



# PATIENT GROUP: PKD FOUNDATION

**Julia Roberts, Volunteer Board Of Trustees Member &  
PKD Parents Chapter Co-Coordinator**



**PKD FOUNDATION**  
Polycystic Kidney Disease

# Disclosure of Interests

No Relevant Financial Disclosures...

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# Why Am I Here?

Their bodies held a secret.



# Experience

- Mom to two kids (teenagers!) with ARPKD, kidney transplanted at age eight
- Volunteer with the PKD Foundation for 14 years
- PKD Foundation Board of Trustees Member for nine years





# Mission/Vision



**PKD FOUNDATION**  
Polycystic Kidney Disease

**“Our vision is that one day no one will suffer the full effects of PKD.”**

They are dedicated to finding treatments and a cure for PKD through promoting research, education, advocacy, support and awareness.



# History



**PKD FOUNDATION**  
Polycystic Kidney Disease

## Milestones

### 1982-Present

- 1982: PKD Foundation founded by Jared Grantham, M.D. & Joseph Bruening
- 1984: First \$25,000 grant awarded to William Bennett, M.D.
- 1994: Discovery of PKD1 gene, 1995: discovery of PKD2 gene, 2002: Discovery of the ARPKD gene
- 2005-2010: Clinical Trials, Government Workshops, Accelerating Treatments to Patients (ATP) initiative launched
- 2012: Drug Tolvaptan is accepted for priority review by U.S. Government
- 2014: Fifteen research grants awarded
- 2015: Fellowship funding



# Challenges

- Shifting Mission
- Volunteer acquisition and retention
- Serving patients with varying degrees of disease onset and severity
- Patient priorities and desires for organization are varied
- Financial crisis in U.S. in 2008, less research dollars
- Changes in leadership and staff
- Patients reluctant to share their diagnosis
- Growth rate of Foundation; either too fast, too slow



# Successes

- Refocused Mission
- Empowered, dedicated staff
- Engaged Board of Trustees
- Engaged physicians, researchers
- Tangible support for volunteers
- Building alliances with other organizations
- Gratitude and recognition for volunteers
- Stability > Funds > Research/Fellowship funds





# Today



**PKD FOUNDATION**  
Polycystic Kidney Disease

- Over 60 volunteer-led Chapters across the country in 40 states
- Nine Webinars last year with 1200 attendees
- Over 200 educational/support meetings on the local level annually
- More than 85,000 people subscribed to receive emails from the Foundation
- Over 30,000 gifts from all over the US and 25 other countries
- Over 50 Walk for PKD events raising over two million dollars



*KDIGO Controversies Conference on Common Elements in Uncommon Kidney Diseases*  
June 16 - 19, 2016 | Amsterdam, Netherlands

# What can you do?



# The Mission.

- Mission Statement usually involves people
- Be clear, concise
- Revisit often to confirm direction

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# What Do People Want?

What motivates people to get involved?

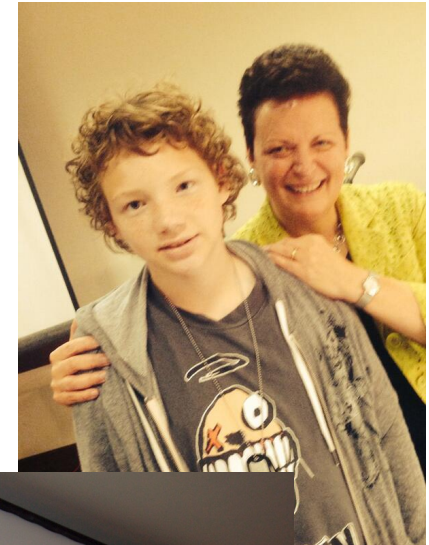
- *“What can I learn?”*
- *“What can I do?”*
- *“How can I help?”*
- *“What does the future hold for me?”*
- *“What does the future hold for my loved one?”*
- *“Am I the only one?”*
- Connection





# We want connection to...

- People like ourselves
- Support
- Latest information
- Access to specialists
- Something positive



# Why do people stay involved?

- Connection to others
- Knowledge of disease
- Gratefulness for the work the organization does
- An opportunity to make a difference, to change the outcome for ourselves or others
- Personal growth



# How to grow?

## Volunteers, Staff, Alliances



Obtain



Retain



Grow



# Mission towards progress.



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# Questions or Comments?

