Welcome to PKDF!

Information for PKD Foundation Volunteers

PKD FOUNDATION
Polycystic Kidney Disease

About PKD Foundation

PKD Foundation

We are the only organization in the U.S. solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD). We fund research, education, advocacy, support, and awareness on a national and local level.

PKD Foundation is the largest private funder of PKD research.

We are on a mission to end PKD

PKD FOUNDATION
Polycystic Kidney Disease

OUR VISION

#endPKD

OUR MISSION

WE GIVE HOPE. We fund research, advocate for patients, and build a community for all impacted by PKD.

How we got started…

https://pkdcure.org/who-we-are/jared-grantham/

https://pkdcure.org/who-we-are/

About PKD

About polycystic kidney disease

- Polycystic kidney disease (PKD) is a chronic, genetic disease, causing uncontrolled growth of fluid-filled cysts in the kidneys. As the cysts accumulate more fluid, they get bigger and bigger, destroying healthy tissue, which leads to high blood pressure, other complications, and often kidney failure.
- A typical kidney is the size of a human fist and weighs about a third of a pound. Polycystic kidneys can be much larger, some growing as large as a football. Kidneys can develop cysts ranging in size from as small as a pinhead to as large as a grapefruit.
- There is no cure for PKD.

What is ADPKD?

Autosomal dominant polycystic kidney disease (ADPKD)

- PKD is the fourth leading cause of kidney failure.
- Dialysis or transplant are the only options to treat end stage kidney failure.
- Approximately 10% of people diagnosed with ADPKD have no family history and have spontaneous (new) mutations.
- Affected parents have a 50% chance of passing ADPKD to their children.

What is ADPKD?

ADPKD Prevalence

ADPKD is the more common type of PKD and occurs in 1 in 500 to 1 in 2000 live births and is **estimated** to affect more than 600,000 Americans and 12.4 million people worldwide.

The number of patients currently **diagnosed** in the U.S. is 140,000 giving ADPKD orphan drug status for emerging therapies.

Symptoms of ADPKD

- High blood pressure
- Kidney pain
- Blood in the urine,
- Urinary tract infections (UTI)
- Kidney stones

What are the symptoms of ADPKD?

There is Hope!

- There is currently one treatment for ADPKD in the U.S.
- The first treatment for adult patients with ADPKD was approved by the FDA in 2018.
- Ongoing clinical trials!

Learn more about tolvaptan

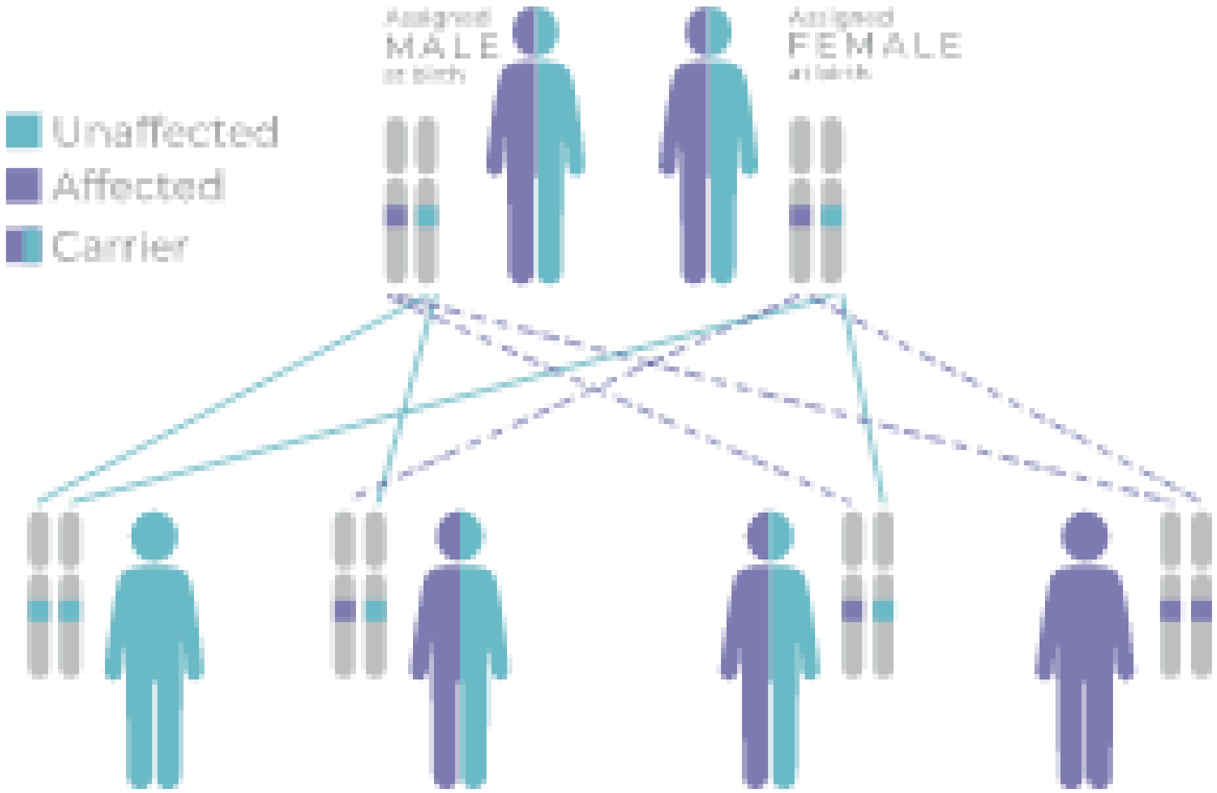
Learn more about clinical studies

Learn more about research pipeline

What is ARPKD?

Autosomal recessive polycystic kidney disease (ARPKD)

- In recessive disorders such as ARPKD, the child must inherit a copy of the gene from each parent.
- The parents only have one copy of the gene. They do not have ARPKD and are referred to as "carriers".
- There is a 25% chance that children of parents carrying the mutated gene will have ARPKD and a 50% change children will not have ARPKD but will be a carrier.



What is ARPKD?

More about ARPKD

ARPKD can cause death in the first month of life. However, almost 80% of ARPKD children now survive the newborn period.

Previously thought to be a fatal condition, the prognosis for children with ARPKD has improved dramatically.

Approximately 1/3 of children with ARPKD who survive the newborn period, will need dialysis or transplantation by age 10.

All children with ARPKD also have the liver abnormality called congenital hepatic fibrosis (CHF) that may lead to enlargement of the liver and spleen.

ARPKD Prevalence

- ARPKD is a rare form of PKD that occurs in 1 in 25,000 children worldwide.

Symptoms of ARPKD

Supporting the PKD Community

No one faces PKD alone

PKDCONNECT

Get Connected

PKD Connect Peer Mentor Program

Hope Line

Local communities

Voices of PKD

Community and Support

PKD in Children

PKD Parents Community

The PKD Parents Community has been serving parents of children with ARPKD and ADPKD since 2000.

pkdcure.org/pkdparents

pkdparents@pkdcure.org

ADPKD Registry

ADPKD Registry is a collection of individuals with autosomal dominant polycystic kidney disease (ADPKD). Research needs information. Joining the Registry gives patients the power to drive the next medical breakthrough.

ADPKD REGISTRY
Powering a Cure

https://connect.pkdcure.org/adpkd-registry/

More resources…

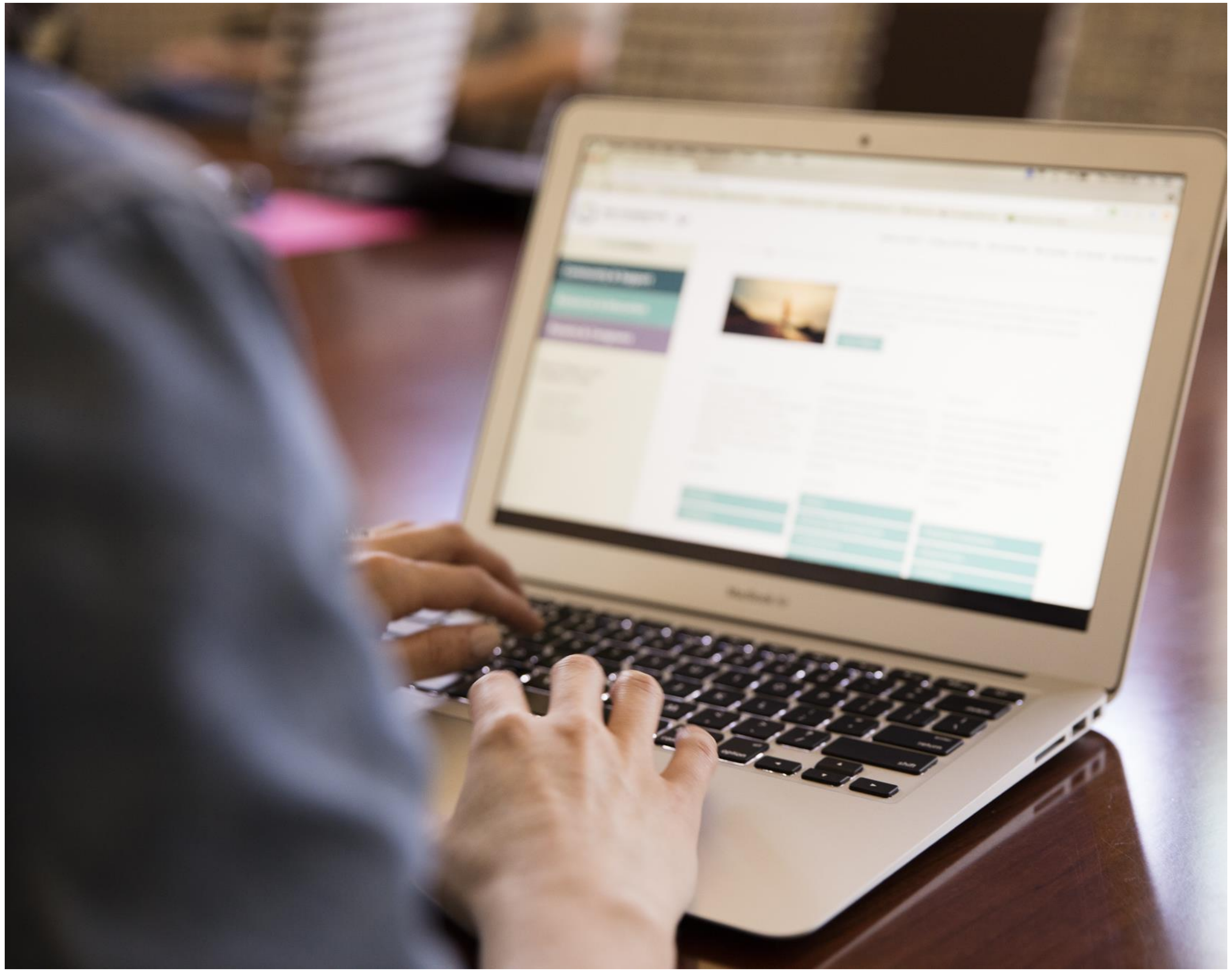
Find PKD Resources

We are committed to providing patients with the education they need. These resources will answer some of your most specific questions about the disease.

Resource Guide

Resource for PKDF volunteers!

This guide will help PKDF volunteers find resources to share with mentees, during community meetings, etc.



Thank you!

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