

Annual report

FISCAL YEAR 2022

This fiscal year contributed to the preparation of the PKD Foundation's 40th birthday.

Since 1982, we have:

- Proudly funded more than 1,300 research projects
- Raised over \$34M since 2000 in our annual Walk for PKD event
- Leveraged \$1.5B in research funds
- Continued to be the only organization in the U.S. solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD)

About the 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. We are inspired by our mission. And driven by our vision.

MISSION

WE GIVE HOPE. We fund research, advocate for patients, and build a community for all impacted by polycystic kidney disease.

VISION

#endPKD



Research

Made up of 14 prestigious PKD physicians and scientists, the Scientific Advisory Panel (SAP) 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 three new research fellows.

✦ Meet our researchers and Scientific Advisory Panel at pkdcure.org/sac



Support & Education

We aim to provide all patients and caregivers with the support and education they need to successfully navigate a new diagnosis or ongoing care.

VOLUNTEERS

Volunteers assist the PKD Foundation in supporting the PKD community and ensuring no one faces PKD alone. Nationally and in 55 local communities across the United States, peer mentors and volunteers—patients, families, friends, and caregivers—support local PKD communities, provide personal support, and organize virtual and in-person events to raise awareness and money for the PKD Foundation's essential programs and services.

✦ Get involved: Find more information at pkdcure.org/volunteer

18,113

Volunteer Hours

1,405

Active Volunteers

\$542,484

Estimated Value

PKDCON 2022

This year's virtual PKD Connect Conference brought together patients, caregivers, health care providers, and researchers from the safety of their homes.

35

Sessions

57

Speakers

1,764

Registered

766

Active Users

16

Researchers

✦ View recorded sessions: resources.pkdcure.org/pkdcon2022



Advocacy

Our work to maintain PKD as a disease area within the Department of Defense (DoD) Peer Reviewed Medical Research Program (PMRMP) last fiscal year resulted in the awarding of over \$12 million in grants focused on PKD research. DoD medical research grants have generated more than \$47 million in PKD-specific research funding since 2014. This fiscal year, efforts to maintain the listing of PKD as a disease area within the PMRMP continued; it's awaiting passage of appropriations legislation by Congress.

TAKING THE FIGHT TO CAPITOL HILL

In 2022, we continued our increased commitment to elevate both awareness of PKD and the voices of patients on Capitol Hill.

→ We furthered our efforts with the Advocacy Champions Network (ACN), a group of PKD community members from across the U.S. engaged in formal advocacy efforts with Federal policymakers.

→ PKDF advocacy efforts engage more than 35,000 advocates across 49 states and the District of Columbia.

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 easy and effective.

 Sign up for Advocacy Alerts at pkdcure.org/advocacy



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 were 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 \$34 million, 100% of which goes to research. This family-oriented event creates a sense of community and provides a unique opportunity to support and honor loved ones.

TOP 10 WALK EVENTS

San Antonio	\$80,565
Chicago	\$74,295
Boston	\$55,891
Pittsburgh	\$43,005
Tampa	\$39,681
Kansas City	\$35,671
Twin Cities	\$34,480
Milwaukee	\$32,277
St. Louis	\$29,886
New Jersey	\$27,908



Learn more about
Walk for PKD:
walkforpkd.org

TOP 5 COMMUNITY FUNDRAISING EVENTS

- | | |
|---|--|
| ① \$466,642
RideforPKD | ④ \$43,982
Celtic Marketing Golf |
| ② \$123,377
20th Annual Driving Home a Cure for PKD Golf Tournament | ⑤ \$40,570
Pedaling for Kidney Disease |
| ③ \$53,009
Stephen Cain's 50th Birthday Celebration | |



Learn more about individual events at pkdcure.org/fyw

TOP 10 WALK TEAMS

- ① To the Nines
CHICAGO
- ② Ivan's Investors for PKD Cure
TAMPA
- ③ Patti's Partners to Find a Cure for PKD
SAN ANTONIO
- ④ Bost Bunch
PITTSBURGH
- ⑤ Mike & Poppy's All-Stars
ARPKD RESEARCH FUND
- ⑥ Joining Judy
BOSTON
- ⑦ Repa's Kidney Kickers
ST. LOUIS
- ⑧ Marilyn's Marchers
HOUSTON
- ⑨ Team Tenacity
SOUTH FLORIDA
- ⑩ UT Health SA Nephrology
SAN ANTONIO

55 *Walk for PKD events*

\$1,141,729
total raised

Nearly
2,000
Walk participants

300
Walk teams

In FY22, 41 Fundraisers raised \$829,060



Your Impact

REVENUE SURPASSES \$15 MILLION IN 2022

Your financial commitment makes it possible for the PKD Foundation 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 to end PKD.

20,320 *donations came from*

50

states + DC & PUERTO RICO

25

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 2021 – 30 JUNE 2022

INVESTMENTS

Research
\$3,191,871
Awareness & Advocacy
\$1,215,137
Education & Support
\$1,687,658
Development
\$847,708
Administrative
\$1,063,116

SOURCES OF FUNDING

Investments
(\$2,828,904)*
General Contributions
\$14,996,481
Community Fundraising
\$2,193,414
Other Sources
\$1,363,646
Bequests/Legacies
\$223,969

* This is a negative number due to realized or unrealized losses on investments.

ANNUAL REVENUES

Fiscal Year 2022
15,948,606
Fiscal Year 2021
\$12,078,443
Fiscal Year 2020
\$16,498,543
Fiscal Year 2019
\$7,231,115
Fiscal Year 2018
\$13,458,451

FINANCIAL POSITION

Assets
\$31,113,409
Liabilities
\$620,624
Net Assets
\$30,492,785

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 for every step of the disease progression.

WHAT ARE OUR STRATEGIES FOR ACHIEVING THOSE GOALS?

The 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 state and federal levels.

In September 2019, the 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?

The 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'S NEXT?

This next year will be one of celebration as we acknowledge the Foundation's 40th anniversary of providing research, education, and advocacy to meet the needs of our PKD community.

We will launch the PKD Foundation Centers of Excellence (COE) program, an initiative to help patients

SENIOR LEADERSHIP

Susan Bushnell
PRESIDENT, CHIEF EXECUTIVE OFFICER

Carmen Gleason
CHIEF OPERATING OFFICER

Jon Rich
CHIEF PHILANTHROPY OFFICER

BOARD OF DIRECTORS

ELECTED OFFICERS

Robert Roth
BOARD CHAIR, EXECUTIVE COMMITTEE CHAIR

Navin Manglani
VICE CHAIR

Amy Omenn
SECRETARY

Stu Caplan
TREASURER, FINANCIAL OVERSIGHT & INVESTMENT COMMITTEE CHAIR

DIRECTORS

Katherine Dell, M.D.

Paula Krumboltz Hutchinson

Julie Marshall

Michal Mrug, M.D.
SCIENTIFIC ADVISORY PANEL CHAIR

Meyeon Park

Christopher Wess

Bruce Winn

Amanda Yen

more easily find quality ADPKD care in late 2022. The PKDF COE designation will be awarded to hospitals and clinics that provide comprehensive multidisciplinary clinical service for families affected by ADPKD.

In 2023 the Foundation's ADPKD Registry will release enhancements to collect health records and to improve the participant experience. New features will help them track their patient journey and equip them with personalized reports to share with their care team.

We're here for the PKD community from care to cure. Your support makes our work possible. ■

