



Understanding Your Kidneys and Kidney Disease

Learn More About a Rare Kidney Disease: Polycystic Kidney Disease (PKD)

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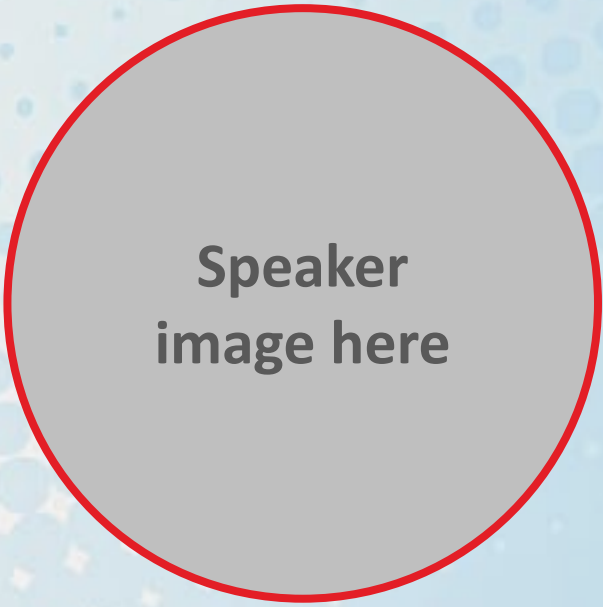
This presentation was developed in collaboration with NephU.org.

TODAY'S AGENDA



- ✓ Introductions
- ✓ Presentation
- ✓ Hear a Patient Story
- ✓ Question and Answer Session
- ✓ Available Resources
- ✓ Survey

SPEAKER INTRODUCTION



Speaker
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<Speaker name>, <Degree Title>

<Place of Employment>

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speaker information>

About Kidney Disease



TEST YOUR KNOWLEDGE

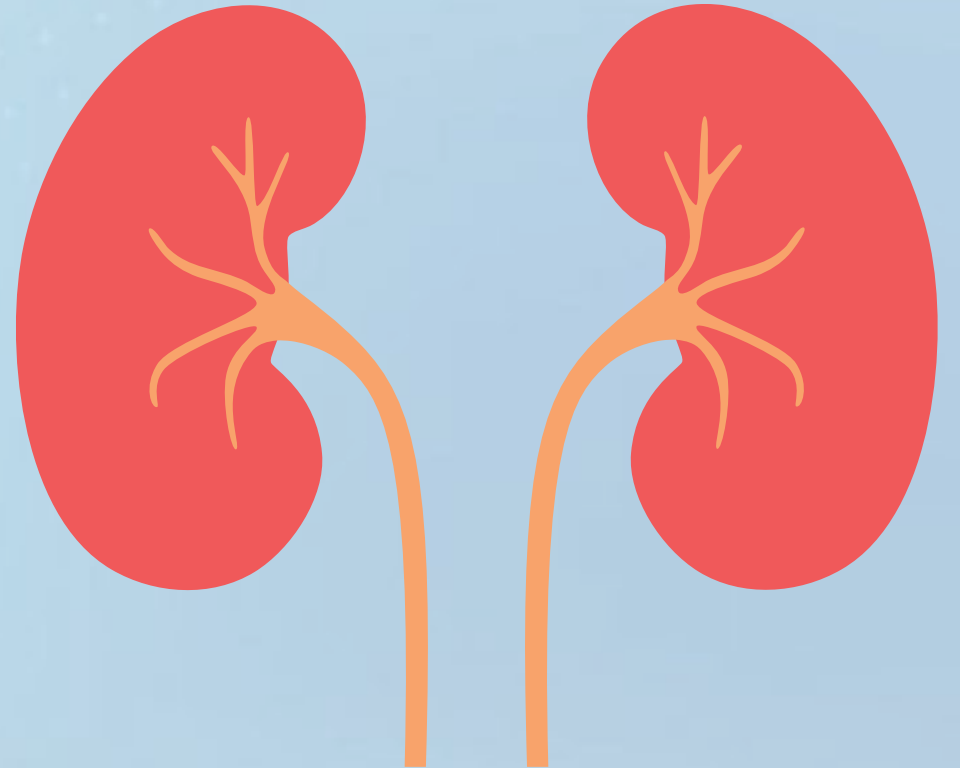


What do your kidneys do?

- A. Break down the food you eat
- B. Pass oxygen throughout your body
- C. Clean your blood
- D. Help your sleep patterns

HOW DO YOUR KIDNEYS WORK?

- Inside each kidney are millions of small units that clean your blood
- Your kidneys give needed food to your blood and take away waste you do not need

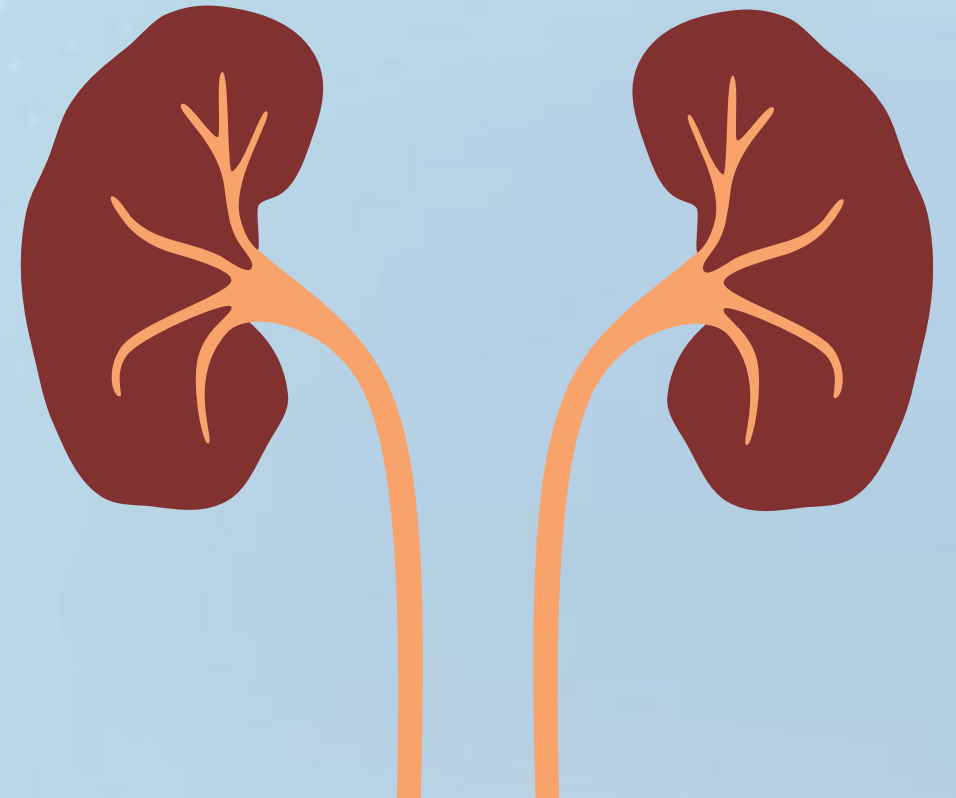


WHAT IS CHRONIC KIDNEY DISEASE (CKD)?

When kidneys don't work as well as they should over a long period of time, this is called chronic kidney disease (CKD)

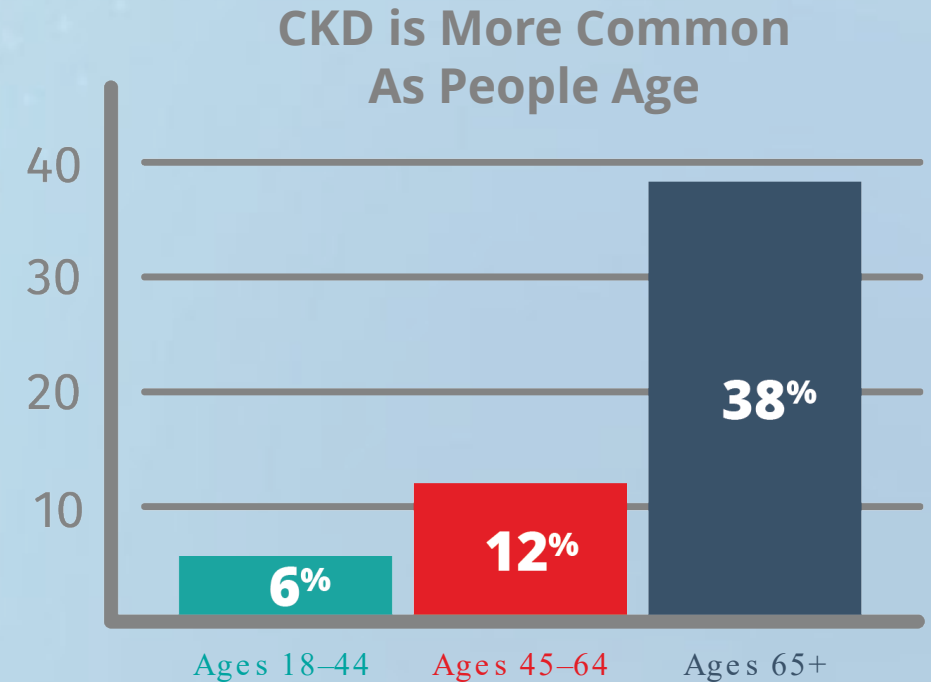
In CKD, toxic waste and extra fluid accumulate in the body and may lead to high blood pressure, heart disease, stroke, and early death.

However, people with CKD and people at risk for CKD can take steps to protect their kidneys with the help of their healthcare providers.



CKD AMONG ADULTS IN THE UNITED STATES

- More than **1 in 7** U.S. adults, that is **37 million** people in the United States are estimated to have CKD
- As many as **9 in 10** U.S. adults with CKD do not know they have CKD
- About **2 in 5** U.S. adults with severe CKD do not know they have CKD
- It is slightly more common in **women (14%)** than **men (12%)**



CKD IN BLACK AND HISPANIC/LATINO COMMUNITIES

Black and Hispanic/Latino adults have a higher risk of having CKD than White adults

16%

BLACK ADULTS

14%

HISPANIC/LATINO ADULTS

13%

WHITE ADULTS

Because of their higher risk, it is recommended that Black and Hispanic/Latino people watch for signs of kidney disease. And they should use the information shared today to see and talk to their doctor about the disease.

WHAT ARE THE RISK FACTORS?

Risk factors to look for include:

- Heart disease
- High blood pressure
- Diabetes
- Being overweight
- Family history of kidney disease
- Older age
- Have low birth weight



WHAT CAUSES CHRONIC KIDNEY DISEASE (CKD)?

Diabetes and high blood pressure are the most common causes of CKD. Other causes of CKD include:

- Heart disease
- Hypertension
- Lupus
- Polycystic Kidney Disease (PKD)
- IgA Nephropathy
- Glomerulonephritis
- Anti-GBM Disease (Goodpasture's)

Polycystic kidney disease (PKD) is a genetic condition that can also lead to CKD through the growth of many cysts

There are two types of PKD

- Autosomal recessive PKD or ARPKD
 - ARPKD is present at birth and leads to enlarged kidneys very early on
- Autosomal dominant PKD or ADPKD
 - ADPKD is the most common inherited kidney disease that typically presents in adulthood and may eventually lead to kidney replacement



ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

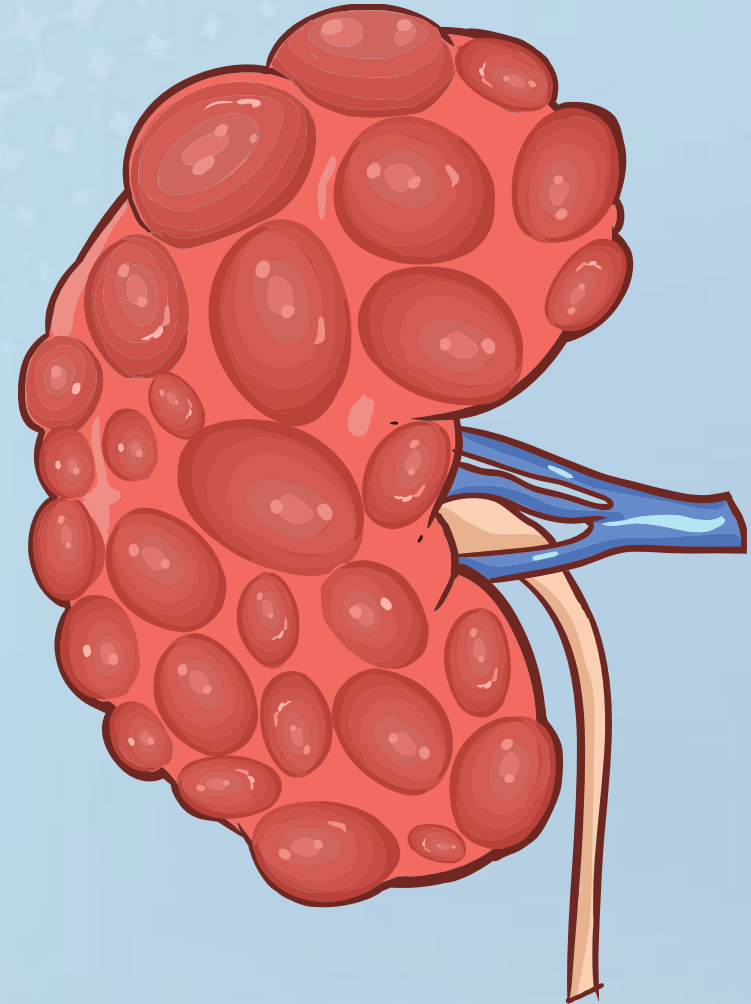
About Autosomal Dominant Polycystic Kidney Disease (ADPKD)



WHAT HAPPENS WHEN YOU GET ADPKD?

With ADPKD, your kidneys will have cysts

- Cysts are sacs that have fluid in them
- As the cysts get bigger, they keep the kidneys from working the way they should
- This could lead to kidney failure



TEST YOUR KNOWLEDGE



A healthy kidney is about the size of:

- A. a watermelon
- B. a jellybean
- C. a golf ball
- D. a fist

TEST YOUR KNOWLEDGE



A polycystic kidney can grow to the size of:

- A. a lemon
- B. a grapefruit
- C. a football
- D. a tennis ball

WHO GETS ADPKD?

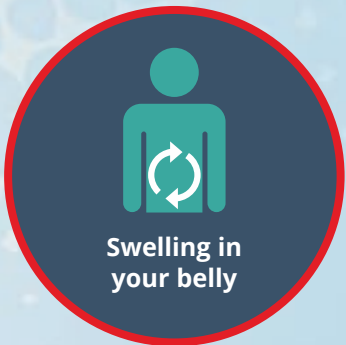
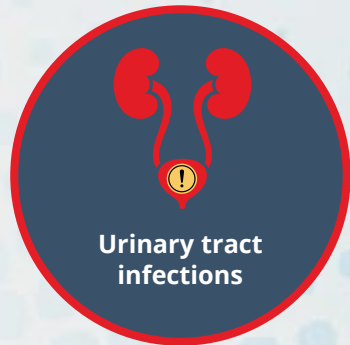
For most people, ADPKD is inherited, or passed down, from one parent

- If either the mother or father have ADPKD, a child has a 50% chance of getting the disease
- There are some people who get ADPKD without a clear family history; this happens to about 1 in 20 people



**ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE**

COMMON SIGNS AND SYMPTOMS OF ADPKD



Symptoms of ADPKD can happen slowly. Some people don't see the symptoms until they are adults (usually between 30 and 50 years old)

ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

ADPKD CAN CAUSE PROBLEMS FOR MANY PARTS OF THE BODY

Cysts can be on the kidneys years before kidney damage is found



BRAIN

You can get a bleed in your brain although it is rare

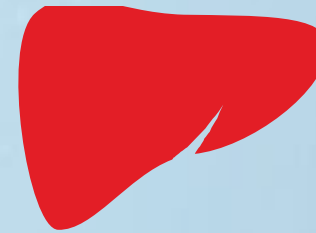
It can lead to a stroke, brain damage, coma, or death



HEART

It can lead to high blood pressure

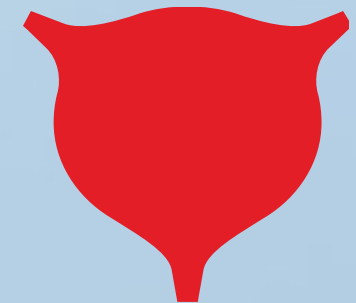
It can increase your risk of heart disease and stroke



LIVER

You can get cysts (sacs of fluid) in your liver

Cysts can cause pain, infection, or bleeding



BLADDER & URINARY TRACT

The cysts in your kidneys interfere with the normal flow of urine and might increase the chance of an infection

ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

HOW CAN A DOCTOR TELL IF YOU HAVE ADPKD?



A doctor, such as your primary care physician or a nephrologist (a doctor who treats kidneys) can tell you have ADPKD by

- ✓ Discussing your health and family history
- ✓ Ordering blood and urine tests
- ✓ Taking a picture, or image, of your kidneys
- ✓ May recommend a genetic test

**ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE**

WHAT CAN PATIENTS LIVING WITH ADPKD DO TO MANAGE THE DISEASE?

Work with their kidney doctor (also called a nephrologist) or your primary care physician to learn more about disease management options

Limit salt intake

Build a strong support system of family and friends

Eat more fruits and vegetables



Write down how they are feeling and questions for the doctor to discuss at their next appointment

Keep a close watch on their blood pressure

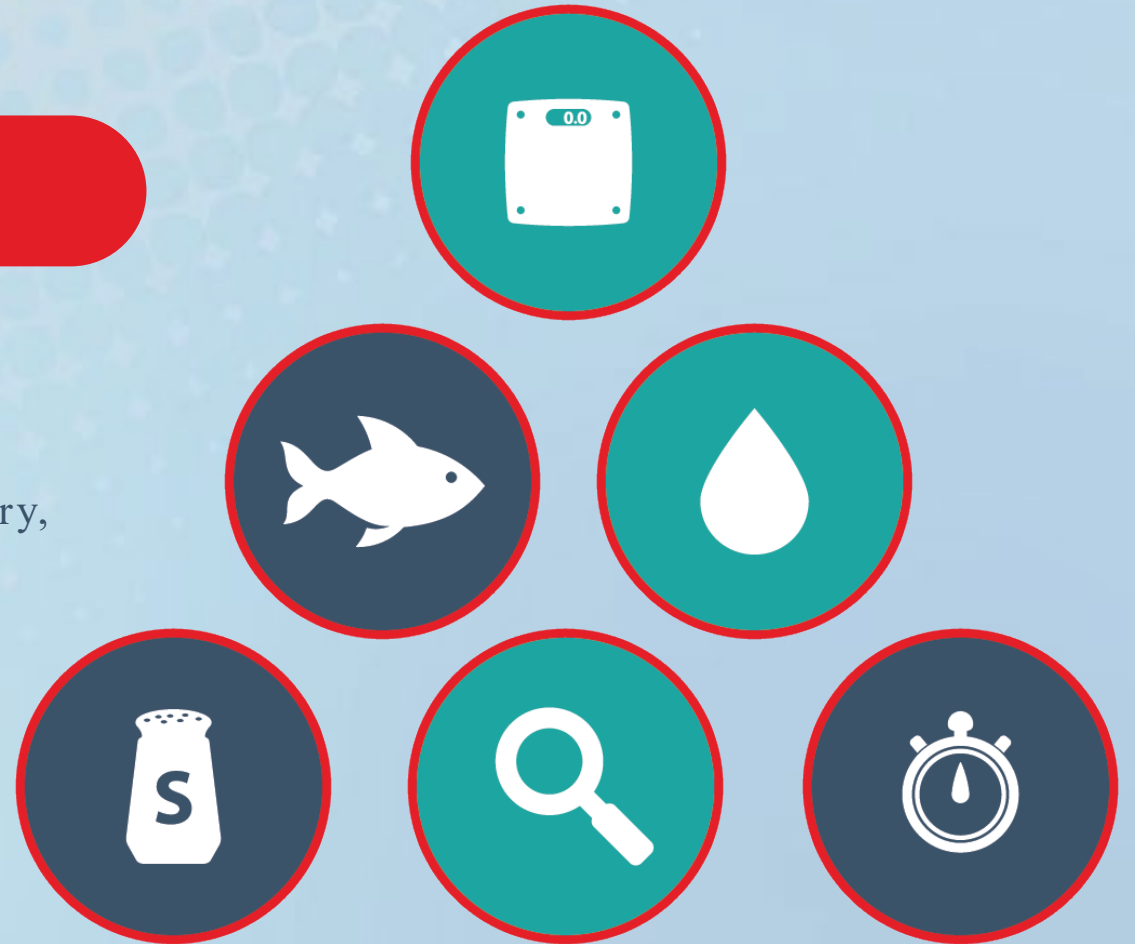
Drink more water

Exercise

ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

NUTRITION AND DIET

- Monitor calories to maintain weight goals and reduce the risk of diabetes and heart disease
- Eat moderate amounts of protein such as meat, poultry, seafood and eggs
- Drink plenty of water
- Reduce salt intake
- Monitor fats
- Regulate potassium and phosphorous intake



TALKING TO YOUR FAMILY ABOUT ADPKD

- An ADPKD diagnosis can be scary for you and your family
- Speaking with your family about ADPKD may help to reduce fears and learn more about the disease
- Here are some tips that can help you start a conversation with family members
 - Explain to your family members that if you have this disease, they might too. Suggest they also get screened
 - Encourage your children and loved ones to ask questions and share their feelings
 - Consider including your loved ones in visits to your doctor



ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

Hear a Patient Story




Question and Answer Session




www.KidneyQuestions.com

UNDERSTANDING ADPKD

“How does ADPKD affect the kidneys?”



With ADPKD, cysts develop and grow in the kidneys over time. As time passes, the growing cysts make it harder for the kidneys to function. These growing cysts eventually lead to kidney failure, which is when your kidneys can no longer work.



Take action and ask your nephrologist the following questions to gain a better understanding of how ADPKD affects your kidneys:


- What steps can I take to keep my kidneys working as long as possible?
- What are the possible complications I should know that are related to ADPKD?
- Even though there is no cure for ADPKD, what treatment options are available, if appropriate?
- Does having ADPKD mean I will need a kidney transplant or dialysis?



Notes:

Keep your pharmacist informed.
In addition to asking your doctor these questions, make sure to talk to your pharmacist about ADPKD and any over-the-counter medications you may be taking.

For more information, visit ADPKDquestions.com.

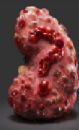
ADPKD=autosomal dominant polycystic kidney disease.

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IMPORTANCE OF KIDNEY SIZE

“What are some questions to ask my nephrologist about my kidney size?”



We know that learning more about your ADPKD diagnosis can be challenging at times, but you are not alone. Ask your nephrologist to take a close look at the size of your kidneys and number of cysts. It is crucial to monitor your kidney size because it is a predictor of disease progression for ADPKD and may grow larger over time.



To gain a better understanding and to start a conversation, ask your nephrologist the following questions at your next visit:


- Doctor, can you assess my kidney size?
- What tests are used to measure the size of my kidneys?
- How long will it take to assess my kidney size?
- When can I expect my results?



Notes:

Be proactive in partnering with your nephrologist.
The questions you ask your nephrologist can change the future of your ADPKD.

For more information, visit ADPKDquestions.com.


ADPKD=autosomal dominant polycystic kidney disease.

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

LIVING WITH ADPKD







“What are some tips to help manage kidney health?”



Follow these tips to help keep a healthy lifestyle for your kidneys:


Eat a heart-healthy diet:



What to eat 	What to avoid 
Whole foods, such as: <ul style="list-style-type: none">• Fruits• Vegetables• Nuts• Whole grains and high-fiber carbohydrates that are low in sodium	<ul style="list-style-type: none">• Food or drinks that contain lots of sodium, as this may cause your blood pressure to rise• Smoking may cause your blood pressure to rise, which can cause damage to your kidneys

-  **Exercise regularly** to improve blood pressure, sleep, heart health, bone mass, and more. Make sure to check with your physician prior to engaging in exercise.
-  **Practice relaxation techniques**, such as meditation and breathing, to help reduce stress.
-  **Drink lots of water** to help suppress vasopressin, an antidiuretic hormone that stimulates cyst growth.
-  **Pay attention to your body** to stay aware of your health so you can respond quickly and correctly to any issues.
-  **Take medications as directed by your doctor** and check with your healthcare provider before you make a change.
-  **Keep all your appointments** in order to schedule and manage checkups and routine testing. Regular appointments will help you and your healthcare team keep track of your condition.

Please consult your doctor about any lifestyle or diet modifications you may need to make. For more information, visit ADPKDquestions.com.

ADPKD=autosomal dominant polycystic kidney disease.

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Resources available in English and Spanish



Talking With Your Family and Friends

Talking about your ADPKD diagnosis and condition is your decision to make. You decide if, when, and to whom you share your story. If you decide to talk about it, do it in a way that feels most comfortable to you.

Talking with family members about ADPKD

Because ADPKD is genetic, meaning it runs in families, it can affect the family as a whole. This is one reason you may find it essential to talk with family about your diagnosis. In fact, many PKD experts suggest you share information about your condition, especially with adult family members. This gives them the chance to learn about what is going on with you, become educated about ADPKD, and possibly make informed choices about their own medical care.


Below are some important reasons for talking about your ADPKD diagnosis with family members:

- It gives you the chance to share how you are affected and learn how they are affected.
- Early diagnosis may mean better disease management by treating symptoms such as high blood pressure and making lifestyle changes to help protect kidney function.
- Early treatment may help manage disease-related complications.
- Early screening and diagnosis may make it possible to continue leading an active and productive life for longer.



Talking about ADPKD is a personal decision. If you decide to talk about it, do it in a way that you are comfortable and feels easiest to you.

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Talking With Employers

Talking about your ADPKD diagnosis and condition is your decision to make. You decide if, when, and to whom you share your story. If you decide to talk about it, do it in a way that feels most comfortable to you.

Talking with employers about ADPKD

You may have concerns about talking with your employer about your chronic condition. This is understandable. However, if it feels right to you and you decide to talk with your employer about your ADPKD, below are some considerations:

- **Be prepared** to educate your employer on ADPKD and CKD. Point them to resources and organizations to learn more.
- **Discuss** both your concerns around how your condition may or may not impact your ability to work as far as capabilities, limitations (if any), and time off requested.
- If you feel **reasonable adjustments** can be made to help you complete your work OR navigate your day, ask. Employers may not know what can help.
- **Topics you and your employer may want to discuss:**
 - Changing your work schedule to allow for healthcare visits
 - Making up time taken off for medical reasons
 - Physical limitations (eg, travel, lifting heavy objects), if any
 - Flexibility with restroom breaks
 - What to do in case of an emergency
- **Discuss** the possibility of assigning any of your non-essential tasks to other employees, at your request.

Employers may not know about tax credits available for making changes to the workplace, such as flexible schedules.

Questions? Concerns? Never hesitate to ask. You have a right to know everything about your health and your care.

To help prepare for your discussion with your employer, consider role playing how it may go with a loved one or friend.

Communication can be an important part of coping with chronic diseases like ADPKD. Again, talking about ADPKD is a personal decision. If you decide to talk with your employer about your condition, it gives you the chance to be open and your employer the chance to provide support.

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Apoyo para el paciente y el cuidador

¿Dónde puedo encontrar ayuda para la ADPKD?

Hay muchas organizaciones y recursos disponibles en la comunidad sobre la enfermedad renal poliquística, o PKD por sus siglas en inglés, para ayudarlo a usted y a su ser querido con ADPKD. Para obtener más información y conectarse con otras personas que viven experiencias similares, visite los sitios a continuación.

Fundaciones y sitios informativos*

Enfoque en la ADPKD

- PKD Foundation (Fundación PKD)** | pkdcure.org
 - Dedicada a la investigación y educación de la enfermedad renal poliquística (PKD)
- PKD International (PKD Internacional)** | pkdinternational.org
 - Alianza global de organizaciones de pacientes de todo el mundo, dedicada a encontrar una cura y ofrecer educación sobre la PKD.

Enfoque renal o de salud general.

- American Association of Kidney Patients, AAKP (Asociación Norteamericana de Pacientes Renales)** | aakp.org
 - Educación y defensa para pacientes renales en los Estados Unidos
- American Kidney Fund (Fondo Norteamericano del Riñón)** | kidneyfund.org
 - Preparación asistencial caritativa a pacientes en diálisis que necesitan ayuda con los costos del tratamiento para la insuficiencia renal.
- MedlinePlus** | medlineplus.gov
 - Un servicio de la Biblioteca Nacional de Medicina de los EE. UU., con información sobre más de 900 enfermedades
- National Kidney Foundation (Fundación Nacional del Riñón)** | kidney.org
 - Apoyo entre colegas e información para pacientes renales

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Cómo apoyar a su ser querido que padece de ADPKD

Comunicación sobre los cuidados

Hablar sobre la ADPKD es una decisión personal y puede ser difícil para su ser querido que enfrenta esta afección. No saber qué decir puede aumentar su estrés y hacer más difícil poder cuidarlo.

- Sea delicado, pero hágale saber a su ser querido que usted estará allí cuando quiera hablar.
- Ayude a su ser querido a prepararse para las citas médicas; esto puede ayudar a abrir la comunicación.
- Recuérdelo a su ser querido que cuanto más sepa de su afección, más podrá apoyarlo.



Cómo ayudar a su ser querido a prepararse para las citas médicas


Como cuidador de una persona con ADPKD, se le puede pedir que acuda a las citas médicas. Puede ayudar a preparar a su ser querido para las citas, a fin de que ambos las aprovechen al máximo. Recuerde: es muy importante ser abiertos y honestos. Conversar sobre las inquietudes e informar con precisión lo que está sucediendo puede ayudar a los proveedores de atención médica a comprender todos los aspectos. Así podrán ofrecer la ayuda y el apoyo necesarios.

Registre las preguntas o inquietudes antes de la cita y lleve sus anotaciones el día de la cita. Esto puede ayudarlo a mantenerse enfocado en lo que es importante.

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Infographics



Understanding Your Kidneys and Kidney Health

Learn more about polycystic kidney disease (PKD)

ABOUT YOUR KIDNEYS


- Kidneys play an important role in keeping you healthy.
- Inside each kidney are millions of small units called nephrons that clean your blood. Your kidneys give needed nutrients to your blood and take away waste you do not need.

CHRONIC KIDNEY DISEASE

- When kidneys don't work as well as they should over a period of time, this is called chronic kidney disease (CKD).
- CKD may cause your kidneys to fail.
- Kidney failure means there may be a need for kidney replacement therapy (such as dialysis, or a kidney transplant).
- Kidney disease can happen to both men and women, and to people of all races and ethnicities.
- However, Black and Hispanic/Latino people have higher rates of diabetes and high blood pressure that increase the risk for kidney disease. That is why it is important to get checked for kidney disease if you experience symptoms.

AUTOSOMAL DOMINANT POLYCYSTIC KIDNEY DISEASE

- Polycystic kidney disease (PKD) is a genetic condition passed down in families that can also lead to CKD through the growth of many cysts. Cysts are sacs filled with fluid.
- One type of PKD is autosomal dominant polycystic kidney disease (ADPKD). Autosomal dominant means that it can be passed from parent to child.
- With ADPKD, both the cysts and your kidneys can grow over time and prevent your kidneys from working the way they should.
- ADPKD signs and symptoms include back pain, high blood pressure, blood in your urine, urinary tract infection, and enlarged kidneys.
- A doctor, such as your primary care physician, or a nephrologist (a doctor who treats kidneys) can tell whether you have ADPKD by discussing your health and family history, ordering blood and urine tests, and taking a picture, or image, of your kidneys.




Take control of your health

- Know your family history of kidney disease.
- Speak to your doctor about kidney disease and ADPKD.

SCAN ME [Visit www.kidneyquestions.com](http://www.kidneyquestions.com)

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Conozca sus riñones y su salud renal

Obtenga más información sobre la nefropatía poliquística (NFP)

ACERCA DE SUS RIÑONES


- Los riñones desempeñan una importante función para que usted mantenga su salud.
- Dentro de cada riñón hay millones de pequeñas unidades, llamadas nefrones, que limpian su sangre. Los riñones aportan nutrientes necesarios a la sangre y eliminan los desechos que usted no necesita.

ENFERMEDAD RENAL CRÓNICA

- Cuando los riñones no funcionan tan bien como deberían durante un período, la afección se denomina enfermedad renal crónica (ERC).
- La ERC puede hacer que sus riñones fallen.
- La insuficiencia renal significa que puede ser necesario una terapia de reemplazo renal (como la diálisis o un trasplante de riñón).
- La enfermedad renal puede afectar tanto a hombres como a mujeres y a personas de todas las razas y orígenes étnicos.
- No obstante, las tasas de diabetes e hipertensión arterial son superiores entre las personas negras e hispanas o latinas, lo que aumenta el riesgo de sufrir una enfermedad renal. Por eso, si tiene algún síntoma, es importante hacerse un examen médico respecto de enfermedades renales.

NEFROPATÍA POLIQUÍSTICA DOMINANTE AUTOSÓMICA

- La nefropatía poliquística (NFP) es una enfermedad genética de carácter hereditario que puede llevar también a la ERC a través de la generación de muchos quistes. Los quistes son sacos llenos de líquido.
- Un tipo de NFP es la nefropatía poliquística dominante autosómica (NFPDA). "Dominante autosómica" significa que se puede transmitir de padre/madre a hijo/a.
- Con la NFPDA, los quistes y sus riñones pueden aumentar de tamaño con el tiempo e impedir que sus riñones funcionen de la manera en la que deberían.
- Los signos y síntomas de la NFPDA incluyen dolor de espalda, hipertensión arterial, sangre en la orina, infección del tracto urinario y riñones hipertrofiados.
- Un médico, como su médico de atención primaria o un nefrólogo (un médico que trata los riñones) puede saber si usted tiene NFPDA si conversa con usted sobre su salud y antecedentes familiares, pide análisis de sangre y orina, y toma una fotografía o imagen de sus riñones.



Tome el control de su salud

- Conozca sus antecedentes familiares de enfermedad renal.
- Hable con su médico sobre la enfermedad renal y la NFPDA.

ESCANÉAME [Visite www.kidneyquestions.com](http://www.kidneyquestions.com)

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In Summary

What you need to remember about ADPKD



SUMMARY

- When kidneys don't work as well as they should over a long period of time, this is called chronic kidney disease (CKD)
- CKD can get worse over time and may cause your kidneys to fail
- Autosomal dominant polycystic kidney disease (ADPKD) means your kidneys have cysts
- Both the cysts and your kidneys can grow over time and keep your kidneys from working the way they should
- If either the mother or father have ADPKD, a child has a 50% chance of getting the disease



ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

SUMMARY *(Continued)*

- ADPKD can happen to men and women, to people of all races and ethnicities who live anywhere in the world
- ADPKD signs include back pain, high blood pressure, blood in your urine, urinary tract infection, and enlarged kidneys
- ADPKD is often diagnosed in patients between the ages of 30 and 50, depending on when symptoms start
- Talk to your doctor if you see any signs; your doctor will help to manage and treat the disease
- Finding ADPKD early is very important



ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE

TAKE CONTROL OF YOUR HEALTH

Know your family history of kidney disease

**Speak to your doctor about kidney disease
and ADPKD**

Visit www.KidneyQuestions.com



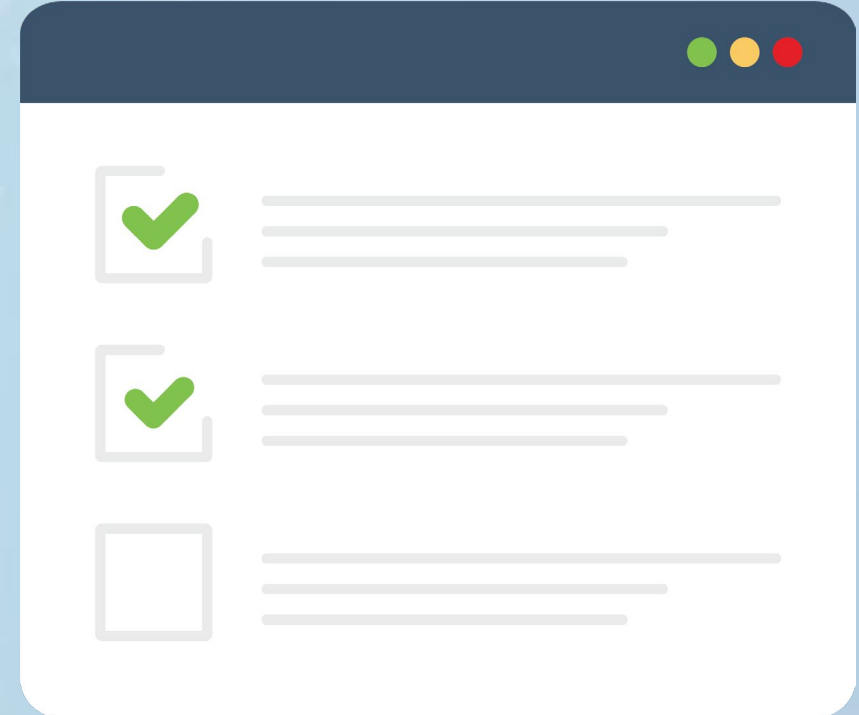
**ADPKD = AUTOSOMAL DOMINANT
POLYCYSTIC KIDNEY DISEASE**

Survey



SURVEY

We would like your feedback so we can keep improving our program. Please complete a quick survey and let us know your thoughts *(your answers will be confidential)*



The illustration shows a survey form with three items. Each item consists of a checkbox on the left and three horizontal lines representing text input on the right. The first two items have a green checkmark inside their checkboxes, indicating they are completed. The third item has an empty checkbox, indicating it is not yet completed. The form is presented within a window-like frame with a dark blue header and three colored window control buttons (green, yellow, red) in the top right corner.

THANK YOU FOR ATTENDING