



# Building a PKD-Free Future

January 2024

# How It Started

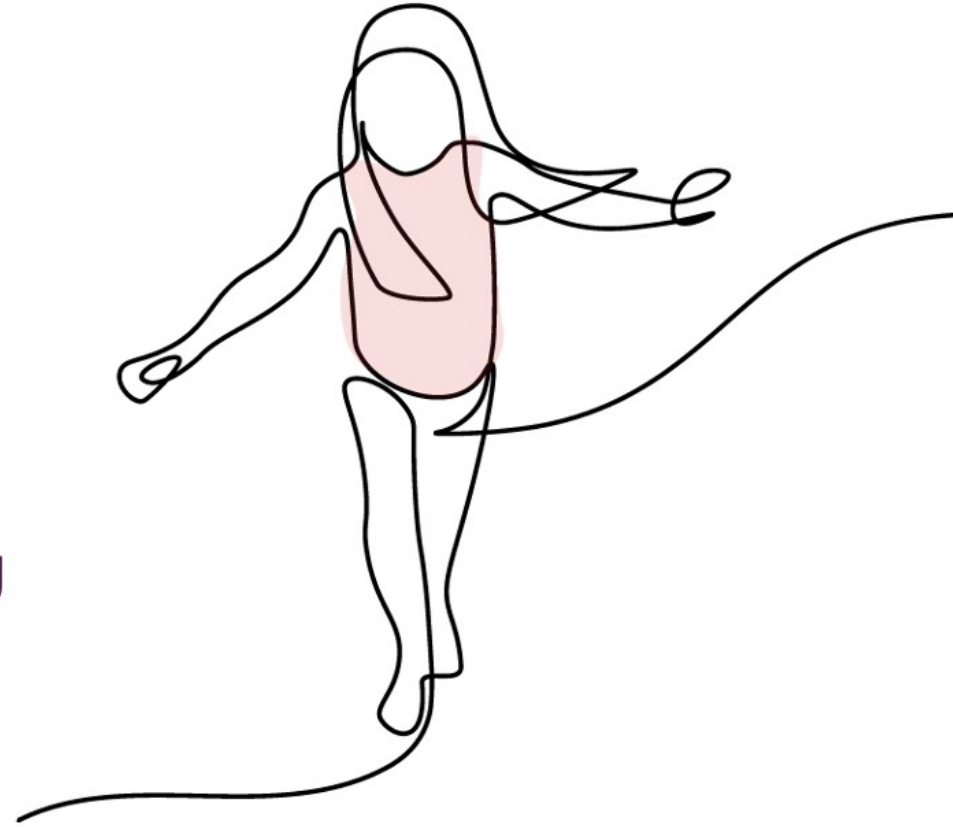
## **Richard Kellner**

Founder of pkDO, with his late wife Joanne and their kids (1998).



# PKD Suffering by the Numbers

- PKD affects 600,000 people in the U.S.
- PKD results in ~4000 kidney failures per year.
- Five to seven year waiting list for a deceased kidney donor.
- A parent with ADPKD has a 50% chance of passing it down to their child.
- Each year ~7500 babies are born with PKD.



# The PKD Myth

There is nothing you can do about PKD but wait for kidney failure.



# The PKD Reality

Solutions exist TODAY to:

- Increase Live Kidney Donation
- Slow the Progression of PKD in Young Adults
- Prevent PKD from Being Passed Down to Future Generations

## Why pkDO?

pkDO is collaborating with the PKD Foundation to actively get these solutions out of the medical journals and make them accessible to PKD-impacted families.



# PKD-Free Babies Initiative



**100 PKD-Free  
Babies**

Today we will focus on our PKD Free Babies Initiative.

The safe and effective IVF/PGT technology for PKD-free births has existed for 25+ years.

Our 100 PKD-Free Babies initiative is providing the funding and support to bring about a new generation of PKD-free children.

# Initial PGT Grant Program

Up to \$3,000 to cover the cost of PGT.

## Eligibility Requirements =

- First 100 participants in US or Canada with ARPKD or ADPKD.
- Direct funding to genetics lab at time of PGT Embryo Testing.



# Expanded IVF/PGT Grant Program

Up to \$9,000 Grant to cover the cost of IVF & PGT. Additional discounts from partner IVF providers may be available to reduce out-of-pocket costs for one round of IVF/PGT from ~\$30k to ~\$15k.

## Eligibility Requirements =

- US residents with ADPKD or ARPDK
- Health insurance does not cover IVF
- Annual HHI less than \$250,000
- Couple with high probability of healthy pregnancy with one round of IVF

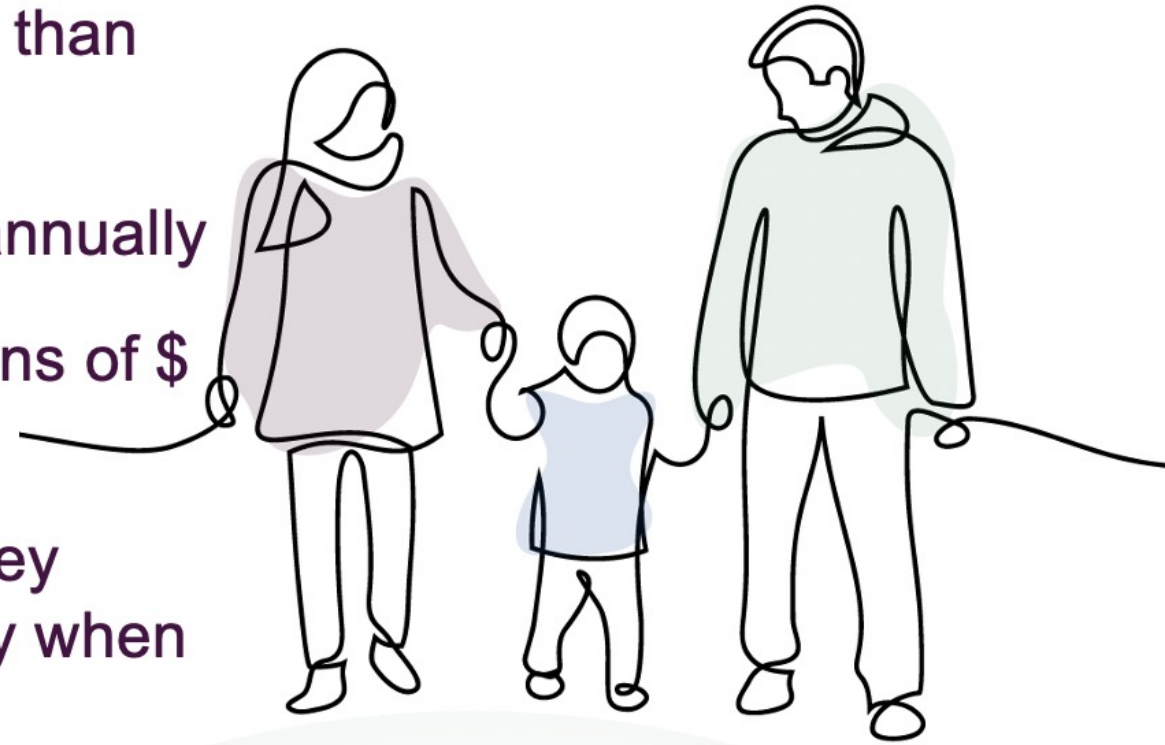




# Impact of Ending PKD

Putting an END to PKD will benefit much more than families with PKD. When we achieve our goal:

- Kidney failures WILL be reduced by ~4,000 annually
- The healthcare system WILL have multi-billions of \$ annual savings
- Years WILL be shaved off the deceased kidney donor waitlist for all others in need, especially when combined with our live donor initiative.
- There WILL be a replicable, scalable model for reducing other genetic diseases.



# 100 PKD-Free Babies – Results to Date

**7**

and growing

Medical Center  
Partnerships

**12**

and growing

PKD-Free Babies  
“on the way”

**50+**

and growing

Families Seeking  
Our Assistance

# 100 PKD-Free Babies – Results to Date

4

PKD-Free  
Babies



**Juliana Charlotte**

Born December 8, 2023

IG:pkdendswithme

The technology to END PKD is here; now it's for our PKD Community to unite and conquer it.



*"It always seems impossible until it's done"*

Nelson Mandela



# Connect



**Instagram**  
pkd\_outreach

**[www.pkdo.org/babies](http://www.pkdo.org/babies)**

# Contact



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