



ARPKD/CHF ALLIANCE - QUICK FACTS

MISSION:

Educate, advocate, support and advance research specific to Autosomal Recessive Polycystic Kidney Disease (ARPKD) and Congenital Hepatic Fibrosis (CHF).

The ARPKD/CHF Alliance is the only organization worldwide solely dedicated to ARPKD and CHF.

HISTORY:

The ARPKD/CHF Alliance has created fantastic 8 year results. As an international nonprofit, public charity, guided by a Professional Scientific Board, we focus on research, education, support, and advocacy for our affected members.

GOALS:

- **Galvanize medical research to better understand the disease process and improve medical care.**
- **Educate and support patients, physicians and the medical community.**

EIGHT YEARS OF ACCOMPLISHMENTS:

- **Created a voice for this disease by advocating and developing professional collaborations.**
- **Generated interest and partner for the landmark study “Clinical Investigations into ARPKD and CHF”, through the National Institutes of Health (NIH).**
- **Developed a Research Grant Program.**
- **Co-sponsored the First Ever Medical Workshop on ARPKD/CHF.**
- **Promoted inclusion of CHF into NIH’s “Action Plan for Liver Disease.**
- **Created clearinghouse information at www.arpkdCHF.org.**
- **Developed an Awareness Program and Public Service Announcements at YouTube—“Faces of ARPKD/CHF”**
- **Created “Regional Support”, “Clinical Care Considerations,” and “Access To Care” documents.**

**Donations are used towards research, education and advocacy.
Membership and programs are free to those affected.**