

Khrystal K. Davis
Rare Disease Parent, Caregiver, & Patient Advocate
Founding President, Texas Rare Alliance

Organizations

3/2020-present Founding President, Texas Rare Alliance

Professional Preparation

<i>University</i>	<i>Location</i>	<i>Major</i>	<i>Degree & Year</i>
Stetson University College of Law	Gulfport, Florida	Juris Doctor	<i>J.D., 2000</i>
Southern Illinois University	Carbondale, Illinois	B.A. in Legal Studies	<i>1997</i>

Appointments

09/2019 – present **Member, Texas Newborn Screening Advisory Committee**

Certifications

Design and Interpretation of Clinical Trials. Awarded October 30, 2016 by Johns Hopkins University through the Coursera Program by Janet Holbrook, PhD, MPH & Lea T. Drye, PhD.

Drug discovery. Awarded January 31, 2019 by University of California San Diego through the Coursera Program by William S. Ettouati, Pharm.D, & Joseph D. Ma, Pharm.D.

Synergistic Activities

- **Rare Disease Parent & Caregiver:** Mother and caregiver to eight-year-old son, Hunter, with Spinal Muscular Atrophy Type 1 (diagnosed September 30, 2011).
- **Early Approval Activities at FDA:** Advocacy efforts at a May 4, 2016 meeting led to an interim look at trial data, the halt of a placebo cohort, EAP for SMA Type 1 patients, early approval (fastest FDA approval to date), and broad label for pediatric and adult SMA patients.
- **2017 Legislative Advocacy in Texas:** Helped secure legislation providing a more standardized process for physician exception requests to step therapy protocols.
- **2019 Legislative Advocacy in Texas:** Testified to help secure funding for the Texas newborn screening program & establish a newborn screening preservation account. Testified for the reauthorization of the Cancer Prevention and Research Institute of Texas (CPRIT).
- **2019 Legislative Advocacy-Federal:** Advocated for the Newborn Screening Saves Lives Reauthorization Act and against external pricing controls for rare disease therapies.
- **Conferences & Workshops:** Frequent session presenter and panelist member at conferences and workshops to improve access to the diagnosis and treatment for rare disease patients.
- **Social Media Education and Advocacy:** Maintain Twitter, Face Book, LinkedIn, Instagram, and YouTube accounts to provide rare disease education and advocacy with channel (33,400 followers).

Awards

2020 Texas Health and Biosciences Institute Luminary Award Recipient.