

## **Vision Statement for 2020 AUCD Board Nominees**

Name of Candidate: Susan Fernbach

AUCD Member Organization: Baylor College of Medicine IDDRC

Current Position (role and date range): Director, Community Engagement and Diversity (2006-present)

Total Years Employed/Active in an AUCD Member Center or Program: 25 years

### **My vision for the Association:**

My vision for the AUCD is for area of the mission to work collaboratively to improve the lives of children and adults with disabilities including those with genetic disorders, many of whom have neurogenetic conditions. In Texas, as most of the U.S., there are tremendous needs and efforts to improve access to healthcare, education, digital infrastructure in addition to safe care for individuals in foster care, group homes or institutions. Having seen the disparities in genetic healthcare and access from the border regions to rural and urban areas, I look forward to including my genetic lens to the distinct areas of AUCD's outreach.

### **What I would like to accomplish on the Board:**

My career has been spent forging connections with healthcare, advocacy and educational organizations and if elected to the AUCD Board, I will include the voice of individuals with disabilities and genetic syndromes who additionally may have complex intersections of disability, gender, race, culture, religion that impact their healthcare. I will work to demystify genetic and genomic information and ensure it is more accessible for members of the AUCD. I would like to be a part of the AUCD umbrella working to keep the IDDRC's, UCEDD's and LEND's working collaboratively to maximal effectiveness.

### **How I have demonstrated and continue to demonstrate leadership in the network:**

As the Director of Community Engagement and Diversity at Baylor College of Medicine, I have had the opportunity to work with communities across the state and provide educational outreach programs for families, healthcare providers, early childhood intervention specialists, as well as undergraduate students. As a few examples, I approached one of the two Texas UCEDD's to discuss a collaboration and reach out to underserved communities in our state. We have subsequently developed a highly successful partnership and held multiple parent conferences presenting current genetic care information along with person-centered practice. In addition, we have collaborated on a successful inter-professional webinar that has served to highlight current best

medical care for people with genetic disorders and the distinction of what is important *for* the health of an individual as well as what is important *to* the individual with a genetic condition. With my participation on the AUCD Rural Access committee, I have learned about communities across the U.S., with many shared needs as well as innovative solutions.

By forging collaborations with community leaders in my home city as well as those across the state, we have had honest discussions about the specific needs and strengths within their community and subsequently have planned conferences specifically for each community. This has given me insight into the unmet and complex of our most vulnerable members in society as well as how to assess those needs and work with parent and community leaders to create meaningful outreach. Each of these collaborations has magnified the efforts of all involved.