ARPKD/CHF ALLIANCE
improving the lives of those affected

Autosomal Recessive Polycystic Kidney Disease (ARPKD) and Congenital Hepatic Fibrosis (CHF)

Autosomal Recessive Polycystic Kidney Disease (ARPKD) is a chronic, progressive disorder that causes eventual kidney failure. ARPKD is commonly diagnosed early in life; up to 40% are diagnosed prenatally, up to 50% die at birth. Early newborn death is most often not from kidney failure, but from pulmonary hypoplasia (underdeveloped lungs). All patients with ARPKD have Congenital Hepatic Fibrosis (CHF). CHF has the potential to cause severe, life-threatening clinical liver complications.

There is no cure or treatments, yet if the newborn period is survived, then the chances of survival increase to good. There is potential for an excellent quality of life with medical management.

The ARPKD/CHF Alliance is a nonprofit, public charity, and the only organization solely dedicated to ARPKD/CHF.

HISTORY: Focus is on research, education and advocacy.

- Generated interest and partner for the largest study to date: "Clinical Investigations into ARPKD and CHF", through the National Institutes of Health (NIH).
- Fund Research.
- Co-sponsored the First Medical Workshop on ARPKD/CHF.
- Held First Patient Conference.
- Promoted inclusion of CHF into NIH's "Action Plan for Liver Disease.
- Developed an Awareness Program and Public Service Announcements at YouTube—"Faces of ARPKD/CHF."
- Created clearinghouse information at www.arpkdchf.org and A Voice for this disease.
- Developed "Regional Support", "Clinical Care Considerations," and "Access To Care" documents.

GOALS:

- Galvanize medical research to better understand the disease and improve medical care.
- Educate and support patients, physicians and the medical community.
- Advocate on behalf of patient needs.

Donations are used to fund research, education and advocacy. All donations are tax-deductible. Membership and programs are free to those affected.

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