Annual report
FISCAL YEAR 2020

About PKD Foundation

The PKD Foundation is the only organization in the US solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD) and to improving the lives of those it impacts. Since 1982, we have proudly funded more than $50 million in PKD research and leveraged $1.5 billion in government funding, while serving our local communities across the country. We are inspired by our mission. And driven by our vision.

OUR MISSION
We give hope. We fund research, advocate for patients and build a community for all impacted by PKD.

OUR VISION
#endPKD

> **"We funded 19 PKD researchers. That's a $2.87 million investment in our research program this year alone."**

Research

Made up of 13 prestigious PKD physicians and scientists, the Scientific Advisory Committee (SAC) oversees our research and medical programs aimed at discovering and delivering treatments for PKD. This esteemed group meets throughout the year to discuss relevant medical issues, provide guidance to our staff and review and approve research applications for grants and fellowships in the field of PKD science.

RESEARCH FUNDING
Our Research Grant Program funds vital laboratory and clinical studies 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 identify them as rising stars in the field. Your generous contributions helped us continue to fund eight grant recipients and one new research fellow.

✳ Meet the Scientific Advisory Committee at **pkdcure.org/sac**

Support

An essential aspect of the PKD Foundation's mission is to give hope and build a community for all impacted by PKD. We aim to provide all patients and caregivers with the outreach and resources they need to manage this disease and live more fully knowing they are not alone in their journey.

57 *Chapters*

27,483 Volunteer Hours

1,871 Active Volunteers

$747,536 Estimated Value

Volunteers assist the PKD Foundation in supporting the PKD community and ensure that no one faces PKD alone. Nationally and in 57 local communities across the United States, peer mentors and volunteers — PKD patients, families, friends, and caregivers — lend a listening ear, support local PKD communities, and organize events to raise awareness and money for the PKD Foundation's essential programs and services.

✳ Get involved: Find a chapter near you at **pkdcure.org/find-a-chapter**

Advocacy

Our work to help reinstate PKD as a disease area within the Department of Defense's Peer Reviewed Medical Research Program (PMRMP) last fiscal year resulted in the awarding of over $14 million in grants focused on PKD research. DoD medical research grants have resulted in more than $34.4 million in PKD-specific research funding since 2014. This fiscal year saw continued effort to maintain listing of PKD as a disease area within the PRMRP, awaiting passage of appropriations legislation by Congress.

TAKING THE FIGHT TO CAPITOL HILL

In 2020, we continued our increased commitment to elevate both awareness of PKD and the voices of patients on Capitol Hill. Over 1,500 advocates took action, and the PKD Foundation had 28 meetings on Capitol Hill.

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.

Learn how you can advocate and receive advocacy email alerts at **pkdcure.org/advocate**

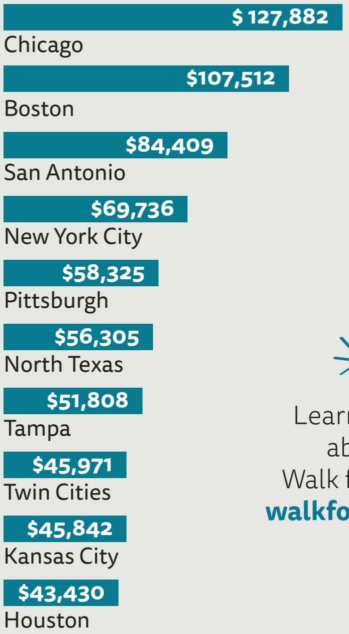
Fundraising

Thanks to the financial commitment of a special group of major donors, we are proud to announce that 100% of all community fundraising proceeds will be used to support research.

WALK FOR PKD

The nation's largest gathering of PKD patients and supporters is our signature fundraising and public awareness event, the Walk for PKD. Since 2000, the Walk has raised an inspiring $33 million, 100% of which goes to research. This family-oriented event creates a sense of community and provides a unique opportunityto support and honor loved ones.

TOP 10 WALK EVENTS



Learn more about Walk for PKD: **walkforpkd.org**

TOP 10 WALK TEAMS

① Going for Geigers
CHICAGO

② Ivan's Investors for a PKD Cure
TAMPA

③ Bost Bunch
PITTSBURGH

④ Patti's Partners to Find a Cure for PKD
SAN ANTONIO

⑤ Team OC
TWIN CITIES

⑥ Three Peas in a Pod
HUDSON VALLEY

⑦ Team Pinnacle
NASHVILLE

⑧ Sack Pack
NEBRASKA

⑨ Team Odyssey
NEW YORK CITY

⑩ Krusell, Nelson & Phyllis Gray Family
NATIONAL CAPITAL

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54 *Walks*

$1,665,253
total raised

More than
10,000
participants

1,607
Walk volunteers

TOP 5 COMMUNITY FUNDRAISING EVENTS

① **$109,352**
Waxman Annual Liberty Mutual Invitational Driving Home a Cure for PKD Golf Tournament

② **$44,601**
Celtic Marketing Golf Tournament

③ **$35,784**
Sacramento Corks for a Cure

④ **$30,000**
Angels Giving Back — Seasons Swing Charity Golf Tournament

⑤ **$27,000**
Ryan's Reason — Putting Fore PKD

FY20 Fundraisers **65 Total organizers** → Total amount raised **$449,731**

Learn more about individual events at **pkdcure.org/get-involved**

Your Impact

REVENUE SURPASSES $16.9 MILLION IN 2020

Your financial commitment makes possible the work that the PKD Foundation does to give hope, fund research, advocate for patients and build a community for all impacted by PKD. We are reliant on private donors to continue our work. As you can see, momentum is building to #endPKD.

24,123 *donations came from*

50
states + DC & USVI

18
countries

OTHER WAYS PEOPLE GAVE

- → Tribute giving
- → Planned gifts and bequests
- → Gifts of appreciated stocks or bonds
- → Workplace giving
- → Matching gifts
- → Vehicle donations
- → Giving Tuesday

Financials

1 JULY 2019 – 30 JUNE 2020

INVESTMENTS

Research	**$2,873,556**
Awareness & Advocacy	**$1,544,295**
Development	**$1,053,315**
Education & Support	**$1,135,988**
Administrative	**$835,062**

SOURCES OF FUNDING

General Contributions	**$3,681,538**
Community Fundraising	**$1,927,126**
Bequests/Legacies	**$9,643,286**
Grants & Sponsorships	**$399,107**
Gifts In-Kind	**$448,859**

ANNUAL REVENUES

$6,680,617	Fiscal Year 2016
$6,424,607	Fiscal Year 2017
$13,458,451	Fiscal Year 2018
$7,231,115	Fiscal Year 2019
$16,498,543	Fiscal Year 2020

FINANCIAL POSITION

Assets	**$20,909,832**
Liabilities	**$3,109,449**
Net Assets	**$17,800,383**

Our Impact

WHAT ARE WE AIMING TO ACCOMPLISH?

We serve the PKD community as the only organization in the US solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD) and to improving the lives of those it affects. We are inspired by the needs of patients, caregivers, treatment providers and researchers whose lives are impacted by PKD and have developed our main programs — Research, Education, and Advocacy — with them in mind.

WHAT ARE OUR GOALS?

Fund research grants supporting laboratory research aimed at increasing understanding of the genetic and pathological processes involved in PKD.

Raise awareness and further legislation, regulation, and federal funding opportunities that improve the lives of everyone in the PKD community.

Empower PKD patients and caregivers to manage PKD while maintaining a high quality of life by providing resources across the continuum of the disease progression.

WHAT ARE OUR STRATEGIES FOR ACHIEVING THOSE GOALS?

PKD Foundation uses multi-channel marketing to increase disease awareness, promote the Foundation's services, and inspire the public to support the Foundation's mission. The Foundation advocates for PKD patients in policymaking, drug development, and regulatory decision-making at the Congressional and federal level.

In September 2019, PKDF launched the ADPKD Registry; the first national direct-to-patient, longitudinal patient registry for individuals diagnosed with ADPKD. The ADPKD Registry also provides targeted clinical study recruitment for both academic and industry-sponsored studies in patients.

We invest millions in research grants and fellowships. In addition, we established the PKD Outcomes Consortium (PKDOC) in 2010. The PKDOC is a significant collaboration between the PKD Foundation, Critical Path Institute, representatives of the pharmaceutical industry, PKD clinicians, and the FDA. It was created to facilitate clinical development for PKD therapies by establishing a clear regulatory pathway for the pharmaceutical industry to evaluate the effectiveness of potential treatments.

WHAT ARE OUR CAPABILITIES?

PKD Foundation is the largest private funder of PKD research with an investment of more than $50 million since our founding in 1982.

Our volunteers reside in more than 50 locations and are directly responsible for fundraising and raising awareness both locally and nationally.

WHAT HAVE WE ACCOMPLISHED SO FAR AND WHAT'S NEXT?

During its first decade of operation, the Foundation brought many firsts for the PKD community. The Foundation awarded its first PKD research grant. The first local PKDF Chapter formed in Chicago. In 1989, the inaugural PKD National Convention educated patients and health care professionals about PKD in Kansas City.

The *PKD1* gene (responsible for 85% of ADPKD cases) and the *PKD2* gene (responsible for 15% of ADPKD cases) were discovered in the 1990s. Polycystin 1 and 2, protein products of PKD genes, were also identified. Along with genetic markers, important factors affecting the progression of cystic disease were found in a large number of patients. In 1993, the National Institutes of Health (NIH) made a major federal investment in PKD research—$5.73 million. Beyond funding, the NIH established PKD Centers of Excellence at four research institutions. From vital research achievements to growing national PKD awareness, the 1990s wrapped up with the launch of the Foundation's website.

When it comes to patients and families, fostering a sense of community is a priority for the Foundation. And the Walk for PKD is the biggest way for the community to connect. At the inaugural event in 2000, 900 PKD patients, families, and friends raised $214,000. By 2006, the U.S. Senate passed the first-ever National PKD Awareness Week Resolution to help promote the Walk for PKD. Today, the Walk for PKD has raised over $33 million for PKD research. After the genes for ADPKD (previously identified) and ARPKD (identified in 2002) were discovered, finding treatments was the next step. The desire for PKD treatments ushered in the start of multiple clinical trials over a five-year period. These trials studied imaging techniques, blood pressure control, and the effectiveness of the drug tolvaptan. Though this was just the beginning, findings from these trials would reap substantial wins for PKD patients down the line.

The first PKD Foundation United on the Hill event was hosted in 2008 to push for more federal funding for PKD research and to pass the Genetic Information Nondiscrimination Act (GINA). After a 13-year fight, GINA was passed by Congress and signed into law. In 2010, the PKDOC was formed to support using total kidney volume (TKV) as an endpoint for human clinical trials. In 2012, results from the TEMPO 3:4 clinical trial were presented. Even bigger findings came the next year as results from the tolvaptan drug trial were reviewed.

In 2013, the early success of tolvaptan led to a priority review by the FDA. REPRISE, a phase 3b study of tolvaptan for adult patients with ADPKD by Otsuka, began enrollment in 2014. That same year tolvaptan was approved in Japan as a treatment for ADPKD. By 2015, the drug would be approved as a treatment in Canada. Finally, in 2018, additional research found tolvaptan reduced the rate of decline of kidney function by 35% over a 12-month period in ADPKD patients and the FDA approved the drug.

Along with the milestones in treatment, funding for PKD research grants increased. Five two-year PKD research fellowships were awarded by PKDF to rising star clinicians and scientists for a total investment of $500,000 in 2015. The Jared J. Grantham Research Fellowship is established with the American Society of Nephrologists (ASN) to support PKD-related research in perpetuity. The ASN then matched the Foundation's $500,000 investment by $1.5 million. One year later, 15 two-year research grants were awarded by the Foundation—a $2.4 million investment.

Comparing the current five-year period to the previous five-year period, PKDF has more than doubled the amount of funding invested in grants, increasing research grant funding from approximately $3.7 million from 2011–2015 to approximately $8.6 million from 2016–2020. Additionally, scientists awarded PKDF Investigator Grant funding have been highly competitive in competing for NIH grant funding, with NIH-eligible PKDF Investigator Grantees awarded grants from 2014–2019 achieving an NIH applicant success rate of 51%, as compared to the general NIH applicant success rate of approximately 20%.

On PKD Awareness Day in 2019, the Foundation launched the first nationwide database of patients with ADPKD. With nearly 2,000 participants to date, the ADPKD Registry will be instrumental in advancing PKD research. It collects information in a standardized and anonymous format, reporting on the patient journey, unmet medical needs, and patient preferences, while revealing more about the disease burden on the lives of ADPKD patients and their families.

PKD Foundation recently established the PKD Advocacy Champion Network (ACN)—an exclusive community of patients, family members and clinicians dedicated to improving the lives of people living with PKD. Over the next several years, the Foundation will continue to invest in and expand this program. The Foundation is also building upon its ADPKD Registry, creating patient and physician education, and working to reach a more diverse patient population. ■