

## **Adult Leadership Advisory Board**

The Adult Leadership Advisory Board (ALAB) commenced in 2018 as a board of adults living with cystinosis sharing a common goal of educating, informing and inspiring the entire community through shared stories and knowledge. Our mission is simple, to teach what we know. The main focus of the board is on tackling the issues and challenges that the cystinosis community faces through development of programming and services to support the cystinosis community and their families. ALAB works to prepare initiatives that bring awareness of the disease to the public. The board is funded and largely supported by the Cystinosis Research Network.

ALAB's intention is to nurture other young patients who have cystinosis, have a positive impact and provide guidance along the disease process with hints, tips, and companionship to reduce isolation. ALAB's mission is "to share our stories and strength to educate, motivate and empower the entire cystinosis community"; The ALAB philosophy is that those who have lived it, can teach it.

Recipients of ALAB content can strengthen their knowledge of cystinosis (including treatment options and adherence); impact other aspects of their lives such as work, employment, and relationships; navigate the healthcare system; and build problem-solving skills. While the lifespan with cystinosis has expanded due to treatment innovations, patients must continually refresh their knowledge and make active decisions regarding their health and healthcare. They must remain advocates for research, treatment, and improvements in quality of life. In the long term, ALAB aims to help improve the health and mental health of adults with cystinosis, empowering them within their own lives and healthcare systems, and within the broader community.

### **ALAB Programs:**

Podcast: Cystinosis "A Journey into the Unknown"

Social Media channels

Cystinosis Memorial Fund

### **ALAB Members**

Chairperson: Jana Healy

Co-chair: Steve Schleuder

ALAB CRN representative: Sara Healy

Secretary: Christina Morris

Katie Morrison

Briana Dundon

Brian Ensor

To find out more information on ALAB, visit the Adult Leadership Advisory Board Facebook page, Cystinosis.org, or contact Jana Healy via email at [alab47213@gmail.com](mailto:alab47213@gmail.com) or telephone: 701-570-5097.