

Working for a Living

Profiling the careers of a select group of adults with albinism

By Kelsey Thompson, NOAH Board of Directors



As children, we were often asked, “What do you want to be when you grow up?” A fireman? A ballerina? A doctor? An astronaut?

Now, as adults, when introduced to a person, one of the first topics of conversation is, “What do you do for a living?” Even though one’s job is only a small piece of who we are, it’s undeniably important. For virtually all adults, a career is an aspect of personality. A career embodies our likes and dislikes, our skills, our temperament, and our values.

For adults with albinism, it’s no different. Most of us go to work every day, interact with coworkers, supervisors as well as customers, and are held to the same standards as other employees. But these stories, as quotidian as they may seem, are important. Collectively, these stories provide a brief snapshot of the sheer range of jobs that people with albinism



can, and do excel in every day.

For many parents of young children with albinism, one of the most mystifying questions is, “Who will my child grow up to be?” Here are some ideas...

When Luke Chastain was five years old, he wanted to be a train engineer. Now, at 30, he works as a Senior Software Engineer for AT&T. As a California Bay Area resident, Luke spends about 30 to 60 minutes on the bus or train every morning to get to work.

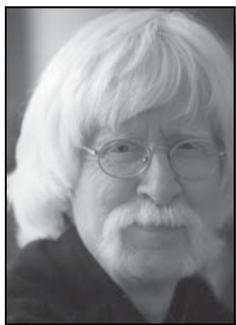
“I found this job through a friend. Only once have I ever gotten a job that wasn’t through someone I knew,” explained Luke. “Software was something I did as a hobby growing up and so it was natural for it to then become a career.”

According to Luke, sometimes it can be challenging to manage time and priorities in the

fast-paced field of software development, but he finds rewards in finding simple solutions to complex problems.

At work, Luke described having a large screen monitor and occasionally using a monocular. It can be challenging sometimes, he said, when looking over a colleague's shoulder to see something at their desk. "People have been understanding when I ask them to explain what they're seeing," he said.

To a young person considering a job as a software developer, Luke recommends starting early to fine-tune your skills and marketing your creations. "Write software as a hobby," he advised. "Do it every day. I think the opportunities to get your work in other people's hands are much better than when I started. It's really a different world."



Jesse Kain

Jesse Kain would agree.

For 30 years, he has worked in the IT field, currently working as a systems

engineer for the New Mexico Public Education Department. Jesse, who has a bachelor's degree in computer science, typically drives the six and a half miles to work, occasionally taking the bus or ride-sharing with other commuters.

On the job, Jesse's responsibilities consist mostly of project management. To accommodate his visual impairment, Jesse uses a few simple adaptations, such as hand-held magnifiers and a giant computer monitor with low-resolution settings.

Jesse loves work that is interesting, intellectually challenging and personally rewarding like software development.

"I've always enjoyed the intellectual challenge," said Jesse, who noted that he found his current job through a friend. "I fell into computers back in high school about 35 years ago. Back then,

there were no computer classes. I joined a high school computer club that met during lunch."

"Learn as much as you can. Read, go to classes, learn from people who have more knowledge than you. Never stop learning. Be enthusiastic about what you do," Jesse's advice to young people interested in the field is, "Don't be afraid to tell people you have difficulty seeing. Be disciplined, organized and structured in your work."

Sheila Tidd, age 26, found that the people she interacts with on her job are usually pretty accepting of her visual impairment. She works as a substitute teacher with grades K-8 for a school system in Michigan.



Sheila Tidd

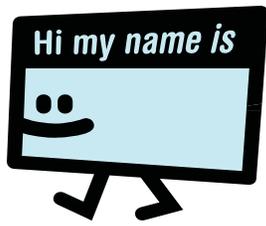
Sheila earned her bachelor's degree in 2007 from Aquinas College, where she majored in Language Arts and minored in Early Childhood Education. She found her current job through her college.

Sheila noted that she always had a love of working with children. She began volunteering at the age of twelve; in high school, Sheila volunteered daily in an elementary classroom, which quickly confirmed that teaching was the job for her.

"I chose this field because I love to interact with children. Children are so full of life and can teach adults a lot."

As a substitute teacher, Sheila rarely has a "typical" day. Using a bioptic telescope and a GPS device, Sheila drives to each of the various schools. Her commute can range from ten minutes to an hour. The subjects she teaches include reading, writing, math, social studies and science.

"I have to be flexible," she said. "I pick up the lessons and teach on the fly."



When reading the tiny print in the teacher's edition of textbooks, Sheila employs a small magnifying glass. For computer work, she positions herself close to the screen or finds a large-screen monitor

when possible.

Reading students' nametags and reading a student's work over his or her shoulder can be tricky, but she has found ways to work around these challenges.

"I explain to children that Ms. Tidd has bad eyesight which means that I have to get closer to things in order to see. If I get close to your work, that is why," she explained. "Experience helps with all of these challenges. I find that the more experience I have the more these situations occur naturally and smooth out."

"Do not let your fears of the unknown scare you away from the job," she cautions young adults considering a career as a teacher. Taking advantage of opportunities to actually get in a classroom and learn from teachers in the field can help a young person to test the waters and experience first-hand what it's like to work as a teacher.

"Most importantly, tell children about your eyesight in a way that is age-appropriate," Sheila added. "Children are more understanding than most adults and are more willing to work with you when they know you are being honest and open with them. You will be amazed how well this helps and works!"

Much like Sheila always felt drawn to a career working with children, Staci Burton, age 31, dreamed of becoming an attorney since she was very young. Currently, she is a social worker and works as a vocational counselor at the Epilepsy Foundation of Greater Chicago. Still hoping to eventually achieve a law degree, Staci is in the process of pursuing her second master's

degree, this time in Public Administration.

"I found my job on the Internet," Staci laughed. "I have chosen to pursue my career as a social worker because I enjoy meeting and connecting with people where they are in their lives as well as helping them achieve that 'light bulb' moment. This field allows me to become more tolerant as a social worker, and as a regular person, of the complexities of society."

Her job entails a mixture of counseling, education and advocacy. Staci helps people with epilepsy to develop job-readiness skills, such as resume-writing and interviewing. She also facilitates groups to educate clients about important legislation, such as the Americans with Disabilities Act.



Staci Burton

"I enjoy empowering people with disabilities, and helping them understand that they too can work and live their lives," Staci said. "I enjoy informing and inspiring these people, which in turn enables them to realize that they too can live."

Staci relies on public transportation to get to work every day, taking a bus and a train for 30 to 45 minutes each way. On the computer, she adjusts control settings to her liking and uses prescription reading glasses

and a small CCTV for reading. Like Luke, occasionally it is difficult for her to view the computer screen when working with a client. "I tell the client that we have to 'work together' and that he or she has to be my eyes and see things that I don't. The clients don't mind."

In Staci's opinion, love and support are the two crucial ingredients for success. She encourages young people with albinism to connect with state vocational rehabilitation services as they begin planning for postsecondary education and a career. She also notes that the unconditional support and understanding of parents can help a child succeed.

Rita Jackson of Euless, Texas believes that she found just that: a dream job. “I love writing. I love editing and I especially love travel,” she said.

For 20 years, Rita has worked for American Airlines. She currently works as a Web Content Analyst, where she is responsible for overseeing writing, editing and marketing on the company’s Web site, AA.com.

“I’ve worked as a content analyst for about seven years,” said Rita. “I’ve managed accounts from fun stuff like entertainment and travel to explaining policies and procedures in a customer-friendly way. Bottom line, I help my company by helping our passengers.”

Because of the nature of her job, Rita explained that her adaptive technology needs have been minimal. When working with fonts that need to be enlarged, Rita can simply copy and paste a section of text into Microsoft Word and increase the font to her heart’s desire. To get to work, Rita typically carools with a coworker or her husband. Because she lives only four miles from her job, she also has the option to walk home on pleasant days (which are most days in Texas).

Rita noted that the biggest challenge she faces on her job is the subtle visual cues involved in professional networking. “Sometimes it’s hard to see people in the corridors or to remember people from meetings, especially if they’ve changed hairstyles. I often schedule one-on-one meetings with my contributors so that they get to know me and I can actually see them close-up rather than from across a conference room.”

And her involvement with NOAH has helped, too. “I also send out emails about the bowl-athon each year detailing my experience with albinism. I often hear, ‘I thought you were just light skinned,’ or ‘I never realized that you didn’t see me when I waved at you.’ It’s been a great mechanism for educating my peers.”



To a young person with albinism who is thinking about a career in the travel industry, Rita says, “Go for it!” Ample opportunities for advancement within the company and being able to travel all over the world make this field a great fit for someone with a love of travel and a passion for writing.

“I was an unemployed school teacher when I found this job,” said Rita, who has a bachelor’s degree in Speech Communication from Cameron University in Lawton, OK. “I thought, hey, it would be fun to travel for a couple of years then I’ll go back to teaching.

Twenty years later, I’m still enjoying traveling and I’m teaching within corporate America!”

Like Staci, Steve Fellin, age 32 of Toronto, Ontario, never had a doubt about what he wanted to do as a career: sports broadcasting. For the past ten years, Steve has been working for The Score Sports Network, currently as a producer.

“It beats working for a living,” Steve joked. “I get paid to watch and analyze sports, there’s no other job that I could possibly find more rewarding than this one, and I never take it for granted.”

Steve earned a dual degree in Broadcast Journalism and Political Science. He first started working at The Score as a college intern and was eventually promoted to producer.

At his job, Steve is responsible for overseeing the production of a one-hour sports highlight show (similar to ESPN’s *Sportscenter* in the U.S.). As a producer, Steve delegates nightly tasks to reporters and editors, including a series of sporting events that each group is expected to review and compile condensed highlights.

“Throughout the evening, I converse with each employee to see what is going on in each game and what I am expecting the final product to look like. Once the final highlight package is



completed, I ensure that all statistics and elements are correct and fit for air.”

Steve takes a combination of bus and subway train to cover the hour and 15 minute

commute each way to work. Once on the job, he utilizes ZoomText to magnify the font of his computer or a glasses-mounted monocular.

“Since I work in a visually intensive field, there will always be challenges,” Steve said. “It is best to swallow your pride and depend on low-vision devices such as reading glasses for small print, Zoomtext for viewing items on a computer or high-powered monacles for watching sporting events.”

If you think a job in sports broadcasting might be right for you, Steve has some poignant words of advice.

“In order to succeed in this industry, a person with albinism – or anyone with a disability for that matter – must be willing to put in more of an effort than a ‘normal’ employee to prove their worth,” he said. “I’ve found that there is an inherent philosophy that a person with a disability requires special treatment and doesn’t possess the traits that are expected to excel. Without appearing to have a chip on your shoulder, it is imperative to go about your job by proving everybody wrong.”

Sandra Saunders of Chicago, Illinois echoes that sentiment.

“Recognize your strengths and weaknesses and be honest about them. Know that everyone has doubts and insecurities, not just people with albinism. Hold your head up and do your best,” she said.

Sandra currently works as the Assistant Director of Services for Students with Disabilities at Columbia College Chicago. She found that her own experiences in college and graduate school influenced her to help other students with

disabilities to become empowered in secondary education.

“I received support and it was valuable to me,” she said. “I want to give back as good as I received.”

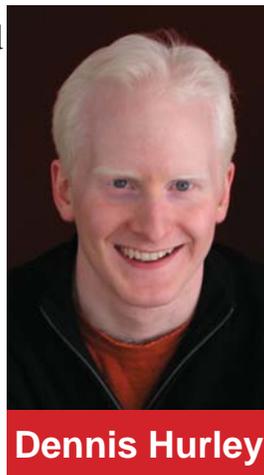
On a typical day, Sandra meets with students and parents to discuss their disabilities and how they affect the student in an education setting. She reviews disability documentation and helps the students to develop a plan for implementing reasonable accommodations.

“I like feeling that I am helping, supporting and inspiring a student to keep going even when things get tough,” she said. “I also like troubleshooting with students who have complicated issues and finding a way for them to function successfully.”

Like Rita, Sandra noted that she sometimes encounters challenges in recognizing students or coworkers on campus. She also noted that her job involves a great deal of reading, for which she relies on magnifiers and ZoomText. Despite these occasional challenges, Sandra believes that every experience, good or bad, has been a learning experience for her. “I know that you cannot succeed at anything unless you do something,” she said. “I feel that if we can take the lumps, we will reap the rewards.”

In Dennis Hurley’s mind, the most rewarding job would be writing and performing sketches for Saturday Night Live. While working toward that dream, Dennis currently works as an actor, writer and film director for ImprovBoston.

Dennis, who you might remember from the satirical short film *The Albino Code*, which parodies Ron Howard’s portrayal of a character with albinism in *The Da Vinci Code*, has worked in this field for about 10 years. He has a Bachelor of Fine Arts degree and believes that comedy is his true passion.



In the entertainment industry, supply is often high and demand is low. For that reason, Dennis makes ends meet by also working part-time as a clerk and barista at a local coffee shop.

“Make sure in whatever field you pursue, you find joy in the type of work you do,” Dennis advised. “There’s a right job out there for everyone.”

For 17 years, Felix Morales worked as a leadman and supervisor for Amerijet International Inc., a global transportation services company. He is now retired, but when he was working, Felix described himself as a “no nonsense kind of boss.”

“My day always began by checking to see how many flights we had for the day and informing my crew of the day ahead,” Felix said. “I was responsible for the loading and offloading of all aircraft within all safety limits and had to make sure everything was done legally and efficiently.”

His job required a lot of patience and he noted that it took years of personal investment in order to move up in his company. “I chose to work with airplanes and in this industry because I love flying and the logistics fascinate me,” he said. “I didn’t know at first that I wanted to work in this field but as time went on I loved what I was doing.”

“I am now retired so I am living my dream job, taking care of my children,” Felix said.

He noted that, although he enjoyed his job, which required him to start a typical day at 4:00 p.m., the recent passing of his wife has given him new perspective on life. He’s realized that, even though a job is important to put food on the table and pay bills, family is more important.

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Brian Evans

Brian Evans, age 65, realized not long ago that his life’s goals had not yet been entirely fulfilled.

Brian holds a Ph.D. in medical physics, has worked for 40 years in scientific research, is a Fellow of the Royal Society of Medicine and holds a number of patents in digital high-definition television.

His own experiences with low vision coupled with his inquisitive nature and research skills have led Brian down another path since retiring from his successful career; He is curious to understand visual

acuity and ways in which it can be improved, so he decided to return to school for a degree in optometry from the University of Manchester, which he hopes to complete in two and half years.

Brian noted that his current career as a student can sometimes be visually challenging, but nothing is impossible. With the help of his illuminated magnifier and enlargement settings on the computer, he feels confident.

“I am challenged but will work around the issues,” he said.

According to Brian, if you have a dream, “Go for it.”

NOAH Member Dinner in Houston



Saturday, November 14th
Save the Date

Check back at www.albinism.org in October.