



Family history
conversation starters



Family tree
activity



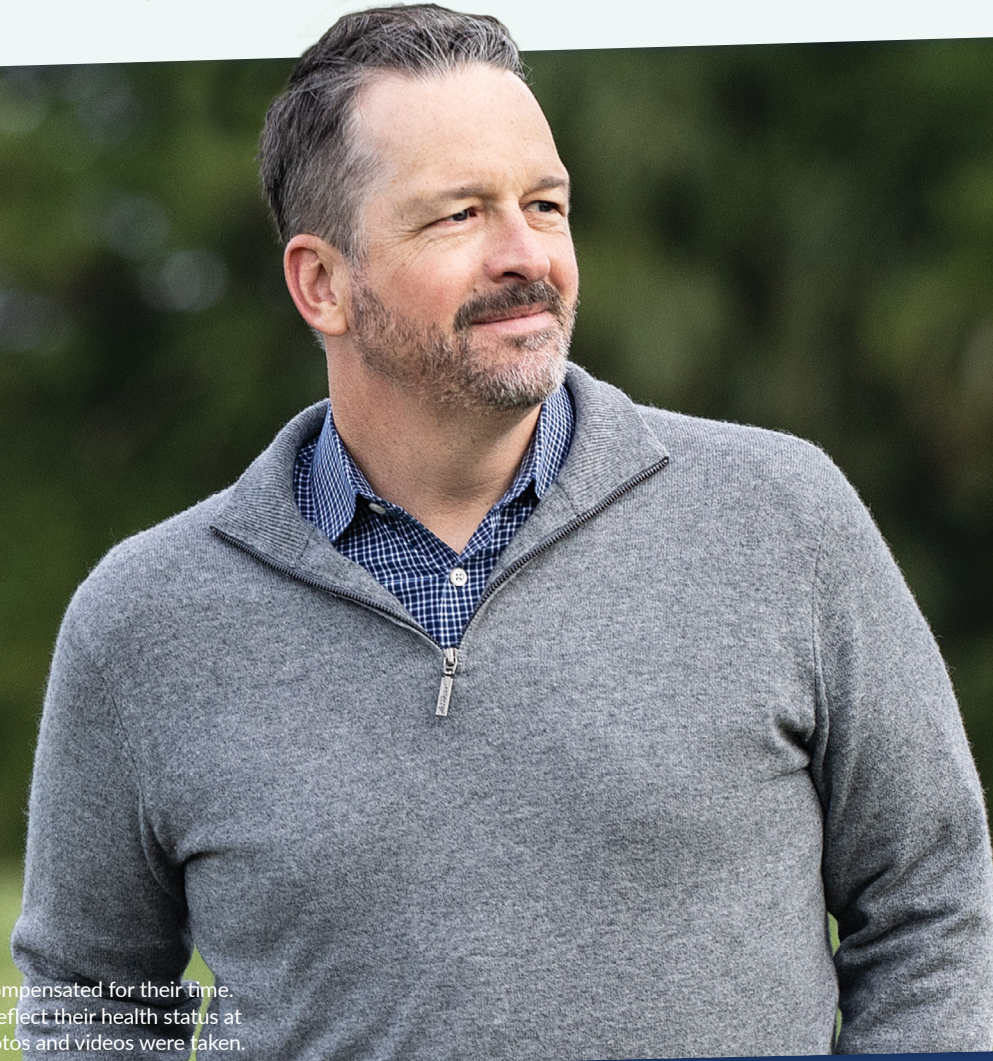
Understanding
kidney size



Doctor discussion
guides



Patient
stories



Let's talk about it

Resources to help navigate family conversations at your fingertips

We know how difficult it can be to talk about autosomal dominant polycystic kidney disease (ADPKD) with your loved ones and your doctor. These tools were designed specifically to help you navigate those tough conversations. Use the navigation bar to choose a topic you'd like to focus on.

Patients were compensated for their time.
Patient images reflect their health status at
the time the photos and videos were taken.

INDICATION and SELECT IMPORTANT SAFETY INFORMATION for JYNARQUE[®] (tolvaptan):

What is JYNARQUE?

JYNARQUE is a prescription medicine used to slow kidney function decline in adults who are at risk for rapidly progressing autosomal dominant polycystic kidney disease (ADPKD). It is not known if JYNARQUE is safe and effective in children.

Serious liver problems. JYNARQUE can cause serious liver problems that can lead to the need for a liver transplant or can lead to death. Stop taking JYNARQUE and call your healthcare provider right away if you get any of the following symptoms: feeling tired, loss of appetite, nausea, right upper stomach (abdomen) pain or tenderness, vomiting, fever, rash, itching, yellowing of the skin and white part of the eye (jaundice), dark urine.



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Family History Conversation Starters

If you're ready to talk about ADPKD and family history with your partner but don't know where to begin, try using the conversation starters below. Click on the + to see what our ambassadors have to say about their treatment journeys and family discussions.



Cari



Lauren

Real ADPKD Patients, Peer Mentors. Patients were compensated for their time. Patient images reflect their health status at the time the photos and videos were taken.

SELECT IMPORTANT SAFETY INFORMATION:

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- before you start taking JYNARQUE
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Family History Conversation Starters

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Cari

Topic: ADPKD is a genetic disease. This means that a parent with ADPKD has a 50% chance of passing it on to each of their children. It's important to discuss when to tell your children that you have ADPKD.

Try this dialogue: "As both a parent and a patient with ADPKD, I've learned that when it comes to our kids, early awareness, education, and understanding are what can lead to early detection."

Topic: Show your children that they can still live healthy and productive lives with ADPKD. Creating an open and safe environment where they can ask questions about the disease is part of that.

Try this dialogue: "As my children learn about this disease, I hope they aren't afraid. Instead, it's my hope that by watching their mom tackle ADPKD from a position of strength, that they, too, will face any potential diagnosis of their own head-on."

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- cannot feel if you are thirsty or cannot replace fluids by drinking
- have been told that the amount of sodium (salt) in your blood is too high or too low
- are dehydrated
- are allergic to tolvaptan or any of the ingredients in JYNARQUE
- are unable to urinate

Family History Conversation Starters

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Lauren

Topic: Decide when to talk to your children about ADPKD. Having a clear understanding of your family history of ADPKD could help your children plan for their future.

Try this dialogue: "I had already decided I would not hide ADPKD from my kids, just like my parents never hid my dad's diagnosis from me. My family's transparency was so important to me and allowed me to better understand what my dad was going through."

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Map Out an ADPKD Family Tree

Autosomal dominant polycystic kidney disease, or ADPKD, looks different for everyone—even within the same family. **ADPKD is a genetic disease, and a parent with ADPKD has a 50% chance of passing it on to each child.** Genetic testing is available to help confirm a diagnosis of ADPKD.

Use the chart below to map out the history of ADPKD and kidney disease in your family.

Share the completed family tree with your loved ones to help guide the conversation about ADPKD and its inheritance rate.

GRANDPARENTS:

Diagnosed with:
ADPKD
Kidney Disease



Diagnosed with:
ADPKD
Kidney Disease

PARENT:

GRANDPARENTS:

Diagnosed with:
ADPKD
Kidney Disease



Diagnosed with:
ADPKD
Kidney Disease

PARENT:



Diagnosed with:
ADPKD
Kidney Disease

Diagnosed with:
ADPKD
Kidney Disease



ME:



Diagnosed with:
ADPKD
Kidney Disease



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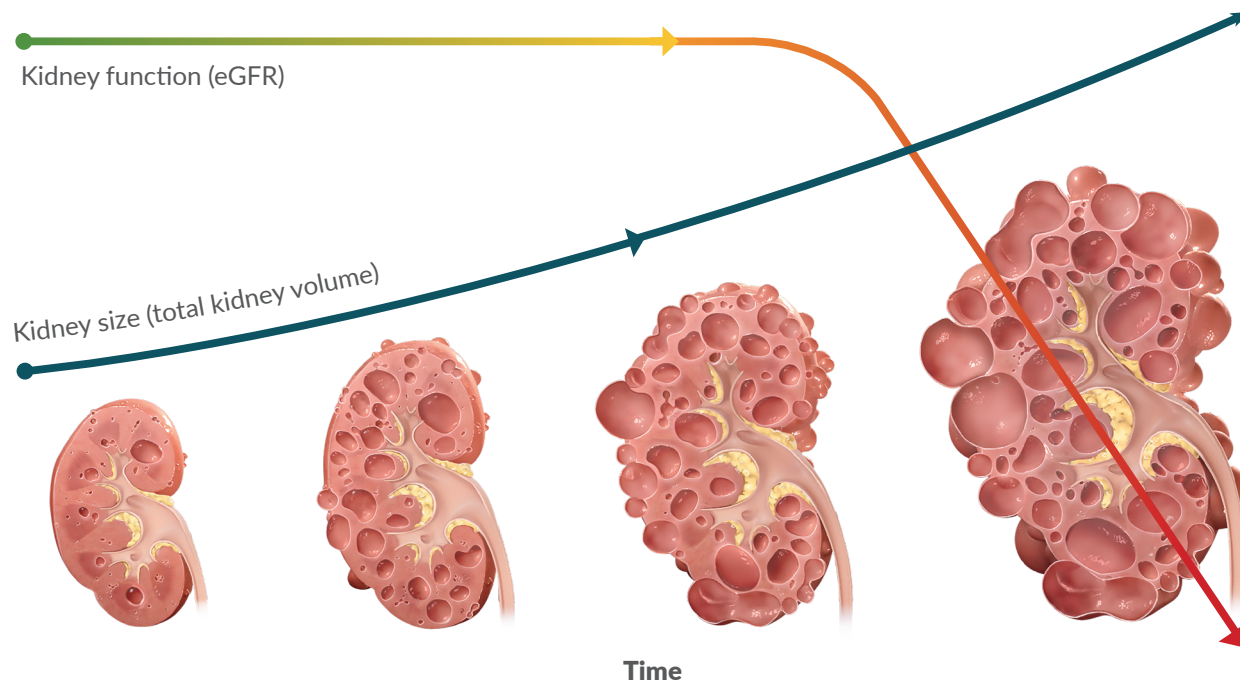
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Why do I need to measure my kidney size?

Your doctor may be monitoring your **eGFR**, or estimated glomerular filtration rate, to determine how well your kidneys are working. Did you know that measuring eGFR alone may not be telling the whole story? Another important predictor of ADPKD progression is **kidney size**, as your eGFR may remain stable while your kidneys are growing.



There are a few ways to measure kidney size

Work with a nephrologist to learn more about how your kidneys look and how rapidly your disease could be progressing. This could include a nephrologist using an **ultrasound**, **magnetic resonance imaging (MRI)**, or **computed tomography (CT)** to get a more detailed picture of your kidneys.

Your doctor will use the results from these imaging tests to calculate your **total kidney volume**, or **TKV**. After adjusting TKV based on your height, they will see if your kidney size puts you at risk for faster ADPKD progression.



CLICK THE QR CODE

to learn more about the risk factors for rapid ADPKD progression

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Patient Family Member or Caregiver



Preparing for Your Next Doctor's Appointment

Bring this page with you to your next appointment to help guide your conversation.

- Q. Should I have my kidney size measured?
- Q. What are the risk factors of rapid ADPKD progression?
- Q. Could JYNARQUE be right for me?
- Q. What are the possible side effects of JYNARQUE?

*Your ADPKD,
Your Voice*



CLICK THE CODE

or visit jynarque.com
to learn more

ADPKD=autosomal dominant polycystic kidney disease.
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Patient Family Member or Caregiver



Family History of ADPKD?





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Helpful Questions in Preparing for Your Doctor's Appointment


If you've learned that you have a family history of autosomal dominant polycystic kidney disease (ADPKD), then you may have some questions for your doctor. Bring this page with you to your nephrologist appointment to help guide the conversation.

-  What are the symptoms of ADPKD?

-  How is ADPKD diagnosed?

-  What does ADPKD progression look like?

-  How do you monitor ADPKD—are there different rates of progression?

-  Are there treatment options or management strategies for ADPKD?



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Hear how real patients have navigated their unique ADPKD journeys



“ I found out how compassionate people are in this world. If you never talk about it, you’ll never find these people in your life. ”

-Will



WILL OPENS UP

about his diagnosis and motivation for family dialogue



“ We choose to have open communication about our health, and it makes our family stronger. ”

-Anthony



ANTHONY SPEAKS

about the importance of advocating for your health



“ As my children learn about this disease, I hope they aren’t afraid. Instead, it’s my hope that by watching their mom tackle ADPKD from a position of strength that they, too, will face any potential diagnosis of their own head-on. ”

-Cari



CARI SHARES

her experiences as both a parent and patient with ADPKD

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INDICATION

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- vomiting
- fever
- rash
- itching
- yellowing of the skin and white part of the eye (jaundice)
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- are dehydrated
- are allergic to tolvaptan or any of the ingredients in JYNARQUE
- are unable to urinate

Tell your healthcare provider about all your medical conditions, including if you:

- have a history of sodium (salt) levels that are too low
- are pregnant or plan to become pregnant. It is not known if tolvaptan will harm your unborn baby. Tell your healthcare provider if you become pregnant or think that you may be pregnant
- are breastfeeding or plan to breastfeed. It is not known if tolvaptan passes into your breast milk. Do not breastfeed during your treatment with JYNARQUE. Talk to your healthcare provider about the best way to feed your baby during this time

Tell your healthcare provider about all the medicines you take, including prescription medicines, over-the-counter medicines, vitamins, and herbal supplements.

- Taking JYNARQUE with certain medicines could cause you to have too much tolvaptan in your blood. JYNARQUE should not be taken with certain medications. Your healthcare provider can tell you if it is safe to take JYNARQUE with other medicines
- Do not start taking a new medicine without talking to your healthcare provider

JYNARQUE may cause serious side effects, including:

- **Too much sodium in your blood (hyponatremia) and loss of too much body fluid (dehydration).** In some cases, dehydration can lead to extreme loss of body fluid called hypovolemia. You should drink water when you are thirsty and throughout the day and night. Stop taking JYNARQUE and call your healthcare provider if you cannot drink enough water for any reason, such as not having access to water, or vomiting or diarrhea. Tell your healthcare provider if you get any of the following symptoms:
 - dizziness
 - fainting
 - weight loss
 - a change in the way your heart beats
 - feeling confused or weak

What should you avoid while taking JYNARQUE?

Do not drink grapefruit juice during treatment with JYNARQUE. This could cause you to have too much tolvaptan in your blood.

The most common side effects of JYNARQUE are:

- thirst and increased fluid intake
- making large amounts of urine, urinating often, and urinating at night

These are not all the possible side effects of JYNARQUE. Talk to your healthcare provider about any side effect that bothers you or that does not go away. For more information, ask your healthcare provider or pharmacist.

If you have any questions about your health or medicines, talk to your healthcare professional.

To report SUSPECTED ADVERSE REACTIONS, contact Otsuka America Pharmaceutical, Inc. at 1-800-438-9927 or FDA at 1-800-FDA-1088 (www.fda.gov/medwatch).



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Click for [IMPORTANT SAFETY INFORMATION](#) on the last page.