PATIENT GROUP: PKD FOUNDATION

Julia Roberts, Volunteer Board Of Trustees Member & PKD Parents Chapter Co-Co-ordinator
Disclosure of Interests

No Relevant Financial Disclosures...
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

“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

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

• 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
What can you do?
The Mission.

• Mission Statement usually involves people
• Be clear, concise
• Revisit often to confirm direction
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.
Questions or Comments?