Advancing the Development of Pediatric Therapeutics (ADEPT 6)

Pediatric Clinical Trial Endpoints for Rare Diseases

with a Focus on Patient Perspectives

November 12, 2019

Patient Advocate Biographies

**Alphabetically ordered by last name*

Audrey Beebe

Audrey Beebe is a sixteen year old from Olathe Kansas and is a junior. She participates in her school choir and her hobbies include cross stitching and diamond painting. Audrey was diagnosed with scoliosis, atrial septal defect, and craniosyntosis.

Regina Bustillos

My name is Regina Bustillos, I am 13 years old, I live in Spring, TX and I am currently an 8th grader. I was born with the most severe type of Spina Bifida which is called Myelomeningocele. I also live with other conditions associated with Spina Bifida such as Hydrocephalus and Scoliosis, among others. I am an iCAN youth member from the Houston Chapter and a member of the Schindewolf Intermediate Chapter of the National Junior Honor Society. I am bilingual, I play the cello and I absolutely love Broadway Musicals.

Anisa Derr

Anisa Derr is a 22 year old rare disease advocate who currently lives outside of Washington DC. Diagnosed with Mitochondrial Disease as a teenager she works as an ambassador for the United Mitochondrial Disease Foundation (UMDF) providing patient support, working on advocacy efforts and spreading awareness. In her free time, she enjoys going to concerts and spending time with her ironically named dog Frosty who really dislikes the snow.

Scott Espich

Scott is a Research Fellow working at the FDA Center for Biologics Evaluation and Research. After being diagnosed with a Mitochondrial Disease in high school, Scott graduated with Honors from DePauw University (2017), where he received his bachelor's degree in Cellular and Molecular Biology, and Yale University (2019), where he received a master's degree in

Microbial Disease Epidemiology and Statistical Modeling. After completing his fellowship at the FDA, Scott plans to pursue a PhD in Molecular Biology, with the goal of improving rare disease diagnostics and treatments.

Ananya Ganesh

Ananya Ganesh is a senior at The Westminster Schools in Atlanta. She is passionate about improving health outcomes and has been involved in independent research for the past 4 years. She has won several research awards for her work on early onset scoliosis. A firm believer of education as a pathway to empowerment, three years ago Ananya launched an initiative called Girls Maker Initiative to bring innovation and creativity through hands-on STEM projects to girls in rural areas. As a member of iCAN, Ananya has been sharing her experience of living with adrenal insufficiency and why empowerment matters. Along with her teammates, she presented research on patient and caregiver perception relating to barriers to academic performance at the 2019 iCAN Advocacy & Research Summit. Ananya's goal is to increase awareness about chronic illnesses and inspire other kids like herself that their voices matter.

Logan Hood

My name is Logan Hood. I am 11 years old and in the 5th grade at Blattman Elementary in San Antonio, Texas. I am a member of my school's Chess Club, and have been titled "Best of the Best" for the last two years in a row out of my entire school in chess. I am also a member of my school's Running Club and a member of the Student Council. I love to play flag football, basketball, and baseball. Other hobbies I enjoy are fishing, hunting, and video gaming.

Olivia Ohmer

My name is Olivia Ohmer. I am 16 years old and live in Pinckney, Michigan. I am in 11th grade and have been part of KIDS Michigan at C.S. Mott Children's Hospital since 2015. I live with multiple autoimmune conditions including Type 1 Diabetes, Hashimoto's Thyroid Disease, and a rare disorder called Chronic Solar Urticaria (an allergy to the sun). I am a youth ambassador for the American Diabetes Association, President of Key Club, member of Student Government and Treasurer of the 2021 Class Council. In my free time, I play competitive golf and am ranked 21st in the state of Michigan.

Rhiannon Perry

My name is Rhiannon Perry. I live in Manassas VA. I'm 16 and I am currently in my junior year of high school. I'm a part of the International Heritage Society, SCA, Girls Who Code, and Science Honor Society. I was diagnosed with sickle cell at birth and lupus at the age of 5. I

developed a vascular necrosis in most of my joints because of the two contrasting diseases. In 2016, I had a haploidentical transplant to cure both the sickle and lupus and now at this time both diseases are cured.

Brianna Worden

Brianna Worden - Former Miss Teen NY International, is a 22 year old who graduated top 10% of her class from Boston University while battling Neurofibromatosis type one. She was diagnosed at 2 months young and is the only one in her family to have NF. She has a plexiform fibroma that encompasses her entire left side. Brianna has endured over 10 surgeries, including three spinal fusions, a wrist stabilization, and three tumor debulkings to her left arm where, each time, three pounds of tumor was removed. She was diagnosed the first time with a Malignant neurosarcoma (MPNST) when she was a freshman in high school. The cancer returned two more times after that. When she had one of the cancerous tumors removed from her throat, her vocal cord was paralyzed for six months. As of now she no longer has a malignant neurosarcoma. Brianna is on a clinical trial in hopes to shrink some of her plexiform. She is excited to announce that she is the 2020 Children's Tumor Foundation's National Ambassador. As the ambassador she will represent CTF and NF awareness and the need to find a cure.
