

FASD United

The FASD Experience

FASD is best understood through the perspectives and abilities of the individuals with the lived experience. The FASD Experience showcases the interests, thoughts, and feelings of the individuals and families touched by FASD, in their own words. Get to know them, the heroes of the FASD community.

FASD Heroes

- Wikner Family 2
- Helen S. 6
- Elizabeth H. 10
- Rebecca T. 12
- Lena 18
- Maryellen W. 20
- Gabby E. 23
- Elizabeth B. 24
- Erin D. 32
- Lucy K. 36
- Chanel T. 41
- Morgan F. 46
- Tracy C. 50
- Frances M. 53
- Jasmine S. 57
- Karli S. 60
- Taylor A. 62
- Rob W. 64
- Erica B. 67

Wikner Family

This article is written by Ben Wikner, a parent of a child living with FASD.

I have two sons, one by birth and one by adoption. They both love baseball; but their baseball stories could hardly be more different. My birth son's love of baseball came easy. It's a simple story: I love baseball and from the day he was born, I shared my love with my son. He took to it like hand to glove.

Ethan, our adopted son, was introduced to America's pastime after we adopted him from the Philippines in the spring of 2016. His love for baseball has not come easy. Then again, as we are learning with Ethan, nothing comes easy. The story I want to share isn't about baseball. Baseball is just the context for the much bigger story—about God's grace to an orphan and to an adopting family.



The Game

It's the bottom of the final inning in the championship game of the season-ending playoffs. The score is tied 5 to 5 against the undefeated and favored opposing team, and my son, William, is on the mound to try and get three big outs so we can take the game to extra innings and hopefully on to victory! In order to even get to this situation, our team has had to win 4 straight games the past 2 days. William has already pitched 6 innings the previous day. But the coach put the ball into his hands to get us to extras. Unfortunately, things go quickly south. The first batter gets on by a fielding error and then proceeds to second and third. With the infield and outfield drawn in (to hopefully get the runner out at home) the next batter gets the walk-off hit over the right fielder's outstretched arm. The other team mobs the field.

Game and season over. Dejection. But there's another part to this story happening alongside the hitting and fielding: Ethan is the batboy on William's team.

The Background Story

Let me be clear: being a batboy for a high school team is not glamorous (think: Summer heat mixed with sweaty adolescent boys). It's not like you get to hang with Andrew McCutcheon or Bryce Harper. It could be fun—if you really love the game. But Ethan came into his role as batboy for William's team on account of *William's* love for baseball, plus the fact that he was the little brother. Understandably, when Ethan first began his batboy duties he did not know a thing about the game. However, in theory, batboy duty should not be too difficult: run, get bat, bring bat back to dugout. Repeat. However, with Ethan, this is no small thing and nothing comes easy. When he first started his batboy duties, well, let's just say it wasn't pretty—constant complaining, goofiness, distractions, senseless chatter – lots of Ethan! But the coach

and the boys on the team embraced him and we kept encouraging him to stick with it (though at one point he did quit and then regretted it). Fast forward to the championship: Ethan was on his batboy game – running, working, pumping up the team! We were thrilled and somewhat amazed.

The Silver Lining

At the completion of a tournament the players line up for the ceremony to receive their first-place and runner-up trophies. The parents and fans stick around to applaud the great effort. As can be imagined, this was a bitter-sweet award for William. But we applauded our son with gusto. Then something amazing happened. After each player was called up by name, Coach Ernie – much to Ethan’s surprise and delight – called his name to come forward to get *his* trophy, as part of the team! It was so unexpected. Ethan’s face radiated surprise and joy. On the ride home, Ethan put it into perspective. He told us, “This is my first trophy and first time my name has been called to receive an award” and he began to cry. He kept saying, they (the team) trusted me (to be the batboy). Suffice it to say, Erin and I were deeply moved. But as you might have guessed, there’s more to this story.

The Hard Reality

The thing you need to know about Ethan, that we are still coming to terms with and seeking to understand, is that he has been diagnosed with Fetal Alcohol Syndrome (FAS). This is, of course, in addition to the adoption issues that come with the territory of being an orphan for the entirety of his eight years prior to entering our home.

When we first began the adoption process we were told that Ethan had been clinically diagnosed with ADHD, that he was having a hard time flourishing—physically as well as emotionally, and that he had a tendency towards self-pity and outbursts of anger. All of this made sense in light of what we knew of his history. While Ethan was well-cared for in the home for orphans in which he grew up, he had been abandoned at birth, knew nothing of his birth parents, and more recently and traumatically, was rejected by a prospective adoptive family at the final step of the adoption process, when he was six years old. We were aware he was a mess, but not more so than the typical eight year-old orphan child. We were very mistaken.

The first few months with Ethan had its precious moments, but if there was a “honeymoon” period it was over within a couple of weeks of his arrival. Instead, it was characterized by constant confusion and frustration that instead of improving over time, got worse as the months progressed. What we saw *was* ADHD, but something so much more severe. We wondered if it was autism. Was it low IQ? We certainly considered the relevance of mischievousness mixed with extreme selfishness. But it wasn’t until someone suggested the possibility of FAS that things started to make sense. And while that helped to explain things, it didn’t make things easier in terms of dealing with Ethan’s needs and behavior.

To give some basic background on FAS, what is now known from scientific research is that when alcohol is consumed while pregnant, there is proven damaging effects (depending on timing, quantity consumed, and genetics) upon the brain and Central Nervous System of the

developing child. Alcohol easily passes unprocessed through the umbilical cord, and acts as a powerful poison that retards brain development in the unborn baby. While the cognitive and behavioral effects can vary case-by-case, it typically shows up as the inability (or underdeveloped ability) to make logical, verbal, social, and emotional cues and connections. It is constant mental misfires that the normal brain gets and develops over time. For my wife, Erin, and me, having a child with FAS has been the most difficult challenge we have ever faced. It has tested our love, our patience, even our faith in ways we could not have imagined prior to this adoption. But this is only part of the story.

The Ongoing Story

To be real, Erin and I have many times over asked God, why? Why us? Why this? Surely, we didn't need this on top of everything else in our lives (including six bio kids with all of their issues and the start-up of a challenging new church plant). But – once again – we are coming to the place of being able to say, God's thoughts and ways are higher than ours. While this is not what we asked for or what we were expecting, it is exactly what the Lord has for us...and for Ethan. God is teaching us all so much through this process. To give one example, I had no idea how limited and shallow my love was until it was examined in my battle to love Ethan. Yes, this has been a hard revelation, but one that I am glad to be shown (most of the time:). Another dad who recently adopted put it this way:

This child, broken and sad, consumes all of my affection, all of my attention, and then looks me in the eye and tells me it's not enough. Meanwhile, my son and daughter get the fringe of my parenting, the scraps of my time, and they tell me "Everything is fine, Dad. It's okay." I know they're all lying. One lies to protect his heart. The other two lie to protect mine. It's infuriating and heartbreaking all at once. One hand wants to pull him close and love him, the other wants to push him far enough away that he can't hurt you anymore.

But it's not his fault. He's broken. Shattered.

So you breathe in, hold it, and exhale through clinched teeth and tears, and promise him, "I'll love you in pieces. You don't have to be whole."

And you recognize that it's not you who's loving him like this, but rather Christ through you. So you hold him closer. (Jon Mays)

In retrospect, this is the very kind of love I have asked God many times over to help me learn. It took Ethan to kick start the process.

God is doing so many things through this adoption. For sure, we are also seeing progress with Ethan. After the baseball game, when we were home and Ethan was heading for bed, he came downstairs and thanked Erin and me for helping him stick with being the batboy. We were blown away by this – his connecting all the struggles and perseverance with this result. The next day, I sent an email to share what happened and to thank Coach Ernie. He replied:

Thanks for the kind words. You brought tears to my eyes as I read your email. It is truly my pleasure and honor to have your family be part of the team. I am so happy for Ethan and will cherish the picture (above) for the rest of my life.

What you and Erin do for Ethan and the community is a testament to 2 amazing people and what a difference you have made in so many lives including mine.

Never change and keep up the GREAT work.

Coach E

Once again. Blown away. This too was so unexpected. But we are coming to appreciate how our God, who called us to this adoption, is also walking with us in sweet, surprising ways to show us his love for us and for Ethan. We are family.



I'll conclude with this photo of the brothers by adoption. It pretty much captures my two boys.

by BK Wikner (in case you are wondering, I also have five daughters, who are also uniquely wonderful and somehow feel so much easier than my two boys)

Helen S.

Helen S. is a 28 year old FASD advocate living in Portland, Oregon with her husband and furbaby. She loves reading, writing, and talking with others. Her passion is to help people. In her blog, "Love Me Enough. Faces of Fetal Alcohol." Helen combines her talents, passion, and diagnosis to create a positive view on FASD. She currently works for a Premiere Google Partner in Client Services and billing.

Cameron Koob, FASD United: I wanted to start by asking you, since it is [FASD Awareness Day], what does advocacy mean to you?

Helen S.: It's a positive thing, there's so many struggles you go through before you even have your diagnosis of FASD, before that moment, through your whole life you're gonna struggle with all the affects you have from that, so FASD Day is a way to show that your life is more than your diagnosis, it's way more than that, you can make something positive out of something that very much so negatively affected your life. It's a way you can thank the people around you that have been such a big support group, that have helped you through those moments. It's just a way for you to bring awareness and hopefully stop women who are going to become pregnant or are pregnant from drinking.

CK: Thank you for devoting yourself to this cause. Do you think you could talk a bit more about when and how you were diagnosed?

HS: Absolutely- I was adopted when I was about 6 months old. My parents knew a little bit of background, that I was born addicted to heroin and cocaine and I had many other birth siblings that my parents knew had suffered from my mother drinking during the pregnancy. So they had a little background about it beforehand, [but] they didn't know exactly how it was going to affect me. I didn't speak for a long time, I had problems with speech, my Mom had me in speech therapy, that was a big part of it. I cried a lot as a child, muscle pains, what have you. I was 11 years old when I actually got my diagnosis, I was attending a Catholic school and other people were really the ones that realized it. People around me saw the tremors, I felt it but I thought it was nerves, maybe. It was definitely affecting my day to day life; I was very self-conscious about it. I had already had a therapist to work through issues, they thought that I was bipolar, they had given me that diagnosis, ADHD, they gave me that diagnosis. So I was already on medications trying to conquer that part of it. So we went to a doctor, my psychologist suggested that we go to a doctor and see what else is going on and that's when they gave me the diagnosis that it was tremors from FAE, that's Fetal Alcohol Effect. They didn't think it was quite to the point where it's Fetal Alcohol Syndrome (FAS) but they saw some aspects of it from my nervous system.

At that point, that kind of made me feel a lot better. I felt different the whole time, my whole life I'd felt different than other people, and that's something I'd really struggled with, my self-esteem, and also why was I not good enough, that my birth mom had to do all this stuff, also

plays a big role in that. Once the diagnosis came we started medications to try to control the tremors, I started at 10 mg of Propanolol and I ended up at 160 because the tremors were that bad, but you know through medication and therapy and support, it definitely helped.

CK: You're incredibly articulate now too- you mentioned speech class helped you, was there anything in particular that worked for you? How did you come around to sharing your story?

HS: You know, I was so young I don't really remember [speech therapy] I have to slow down and really think about my words because in the moment I'll mess up words a lot because I'm overly excited or anxious, words just come out a jumble, writing's always been a lot easier. What really made me want to become an advocate is in junior high school I started talking to one of my birth sisters that's a year younger than me, Gabriella, and our stories were very similar. She had effects, she was diagnosed bipolar, she was drug-addicted at birth to methamphetamine, and I felt like I was supposed to do something really great with this, because she really struggles a lot more than I do. I also have another birth sister, Carmen, and the effects that it's had on her- and I don't want to say I'm doing better by any means, but the effects that it's had on all of us have affected us differently, and I thought "Okay, I'm doing pretty good in life, I'm doing pretty good, I've got a good handle on this, but I need to do something about it." Because when you're a kid it's a lot harder to deal with- it's already sucky to be a teenager- and you throw [FASD] into the mix and it's just makes it hell, I mean high school and middle school were hell, you couldn't pay me a million dollars to ever go back to those days.

I needed to do something positive, and I went to college right out of high school, and this was the defining moment- I had just graduated high school early, I was 17 years old, I wanted to be an English teacher, and so I went to Harford Community College in Maryland. So I was in my English Class where I had an incredible teacher, Miss Hutton, and I went to my speech class – that was really hard. Speech class was so difficult because A) I've already tried to conquer the speech thing and B) I'm nervous you have to be in front of this whole classroom talking.

Our first speech was an informative speech, so we could choose anything we wanted to talk about that we informative, so I decided to talk about Fetal Alcohol Syndrome. I practiced and I practiced, and I cried in front of my family every time I tried to read it because it really impacted me. After I gave the speech in front of my class, my professor, Mrs. Hart, she says "Listen, I just want to let you know that your speech really touched me, I don't know if you know this but, my niece has Fetal Alcohol Syndrome." It turned out her sister in-law was my professor Mrs. Hutton, and she had adopted a child with special needs who has Fetal Alcohol Syndrome. So my speech professor said "You're doing really great, I've never met anyone with FAS who is doing this well, and you really gave me hope." And she was so touched by this, and I had never met anybody else with Fetal Alcohol Syndrome, maybe I had, but it's not something anyone is ever open about. It's not like you meet somebody going down the street and you say "Hey I got Fetal Alcohol Syndrome" – that's really not how it goes.

I was really blown away by that- I've always been a writer so I talked to Professor Hutton and told her that Professor Hart informed me she had a daughter with special needs, and I told her that I had FAE, and that I think it's amazing she adopted this girl and is fighting so hard for her, because when people fight for you, it makes an incredible difference. Long story short, they just really filled my heart with hope and made me feel like I could make a difference, since I had an impact on their lives. I started to write a book about Fetal Alcohol Syndrome called *Shameless* and my Education Professor really worked with me on it, really cared about how it was going along, and the story I had to tell. I had an article written about me at that college about how I wanted to be an advocate, and that really resonated with me. I thought this is what I am supposed to do, I want to make a difference in people's lives, and if this is the way I'm going to do it, then yes, absolutely.

CK: That's wonderful, and you took all of this in stride and made it something you're passionate about. That's impressive- do you attribute your vastly positive experience overcoming adversity to your upbringing at all?

HS: 100 percent. My parents are absolutely amazing. My dad is a retired minister; my mom worked a lot in the mental health area and wanted to be a nurse. They've adopted 6 girls in total and they have done everything possible for their children. A lot of my siblings had many issues growing up, and there's nothing that my parents didn't do. They sacrificed their whole lives to make sure that their children know they're loved, have had all their needs met, and having said that, our needs go far beyond any "normal" child- we're talking therapy sessions for all of us, doctor's appointments. My mom was so busy doing all of this stuff. They really did give their life to do that. Had I not had parents so willing to really make sure that I was okay, I think my outlook would be very different.

CK: Do you have any advice for parents or relatives who recently came into a position where they are caring for a child suffering from prenatal alcohol exposure? Anything you wish more people would know?

HS: There are moments where you're going to be really frustrated, as a teacher or a parent, because your child will be hard to deal with at times, but at the end of the day just keep in mind that this child so desperately wants to be accepted by other people, and this child is going through a million things in their own mind that they're not good enough, that they're different, that they just want to make their parents proud. They're already fighting a million battles in their own head, and I know it can be frustrating, but just don't give up on your child. Every day let your child know they're loved at the end of the day, after an argument or whatever, at the end of the day just regroup and remember that your child is doing the best that they can do at that moment, whether you see it or not.

CK: Thank you for that. Would you be able to talk a bit about your job, and if your life with FASD has affected it at all?

HS: Like I said, I still shake, even with medication I shake a lot, so I'm really self-conscious being in front of other people. I have really bad social anxiety so being in front of people period is just a hoot and a half I guess. I do customer service, and it can be really frustrating. I had one customer tell me "Are you deaf and dumb? Why do you talk like that?" because I was getting really worked up and my words weren't coming out necessarily the greatest, and I replied "I have a problem speaking" and she responded "Yeah, whatever."

But you've got to put yourself out there, you always need to set better goals for yourself, see if you can reach those. I really love my job, my bosses are incredible and my peers are amazing, really supportive of my blog, of everything I do and who I am as a person. It can be demanding, but you've got to put yourself out there and prove that you can do it, and I'm really blessed that my coworkers and everybody have been so supportive.

CK: Thank you so much for sharing your story!

HS: Thank you!

Elizabeth H.

By Andrea Dressel, FASD United

Earlier this spring, I got the chance to sit down with Elizabeth Hitchens and her parents, Janet and Ralph, to talk to them about Elizabeth's journey as an adult living with FASD. Elizabeth is currently 28, and her parents adopted her from Russia when she was 5. They didn't know at the time that she had FASD, and they will never know the extent to which she was prenatally exposed to alcohol. But as she grew up, cognitive and learning differences led them to believe that she may have a disability. It wasn't until Elizabeth was eight years old that a geneticist informed Ralph and Janet that she may have FASD, which at the time was called fetal alcohol effect (FAE).



Talking with Elizabeth (pictured) and hearing her tell her life story was a pleasure; she is articulate, honest, kind, and has a great sense of humor. The first thing we discussed was her education, and she was not shy to inform me that it had its ups and downs. FASD makes learning in a traditional classroom environment much more difficult, and she described to me the frustration she experienced trying to understand what the teacher was saying, "Being in the classroom with the teacher speaking... it was like a foreign language. They thought I understood but I didn't, and that is why it's hard for people like us with disabilities." She went on to say that the bullying she faced in public school led her to attend a private middle school for children with disabilities,

which was a much more positive experience. She graduated from a similar private high school in 2009.

Next, Elizabeth shared her employment experiences with me, and she explained that her FASD made it hard to hold a job. She said, "The boss would yell at me- or get very frustrated and I would say, "I'm sorry; I just didn't realize." Her time as a cashier in a convenience store, an employee in a fast food chain, and as a restaurant hostess all came to an end due to short-

tempered bosses that didn't take the time to understand Elizabeth's differences. Typically, she only required a bit more explanation and training, but she wasn't able to find such compassion in a mainstream work environment.



However, Elizabeth (pictured with her parents, Janet and Ralph) loves animals. She finds joy in them and is very good with them; she used to volunteer at an animal sanctuary and also helped care for farm animals when she lived in a group home for adults with disabilities in Montana. Janet echoed how much Elizabeth is drawn

to animals and how much they are drawn to her: “They seem to sense something in her that they like.”

In addition to her care of animals, Elizabeth is also a dancer and actress. She has been an extra in a few productions, including the Disney Channel Movie *Step Up 2*. Although her FASD sometimes affects her memory, she has a knack for performing and memorization. Janet added, “Reading and math were hard for her [in school]. And yet the first time she got a script, when she was seven years old, for a summer theater program, she had her part memorized almost immediately, before anyone else.”

FASD continues to affect Elizabeth’s day to day life, and in the past has affected her decision-making skills and led her to sneak out, steal from her parents, and enter into manipulative and harmful relationships. The most difficult part about FASD, according to Elizabeth, is that it is a hidden disability. “I don’t look like I have a disability” she said, “So people assume that I can do everything. When I try to explain it [to others], it’s hard, because I want to go out and do fun stuff like regular people my age.” Yet her experiences growing up and living with a disability have made her extraordinarily compassionate and understanding: “I have a strength that is empathy for people with disabilities and I don’t judge them. I like to hangout more with people with disabilities because I relate to them more.”

Later in life, Elizabeth would like to become a spokesperson for FASD and give a voice to everyone with FASD that doesn’t have support. She has begun to vocally advocate for a group home for adults living with FASD. Ralph added that an organization in Wisconsin is opening up an FASD-specific group home, but it is strictly for men. Elizabeth and her parents believe that a co-ed, adult group-home that specializes in caring for those with FASD is an immediate need, because it can be difficult for people with FASD to function in a group home that includes adults with many different disabilities. Elizabeth described that, in her experiences in Montana, the staff was generally uneducated about FASD and frequently confused the symptoms with those of Autism. Moreover, such a group home would help people like Elizabeth form deeper social connections. Elizabeth says that “People like us who have FASD, we like to relate to each other.” She sincerely hopes that a co-ed, FASD group home comes to fruition by the time her parents are too elderly to care for her, so she is able to move there and lead a happy and purposeful life.

When asked what advice that Ralph and Janet have for other parents who have just found out that their child has FASD, they advised to “Get a formal diagnosis as soon as you can... Make sure the school knows what the diagnosis means and educate everybody.” In general, the public is widely uneducated about this disorder. Stories like Elizabeth’s can help people understand some of the issues caused by FASD, and how important prevention is as well as support services for those with FASD.

Rebecca T.

Rebecca T. is 34 years old and lives in Albany, New York with her husband and two sons. She works as a claims representative at an insurance company and recently found out that she lives with a Fetal Alcohol Spectrum Disorder. In this interview, Rebecca discusses her experience, talks about how she learned that she has an FASD, and shares strategies she is using to help manage her behavioral challenges. Rebecca hopes to spread her knowledge of what it is like to be diagnosed as an adult with an FASD.

You can order the book *Tenacity*, written by Rebecca on Amazon.

Andy Kachor, FASD United: Hi Rebecca, we really appreciate you giving FASD UNITED the opportunity to share your story. Could you talk about how you were recently diagnosed with an FASD?

Rebecca T.: Hi! I was adopted at birth, and my adoptive parents didn't know much about my birth mom. They knew she may have been drinking during the pregnancy, but nothing was confirmed. When I was a baby I kept getting ear infections, I didn't eat, I was very quiet, and I started to drop off the growth chart. I was very tiny and very sick. My pediatrician had mentioned back in 1980 that fetal alcohol was a possibility for why I wasn't eating and why I wasn't gaining weight. As a baby, I had physical characteristics, including a long philtrum between the nose and the upper lip, and a problem with my eyes, something about the distance between the eyelid and the under eye. And my pinky toes never formed completely. So, my parents took that under consideration but in 1980 there wasn't much out there on fetal alcohol and not many resources or help. My parents had me tested at John's Hopkins for Cystic Fibrosis, hoping for an answer.

So as I got older, I got tubes in my ears. I started eating again. I was a happy, content, successful child. I did great in school, grade-wise. I was very amicable and fun to be around, very quiet and shy. In high school I had some typical teenage drama with my parents, like dating people they didn't like, but nothing too bad. Then I applied to colleges. I went to SUNY Geneseo in New York, outside of Rochester. I majored in Speech Therapy. I did great in the classes, but I found myself really struggling when it came to teaching and trying to make lesson plans. I just couldn't get my head around making a lesson plan so kids would understand it. And I didn't know how to change a lesson so that children at different abilities would be able to understand it. In graduate school, the same thing happened; my lesson plans fell apart and I actually ended up failing graduate school because I could not get lessons together to teach children. My paper writing was atrocious. I couldn't get my thoughts in a cohesive manner.

That prompted me to look back to my elementary and high school experiences. I never understood outlines—I never knew what to put under the 'A' and the Roman numeral "I." In textbooks, I would highlight every single word because I couldn't figure out what was important and what wasn't. I never really understood the little increments on a ruler—I still don't. Now I

can tell time with analog clocks, but that was a struggle for me. All of these things just came back to me when I failed grad school. But I just thought 'Oh you know, whatever' and I let it go. I didn't talk to anybody. I didn't know how it all applied to my life; I just thought it was who I was.

Fast-forward to now; I work at an insurance company. I'm a very successful claims representative for medical claims. I've been married for ten years; I have two beautiful children—very, very smart children. One child is almost seven and the other is almost three. When I had my first, I backed off, and I let everyone else take care of him. Now that I look back, I think I was overwhelmed. Now that I have my diagnosis, I think I just didn't know how to do certain things or how to handle a baby or how to prioritize what needed to be done with him and be able have time for just me, my husband, and work full time.

As my child got older, it got easier, and then I had my second son. And with two kids and working full time, I was very overwhelmed. And I found myself going from zero to sixty over nothing. Like if one of them spilled milk, it was a disaster. And I would cry and scream at them, and it's really not their fault. It's only spilt milk—no pun intended there—but I couldn't cope. The littlest things set me off. I'm a full time working mom with two kids, and a house and a husband and I think I struggle with it a little more because my brain is a little mixed up with the fetal alcohol.

Years went by after I had my kids. My mom sometimes gets frustrated because we'll go somewhere and I'll forget the diaper bag or forget to bring extra diapers. And it's the details; I'll remember details about stuff that no one cares about but things like that—life skills—I do struggle with and this is when fetal alcohol was brought to light—when we started wondering if I had it. I started to look back over my life and...I'm 34, but I act young sometimes. I act young some of the time and it's hard for me to figure out what the best things are for my sons and my husband and me sometimes. And I can act selfish...a lot. Which is part of fetal alcohol; because my brain will sometimes act like an egotistical child—like an eight or nine year old where I want what I want and I don't really care about other people.

One day, my mom called me, crying. She had received a pamphlet in the mail from Bethany Christian Services (I was adopted through their agency) and the pamphlet was about FASD. She saw the letters and she put it aside. And she looked at it later and thought, 'Hmm, what is that?' So she's looking at the pamphlet and she called me and said 'I got this pamphlet. I want to read this to you.' And I had probably 95% of every symptom and characteristic listed in the pamphlet minus the facial abnormalities because as I got older, they faded. So it was a shock, but it made sense, and now my mom and I were on a quest (me more so) to get a diagnosis because I finally thought I had figured out why I was the way I was. After I got married and even before—even now—I have a lot of impulsivity issues where I do things and don't think about consequences. For example, when I found my birth family, I booked plane tickets to go meet them, and then I told my husband. I don't think about the consequences or if we have enough money. Again, it's the impulsivity and that's a big thing that worries me. It's the one thing that I keep thinking about.

So my mom gets the pamphlet, she talks to me, and I decide that I want answers. I had support from my mom and dad, and my husband. My parents were totally supportive; I was able to talk to them about how to go about finding answers and getting a diagnosis. So I went to my primary care doctor and started listing the characteristics I had had throughout my life and the pamphlet my mom had read. And he looked at me and said, 'Hmm!' He'd had some patients that had fetal alcohol spectrum disorder so he referred me to a neurologist. I walked in to the neurologist appointment and thought that he could diagnose me, he knows parts of the brain; this is going to be easy.

So I walk in and the neurologist comes in and said 'Well, I Googled FASD right before you came and I don't really see any facial characteristics and I don't really know anything else about it so we'll do a neurological assessment on you but I can't diagnose you. And you're older and you seem successful, so I'll see if you have any neurological/learning deficits and we'll go from there.' And he was great; I mean, he tested me and I faltered on spelling words backwards, categorizing animals (and I don't know any day to day news that goes on unless it's associated with celebrities or music and apparently that was a deficit as well) so he referred me to a neuropsychologist. They didn't take my case because I wasn't a stroke patient; they referred me to another neuropsychologist—I never heard back from them. So I was at a crossroads whether I just let it go and think I had fetal alcohol because at 34, how is a diagnosis really going to change me? But I wanted a diagnosis so I could work from there and be even more successful.

So I went online and I Googled "Albany, New York doctors for FASD." I don't know how I came up with it but every doctor treats and diagnoses children. There are no doctors that I have found that diagnose adults. Everything is geared around children because early intervention is so important. I called this one geneticist in Albany where I live. She's a pediatric geneticist and I sent her pages of why I thought I had it and pictures of me as a baby. She took my case. I went the week before this past Thanksgiving to see her. She was extremely excited because she'd never diagnosed an adult. She said I had some facial features; between my upper lip and my nose and my eyes, my toenails, I have a palmar crease—the hockey stick crease on my palms, which can be indicative of fetal alcohol.

I know the history of my birth mom now because I found out last May who she was. I found out she was a chronic alcoholic through people that worked with her. She died. She fell down the stairs in an intoxicated state in 1999 and broke her neck. I got her autopsy report and her blood alcohol level was a .4-something at the time of her death. So I knew that she was an alcoholic—she always drank; no one ever knew her sober.

I told the geneticist about my birth mother, and in the end, I got an FASD diagnosis and she referred me to a behavioral cognitive therapist. I had to look for one because she didn't have any that dealt with adults. So I found one through my primary care doctor and I had my first session last week. And my impulsivity is due to fetal alcohol spectrum disorders and he is helping me with any decision I make to lay out all of the pros and all of the cons and if it's not a

good decision to switch my train of thinking and say 'I shouldn't do this because A, B, and C' before I go forward with anything. It's very intense therapy, but it is going to help and...when I actually got that diagnosis, my mom drove with my dad to South Carolina to go to the doctor's appointment. And when the geneticist gave me the diagnosis my mom was relieved, and I was relieved because I now had an end result but I also had a starting point for my future to help me.

AK: Great, thank you! Why did you decide to tell your story?

RT: My whole reason for telling this story is that I'm one of the few people who were diagnosed with an FASD later in life. I struggled for 34 years just thinking it was me—you know, I'm Polish so I was thinking, 'It's just me, I'm Polish, I'm dumb.' I got laughed at a lot by my friends and I laughed with them because I do stupid things, I don't get jokes and now I know why and I just hope that more adults who may have struggled in life—and I didn't struggle a ton because I grew up in such an amazing environment; I was loved a lot, I was educated thoroughly, I had great teachers who helped me when I needed help until I got to college and grad school and then the help stopped, which made me falter—but I just hope that older people like me who know that their mom drank and they wonder why they're struggling...I just hope that they know that they should look into it because there are ways out there to make them successful and I just hope in the future there are more doctors and more neurologists who get more education on this disorder because it's so widespread and I just feel like we're just touching the tip of the iceberg with all of it—all of the disorders and all that comes with it. Maybe it's because I've been looking for it now, but it feels like now is when everything comes to light with what the disorder is and I just hope it keeps coming to light and educating everybody. And that's it!

AK: That's really great of you to share your story and it's just really helpful to have your perspective of an adult living with an FASD, especially one who was diagnosed later in life. It's going to be really helpful to other people with an FASD, or who think they may have an FASD, to hear your story. I think your story is interesting there are some relatively subtle behavioral challenges that can be overlooked when you're that successful. Have you experienced any specific consequences of FASD at work?

RT: Actually, at my job what I do—I'm a claims representative—and we have to write up proposals to get more money from people's claims to pay different parts of it. We pay for people to be out of work from their policy, but we have to write a whole proposal to management stating why we need more money based on how the accident happened. We write two-three page reports with details like how they got injured and whether or not the injury makes sense. Then we send the reports to upper management. Mine are one of the only ones that come back and I have to redo them two or three times. Before I got diagnosed that was a big struggle.

It's hard because it affects my job and my work ethic because we are under time restraints, so when I have to spend so much time fixing one report all my other duties at work fall by the wayside, and while my boss is extremely understanding, my trouble with writing these

proposals is concerning because it seems like I can't keep up. Well, I can, but I struggle with this kind of writing. So I went as far as to go to upper management and asked them how to write these proposals because they're the ones checking it. One of them gave me some suggestions but they don't help because I think I understand the suggestions, but I don't. She'll tell me to try and make the proposals concise, but what is concise in my words isn't concise in hers. It's affected my job. The good thing is that I work for a good company who is inclusive of people who may have struggles, but it affects me so, it's hard.

Also, my impulsivity has made me make choices that are extremely regretful and the consequences have not been so good. I take responsibility for my choices, but I strongly believe that FASD has contributed to my impulsivity. So there have been some bad choices, in high school as well, and I take responsibility.

AK: Yes, there's a certain subtlety to your problems at work—not enough to make you lose your job, but enough to make things more difficult for you and I don't think everyone understands the subtlety of that.

RT: Yeah, well there's a domino effect. You know, because I work on a team so if I fall behind then other people have to take up the slack.

AK: Could you talk briefly about your environment growing up? How would you describe your household, your parents, and the resources and community you had growing up?

RT: I had an amazing childhood. I grew up with my parents and my older brother, who was their biological son. I never felt like an outsider, ever—they loved me and I was their child. What had happened is that my parents gave birth to my brother and then had a baby girl who passed away at one week old and my mom was told she couldn't have more kids so that's why they turned to adoption. But when I entered their family, I was theirs. We grew up in the suburbs of Maryland. The school system was ranked top five in the state I think, and it was an excellent school system. My parents from day one read me books about adoption, even though I couldn't understand it at that point. They were open to me asking questions and never hid it from me, which I think was incredible. They understood that I was going to have questions and they weren't going to hide anything.

My parents and I always got along; I never got in trouble until my senior year in high school. I always did what I wanted, I was a straight A student. I was very close, very close to both of them.

AK: That sounds great. I know you talked a lot about struggling with abstract concepts like reading a ruler and telling time. I was wondering if you had trouble finding friends or if you were comfortable with other people?

RT: That was always an issue for me. Growing up I had two best friends who weren't friends with each other. I didn't have a ton of friends; I mean I was friendly with everybody and

everyone was nice to me but I didn't go out with groups of 10-12 girls and go wild or go hang out at somebody's house. I was never that person. To this day, I don't like too many people. It makes me overwhelmed and I don't know where to go or what to do. So I stuck to my two best friends. I had a couple of other friends who I hung out with occasion, but that was pretty much it and I was okay with it. Sometimes I wanted to be popular because that was the thing to do, but I was never outgoing. I'm way more outgoing now than I ever was.

AK: Cool. Are there any other hobbies or interests you'd like to share to give us a better idea of who you are?

RT: Sure! Back in high school I was a runner and I ran cross-country and track and I loved it. Now I'm trying to get back into it but I'm older now so it's kind of slow going and painful. But I do it, and I love to run. I love spending time with my kids, I love it. Today's a snow day and they're both home with me. So, I'm a runner, I take care of my kids—I love that. I'm a family person; I love just hanging out.

AK: Sounds great. How has knowing about your FASD diagnosis helped you deal with your behavioral challenges and clarify your understanding of the disorder? Have you found specific interventions to be helpful in your behavioral therapy?

RT: Well, I'll start with being diagnosed. I felt like I wanted the answer, and that with an answer I could go further in trying to figure out strategies in trying to help deal with my deficits. I don't like that word, but...the behavioral cognitive is going to help me with my impulsivity, which has had negative effects on me and my family. With every decision I have made or want to make, I have to stop and just break it down, which is very hard for me because I don't like breaking things down. I like to just plow forward and that's how I got through school too but now I need to be more cognizant and break down everything. I'm impulsive when I want to visit somebody and buying a plane ticket. I don't worry about the money; I just click and think it'll all be okay. Now with the therapy sessions, I have to bring those decisions to the therapist and together we'll break down the pros and cons of making that decision and deciding if it's a good idea. It's great to have strategies I can utilize.

AK: Well, thank you so much for sharing your story. Is there anything else you'd like to add before we conclude?

RT: Well, I just really hope it can just bring to light that it's never too late to get tested and get an FASD diagnosis and get assistance or strategies.

AK: Great, well it's been great talking to you!

RT: You too!

Lena

This is Lena's story of faith, perseverance, and optimism in the face of a disability. Although Lena was diagnosed with Fetal Alcohol Syndrome (FAS) as a small child, the absence of sufficient knowledge about FAS and ineffective communication on behalf of her family and healthcare system hindered Lena from understanding her disability until adulthood. It was at 26 years of age, after the suggestions of a social worker that Lena finally came to understand her disability. Now as an adult, Lena shares her journey of living with FAS and inspires true feeling of goodness.



Lena (pictured with her son Johannes) was born with intellectual and developmental disabilities, including a clubfoot, malformations of her fingers, and congenital heart problems that needed several surgeries. Lena was born with these lifelong damages to her body and brain because her mother drank while she was pregnant. When Lena was one and a half years old, she was taken from her mother and was placed in the foster care system where she would live until her 21st birthday. Contrary to how some would respond in the face of Lena's challenges, Lena's experiences perpetuated her spirit of happiness.

Throughout her early development and throughout grade school, Lena had a normal IQ and went to school, but had larger problems with learning and attention. Not only did Lena struggle with certain aspects of academia, but she also ran into social and emotional issues stemming from difficulties with social life. She felt like an outsider, didn't understand social cues, couldn't make friends, and consistently felt like an outsider. She was often teased and bullied, leading to feelings of frustration, sadness, and depression. These internalized feelings manifested themselves into many years of self-harming behaviors, including anorexia and bulimia. In spite of the academic, social, and emotional troubles Lena experienced in school, she persevered through the educational system with the help of a few teachers. She graduated as a nursing assistant.

Lena had several attempts at a job as an adult, including a quick stint as an au pair and four years as a nursing assistant at a nursing home, but nothing ever resulted in long-term job satisfaction and success. Her work mates had too high of expectations and Lena often felt like she could not live up to their expectations or relate to them. Even if she did understand the tasks at hand, Lena would react too slowly, couldn't keep attention, and felt like she was constantly forgetting and messing things up. Lena still struggles relating to people and finds that sometimes people can be uncomfortable around her. Her social skills have led her to troublesome situations and relationships, including emotional and physical victimization. She finds it hard to be a good judge of character and feels naïve at times. Lena says 'I want to believe that all people are good, but they are not'.

As a single mother with FAS, parenting can be a challenge, but Lena says joy outweighs all the rest. Her nine year old son, Johannes, understands that his mother has FAS because Lena reads him children's books about the disability. Lena says that being a single parent is not easy for anyone and to be a single parent when you have FAS is tough. For example, helping her son with his homework is difficult. Even if she understands what he is supposed to do, she cannot explain it to him. A growing boy also needs parenting and limits. It's hard for her to set the right limits - and to stick to them. To manage as a single parent with FAS, Lena is in need of extra help. She goes to parent education courses, which teach her how to cope and set limits. To organize herself, Lena uses step by step pictures to sequence her schedule. The parenting classes and this unique organizational method bring relief to her.

To center herself, [Lena writes poetry](#) and pulls from the strength of God and the support of her church. She converted to Catholicism and has been on a pilgrim journey to Medjugorje, Bosnia twice. Amidst her challenges living with FAS, Lena's life is joyous. She loves people and animals, and when her young son is in school on a more consistent basis, Lena would like to spend time outside, working with animals. Lena currently serves as a support person for people with disabilities for an online/postal Christian support group. Lena says that she likes to cook, and like most things in her life, tries to keep it simple. She is a self-proclaimed social, happy, smiling person. Lena emphasizes her ability to laugh at herself and exclaims that her life is not full of many failures! She has managed to overcome many challenges in her life. She is a fighter. Lena says 'These journeys have changed me very much and have given me the joy of life! Thank you for listening and God bless you all!'

Maryellen W.

Maryellen W. is a 22-year old living in Utah. She recently spoke with FASD UNITED Media Producer, Andy Kachor, sharing her insight on living with FASD and the stigma that surrounds the disorder.

Andy Kachor: Hi Maryellen, thank you so much for sharing your story with us. Would you mind introducing yourself and telling us a little bit about yourself?

Maryellen W: Hi! I was born in a small village in Russia. My mom was an alcoholic and a drug addict who used and drank when I was in her belly. When I was born she put me in a pig trough, where pigs eat, and then a nurse found me and brought me to an orphanage. I was later adopted by two wonderful people when I was 21 months old. I lived in Michigan until I was fifteen, when I moved to a group home in Arizona, staying there for about two and a half years. Then I moved to Utah.

AK: Could you tell me about how and when you were diagnosed with an FASD?

MW: I think I was about ten when my mom found out that I had FASD. I'd had a lot of testing done by different doctors and we finally went to some sort of doctor who did a test and told me I had FASD. I'd never heard of it before so I did a lot of research and it kind of made me feel bad.

AK: How did your life change after being diagnosed and how did you adjust to living with FASD?

MW: Finding out I had FASD really did change my life because my mom had to request extra help from my school IEP [Individualized Education Plan] because even though I was smart and did my homework, there were things I needed help with so the teachers helped me. Once I got into high school, everything changed. No one respected me and I became an outcast, so I started using drugs and just went haywire! When my mom found out that I was doing drugs, she looked into some group homes and sent me to a group home in Arizona to get help. People with FASD shouldn't freak out because of it. It may be bad, but if you can look at it the right way and you can control your emotions and get the right medication, you can have a good life! I have a mom and a dad and I live with someone right now who owned the group home I was in and they've been helping me ever since I was fifteen. I don't know if this is the same for everyone with FASD, but I can't hold a certain amount of money because I spend it really fast and can't control it.

AK: Could you talk more about your experience with the group home in Arizona? How was it living with other people with FASD and did that experience help you?

MW: I was scared and really rebellious when I first moved into the group home. I refused to do anything for the first few weeks, but after a while I realized that I wouldn't be going home so I

might as well start the program. Later on, another girl with FASD came to the group home and we butted heads. We still butt heads now, even though we're both outside of the program. I think that people with FASD don't get along because we're too similar and we butt heads. The program helped. The staff had to do a lot of research because at first they had no idea what FASD was because they'd never dealt with it before. Once they did some research, they knew how to handle us. We [those of us with FASD] had some ground rules we had to follow, but we still had less supervision than the others. It was weird.

AK: I'm glad that the staff was able to research FASD to better help you and hopefully others because I know that most people aren't really aware of FASD.

MW: Yeah, when I was living in Michigan I was hospitalized a few different times and the doctors never knew about FASD and they wouldn't even do the research. They would let me wander the halls and get into fights and they still thought I was just a normal girl. They didn't know why I acted differently and they didn't care

AK: I was wondering if you could talk a little more about the difficulties you had with drugs when you were younger and how you were able to break out of that?

MW: My friend introduced me to cigarettes when I was eleven but I didn't start smoking until I was thirteen. When I turned fourteen, I was introduced to meth, which messed everything up for me. When I was twelve, I started drinking and ever since then, I have always craved a drink. It doesn't matter if it's Vodka or beer; I need to drink something because if I don't, my mind just races.

AK: I know a lot of people struggle with drinking and recovery, so I wish you all of the best. I was wondering if you would mind talking about what you do now; if you have a job or any hobbies?

MW: I used to work for a facility in Cedar City, Utah. It was a group home that I'd lived in after I left the group home in Arizona and the person who ran the program wanted me to work there so I did for maybe about two years. Then after a situation happened at the group home I quit, and I don't really want to work another job because I won't know what to do--the only thing I've ever done is work at a group home. It kind of sucks! I mean, I'm home all of the time and all I really do is watch movies and go to the library. I do like going to the library because I love to read. During the summer I like to sit outside and read, and during the winter I like to snowboard.

AK: Reading and snowboarding sound great! I know it can be difficult to find a job and it sounds like you're doing the best you can during a difficult situation. Could you tell me more about what books and TV shows or movies you like?

MW: My favorite TV show is *Bones*, which is an investigative show. It's really good! I've seen almost the whole series, and I'm excited because they're making a new one soon. I found the

show on Netflix; I'll just go on there and watch for hours and hours. I also like to read mystery and romance books. I remember in school they would assign us books that weren't interesting so I never got into reading then, but once I got out of school I was able to pick whatever I wanted. So now I get books and I just can't stop reading them!

AK: Cool! Could we switch gears and talk about your friendships and relationships and maybe some of the challenges of social relationships, if you're comfortable doing so?

MW: Yeah, I have a few good friends from Michigan and only one of them has FASD. We kind of get along but, I mean, I haven't seen her in over ten years. We talk on Facebook, but it's not like we're talking in person.

Relationships are hard. With dating, I want to act normal around my date but I know that they'll find out about my FASD eventually so I feel like I have to do all of this explaining about my whole entire life.

AK: I know that FASD can make having relationships and friendships challenging. Is there anything you would like for more people to know about having FASD?

MW: People with FASD have our problems, but we can also do well in this world. A lot of people say, "You can't do this; you can't do that." Well, it's a bunch of bull. We can do anything we want if we put our minds to it. Don't let other people put you down! Hold your head up high and believe what you want to believe. If you can do it, you can do it. Don't set yourself up for failure. If you're looking at the bright side of life, you can do a lot of good in this world! That's how I look at my life. Yeah, I have a lot of people telling me, "You can't do this or you can't do that," but you know what? They're wrong, and I can do whatever I want if I put my mind to it. Some people say that I can't go to college because I can't handle all of the homework. You know what? I'll do it. If I want to do the homework, I will! I'll put my mind to it and do it!

AK: Well that's a great attitude, and I thank you for taking the opportunity to share your story. Is there anything else you'd like to add?

MW: Yes. People without FASD may look at people with FASD and think that they don't want to be friends with that person. But they shouldn't judge a book by its cover. Get to know the person and you may find out that they're really nice.

AK: Great! Thank you very much, Maryellen.

MW: This was great!

Gabby E.

My name is Gabby E. I am 13-years-old and I have Fetal Alcohol Syndrome (FAS). Fetal Alcohol Syndrome and Fetal Alcohol Spectrum Disorders are caused by the mother drinking alcohol during pregnancy. That is why I am here today to talk to you about my FAS. FAS affects my life in many ways. I cannot jump or run very well and my motor skills aren't as up to par as most of the kids my age. I struggle in my classroom studies, I need constant help at school, and I am not very organized. I have a hard time keeping my room clean and remembering to do daily living tasks. I am very social and I know a lot of people, but sometimes I am TOO social, so in the classroom I drop whatever I am doing and lose my focus. I cannot do more than one thing at a time or else I become very frazzled, and either just give up on everything or just shut down. I am very unorganized and various teachers at my school have to help me pack my organizer bag and my mother has to label all of my school folders so I know which is what classroom stuff. I don't have very many TRUE friends who see me as me and who I am. I rarely get asked to attend birthday parties or go to sleep overs at other girls houses. There are some other people who treat me very unkindly like I am a very different person. Sometimes I just wish they would be nice and remember I have feelings too.

My twin brother's name is Joe and he also has FAS. It is hard to think when you have FAS which does not help his life at all. If something happened an hour ago, he probably would not remember it. His FAS also affects other people's life too and causes a lot of stress for everyone in our family and his teachers at school. If he did not have our family to help him, he would probably not be able to function daily. He is in Special Education classes because he has FAS. His writing is bad and he cannot write in cursive because of his motor skills. He cannot think straight and sometimes needs help at school to figure something out. He takes medication for ADHD to try to help him focus daily in life and at school. He barely has any friends at school because of FAS and gets picked on and bullied because he is small. It is hard for him to go to bed because of his FAS and he only sleeps about 4-5 hours a night.

I belong to the International Order of the Rainbow for Girls and my brother is in the Order of DeMolay, which is a brotherhood for boys. I love singing and being in plays at school while my brother likes anime and comic books, riding his bike, break dancing, playing with our five dogs, going to our brother's house, Yu-Gi-Oh cards, and video games. He likes to read Percy Jackson books and has read them all.

Sometimes I wish I can take a magic pill and my FAS/FASD would be gone but other times I am happy just the way I am. I want people to know FAS/FASD is not all that bad, if you have great family and friends to support you. I have a wonderful mother, father, big brother, sister, and sister-in-law who help me and my brother with my FAS/FASD struggles.

Thank you for reading our story.

Elizabeth B.

Elizabeth B. is the Owner and Director of [Thames Centre Service Dogs](#) of Ontario, Canada, an organization that trains service dogs for children with special needs including FASD. She is a mother and step-mother of five children and partner of ten years. She is an author, public speaker, consultant, and advocate for service dogs and their handlers and has been working with dogs for twenty years.

Brianna Montgomery, FASD United: Hello Elizabeth! It is such a pleasure to speak with you. I thank you for agreeing to speak with me today.

Elizabeth B.: I am happy to.

BM: Let's get started. Tell me a little about yourself.

EB: I am currently 47-years-old and was adopted by my amazing parents when I was 5. I was diagnosed with FAS when I was 14, along with PTSD.

BM: How has having FASD affected your life?

EB: When I was younger, it definitely affected me in school in terms of having multiple learning disabilities. It made school very difficult for me. I remember my first grade teacher calling me the "R" word and that stuck with me my entire life.

BM: I'm sorry to hear that. That's such ignorant thinking and horrible for you to have to endure.

EB: On the positive side though, my amazing mother went in to the school with her war bonnet on and said 'how dare you say that to a child.' She has been the biggest advocate and supporter of me for my life. If it were not for being adopted by these amazing people, I truly do not know where I would be.

BM: That's wonderful. Family is so essential. You've shared with me how FASD affected you when you were younger; tell me a little bit about how it affects you now?

EB: There are physical effects to having FASD. For example, I have multiple medical issues that require daily care. I am also going deaf very quickly and we can't find out why. I now have hearing aids. I know I will lose my hearing eventually down the road, but considering everything that I have been through in my life that is really not as big of a deal as one might expect for me. It's just another thing on the hill that has been my life. You get on with it.

BM: I'm sorry about your hearing, but it's admirable what a positive outlook you have on everything. You aren't letting FASD hold you back. Other people could really learn something from you!

EB: I have had a great life, but not without many, many challenges. As a teenager I was extremely challenging for my parents and I really put them through the ringer. I was trying to figure out who I was and I was dealing with the abuse I had experienced prior to being adopted. That mixed me up emotionally a considerable amount and for many years I did not have a relationship with my parents. I felt like they didn't understand me. It was only until I finally grew up and became a parent myself that I realized just how important parents are.

BM: It sounds like your parents, especially your mother, have been so essential in your growth. That is fantastic. Tell me a little bit about your family. I know you had mentioned that you have children.

EB: I have a life partner who I have been with for ten years. He's an amazing, miraculous man in that he puts up with me on a daily basis. He is extremely understanding and supportive. I have five children from our blended union. My partner has three sons and I have a son and a daughter. My eldest stepson is 30-years-old with autism and he is in the process of finding a new job and a new walk in life. My second stepson is 28-years-old and he is an executive for a company. My third stepson is 24-years-old and he is on his way to college to study IT. My daughter is 24-years-old and is a budding photographer with talent beyond imagination. My son is autistic and has recently changed his coursework in high school to academic so that he can go to university.

BM: What a great family and such wonderful successes! Has having two autistic sons been challenging for you and your partner?

EB: The biggest fear that I had was that my FASD was somehow related to my son having autism. I know that FASD is not genetic, but there is guilt associated with my son having autism even though there is absolutely no way that I could control whether he has it. I never drank during my pregnancy and didn't even take Tylenol. I was paranoid, even militant about being absolutely clean during my pregnancies. I did not want any of my issues to be passed on to my children and yet here I have a son who's born with autism and a daughter who suffers from depression. It's natural for a mother to wonder if there something that I did or could have done differently to change this outcome. Intellectually, I know there is nothing that I could have done differently. Emotionally, I don't necessarily know that.

BM: I understand that with autism everything is so unknown.

EB: Having a special needs child and being someone who is considered disabled by the outward world, I think it lends you a significant amount of patience that you would not normally have to deal with the issues that come up. My patience with my son is limitless.

BM: That's an incredible quality to have.

EB: I'm often very quick to spot other children in the community who have special needs whether it be FASD, autism or another disability because you recognize the behaviors. You

recognize the behaviors in yourself or in your own child. You are more inclined to go and offer the other parent assistance when their child is melting down, instead of doing what many other parents may do and just think that the child needs to be disciplined better. That couldn't be further from the truth.

BM: Absolutely. They need more love and care.

EB: They need more understanding. Society as a whole generally does not have much understanding when it comes to special needs children unless the special need is visible. The cruel thing about FASD and autism is that they are both invisible. You cannot recognize a difference between these children and others because there is no wheelchair, no crutches and no major deformity that would isolate them as being different.

BM: That's so true. That's why FASD is so difficult. Even with an "FAS face", the disorder is invisible.

EB: If you look at the FAS face, there are traits about the face that society finds attractive. One downside that people do not consider is that with FAS you are usually a pretty good looking individual and because you are good looking society expects more from you. That is a tough burden to carry when you cannot meet the average expectations of society, let alone the extended expectations.

BM: I agree; that's very true. I understand that you have your own service dog organization, tell me about how you got involved working with service dogs.

EB: Prior to working with service dogs, I was working on rehabilitating dogs with aggression and other behavioral issues. I did that for about twenty years. I always loved working with dogs. I preferred dogs over people because they are less judgmental and manipulative...unless you have a cookie in your pocket, then a dog will manipulate the heck out of you.

BM: Very true.

EB: Dogs are very easy to read behaviorally and you always know where you stand with them. When my son was diagnosed with autism I began to look at including dogs in to my son's life in an extended way and I found out that they had autism service dogs. I became trained to train service dogs for people with autism and I very quickly expanded my training to include psychiatric illness, brain injury, disease and disorder, and FASD.

BM: Tell me about your organization, Thames Center Service Dogs.

EB: I started the organization when my son was diagnosed with autism and we started including other issues in to our training protocol, including FASD. We are very advocate minded in terms of our clients and our service dogs. We make sure that we are there for the duration of the service dog's life. Once the client receives the dog that is not the end of our involvement. We

become part of their family. We are continuously there to train for any additional services that the client may need and we love every single one of our clients and our dogs. In addition to the organization, I am the person that developed the psychiatric service dog protocols for Ontario and I developed the FASD service dog protocols for Canada.

BM: It sounds like you have done a lot of amazing work. We in the FASD field along with individuals with FASD and their families are so thankful for you and your efforts.

EB: I have also begun a psychiatric service dog program here in Ontario. We deal mostly with veterans with operational stress injury. We have a commitment to providing service dogs at a reduced cost to our veterans. It's our own way of saying thank you for all that you have done for us.

BM: What an amazing program. They deserve it. Are there particular dog breeds that are good for service dogs?

EB: I predominantly use Labrador Retrievers because they are a "bomb proof dog." They have such wonderful temperament and it takes a lot to upset a Lab, if at all possible. Having said that, all of our dogs are thoroughly temperament tested to make sure they are "bomb proof" before they even enter our training program.

BM: I understand that is very important.

EB: We also use Standard Poodles for extensive health issues such as asthma or allergies or medical issues such as feeding tubes or colostomy. If it needs to be a cleaner environment, we will use the Standard Poodles because they are less allergenic. There is no such thing as a hypoallergenic dog; please make note of that!

BM: I am aware of that now. Thank you.

EB: Standard Poodles are a low shed and low dander dog. It's mostly the dander that people are allergic to, not necessarily the fur.

BM: I have heard that Poodles are easy to train and are very well tempered dogs, is this true?

EB: Yes, they are. They tend to be a bit goofy until about the age of one year. They are quite hilarious. They are the jokester dog and if you have a sense of humor, you'll be laughing a lot.

BM: That's wonderful. What do these service dogs bring to those with FASD and other special needs?

EB: I'll give you two examples. My first example is a little girl that I work with and she has FASD. She suffers from severe anxiety. Her anxiety is to the point where her vision becomes affected if she becomes too overstimulated. She can occasionally have seizures as well. Her dog is a

companion dog that goes to school with her every single day and offers her support. When she becomes over anxious she will go and lay with her dog and the dog will comfort her and provide her deep pressure therapy, where the dog will push against her. Pushing is comforting. If the dog sees that she is becoming overstimulated, the dog will go and alert her as if to say 'come and spend some time with me.' The dog could also alert her teacher to let the girl know to go and lay on the dog bed with her dog. Example number two is a young man who becomes extremely violent when he's confronted. Instead of lashing out and hitting or destroying things, he will go and lay with his dog. The dog will cuddle up to him and wrap her paws around him. They lay together and the anxiety and anger will dissolve. Since his parents have gotten the dog for him and the dog has been trained to do its job appropriately, they have not had one hole put in their wall, no broken doors and no damage done whatsoever. Prior to the dog being there, they were repairing something every week. Their son's ability to manage his anger was simply non-existent and having the dog has given him an outlet to go and spend time with his dog and be left alone and not confronted. She handles his anger and encourages him to pet her which is a calming technique. A bond has developed between them.

BM: Wow, that's so amazing to me. It's absolutely marvelous what dogs can do.

EB: There is a basic instinctual understanding between children with FASD and dogs. It's an animalistic behavior that they can relate to and understand. No one is pushing and prodding the child to do things that causes them high anxiety; instead they have a buddy on an even level. They know where their buddy stands, their buddy knows where they stand, and when they start getting upset their buddy knows that they are getting upset and says 'come with me.'

BM: That's incredible. You have touched on some of the techniques that are used by service dogs for people with FASD like deep pressure therapy, petting, and cuddling; are there any other recommended techniques?

EB: There is night terror and nightmare rescue. When the child begins to stress or make noise in their sleep the dog will climb on the bed and provide deep pressure therapy thus enabling the child to relax and go back to sleep. If the child wakes up, having the dog there to pet and cuddle is far more comforting than having a parent come in and touch the child. This is something that is very important for people to understand. When a child with FASD says 'don't touch me, that hurts', we mean it. It is physically hurts. It is not said for attention seeking and it is not said to make you feel guilty or bad. It is an actual honest statement. At times when we are very, very anxious, physical touch feels like sandpaper on our skin. It hurts. It is easier for us to take the touch of a dog than it is for us to take the touch of another person.

BM: That is very important to know. Do you have a service dog for you?

EB: I sure have my own dog, of course! I had my own dog up until last year. His name was Maxwell and he was a 165 pound Rottweiler. He was solid mush. He got the reputation of being our "Wal-Mart greeter" because he would run out and say hello to everyone who came by. He

didn't have a mean bone in his body. He went everywhere with me until last year when he passed away.

BM: I'm so sorry to hear that. It's hard to lose a companion like that, I know.

EB: It's a very tender spot. Now, I am training my new service dog; his name is Sir Winchester. He is currently 5 months old and he is coming along beautifully.

BM: What breed is he?

EB: He is a mix of Labrador retriever and Dutch Shepherd. He looks like a Yellow Lab with a bit more perky ears.

BM: Very cute. How do your service dogs personally help you and your FASD?

EB: When I go out in to the community and speak, which I do often, I have great difficulty with public speaking and I become overly anxious to the point of having panic attacks. Having my dog there pressing up against me is just enough to keep me from becoming overly anxious. Also, there are some people in the world that for some reason I don't feel comfortable near. It could very easily have nothing to do with them and it could be a memory trigger from my past or whatever. If my dog feels that I am uncomfortable, he will place himself between me and the other person and press against me to let me know he's there and I'm okay.

BM: It's wonderful that you are training the dog and then in the end the dog helps you.

EB: Exactly.

BM: Tell me a little bit about your public speaking appearances. I also saw on your website that you are an author and have done many TV appearances.

EB: I have done a lot of public speaking in regards to veterans and service dogs and trying to allocate funds from Veteran's Affairs Canada for service dogs for veterans. I've been in that battle for the last five years and haven't made much headway, but I'm not going to give up.

BM: Don't give up. They need an advocate.

EB: I have no intention of it. I have gone around the country introducing the concept of psychiatric service dogs and the benefits that they can provide. Most notably, less involvement by EMS personnel because the assistance is already there from the service dog. EMS is less likely to be called, thus saving tax payers more money.

BM: Absolutely.

EB: I have also just started speaking out about FASD. I have just recently come out of my own FASD closet. I am writing my first article for Adoption Magazine with regards to having FASD. I have done a couple other articles with regards to service dogs in the community and have done three separate articles for Disabled World Magazine. I also just had an article published in City Parent Magazine. I wrote a portion of a book called Lab Stories that was published by Scott Hall. I have a story about one of our service dogs within that book. I have also been accepted to publish a book called Living with FASD.

BM: Please let me know when your articles come out and your book becomes available, we would love to feature them on the FASD United website and in our FASD United Weekly Roundup newsletter. Is writing a passion for you?

EB: I really enjoy writing. I find that it comes relatively easy for me, especially when I have my subject firmly planted in my brain.

BM: Do you have any other passions beside service dogs and writing? What makes you happiest?

EB: I love being with my family. I think one of the greatest joys that I get is cooking for my family. The biggest reward that I get is doing a huge Christmas dinner, and I do mean huge. I usually make turkey, roast beef, and ham with an entire dessert table. I like when everybody is on the sofa after dinner and cannot move because they ate too much. That's when I am grinning from ear to ear.

BM: I'll be stopping by your house next year.

EB: You are welcome. We always have an empty space at our table for someone that has no one to celebrate Christmas with.

BM: That's a wonderful tradition.

EB: That's a rule at our house and a lot of times we have someone new come over. No one should ever be alone around the Holidays.

BM: Absolutely. That's wonderful how warm and welcoming your family is.

EB: The other thing that makes me the happiest, like any other mother, is seeing my children succeed and exceed expectations.

BM: You are a terrific mom. I have just one question left. What is the one message that you

EB: Even one drink can hurt.

BM: Simply stated, but powerful. Thank you for sharing your story with me. I have learned so much about the incredible use of service dogs and only hope that everyone with FASD gets the chance to have one. Keep up your incredibly important work!

EB: I will, thank you.

After this interview was conducted, Elizabeth's service dog, Winchester, passed from complications of a birth defect. He is very sadly missed and this interview is dedicated to his memory.

Erin D.

Erin D. is a 25-year-old with FAS. She was adopted by a great Christian family after being in foster care. She is a very creative and friendly person and loves to use her hands to make things like her jewelry. Discover Erin's jewelry at <http://www.madaboutbeading.blogspot.com/>.

Brianna Montgomery: Welcome and thank you for agreeing to speak with me today. Let's get started! Tell me a little bit about yourself and having FASD.

Erin D.: I grew up in foster care and was adopted at 1 ½ years old. I was diagnosed with FAS and it has been interesting. School was difficult, but I had a lot of help. I was born blind in my right eye and because of that I cannot drive.

BM: Tell me about some things that you excel at and what things have been difficult for you.

ED: Well, obviously driving is difficult for me and the mental part of having FASD, like understanding what people are saying, has been difficult. Actually, I haven't had too much difficulty with things. It has been mostly just gullibility and understanding when someone is being truthful or not.

BM: What things are you good at?

ED: I do a lot of crafts.

BM: Oh yes, I was on your website and I saw your jewelry. It is incredible; I am very impressed!

ED: Thank you, I have been doing a lot of crafts and trying to keep myself busy now that I am not working anymore.

BM: Tell me a little bit about your background. Did you go to school?

ED: I graduated high school and decided not to go to college. I worked at a greenhouse since April of 2006.

BM: What was your job like at the greenhouse?

ED: I did carry-out. I helped people carry plants and bags of soil and mulch out to their cars. It was tiring after a while.

BM: What interested you in working at the greenhouse?

ED: I have always liked nature. Ever since I was little I loved being outside. I would take rocks and seeds and bring them in. I was always a rock collector. I also took a class at a transition

center to prepare me for having a job and I was in the agriscience program for one year and I really liked that. I've always been fascinated with how things grow. I also took a retail class, so that helped with my job.

BM: That's a wonderful experience. Do you talk to people about having FASD or educate people about FASD?

ED: I do talk to people about having FASD. In middle school, I gave my first speech about having FASD. In high school, I spoke to our family living class about what FASD is and how it affected me. I also do my jewelry and pass out my cards with information about me and FASD prevention. I have spoken in front of my church on "Disability Sunday" as well. They pick someone from our church group that would like to share about their experience with a disability and how it has affected them and their Christian life.

BM: It sounds like you have done a lot of great things! Earlier you touched on how you excel at crafts, especially beading. How did your passion for beading start?

ED: I am not really sure where that started. I like little things and I have always been in to beads. I started with stringing beads on a necklace and then I went on to YouTube and looked up different designs. That is where most of my design ideas for bracelets and jewelry have come from. Someone tried to teach me bead weaving and I didn't get it at first, but then I taught myself by watching more YouTube training videos.

BM: So you are pretty much self-taught; that's great! What is your favorite part of beading? What are your favorite things to make?

ED: I like creating different designs and coming up with new ideas. Just showing people that I can do this is important to me. With FASD there are no limits. I am a go-getter and I am going to try it.

BM: How are your beading projects a reflection of you?

ED: In each bracelet or piece of jewelry, I always have one wrong bead to show I'm not perfect.

BM: That's such a good message to send. There is a little lesson in each of your pieces of art.

ED: It has also helped me to realize that I am not perfect. I know people want things to look right and I was always struggling with that. I brought this up to my friend Rob and he told me "who cares what people think." I went with that philosophy and he helped me develop the cards with my story on it.

BM: That's a great way to look at things. Tell me a little bit about your beading blog, "Beadweave it or not", (which is a very cute name, by the way).

ED: Thanks. I started my blog because I wanted to raise awareness of FASD and show my jewelry. My jewelry is my way of showing that I have FASD and people with FASD can be creative. On my blog, I also include when I will be at FASD meetings and things like that.

BM: Your blog is very impressive and a great educational resource. How does blogging and beading help you with your daily life?

ED: Funny thing is that I always have to remember to put the wrong bead in when I am making my jewelry. Those activities help to relax me and help me remember that I am creative, but I'm not perfect.

BM: Do you have any other hobbies besides beading and blogging?

ED: I just went to a recycled craft show about a month ago. It was all things that were made from other things. We went to a booth where a woman crocheted with plastic bags. I have now started crocheting with plastic bags and I've made pouches, purses, placemats and I'm in the process of making a couple doormats. My newest thing is making beads out of paper. I will be blogging about my new activities soon.

BM: That's so neat! Do you sell the jewelry and crafts that you make on your website?

ED: Yes I do. You can go to <http://www.madaboutbeading.blogspot.com/>.

BM: Do you ever go to craft shows to sell your art?

ED: I sell my jewelry at a coffee shop nearby called Urban Mill. I showcased my stuff there in August at their two-day art fair. Actually a woman that bought my jewelry told me that she had a relative with FAE and that was interesting to hear about her.

BM: That's nice to be able to help someone understand more about FASD. What do you do with the proceeds that you receive?

ED: I am raising funds for FASD United. I've raised almost \$300.

BM: That's incredibly kind of you. Thank you for thinking of us. I hope that you'll keep most of the money for yourself; you have worked hard for it! Thank you. Tell me a little bit about your friends. Do any of your friends also have FASD?

ED: A couple other people including my friend Rob. He started a group for adults with FASD in our community. At one of the group meetings this summer, I met a couple new friends.

BM: That's great! What do you do at your meetings?

ED: We chat and catch up with what we have all been up to. It's basically just a get together.

BM: That's nice to have friends that are going through similar circumstances as you.

ED: Yes, it's good to have them.

BM: Do you have any other interests or things that you like to do with friends?

ED: I like to be on the computer, watch movies and listen to music. I hang out with friends when I can.

BM: Do you have a favorite musical artist? Movie?

ED: I like all kinds of music and I really enjoy family movies.

BM: I only have a couple more questions for you. What do you want people to know about individuals with FASD?

ED: Just because we have a disability doesn't mean we can't do stuff. We strive to do our work the best we can. We are not stupid and we do get things. We are unique.

BM: That's exactly right. I have met so many incredible people with FASD and you have overcome your challenges so well. If you had one message for women thinking of becoming pregnant or mothers-to-be, what would that be?

ED: Stop and think about what you are doing. My birth mom didn't really do that, but I do not blame. There is no use of playing the blame game. I am alive.

BM: That's very mature thinking. Thank you so much for taking the time to speak with me. I am so impressed with the wonderful things that you have achieved and are doing. Also, thank you again for thinking of FASD UNITED for your fundraising. You are incredibly generous and kind.

ED: I am happy to help. Thank you for this opportunity.

Lucy K.

Lucy K. is a 16-year-old from Northern Virginia.

Brianna Montgomery: Welcome Lucy, thank you for agreeing to speak with me today. I am very interested in learning more about you. Let's start first with some fun questions, what kind of music do you like? Do you have a favorite singer or band?

Lucy K.: I like Beyonce and Weird Al.

BM: That's an interesting combination. I saw Weird Al in concert when I was younger, he was great. Do you have a favorite song by him?

LK: I like "White and Nerdy."

BM: That's a great song. Do have any favorite movies?

LK: I like Harry Potter.

BM: Have you seen the newest Harry Potter movie yet?

LK: Yes, twice.

BM: Wow. Have you seen all of the Harry Potter movies?

LK: Yes, many times.

BM: Are there any other films that you like?

LK: I like Master of Disguise.

BM: That's a great movie, Dana Carvey is really funny. I know that you just recently went back to school are a sophomore now, what is your favorite subject in school?

LK: I like science.

BM: What interests you about science? Why do you like it?

LK: I like the experiments.

BM: Do you have any favorite experiments that you have done?

LK: Not really.

BM: Do you have a least favorite subject or one that is more difficult for you?

LK: English is hard with writing.

BM: Writing papers can be difficult. Do you play any sports?

LK: I do gymnastics.

BM: Are you on your high school's gymnastics team?

LK: Yes.

BM: What is your favorite part of gymnastics? Do you like balance beam, bars, floor?

LK: I actually really like the vault.

BM: That's great. The vault is pretty tough! In addition to playing sports, do you like watching sports?

LK: Yes, I like baseball.

BM: What is your favorite team?

LK: I like the St. Louis Cardinals.

BM: They are a great team! So you like watching the Cardinals, what other things do you like to watch on TV?

LK: I really like Tom and Jerry, Spongebob Squarepants and Super Nanny.

BM: Those are great shows. I heard that your birthday was a couple weeks ago and you turned 16. How did you celebrate?

LK: My family and I went to a Japanese restaurant.

BM: That sounds like fun. Is Japanese food your favorite?

LK: Yes, I love sushi.

BM: Did you have a cake for your birthday?

LK: My mom made a sand castle cake.

BM: Wow! That's cool! 16 is a pretty fun age. Are you planning on getting your driver's license?

LK: I'm trying, but I'll probably wait until I'm older.

BM: That's a good idea. More time to practice. I also heard that you recently visited South Carolina with your family. Do you enjoy traveling and what is your favorite place to travel?

LK: I like to go to Hawaii.

BM: Have you been there before?

LK: Yes, I was there last year.

BM: What did you do while you were in Hawaii?

LK: We went snorkeling and I got to see my cousins.

BM: That sounds like fun. What island were you visiting?

LK: We went to Maui and the Big Island.

BM: Oh wow, I hear those places are beautiful.

LK: They are. I had a lot of fun.

BM: That's wonderful. Do you have any other favorite vacation spots?

LK: I really like New York.

BM: What do you like to do in New York?

LK: I like to go to the American Girl store.

BM: That's fun, what else do you do in New York?

LK: We go to Ripley's Believe It or Not.

BM: I've heard that's a fun place. Do you have any favorite celebrities or is there someone really famous that you'd like to meet?

LK: I'd like to meet Ke\$ha. I really like her music.

BM: She has fun music. Do you have a favorite actor and/or actress?

LK: I like Sam Puckett from iCarly.

BM: Do you have a hero?

LK: Well, I have more than one.

BM: That's okay.

LK: My mom is one.

BM: That's very sweet, who is your other hero?

LK: Svetlana Boginskaya.

BM: Is she a gymnast?

LK: Yes, she is a famous Russian gymnast. She is the best.

BM: That's great. Tell me a little bit about your family. I know your mom and dad. Do you have any siblings?

LK: Yes, I have a sister Laura who is 23 and my brother Paul is 15.

BM: What does Laura do? Is she in college?

LK: She is going back to school to get her Master's degree in Virginia.

BM: That's great. Do you have any pets?

LK: I have two cats.

BM: What are their names and what kind of cats are they?

LK: Their names are Zak and Bailey, both boys and they are tabby cats.

BM: Are there any other pets that you would like to own?

LK: I would like a dog.

BM: What kind of dog would you like?

LK: Either a Poodle, a Boxer or a Chihuahua.

BM: Those are all very nice dogs. Do you plan on getting a dog soon?

LK: No, I'll probably get one when I'm older.

BM: That's something to look forward to. I know that you are really in to technology and you have an iTouch. What are your favorite things to do on the iTouch?

LK: I like to listen to music.

BM: I only have one more question for you and it's about living with FAS. Do you ever talk to anyone about having FAS?

LK: Sometimes, but not very often.

BM: Thank you for talking with me. I enjoyed learning more about you.

LK: Thank you.

Chanel T.

Chanel T. is a 21-year-old Veterinary Technician from St. Petersburg, Florida. Her greatest passions in life are dogs and parrots, of which she owns two: dog Elizabeth Taylor and parrot Johnny Angel. She is also passionate about educating others about preventing FASD and ensuring that no one else is affected by this lifelong disability.

Brianna Montgomery: Welcome, Chanel! It is so nice to meet you. Thank you for agreeing to participate in this interview. I look forward to learning more about you.

Chanel T.: Thank you, you too.

BM: Let me get started and I will ask you a few questions about your life and your interests. First question for you, how does having FAS affect your life on a daily basis?

CT: FAS is very, very difficult. I don't get up everyday with the same question. This is something that I just have to deal with.

BM: What are some of your biggest challenges with having FAS?

CT: My speech impediment is one of the most hard. I go through it every day. Another problem that I have is that I don't learn the way that other people learn. It is very challenging for someone that does not know my disability. They don't understand that they have to slow it down. They can't give me five steps to do something; they can probably just give me two or three at a time.

BM: What tools do you use to overcome these challenges?

CT: The teachers have been keeping me in front of the classroom and it really helps me to not get distracted and things like that.

BM: Anything that helps! Earlier today you had shared your FASD website with me. Along with the website, what do you do to educate others about your disability?

CT: This is a 100% preventable disability and I present in the classrooms of younger teenagers and they don't really realize that drinking can give the unborn a very hard life. I have learned so much about myself through helping others with these presentations.

BM: That is definitely true. When you are teaching others about yourself, you learn more about yourself.

CT: Exactly.

BM: So you give presentations in classroom settings, have you ever spoken at a conference before?

CT: Not yet. That's the next part that I am working toward. I would love to give a presentation for your organization.

BM: We would love that! Thank you. Tell me a little bit about your website, <http://advocatefortheunborn.com/default.aspx>. How did it get started?

CT: I love presenting, but I never really wanted to do a website. Then when one of the teachers from school was like "Chanel, you need to do a website", that's when my older sister helped me get it going.

BM: Was it easy to put together?

CT: My older sister helped a lot and got it done in like two hours.

BM: Tell me a little bit about the content of your website. I saw that you are a strong advocate for the incarceration of women that are consuming alcohol during their pregnancies until the child is born. Why do you feel so strongly about that?

CT: Most women that drink while they are pregnant are already addicted to alcohol. What I was thinking that if they were clean before the baby was born that they would see that new life and continue to be clean. I think that is very important.

BM: FASD UNITED has a strong stance on this issue as well. We believe that women who are pregnant should not be incarcerated but helped in to treatment. Are you saying that you want the women do be incarcerated in jail or put in to treatment facilities?

CT: They should be in treatment so that they can receive the help that they need. Jail wouldn't provide that.

BM: When were you diagnosed with FAS?

CT: At birth, I was six weeks premature.

BM: Wow, very early. You seem like you are doing very well now though. What do you do now? Do you work or go to school?

CT: I work and go to school.

BM: Are you in college? What do you study?

CT: I am a senior this year and I am studying to be a Kennel Technician at Richard L. Sanders School. I love animals.

BM: Tell me about your passion for working with animals. Do you have any pets?

CT: I have one dog and one parrot. My parrot's name is Johnny Angel and my puppy's name is Elizabeth Taylor.

BM: Very cool names! What kind of dog is Elizabeth Taylor?

CT: She's an Italian Greyhound.

BM: Wow! So you are a dog and a parrot person, do you like cats and other animals too?

CT: I'm not a cat person, really. I like parrots, rabbits and puppy dogs.

BM: What kind of work do you do right now? Are you working with animals?

CT: I am a Veterinary Advocate.

BM: Do you like your job?

CT: It is a very high stress job.

BM: What causes it to be high stress?

CT: Lots of animals to take care of.

BM: I bet that would be tough, but rewarding.

CT: It is.

BM: What other interests do you have?

CT: I enjoy watching TV. I like the Golden Girls.

BM: Which Golden Girl is your favorite?

CT: That's a hard one. I probably have to say Dorothy.

BM: She's funny. What other television shows do you like?

CT: Let me think...I like Life in the ER.

BM: Another good one, what other things do you like to do?

CT: I like to talk on the phone and go on the computer...especially YouTube.

BM: Do you have your own YouTube site or do you just like to watch videos?

CT: I like to watch videos on FAS on YouTube.

BM: Have you seen the FASD United YouTube site, AlcoholFreePregnancy?

CT: No, I haven't, but I would like to.

BM: We have some great videos on there from experts in the field and of people with FASD. I will send you the link. Do you have any other hobbies or do you have a favorite place to visit?

CT: I really like to go to Busch Gardens. It is close to where I live. I love rollercoasters.

BM: Rollercoasters are a lot of fun. That must be nice to live so close to such a cool place.

CT: It is. I like it.

BM: Do you do any volunteer work?

CT: I volunteer at a nursing home. I take Elizabeth Taylor over there.

BM: That's so nice! I bet the residents really like that.

CT: Yes, I like to see everybody and go over there.

BM: That's very nice of you to do that. I only have one more question for you, what is the most important thing that you want people to know about FASD?

CT: This is a lifelong struggle and is 100% preventable. This is not my fault at all. You can bring 100 doctors in to a room and they can all tell you not to drink while pregnant, but when you bring a child with FAS in to a room and they see that this is what she goes through every day, they listen more to that than what you are hearing from the doctors.

BM: That is so true. This is your life everyday and you have done so many great things with your life. Thank you so much for speaking with me and for all of the amazing work that you do. I have greatly enjoyed learning about you.

CT: Please let me know if you know of anyone that would like a presentation on FAS. As many presentations as I can get, one more child is saved.

BM: I would be happy to let people know. Thank you, Chanel.

CT: Thank you, Brianna.

Morgan F.

Morgan F. is a young Alaska Native living with FASD. He is Tlingit and of the Eagle Moiety. He enjoys playing the Native American flute and sharing his experience of having FASD with others. Four years ago he founded One Heart Creations to raise awareness of FAS and FASD. Morgan recently spoke with FASD United Program Manager, Brianna Montgomery.

Brianna Montgomery: Thank you for agreeing to be interviewed. We are so excited to learn more about you. The first question that I have is how does FASD affect your life?

Morgan F.: FASD affects every part of my life. Because I live with FASD, there are many challenges that I have to overcome every day from my own physical body to my own neurological deficits. Some days are better than others and you just have to adapt with every changing day.

BM: I agree. The second question that I have for you is what do you believe needs to be done to address FASD in the community and among experts in the field?

MF: Believe it or not, my grandmother and I were just talking about this [topic]; we need to find a balance between prevention and research. Education and prevention are key in improving upon the problem that we are facing, but we also need to find that balance between also having research. Right now we are kind of at an impasse because more money is going to research than education and prevention. One thing that we need to do, not only at the community level but at the expert level, is promote better understanding. At the community level most people do not know about FASD and because there is such a lack of knowledge we are facing an epidemic. At the expert level we need to promote that same understanding. You can look at something clinically through the eyes of a researcher and only see one aspect. It's great that they can look in to the research, but understanding the whole picture is absolutely necessary.

BM: Very well stated; prevention, education and research are definitely all important to the cause. My next question is as an individual with FASD how important is it to you to educate others about the disorder?

MF: It is very important to me to educate others because as an individual with FASD I know first hand what it is to live with the disorder. Because of the struggles that I go through, it is difficult and I don't enjoy it. I don't want someone else to go through the same difficulties I am going through or go through even more difficult trials. That is the fuel to my fire. It is what keeps me going. The knowing and understanding my own brain damage and physical disabilities on top of wanting other people to understand what's going on with me, with others and with themselves.

BM: What have you done to educate your peers?

MF: I share my story and give presentations across the United States. I believe that it is a very effective means of education on FAS and FASD. I can provide a unique look in to how FASD affects an individual. I have the gift of articulation. I have the ability to do a public presentation and talk to doctors and researchers on their level. I can also provide an understanding for younger group or less informed group.

BM: That's wonderful that you share your experiences and tell others about your life. It is helpful to other people who are going through the same thing and is also helpful to prevention of FASD.

MF: When I do my programs I always point out that it was such as relief to understand what was going wrong with me. To know that I have organic brain damage and that there is a reason why things are going wrong and things are going right.

BM: How did you get involved with giving presentations?

MF: This all started at a little booth in Utah. We had one table, some flyers and drums that we had made to attract attention. I spent all day talking to people. From that day to now, we never could have imagined what it would become. It has been great to be able to do this.

BM: The next question that I have for you is what skills have you adapted to overcome the challenges of having FASD that other individuals that are living with the disorder may benefit from?

MF: A lot of the skills that I have implemented are not skills that I have adapted by myself. I have received a lot of support from my family and good friends. I think that is the most important skill that I have acquired, is learning to accept help and knowing that I need help. That comes from my understanding of my own unique FASD's. I would not be able to get through my day to day life without that support.

BM: What other skills do you use?

MF: Before interviews and presentations, I play my Native American flute. I have to do so because due to my brain damage my thoughts are scattered and I cannot concentrate. I don't have the attention span to answer the questions in a clear and understandable way.

BM: So the flute has a calming affect on you and helps you collect your thoughts?

MF: Yes, it does.

BM: Tell me a little bit more about playing the flute; how long have you been playing?

MF: I have been playing for about four years. The flute is an absolutely key part of my life. If it wasn't for my family, but also for the flute, I would not be where I am today. It has been that

important of a tool throughout my lifetime so far. It is something that cannot be explained in words.

BM: I understand. It's more of something that you feel. Who taught you how to play the flute?

MF: I am actually self-taught.

BM: Wow. That is incredible!

MF: Thank you. For the most part I am self-taught. I started playing on my own and developed my own unique playing style. After I had been playing for a period of time, I started meeting other flute players and picked up other techniques and adapted those in to my playing style.

BM: What made you want to start playing the flute?

MF: To understand I have to tell you the story of how I got my first flute. At the time we were living in Powers, Oregon and we made a trip on a regular basis to visit my great-grandparents in Santa Rosa. From Powers to Santa Rosa is about an eight hour trip and we would always take the Coastal Highway. About half way is Crescent City where the Trees of Mystery are located. The Trees of Mystery is a privately-owned Native artifact museum. We would always stop at this museum on our trips and at the time the museum was featuring Native American style flutes.

I was just out of Alaska at this time and I didn't have experience with the Native American flute. I hadn't heard it or seen the instrument itself. Even if I had heard it, I wouldn't have known what it was. At the museum the music was piped throughout the building and my grandmother asked me if I wanted to try one of the instruments. The curator of the museum showed me the pentatonic scale and let me play the flute. I played it twice then composed my own music.

BM: That's amazing! You just knew how to play right away?

MF: Yes, that is where my interest started. When I arrived in Santa Rosa I told my great-grandparents what I had experienced and what I felt. My great-grandparents agreed to purchase a flute for me for my birthday as long as I played. That certainly wasn't a problem for me.

BM: That's truly incredible that you instantly knew how to play. It's amazing that something that you simply play can make you understand yourself better and feel something you have never felt. What other things, besides playing the flute, do you enjoy doing?

MF: My personal interests vary. It isn't just music. I am an avid reader.

BM: What do you enjoy reading and who is your favorite author?

MF: I love to read history and suspense novels. My favorite authors are Robert Ludlum and Sherman Alexie. Besides reading, I also enjoy research and beading. I'm a photographer as well.

BM: I have seen some of your photos on your website. They are very good.

MF: Thank you. It is something that I enjoy very much.

BM: I have one more question for you: what is the most important thing that you want others to know about FASD?

MF: As everybody knows, FASD is 100% preventable and because FASD is 100% preventable we have to understand that there are only victims, never perpetrators. My mother and my family are as much victims to FASD as I am. We are all affected and because we are all affected we have to work together as a community to prevent FASD and help those affected.

BM: That's a great message. I want to thank you so much for sharing your story with me.

MF: Thank you.

Tracy C.

Tracy C. is a 26 year old from San Diego, California, who was diagnosed at age two with FAS. She attends a community based day program and does volunteer work for various organizations. For many years Tracy has participated in FAS research at the Center for Behavioral Teratology at San Diego State University led by renowned scientist Dr. Edward Riley. An MRI image of Tracy's brain depicting the hallmark effects of prenatal alcohol exposure is used in FAS medical literature, textbooks and presentations worldwide. Tracy was a featured guest at the Los Angeles premiere of the award-winning FASD United public service announcement "Infinite Power," produced by Women in Film, and also was a guest speaker at the SAMHSA FASD Center for Excellence Building FASD State Systems meeting in San Francisco.

Tracy recently talked with FASD United Program Manager Brianna Montgomery.

Brianna Montgomery: Thank you for agreeing to be interviewed. I look forward to learning more about you. My first question is: what has your life been like living with an FASD?

TC: I have Fetal Alcohol Syndrome and it's been so hard for me. Sometimes I get really upset and frustrated and I need to calm myself down.

BM: What do you do that helps you calm down?

TC: I go outside and relax until I figure out what I need to do. I also watch movies at night time before I go to bed and it helps me sleep.

BM: That sounds like a good way to calm down. What other things do you like to do for fun?

TC: I love spending time with family friend Amber K. and her kids and dogs. I love them and they have always been there for me. I really like visiting them. My mom just got married on October 2nd and we went to Las Vegas. My whole family was there and it was great to see my friends and family.

BM: That's wonderful for them! I bet you had a lot of fun. When you are with Amber and her family, what do you enjoy doing together?

TC: We like to go bowling, walking, and dancing. We have been shopping for Christmas presents too.

BM: Sounds fun! What are your plans for Christmas?

TC: I celebrate Christmas with my mom and her new husband. We set up a tree every year and put ornaments on it and decorations. I am also going to the Teddy Bear Dance.

BM: Fun! What do you want for Christmas?

TC: I haven't made a Christmas list this year. My mom always talks to Santa to see what I am going to get.

BM: I bet you'll get some great gifts! Let me ask you another question, I hear that you are friends with Dr. Ed Riley. What do you think of Dr. Riley?

TC: He's a good guy and he's helped me a lot with my FAS. He has helped me understand my brain better.

BM: That's good...As an individual with FAS, how do you help others understand the disorder?

TC: I speak at conferences. I will be speaking at the [People First](#) Conference in June. I have spoken at many conferences with my mom and Amber in California. I received an award from FASD UNITED too. I got to see Karli S. when I got my award. She's a good friend.

BM: That is wonderful...What are some of your favorite TV shows and favorite movies?

TC: I like watching the movie Selena and I watch the Disney channel on TV. I really like Hannah Montana. I like to go to the movies. I just saw Tangled.

BM: Was it a good movie?

TC: I loved it! I was laughing the whole time.

BM: That sounds fun. Another question that I have for you is: do you have any pets?

TC: I have a dog named Sammy. He's 8 years old.

BM: What kind of dog is he?

TC: He's a poodle mix. My mom got him when he was a puppy. He was a rescue dog.

BM: Oh, that's so nice of you to adopt him.

TC: I have three cats too.

BM: That's great! I have one last question for you...what do you want other people know about your life with FAS?

TC: I want people to know about my brain and FAS. I want them to learn from my life. I have a giant heart and I love people. I'm a people person.

BM: That's wonderful, Tracy! It has been so great to speak with you. I have enjoyed learning about you and your life.

TC: Thank you so much!

Frances M.

Frances M. is a 50 year old woman that was born and raised in Washington Heights in New York City. She grew up in a family of four and is the youngest of one sister and two brothers. Frances now lives in Fort Lee, New Jersey with her very dear friend Mary.

Frances recently talked with FASD United Program Manager, Brianna Montgomery.

Brianna Montgomery: Thank you for agreeing to be interviewed; it is a pleasure to have you share your story with us. My first question for you is, how does FASD affect your life?

FM: It has affected my life in many ways. I was born six weeks early and weighed three pounds, eleven ounces. As a child, I never knew what it was but it was hard for me to make friends and I found myself feeling afraid of others. School was very hard for me, especially Math and English. I couldn't comprehend them. I completed high school and tried college, but it didn't go well. Then I got a job.

BM: Where did you start working and how did that work for you as compared to school?

FM: Working was hard. I didn't know what I wanted to do and I went from job to job. I couldn't hold on to a job. It was hard for me because I developed anxiety, depression and an eating disorder. I still deal with that today.

BM: How do you deal with having anxiety, depression and an eating disorder?

FM: I see a therapist often and take medication. It's still a struggle.

BM: Do you think that these issues are direct results of you having an FASD?

FM: Yes. I believe it is.

BM: I understand. So, what do you do now? Are you still working?

FM: Yes, I work as a cashier for CVS Pharmacy.

BM: That's great. Do you like your job?

FM: I do. My job is getting more challenging though because it gets busy around this time of year.

BM: What parts of your job do you find to be the most challenging?

FM: When I am pushed to go faster than I am capable. I have to go at my own pace and if I'm rushed I get anxious. Also, if the environment is too loud that bothers me. Sometimes I find myself shutting down.

BM: You said that you shut down when you become overwhelmed with anxiety. How do you deal with the anxiety in your workplace?

FM: Sometimes I will take a break and step outside. I remove myself and come back. Also, I call friends for support sometimes.

BM: It sounds like you have a good control over your anxiety and have your strategies down.

FM: I try. I have been on this job for ten years and it is the only job that I have held on to. I put all of the credit of holding on to this job for so many years on going to therapy and being involved in support groups.

BM: Which support groups are you involved with?

FM: I am very involved with Al-Anon. I have a lot of friends in that group.

BM: That's great. My next question is, what do you believe needs to be done to address FASD in the community and among experts in the field?

FM: We need doctors to be aware. I have been to many doctors where I tell them I have FASD and they just look at me. I have to educate them. It is sad seeing how much they don't know.

BM: We see that often.

FM: My goal is to get information on FASD to all of my doctors.

BM: That is a good segue in to my next question, as a person that has FASD, how important is it to you to educate others about the disorder? What have you done to educate your peers other than educating your doctors?

FM: I think it is very important. I have done a couple workshops with Dr. Susan Adubato and she has given me the opportunity to share my story. I also run the Alateen meeting in my area.

BM: How did you get involved with Al-Anon?

FM: I first got involved with Al-Anon way before I knew that I had FASD. I got involved with Al-Anon because I grew up in an alcoholic family. I am involved with Alateen and I lead the meetings, but I don't share my FASD story yet because it's hard to explain to 9-15 year olds. There's a right time and a right place to share my story. I do share my story at the Al-Anon

meetings. I always tell myself if there is one young woman who is thinking about having a child and who is drinking, if I share my story and that one person hears me it's worth it.

BM: That is totally true. You are saving a life in a way. Let me ask you the next question, what skills have you adapted to overcome the challenges of having FASD that other individuals with FASD may benefit from?

FM: I do a lot of writing to express my feelings. It helps me. I also watch people very carefully to learn how to do certain things. I tend to read everything twice to comprehend what I am reading. For my anxiety, I avoid loud and crowded places. I always surround myself with people that I feel comfortable and safe with.

BM: That's always good; do you have any other friends with FASD?

FM: No, I don't, but the people that I hang out with and feel safe with most are my friends from Al-Anon. They are very loving, caring and supportive.

BM: That's great. You talked about how you like to write, that leads me in to my next question. What are some of your personal interests?

FM: I like sports. I really enjoy football and baseball.

BM: What teams do you like?

FM: I like the Jets and the Red Sox.

BM: Those are two really great teams. Do you go to games or watch them on TV?

FM: I mostly watch them on TV. I also really love animals. I love working with dogs and cats.

BM: Do you have any pets?

FM: Yes, I do. I have a dog. I always had an animal in my life. Now that I think about it, having an animal in my life, even growing up, was probably a coping mechanism for me.

BM: That's a good coping mechanism. What kind of dog do you have and what is his/her name?

FM: I have an 11 year-old toy poodle and her name is Friday.

BM: That's cute!

FM: She was my niece's dog and when they moved, I got the dog. She's spoiled rotten.

BM: Do you have any cats?

FM: I like cats, but I am allergic to them.

BM: So you enjoy animals and sports, do you play any sports?

FM: No, I don't play sports. I have brittle bone disease and I have to be careful.

BM: So, your bones would have a hard time healing if they broke, correct?

FM: That's right. I was never able to get involved in any sports. I would rather watch sports on TV anyway because you can see everything.

BM: That's very true! Okay, I have one last question for you. What do you want other people to know about FASD?

FM: I want people to know that there is hope. I keep telling myself, if I can survive others can too. FASD comes with a lot of shame and challenges. I always tell people to stop and think before taking that drink. Pregnant women should remember that they are not drinking alone.

BM: That's a positive message to send. I want to thank you so much for participating and telling me your story. I enjoyed learning more about you. I hope that you enjoyed the interview.

FM: I did. Thank you for inviting me to speak with you.

Jasmine S.

Jasmine S. is the 19 year old daughter of Mickey and Dianne. She graduated Scotia Glenville High School in June 2008. Jasmine was diagnosed with Fetal Alcohol Effects when she was 3 years old. Jasmine was a general session speaker, along with her mother Dianne and sister Elizabeth, for the Sharing Personal Stories panel at the 2008 Building FASD State Systems meeting. Jasmine is interested in bringing her voice to the SAMHSA FASD Center for Excellence Expert Panel on how FASD has affected her life and finding ways to help families and caregivers living with FASD lead successful lives.

Jasmine recently talked with FASD UNITED Program Manager, Brianna Montgomery.

BM: Thank you, Jasmine for agreeing to be interviewed for our “Get to Know Me” series. We are so excited to learn more about you. First question, how does having FASD affect your life?

JS: For me I feel like I always have to be one step ahead of everybody because I don’t always understand everything. I have to really pay attention all the time. If I don’t pay attention I miss things. It also affects my social life because people do not understand that I have a disability. There is information out there, but not a lot of people have access to it. It’s hard.

BM: I hear that you recently had a baby. Congratulations! Do you want to tell me a little bit about what it is like having FASD and being a parent?

JS: Thank you, I have a son. He makes it a little bit easier for me, but I have a lot of help. I have a notebook that I use as a schedule for all the things that he will need and what I need to do. I always refer to that. My mom also helps me a lot. My son is really good and makes it really easy.

BM: That’s wonderful! What is his name?

JS: Avery.

BM: What a cute name! Congratulations again! The next question that I have for you is, what do you believe needs to be done to address FASD in the community and among experts in the field?

JS: I have been thinking about how we need FASD education in public schools. We learn about all sorts of diseases in health class, but FASD never comes up. There should be a little course in health class on FASD.

BM: That’s a great idea. We have a curriculum that hopes to achieve that. As an individual with FASD how important is it to you to educate others about the disorder? What have you done?

JS: It is a really big problem. When I had my baby I also had a friend that drank the whole time that she was pregnant because she had no idea about FASD. By the time that I found out she was pregnant, it was too late for me to educate her about it because the damage was done. If she would have been educated her child would not have as many problems as he does.

BM: What other things have you done to educate others?

JS: I tell people about my story and tell them that this is a real problem and no one should drink while pregnant. It's worse than cancer.

BM: Definitely, it's a lifelong disability. What skills have you adapted to overcome the challenges of having FASD that others may benefit from? You have already shared that you use schedules, what else works for you?

JS: I started really early in my life and my mom got me in to a support group for kids with FASD. The programs there were instituted in to my life really early on and that helped me more than anything else. In school I had aides to help me organize myself. I had to learn to accept help.

BM: I know it's sometimes hard to accept help. What other things have helped you?

JS: Resource room in school was very helpful and being scheduled with after school sports and homework.

BM: You enjoy playing sports? That is a great segway in to my next question, what are some of your personal interests?

JS: I love to write. I have been writing a story since I was a freshman in high school. I still haven't finished it yet. I like to write songs and draw. I think I am very creative. I also enjoy playing basketball, but I am busy with work now, so I don't play very much.

BM: Where do you work?

JS: I work as a Deli Clerk at Price Chopper.

BM: Do you enjoy your job?

JS: Sometimes. It gets overwhelming, but it's an easy job.

BM: One more question, what do you want others to know about FASD?

JS: That's a tough one. There's so much. The most important thing is how it affects younger children. If you educate younger people, it is going to change faster. Younger people are our future.

BM: Very true. Those are all of my questions. Thank you again for interviewing with me. It has been wonderful speaking with you!

JS: Thank you.

Karli S.

Karli S. is a thirty-seven year old woman with FAS. She was diagnosed at age 16. Karli has volunteered with FASD UNITED for nearly 15 years and she illustrated the NOFAS logo. She has received numerous awards for her advocacy for FASD including a Point of Light award presented by former President George Herbert Walker Bush.

Karli sat down with Brianna Montgomery on a recent visit to NOFAS.

Brianna Montgomery: Welcome Karli. I am glad that you were willing to participate in our interview series about people with FASD.

BM: The first question that I have for you is what things are difficult for you with your disability?

Karli S.: Riding a bike and swimming are difficult and sometimes I can't remember things.

BM: What is your life like with FASD?

KS: It is harder to do things.

BM: You are doing very well for yourself. I know that you have had a couple jobs, what was your most fun job to work at?

KS: I worked at TJ Maxx.

BM: What did you do there?

KS: I helped hang up clothes in the basement and worked with the boxes.

BM: That sounds like fun. I hear you like to shop, what are your favorite things to shop for?

KS: I like purses and make-up. I like to shop for clothes, wallets and sandals too.

BM: Those are all great things to shop for. I understand that you are involved with a group called Social Climbers, what activities do you like to participate in there?

KS: My favorite activity at Social Climbers is dancing.

BM: Why do you like to dance?

KS: Because the music is good and it is fun.

BM: What do you like about FASD UNITED?

KS: It is good and I like the work that you do.

BM: Thank you. Have you met other young people with FASD?

KS: Yes, Tracy Combs is my friend.

BM: That's fun to be with a friend. Do you talk to others about having a disability?

KS: Yes, I go to FASD UNITED with my mom and talk about FAS.

BM: We love to have you here to help us spread our message.

KS: Thank you.

BM: What do you enjoy doing every day?

KS: I like relaxing, watching movies and playing with sticker books and coloring books at home.

BM: Do you like to be outside too?

KS: Yes, I take walks, relax outside with a magazine, and I like to go to the beach.

BM: What is your favorite part about going to the beach?

KS: I like the Boardwalk because I walk around and look at some of the stores and ride some of the rides.

BM: Sounds like a lot of fun. Who are your favorite people to spend time with?

KS: I like my dad and mom and all of my family.

BM: Family is always great to be with. One more question. What do you want others to know about FAS and your disability?

KS: I want to tell other people that people with FAS are smart and pretty.

BM: They definitely are! Thank you for letting me interview you. This was very fun.

KS: Thank you.

Taylor A.

Taylor A. is a 17 year old teenager with FASD, who was born in Vermont in June 1992. He was put up for adoption by his birth mother, who was an alcoholic, and was adopted the next day by his current parents. Unlike others with an FASD, he does not have any of the facial characteristics that are attributed to the disorder. Others sometimes find it hard to believe that he has a disability because he is verbally and literarily proficient, funny, outgoing, caring, and very smart.

What many do not know are all of the things that lie beneath the surface. He exhibits almost all of the behavioral and mental symptoms of FASD, and has struggled with them his whole life. He has also had problems with skipping school. However, if you spent one day with Taylor one would realize none of that is who he really is.

Taylor recently spoke with FASD United Program Manager Brianna Montgomery.

Brianna Montgomery: Welcome Taylor. Thank you for participating in this interview with me. I look forward to learning more about you. First question, how does FASD affect your life?

Taylor A.: FASD has affected my life socially, mentally, academically, and caused strain in my family, yet has also benefited me in a strange way.

BM: What do you believe needs to be done to address FASD in the community and among experts in the field?

TA: FASD needs to be addressed in the same way that AIDS, cancer, and other diseases like those are being addressed, which is with a fervor.

BM: Next, as an individual with FASD, how important is it to you to educate others about the disorder?

TA: Educating others about FASD is one of my top three priorities in life.

BM: So what have you done to educate your friends and peers?

TA: I have spoken out to my peers, written papers for classes, and used other ways of communication to get my message across.

BM: That's great that you are so passionate about helping others understand FASD. Next question, what skills have you developed to overcome the challenges of having FASD that could benefit other individuals living with the disorder?

TA: I am verbally and literarily proficient, I am determined, outgoing, caring, and I will do anything within my abilities to advocate for myself and others in need.

BM: Now for a more of a special, fun question, what are some of your personal interests?

TA: Some of my personal interests include baseball and other sports, history (mainly the WWII era), computers, engineering, reading, and like most other kids my age, video games.

BM: One last question, in closing, what do you want others to know about FASD?

TA: I want others to know how devastating FASD really is, how deeply it affects a person and those around them, and also I want them to remember a small phrase: "My name is Taylor, and I am going to prove FASD does NOT define me." So you can see that I am not going to give in, and that there is a fighting chance for those of us with FASD to succeed.

BM: That's a wonderful attitude to have. Thank you so much for participating in this interview. It was wonderful to learn more about you and get insight into your life.

TA: Thank you.

Rob W.

In 1973, Rob W. was the first infant diagnosed with FAS in the United States. Having a diagnosis at birth has been extremely helpful to both Rob and his parents. Although there were no conferences, books or videos on FAS in 1973, having the diagnosis helped his parents think and parent differently.

As Rob grew older he wanted to become part of the solution to the FASD puzzle. He has been involved in the areas of prevention as well as intervention. His bumper stickers patterned after bus signs in Seattle have found their way to Cape Town, South Africa, and Paris, France as well as all 50 states. He was also featured on the video "Students Like Me." He was on a national committee, NAG for Justice, to help individuals with disabilities understand their rights in the criminal justice system, and he does trainings for peers, based on their project, "The Right Rules."

He served on the planning committee of the first ever conference by and for individuals with an FASD. He has been a speaker at two FASD Center for Excellence, Building State Systems conferences as well as events in Alaska, Florida, Kentucky, Michigan, and Washington D.C. He serves on the steering committee for the FASD Center for Excellence, and is the first consumer to be on a national committee for FASD. In 2010, he will also be presenting at the FASD conference in April.

Rob recently talked with FASD United Program Manager Brianna Montgomery.

Brianna Montgomery: Welcome to you, Rob. Thank you for participating as the very first guest in the new FASD United Interview series. Let's get started. First question, how does FASD affect your life?

Rob W.: It has affected my life in several ways. I explain it this way to my friends, my body is 37 years old, but my brain is 20 years old. My cognitive age is a lot younger than my biological age. People have a hard time telling that I have FAS; they don't believe I have FAS until I start stumbling when adding things up or remembering things. When I am given multiple tasks and verbal directions, it shows.

BM: What do you believe needs to be done to address FASD in the community and among experts in the field?

RW: I would like to have more conferences. I want the experts to work with the school and legal systems to educate them about FAS. The school systems are the ones that need it the most. I would also like employers to be educated so that they can feel comfortable hiring people with a disability and understand that things will go wrong and not to just fire them because something goes wrong, but work with the person.

BM: I understand that you are currently employed with the ARC. How do you like that job?

RW: Yes, I am. It's great.

BM: As an individual with FASD, how important is it to you to educate others about the disorder? What have you done to educate your peers about FASD?

RW: It is very important to educate, but you have to educate the right people. They are people who are willing to learn about the disability and those who are willing to take it seriously and teach others. I tell others how my disability affects me and what supports I need in place so that I can succeed.

BM: I hear that you do a lot of speaking engagements.

RW: Yes, I have. I have also worked with Georgiana Wilton [of the Family Empowerment Network (FEN) of Wisconsin] on coming up with a brochure for employers regarding FAS. I also have bumper stickers and a video called "Students Like Me."

BM: Next question, what skills have you adapted to overcome the challenges of having FASD that other individuals living with FASD may benefit from?

RW: I work with constant support from peers, but I have also built a group of support people, like FASD United and people that know about FAS that can help me with getting resources that I need for school and work. If I want to live on my own, the ARC will help me pay my bills and will help me look for an apartment of my own.

BM: That's wonderful. Those are great things for others with FASD to know. I personally receive many calls from people saying "I don't know what to do, I am in a situation where I can't hold down a job and I need some help." Your advice is great.

RW: People need to know that there are services available. I suggest vocational rehabilitation. Classes on life skills would be also be helpful for people with FAS. There is a program called "Do 2 Learn" (www.dotolearn.com) that educates teachers how to design the classroom for kids with learning disabilities to help them function better.

BM: Next question, what are some of your personal interests?

RW: I like computer games, crafts, gardening, and hanging out with friends. I also like speaking at conferences. I really like being a mentor to other people that have FAS and teaching them that I have FAS too and I have some of the same problems that they do. I am also a part of a Monarch Watch Program. I tag and release monarch butterflies every year before they fly south to California and Mexico.

BM: What does that program involve?

RW: I tag the monarchs with an identification sticker that has my name and home address on it and a special computer code; so that when someone finds them they can see where the butterfly came from.

BM: What an amazing program. Do you keep the butterflies at a sanctuary or at your house?

RW: I find the caterpillars in the plants in my garden and then I bring them in the house and raise them inside. I built a cage for them that I have in my room. They have a better success rate if I bring them in the house because there are no predators inside my house to get the caterpillars.

BM: How did you get involved in this program?

RW: I learned about it when I worked at the Frederik Meijer Gardens in Grand Rapids, Michigan.

BM: One last question, what do you want others to know about FASD?

RW: I want others to know that FAS is completely preventable and that there are other people that have FAS, so they are not alone. I am trying to start a support group for adults with FAS where they can get together, talk about FAS, and work with the [FASD Center for Excellence] steering committee. I would like to have more conferences for kids with FASD, too.

BM: Thank you so much for talking with me. Your interview was great and I learned a lot about you. I know this will be very helpful to other individuals with FASD.

RW: Thank you, I am glad that I could help others with FAS.

Erica B.

Erica B. is a 31-year-old from Minnesota living with FASD. She was born to a single mother struggling with alcoholism and grew up with a wonderful adoptive family. She currently holds a Bachelor's of Science degree in Human Development and Family Science from the University of South Dakota and holds a graduate certificate in Substance Abuse Rehabilitation Counseling. Erica is currently studying to take the CSAC-A exam and is working as a nanny for one-year-old twins in Arlington, Virginia.

Brianna Montgomery: Welcome and thank you for participating in this interview with me today. I am excited to learn more about you.

Erica B.: Thank you for interviewing me.

BM: First question, how does having FASD affect your life?

EB: It has changed over the years. When I was younger there were a lot of school-related issues and some behavioral issues. As I got older, I grew out of a lot of those problems and I'm not in school, so clearly school isn't affecting me right now. Now I've noticed that I have trouble staying organized and keeping myself from getting distracted. When I need to start a big project like cleaning the house or running errands I have make sure that I have everything written down, otherwise I will forget things. A lot of these issues are helped by my husband, Brian who is always there to keep me on track.

BM: That's great to have help. Tell me a little bit about your husband. How did you meet him and what effect has he had on your life?

EB: We actually met through Facebook right before I moved to Washington, DC to intern with FASD United. We kicked it off really well right away and emailed back and forth for several months and have been together ever since.

BM: That's wonderful. When did you get married?

EB: We just celebrated our two year anniversary in August and we got married in California.

BM: Congratulations! That's great. What does your husband do?

EB: He is a lawyer.

BM: Wonderful. You said that your husband has been instrumental in helping you deal with FASD, what other skills have you developed to help keep you on track?

EB: I would say that the most important skill that I have learned is to ask for help. That took me the longest time to learn. I was always too afraid to ask for help and would struggle. I was discouraged because the teachers and professors didn't know how to help me in a way that I needed. I never really did that well in school until I came out to DC and got my Graduate Certificate in Substance Abuse Rehabilitation from Northern Virginia Community College.

BM: What made that program different and why did it work for you?

EB: Because I really enjoyed what I was doing and I'm passionate about it.

BM: Do you ever talk with people about having FASD or educate others about the disorder?

EB: Yes, I speak at conferences and give free presentations because I want people to be educated about FASD. Everyone that knows me knows that I have FASD. It's not the first thing that I bring up though. In addition to speaking engagements, I also used to read various articles on the disorder and look at the comments on the articles. I was finding there were still a lot of people that thought that drinking during pregnancy was perfectly okay. So I started to make comments myself and educate others about FASD, but I got myself frustrated because people just weren't getting it. No matter what I would say it just wasn't going through, so I stopped trying to educate people that way.

BM: It's understandable. There are still so many people that think it is okay because of the conflicting information that they are receiving from the media and other sources.

EB: It is amazing to me how many doctors are still telling women it is okay to drink, especially in the early stages of pregnancy. I read an article one time that made me really emotional because a woman was just disputing that it really is unsafe to drink during pregnancy. So I called my dad and I asked him, why are doctors still telling women that it is okay to drink? He couldn't understand it either, and he's a doctor. I think medical students need to be taught about FASD in school.

BM: Totally agree. We have been working with medical schools here at FASD UNITED for some time (as you know), but it would be great to make sure that all of the medical schools have an FASD education program in place.

EB: I agree.

BM: So tell me a little about your background, I know you are originally from Minnesota and you went to school in South Dakota, tell me about your experience in the Midwest.

EB: I majored in Human Development and Family Science at the University of South Dakota.

BM: What made you want to move out to DC?

EB: I wanted to work with FASD UNITED and prevent FASD.

BM: I heard that you worked on Capitol Hill. Tell me a little bit about your experience working there.

EB: I worked in the Media office for Senator Tom Daschle of South Dakota. I did a lot of communicating with the various media sources and making sure that everything got where it needed to go.

BM: That sounds great. I know that you are close with the Daschle family. What has your relationship with them meant to you?

EB: I still keep in touch with them and see them at the FASD United benefit every year, but obviously they are very busy. They mean a lot to me.

BM: Have you ever thought of going back to work on Capitol Hill or running for political office?

EB: At one point, I really wanted to run for office but I decided against it. Working on the Hill kind of soured me against it because of some of the politics I've seen. What I saw was heartbreaking and it ruined it for me. I feel now that I can do so much more on the sidelines.

BM: I can understand that.

EB: I'm very belief oriented and I feel like the political climate right now would not allow me to actually change things for the better. Everything is so negative. No one seems to have respect anymore like when I worked on the Hill.

BM: Okay, off politics now. Tell me about your goals and aspirations for the future.

EB: Personally, I would like to start a family. Professionally, I would like to work for a non-profit and do more volunteer work. My main goal is to work with families, mothers and children and those dealing with substance abuse issues and domestic violence.

BM: Those are great plans and you have the background to accomplish them. What activities do you enjoy doing?

EB: My husband and I love to travel. We go on cruises every year.

BM: That's cool. Where have you gone?

EB: All over the place. We have been to Mexico and the Caribbean several times. This November we are going on a cruise to Jamaica, the Bahamas and Haiti.

BM: That sounds fun. What do you like best about cruises?

EB: I like that you can visit multiple places at once and I actually really like being on the boat. Everything is provided for you.

BM: That is a nice feature. Have you travelled anywhere else via cruise or otherwise?

EB: I have travelled to Italy, France, Holland and Spain with my family. I also had the incredible opportunity to travel to Bosnia during the Kosovo crisis with my dad when I was younger.

BM: Wow. What was that like?

EB: My dad went because he was the Director of Medical Services for the American Refugee Committee and he decided to take me with. My mom was very against it because it was so dangerous, but I went anyway. We each had our own soldier with us because we were walking through landmines and minors like me were susceptible to getting kidnapped.

BM: That's a crazy experience to have when you are so young.

EB: That experience definitely stayed with me. It changed how I viewed the world and war. I would actually like to go back to Bosnia now and see how it has changed. Things are more positive now.

BM: Definitely. Are there any other places that you have travelled or would be interested in travelling to?

EB: I would love to visit some of the Scandinavian countries because that's where my heritage is. I am mostly Swedish and partly Norwegian and Danish.

BM: Tell me more about your family. Do you have any brothers and sisters?

EB: I have one biological sister that was adopted by a different family but we were raised in close contact. I am very close to my biological family. In my adoptive family, I have a 21-year-old sister and an older brother who is a Cambodian refugee that my parents brought over when he was 17. His entire family died in the war in Cambodia.

BM: That's awful, but wonderful that your parents brought him to a safe place. Where are your brother and sister now?

EB: My brother lives in Minnesota with his wife and two daughters. My sister is in the process of going to veterinary school, but right now she is working and living in Minnesota.

BM: What do your parents do?

EB: My dad is a doctor and my mom is a homemaker and volunteer tour guide at the Minnesota State Capitol in St. Paul. They live in Minneapolis.

BM: It sounds like you have a very interesting and diverse family. What other interests do you have?

EB: I love shopping. I like shoes and clothes. My husband and I really enjoy going to movies.

BM: What kind of movies do you like?

EB: Mostly big-name, action movies like Transformers and Harry Potter.

BM: What is your favorite film?

EB: I have a lot. I like Harry Potter, Unstoppable, anything with action and suspense.

BM: Do you enjoy reading? If so, do you have a favorite author?

EB: I really enjoy reading on my iPad. I like Harry Potter, the Shopaholic series, and suspense books.

BM: Do you have a favorite TV show?

EB: I like 19 Kids and Counting, Extreme Home Makeover and shows that aren't on the air anymore like Golden Girls, Friends and The Cosby Show.

BM: Any other interests?

EB: I enjoy crafting, puzzles and games, especially video games.

BM: What video games do you play?

EB: I'm big in to World of Warcraft.

BM: Fun. What other games do you like?

EB: I like any game that I can play on my iPhone or iPad and I really like board games because I can interact with people. I also enjoy any game that I can play on the Wii.

BM: Sounds fun. One last question, what is the most important thing that you want people to know about FASD?

EB: The most important thing is that it is completely preventable if you don't drink; not only during pregnancy but also during breastfeeding. That's ultimately the only point that you need to drive across. Also, people with FASD need proper supports in order to thrive, so that is very important as well.

BM: Very true. Thank you so much for speaking with me. It was a pleasure learning more about you.

EB: Thank you.