ADPKD
Patient Forum

Questions, answers and discussions about living with ADPKD

KEY ROLES OF HEALTHY KIDNEYS

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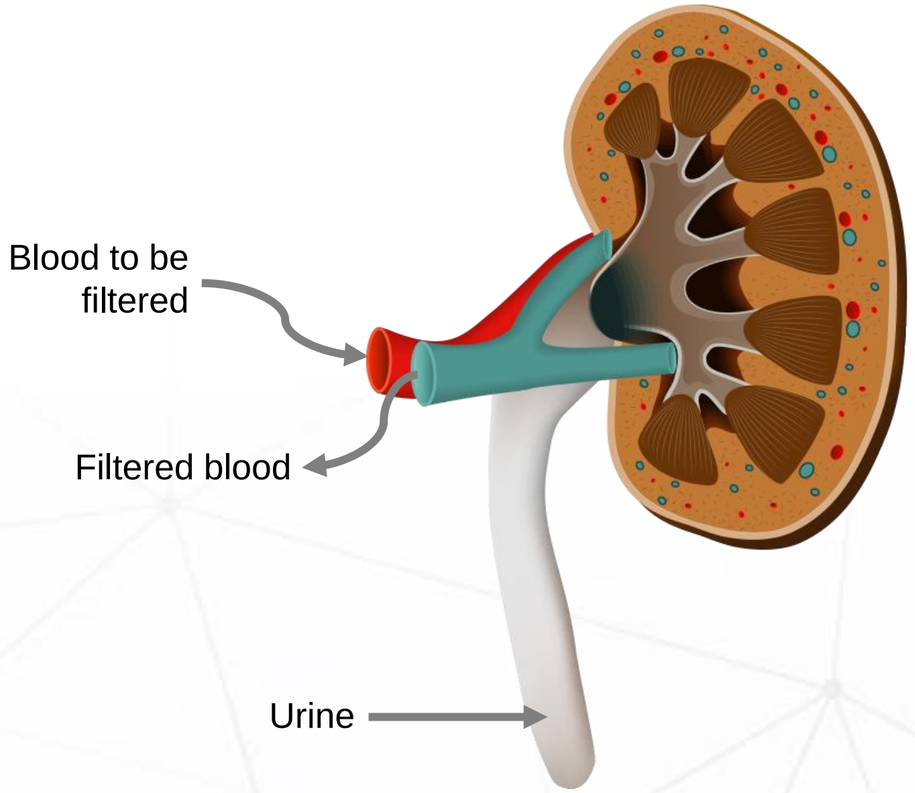
- The kidneys filter approximately 200 liters of blood daily to remove water, waste and maintain healthy blood composition

- Other important roles
  - Red blood cell production
  - Blood pressure control
  - Bone and mineral metabolism

Healthy Kidney



Adapted from www.endpkd.ca

WHAT IS ADPKD?

ADPKD Patient Forum

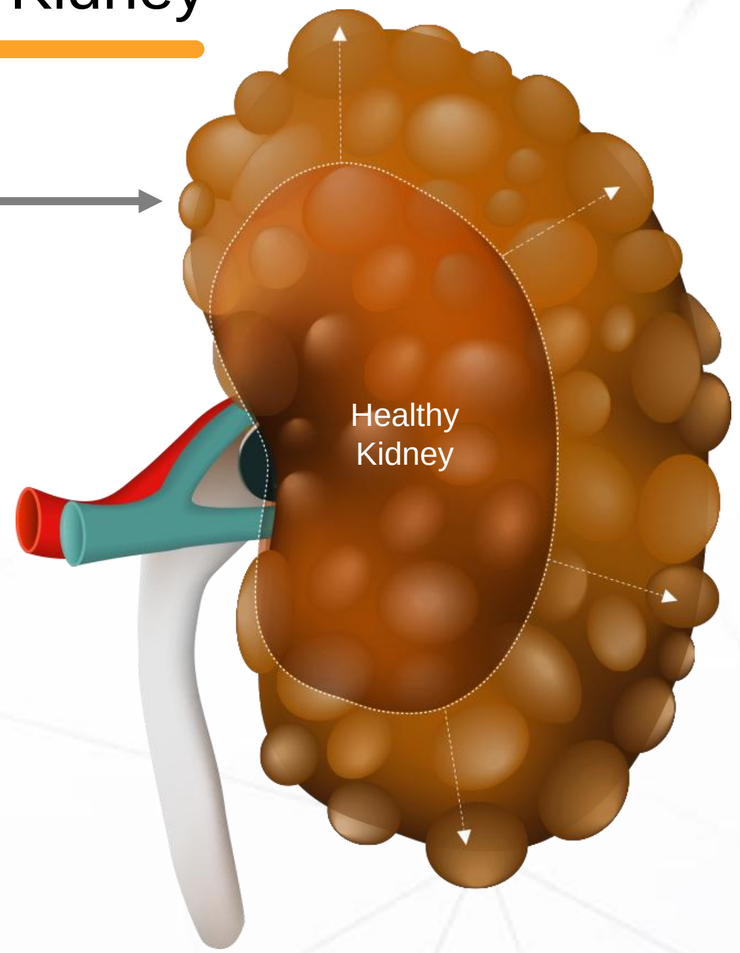
Autosomal **D**ominant **P**olycystic **K**idney **D**isease

A genetically inherited disease that affects about 1 in 500 people, although new cases (i.e. no family history) can occur

- **Healthy Kidney**
  - Size of a fist
  - Weighs about 1/3 of a pound

- **ADPKD Kidney**
  - Cysts develop in both kidneys
  - Kidneys can increase in both weight and size
  - There may be just a few cysts or many
  - Cysts range in size from a pinhead to the size of a grapefruit

ADPKD Kidney



Adapted from www.endpkd.ca

WHAT ARE THE CYSTS IN ADPKD?

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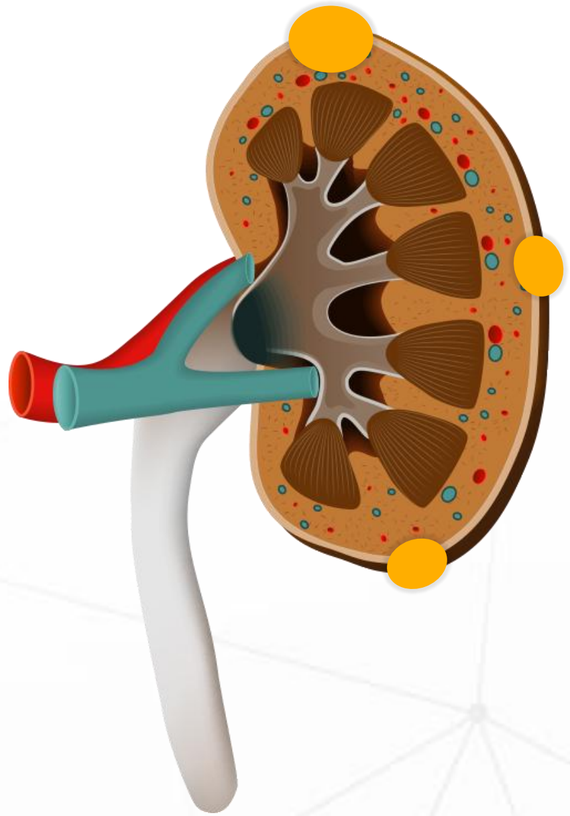
- Kidneys are made up of about a million tiny filtering units called nephrons
- A cyst in the kidney begins as an outpouching of the nephron, like a blister, and can occur anywhere along the nephron's length
- Over time with ADPKD, more of these cysts develop and grow as they are filled with fluid

CYSTS



ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

WHAT MIGHT I EXPERIENCE EARLY IN THE COURSE OF ADPKD?

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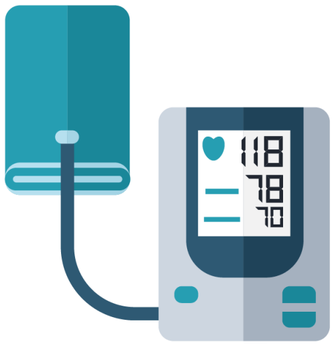
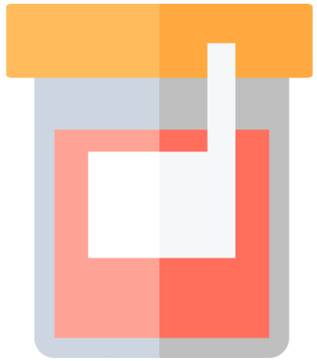
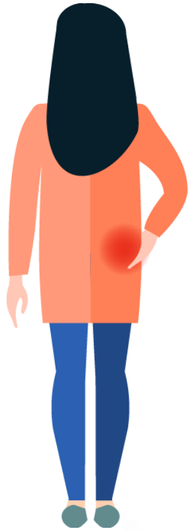
SOME FIRST SIGNS AND SYMPTOMS MAY INCLUDE:



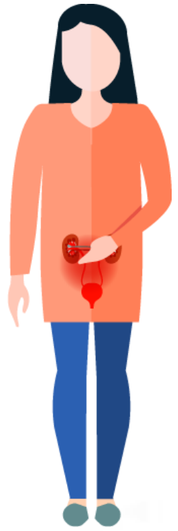
High blood pressure



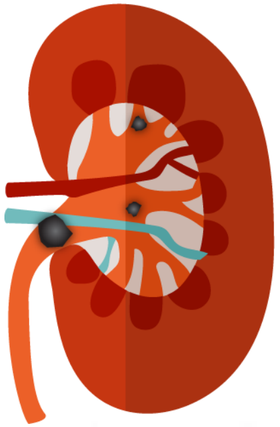
Blood in the urine



A feeling of heaviness or pain in the back, sides, or abdomen



Urinary tract / cyst infection



Kidney stones

HOWEVER, THERE ARE OFTEN NO SYMPTOMS AT ALL

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.endpkd.ca

WHAT MIGHT I EXPERIENCE LATER IN THE COURSE OF ADPKD?

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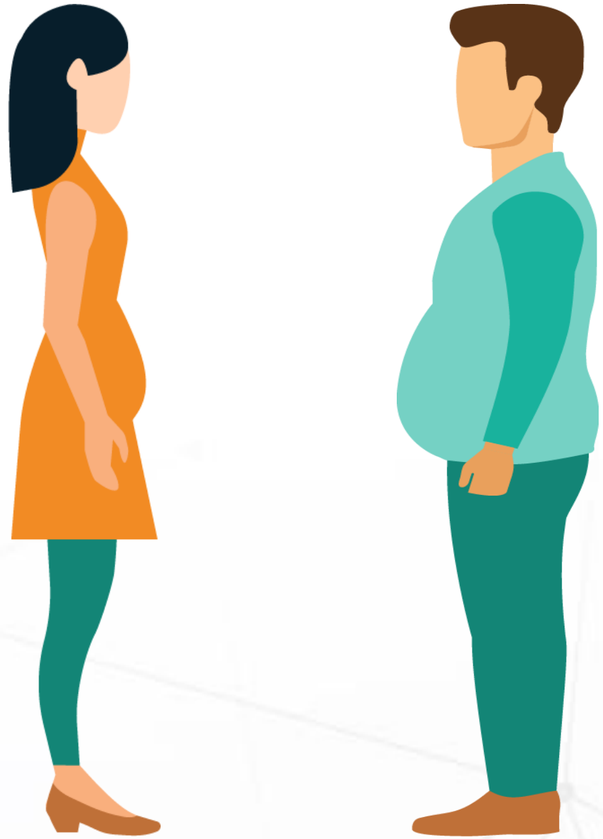
AS CYSTS AND KIDNEYS CONTINUE TO GROW

- Other organs can become crowded, causing discomfort or even pain
- The kidneys become so large that they cause the midsection to bulge in severe cases
- Kidney function may decline as cysts enlarge
- NB: Cysts may also develop on other organs (*e.g.*, liver, pancreas), contributing to discomfort/pain and abdominal enlargement
- Women are often mistaken as being pregnant, men with beer bellies



ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.endpkd.ca

HOW IS ADPKD DIAGNOSED?

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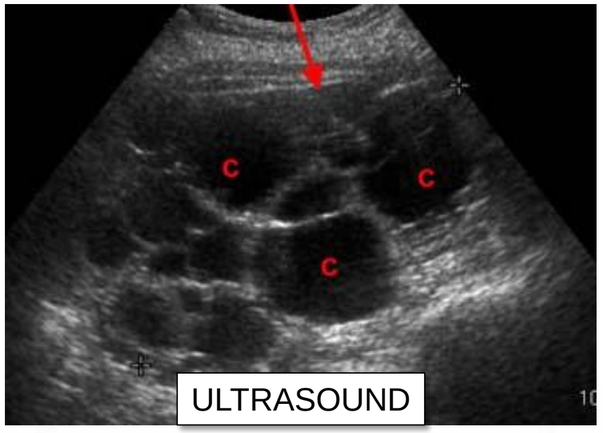
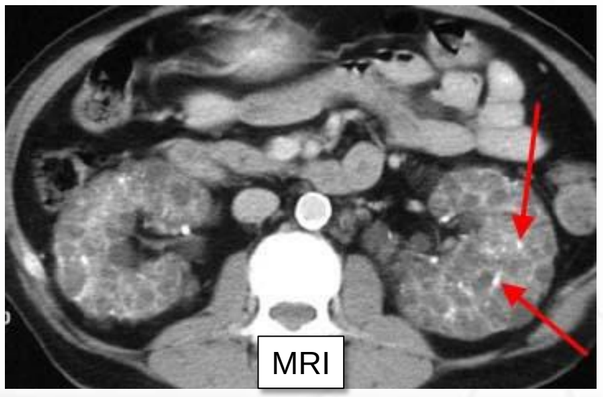
- **ADPKD may be suspected if:**
  - There is a family history of PKD
  - There are signs and/or symptoms (e.g., blood in the urine, high blood pressure [in some cases at an early age], kidney stones, chronic pain or heaviness in the back, sides or abdomen, urinary tract infections)
- **Not all cysts are PKD**
  - Other kidney diseases can also lead to kidney cysts
  - The number of cysts needed to make a diagnosis varies according to age and other risk factors (e.g., family history)
- **A diagnosis is confirmed by imaging the kidneys with:**
  - Ultrasound;
  - CT scan; and/or
  - MRI
- **Genetic testing can also be used to confirm a diagnosis**

KIDNEY CYSTS IN ADPKD SHOWN BY





ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; PKD: **P**olycystic **K**idney **D**isease; CT: **C**omputed **T**omography; MRI: **M**agnetic **R**esonance **I**maging
Adapted from www.endpkd.ca

THE GENETICS OF ADPKD: TWO MAIN DISEASE TYPES

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ADPKD IS CAUSED BY A MUTATION IN ONE OF TWO GENES

	PKD1	OR	PKD2
Occurrence in ADPKD cases	80-85%		15-20%
Disease progression for declining kidney function	Faster		Slower
Complications e.g. Cyst, hypertension, loss of kidney function at an earlier age	More		Fewer

Even among people with the same genetic type (and members of the same family), there can be substantial differences in the course of the disease, although family history can be helpful as a guide.

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

WHAT DOES MY ADPKD MEAN TO MY FAMILY?

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- The chances of inheriting ADPKD from an affected parent to a child is 50%
- In individual families, the number of affected children is entirely due to chance

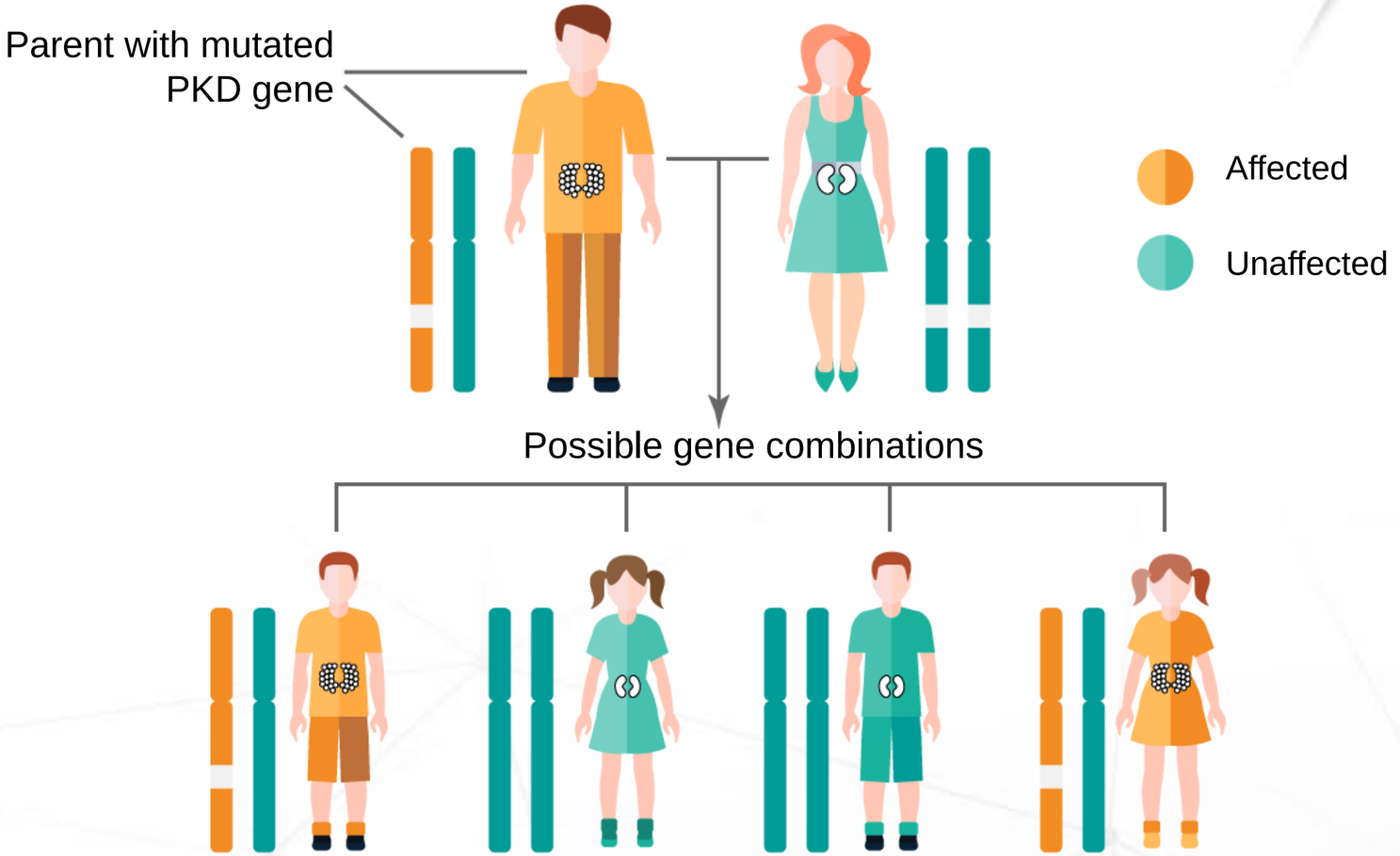

Image source: PKD Foundation of Canada

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

SHOULD MY FAMILY GET SCREENED FOR ADPKD?

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WHY TO GET SCREENED

Early detection in asymptomatic individuals can allow:

Tracking and management of complications

A better understanding of possible risks related to family planning

---

Implementation of lifestyle modifications

Possibility of early therapy to delay disease progression

Kidney donor consideration

WHY TO NOT GET SCREENED

Increased psychological burden of having a chronic disease

Diagnosis of an inherited kidney disease can limit access to life and health insurance coverage

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Consider critical illness and insurance before getting screened

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This can affect decisions regarding change of employment

At an early age, it may be difficult to confirm a diagnosis (by imaging)

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.endpkd.ca

HOW CAN FAMILY MEMBERS BE SCREENED FOR ADPKD?

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- Imaging (typically ultrasound)
- Genetic testing, looking for:
  - Any genetic abnormalities (full gene sequencing)
  - Specific PKD mutation (familial mutation analysis)
- If a family member requests testing, speak to your healthcare team about options in your area

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; CT: **C**omputed **T**omography; MRI: **M**agnetic **R**esonance **I**maging
Adapted from www.endpkd.ca

RECOMMENDATIONS FOR PEOPLE WHO DO NOT WANT TO BE SCREENED FOR ADPKD

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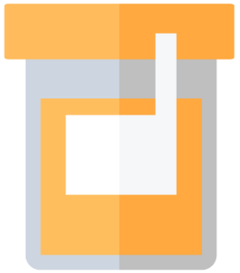
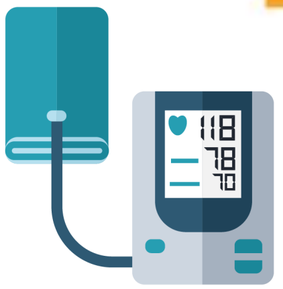
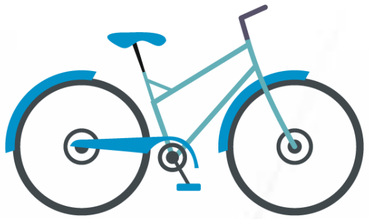
Regular checkups with family doctor



Regular urine tests and blood work



Monitor blood pressure



Healthy lifestyle choices

Be vigilant for any abnormalities that suggest ADPKD might be present.

If abnormalities are observed, consider diagnostic testing

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; CT: **C**omputed **T**omography; MRI: **M**agnetic **R**esonance **I**maging

WHAT ARE THE POSSIBLE COMPLICATIONS OF ADPKD?

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KIDNEY-RELATED

Pain and discomfort

Kidney stones

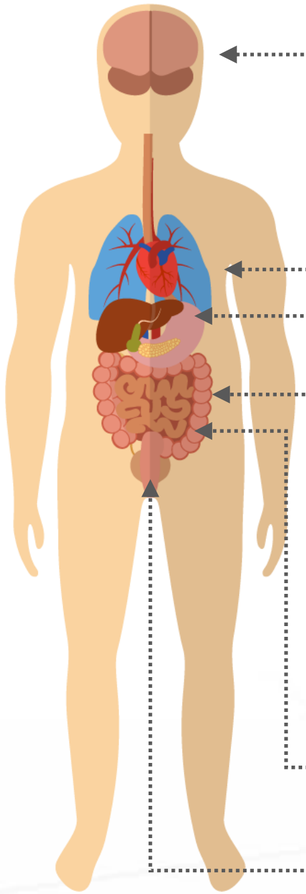
Cyst bleeds

Infected cysts

High blood pressure

Blood in urine

Worsening kidney function / kidney failure



NON-KIDNEY-RELATED

Brain aneurysm*

Cardiovascular*
(e.g., heart valve problems)

Liver cysts

Hernias of the abdomen

Diverticulosis*
(outpouchings of the large intestine)

Seminal vesicle cysts

Not everybody with ADPKD will experience all of these complications

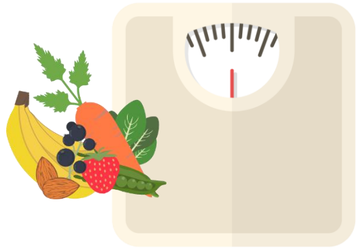
*Less frequent

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease

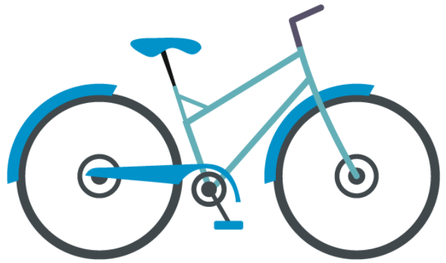
Adapted from www.endpkd.ca; and Harris PC, et al. Gene Reviews, last updated June 11, 2015.

TIPS FOR OPTIMAL KIDNEY HEALTH IN ADPKD

ADPKD Patient Forum



Maintain healthy diet and body weight



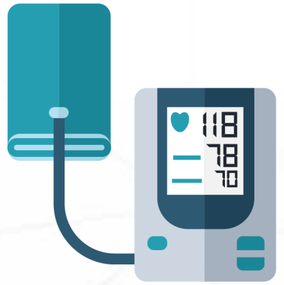
Exercise regularly

Avoid smoking

Avoid excessive caffeine intake

Ensure you are drinking enough water

Avoid non-steroidal anti-inflammatory drugs



Keep your blood pressure in the target range

There are medications that may help slow kidney/cyst growth.

Talk to your doctor about whether or not you can benefit from these.

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.endpkd.ca

WHO MIGHT BE PART OF MY ADPKD TEAM?

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PERSONAL SUPPORT SYSTEM

Family / Friends / Coworkers

Various Support Organizations
e.g. PKD Foundation of Canada

HEALTHCARE PROFESSIONALS

Family Doctor

Specialists
Nephrologist (Kidney)
Hepatologist (Liver)
Transplant

Dietitian

Pharmacist

Social Worker

Who your team consists of and their level of involvement will depend on many factors, including where you live and what resources are available near you.

In the early stages of one's ADPKD diagnosis, your family doctor and nephrologist will be your primary healthcare team, and they will advise you when other team members and resources will be beneficial.

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

THE PATIENT PERSPECTIVE: RECEIVING THE DIAGNOSIS

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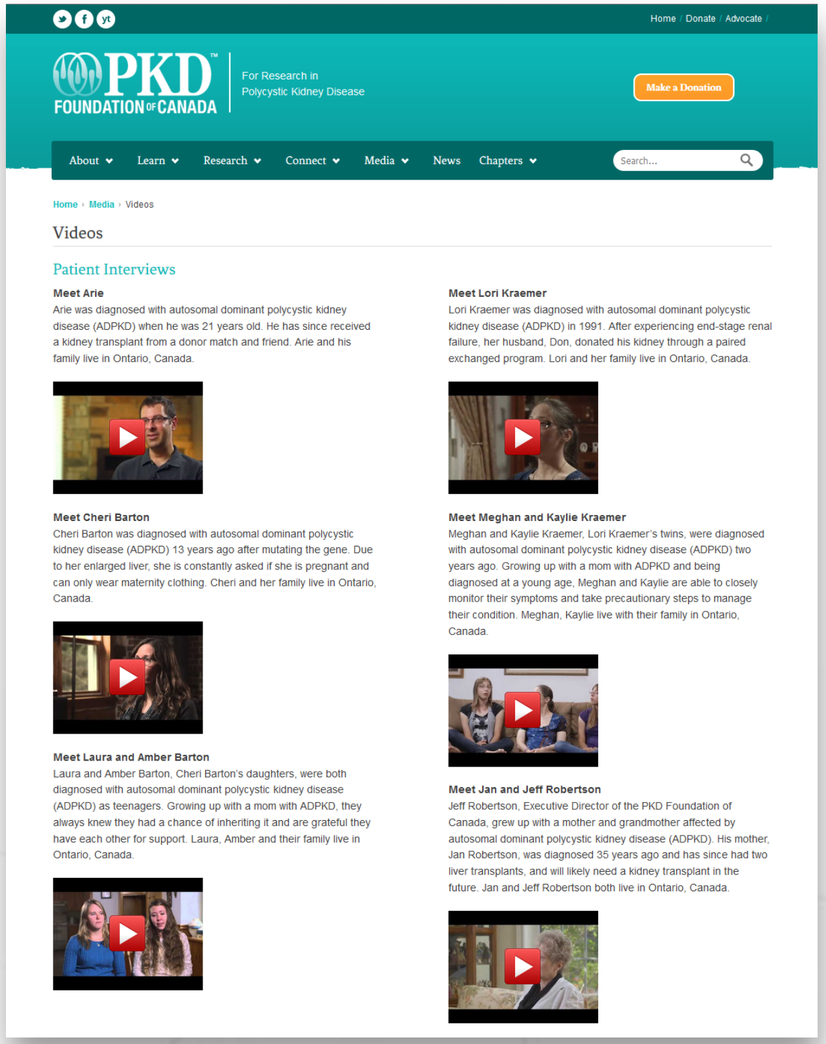
CLICK HERE TO ACCESS TESTIMONIALS ON THE PKD FOUNDATION OF CANADA'S WEBSITE



SECTION 1: NEWLY DIAGNOSED DISCUSSION

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- What kinds of things should I ask my nephrologist?
- How often should I see my nephrologist?
- Am I at risk for other diseases because of my ADPKD?
- How do I talk to my family about ADPKD?
- Will ADPKD limit my lifestyle (*e.g.*, sports, activities)?
- Can I have children if I have ADPKD?
- How can my family members access genetic testing if they want it?
- What if my family member(s) decide not to get tested for ADPKD?

For answers to questions on being newly diagnosed and the first steps to take, visit the PKD Foundation of Canada's website

Just Diagnosed

www.endpkd.ca/learn/learn-about-adpkd/just-diagnosed/

First Steps

www.endpkd.ca/learn/learn-about-adpkd/first-steps/

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease

SECTION 2

LIVING WITH ADPKD

LIVING WITH ADPKD: TOPICS TO BE DISCUSSED

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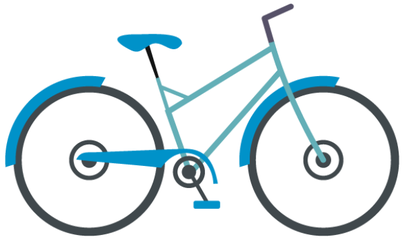
MANAGEMENT OF ADPKD

Diet

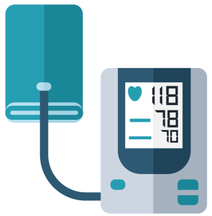


Exercise

Water intake

Medications to slow kidney / cyst growth

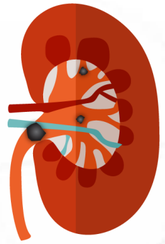
MANAGEMENT OF COMPLICATIONS



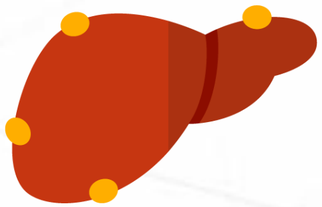
High blood pressure

Pain

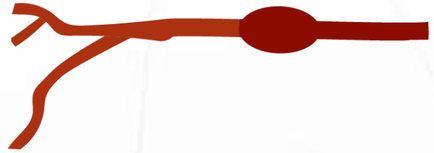
Urinary tract problems



Kidney stones



Liver cysts



Aneurysms

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease

WHAT DO I NEED TO KNOW ABOUT DIETARY CHOICES?

- Follow a kidney conscious diet as a heart-healthy diet
  - Kidney disease increases the risk of heart disease
- General tips:
  - High fiber: fresh vegetables and nuts
  - Carbohydrates: minimize intake of bread and pasta
  - Protein: moderation of red meats
  - Fat: moderate intake may actually decrease hunger drive
    - E.g. Olive oil in salad dressing to increase fat intake
  - Avoid: processed food and sugary drinks with fructose syrup
  - Aim for/maintain ideal body weight
- Consultation with a renal dietitian may be recommended for people with advanced kidney disease

Adapted from www.pkdcure.org and www.endpkd.ca

WHAT DO I NEED TO KNOW ABOUT EXERCISE?

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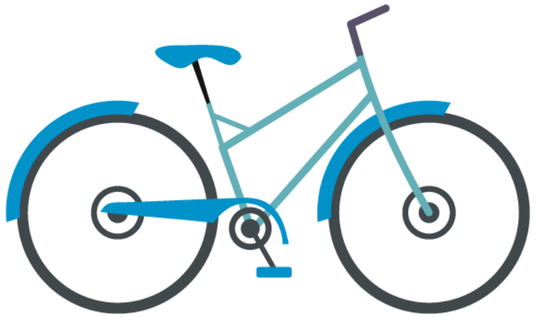

- Find an activity that is comfortable for you and that you enjoy doing
- Avoid high-contact / high-impact activities to reduce risk of cysts rupturing
- Remember to always keep well hydrated when exercising
- Regular exercise can help you improve blood pressure, weight, muscle strength, heart function and overall well being

Adapted from www.pkdcure.org

HOW MUCH WATER SHOULD I DRINK?

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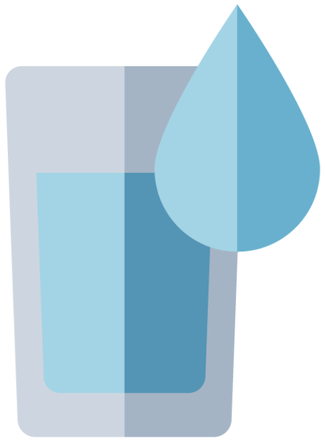

2-3

LITERS DAILY

- A reasonable water intake for people with ADPKD - enough to always maintain pale urine colour
- Generous water intake can help decrease the risk of kidney stones
  - It is unclear whether high water intake can slow progression of ADPKD and possible risks are not well understood

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

RESEARCH WITH ADPKD-SPECIFIC TREATMENT IS ACCELERATING

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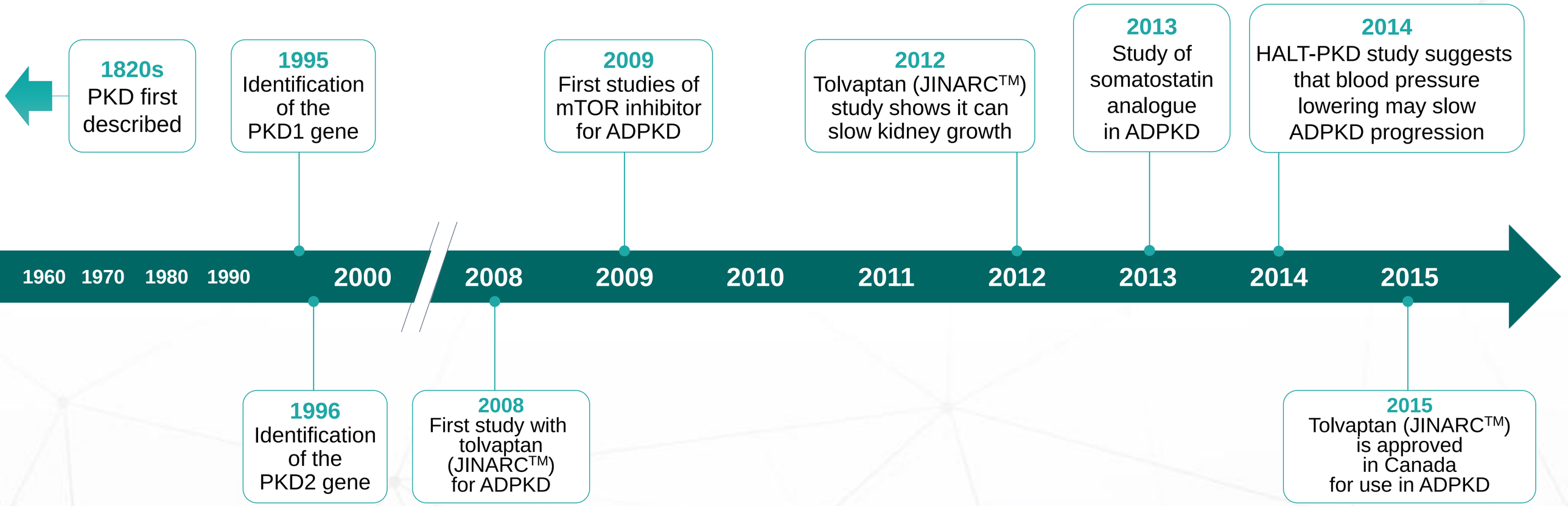


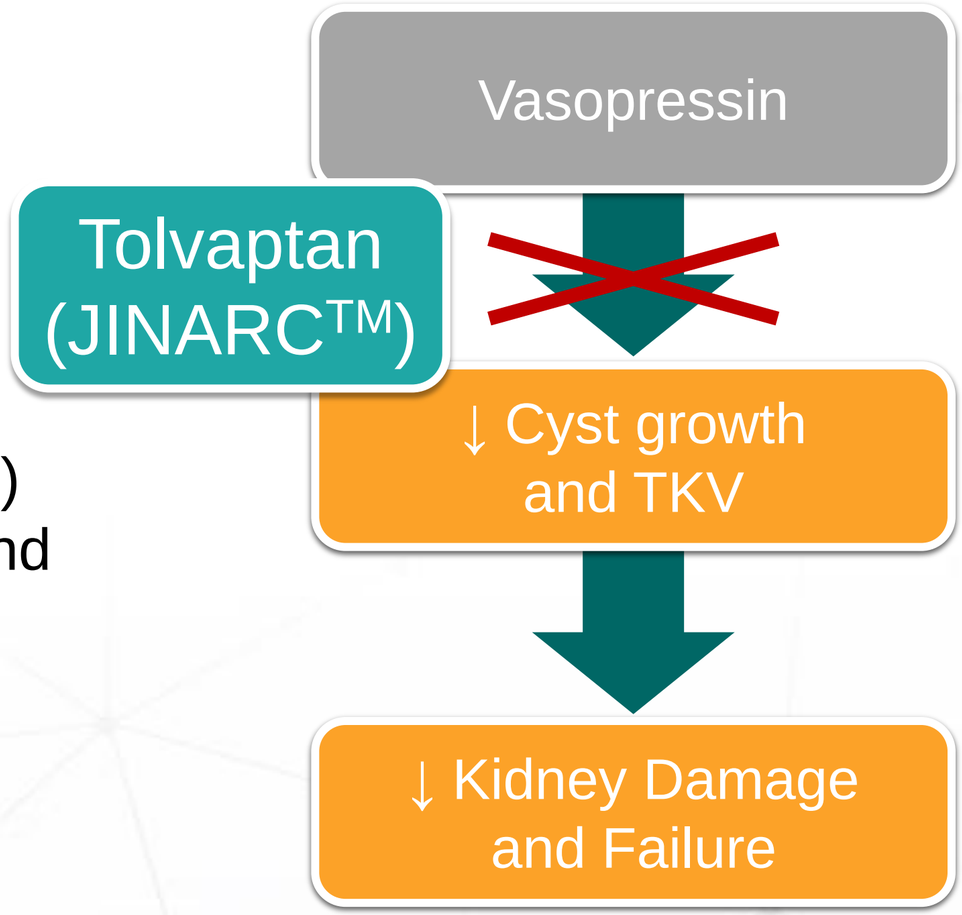
ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; PKD: **P**olycystic **K**idney **D**isease; HALT-PKD: **HALT** Progression of **P**olycystic **K**idney **D**isease ; mTOR: **m**ammalian **T**arget **O**f **R**apamycin

HOW DOES TOLVAPTAN (JINARC™) WORK?

ADPKD Patient Forum

TOLVAPTAN (JINARC™) WORKS BY BLOCKING THE EFFECTS OF A HORMONE CALLED VASOPRESSIN

- Vasopressin normally promotes cyst growth in the kidneys in patients with ADPKD
- By blocking vasopressin, tolvaptan (JINARC™) may help protect your kidneys from damage and failure by slowing the growth of
  - Kidney cysts
  - Total kidney volume
- Another effect of vasopressin blockade is the increase in urine output



TKV: **T**otal **K**idney **V**olume

PrJINARC™ Product monograph. Date of Preparation: February 23, 2015.

WHO ARE POTENTIAL CANDIDATES FOR TOLVAPTAN (JINARC™)?

ADPKD Patient Forum

PEOPLE MOST LIKELY TO BENEFIT ARE THOSE WITH RAPIDLY PROGRESSING ADPKD OR WITH SIGNS OF RISK FOR RAPID PROGRESSION:

- Large number or volume of cysts for a given age, as measured by imaging
- Chronic kidney disease Stage 2 (eGFR* 60-89 mL/min) or Stage 3 (30-59 mL/min)
- Tests showing rapid deterioration in kidney function
- High blood pressure or protein in the urine
- Family history of rapid disease progression (e.g., dialysis in a family member before the age of 55 years)

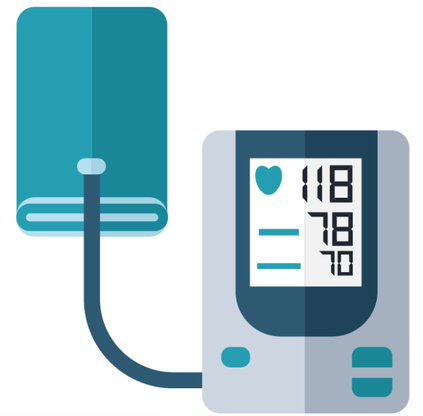
TOLVAPTAN (JINARC™) IS NOT FOR EVERYONE

e.g., children / ARPKD / post-transplant / late-stage patients

eGFR: **e**stimated **G**lomerular **F**iltration **R**ate – an estimate of kidney function based on a blood test;
eGFR numbers are approximately equivalent to % function.
PrJINARC™ Product monograph. Date of Preparation: February 23, 2015.

WHAT CAN I DO TO MONITOR MY BLOOD PRESSURE?

ADPKD Patient Forum



- KNOW YOURS!
  Early detection of high blood pressure is important
- You can play a key role by measuring and recording your blood pressure at home

HALT-PKD: **HALT** Progression of **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

TREATMENT OF HIGH BLOOD PRESSURE

- High blood pressure needs to be treated
  - If not treated, high blood pressure can cause further damage to the kidneys, enlarge and thicken the heart muscle and increase the risk for strokes, heart attacks and other cardiovascular problems
- There are several types of blood pressure medications, which work in different ways
  - Most commonly used in kidney disease: ACE inhibitors and ARBs*
  - Other blood pressure medications: diuretics (aka "water pills"), calcium channel blockers and beta-blockers
- Often, multiple medications are required
- Controlling blood pressure may help reduce the rate of kidney growth in ADPKD (based on the HALT-PKD study)
- Talk to your doctor to determine the best course of action for you

*ACE: **A**ngiotensin-**C**onverting **E**nzyme, ARB: **A**ngiotensin II **R**eceptor **B**locker
Adapted from www.pkdcure.org

WHAT SHOULD I KNOW ABOUT BLOOD PRESSURE MEDICATIONS?

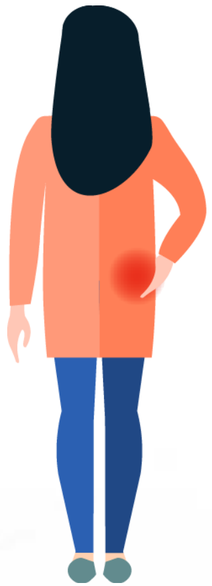
ADPKD Patient Forum

	ACE inhibitors	Angiotensin II receptor blockers (ARBs)	Beta-blockers	Calcium channel blockers (CCBs)	Diuretics
Examples	Captopril (Capoten®) Enalapril (Vasotec®) Fosinopril (Monopril®) Ramipril (Altace®)	Candesartan (Atacand®) Irbesartan (Avapro®) Losartan (Cozaar®) Telmisartan (Micardis®) Valsartan (Diovan®)	Atenolol (Tenormin®)	Amlodipine (Norvasc®) Nifedipine (Adalat XL®)	Chlorthalidone (Hygrotron®) Furosemide (Lasix®) Hydrochlorothiazide (HydroDIURIL®) Indapamide (Lozide®)
How they work	Help blood vessels to relax and widen by preventing the formation of a hormone called angiotensin	Help blood vessels to relax and widen by blocking the action of angiotensin	Reduce the heart rate, the heart's workload and output of blood	Decrease force of heart contractions, relax and open up blood vessels, reduce heart rate	Help the body get rid of excess sodium (salt) and water to help control blood pressure
Possible side effects / considerations	Chronic dry, hacking cough Can lead to high potassium	Can lead to high potassium	Insomnia; cold hands and feet; fatigue or depression; slow heartbeat; symptoms of asthma	Heart palpitations Swollen ankles	Decrease potassium; supplementation may be needed

* any medication that lowers blood pressure can cause dizziness

Adapted from www.heart.org

WHAT CAUSES PAIN IN ADPKD AND WHAT CAN I DO ABOUT IT?



CAUSES

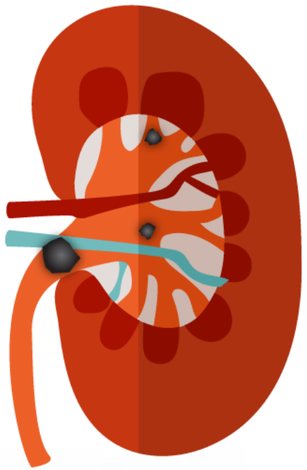
- Kidney stones*
- Cyst infection *
- Cyst rupture*
- Urinary tract infection*
- Kidney growth can be painful in itself, can put pressure on nearby organs and/or can cause altered posture and low back pain
- Some people with ADPKD also develop cysts on the liver, which can be painful

MANAGEMENT

- Depending on the source and degree of the pain, many different treatments may be considered (e.g., medication, ice, heat, massage, whirlpool bath)
- Can be complex and difficult to treat: referral to specialized pain clinics or other specialists may be necessary

* Can cause blood in the urine
Adapted from www.pkdcure.org

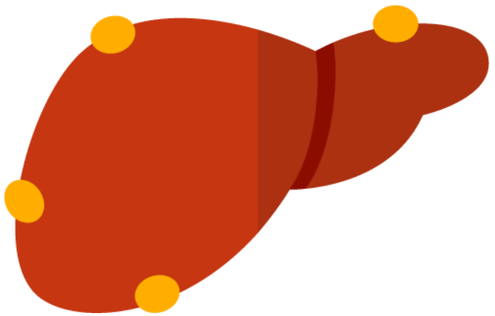
WHAT ABOUT KIDNEY STONES?



- Kidney stones are more common in people with ADPKD than the general population
  - Related to impaired urine drainage due to cysts
  - Uric acid and calcium are the common types of stones
- Smaller stones can be passed with the urine
- Bigger stones may be treated by other methods:
  - Lithotripsy using ultrasound waves or laser, cystoscopy, surgery (rarely)
- Increase fluid intake
- You may be investigated for other risk factors for stone formation, and dietary modification or medications might be required

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease
Adapted from www.pkdcure.org

WHAT ABOUT LIVER CYSTS?



- More than 80% of people with ADPKD have cysts in the liver during their lifetime
- Female hormones (e.g., estrogen) may influence liver cyst development
  - Liver cysts occur more often in women than men, occur at a younger age, and are more numerous and larger
  - Women who have been pregnant are more likely to have liver cysts and more numerous and larger cysts compared to women who have not been pregnant
- The liver can remain normal in size or become enlarged
- Normal liver function is usually preserved, even with many cysts and enlarged liver size
- Some people with ADPKD develop severe polycystic liver disease (e.g., liver 5-10x normal size)
  - In severe cases, liver surgery / transplantation may be needed; medication is also an option

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease

Adapted from: www.endpkd.ca Bae KT, et al. Clin J Am Soc Nephrol 2006; 1(1):64-9. Chauveau D, et al. J Am Soc Nephrol 2000; 11(9):1767-75. Drenth JP, et al. Hepatology 2010; 52(6):2223-30. Hogan MC, et al. Nephrol Dial Transplant 2012; 27(9):3532-9.

WHAT DO I NEED TO KNOW ABOUT ANEURYSMS?

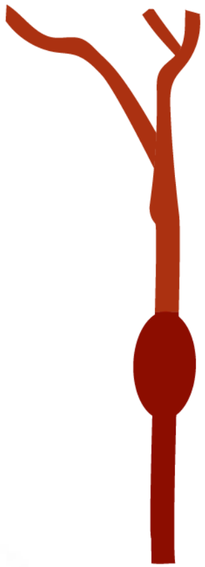
ADPKD Patient Forum

SIGNS AND SYMPTOMS

- Mostly asymptomatic
- Signs and symptoms may include severe or new headaches, stroke-like syndrome

SCREENING

- There may be a higher risk of brain aneurysm in ADPKD compared to the general population
- Aneurysms are rare complications, yet very important to screen and manage
- Those with a family history of aneurysm or sudden death should be screened with an MRI



MANAGEMENT

If an aneurysm is detected, your team of doctors will suggest the best management plan that may include:

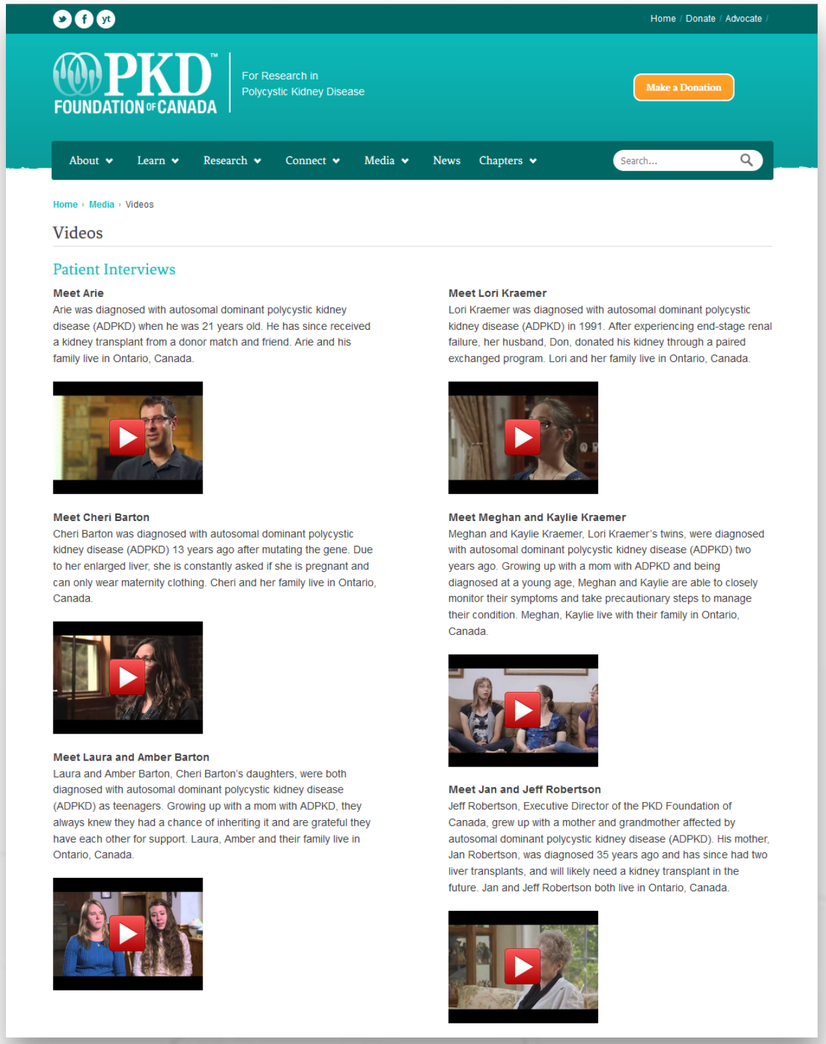
- Regular monitoring for aneurysms with low risk of rupture, slow progression
- Medication to effectively control blood pressure
- Rarely, surgery (e.g., for higher-risk aneurysms)

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; MRI: **M**agnetic **R**esonance **I**maging
Adapted from www.pkdcure.org

THE PATIENT PERSPECTIVE: LIVING WITH ADPKD

ADPKD Patient Forum

CLICK HERE TO ACCESS TESTIMONIALS ON THE PKD FOUNDATION OF CANADA'S WEBSITE



SECTION 2: LIVING WITH ADPKD DISCUSSION

ADPKD Patient Forum

- Should I stop eating protein?
- Should I stop / limit salt intake?
- Can I drink alcohol?
- Do I need to take vitamin supplements?
- Can caffeine damage my kidneys?
- What about potassium, calcium, magnesium?
- What's an ideal weight or BMI for a PKD patient?
- Can I still work with ADPKD? Do I need to tell my employer I've been diagnosed?
- How does PKD affect male fertility?
- Is it OK to get pregnant?
- Should I be screened for complications like aneurysm and heart problems?
- What kind of testing will I need for my ADPKD?
- What do the results of the tests mean?
- How do I know if I'm a candidate for tolvaptan (JINARC™) therapy?
- What side effects can I expect with tolvaptan (JINARC™)?
- What are the benefits and risks of taking tolvaptan (JINARC™)?
- What is the current status of research into other ADPKD treatments?
- How will I know when I need dialysis or transplant?

For answers to questions on living with ADPKD and tolvaptan (JINARC™), visit the PKD Foundation of Canada's website

Living with PKD

www.endpkd.ca/learn/learn-about-adpkd/living-with-pkd/

About tolvaptan (JINARC™)

http://goo.gl/SBLmpk

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; PKD: **P**olycystic **K**idney **D**isease

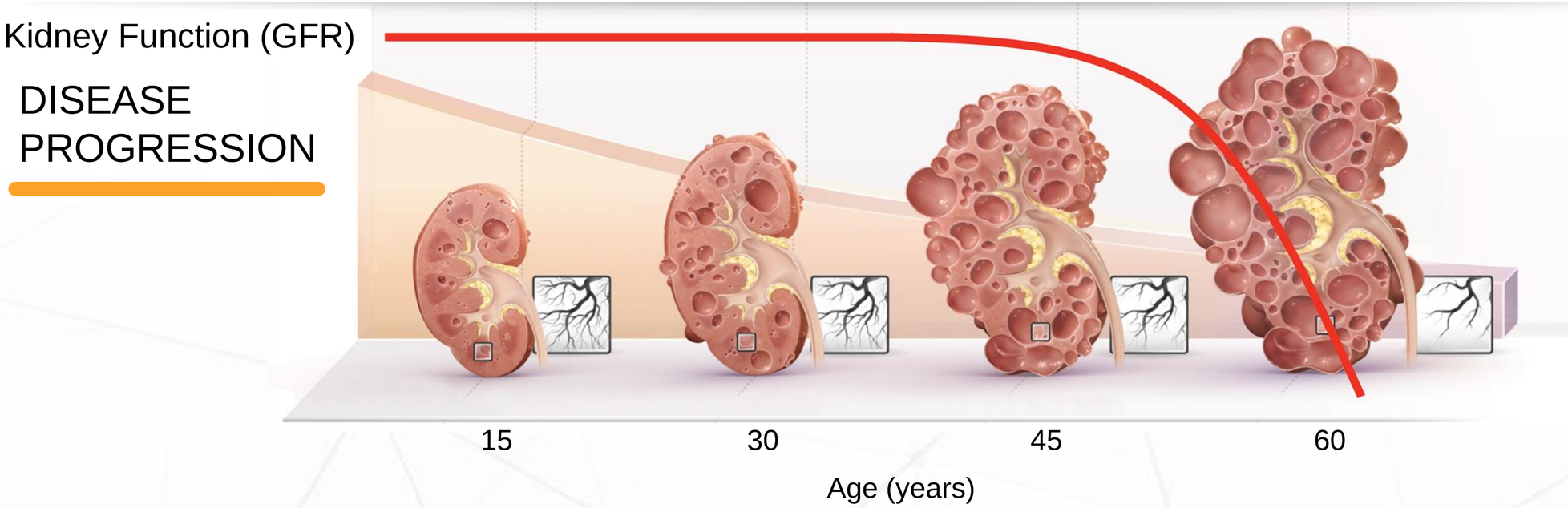
SECTION 3

LONG-TERM OUTLOOK

ADPKD AS A PROGRESSIVE DISEASE

ADPKD Patient Forum

- As time goes on in ADPKD, cysts and kidneys continue to grow
- In those people with progressive ADPKD, eventually the kidneys start to lose their ability to function properly
  - The timing of decline in kidney function / failure varies from person to person, even within families



NB: This model shows how ADPKD might progress for some, but not all people.

ADPKD: **A**utosomal **D**ominant **P**olycystic **K**idney **D**isease; GFR: **G**lomerular **F**iltration **R**ate
Adapted from www.pkdcure.org

HOW CAN I TELL IF MY KIDNEY FUNCTION IS DECLINING?

ADPKD Patient Forum

- Early on in the course of the disease, there are no symptoms of declining kidney function
- Blood tests can show that kidney function is declining
  - You should have regular visits with your doctor to monitor and track changes in your kidney function
- Later in the disease, if the kidneys start to fail, one can experience a number of different symptoms

  - Decreased energy and mood
  - Weakness
  - Shortness of breath
  - Weight loss
  - Nausea and/or vomiting
  - Metallic taste in the mouth
  - Difficulty concentrating
  - Swelling of legs
  - Itching

Adapted from www.pkdcure.org

WHAT ARE MY OPTIONS WHEN MY KIDNEYS ARE NO LONGER FUNCTIONING?

ADPKD Patient Forum

DIALYSIS

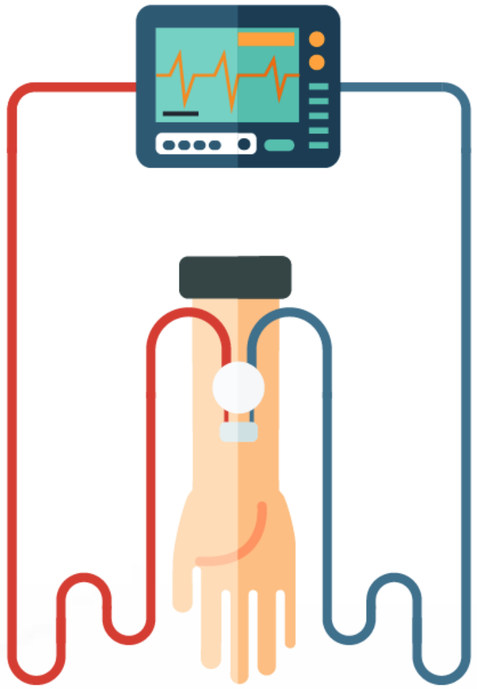
- A treatment option that does some of the things healthy kidneys do
- Required when your own kidneys can no longer function well enough to take care of your body's needs or completely fail
- Types of dialysis include **hemodialysis**, and **peritoneal dialysis**
- Needs to be done daily or several times per week

TRANSPLANTATION

- Replacement kidney(s) from a living or deceased donor
- This is the preferred option

Adapted from www.pkdcure.org

WHAT IS HEMODIALYSIS?



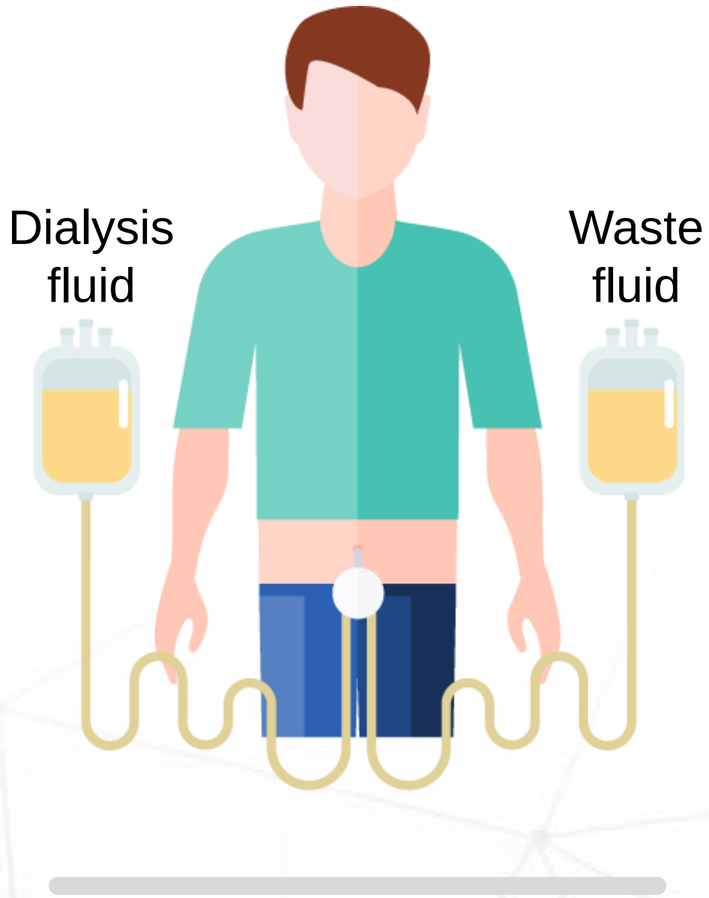
HEMODIALYSIS

uses a machine to clean your blood

- Removes waste (extra fluid, electrolytes, etc.) that have built up in the blood
- Can be done at home or in a clinic

Adapted from www.pkdcure.org

WHAT IS PERITONEAL DIALYSIS?



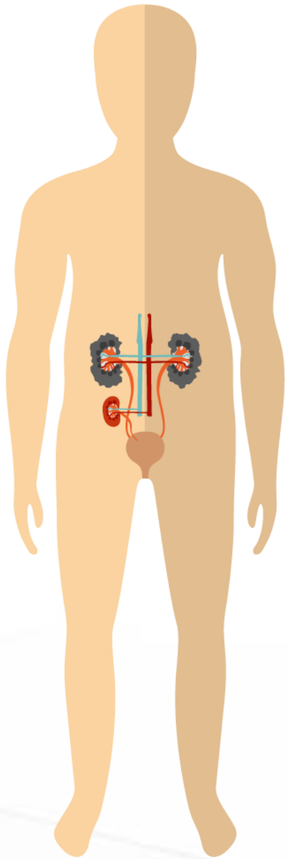
PERITONEAL DIALYSIS

removes extra fluid, electrolytes and waste using the lining of the abdominal cavity (peritoneum) as a filter

- A soft plastic tube is placed into your abdomen by a trained surgeon, radiologist or nephrologist
- A sterile cleansing fluid is then put into your belly via the tube to filter the fluid
- Can be done with the use of a machine at night while you sleep

Adapted from www.pkdcure.org

KIDNEY TRANSPLANTATION: SOME CONSIDERATIONS



- Declining kidney function will signal to your healthcare team that you may need to start considering a transplant
- It is important to consider the possibility as early as possible – even before dialysis is necessary (pre-emptive transplant)

Adapted from www.pkdcure.org

HOW DOES THE TRANSPLANT REFERRAL PROCESS WORK?

- When suitable, your kidney specialist will refer you to a transplant centre
- Your testing for transplant may be done locally or may require some or all testing at the transplant centre, depending on many factors
- Your team will inquire about possible living donors. If so, your team may attempt to plan for a pre-emptive transplant, where you could possibly avoid dialysis altogether
- Your team will ensure you are ready for listing on the transplant list once you start dialysis
- Transplant lists in Canada are handled at the provincial level; there are national programs as well

Adapted from www.endpkd.ca

NATIONAL PROGRAMS IN KIDNEY TRANSPLANTATION

ADPKD Patient Forum

HIGHLY SENSITIZED PROGRAM (HSP)

- Lists highly sensitized patients waiting for a match
- Manages the data to allow for precise donor matching
- Provides technology for organ donation organizations to input data on deceased donors

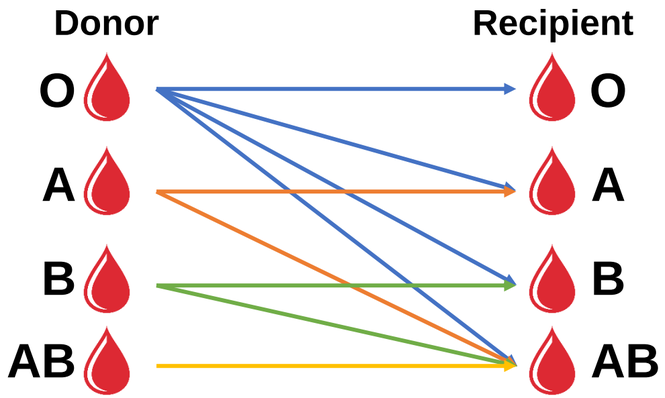
KIDNEY PAIRED DONATION (KPD)

- Donors and recipients that are not a match may be entered in the program
- Finds pairs that are a good match with a very low chance of rejection.
- Willing, living donors without a specific intended recipient may also register; these donors are able to start 'domino' chains of transplants where one donor can trigger up to 6 transplants

Both programs are administered by Canadian Blood Services
For more information, visit www.blood.ca

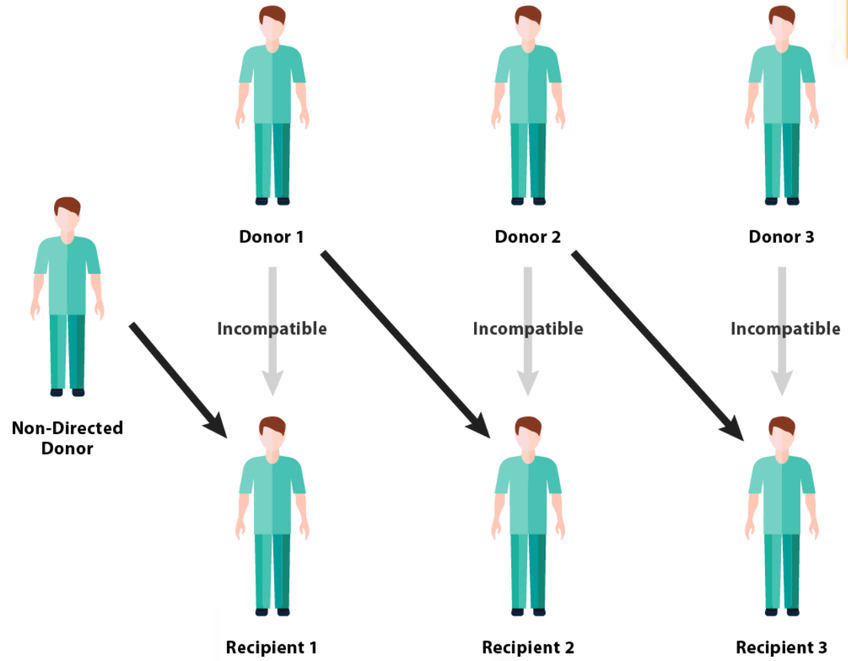
HOW ARE KIDNEY DONORS MATCHED TO POSSIBLE RECIPIENTS?

ADPKD Patient Forum



BLOOD TYPE

- You must have a blood type that is compatible with your donor (not necessarily the same blood type)
- **Other blood tests:** HLA antigen, crossmatch testing help determine donor suitability



INCOMPATIBILITY

- The kidney paired donation (KPD) program is an option
- **Note:** A family member can be a kidney donor if that individual does not have PKD

PKD: **P**olycystic **K**idney **D**isease; HLA: **H**uman **L**eukocyte **A**ntigen
Adapted from www.pkdcure.org
http://www.kidneylink.org/PairedDonationHowItWorks.aspx

RESOURCES FOR INDIVIDUALS WITH ADPKD AND THEIR FAMILIES

ADPKD Patient Forum

GENERAL RESOURCES FOR ADPKD

PKD Foundation of Canada	PKD Foundation (USA)	Kidney Foundation of Canada
www.endpkd.ca	**www.pkdcure.org**	**www.kidney.ca**

TRANSPLANT-SPECIFIC RESOURCES

Canadian Transplant Association	Trillium Gift of Life network (Ontario)	Transplant Quebec
www.organ-donation-works.org	**www.giftoflife.on.ca**	**www.transplantquebec.ca**

BC Transplant	Multi-Organ Transplant Program of Atlantic Canada (MOTP)
www.transplant.bc.ca	**www.motpatlantic.ca**

THE PATIENT PERSPECTIVE: LONG-TERM OUTLOOK

ADPKD Patient Forum

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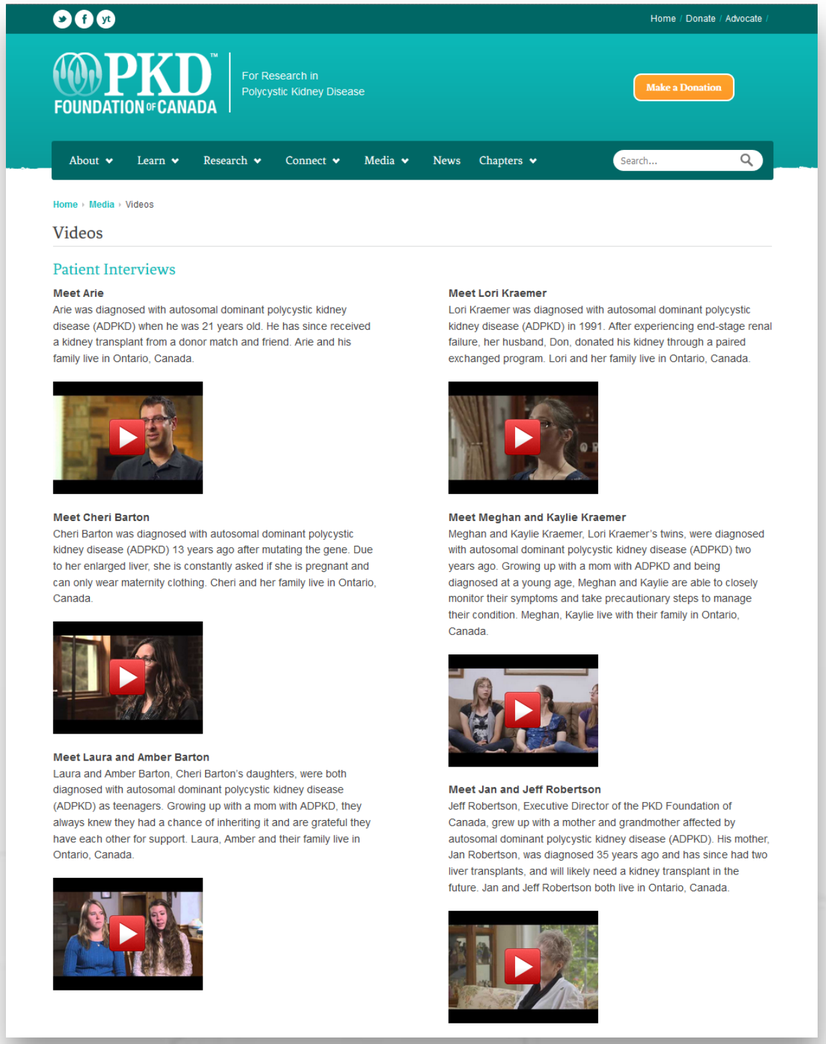

SECTION 3: LONG-TERM OUTLOOK DISCUSSION

ADPKD Patient Forum

- How and why does the body reject a transplanted kidney? What happens then?
- What kinds of medications will I need to take after a transplant?
- Is it better to receive a cadaver or living donor kidney? What's the difference?
- When can I get on a waiting list for a transplant?
- Will a transplant cause any complications?
- How often do I need to see my doctor before and after a transplant?
- After a transplant, am I cured?
- Is it possible to sleep at night during peritoneal dialysis?
- Which is better, hemodialysis or peritoneal dialysis?
- Will I have to quit work when I start dialysis?
- Can I travel on dialysis?
- Do I have to do anything to prepare for dialysis?

For answers to questions on dialysis and transplantation visit the PKD Foundation of Canada's website

Kidney Failure

www.endpkd.ca/learn/learn-about-adpkd/kidney-failure/