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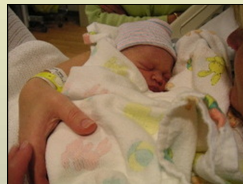


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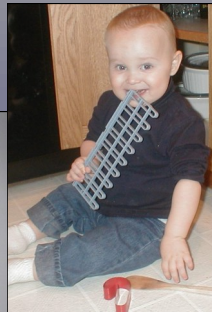
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**Research.
Education.
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specifically for
ARPKD/CHF

Learn more at
www.arpkdCHF.org



from the **ARPKD/CHF Alliance**

What you should know about ARPKD and CHF...



What is ARPKD/CHF?

Autosomal Recessive Polycystic Kidney Disease (ARPKD) and Congenital Hepatic Fibrosis (CHF) are genetic diseases that occur together and affect approximately 1:20,000 persons in the general population.

Commonly diagnosed prenatally, it results in high infant mortality. If the newborn period is survived, chances of survival increase significantly, however this is a chronic, progressive disorder, with a spectrum of clinical manifestations, from difficult to manage hypertension and failure to thrive, to life-threatening GI bleeds and organ failure.

Primarily two organs are involved, always both kidneys and the liver. Only symptomatic therapy is available at present (based on other diseases), no specific treatments are available and many unanswered questions remain.



Shelby with ARPKD/CHF to left, and front cover at 4 years of age. Other child unaffected.

Not long ago, many medical professionals considered this a dismal, hopeless condition. The outlook is slowly changing, as more affected individuals survive and thrive into adulthood, due to enhanced general medicine. With good managed care, there is potential for an excellent quality of life. Now there is hope and anticipation for treatments and improved healthcare.



ARPKD/CHF child and researchers during the NIH research study "Clinical Investigations into ARPKD/CHF", the largest research study to date, which the ARPKD/CHF Alliance generated interest for.

ARPKD/CHF Alliance

The ARPKD/CHF Alliance was created with the purpose of *improving the lives of those affected*. Our mission is to *educate, advocate, support, and advance research*.

We began in 1993 by supporting families and broadened our outreach with an international ARPKD/CHF Newsletter. Wanting a more focused and comprehensive approach to ARPKD that included CHF, the ARPKD/CHF Alliance was incorporated in 2001 and is a 501(c)(3) public charity.

We are the only organization solely committed to this disease, managed by a Board of Directors and guided by a Professional Advisory Board. As a patient advocacy organization all our goals focus on patient needs. Founding board members had a clear vision more could be done for this two organ disease. Our success is not based on luck, but constant toil, intensive efforts, and faith in goals initially only imagined and hoped for. We have been powerful advocates for the patient community; and inspired others to follow our lead as we continuously increase the voice for this disease.

Our code of conduct standards and ethics are based on honesty, integrity, respect, responsibility and accountability in nonprofit operations, governance, financial management and fundraising. They go beyond minimum legal requirements. All volunteers and board members are required to sign a Confidentiality and Code of Conduct Agreement.



Supporters of Ezra's Event, an annual walk that benefits ARPKD/CHF. Specialized event kits are available through the ARPKD/CHF Alliance. Call for more information.

Read more at www.arpkdchf.org