Khrystal K. Davis
Rare Disease Parent, Caregiver, & Patient Advocate
Founding President, Texas Rare Alliance
Phone: [redacted] Email: [redacted]

Organizations

3/2020-present Founding President, Texas Rare Alliance

Professional Preparation

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

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

- **2022 Invited Participant at the US House Ways and Means Healthy Future Task Force Drug Pricing Roundtable**
- **2022 Invited BIO Panelist: Fireside Chat on Accelerated Approval Pathway Treatments**
- **2021 Invited Witness at the US House of Representatives Energy and Commerce Hearing: Negotiating a Better Deal: Legislation to Lower the Cost of Prescription Drugs (May 4, 2021)**
- **2021 Testimony in Texas House Insurance Committee for Copay Accumulator Reform**
- **2020 BIO Panelist: Alternatives to Quality Adjusted Life Year Metrics**
- **2019 BIO Panelist: Finding the Nexus between Patient and Payer Needs in Rare Disease**
- **2019 Global Genes Patient Advocacy Summit Speaker: The Value of Rare Disease Therapies: Patient Perspectives Needed**
- **2019 Testimony in Texas House Public Health Committee and Senate Health and Human Services Committee for the Creation of the Newborn Screening Preservation Account**
- **2019 Testimony in Texas House Appropriations Committee and Senate Finance Committee for Newborn Screening Appropriations**
- **2019 THBI Presenter THBI Texas Capitol Briefing on Gene Therapies and Gene Replacement Therapies**
- **2019 Commented at the Institute for Clinical and Economic Review (ICER) Review of Spinal Muscular Atrophy Treatments**
- **Rare Disease Parent & Caregiver:** Mother and caregiver to ten-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.

Memberships

- **Member, Texas Newborn Screening Advisory Committee**
- **Chair, Rare Disease Subcommittee to Texas Newborn Screening Advisory Committee**
- **Co-Chair, Rare Disease ICD-10 Code workgroup**
- **Member, Institute for Gene Therapy (IGT) Patient Advocacy Advisory Council**
- **Member, Rare Disease Institute at NIH workgroup**
- **Chair, Texas Alliance for Regenerative Medicine (ARM) State Rare Disease Education Initiative (STRiDE) Rare Disease Education Forum (2020-2021)**

Awards & Nominations

2023 EveryLife Foundation Rare Voice Nomination (Texas Rare Alliance)
2021 Rare Access Action Project Rare Disease Access Leadership Award
2020 Texas Health and Biosciences Institute Luminary Award Recipient