Distance Viewing Skills

Eye Lead Distance

Knowing how far out in front of one’s vehicle a person should be looking depends on one’s driving speed. The faster one drives, the further out in front of their vehicle they should be directing their line of sight, in order to establish and maintain an appropriate and safe line of travel. This is referred to as “eye lead time or distance” or “forward scan”. For example, when driving in a residential area at speeds of 15-20 mph, one’s eye lead distance might be a linear block or two ahead. Whereas if one finds themselves driving in a commercial environment at speeds of 35-40 mph, one’s eye lead distance might subsequently extend out to 3-4 commercial blocks or a half a mile distance in length. At interstate speeds of 65-70 mph, one’s eye lead distance might extend out to a 1-2 mile approximate distance down the roadway.

Eye lead distance expressed in units of time is equivalent to looking 10-20 seconds down one’s path of travel.

Head and Eye Scanning

In addition to eye lead-time or distance, novice driver candidates also need to be taught to scan with their eyes and head laterally as wide as possible. For example, in a residential area, from the front entrance of homes on one side



of the street to the other; in a commercial area, from the front entrance of a business on one side of the street to the opposite side; and in a rural area, from a homestead or barn on one side of a roadway to the opposite side.

Following Distance

Following distance refers to the linear distance (in seconds of time) that a driver should attempt to

establish and maintain (3-4 seconds is the suggested minimum) from their vehicle to the vehicle ahead in the traffic formation to reduce the possibility of hazard or collision.

When travelling a prescribed route behind another vehicle, have students select a stationary object or form alongside of the road (for example a telephone pole or large tree) and begin counting aloud slowly in seconds of time (for example “1000-1, 1000-2, 1000-3, 1000-4”) when the end of the vehicle ahead passes such object or form, until the front end of their parents’ or instructor’s vehicle passes said same object or form. If your vehicle reaches said same stationary object before the count of 1000-3 or 1000-4 is reached, you are following too close to the vehicle ahead.

When used in combination with one another (eye lead, head and eye scanning and adequate following distance) a driver will have sufficient time or distance to detect, identify, predict and decide what to do in terms of speed or lane adjustment to critical objects or conditions

located within, approaching or alongside of their path of travel, that may require a timely response to while driving.

Critical Object or Condition Awareness Skills

Critical objects are defined as any object or condition that can be predicted to cause drivers to alter their speed, lane position or planned path of travel.

Knowing when to adjust one’s speed, lane position or both while driving is extremely important for novice driver candidates as they continue to learn and transition from active passenger to active driver.

Driver education professionals stress that all drivers, including those with visual challenges, learn how to group critical objects or conditions into three general categories: roadway characteristics, other road users, and traffic



Bioptic training exercise (on foot)



Passenger in-car lesson

control devices.

- **Roadway characteristics** consist of such objects or forms as a lane(s) of roadway, road shoulder, an approaching intersection, a hill, dip or sharp curve in the roadway ahead.
- **Other road users** would entail anything on two or more feet or two or more wheels.
- **Traffic control devices** are such things as yellow or white pavement markings, various types of road signs (i.e. regulating one’s speed, lane position, allowance or restriction, right of way, curvature of the

- roadway), and traffic lights that regulate the flow of traffic through intersections.

Grouping of critical objects or conditions facilitates object recognition and decision-making, affording drivers an increased margin of safety to decrease the likelihood of hazard or collision in one's dynamic driving environment.

Basic Bioptic Usage Skills

Once the above distance viewing and critical object awareness skills are in place, then previously introduced on-foot basic bioptic usage skills can be reinforced under dynamic, yet controlled passenger-in-car conditions; for example, with students using solely a brief, intermittent, vertical spotting technique (from carrier to telescopic lens, back to carrier lens of their bioptic lens system) while being driven on straight stretches of roadway, in the absence of other road users in their surrounding space cushion.

In The Driver's Seat: Introduction to Low Vision Driving Workshop

Has integration of basic distance viewing, critical object awareness and basic bioptic usage techniques or skills ever worked or been tried with novice low vision candidates interested in exploring the driving privilege? Yes, one example is as follows...

Since 2012, an annual spring workshop has taken place and has been sponsored by the Texas School for the Blind and Visually Impaired (TSBVI) at its residential facility located in Austin, Texas. Approximately 15-18 Texas teens, who meet the vision requirements for consideration of future restrictive driving privileges using a prescription bioptic lens system, and their parent(s) are invited to participate in this 3-day workshop at no personal expense. The latter includes an overview by a multi-disciplinary panel of presenters of the:

- Clinical low vision examination (including

visual factors affecting driving)

- Bioptic evaluation, fitting and prescription
- Criteria to qualify as a bioptic driver in Texas
- Advanced pre-driver readiness skills
- Bioptic drivers' panel discussion
- Non-driver transportation options

From comments shared by parents on their evaluation at the conclusion of such workshops, you can decide for yourself if any positive outcomes surfaced from attending:

- I feel so much better now about the possibility of him driving.
- I have a lot of information that I didn't know or other people couldn't explain to me in the right way. I now feel better about letting my son drive.
- Very friendly presenters who were personable, honest, and believable.
- Just wish we knew about all of these things years ago!
- We have gained so much knowledge as well as met parents that we can network with. I am thankful that TSBVI put the program together.
- Now confident we can apply strategies to help my son or daughter become pre-driver ready!
- I would like to thank your speakers and the staff for an awesome weekend with so much needed information. We appreciated your knowledge and attention. Please continue to do this program.

For a regular or large print copy of a 22-page *Step-by-Step Guide to Reinforcing Basic & Advanced Pre-Driver Readiness Skills with Novice Bioptic Driving Candidates*, developed by this author for the TSBVI Outreach Program, send your e-mail requests to:
Chuck.P.Huss@wv.gov.

Special Accommodations Show Caring and Make a Difference

By Rachel Revennaugh



Before college, I rarely ever had accommodations because I did not realize that my visual impairments actually could be considered a disability. Having accommodations in college has helped validate my experience that some things are genuinely harder for me to accomplish because of my eyes, and I am not simply imagining things. This was a strange transition for me because at first I felt guilty for having accommodations, or perhaps it was wounded pride that made me not want to admit needing help. But I am extremely thankful for the help that my professors and my friends give me because it is a picture of God's love for me, and it encourages me to know how to accommodate other people with disabilities I come into contact with.

I am finishing up my junior year, majoring in music and English, and I have been enrolled in disability services since the summer before freshman year. Within the first two weeks of every class I show my professors my accommodation sheet and then give them a small pink slip that says I get extended test time.

I get extended test time and the option to not fill out scantrons because I lose my place switching back and forth between test pages

because of tracking and seeing double. I always get priority seating that means that I can sit in the front of every room. When possible, I try to sit on the right side of every room because I see double less when I look out of my left eye at an angle.

My accommodation sheet asks professors to tell me before taking the class outside. One thing that has really shown me sensitivity from my professors is that they keep the classes inside and even accommodate my need to shut the blinds when it is sunny. Sometimes

they remember without my reminding them. And when my friends know about my eye issues they can help by reading whiteboards or subtitles to me.

Overall, I have definitely been shown love by my professors because they genuinely want to help me succeed and feel comfortable.

Having accommodations and communicating with professors has really helped me. I do not usually need to worry that I take longer than most people do to take an exam; I know my professors will be sensitive to my needs and this has helped eliminate some of the anxiety related to learning.



An Ode to the Sandy (sdy) Mouse:

My Experience as a Visually Impaired Research Assistant Through a Fellowship Promoting Diversity

By Arielle Fay Lewis



In the Autumn 2014 issue of *Albinism InSight* I wrote an article (“Perseverance is Key”) about my first 10 weeks as a Neuroscience Education and Training (NET)/work Atlanta fellow. I’m happy to follow up today and share that on April 14 I graduated from the (NET)/work program. While listening to a main keynote speaker, she briefly discussed the importance of diversity in the STEM field noting that, “I am the only...” which is considered the norm in this field. This statement really hit me. Then I started to think;

I may be the only visually impaired student in my field. This reality wasn’t unlikely, since I was the first and only visually impaired student accepted into this program.

As a side note, the National Institutes of Health (NIH) defines diversity as a person from one or many

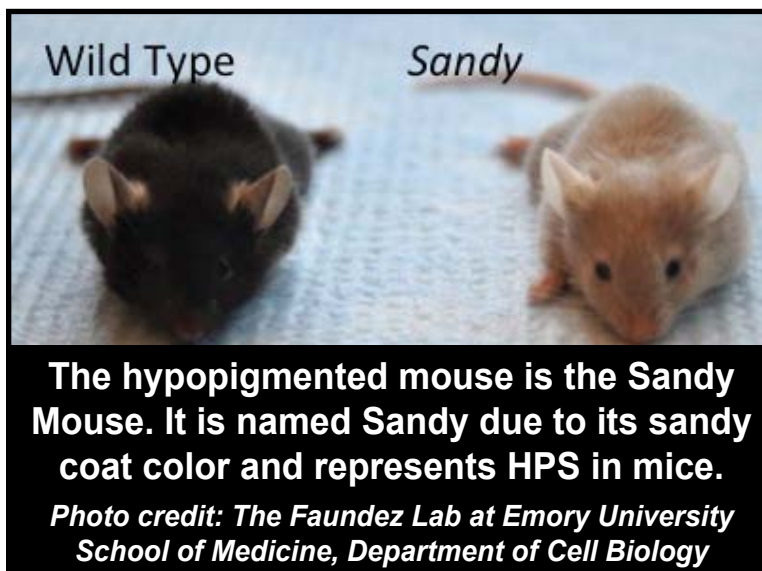
underrepresented backgrounds. There is a list of the underrepresented backgrounds and “disability” is on that list. How was I able to spend two years in a research fellowship in neuroscience? Why would they accept a student like me that had so many uncertainties?

I was accepted in April 2014 and hit my first obstacle two weeks later. All four directors didn’t know what to do with a visually impaired person. For the decade this program

has existed, they have never had a visually impaired student participate. Before we were allowed to choose a research mentor through some “speed-dating-esque” interview, I remember receiving an email from the Emory University director about their “concerns”. I found it very interesting that they doubted my scientific ability and worried about the possible physical obstacles, which came much later.

What makes neuroscience so interesting to me is that it is a multidisciplinary field, divided

by cell biology, psychology and behavior biology. The directors strongly advised me to work on the behavioral side of the neuroscience spectrum, but I wanted to work more with the biology. They tried to be of assistance by contacting a lab at Purdue University that works on adapting lab techniques for visually



impaired students. Disregarding their attempt to advise me, I decided to limit my options based on what I was interested in and not based on what I was capable of doing. As you will see, this worked out for me in the end.

During interviews with over 20 Primary Investigators (PIs), I remember for some I started to disclose my disability. This produced obvious expressions of fear and doubt. After the same repeated reaction was presented on

several different PIs' faces, I knew I wanted to find someone who was willing to work with me regardless of my visual "obstacles" and who would want me to be in their lab. I also realized that it was a good idea to not disclose my disability so quickly in the process. I remember starting a conversation with a man named Victor who eventually became my research mentor for the next two years. He asked me if I had OCA and we talked about albinism. He told me they use a mouse model called the Sandy (sdy) mouse that represents the Hermansky-Pudlak Syndrome phenotype in mice. (On a side note, I should thank this hypo-pigmented mouse for allowing Victor and I to cross paths.)

We had several other things in common; we lived in the same neighborhood, I went to the same high school as his son, and my alma mater (Oxford College of Emory University / Emory College of the Arts and Sciences) would soon become his son's place of study. I was also really interested in his lab's research - understanding molecular pathways of Neurodevelopmental Disorders. Again, the (NET)/work directors still had doubts about my ability to work in the Faundez Lab at Emory and again, I followed my gut.

There was a possibility of switching labs at the end of the first 10 weeks of the program, but I was determined to work in this lab. A couple weeks later, I sat down with Victor and discussed what I was supposed to do in the lab for the summer. My vision was of course an obstacle, but Victor let me run these experiments over the 10 weeks to see how I performed. Victor could tell how driven I was with these experiments but he could also sense my frustrations. Near the end of the first

10 weeks, I stayed late trying to run multiple experiments to match the results of the other undergrads in the lab.

The following semester we sat down again to discuss my plans for the school year. I remember him telling me that it would take me 15 years to complete a PhD in neuroscience based on how long it took me to run experiments over the course of 10 weeks. However, instead of sending me to another lab, he introduced me to a field called Bioinformatics (tools that aid in collecting

and computing complex biological data). He gave me some scientific journal articles, a link to an application and asked me to figure out how to use different databases and applications. Moreover, I was going to have to teach him after I figured out how to use these bioinformatic tools.

This was very stressful at the time, considering I had to learn all of this before I would present at the Society for Neuroscience three months after learning how to do this type of analysis. As I look back on this experience, I can see how much I have grown as a scientist.

After a year of playing around with my computer, I now understand the importance of bioinformatics both in the lab and as someone who is visually impaired. Bioinformatics has allowed me to analyze data without the struggle of continuously trying to run visually intensive experiments without getting frustrated. Although my work was completely different than what would be considered standard traditional science research, I am able to present my actual work like my sighted peers at poster sessions and/or symposiums.



Arielle with her research mentor at Neuroscience and Behavioral Biology (NBB) research symposium

As of now, not only do I have the honor to continue to work in the Faundez Lab post (NET)/work, but am also looking into graduate schools offering programs in bioinformatics. I recently received authorship on a manuscript based on my work with bioinformatics that is in the process of being reviewed by a scientific journal. I hope to become a primary author as I continue down this newly found path as a scientist. Since I was able to find a mentor who was extremely supportive and took a risk trying to help me find my way in scientific research, my confidence as a scientist and as a person has grown exponentially. For those interested in scientific research, I hope you find your "Victor". For those who are not pursuing a scientific career, there is a moral to this story. Surround yourself with those who are willing to support you regardless of your obstacles. I

understand that we live in a world that was "not meant" for us, but creativity and flexibility are two things that allow us to remold the world around us and make it our own.

I would like to especially thank my research mentor and professor Dr. Victor Faundez, the Faundez Lab, the Sandy mouse, and my Emory (NET)/work director Dr. Yoland Smith for believing in me and allowing me to be a part of the (NET)/work program. Without their help and support, I do not know where my research career would be. I would also like to thank the National Institute of Health Blueprint Program for Enhancing Neuroscience Diversity through Undergraduate Research Education Experiences (BP-ENDURE) grant, and Dr. Kyle Frantz at Georgia State University for allowing the (NET)/work program to exist.

CFTB Announces New Grant

By David Jeppson, Executive Director, CFTB



Professionals in assistive technology for the blind know that good keyboarding skills beyond just the alpha-numeric keys are essential to effectively using screen reader and screen magnification software.

Since November 1, 2015, Computers for the Blind (CFTB) has been installing a demo version of MarvelSoft's Talking Typing Teacher (TTT) on all CFTB computers and MarvelSoft has generously reduced its price by 50% to make them affordable to CFTB consumers. The response and the simple process has been overwhelmingly successful for all parties.

In an effort to make TTT available to significantly more consumers, CFTB is pleased to announce the receipt of a generous

grant from Communities Foundation of Texas to provide 1,000 copies of TTT for \$10 each to consumers and agencies. This is a 90% discount off of the retail price.

We encourage all consumers who do not have strong keyboarding skills beyond the alpha-numeric keys to obtain this software. It will greatly increase their productivity in areas of employability, independent living, and quality of life activities.

For more information or to obtain a computer please contact CFTB customer service at 214-340-6328. Email inquiries can be sent to info@computersfortheblind.net.

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

Low-Vision Tips & Favorite Finds

I use a computer program called MAGic. It's a combination of a screen reader and large print. It's such a relief to my eyes to be able to listen to what's on the computer screen, as well as to be able to read documents enlarged to my heart's content. In addition, I'm so grateful to have my "tricks for getting through the everyday", such as using a white cane, monocular and 6X magnifier. They're always with me when I leave the house to step

outside into the hectic and crowded city known as Manhattan.

- Karen Kacen

For reading, my favorite program is Learning Ally. There are actual people reading books instead of a computerized voice.

- Rachel Revennaugh

