0:00

all right hi everyone i'm michelle i live in new york i have two sons with arpkd

0:06

who are 21 and 15. and then i have one in the middle who's 18 just graduated from high school and

0:12

they're doing well and i'm going to be the hospitality host so just a couple of reminders

0:17

mute yourselves please and if you have questions you can type them into the chat

0:22

and then we will be addressing questions throughout but then also questions at the end and we are

0:30

going to have it's kind of going to be a back and forth between the core max and dr hartung so i'm going to introduce dr

0:36

hartung i'm very pleased for our panel today dr hartung is an attending pediatric nephrologist

0:43

at children's hospital of philadelphia and chop an assistant professor of pediatrics

0:48

at the university of pennsylvania apparel pearlman school of medicine she also serves as

0:54

director of the pediatric nephrology fellowship program and co-director of the combined kidney

0:59

liver program at chop dr hartung's clinical and research focuses pkd particularly particularly arpkd

1:07

through studies to better define the natural history of arpkd and imaging studies to develop new

1:12

biomarkers of kidney and liver disease progression her research aims to accelerate the development of new treatments for arpkd

1:20

dr hartung also serves on the pkd foundation's science advisory committee the pkd and

1:26

children council and was the lead author of their arpkd patient handbook and we are so pleased dr arton hartung

1:34

has done so much for the pk dave foundation and not only that she's just a really nice person and whenever i email her to

1:40

ask her questions she's always very willing to email me back and answer so many of my questions

1:46

i wish i lived closer she's an awesome doctor and joining dr hartung on our panel are lisa and doug

1:51

cormack and their daughter jaina and you guys want to introduce yourselves real quick

1:57

absolutely good afternoon everyone my name is lisa and this is my daughter jaina and my husband

2:03

doug and we would like to take a minute to share our family ar pkd story

2:08

our oldest daughter jaina was born a healthy seven pounds 12 ounce 12 ounces in july of 2010

2:16

she was a beautiful and sweet baby and we thought she had no physical problems at two and a half months she began to

2:22

have multiple urinary tract infections and terrible fevers she was hospitalized several times and

2:28

had multiple tests done but the doctors were inconclusive she seemed to outgrow the infections but

2:33

always had multiple unexplained fevers each year in september of 2012 we had our healthy sun

2:40

and in may of 2014 our sweet daughter chesley at chesley's two-week checkup the doctor

2:46

also performed jaina's preschool physical during the physical our pediatrician found a small lump in jaina's abdomen

2:52

she was three and had no signs of being sick an ultrasound found her kidneys to be larger than in adults and fibrosis of

3:00

her liver as well she was then clinically diagnosed with autosomal recessive polycystic kidney

3:05

disease and congenital hepatic fibrosis her blood pressure was double what a child

3:11

her age should be and the left side of her heart was also enlarged in january the following year through

3:16

genetic testing the diagnosis was confirmed genetic testing also revealed our younger daughter has arpkd as well

3:23

our sun was found to be a carrier of the gene and could pass it on to his own children

3:29

i'm now in four blood pressure medications a day reflex meds iron which seems to hurt my

3:35

stomach a bit tons of other meds and growth hormone shots my little sister chesley takes one blood

3:42

pressure red reflex meds and iron each day we have yearly ultrasounds and mris

3:48

quarterly blood draws and lowered immune systems we both have a team of specialists

3:53

including nephrology gi cardiology neurology endocrinology dermatology and in the

4:01

past pt and mental health and we visit the doctor more often than normal healthy

4:06

children should i would like to mention that if any of your children are interested i am

4:12

hosting a fun summer kidney kids zoom on wednesdays this summer contact

4:17

us after the session if you would like more info or would like to join in the fun

4:22

thank you so we're going to go over some of the

4:29

topics for advocating for your child with uh with arpkd and dr hartung when you were

4:36

first when we first learned about this disease a lot of the information that you get as

4:42

a parent can seem very grim and negative and a lot of parents whose children are diagnosed in utero are given a very

4:49

small chance of survival even though this may not be true so what can someone in that situation do

4:55

to find more answers and proper care during their pregnancy or shortly after birth

5:01

yeah that's a great question um so yeah so a lot of that i think comes from

5:07

the historical way in which people were taught about arp kd and probably even to some extent now i think

5:14

a lot of times even when you go into you know textbooks and particularly i think in the ob gyn

5:20

literature there is a lot of doom and gloom surrounding ar pkd and a lot of that comes from the

5:26

fact that you know maybe 15 20 years ago all anybody knew about ar pkd were the

5:32

most severe cases and we didn't necessarily know as much about kids like jaina who are diagnosed

5:38

a little older or even people who are diagnosed in their teens or sometimes even 20s or later

5:44

so i think the best thing i mean you know all of you are here connected with the pkd foundation which is great

5:50

and i think um you know thankfully nowadays through uh some of the social media efforts like

5:56

the pkd and parents chapter pkd parents chapter and the facebook group and things like that

6:01

um it becomes a little easier to find uh information about the the broader

6:08

spectrum of what to expect i would also encourage people to look

6:13

around for the option of getting a prenatal counseling session with a nephrologist not every place

6:19

has that capability but i know you know we do that at chop where um you know we have we have

6:24

obviously a very uh excellent and specialized team of ob gyns called maternal fetal medicine

6:30

specialists um but as part of that we often do prenatal consultations with

6:35

pregnant moms and and we you know talk to the ob gyn we give some information to the moms

6:41

about what we're seeing and uh and try to give some perspective about the range of possibilities to

6:47

expect i think the other thing to just remember is that um it is very very difficult to make

6:53

predictions based on anything you see prenatally and there are many children who

6:59

things looked very bad so to speak prenatally even people with very low

7:04

fluid and they've been told that story of gloom and doom and then they turned out to

7:09

do very well and um and that is you know i really see that i think that is something that can cause

7:15

a lot of trauma to families i still and you know i see that even among i've had patients who recently kind of

7:21

graduated out of my care and they're off to college but the parents still hold in their hearts that fear that

7:27

that stems from the fact that when that child was in utero that they were told that they won't survive

7:32

um and so um so i think just you know looking to to looking to outside your direct care

7:39

team seeking out uh family opinions potentially seeking out prenatal counseling those things

7:44

could be helpful well after our daughters were first

7:51

diagnosed uh we eventually sought out a second opinion just to make sure they were getting

7:56

uh the appropriate care and since diagnosis happens at different stages

8:02

i mean you have any suggestions about how to start getting in touch with doctors who are more familiar with arpkd

8:08

and is there a healthy way to promote the interaction with your

8:14

existing doctors and the new specialists yeah um yeah that's a great question i think

8:20

um so first of all even pediatric nephrology as a specialty in general

8:26

can be uh is is a smaller specialty so depending on where you live sometimes people are having to travel

8:33

several hours even to see a general pediatric nephrologist and then those of us who specialize or

8:38

have an interest in pkd or even for fewer and farther between but i think the key is really

8:44

um doing your own research and using things like the pkd foundations uh they have a list on their website for

8:51

pkd centers many of which are adult centers but but i know you know we've contributed our information from chop and some other

8:58

of the pediatric centers are listed there as well but also making it an open conversation

9:03

with your existing pediatric nephrologist we are quite a small community in

9:08

pediatric nephrology and i'm sure it's the same in in gi um and i think this um i think

9:14

sometimes people feel maybe uncomfortable or that they're kind of cheating on their doctor by by seeking a second opinion but i

9:20

really i don't think any of us in the profession feel that way i think especially for people taking care of

9:26

rare diseases i think you know if i'm taking care of something that is not my direct area of research i

9:31

would happily have my patients go and see somebody who really knows a lot about that disease or

9:37

you know i'm constantly reaching out to colleagues for their advice and so i think in a lot of ways as long as you create that open

9:42

partnership that um you know and it doesn't mean that there's you have anything against your pediatric nephrologist but maybe you

9:49

want to go and you know just get some more information maybe about bigger picture things or more specialized things or

9:55

research that your pediatric that your local nephrologist may not be as well-versed

10:00

in um and and ideally that should be a very healthy and open two-way relationship

10:07

and i you know i've certainly seen patients um in all different kinds of ways so i've had some patients come

10:12

to me for a second opinion um you know maybe they just come once they just wanted to kind of

10:18

you know get some of their bigger questions answered get a little bit more perspective they're very happy with their local team and maybe i just see

10:24

them once and then they go back to their local team and i don't see them again um sometimes i do have families actually

10:30

who just come and see me maybe once a year once every two years just to check in um and you know from my

10:36

end sometimes i don't feel like i'm doing anything because they have a great local team but i think it it um but you know i think that for that

10:41

family it makes them it gives them that reassurance that you know this is i came to see somebody who

10:46

thinks about this disease day in and day out and and it reassures me that my local team is doing

10:52

everything that they're supposed to be doing um and so i think there's all different ways to do that but i think just keeping

10:58

um you know being open about it and asking your nephrologist for advice can be really helpful

11:06

yeah speaking of um all the doctors our daughters have over probably a half a dozen doctors and

11:12

specialists on their team and i mean we have tons of appointments i'm sure all parents can relate to that

11:18

in this zoom call right now it can be taxing to keep all of their medical care and appointments in order

11:25

i know i've even left a daughter at home one time and you know it so do you have any

11:31

suggestions on how to keep their medical plan organized for parents um you know

11:36

i would defer to you actually as really the expert in that realm um i do think depending on your

11:42

hospital system there are sometimes resources that different hospitals have and obviously this is very variable from

11:48

one place to another um so you know but certainly ask your provider

11:53

whether they have anyone like nurse navigator or any sort of uh system like at chop

12:00

for example we have a team that is called the complex scheduling team that if patients if parents are trying

12:05

to coordinate a lot of different appointments that they you know that you kind of send appointment requests through that complex scheduling team and they help

12:12

families to kind of manage a lot of things um not all hospitals would have that sort of thing

12:17

but i think um the other thing i would definitely recommend for people is if your hospital offers like a patient portal an online

12:25

patient portal like we have something called my chop i think a lot of health systems have similar things definitely sign up for that i think not

12:32

just for your own uh ability to track things in terms of all your appointments are listed in one

12:37

place etc but it also often really facilitates communication and allows you to um you know do things

12:45

that are helpful to the medical team for example um you know if you're trying to coordinate multiple appointments between

12:51

specialists and you send a message to your doctor saying oh you know i'm i have an endocrinology appointment

12:56

coming up um they're going to do labs do you need any labs at that time you know there are things that you as a

13:02

parent can do and communicate in advance and these portals make that kind of

13:07

stuff much easier and that helps your medical team to kind of coordinate with each other as well

13:13

but definitely you know again ask ask your medical team about these types of coordination things like

13:19

you know we really try to you know especially if i know that a family is traveling from really far away

13:24

to come see me um and you know they might call our office and say okay i'm going to be there on such and such date because i

13:31

have an appointment with this and the specialist and and even though i may not officially

13:36

have a clinic appointment that day often i'm able to rearrange my schedule so that i can see the family on the day that

13:42

they're coming to the hospital so that you know they're not having to drive three hours another day to come and see

13:47

me and obviously you know not necessarily everyone's able to do that but there is but oftentimes the um the answer you

13:55

get from the scheduling folks may not be the final word right if they say oh yeah there's no appointments for another three months like sometimes you know

14:01

there is there are things that often happen behind the scenes that we do on our end scheduling wise in order

14:06

to get people in who really need to be seen i know we have a binder for each girl um

14:14

so we have things from through cleveland clinic on my chart but then anything like the research studies that they're

14:19

in or things like that we keep track of in our binder and that seems to be a little helpful

14:25

but yes the binders are great and as a physician i love it when a family comes in with a binder it um you know especially if

14:32

it's someone who's been seen in a lot of different places or even honestly sometimes if it's somebody who's in our

14:37

own system because i think you know people's medical records particularly young kids who've been in

14:42

the health system for a long time that is there's a ton of information in the computer system and

14:47

and so we really rely on families to to kind of help us to distill that information to

14:53

um you know oh when was it again that such and such thing happened and even though i could probably spend 10 minutes

14:59

and find that in the medical record um you know families recollections of things but also your personal

15:04

notes and records and you know if you're taking blood pressures at home and your little blood pressure log in your phone or on

15:10

your in your binder those things are incredibly helpful yeah um so at one visit to the er an

15:18

emergency room doctor said something about an ar pkd death statistic in front of jayna she was six years old

15:25

at the time and he didn't know anything about her clinical history or being familiar with

15:30

arpkd and it had such a profound effect on her that we had to go speak with a mental

15:37

health professional so do you have any recommendations on how to deal with those types of situations

15:44

oh wow um i think um yeah i mean that sounds uh very

15:49

difficult i think one thing that can be helpful up front because i think a lot of times

15:55

uh physicians aren't uh as good at proactively navigating what

16:02

types of conversations to have with what people so maybe you know particularly if you're

16:08

um you know maybe if you're going to see a second opinion or a new doctor for the first time that maybe being up front and

16:13

saying you know uh we'd like to talk to you with jaina here about some of the medical stuff but then maybe

16:20

um you know is there a time that maybe jaina could go out and play in the waiting room or

16:25

or sit with a nurse somewhere so that we could talk about if there's any other things that you think she shouldn't hear

16:31

or things like that um you know i think unfortunately uh physicians and medical

16:36

care providers are human and sometimes some uh unfortunate things come out of people's mouths um

16:42

but i think you know as a as a family uh maybe trying to be proactive and trying

16:47

to at least put that on somebody's radar that to be careful

16:53

about what types of things they might say in front of the child

17:00

so over the years my sister and i have been part of several research studies and i was

17:06

wondering if there are any good resources to find out about current studies in arpkd that you

17:12

would recommend that is a great question and yes you guys really have been quite the champions of doing research was

17:19

awesome um so yes a few different uh places so you know i know the pkd

17:26

foundation has some information on their website um the other place for uh to look for

17:32

clinical trial there's a site called clinicaltrials.gov which is um it's run by the

17:39

national institutes of health but it actually does cover studies um worldwide actually so a lot

17:45

of studies even if they're based in you know australia or europe or elsewhere will be listed

17:51

on clinicaltrials.gov and so that's something that is searchable uh by keyword by so for disease or

17:58

locate you're able to narrow it down by location etc and so certainly for ar pkd and i don't

18:03

know if we have any families on the line who have children with adpkd um you know if you go on there there's

18:09

definitely studies going on in all of those areas um that particular website focuses more

18:15

on clinical trials meaning uh most of the time it'll be uh drug studies on there but sometimes people

18:21

will put what are called observational studies so studies where you're just perhaps taking measurements or trying to learn more about the

18:27

disease um and then you know honestly google can be your friend as well um

18:32

or um and then actually asking your physician as well and so often you know

18:38

if it is if you do end up having a second opinion with somebody who is more pkd focused then

18:43

you know all of us are kind of in tune with what's happening around the country or or even studies that might be coming

18:48

up that aren't kind of public uh you know that haven't started advertising yet those types of things

18:53

um so so definitely use your medical team as well

18:59

um another thing is our uh our daughter's school experience has been a little bit different than

19:05

that of a typical typically healthy child so both of our girls have a 504 which is

19:11

a legal document sharing her medical needs at school uh we can share jane is here

19:19

and there it is all right here

19:27

so get it there can you everybody see that

19:34

okay good so we put her um her name her teacher

19:39

and her grade on this paper and it goes in the bin um in like their sub file so all the

19:44

teachers if they have a substitute teacher um they will see her face first thing in the morning and just hear some of the

19:50

things that um she has at school unlimited restroom and water breaks when she needs

19:56

them no contact sports they do a really good job at finding other things for her to

20:01

do in p.e. like be the time keeper if there's a sport that she's not allowed to play that day

20:08

inform mom or dad if hit in the abdominal area she does recess inside and i know we have somebody from

20:13

australia you might get really hot out there i would say sometimes though we have recess that's 85 - 90 degrees and she just

20:20

gets too hot so i get to pick a friend and then we spend the recess inside yeah it's pretty cool um

20:28

we have the the knee pain in here because of her growth hormone shots but you know any

20:34

terrible pains going on water bottle goes with her everywhere no penalty for absences

20:40

she usually carries purell around in her book bag and then she can pretty much snack when

20:46

needed or go and take a nap if she needs and then the really cool thing before

20:52

quarantine is that she had been zooming sometimes if she didn't feel well enough or if she was in the hospital she would

20:58

zoom from the hospital into school so when quarantine started and everyone

21:03

had to learn how to zoom she already knew how so what's that my share here

21:08

okay yeah that's thank you for sharing that that's really great

21:16

do you have any more suggestions for parents um maybe for some individual education

21:22

plans yeah for sure so you know i think for for those of you who live within the us

21:28

remember that both 504 plans and ieps schools are legally mandated to have those and you as a as a

21:36

parent are legally entitled to request those um also remember that probably almost all i

21:42

would imagine all pediatric nephrology practices will will have a social worker that um is

21:49

often somebody who works um you know within with nephrology patients and can help with these types of things so

21:55

um you know if you're encountering uh anything um uh you know often your your

22:01

physician's office and the social worker affiliated with that office can often help um and then just to kind of touch a

22:07

little bit on the distinctions between the two so 504 as you said is a medical plan that

22:13

might say things related to uh the medical accommodations related to the medical

22:19

condition so you know and i do these four 504 letters all the time most of that mostly around the things of you know

22:24

they should be allowed to carry their water bottle with them all the time they should be allowed unlimited bathroom breaks

22:30

um or sometimes related to pe as you said that you know they're not allowed to do this this activity

22:35

um but then again you know the school is legally mandated to to follow that but um but sometimes

22:42

parents do have to be persistent i mean depending on what your school system is how responsive the administrators are

22:48

sometimes you know you really have to kind of ask and ask and ask again but remember this is your legally mandated right so

22:54

be persistent and uh and uh assert your rights um an iep

23:00

or an individualized education plan is slightly different so that also is legally mandated but that's around

23:06

learning differences and and again and you know not everyone will need that it all

23:12

depends but certainly there are people who have particularly if you have more advanced kidney disease where that does

23:17

interfere with learning or perhaps if you're having repeated illnesses and having to spend time in the hospital and

23:23

you're missing school and things like that and so again as part of an iep you're you're entitled to get

23:30

testing done through the school entitled to have uh you know some sort of assessment of

23:35

what your needs are in different areas and if needed have accommodations made so that you're able to reach your

23:41

educational goals and those are both things um that i think have to be renewed every year you have to redo this every year right

23:47

you're 504 yeah we have a meeting once a year um and then do you do you require does

23:54

your school require the documents to be signed off by your medical team every year or now that it's in place are you just

24:00

on autopilot first year it was

24:07

but i bet maybe states it might differ by state differ by state too yeah our our understanding or what we've

24:14

always practiced was after we set up our initial 504 was that's just the base

24:19

we can always add to it we can amend it we can whatever we need to do we can always meet with them again

24:25

and whatever needs to be done they can they can kind of adjust yeah and i think um even though in

24:32

theory uh like private and parochial schools aren't necessarily bound by the same rules but obviously you know sometimes

24:37

the benefits of those those schools are sometimes smaller or uh you know more

24:43

uh able to accommodate individual situations so just you know start that dialogue early with your school

24:48

administrators okay so on jenna's most recent rabbit

24:55

lab reports indicated that her kidney function is beginning to decline more rapidly

25:00

than it had been in the past so now we are discussing our plan of action for

25:05

her kidney transplant so is there a good place to learn about that process

25:11

or to connect with a transplant center or or what do you suggest for that the

25:17

next the next step so um yeah so for most so many

25:24

pediatric nephrology practices will have well probably all of them have some connection or affiliation with a

25:29

transplant center so some of them are part of a transplant center or some of them will have defined relationships with transplant centers

25:37

where they consistently refer their patients to um so that's you know asking your own doctors is always a good starting point

25:44

um there are um there are different organizations online there are there are national organizations that kind of

25:49

regulate and govern kidney transplant so um and they come by all different acronyms so you know uh

25:56

eunos and the uh and the organ procurement transplantation network but anyway if you if you

26:02

even if you just google kidney transplant center liver transplant center you should be able to find or pediatric liver transplant or kidney

26:08

transplant center i think um the

26:14

uh one of the things to always ask about is a center's experience with pediatric transplants so

26:20

there's many um and you know this differs the way that transplant programs look can differ from one hospital to

26:26

another and that varies by size of center by whether it's a standalone children's hospital versus a

26:32

children's hospital that's part of an adult hospital um and so you know and and so the way

26:38

things are exactly arranged differs from one hospital to another um but oftentimes what happens so say if

26:44

you're at a um a smaller pediatric nephrology practice where they they don't necessarily

26:50

themselves uh do transplants there or kind of take care of patients with kidney transplant

26:56

in the immediate transplant period they will often have relationships with the transplant center say in the next big city a couple of

27:02

hours away and often what they'll have is some sort of established pathway of referral where

27:09

they refer patients to the center that center does the transplant maybe manages things for

27:15

the first three to six months and then there's an official kind of hand back process

27:20

where you then go back into the care of your local uh nephrologist and then sometimes people

27:26

will alternate appointments between their local nephrologists and the transplant center i saw in the chat someone mentioned

27:33

telehealth and actually um you know i mean these things at least in the u.s are constantly changing and evolving about the rules regarding

27:39

telehealth but um like at our center for example um we have many patients who uh who live quite far away

27:47

come to chop maybe to get their transplant but then um you know in between they're

27:53

maybe just getting labs done locally sometimes they're alternating you know every three months one appointment they

27:59

do it with their local nephrologist one appointment they do at our transplant center um or they're getting their labs done

28:05

locally and and nowadays thank being able to do telehealth appointments with our transplant center um and so there's so the exact specifics

28:12

of of how it might work for a given family can can vary um depending on where you live

28:18

and what your local resources are but i think often the best starting point is your own local team

28:26

thank you throughout our journey we have hit plenty of hurdles we've missed

28:32

pills i've had to call the doctor about too many pills uh we've missed appointments we've

28:38

canceled plans many times because our girls just sometimes they just don't feel well and

28:43

we have found some non-profits that work with medically fragile children and their programs have really

28:49

brought a lot of joy back into our family's lives two wonderful programs we have in the

28:55

cleveland area is flying horse farms there it's a paul newman camp

29:01

with serious fun network so i know that's a really cool thing to look up the serious fun network they have

29:07

camps all over the world and then another local thing we have is called a kit again where they do special events

29:14

and things for the medically fragile children so do you have any suggestions for families on how

29:20

to cope with the hard parts of having a child with arpkd um i mean you know part of it i think is

29:27

like something like what you just said jaina right like the fact that you're doing the zoom group with kids who have kidney disease

29:33

i think that is so awesome um and i think um you know because obviously you're

29:38

you all are dealing with a rare disease and i'm sure there's a lot of times that you're feeling really alone like you're the only person

29:44

who has this and probably um you know you feel like there aren't really other folks around who are

29:50

dealing with what you're dealing with um but a few things that i would say about that so first

29:57

is that even though the disease you yourself has have is rare there are many many

30:04

kids dealing with medical problems all the time and so what i always tell kids is that you know like if i saw you

30:10

walking down the street jaina i would say oh yeah there's just a kid right um and you probably look around at school

30:17

and and just say oh yeah that's a bunch of kids right but you don't know like a lot of those kids like maybe some of them have some

30:24

you know stomach problem or a brain problem or a heart problem or other kinds of things right

30:29

um and so i think um you know remembering that yes even though you're having to go through all that

30:34

stuff and it doesn't feel normal there's a lot of kids out there who are going through things that are not normal um and you

30:42

know it doesn't make it any more fun but hopefully it makes you feel like you know what i'm you know i'm not alone

30:47

um the other thing the camp thing actually that you brought up um that is that's a really great thing

30:53

there's actually some really great kidney camps around so i don't know um if uh there are camps even that can have

31:00

the ability to do dialysis at a camp um and and like you know kidney focus camps that are

31:06

uh dialysis and transplant focused um you know we at chop have a cooking camp

31:11

design you know we partnered one of my colleagues partnered with the local restaurant school and they have a cooking camp that's just for kids with

31:17

kidney disease um and so again um the social workers at your uh

31:22

hospital may be able to have some access to that re those resources um or if you just you

31:27

know again just google uh uh camps for kids with kidney disease

31:32

um um or things like you know make the make a wish foundation um you know our patients and i think you

31:39

guys mentioned that you were looking into that as well um you know we've had our patients do some really great and memorable

31:46

trips with them so so i think there's a lot of organizations out there doing some really great work so that people

31:51

don't feel as alone and that kids get to be kids and have fun right

31:59

yeah yeah gina just got her wish um the wish was approved so now she has to

32:05

decide what she's gonna wish for oh that's a lot of pressure have you thought about it

32:10

uh some of that options i think when my top one right now is hawaii oh

32:17

that sounds awesome do you need a doctor to go with you [Laughter]

32:25

we might need a whole team so yeah all right all right keep me posted um you know actually just

32:31

before we move on from transplant because i don't remember if we were planning to have any more discussion about that um but

32:37

one thing i just wanted to bring up actually and because um especially for those of you who have kids with ar pkd you're in a

32:44

uh this unique situation well not really completely unique but you know this situation of having both kidney and

32:51

liver disease to deal with um and i think one of the questions that can come up

32:56

is you know if you are heading towards kidney transplant um really getting a sense of you know

33:02

what's the status of your liver and is that causing problems is there any chance that that might need to be

33:08

paid attention to or or had have anything differently done there are i mean it's it's much more

33:15

unusual but there are some people who end up needing a combined kidney and liver transplant um but you know bringing that question

33:22

up early um in the course of you know as you're starting to head down that transplant path

33:28

um to to really think about so that so that that planning all goes forward and that the

33:33

teams are talking to each other and really uh making that plan and certainly you know there's a lot of times where where

33:39

we will get contacted and and we we sometimes will see families who uh

33:44

they've been referred to ask oh you know my patient my child needs a kidney transplant will they often need a liver transplant

33:51

and a lot of times the answer is no but at least that gives you that reassurance that um you know you're kind of going down

33:57

the path that you need to be 10 minute warning

34:08

thank you i think that those were all the questions that you had on your list correct all your topics yep okay so if

34:15

people want to start typing in questions into the chat feel free i haven't seen any questions yet but of

34:22

course i have one um so my big one right now is transition to adult care

34:28

and within transitioning to adult care when when do you start that and

34:35

how do you as a parent how do you kind of remove yourself and feel that you are

34:42

should or shouldn't be as involved and what what do they need to bring like all

34:47

their paperwork from their whole life or um that is a great question um so

34:54

so ideally transition so i'll make a distinction actually between the word transition

35:00

and transfer so transfer is you know i've had my last appointment with my pediatric doctor and now i'm

35:06

going to my adult doctor and i'm done seeing my pediatric doctor transition actually

35:13

should be a process and so really you know when people like there there's actually an entire field of medical literature around this

35:20

for how to do transition well but ideally that should be a process that actually starts at age

35:26

12 13 14. um and it's a whole series of things it's it's um you know you as parents starting

35:34

to gradually give more responsibility to the child uh in in you know developmentally

35:40

appropriate ways so everything from you know starting to talk to the child you know making sure the child has the

35:46

vocabulary to be able to explain what their disease is i mean jaina you're you're far ahead than a lot of people

35:53

but you know i need a lot of people who are maybe you know eight years old older than you

35:58

are and you know they're they're teenagers and they can't really understand what their disease is they

36:03

might not even know what their medicines are um so you know those types of things like really kind of getting the kid to

36:08

take ownership of knowing what their disease is knowing what their medications are starting to learn their doses

36:14

taking more responsibility for being the person who takes the medicines each day and then as they get older say they're

36:20

getting to age 16 age 17 starting to maybe have you know maybe with you as the parent next to them

36:26

having them be the person who calls the pharmacy for refills maybe having them be the person who

36:32

calls the doctor's office and talks to the nurse to describe some problem because i think you know obviously i'm a

36:38

parent too i know what it's like to you know want to you know be the be the good mom and and

36:43

uh you know take care of everything but you know ultimately a lot of times you end up doing your child a disservice

36:48

by hovering too much right and so i think um and so that whole thing you know um

36:54

and ideally uh your pediatric nephrologist should be part of that conversation um you know throughout the

37:01

kind of pre-teen to teen years um the actual kind of getting closer to the time and starting to think about

37:08

the the actual transfer to the adult center um i think one a couple things to think

37:14

about are uh kind of location so at our center we transition people at anywhere from age

37:20

18 to 22 and when exactly in that spectrum we do it depends a lot on where that

37:27

child is in their life and what they're going to be doing with their lives so for example if it's a kid who's about to

37:33

graduate from high school they maybe they're going away for college but they're going to be coming

37:38

home to visit every spring break every winter break and their disease is pretty mild they really only need labs every few months

37:46

and and they're not quite ready and and and then beyond that they don't know where they're going to end up after that

37:51

so they don't want to commit to finding a whole new team that's near to where they're going to college so i might continue to follow

37:57

that patient in my pediatric practice throughout their college life because i can you know arrange it so

38:02

that when they're home for spring break home for the summer i can we can get their appointments and get their labs in um there are other times where you know

38:09

maybe that graduation from high school is a good time to transition um the other thing also is um sometimes

38:15

the transplant thing will factor into the transition decision so if somebody is approaching the need

38:20

for transplant around the time when they're turning 18 often it is better to start that transplant work up at the

38:26

adult center so that you don't go through the whole transplant evaluation process at your pediatric center and then

38:32

and then have to switch midway um it can be done but but you know you can always that can be a discussion between you and

38:38

your doctors for for what's ideal um and then yeah communication is key and and

38:44

good transfer of information is key um like you said michelle that you know do i take everything for you know 18 years of medical records

38:51

and show up with giant boxes i mean thankfully nowadays with electronic medical records some of this

38:56

is becoming easier there are medical assist record systems that talk to each other so you know for for us for example like

39:04

pen the adult hospital next to chop is a completely different entity uh but we are able to see some limited

39:11

versions of their medical records and they can see hours so when i've transferred patients to them um

39:16

you know they they will have that information on hand um and then having ideally if your

39:23

nephrologist can have a conversation or send a email summary or some sort of summary to the adult doctor that's very

39:29

helpful because i think you know when we take on a new patient and there's a ton of information to sift through

39:35

often the very most helpful thing can be a brief conversation from the person who's transferring that patient to me

39:42

or if not that then at least a well-written and comprehensive like the last clinic note if it has

39:48

enough information about all their you know history current medications um and you know what the what the plans

39:53

and outlook is interesting okay perfect great answer thank you

40:01

does anyone else have any other questions i think it's about time anyway i'll if

40:07

anyone else has sorry if anyone else has questions go ahead and type them in i will just make a couple of announcements while we're

40:13

doing that before you leave the session you there will be a survey and they'll put the

40:18

link in the notes so don't forget to um in the chat session so don't forget to fill that out

40:25

but up next there will be a mindfulness break thanks again for joining us during the break grab some lunch or a snack

40:31

take the opportunity to visit our exhibits when you're ready you'll need to leave our zoom breakout and navigate

40:37

back to our virtual platform homepage you will find our exhibits by clicking on the exhibitor button or the link at

40:44

the top of the home page our next section is genetics well i don't think that's for us

40:49

um maybe our next session is genetics how your genes impact your family tree

40:55

uh the session begins at one o'clock central time i know for pkd for ar pkd there's at 2 30 or 1 30

41:02

central time is the liver chf and a question jano what is the kids zoom

41:10

session you were talking about um so i think it would be best tracy if

41:15

you want to email me at um my email address and i can just send you out the zoom link

41:20

but it might be kind of hard since you're in australia but we record them so we could like

41:26

we're gonna interview um a uh she's how old is she i think

41:31

she's 20 years old she has arpkd and so the kids are going to come up with questions that they want to ask her

41:37

and then they're going to interview on interview her on the zoom um soon and then we do some other fun things like

41:43

you guys did a drawing class we did some pet questions

41:50

they shared their pets one week so i could even send you the recordings uh if it's going to be something like

41:55

that so you can email us i think that would be best and why don't

42:00

you type in your email address into the chat real quick lisa and then also anyone who's on the

42:07

call we have a really good facebook group parents um pkd and children parents group where

42:15

we have a lot of information you can also connect that way with other parents yeah we have that

42:22

last slide actually with resources right do you i don't know if uh you have that to put up all right

42:28

yes caitlyn can you put that up for us real quick please

42:33

and i know um amanda your son's gonna come this week right

42:39

hopefully he was a little nervous last soon he didn't he got it all ready she said

42:44

and then he chickened out oh that's so nice though super cute

42:50

i don't know if i can convince my teenagers to come but probably not maybe we could interview

42:57

your oldest yes definitely he would do that well thank you so much dr hartung and

43:05

the cormack family and jaina especially i think your questions were perfect and the answers were great and

43:11

i really appreciate it it's always so nice to see a face like jaina's and

43:18

loves having you here thank you she's she's definitely the cutest person on this zoom so no offense to the rest of you

43:28

um yeah thank you it's great to see you and hopefully we'll be able to get back to doing this in person because i think one of the most fun things for me is to

43:34

get to you know meet families and and hear from all of you and i think as a final kind of plug i

43:40

think just you know talk to your doctors about what it's like to live as a family right because i think that's where

43:47

you know we learn so much from you you're the ones going through this um and i think it's uh and and so yeah

43:53

so hopefully in future years we'll be able to see each other in person and i'll get to we'll get to

43:58

have some more fun together thank you dr hartung thank you yes thank you very much thank

44:03

you all right i think we're going to get that screen up now with some resources

44:16

was there one more

44:23

i just have this powerpoint i'm not sure if this is exactly the one um you guys were all hoping for

44:31

is there another page i could share it okay i think i can find it real quick

44:41

[Music] it's in my downloads this one here we go

44:50

is it this one and then our resources oh we're not seeing the

44:57

powerpoint i think we're still seeing your file list [Music] shoot let's try it now there we go

45:08

yes there you go there you go

45:17

perfect thank you yes so definitely if you're not in the facebook group join the facebook group

45:23

and if you don't have the arpkd handbook i definitely recommend that

45:30

and then feel free to email the parents chapter the emails would come to me and if you i could connect you with

45:35

anyone you needed to be connected with or answer any questions that i'm able to

45:42

thank you michelle thank you thank you it's great to see you all have a good day bye thanks