



**PKD FOUNDATION
ADPKD REGISTRY**

ANNUAL
IMPACT
REPORT

2022



In 2019, we launched the ADPKD Registry. As we reflect on the impact this program has had on ADPKD research, we are so grateful to the clinicians, researchers, and members of the patient community who helped us design and manage the Registry, as well as those who have contributed their data to the program.

We're proud to call this patient-powered, because we're not only getting details of the disease journey from nearly 2,700 individuals (and counting!), but we're constantly learning through new initiatives to engage participants and grow the impact of the data.

Due to the support we've received from the community, the Foundation plans to expand the kinds of data we'll collect. Researchers will soon be able to study module answers on quality of life, family history, diet, and access to care alongside health record data. And, we plan on asking for this data in an innovative way.

Traditionally, a Registry would create partnerships with nephrology clinics to ask doctors to consent their ADPKD patients to the study and share their health records through the hospital system.

However, the ADPKD Registry will instead go directly to patients. Thanks to new federal regulations (21st Century Cures Act), patients now have access to their health data and have the power of choosing who to share it with. In a new version of the Registry launching this year, participants will be able to quickly and easily connect their health record portal. And because the Registry automatically de-identifies (removes any personally identifiable information and replaces it with a participant ID) the data you provide, we believe this is more secure than going to clinics themselves.

In the SUMMER of 2023, WE'LL BE ADDING a DATA ACCESS PORTAL, WHERE RESEARCHERS CAN SEE the KINDS of DATA WE'RE REQUESTING, PUT TOGETHER PROJECT PROPOSALS, and GET ACCESS to DEIDENTIFIED DATA SO WE CAN ANSWER EVEN MORE RESEARCH QUESTIONS.

Let's talk about what "secure" means to our team. It means that we value the confidentiality and privacy of your information. We recognize that the Registry asks very personal questions about diagnosis, family history, symptoms, and your relationship with your health care team. We know that this information is confidential, and we're proud to work with a platform (IQVIA) which has an excellent reputation for storing this data in a way that protects patient information. We've put policies in place ensuring that any data we share with researchers does not include information that could be used to identify an individual such as name, contact information, or date of birth. We hope that you feel safe sharing your information with us — the trust of the PKD patient community is so vital to the work we can do together.

Whether you choose to answer survey questions, share your health records, or both, we thank you for being a part of the ADPKD Registry and hope we can find new ways to return value to you. In this Annual Impact Report, you'll see some ways we've already begun to use the data to enhance the understanding of ADPKD for both researchers and clinicians.

Thank you so much to all those who have signed up in our first three years! Let's continue to grow and work together to #endPKD.



EH

Elise Hoover, MPH
VICE PRESIDENT OF RESEARCH PROGRAMS



Vanessa Holliday

Vanessa Holliday, MPH
RESEARCH STRATEGIST

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About the PROGRAM

On September 4, 2019 (PKD Awareness Day), we launched the ADPKD Registry, a collection of information about individuals with autosomal dominant polycystic kidney disease (ADPKD).

Participation is entirely online: through a phone, tablet, or computer. All those diagnosed with ADPKD in the United States are invited to participate.

- **Answer survey questions** — Answer survey questions about your experience with ADPKD.
- **Keep information current** — Update us on your quality of life and PKD symptoms through-out the year.
- **Participate in research** — Find out about research studies for which you might qualify.

The ADPKD Registry was built by the PKD Foundation with the help of patients, researchers, clinicians, and other members of the PKD community. We are so grateful for their help and dedication to our mission: to find treatments and a cure for PKD.

ABOUT THE MODULES

When we think about what questions we want to ask in the Registry, we bring together working groups made up of clinicians, researchers, patients, and caregivers. These groups discuss the gaps in knowledge in the clinic, overlooked parts of the disease experience, and research questions that need data to answer. We agree on how to ask these questions and then bring in real Registry participants to test the modules for us and ensure it all makes sense.

[Learn more](#)

pkdcure.org/registry

Through the **WORK** of **THESE INDIVIDUALS**, **WE'RE PROUD** to **CALL THIS PROGRAM PATIENT-POWERED.**



ADPKD Impact Scale



Core Questionnaire



Diet and Lifestyle



Engagement



Experience with Liver Cysts



Family History



Health Care Access and Utilization



ADPKD Pain and Discomfort Scale



Vascular Outcomes



David
PATIENT
ADVISORY
GROUP

Having the ADPKD Registry adds such value to the PKD research being done by so many. I come from a family of three generations who are affected by PKD (that we know of). Losing my mother in 2020 due to PKD caused me to seek out ways that I might get more involved in the work being done around PKD. Taking a few minutes out of my day to answer the survey questions in the registry is such a small contribution to the big work that the PKD Foundation is doing. We now have had the registry for a few years, and it has begun to show us valuable data not only in trends around the disease but in the eye-opening details of those who are living day in and day out with this disease. It is my honor to be a part of this life changing work and I hope you will join me in being a part of the registry as we seek to find a cure and end PKD.

About RECRUITMENT

As of DECEMBER 2022, THERE WERE **2,774 PARTICIPANTS ENROLLED** in the ADPKD REGISTRY from ALL 50 STATES and the DISTRICT of COLUMBIA.

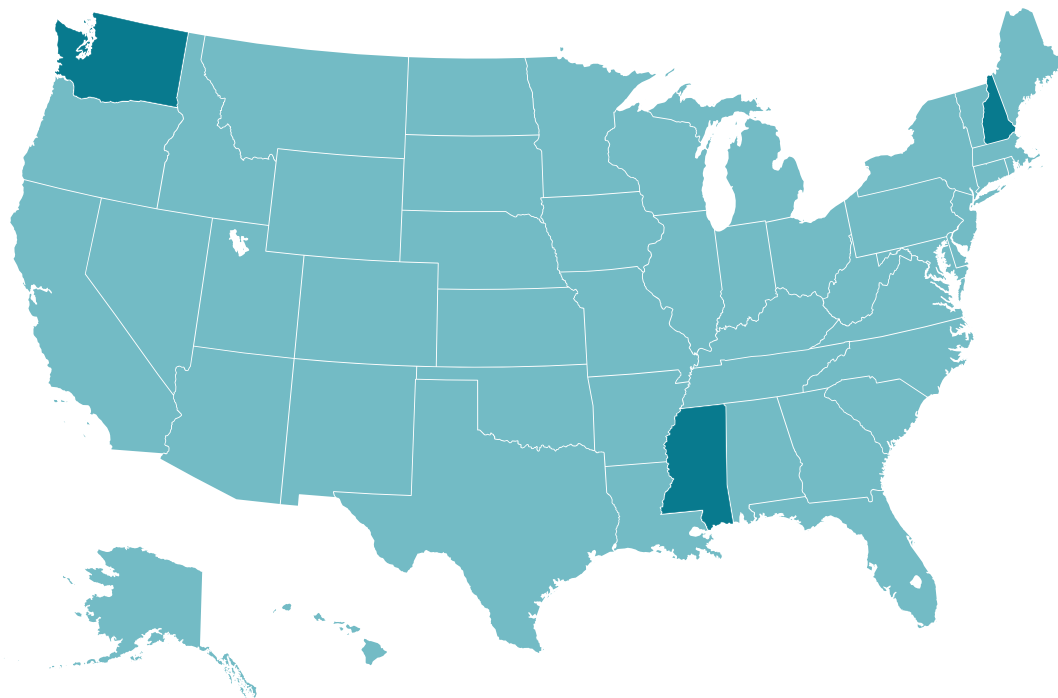
Signing up is easy.

1. Create an online account.
2. Agree to an informed consent.
3. Start completing the available modules!

ENROLLMENT INCREASE

The following states had the highest enrollment increase compared to 2021:

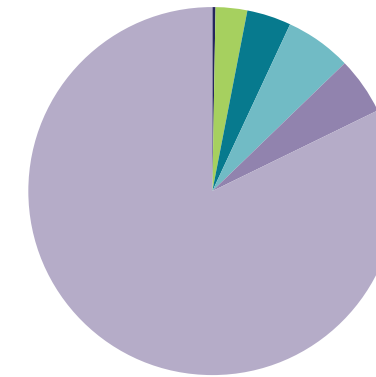
- Mississippi **75%**
- New Hampshire **80%**
- Washington **73%**



In 2022, a **MORE DIVERSE GROUP** of PARTICIPANTS SIGNED UP for the REGISTRY than in PREVIOUS YEARS. We SAW **INCREASED DEPTH** across RACE, ETHNICITY, GENDER, and CKD STAGE.

RACE & ETHNICITY

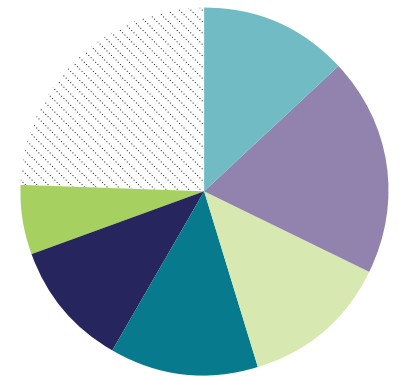
- Caucasian **85%**
- Black or African American **5%**
- Asian **6%**
- Multiple races **4%**
- American Indian or Alaska Native **3%**
- Native Hawaiian or Other Pacific Islander **0.06%**



8% also self-identified as Hispanic or Latino

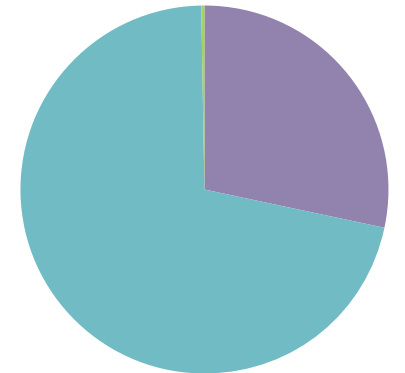
CKD STAGE

- Stage 1 **13%**
- Stage 2 **19%**
- Stage 3a **13%**
- Stage 3b **13%**
- Stage 4 **11%**
- Stage 5 **6%**
- Unknown **24%**



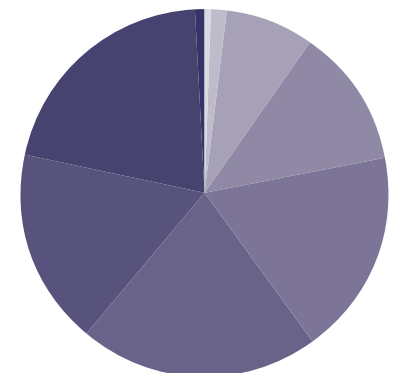
GENDER

- Male **28%**
- Female **71.5%**
- Non binary, transgender, or other **0.5%**



AGE

- 1-10 years **1%**
- 11-20 years **1%**
- 21-30 years **8%**
- 31-40 years **16%**
- 41-50 years **17%**
- 51-60 years **20%**
- 61-70 years **17%**
- 71-80 years **20%**
- 81+ years **1%**

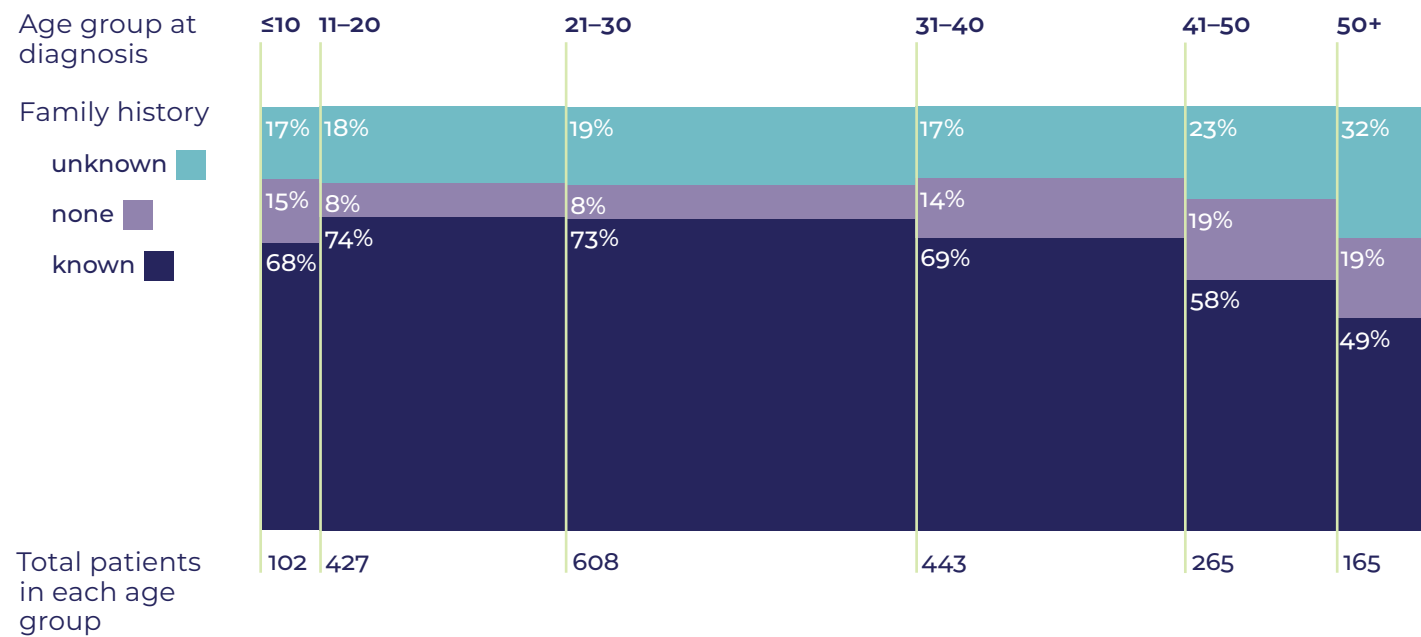


DATA HIGHLIGHTS

Making the choice to discuss your ADPKD diagnosis with family members may not be easy. The Registry strives to understand the connection between knowledge of family history and the age of ADPKD diagnosis.

[Learn more
pkdcure.org/living-with-pkd/
chronic-pain-management](https://pkdcure.org/living-with-pkd/chronic-pain-management)

AGE GROUP AT DIAGNOSIS BY KNOWLEDGE OF FAMILY HISTORY OF DISEASE
of 2,010 who responded



REGISTRY PARTICIPANT
Florida

My father and his father did not have a family relationship and therefore my father did not know PKD was a real possibility for him. My father was diagnosed the same year that I was; his diagnosis led me to go get checked.

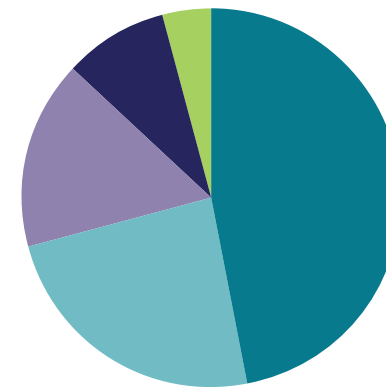


REGISTRY PARTICIPANT
Massachusetts

I want to see more studies looking at pain. I was very glad to be enrolled in TAME study for two years. The constant medical evaluations were reassuring at a time when I was worried about my new diagnosis, and it was comforting to be able to ask the PKD specialist about my pain even though it wasn't part of the study.

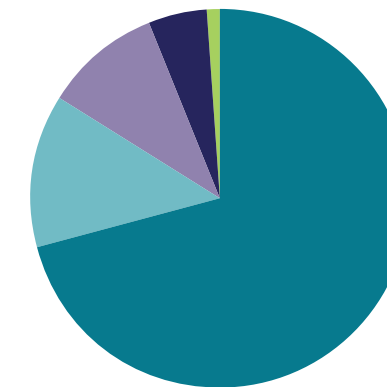
Knowing more about kidney pain as the disease progresses will help inform clinicians about the symptoms that impact their patients' daily lives. Since the ADPKD-PDS* and ADPKD-IS* only ask about the past two weeks, we ask them multiple times to measure pain throughout the year. There are slight differences between patients at different stages of chronic kidney disease, but overall we can see that pain is a constant feature of PKD.

Over the past two weeks NEEDED TO MODIFY LIFESTYLE BECAUSE OF PKD PAIN & DISCOMFORT
of 1059 who responded



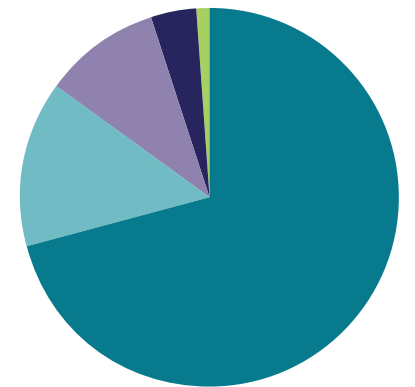
Extremely bothered **4%**
Very bothered **9%**
A little bothered **16%**
Somewhat bothered **24%**
Not bothered at all **47%**

In the last seven days RELATIONSHIPS AFFECTED BY DULL KIDNEY PAIN
of 946 who responded



Completely interfered **1%**
Very much interfered **5%**
Somewhat interfered **10%**
Slightly interfered **13%**
Didn't interfere at all **71%**

In the last seven days RELATIONSHIPS AFFECTED BY FULLNESS OR DISCOMFORT
of 946 who responded



Completely interfered **1%**
Very much interfered **4%**
Somewhat interfered **10%**
Slightly interfered **14%**
Didn't interfere at all **71%**

*ADPKD-IS and ADPKD-PDS contact information and permission to use: Mapi Research Trust, Lyon, France, <https://eprovide.mapi-trust.org>

OUR IMPACT SO FAR

The ADPKD Registry's goals are to:

1. Create a valuable outcomes research tool to better understand the ADPKD patient journey;
2. Accelerate clinical research by helping to recruit for clinical trials.

And we are making progress!

The Registry now has data on the disease experiences of over 2,700 individuals with ADPKD, and has started to make connections between disease stage and health-related quality of life, among others. We've also made research more accessible by sending information about 18 clinical studies to those we thought might be eligible. Your data is powerful!

Here are a few examples of where your data has been making an impact. We have presented insights from Registry data at professional meetings since 2020 and will summarize highlights from each of the three years' events in this section.

OUR IMPACT SO FAR

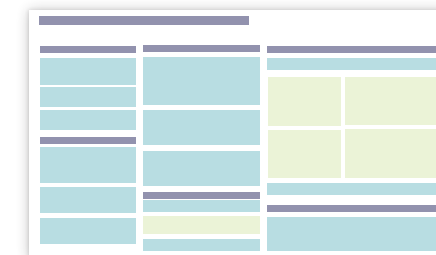
2020 ASN poster

PKDF presented a poster at the American Society of Nephrology's 2020 Kidney Week, along with members of the Patient Registry Advisory Committee. It is an annual event that brings together more than 10,000 professionals working in the kidney health care space from around the world. They meet to exchange knowledge, get up to date on the most recent advances in the scientific and medical communities, and hear sessions from across hundreds of focuses, including PKD.

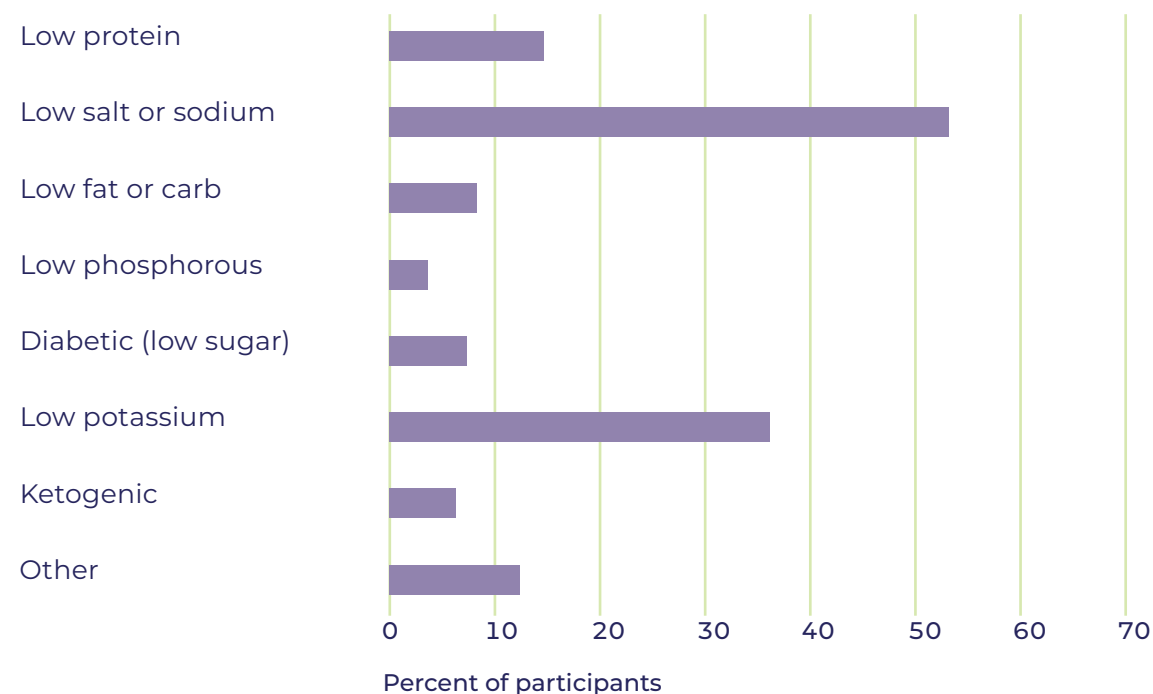
The PKDF team created a poster to present the ADPKD Registry to the nephrologists attending the virtual conference to both introduce the program as a research tool, and to encourage them to tell their patients about it.

[Learn more
pkdcure.org/asn](https://pkdcure.org/asn)

DOWNLOAD THE 2020 ASN POSTER



PARTICIPANT-REPORTED DIETARY RESTRICTIONS of 1,173 who responded



Poster conclusions — The ADPKD Registry is a longitudinal research tool intended to capture patient-reported data with respect to ADPKD and is designed to impact research in multiple ways. All participants have consented to be notified about future clinical trials for which they will likely qualify and a process has been established to enable researchers to submit content for new outcome modules. Thus far modules addressing extra renal complications such as PLD and vascular aneurysms have been developed. In addition, the variety of disease stages reported by participants will allow for a range of research questions related to the clinical management of ADPKD from early stage disease through dialysis outcomes and post-transplant complications.

OUR IMPACT SO FAR

Design manuscript

The next step in raising awareness of the program and the data we have available to research was to publish our manuscript, “Design and Basic Characteristics of a National Patient-Powered Registry in ADPKD.”

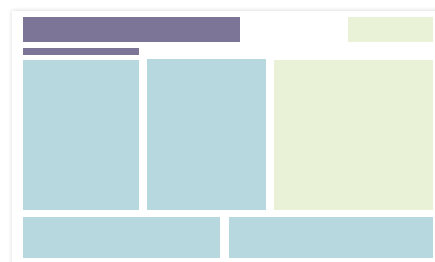
We wrote this paper with our Registry Advisory Group made up of clinicians, researchers, and patient stakeholders.

Key points —

- As of October 2021, more than 1500 patients with autosomal dominant polycystic kidney disease (ADPKD) have signed up to participate in the ADPKD Registry, which collects patient-reported data.
- The Registry is a valuable tool for dissemination of information about studies for which individuals may qualify.
- By incorporating two validated outcome measures, the ADPKD-IS and ADPKD-PDS, the Registry holds unique data on a national scale.

[Learn more
pkdcure.org/design-manuscript](https://pkdcure.org/design-manuscript)

**READ THE KIDNEY360
MANUSCRIPT AND VISUAL
ABSTRACT**



**REGISTRY PARTICIPANT ELIGIBILITY FOR CURRENTLY
ENROLLING ADPKD CLINICAL TRIALS
when paper was published in October 2021**

Compound CLINICALTRIALS.GOV IDENTIFIER	Relevant eligibility criteria			Number of potentially eligible ADPKD Registry participants
	Age yr	eGFR ml/min/1.73 m ²	BMI kg/m ²	
Bardoxolone methyl NCT03918447	18–70	30–90	>18.5	1097
Caloric restriction NCT04534985	18–65	>30	25–45	337
Lixivaptan — ACTION NCT04064346	18–60	25–90	18–40	1101
Lixivaptan — The ALERT Study NCT04152837	18–65	>20	18–35	1109
Pravastatin NCT03273413	25–60	>60	N/A	788
RGLS4326 NCT04536688	18–70	30–90	18–35	1097

Study inclusion criteria accurate as of October 12, 2021. Counts of those with unknown eGFR values were included if they met other eligibility criteria (e.g., age, no history of kidney transplant or dialysis). This is not intended to be a comprehensive list, and only includes those studies with open enrollment in October 2021 in the United States, studying ADPKD exclusively and those with current collaborative recruitment efforts with the PKD Foundation. ADPKD, autosomal dominant polycystic kidney disease.

Conclusions — The Registry described here is the only one of its kind and is a valuable longitudinal research tool encompassing all stages of ADPKD. The registry will allow investigators to pursue a range of research questions related to the management of ADPKD, including definition of health-related quality of life (HRQoL) outcomes and recruitment for a variety of observational and therapeutic clinical protocols.

OUR IMPACT SO FAR

2021 ASN poster

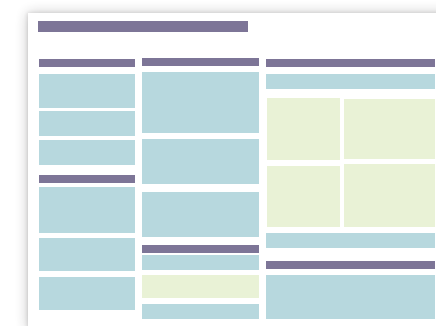
In 2021, PKDF again presented a poster at the American Society of Nephrology’s Kidney Week with updates on how the program has grown, along with members of the Patient Registry Advisory Committee.

We focused on our three newest modules looking at impacts of the COVID-19 pandemic, vascular outcomes (such as brain aneurysms), and health care access.

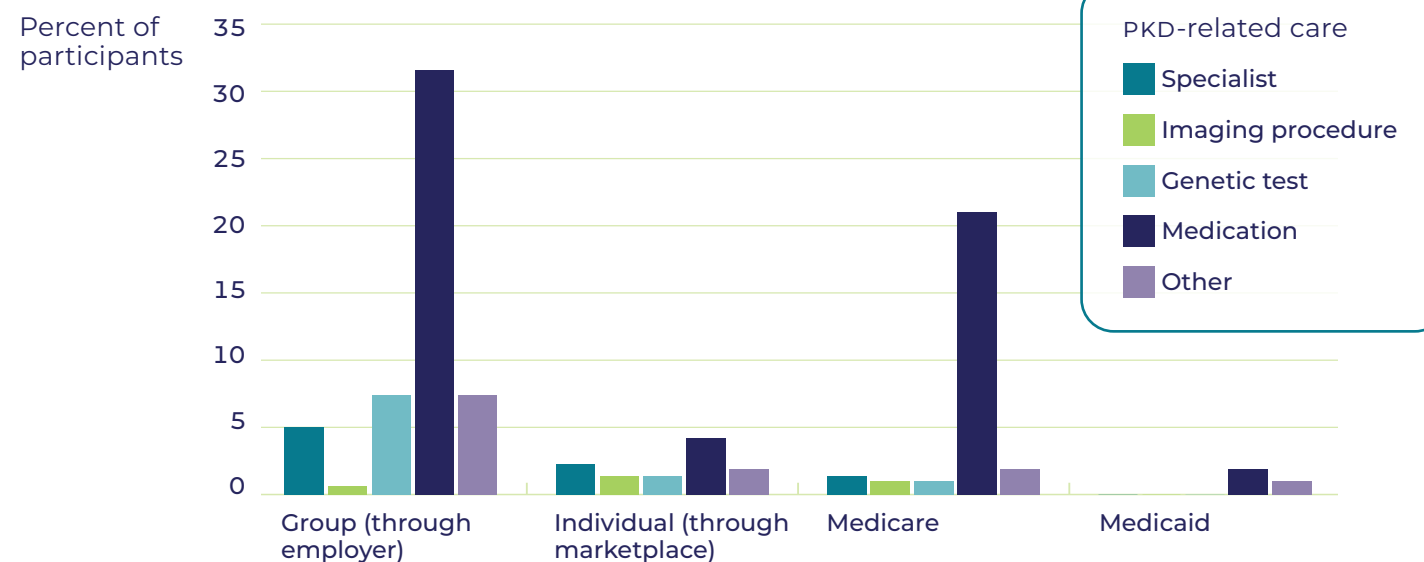
We shared that the vast majority of patients reporting barriers in access or affordability was around medication for their PKD, especially through employer insurance or Medicare. And when we asked what kind of medication they were having trouble accessing, almost 93% said blood pressure medication. We also saw issues accessing specialist referral and genetic tests.

[Learn more
pkdcure.org/2021-asn-poster](https://pkdcure.org/2021-asn-poster)

**DOWNLOAD THE 2021
ASN POSTER**



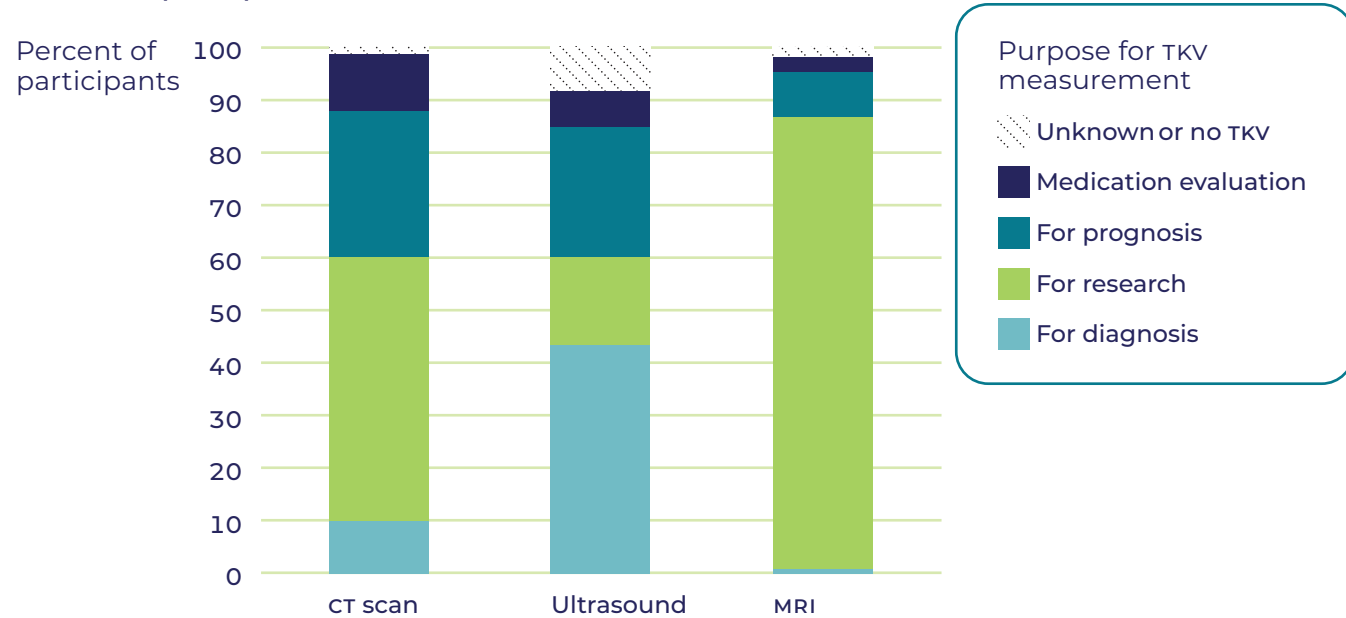
**PATIENTS WHO REPORTED BEING DENIED ACCESS TO
PKD-RELATED CARE BY HEALTH INSURANCE TYPE
of 429 who participated**



This is the kind of data that can help us understand the challenges our community is facing, and advocate for them on various levels.

We know that total kidney volume (TKV) is important for understanding risk of rapid progression of ADPKD. It's a required measurement to get someone prescribed tolvaptan. It's also a valuable tool to understand prognosis.

PATIENT-REPORTED PURPOSE FOR TKV MEASUREMENT BY IMAGING MODALITY of 429 who participated



However, 69% said they've either never had their TKV measured or were unsure. Of those who reported getting a measurement, especially by CT or MRI, a large majority was for research purposes, not even for prognosis or medication evaluation.

It was important that we presented this to clinicians to highlight the adoption gap in measuring TKV for every patient with a diagnosis.

Poster conclusions —

- The ADPKD Registry is a valuable resource — patient-reported data at this level is unique!
- Program is flexible and can react quickly to real-world events that change patients' relationships with the health care system.
- 64% of participants are between the ages of 18–55 with a eGFR above 30 mL/min/1.73m², which meet eligibility criteria for many ADPKD clinical trials.

OUR IMPACT SO FAR

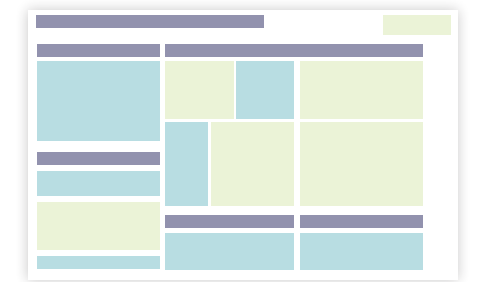
2022 NKF poster

To get in front of more clinicians treating ADPKD patients, the PKDF presented a poster at the National Kidney Foundation's Spring Clinical Meeting. This meeting presents a unique opportunity for busy kidney health care providers to learn new developments related to all aspects of nephrology. It is designed for nephrologists in the private sector and academia, fellows and residents with a special interest in kidney disease, general internists, pharmacists, physician assistants, nurse practitioners, nurses and technicians, social workers, dietitians, and transplant coordinators.

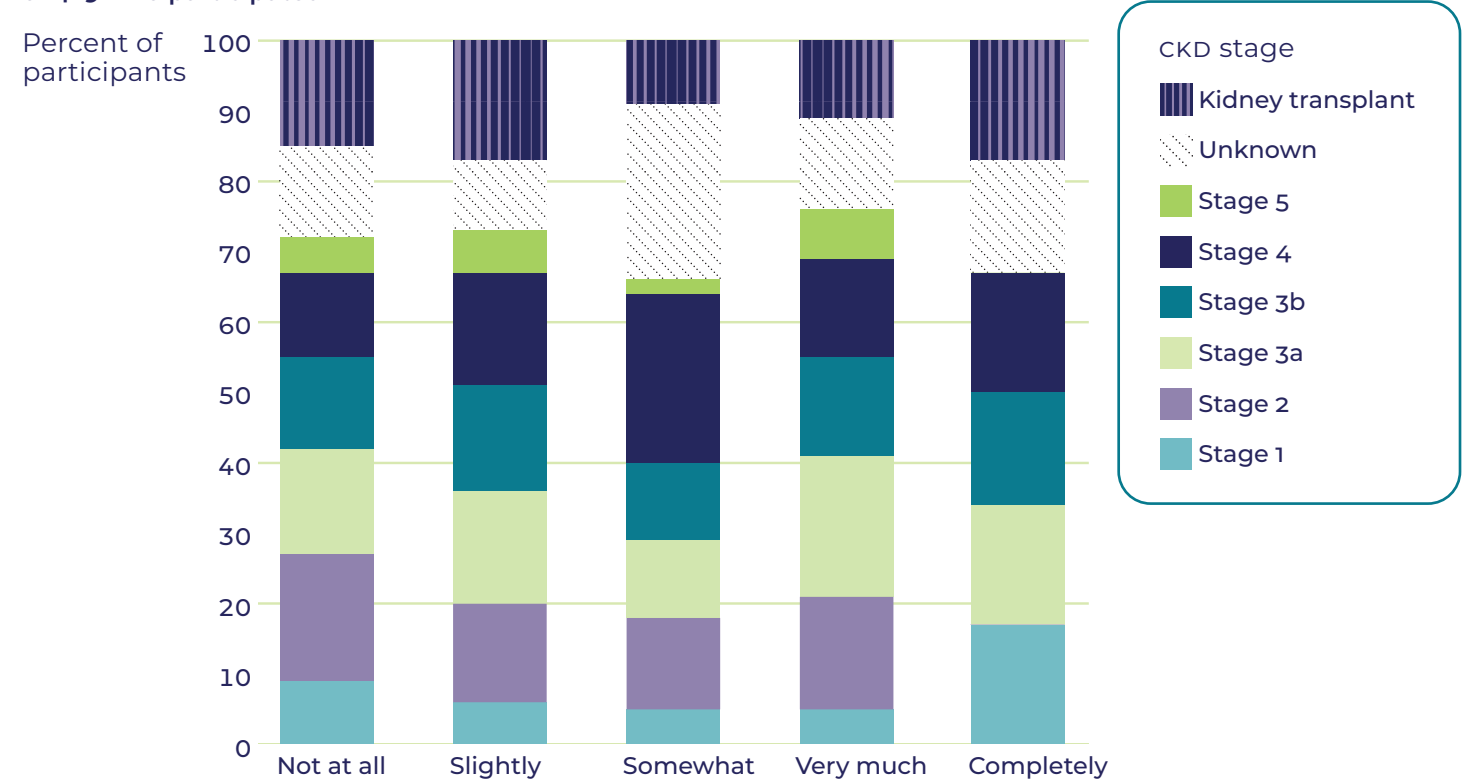
[Learn more](#)

pkdcure.org/2022-nkf-poster

DOWNLOAD THE 2022 NKF POSTER



IMPACT OF DULL KIDNEY PAIN ON SLEEP, STRATIFIED BY CKD STAGE of 429 who participated



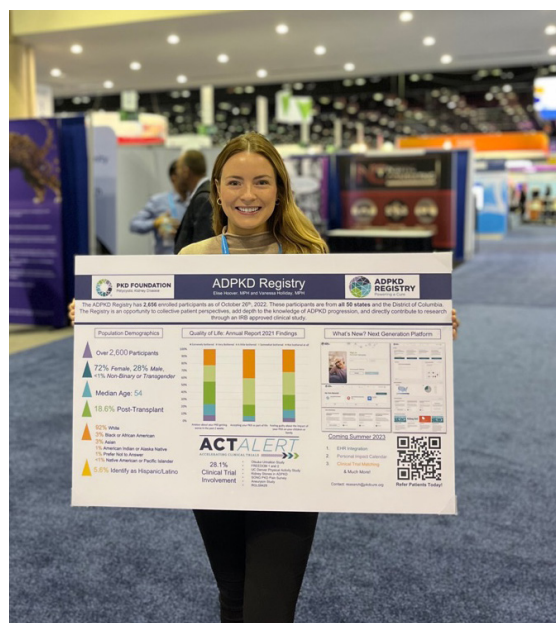
Poster conclusions — Kidney growth and gradual function decline impacts health related quality of life (HRQoL) in people with ADPKD. The Registry collects data on individual disease characteristics, demographics, and diagnosis. Participants also periodically report their latest kidney function lab values and complete validated HRQoL standardized instruments (the ADPKD-Pain and Discomfort Scale (PDS) and the ADPKD-Impact Scale (IS)). Patient-reported pain is then tracked longitudinally with eGFR-estimated chronic kidney disease (CKD) stage and other characteristics. These data will contribute to the increased understanding of pain experience in ADPKD, including characterization of the kind of patients more likely to report it.

OUR IMPACT SO FAR

2022 ASN poster

After two years of virtual meetings, we finally sent our research team to Kidney Week in person. We shared the value of the Registry program as a research tool and encouraged clinicians to use it to help recruit for clinical studies. We also discussed with clinicians the upcoming features that will be available summer 2023. Conversations throughout the week pointed out how valuable the Registry is for patients and clinicians alike.

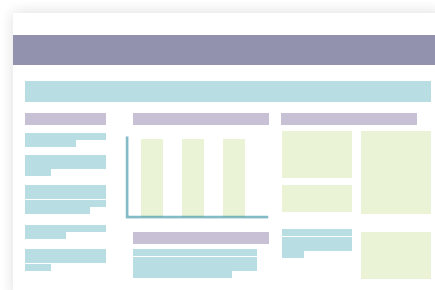
Vanessa Holliday at ASN 2022, holding her research poster in the exhibit hall



Learn more

pkdcure.org/2022-asn-poster

DOWNLOAD THE 2022 ASN POSTER



OUR IMPACT SO FAR

Research recruitment

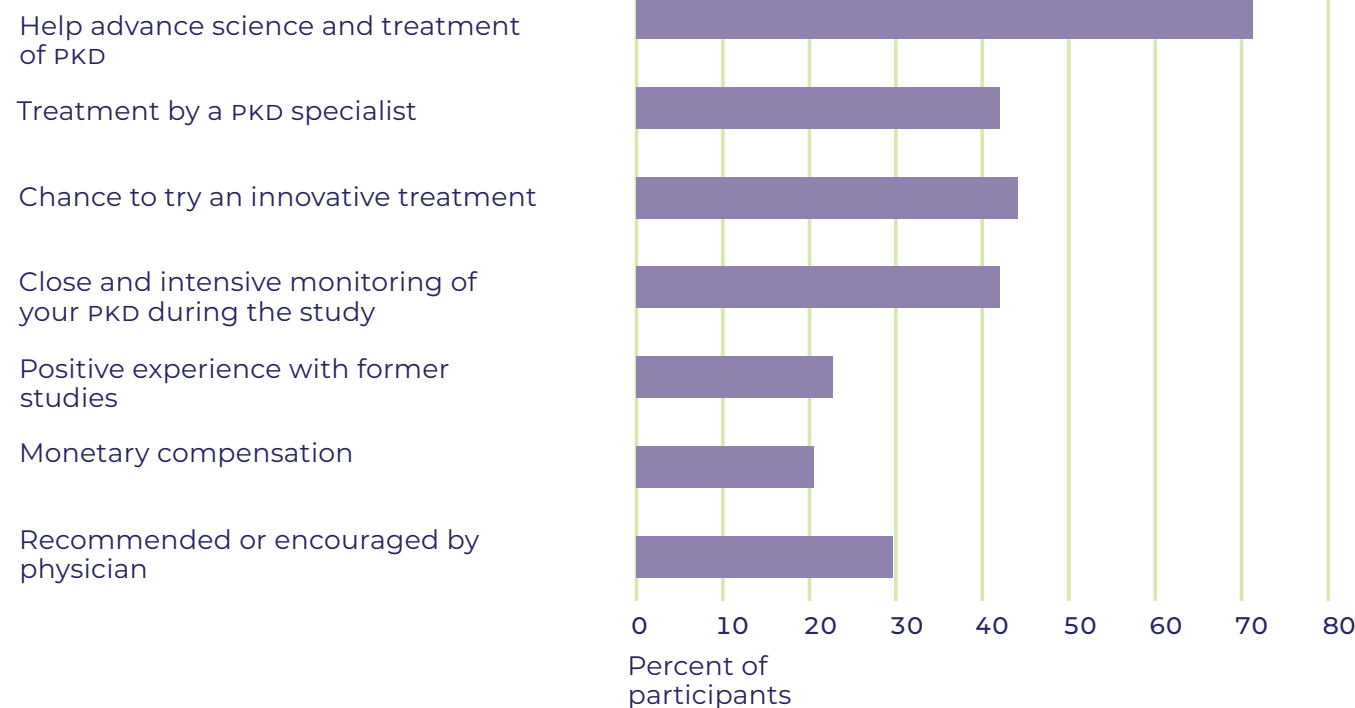
Since we launched the Registry, we've helped to recruit for 18 clinical studies, and contacted nearly 9,000 of those who may be eligible (some were contacted more than once). After sending information about the study, we asked those same individuals to tell us if they decided to sign up to participate, as well as what motivated them.

Learn more

pkdcure.org/clinical-studies

WHAT WOULD OR DOES MOTIVATE TO PARTICIPATE IN PKD RESEARCH

of 811 who responded



KINDS OF RESEARCH STUDIES

Interventional studies test new ways to prevent, detect, or treat diseases. Treatments may be new drugs, combinations of drugs, surgical procedures, medical devices, or lifestyle interventions like diet and exercise.

Observational studies do not test new drugs or treatments. In observational studies, doctors and researchers analyze health data to find links between a diagnosis and certain health conditions, disease progression, symptoms or quality of life.

7

interventional studies & clinical trials

11

observational studies or surveys

STUDIES STILL ENROLLING!

Aneurysm study at the University of Maryland Baltimore

Empagliflozin clinical trial

FALCON clinical trial

Nutrition Study at University of Colorado Denver

PB to reduce increased urination due to tolvaptan therapy

Pediatric ADPKD registry at Children's National

RGLS8429 clinical trial

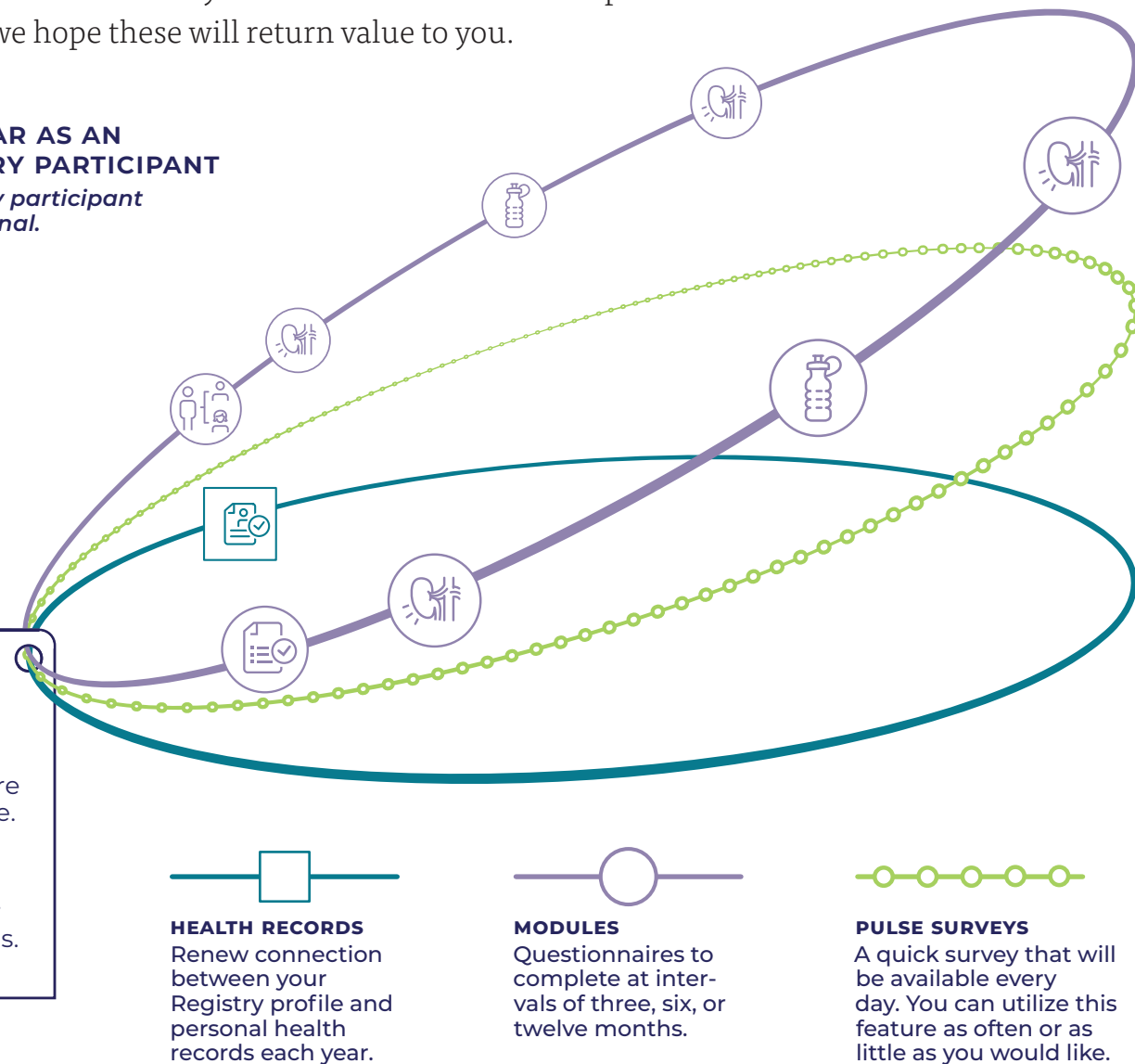
FIRST-YEAR PARTICIPANT JOURNEY

When you sign up for the ADPKD Registry, we're asking you to engage with us all year long. Most modules repeat at least once a year to make sure we have the most up to date details of your disease journey available to researchers. Our automated portal will make sure to email you when a new module is available, but check back whenever you like to interact with our portal features — we hope these will return value to you.

[Learn more
pkdcure.org/registry](https://pkdcure.org/registry)

YOUR FIRST YEAR AS AN ADPKD REGISTRY PARTICIPANT

All ADPKD Registry participant activities are optional.



The MORE INFORMATION YOU GIVE, the MORE YOU MOVE RESEARCH FORWARD.



UNLOCK PORTAL FEATURES

When you answer new questions or complete tasks in the Registry, **special features and insights will be unlocked to help you understand your disease journey.** Compare your own longitudinal data to Registry averages. See trends in your symptoms. All of these features were created with you, the participant, in mind.



POWER RESEARCH

The more information you provide, the more you **help researchers ask and answer questions about PKD.**



When you complete a pulse survey, your responses will be reflected on the Personal Impact Calendar. This calendar will help you visualize what living with ADPKD is like and provide a conversation tool for physician appointments.



When researchers know where individuals with ADPKD are located around the U.S. it helps with study recruitment so we can accelerate clinical trials.



Each time you update your answers or complete a module, your Care Summary will become more comprehensive and complete!

Everyone's journey looks different, and changes as the disease progresses. Researchers value data that they can track over time to see how responses change.



If you choose to connect your electronic health records to the Registry, we aim to help you understand your disease progression on a better level. Just like answering module questions, the electronic health record data will enhance the Care Summary and provide great conversation tools for physician appointments.

Pairing your module data with health records maximizes the ability to understand diagnosis, treatment, risk factors, and others, and will inform care guidelines for ADPKD.

LOOKING to the FUTURE

The PKDF Research team is excited to expand the features available in the ADPKD Registry in summer 2023. This project has been carefully planned and executed with our patients at the center. The last few years have been spent building the largest ADPKD patient-reported outcomes dataset.

Looking to the future, we want to keep collecting data that deepens the understanding of ADPKD, for patients and clinicians. We are looking to accomplish this in four key ways.

- **Electronic health records** — maximizing research impact by introducing the sharing of electronic health records. All health record data is de-identified, just like any other information you share with the Registry.
- **Care Summary** — providing informative summaries of your data that can be shared with your clinicians.
- **Personal Impact Calendar** — visualizing what living with ADPKD is like through the events such as pain, fatigue, or missed days at work, school, or social events.
- **Researcher Portal** — the Registry data will be de-identified and open to researchers through the new Researcher Portal, looking to open Summer 2023. This portal will allow PKD researchers to utilize Registry data in a way that hasn't been accessible before.

Starting this summer, there's a new way you can step up to provide hope for future generations. Share your electronic health records with a few simple steps on the ADPKD Registry. As a community, our health information is powerful and essential to research.

[Learn more
pkdcure.org/registry](https://pkdcure.org/registry)

**THERE ARE
EXCITING CHANGES
HAPPENING in the
ADPKD REGISTRY,
and WE WANT YOU
to JOIN US for the
JOURNEY.**

CARE SUMMARY
Share this helpful report
with your physician.

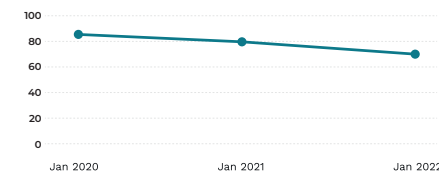
Care Summary

Bring this with you when you visit your doctor

Print

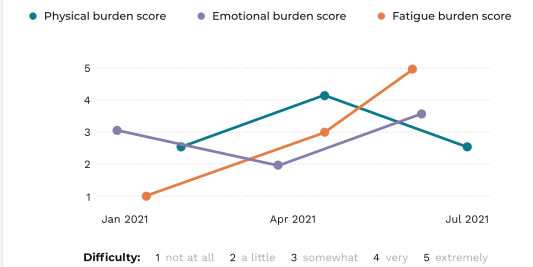
Kidney function over time

As your PKD progresses, your kidneys will grow and lose function. This is measured through your blood or urine and is called eGFR. Knowing your disease progression can help you to plan your future.



Quality of life scores over time

As your PKD progresses, you may see changes in your quality of life and the impact it has on your life. Share details of your pain, fatigue, or other factors with your care team.



Blood pressure control

High blood pressure affects 60-70% of ADPKD patients and begins early. Many times, this is the first sign of PKD. If not treated, it causes further damage to the kidneys, enlarges and thickens the heart muscle, and increases the risk for strokes and other cardiovascular events.



Total Kidney Volume (TKV)

TKV can help predict disease progression in ADPKD. It is measured using imaging tests (such as MRIs or CTs). Measuring TKV can give your nephrologist a lot of information about your disease and how quickly it might get worse.

Reported imaging test(s):

- MRI in May 2019 at Yale New Haven Health
- Ultrasound in July 2021 at University of Connecticut Medical Center

Personal Impact Calendar

Receive weekly pulse-survey via sms On Off

Keep track of your pain and the fatigue impacts on your life over the calendar year.

By answering these questions each time you log-in, we'll be able to fill in the heat map to the right and organize your responses into a report.

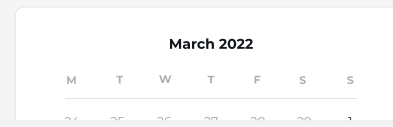
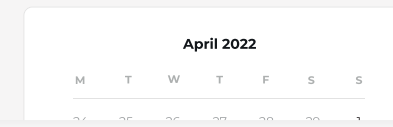
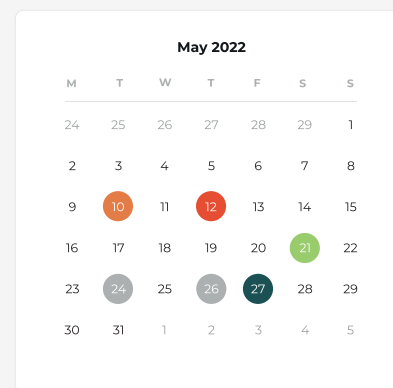
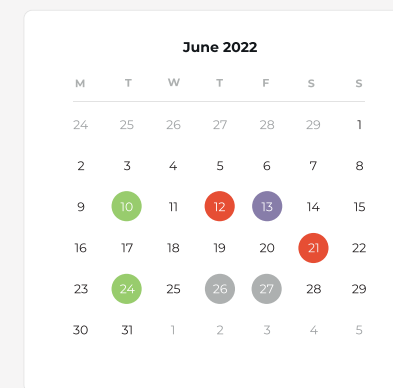
We hope this will help inform conversations with your doctor.

Pulse Survey Questions

Type of pain

Period

- Not bothered by pain
- Sharp pain
- Dull pain
- Fullness/discomfort
- Sharp pain & dull pain
- Sharp pain & fullness/discomfort
- Dull pain & fullness/discomfort
- Sharp pain, dull pain, & fullness/discomfort



PERSONAL IMPACT CALENDAR
As you complete pulse surveys,
you can utilize this calendar to
see your symptoms over time.

MEET OUR TEAM

We're lucky to have a great group of collaborators from all over the United States who advise us on how to make the Registry the best research tool it can be. This group includes researchers and clinicians, but most importantly, patient stakeholders.

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About the FOUNDATION

The PKD Foundation is the only organization in the U.S. solely dedicated to finding treatments and a cure for polycystic kidney disease (PKD) and to improving the lives of those it affects.

Since 1982, we've proudly funded more than \$50 million in PKD research and leveraged \$1.5 billion in government funding, all while serving our local communities across the country.

We're inspired by our mission. And driven by our vision.

ADPKD PATIENTS

JOIN OUR MISSION to ADVANCE PKD RESEARCH by SIGNING UP for the ADPKD REGISTRY TODAY. WE INVITE YOU to SHARE THIS REPORT with ANYONE YOU THINK WOULD BE INTERESTED IN LEARNING MORE about the PKDF'S MISSION and IMPACT.

PKD CLINICIANS

Tell your patients about this research program and encourage them to sign up.

PKD RESEARCHERS

The ADPKD Registry is a powerful recruitment tool. Do you have upcoming clinical studies? Let us help with your enrollment by spreading the word about your research and the potential impact on the patient community.



PKD FOUNDATION

Polycystic kidney disease

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FIGURE PERMISSIONS

To request use of charts and data provided in this report, contact the ADPKD Registry team by emailing registry@pkdcure.org.

SUGGESTED CITATION

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