



PKD FOUNDATION
Polycystic Kidney Disease

Annual Report

Together, we made significant strides toward finding treatments and improving the lives of those impacted by PKD.

THANK YOU

FOR AN INCREDIBLE YEAR!

Your generous donations and volunteerism make our work possible. Read on to learn more about the impact you made during fiscal year 2017 (FY17).

OUR MISSION

We give hope. We fund researchers, support patients and build a community for all affected by polycystic kidney disease (PKD).





RESEARCH

Since our founding in 1982, we have invested more than \$42 million in research, clinical and scientific grants, as well as fellowships and scientific meetings on an international scale. This makes us the largest private funder of PKD research in the United States.

Research Funding

Our Research Grant Program funds critical research to increase understanding of the genetic and pathological processes involved in PKD and to accelerate the development of potential treatments. PKD Foundation Fellowships build momentum in PKD research by recognizing early-career scientists whose achievements and potential identify them as rising stars in the field. In FY17, you helped us continue to fund 15 grant recipients and finish funding five research fellows.

Scientific Meetings

Collaboration among PKD researchers is imperative to make advancements in research. In FY17, we sponsored and attended 5 scientific meetings that brought PKD experts together.

CTAP

CLINICAL TRIAL AWARENESS PROGRAM

Clinical studies are a critical and required step to develop new therapies. Our Clinical Trial Awareness Program (CTAP) creates awareness among patients and families to speed up recruitment and increase participation in clinical studies. The program focuses on educating patients about current studies so they can make informed decisions about their participation. To simplify the process of finding clinical studies for PKD patients in their geographic areas, we send Accelerating Clinical Trials (ACT) Alert emails about studies that are being conducted.

In FY17, we sent 10 ACT Alerts in the interest of getting patients involved in finding treatments. These included recruiting patients to join an ARPKD database, a PKD biomarker research study, a curcumin study in children and young adults with ADPKD, and studies surrounding three of five notable potential treatments: tasevatinib, pioglitazone and metformin.

WE FUNDED

20

PKD RESEARCHERS

THAT'S A

\$1.45M

INVESTMENT

Learn more about our fellows and grant recipients.

 pkdcure.org/fellowships
pkdcure.org/grants

Meetings we sponsored

On Cell Volume Regulation

Aug. 13, 2016 | Chicago, Ill.

Cilia 2016: From Fundamental Biology to Human Disease

Oct. 4-7, 2016 | Amsterdam

Harvard 10th Annual PKD Symposium

May 8, 2017 | Boston, Mass.

Jared J. Grantham Symposium

June 8, 2017 | Kansas City, Kan.

FASEB - Polycystic Kidney Disease: Challenges, Differing Viewpoints and Ways Forward

June 25-30, 2017 | Big Sky, Mont.

Sign up for ACT Alerts.

 pkdcure.org/email



SUPPORT

A major part of our mission is to support patients and build a community for all affected by PKD. We aim to provide all patients and caregivers with the outreach and resources they need to live with this disease and understand that they are not alone in their journey.

No one should face this disease alone.



1,790
ACTIVE VOLUNTEERS

27,520
VOLUNTEER HOURS REPORTED

AN ESTIMATED VALUE OF
\$664,332

Local Chapters

Our Chapters, and the volunteers who lead them, are the backbone of the PKD community. They are comprised of PKD patients, family members and friends who want to learn, connect and take action with other committed individuals. Chapters regularly hold events to raise awareness for PKD and offer education and support. They reinforce our belief that no one has to face this disease alone.

In FY17, Chapters collectively hosted over 100 education and support meetings for their local communities.

Learn about our Chapters.

 pkdcure.org/chapters



EDUCATION

Our education resources aim to help PKD patients fully understand their disease, live their best lives and empower them to educate others.

Webinars

Webinar Wednesdays, our monthly education webinars, highlight targeted topics in PKD science and research. From basic kidney anatomy to Q&As with Scientific Advisory Committee members, these are a go-to resource for PKD knowledge and education.

Watch the webinars from FY17 on a variety of topics.

 pkdcure.org/webinars

Online Education Conference

On March 25, 2017, PKD community members all over the country joined their local Chapters to participate in our exclusive, online education conference “What’s new in PKD: A day of learning.” The conference was organized in an effort to offer remote learning opportunities that increase accessibility to information without limiting patients’ sense of togetherness. The event featured PKD experts from Mayo Clinic in Rochester, Minn., who discussed the kidney transplantation process.

What's New in PKD: A Day of Learning

31
CHAPTERS
PARTICIPATED

28
DIFFERENT
LOCATIONS

6
KIDNEY EXPERT
SPEAKERS

Watch the presentation on our website.

 pkdcure.org/resource/whats-new-pkd-2017



Speakers Tammy Kozel, Dr. Patrick Dean, Margo Vandrovec, Erin Hamilton, Lisa King, Dr. Naim Issa and emcee Dr. Peter Harris



Phoenix Chapter members participating in online education conference



ADVOCACY

By getting involved in advocacy efforts, you can educate your elected officials about how they can help fight PKD. Constituent voices are vital to increasing PKD research dollars to bring treatments and therapies to patients, and providing the best care for those who are reliant on dialysis or a kidney transplant to stay alive. We encourage people with PKD and those that care about them to meet with their local congressional representatives because just one personal story can make a significant difference.

Advocacy Alerts

Our Advocacy Alerts empower PKD patients and members of the community to raise their voices when important legislation hangs in the balance on the Hill. Prepared call scripts and email templates make taking action quick and easy.

Just a few of the important pieces of legislation our PKD community had an impact on:

HEALTH CARE

When the new administration pushed the American Health Care Act as a repeal-and-replace option for the Affordable Care Act, PKD patients raised their voices for affordable insurance coverage for people with pre-existing conditions.

21ST CENTURY CURES

Signed into law on Dec. 13, 2016, 21st Century Cures provides \$4.8 billion in new funding to the National Institutes of Health (NIH) and assures that patient voices will be included in the drug development process for treatments and therapies.

Taking action in FY17

WE SENT

10

ADVOCACY ALERTS

653

CONSTITUENTS CALLED THEIR MEMBERS OF CONGRESS

3,584

CONSTITUENTS EMAILED THEIR MEMBERS OF CONGRESS

Learn how you can advocate and receive advocacy email alerts.

 pkdcure.org/advocate



FUNDRAISING

Chapter and individual fundraising events are critical to raising the money that allows us to continue working towards our mission. Led and organized by a wide variety of volunteers throughout the country, we could not continue to build the funds that come from these events without our PKD community.

Fundraising Events

The top five fundraisers of FY17

Memphis/Liberty Mutual Driving Home a Cure
\$118,051

Miami Kidney Casino
\$115,461

Celtic Marketing Golf Tournament
\$41,510

Sacramento Corks for a Cure
\$21,575

Ryan's Reason Putting Fore PKD
\$18,000

FY17 Fundraisers

76

TOTAL ORGANIZERS

\$304,586

TOTAL AMOUNT RAISED

Learn more about individual events.

 pkdcure.org/get-involved



Sacramento
Corks for a
Cure attendees



Walk for PKD

The Walk for PKD is our signature fundraising and public awareness event, and the largest gathering of PKD patients and supporters. Since 2000, the Walk for PKD has raised more than \$28 million. This family-oriented event creates a sense of community and provides a unique opportunity to support and honor loved ones.

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TOP 10

Walk teams

Bost Bunch

Pittsburgh
\$32,030

Ivan's Investors for a PKD Cure

Tampa
\$26,266

Team Odyssey

New York City
\$24,200

Going for Geigers

Chicago
\$21,250

Mike & Poppy's All-Stars

New York City
\$18,770

Support a Cystah

Seattle
\$18,290

Team Rechter

South Florida
\$18,083

Team Pinnacle

Nashville
\$17,610

Three Peas in a Pod

New York City
\$16,770

Team OC

Twin Cities
\$14,700

TOP 10

Walk events

Boston

\$111,168

New York City

\$110,692

North Texas

\$79,076

Nashville

\$64,877

Kansas City

\$63,585

Chicago

\$62,058

San Antonio

\$56,075

Pittsburgh

\$48,977

Tampa

\$47,180

Los Angeles

\$46,599

51

WALKS

TOTAL RAISED:

\$1,688,050

MORE THAN

10,000

PARTICIPANTS

1,569

WALK VOLUNTEERS

Learn more about Walk for PKD.

 walkforpkd.org



Las Vegas Walk for PKD participants



FINANCIALS

1 JULY 2016 – 30 JUNE 2017

Where your money went



RESEARCH
\$2,184,499



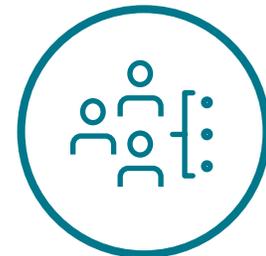
AWARENESS & ADVOCACY
\$1,354,957



DEVELOPMENT
\$763,596



EDUCATION & SUPPORT
\$1,273,991



ADMINISTRATIVE
\$971,301

Where our money came from

INDIVIDUALS
\$4,008,670

CORPORATIONS
\$1,010,153

FOUNDATIONS
\$742,292

BEQUESTS
\$130,375

TOTAL DONATIONS
\$5,891,490

Annual revenues

FY15
\$7,925,685*

FY16
\$6,680,617

FY17
\$6,424,607

Financial position

ASSETS
\$5,218,772

LIABILITIES
\$503,054

NET ASSETS
\$4,715,718

* Includes a single bequest of \$1 million