

*Developing Clinical Pharmacokinetics and Safety Trials in Down syndrome*  
PTN DOWN SYNDROME 2020 VIRTUAL MEETING  
ADVOCATE BIOS

***ADRIAN FORSYTHE***

Adrian Forsythe is the Advocacy Programs Specialist for the National Down Syndrome Society (NDSS) where he works to advance legislation beneficial to the Down syndrome community. Since 2016, Adrian has participated in advocacy initiatives on the federal and state levels and provided administrative support for the NDSS National Advocacy & Public Policy Center. Adrian also serves as the staff liaison to the NDSS Self-Advocate Resource Council and is the second registered lobbyist with Down syndrome.

***JULIE HAJEWSKI***

Julie and her husband, Steve, are the parents of two boys, Calvin (11) who is typically developing, and Mikey (9) who has Down Syndrome. She lives in Columbus, WI, about 25 miles outside of Madison. Mikey attends public school with an IEP, but currently, during the Covid 19 pandemic he is attending school virtually with 1:1 assistance. He is primarily non-verbal and uses an AAC device to aide in communication. Julie works full-time for the University of Wisconsin Medical Foundation as a Nurse Practitioner in Internal Medicine and part-time for the University of Wisconsin-Madison Waisman Center with 2 grant funded programs that support the disability community.

***TAVRICK LAWLESS***

Hello, my name is Tavrck. I live in Kansas. I am 24 years old and I graduated from a Life Skills program. I am the CEO of a new business called All Abilities Art. You can soon find our cards and products on Etsy and at [allabilitiesart@gmail.com](mailto:allabilitiesart@gmail.com). I volunteer for Wichita State University and at a nature center in an art and craft program for children. I am also on a state wide Diversity Council and am on the Self Advocacy Resource Council of the National Down Syndrome Society.

I have been paid as an extra in a movie, to model, and to work on the windows of Cessna airplanes and at an event center.

I was a high school intern at a tattoo parlor, and at a physical therapy clinic.

I am a graduate of Product Search. My first rotation was at my county's Election Office (during our state and national elections - which was pretty exciting.)

My second rotation was at a 700 bed hospital.

My third rotation was at a science museum's gift store.

My last internship was at a living history museum's cafe.

You might wonder how I got the tattoo parlor job while still in middle school. Well, I told my mom about my interest and we just walked in and asked!! We were pretty amazed when the owner said "yes." He was excited about trying me out. My mom said it was just like in the movies and she could not believe it was actually happening.

All together my 3 Project Search rotations took about the whole school year.

I enjoy learning new skills in new places that will help me get my dream job. But, honestly, my dream job changes.

I like music, arts and entertainment so I would like to work in that area somehow. I would like to help set up for entertainment events. Right now I do a little of that by volunteering at a film festival and a living history museum. I volunteer whenever I can and started when I was young.

I also want to design T shirts, and own a tattoo parlor, and write a book about musicians and..you see...I have a few too many dream jobs and every week I add more dream jobs! After all, I am still pretty young.

In all my jobs I like the people I work with the most, that I am making a difference, and the food! My old tattoo parlor boss used to treat me to burgers and tacos. That was fine with me!

My advice is to have a good work attitude, do what your bosses and coaches ask you to do in a happy and cheerful manner, speak up if you are unhappy about something, are confused or need more information and listen to your parent/guardian's advice and do volunteer work

### ***EMILY MONDSCHIEIN***

Emily Mondschein is the proud mother of two boys, one who was born with Down syndrome. She has a master's degree in education and has founded 2 not for profits that serve individuals with Down syndrome. She currently serves as the Executive Director for GiGi's Playhouse in Buffalo, New York. She is a member and leader on multiple councils, both local and national that support individuals with disabilities. Emily has advocated to Congress on behalf of individuals with Down syndrome and is a member of NDSS' National Inclusive Education Task Force.

### ***JACOB MURASKO***

I am a Special Olympics Athlete, Advocate, and Past Manager of the 8<sup>th</sup> Grade Basketball team. My hometown is Hopkinton, MA. My hobbies are basketball, swimming, golf, member of the Boston College Swim & Dive Team. I like music, sports, chicken wings, and spending time with my family in Hilton Head, SC. My dreams are to go to college and to play in a golf tournament with my dad.

### ***MARLA MURASKO***

Marla Murasko is an award-winning Advocate, published Author, Public Speaker, Inclusion Educator, Talk Show Host, Community Influencer, Vice-President of Special & Determined (family nonprofit), Wife and a mother. She has spent the last 14 years advocating and educating society on the misconceptions surrounding Down syndrome. Her mission is to show that individuals with Down syndrome are fully capable in reaching their fullest potential, and being an active member in their community. Her 14 year old son Jacob, with Down syndrome has not yet participated in any research, but would consider him participating in a study that is the best fit for him.

### **SARA NYE**

I live at home near Hershey, PA with my parents and my chickens. I like to ice skate, play piano, play Minecraft, and go primitive camping. I participate in my church and local Down syndrome groups.

### **MICHELLE PFEIFFER**

Michelle Pfeiffer lives in Cary with her husband and three children. Her daughter Anna who is 19 has Down syndrome and provides the passion for her to help improve the lives of individuals with Down syndrome.

Michelle has her MBA and was a Senior Manager at MCI Communication. In 2001 when her daughter Anna was born in she made the decision to put her career aside to ensure Anna received the best healthcare and therapeutic care available. When Anna was a year and half old she was diagnosed with leukemia. During Anna's chemotherapy treatment and recovery Michelle learned about the lack of research in the Down syndrome field. In 2003 she founded Anna's Angels, a fund under Duke Children's Hospital and Health Center. To date Anna's Angels has raised over \$1.6 million for this important research effort.

In 2016 Michelle was part of the start up team to open GiGi's Playhouse Raleigh, a Down Syndrome Achievement Center providing free educational and therapeutic programs. She currently resides as the board president.

### **MATTHEW SCHWAB**

Matthew Schwab is a 23 year-old North Carolina native, who has Down syndrome. He graduated from high school in June 2017, and in May 2019 completed an internship-based educational program, at Wake Technical Community College.

In addition to his very own public speaking business *MatthewSchwabSpeaks*, Matthew has held several jobs, including AMC Theaters and Chick-Fil-A. He currently works at *321 Coffee*, NC GOP and Fuquay Revolution Volleyball.

Matthew was a paid intern in the NC State legislature in 2018 and is now satisfying his political interest by serving as a co-deputy campaign manager. In December 2019, he gave a TEDx talk about the importance of employing those with IDD. Matthew volunteers on the Advisory Council at *321 Coffee* and with *GiGi's Playhouse*, a Down Syndrome Achievement Center, as an ambassador and on their Youth Advisory Board.

Matthew is passionate about raising awareness about Down syndrome, and the entire IDD community. He enjoys speaking to groups, large and small, about a variety of topics.

### **MICHELLE SCHWAB**

Michelle is a wife and mother of three boys. She has a BSW and worked as a social worker before going back to graduate school to earn a Masters of Education in early childhood. She taught 2nd grade in a low-income, multicultural elementary school before having children.

Michelle has been involved with the special needs community since Matthew was born. She helped found the Triangle Down Syndrome Network 20+ years ago and served in a variety of roles over the years. Michelle was part of the start-up team for GiGi's Playhouse Raleigh and currently serves on the board.