PKD Bridge School Outreach Toolkit: Speaker Talking Points

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How to use this toolkit

This toolkit is designed primarily for an adolescent with ADPKD, or with known familial risk for ADPKD, who wants to lead a short awareness session at their own school. Because the materials are open access, another student or an educator may also adapt them with the school's approval. The session is educational. It does not require a doctor, a lawyer, or any other professional in the room, and it is subject to the school's ordinary approval and supervision, the same as any student presentation.

The toolkit has four parts:

- **Slide deck.** Sixteen slides, adaptable to middle school or high school audiences. Twelve are core; four are optional. Each slide carries the same talking points as this document in its speaker notes.
- **Speaker talking points** (this document). What to say on each slide, how to adjust it by age group, what to do with common questions, and where the lines are.
- **FAQ.** Plain-language answers to the questions classmates and staff ask most, including the misconceptions.
- **Teacher or administrator one-pager.** A single page for the adult who approves or supervises the session, explaining what it is, what it is not, and where accommodation decisions actually live.

The words in this document are a starting point, not a script you have to read. Put them in your own voice. The one thing not to change is where the lines are (see "Where the lines are" below).

Before you present

1. Get the school's approval the way you would for any student presentation. Give the teacher or administrator the one-pager. Ask what time you have and who will be in the room.
2. Decide, with a parent or guardian (or another trusted adult), what you will and will not say about yourself. Slide 2 gives you four openers, and none of them requires you to say you have ADPKD. Slide 14 ("My story") is optional and can be deleted. Decide this before the session, not on your feet.
3. Choose your slides using the table below. Delete the ones you are not using. Nothing else in the deck depends on them.
4. Read the FAQ once. Most questions you will get are in it.
5. Rehearse out loud once, with a timer. The core deck runs about ten to twelve minutes at a normal pace. Optional slides add two to four minutes each.
6. Bring a printed copy of this document or open the speaker notes on the slides. Nobody expects you to have it memorized.

Choosing your slides

Slide	Title	Core or optional	Middle school	High school
1	Title	Core	Use	Use
2	Why I'm talking about this	Core	Use	Use
3	First, what kidneys do	Core	Use	Use
4	What ADPKD is	Core	Use, simplified (skip the genetics terms)	Use
5	Three things ADPKD is not	Core	Use, slowly	Use
6	What it can feel like (or not feel like)	Core	Use, shortened to three items	Use
7	How it is cared for	Core	Use, shortened	Use
8	Why it can show up during the school day	Core	Use	Use
9	"But you look fine."	Core	Use, skip the 504 sentence	Use
10	What helps, as a classmate	Core	Use, spend the most time here	Use
11	What helps, from teachers and coaches	Optional	Usually skip	Use if staff are present or for health class
12	Privacy: who gets to know	Core	Use	Use
13	Quick check: true or false?	Optional	Recommended	Optional closer
14	My story	Optional	Only if decided in advance; two prompts	Only if decided in advance
15	Questions, and where to learn more	Core	Use	Use
16	Thank you	Core	Use	Use

Where the lines are

This session teaches what ADPKD is and how it can show up at school. It is not medical advice, legal advice, school-advocacy representation, counseling, or crisis support. In practice that means you do not:

- Give numbers or targets for water, salt, blood pressure, or anything else. "That's a question for their clinician" is the answer.
- Name specific medicines or say what anyone should or should not take.
- Talk about any particular person's health, including other students, family members, or yourself beyond what you decided in advance to share.
- Tell anyone whether they should be tested, how testing works, or what their risk is.

- Tell teachers or staff what accommodations a student should get, or explain how to get a 504 plan. The school's own staff and processes handle that.
- Give advice to a classmate who tells you about their own health. Listen, and point them to a parent, the school nurse, a counselor, or their doctor.

None of this makes you less credible. Knowing where your role ends is part of what makes you credible.

Handling questions

A question about a specific person. "I'm keeping this about PKD in general. I'm not going to talk about anyone's health, including anyone here."

A question about you that goes further than you want to go. "That's as far as I'm going to take it today." You do not need a reason, and you do not need to apologize.

A question you do not know the answer to. "I don't know. I'd check with a kidney doctor on that." This is a good answer and a true one. Do not fill the silence with a guess.

A question about testing, treatment, or risk for the person asking. "That's a real question, and it's one for your parents and your doctor, not for me. If it's on your mind, that's a good reason to ask them."

A joke at the wrong moment. Let it pass, or say "Fair enough" and move on. You do not have to win the room. You have to finish the talk.

A classmate who tells you, during or after, about their own health. Listen. Do not give advice. Say something like "Thanks for telling me. Have you talked to your parents or the nurse about it?" If what they say worries you, tell a trusted adult. That is not gossip; that is what adults are for.

Slide-by-slide talking points

Each slide below has what to say, how to adjust it for a middle school or high school audience, what to do if asked the questions that usually come up, and what not to do. The same text appears in the speaker notes of the slide deck.

Slide 1 (Core): What Is ADPKD?

What to say

Hi, I'm [name]. I'm going to take about ten minutes to talk about a kidney condition called ADPKD. That stands for autosomal dominant polycystic kidney disease. It is one type of polycystic kidney disease, or PKD. I'll say the long name once and then just call it ADPKD. Most people have never heard of it, and I think it's worth knowing a little about, because it can show up at school in ways that look pretty ordinary from the outside.

You don't need to know anything about kidneys to follow this. I'll keep it simple, and there will be time for questions at the end.

Middle school

Same opener works. If you want, add: “Raise your hand if you know what your kidneys do.” Most hands stay down, and that is a fine place to start.

High school

You can add that ADPKD is the most common inherited form of PKD and the one this session is about. You will explain the long name on slide 4.

Do not

Do not open by announcing your diagnosis unless you have decided in advance that you want to. Slide 2 gives you a choice of openers.

Slide 2 (Core): Why I’m talking about this

What to say

Pick ONE of these openers. Any of them is complete on its own. You do not owe anyone an explanation of which one is true for you.

Option A (personal): “I’m talking about this because I have ADPKD. I usually feel fine, and I’m not looking for anyone to treat me differently. I just think it helps when people know what it is.”

Option B (family): “I’m talking about this because ADPKD runs in my family, so it’s something I’ve grown up knowing about.”

Option C (someone I know): “I’m talking about this because someone I care about has ADPKD, and I’ve seen how much easier things are when the people around them understand it.”

Option D (interest): “I’m talking about this because I learned about it and realized almost nobody knows what it is, even though it’s the most common inherited kidney disease.”

Then: “Here’s what I want you to take away: it’s real, it’s usually invisible, and a little understanding goes a long way.”

Middle school

Keep it to the opener plus the one-sentence takeaway. Skip the phrase “most common inherited kidney disease” if it feels like too much; slide 4 covers it.

High school

You can add: “By the end you should be able to explain ADPKD to someone else in two sentences, and you’ll know what to do if a classmate mentions it.”

If asked

“Do you have it?” You can answer, or you can say: “I’m going to keep this about ADPKD in general, but I’m happy to talk after.” Either answer is fine, and you can change your mind later.

Do not

Do not name any other student or family member who has ADPKD. Their information is theirs.

Slide 3 (Core): First, what kidneys do

What to say

Your kidneys are two organs in your back, just below your ribs, one on each side, each about the size of your fist. Their main job is filtering. All of your blood passes through them many times a day. They pull out waste and extra water, and that becomes urine.

They also keep the balance of salts and fluids in your body right, and they help control your blood pressure. So when something affects the kidneys, it can affect a lot more than just going to the bathroom.

Middle school

The fist comparison and the filter idea are enough. You can say: "Think of them as the body's water filter."

High school

You can add that the kidneys also make hormones, including one that tells the body to make red blood cells, which is one reason kidney problems can make people tired.

If asked

"Can you live with one kidney?" Yes, many people do. That is a different situation from ADPKD, where both kidneys are usually affected.

Slide 4 (Core): What ADPKD is

What to say

PKD stands for polycystic kidney disease. "Poly" means many, and a cyst is a small sac filled with fluid. In PKD, cysts grow in the kidneys. They grow slowly, usually over many years, and over time the kidneys can become larger than usual and work less well.

The most common inherited form is called autosomal dominant PKD, or ADPKD. The long name describes how it's passed down: if a parent has it, each of their children has a 50/50 chance of inheriting the changed gene. A person is born with it. Nobody does anything to cause it, and nobody can catch it.

It's the most common inherited kidney disease, but it's still uncommon enough that most people, including a lot of adults, have never heard of it.

Middle school

Lead with "many fluid-filled bubbles in the kidneys" and "it runs in families." You can leave out the words "autosomal dominant" entirely.

High school

You can add that the two genes most often involved are called PKD1 and PKD2, and that the type of gene change affects how fast the condition tends to progress, which is one reason it looks different from person to person.

If asked

"Is it cancer?" No. Cysts are not tumors and ADPKD is not cancer.

"How many people have it?" About one in a thousand people carry the gene change, and fewer than that have actually been diagnosed. For a school talk, "about one in a thousand" is enough.

Do not

Do not guess at anyone's individual risk, including your own family's. That is a question for a clinician or genetic counselor.

Slide 5 (Core): Three things ADPKD is not

What to say

Three quick things that people sometimes get wrong.

First, it's not contagious. You can't catch it. You can share a water bottle, sit next to someone, be on a team with them. Nothing changes.

Second, it's not caused by anything the person did. Not something they ate, not something they didn't do. It's a gene they were born with.

Third, it's not the same for everyone. Two people with the same condition can have completely different experiences. One might have symptoms as a teenager and another might not notice anything until they're an adult. So if you know one person with ADPKD, you know one person with ADPKD.

Middle school

This is the most important slide for a younger audience. Slow down here and say each one twice if you need to.

High school

You can add: "That variation is why you shouldn't assume anything about a person's ADPKD from what you've read online."

Slide 6 (Core): What it can feel like (or not feel like)

What to say

A lot of teenagers with ADPKD feel fine most of the time. That's a big part of why it's easy to miss.

But some people do have symptoms. Pain in the back or side is one. Feeling more tired than you'd expect is another. High blood pressure can happen even in young people with ADPKD, which is one reason their doctor checks it. Some people get kidney or bladder infections, or see blood in their urine. Those are things a doctor sorts out. They're not something a classmate should try to read anything into.

The key thing: everyone's list is different, and it can change. Someone can feel fine for years and then have a rough stretch. Feeling fine today doesn't mean the condition isn't there.

Middle school

Shorten to three items: back pain, tiredness, and "blood pressure that needs checking." Leave out blood in urine for this age group unless a clinician has told you it belongs.

High school

You can keep the full list. If you have personal experience you have decided to share, this is a natural place for one sentence, but it is not required.

If asked

"Does it hurt?" Sometimes, for some people. Not always, and not all the time.

"Will they die from it?" Say: "ADPKD is a lifelong condition, and people live with it for decades. Some adults eventually need treatment when their kidneys stop working well, usually much later in life. That's a question for their doctors, not for me."

Do not

Do not describe anyone's symptoms other than your own, and only your own if you have chosen to. Do not rank symptoms or say what is "normal" for ADPKD.

Slide 7 (Core): How it is cared for

What to say

There isn't a cure for ADPKD yet. But there's a lot that can be done, and most of it is ordinary-sounding.

People with ADPKD see a kidney doctor, called a nephrologist, or a care team, for regular checkups. Blood pressure gets a lot of attention, because keeping it in a healthy range protects the kidneys over time. Staying active matters. Some people are told to drink more water and go easy on salt, but that's individual advice from their own clinician, not a rule for everyone with ADPKD.

Some people take medicine, most often for blood pressure. And there's real research going on. There are treatments approved for adults, and the picture keeps changing.

Middle school

Keep it to: checkups, blood pressure, staying active, and following their own doctor's advice about water and food. Skip medicine and research.

High school

If someone asks about medicines or supplements, keep the answer general and point back to the person's own clinician. Medication choices are outside your role.

If asked

"How much water should they drink?" Say: "That's a question for their clinician. It's different for different people, and I'm not going to give a number."

"Can they play sports?" Say: "Usually yes. Being active is encouraged. For contact or collision sports, some people have an individual conversation with their doctor, for example if their

kidneys are enlarged or an activity has caused bleeding before. So it's not automatically no, and it's not automatically yes."

Do not

Do not give amounts, targets, or numbers for water, salt, blood pressure, or anything else. Do not name specific medicines. Do not say what anyone "should" do about their own care.

Slide 8 (Core): Why it can show up during the school day

What to say

So here's where it actually touches school. None of these is dramatic. That's the point.

Water. Some students with ADPKD are told by their own doctor to keep water nearby and drink during the day. That's their doctor's advice for them, not a rule for everyone with ADPKD. Restroom. If you drink more, you need the restroom more, and some people have kidney-related reasons to go more often. Either way, it's not something they should have to explain in front of the class.

Appointments. Checkups, blood or urine tests, sometimes scans. How often depends on the person, and missing class for them isn't a choice. Tiredness. Some people run out of energy before the day is over. Pain. Back or side pain that comes and goes, and can be there while someone is sitting perfectly still at their desk.

And activity. Most people with ADPKD can be active. Sometimes one specific activity gets adjusted for one person. If someone is sitting out of something, don't assume you know why.

Middle school

Point at each box and say one sentence each. Water and restroom are the ones that come up most at this age.

High school

You can add: "If you see any of these and think 'why do they get to do that,' now you know one possible reason."

If asked

"Do they get to skip PE?" Say: "Not as a rule. Being active is encouraged. Sometimes one specific activity gets adjusted for one student, and that's worked out with their doctor and the school."

Do not

Do not describe what accommodations any specific student has. If you have a 504 plan, you decide whether to mention it; you do not have to.

Slide 9 (Core): "But you look fine."

What to say

This is the line people with ADPKD hear most: "But you look fine."

And usually they do look fine. That's the thing about ADPKD. It's on the inside. Someone can look completely healthy and still need water nearby, leave for the restroom, or miss a day for medical care.

Those things aren't perks or special treatment. They're what lets a person with a health condition get through an ordinary day like everyone else.

In U.S. schools, some students have a written plan with the school that spells out practical supports. You might hear it called a 504 plan. Some students with ADPKD have one and some don't. Whether someone has a plan, and what's in it, is private.

Middle school

Say the "you look fine" line, then: "Looking fine and being fine are not the same thing." You can skip the 504 sentence entirely.

High school

If you have decided to mention a school plan of your own, keep it general: "I have a plan with the school that covers a few practical things." Do not list its contents unless you have deliberately chosen to.

If asked

"What's a 504 plan?" Say: "It's a written plan that a U.S. school puts together, through its own process, for a student who qualifies because of a health condition. What goes in it is worked out by the school with the family. I'm not going to explain the process. The school's own staff do that."

Do not

Do not explain the law behind 504 plans or how to get one. That is not your role in this session, and the school's own staff handle it.

Slide 10 (Core): What helps, as a classmate

What to say

So what do you actually do with all this? Mostly, less than you think.

Take it in stride. If someone has water nearby or leaves for the restroom, don't make it a public thing. Don't quiz them. "What's wrong with you?" is a hard question to get in a hallway. If they want to tell you, they will.

Keep it private. If you know, it's not yours to pass along, even to be helpful. The one exception: if you're worried about their health or safety, tell a trusted adult. Otherwise, ask how they want it handled. "Do you want me to say anything if someone asks?" is a great question, because it puts them in charge.

And treat them like anyone else. Because they are.

Middle school

This is the slide to spend the most time on. You can ask: "Which of these do you think is the hardest to actually do?" and take a couple of answers.

High school

Same.

If asked

“What if I’m worried about them?” Say: “Tell a trusted adult. A teacher, the nurse, a coach, a counselor. That’s what they’re for, and it’s not the same as gossip.”

Slide 11 (Optional): What helps, from teachers and coaches

What to say

Use this slide when there are teachers, coaches, or staff in the room, or when the session is for a health or advisory class where that’s the point. Skip it for a classmate-only audience.

For many students with ADPKD, the practical needs are small: water nearby, a restroom pass without a conversation, and understanding when they miss class for medical care. How often that happens varies by student, and the school’s own plan or process for that student is what staff should follow.

A private check-in can be respectful. Being singled out in front of the class is not. For PE and sports, follow whatever school plan and clinical guidance is already in place for that student, and don’t assume limits from the diagnosis alone. This session isn’t part of the accommodation process. It’s background.

Middle school

Usually skip for a middle school classroom unless your teacher asked for it.

High school

Useful for health class, advisory, or a faculty meeting.

If asked

“What should we do if a student with ADPKD is in pain or looks unwell?” Say: “Same as any student: send them to the nurse or health office, and let their family and clinician handle the rest. Nothing about ADPKD changes that.”

Do not

Do not tell staff what accommodations they should give, or how a 504 plan should be written. The teacher one-pager in this toolkit covers the boundary.

Slide 12 (Core): Privacy: who gets to know

What to say

Last main point, and it matters a lot. The person with ADPKD gets to decide who knows, how much they know, and when.

Telling a friend is one decision. Telling a teacher, a coach, or the school nurse is a different decision, and there can be good reasons to do that even if you’d rather not tell your friends. Those are all the person’s choices to make, with their family.

“I’d rather not get into it” is a complete answer, and you can take it at face value. And if you’re one of the people who does know, you hold it. The one exception: if you’re worried about their health or safety, tell a trusted adult. That isn’t gossip.

Middle school

Say: “If someone tells you they have ADPKD, that’s them trusting you. Don’t hand it to someone else.”

High school

You can add that this is true for any health condition, not just ADPKD, and that the same rules apply to things classmates might mention about their own health.

If asked

“Should they tell their teachers?” Say: “That’s a decision for the student and their family. There can be good reasons to tell school staff, but it isn’t something a classmate decides for them.”

Do not

Do not name anyone at school who has told you they have ADPKD or any other condition.

Slide 13 (Optional): Quick check: true or false?

What to say

Optional. Works well as a two-minute recap for any age. Read each one, take a show of hands, then give the answer.

1. False. Not contagious. 2. False. Usually you can’t tell at all. 3. True. 4. False. It’s different for everyone. 5. True for some people. It depends on their own doctor’s advice; there’s no single water rule for everyone.

If you get a wrong answer from the room, that’s fine. That’s the whole reason you’re up there.

Middle school

Very good for this age. Make it loud and fast.

High school

Can skip, or use as the closer before questions.

Slide 14 (Optional): My story

What to say

Optional, and only if you have decided ahead of time that you want to share. This slide has four prompts. Fill in as many or as few as you want, in your own words, before the session. Delete the ones you don’t use. You can also delete the whole slide and nothing else in the deck changes.

If you use it, keep it short and specific. One thing that’s true for you beats a general statement about ADPKD. And you are describing your experience, not giving advice. “This helps me” is fine. “This is what people with ADPKD should do” is not.

Talk to a parent or guardian, or another trusted adult, about what you plan to say here before you say it to a room. Once it's said, you can't unsay it, and you may feel differently about it later.

Middle school

If you use this slide, two prompts are plenty.

High school

Four prompts are fine. Still short.

If asked

If a question goes further than you want to go, say: "That's as far as I'm going to take it today." You don't need a reason.

Do not

Do not describe your medical details (test results, medicines, scans). Do not mention family members' health without their permission.

Slide 15 (Core): Questions, and where to learn more

What to say

That's the talk. Happy to take questions about ADPKD in general.

Two ground rules. I'm not going to answer questions about any particular person's health, including anyone at this school. And I'm not a doctor, so if I don't know something, I'll say so.

If you want to read more, PKDBridge.org has articles written for teenagers, the PKD Foundation has a lot of general information, and NIDDK, which is part of the National Institutes of Health, has a plain-language overview. And if this made you wonder about something in your own health or your own family, the right people to ask are a parent, the school nurse, or your doctor.

Middle school

Keep the ground rules. For the sources, PKDBridge.org alone is enough.

High school

Same.

If asked

"Should I get tested?" Say: "That's a real question, and it's one for your parents and your doctor, not for me. If it's on your mind, that's a good reason to ask them."

A question you don't know the answer to: "I don't know. I'd check with a kidney doctor on that." That is a good answer and a true one.

Do not

Do not answer questions about testing, treatment, or risk for any individual, including yourself if you would rather not. Do not try to fill a silence with a guess.

Slide 16 (Core): Thank you

What to say

Leave this slide up while people pack up or while you take the last questions. You don't need to read it aloud, but if a teacher or administrator asks what the session is and isn't, this is the answer.

Sources used in preparing this toolkit

The clinical statements in this toolkit are drawn from the following sources, which are also cited in the PKD Bridge protocol. They are listed here for anyone who wants to read further; the slides themselves carry no citations.

- Kidney Disease: Improving Global Outcomes (KDIGO) ADPKD Guideline Work Group. KDIGO 2025 Clinical Practice Guideline for the Evaluation, Management, and Treatment of Autosomal Dominant Polycystic Kidney Disease (ADPKD). Kidney Int 2025;107(2S):S1-S239. doi: 10.1016/j.kint.2024.07.009
- Oberdhan D, Schaefer F, Cole JC, Palsgrove AC, Dandurand A, Guay-Woodford L. Polycystic Kidney Disease-Related Disease Burden in Adolescents With Autosomal Dominant Polycystic Kidney Disease: An International Qualitative Study. Kidney Med 2022;4(3):100415. doi: 10.1016/j.xkme.2022.100415
- Dodd S, Widnall E, Russell AE, et al. School-based peer education interventions to improve health: a global systematic review of effectiveness. BMC Public Health 2022;22(1):2247. doi: 10.1186/s12889-022-14688-3
- Shah S, Peat JK, Mazurski EJ, et al. Effect of peer led programme for asthma education in adolescents: cluster randomised controlled trial. BMJ 2001;322(7286):583. doi: 10.1136/bmj.322.7286.583
- Canter KS, Roberts MC. A Systematic and Quantitative Review of Interventions to Facilitate School Reentry for Children With Chronic Health Conditions. J Pediatr Psychol 2012;37(10):1065-1075. doi: 10.1093/jpepsy/jss071
- National Institute of Diabetes and Digestive and Kidney Diseases. Polycystic Kidney Disease. niddk.nih.gov
- U.S. Department of Education, Office for Civil Rights. Protecting Students With Disabilities: Frequently Asked Questions About Section 504 and the Education of Children With Disabilities. ed.gov

Disclaimer

PKD Bridge provides educational information only. This toolkit, and any session presented with it, is not medical advice, legal advice, school-advocacy representation, counseling, or crisis support. It does not create a clinician-patient relationship or an attorney-client relationship with anyone. Questions about a specific student's health belong with that student, their parent or guardian, and their own clinician; questions about a specific student's accommodations belong with the student, their family, and the school's own staff and processes. PKD Bridge is an

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