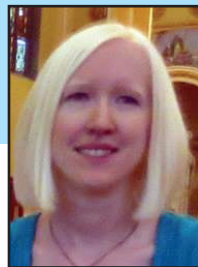


Let's Talk About Love

By Kelsey Thompson, NOAH Board of Directors Vice Chair



Warning! It's about to get sappy in here!

The albinism community has its share of romance, and I'd like to introduce you to a few of the NOAH couples in our midst. Many started as "just friends" who reconnected every other year at NOAH events and gradually became something more. They've navigated the tough waters of long-distance relationships, coordinating household responsibilities with low vision, and handling laughable questions from strangers, like, "Are you brother and sister?"

Aside from a larger-than-usual budget for sunscreen and certain unspoken understandings, most of these couples believe their relationships are like any other. They're based on common interests, values and attraction. I asked each couple what they loved most about their significant other, and each responded with nearly a page of gushing praise. Let's get to know the lovebirds!



Ed & Kristen (Daley) Dalton – Chicago, IL

It all started at the 2000 NOAH National Conference in Boston when they met as teenagers with a game using large print playing cards. Six years later at the conference in the Twin Cities, “sparks flew.”

For Ed and Kristen, two years was too long to wait to see each other again. Shortly after the 2006 conference, Ed visited Kristen in Boston for their first date.

“He swept me off my feet with his hunky smile, nerdy humor and down-to-earth charm,” Kristen noted. “We began dating despite the 867 miles that stood between us. Two years and hundreds of airline miles later, I moved to Chicago where we reside today. After seven years of dating, we tied the knot last summer.”

The journey to Ed and Kristen’s eventual I-do’s had its highs and lows as they got into the routine of a long-distance relationship. Ed remembered, “Our second date was two months after our first. It was always amazing to see her waiting for me at the airport, but it was also devastating to say good-bye in the same spot not knowing when I’d see her again.”

Kristen recalled, “When we first started to date, we corresponded primarily through email. The long messages we sent were our own version of modern love letters. Every day we were apart, I looked forward to seeing his name pop up in my inbox. When we did spend time together, it felt like we had never been separated.”

Ed and Kristen’s relationship was founded on shared interests such as their love of long-distance running.

Kristen said, “When we’re

on a long run together, we signal each other to warn of oncoming city buses, small dogs, mailboxes and speeding cyclists. It’s nice to know he’s got my back, even though I know he sees the same as I do.”

Ed said, “We’ve also developed an unspoken language that we use when we’re walking around. We hold hands and, when one of us notices an obstacle, we’ll give a few quick squeezes or a pull or push as a signal. This has saved us from running into or tripping over things on countless occasions.”

According to Ed, the fact that they both have albinism makes them more memorable. “Everybody knows us. Walking into a restaurant for the second time, the hostess will always welcome us back.”

“Our marriage is unique in many ways, but it’s also so normal,” said Kristen. “We pay bills, enjoy date nights, share family holidays, go to school, work long hours, vote, compromise, laugh, read books beside each other on the couch, cook dinner, entertain, drink wine, and plan for the future.” Of course there are those quirks that make being in a relationship with another person with albinism special. “He always knows I have a monocular in my purse, and I am constantly borrowing his handheld magnifier. We laugh when neither of us knows

what to order at a food court because we can’t see the menus.”

“I get a good laugh when she tells me to swat a fly for her. I have to remind her that if she can’t see it, neither can I,” Ed joked. “Neither of us gets frustrated when we have to pause a movie because there’s text on the screen and one of us has to walk over to the TV to read it.”

“It’s hard for guys to admit

Courtesy of Hitched Studios



Kristen and Ed Dalton



when they can't do something, especially to a girl, but I never feel like I need to explain myself to my wife. She knows I have limitations just like she does. But, she also knows that a person's limitations don't make them who they are. She knows that limitations are an excuse to be creative. They're an endless source of laughs. They're the obstacle in your path that only intensifies your desire to move forward. In short, she just gets me."

Tim & Lee (Ryan) Laughlin – Loudon, NH

Lee and Tim's story starts right around the same time as NOAH's story: 1982. They met when they were teens when NOAH was in its infancy. In fact, Lee and Tim, as well as their families, were key players in founding the organization.

According to Lee, the one thing that first brought them together was music (they were teenagers, after all). "We liked many of the same bands and he mailed me a few cassettes when I was in college."

For a long time, they were friends whose paths crossed at NOAH events. It wasn't until 1994 at the NOAH National Conference in Philadelphia when, according to Lee, "Something just clicked."

"I think [our relationship] is special because



Tim and Lee Laughlin and family

of who we are, not because of albinism," said Lee. "I like to think we'd be together if we were normally pigmented, but for the life of me, I don't know how we would have met. We are complete opposites in many ways, but we complement each other. He's patient, I'm not. I'm organized, him, not so much."

Thirty-one years after they met and 19 years after they officially became "an item," Lee and Tim have two children, both of whom have albinism. Although parenthood is undeniably an adventure for everyone, they often find that because they all have the shared condition of albinism, there are certain things that are a bit easier – explaining needs to teachers and understanding what life is like for a person with albinism.

Matt Bailey & Meliké Warrick – Chapel Hill, NC

Cupid hangs out in all kinds of places, but few would suspect his amorous presence in a bioptic driving session...well, except perhaps Matt and Meliké.

At the NOAH National Conference in Chicago in 1998, Matt and Meliké had their first of what would become many deep conversations that went late into the night.

"Although I was first attracted to Meliké only platonically, I almost instantly noticed she's very smart, has an interesting life, she's deep thinking, and wonderfully kind," said Matt.

A friendship developed into a long-distance relationship. Today, Matt and Meliké are happily married with a beautiful family.

In 2008, they welcomed their daughter, Anna, into the world. And – surprise – she does not have albinism! Because they have two different genetic types of albinism, their daughter is a carrier of both types, but is normally-pigmented with perfect vision.

Becoming a parent was life-changing for them both. They noted how novel it is to have a child who sees things they can't.



Meliké said, “Now that she’s in kindergarten, we ask her to read signs for us. I sometimes worry about relying on her for help seeing things (don’t want her to feel burdened), but she enjoys helping and likes being better at something than we are.”

“The main thing [that’s different about our relationship] is that you don’t have to explain things,” said Matt. “Your partner knows what you struggle to see or why you don’t want to go to the beach at noon. Also, much to her annoyance, I can always bum low vision aides off of Meliké since I’m too lazy to bring them.”



Meliké, Anna and Matt Bailey

Meliké agreed and noted the level playing field that this scenario brings in their relationship. “I feel understood and I think we are better able to empathize with each other about difficulties that arise from low vision. I am less dependent than I have been in relationships with pigmentos; my relationship with Matt feels more equal.”

Matt said, “I love that she’s compassionate and empathetic. I love that she cares about people that others don’t take the time to understand. I love that she’s capable of deep, insightful conversations. I love that she’s a lot tougher than you’d think. I love how she’s taught our daughter to be such a loving person and to be really aware of her feelings.”

Fifteen years after their first meeting over a conference session on low vision driving, Matt and Meliké were instrumental in leading the advocacy efforts for bioptic driving legislation in their home state of North Carolina.

Andrew Sartorius & Katherine Hoffman – St. Louis, MO

The wedding plans are in full swing for Katherine and Andrew, who have been engaged for over a year.

They met in the college cafeteria six years ago. Not surprisingly, the first thing they noticed about one another was that they both had albinism. Katherine and Andrew noted that the early days of their relationship felt exciting as they got to know each other and found common interests.

Andrew mentioned that he initially felt uncertain about dating a person who was visually impaired, especially when it came to transportation since neither of them drove. But they quickly learned this was a minor inconvenience that they learned to work around.

“All of our challenges are mutual,” said Katherine. “You do not have to explain yourself to the other person because they are experiencing the same thing. It is nice because there is always someone who understands what you face as a person with albinism. We are like everyone else because we love each other, have similar interests, and enjoy



Katherine and Andrew



being together. We are different because we, sometimes, need to be creative to accomplish things that normal couples may take for granted.”

“I believe that most relationships begin with people trying to conceal who they are or the part of themselves they find unattractive,” observed Andrew. “For me, I was forced to address my biggest fear in a relationship even before our first date. This made us much stronger as a couple.”

Andrew said, “Katherine complements me. It may sound corny but she is the yin to my yang. I am more reserved, she is more outgoing, I am more pessimistic, she is more optimistic, I am good at seeing the big picture, she is good at small details. I think this is what makes us work so well: we are always bolstering the other’s natural talents.”

Matt & Ashley (Vaughn) Montes – Atlanta, GA

For Ashley and Matt, it went like this: “Just friends” for about a year and a half, lovebirds for almost four, and husband and wife since May.

In a true sign of the 21st century, they met in cyberspace via the Albinism Online Community where neither initially went looking for love. Ashley lived in Georgia and Matt in Southern California.

Deep conversations, side-splitting laughs, an undeniable physical attraction and heartfelt confidences paved the way to a more serious relationship. For over two years, it was the long-distance variety, which equated to hours spent on the phone every day, text messages, video chats and semi-annual meet-ups.

Despite the challenges, the couple agrees the early years helped build a strong foundation for the rest of their lives. “We had no other choice but to talk and get to know each other on such a deep level,” said Ashley. “We always appreciated having someone to talk to that was supportive, attentive and provided advice.”

Ashley and Matt agree that there are very few things that make their relationship different or special. The fact that they both have albinism adds some challenges and laughs that a “pigmento” might never understand, but ultimately their marriage is based on so much more than that.

“I love that Ashley is in love with me. If it weren’t for that, I would not get to enjoy and celebrate all of her endearing qualities. I cherish the fact that I know her in ways that nobody else could,” said Matt.

“Although I adore everything about Matt, I most admire his genuine heart. Not only does he care about me and make me feel special, but the way he cares about others is a quality I think is hard to come by,” said Ashley. “He’s pretty attractive, too!”

“We are always asked if we are brother and sister,” recalled Matt. “We just laugh about it now.” In fact, Matt now finds it fun to give these inquisitive strangers a double-take by responding, “Yes, we’re just a really close family,” while putting his arm around his wife and giving her an affection peck on the cheek.

Like all the lovebirds mentioned, Matt and Ashley feel lucky to find someone to spend the rest of their lives with.



Ashley and Matt Montes and friends

