0:02

hello everyone thank you for joining us my name is elise hoover and i'm the hospitality

0:08

host for this session you've joined us for best practices for disease management

0:13

working with your healthcare team before we get started if you have any questions during the presentation please type them into the

0:19

chat we'll try to answer them as we go or at the end during the q a session

0:26

we also ask that you please keep your microphone muted during the session so that we can ensure good quality audio

0:33

i'm very pleased to introduce our speakers for this session dr ronald perrone is a member of the

0:39

division of nephrology at tufts medical center scientific director of the clinical and translational research center

0:45

and professor of medicine at tufts university school of medicine he has a long-standing and wide-ranging

0:51

interest in adpkd focusing on clinical trials and the use of total kidney volume as a potential

0:56

regulatory endpoint he served as the clinical lead of the pkd outcomes consortium

1:02

whose work led to qualification of tkv as a prognostic biomarker by both the fda and the ema he also

1:09

participated in a number of clinical trials in adpkd including the halt study the tempo 34

1:16

the reprise trials of solaptin and pkd the tame pkd study of metformin

1:21

the bangladesh study and more joining dr perrone is judy ehrlich

1:26

judy was diagnosed with adpkd when she was 25 and almost immediately became involved

1:32

in the pkd foundation as a volunteer in the boston area 38 years later

1:37

she remains a passionate pkd advocate networker supporter research participant and

1:42

strong believer in being educated to live your best life with pkd this past january judy stepped down as

1:49

the long time new england chapter coordinator but serves on the pkd foundation patient advisory group

1:56

her relationship with dr perrone her longtime nephrologist and co-presenter today goes back decades and is added

2:02

enormously to her ability to manage her pkd journey at every stage for the best most optimal outcomes dr

2:09

prone judy it's all yours uh elise thank you

2:17

so i'm gonna share my screen uh we're gonna go through this together

2:22

again we'll encourage questions in the chat and at least we'll try and

2:29

gather those so we can

2:34

um things uh throughout the meeting so again this is best practices for disease

2:41

management working with your health care team uh this is this disclaimer uh which

2:47

you've seen on other presentations these are my disclosures on the bottom

2:53

related to research support for studies and some consulting i've done related to pkd clinical trials i believe

3:00

judy has no disclosures no disclosures so um

3:06

i guess um the important thing one of the most important things to take

3:11

from this is don't be shy with regard to speaking to your

3:16

physicians and health care team so judy can certainly emphasize that but

3:23

what to ask and what you should expect in return okay so we're going to

3:31

basically do this in a chronological fashion and we'll get to the stage that may

3:36

apply to you as we go but you will hear both from me with the patient perspective

3:42

and then from dr perrone and back and forth as we go as he said we are going to try something

3:48

different which is fielding your questions as we go so do put them in the chat if it works

3:54

well we'll continue to do that if not we may save them till the end so let's start with people who are

4:00

relatively new to their diagnosis or they're becoming proactive about their pkd

4:06

um at the beginning of this journey um the one thing i want to say and i will say it over and over

4:12

is that every one of us deserves to have the best care that we can

4:17

uh that is going to entail some work on our part and it starts with knowing that you can

4:23

and should be your own advocate if you cannot advocate for yourself for whatever reason

4:28

you can find people who can and so you want to find the right nephrologist and learn

4:35

about her or him knowledge of pkd their experience and

4:40

very importantly whether there's a good fit and that's not always the case so

4:47

the way you learn that is just like you would learn about anyone a new friend a new colleague you would ask people

4:53

questions you will talk to them you can ask specifically about their experience with pkd

4:59

and don't be totally concerned if you may have more

5:06

information about pkd based on research you've done then the first doctor that you may visit

5:12

always feel free to ask questions and among those questions you'll hear and you have heard

5:18

if you've participated over the last day and a half is what about clinical trial opportunities now that you've gotten to

5:24

know me what is available for me how can i help myself my family members and how can i help

5:32

the larger pkd community and i i just want to point out and i know many people who

5:37

have been in this situation the first doctor or doctors you see may not be the right fit for you and it

5:44

is okay you know what feels right and that's what you should be seeking in the early

5:50

stages of finding a provider

5:55

one of the common complaints that i've heard from new patients over the years

6:00

is that they feel that they know more about pkd than their doctor even a nephrologist and and so judy's

6:08

absolutely right you need to pick someone who's interested and and knowledgeable

6:16

all right so what to expect from your physician

6:21

so the doctor should inquire and you should make the doctor aware

6:27

what are your manifestations of adpd do you have liver cysts do you have high

6:34

blood pressure do you have symptoms related to your cyst um

6:40

what is your level of kidney function and so what is your your present status and then you want to

6:47

know what are the potential treatments and interventions both for adpkd and for general and

6:53

cardiovascular health also let's not neglect psychosocial

6:59

function and well-being and i think it's important to have conversations with knowledgeable

7:06

providers regarding genetic counseling family planning

7:12

kids some of that may require uh specialized interaction with a geneticist

7:21

okay so if someone is seeing a nephrologist that is located in a group of nephrologists at a clinic and they are

7:28

they want to explore perhaps a different person on that team what do you advise for um asking to see

7:35

a different nephrologist in that group sure um that could be a challenging situation

7:43

depending on how the practice is organized um so it would first of all it would be

7:48

important to understand why you want to see a different doctor so that's perhaps talking to other people with pkd

7:56

talking to your local chapter of the pkd foundation there may be individuals there with experience

8:03

one of the other doctors may be involved in clinical trials may have lectured about pkd so those would be

8:09

good reasons my general philosophy if if you ask your doctor something and

8:16

they don't you don't like their answer well i think it might be time to move on to a new doctor and

8:22

and sometimes that might involve changing a practice if they're not willing to accommodate what what you would like

8:29

judy any experience in that area um no fortunately i live in a geography

8:36

that has offered me a lot of pkd's special specialization but i

8:44

would would echo the fact that this is your health and you are going to be an advocate for

8:50

yourself and so don't just change for the sake of changing um and you may have to tap

8:57

dance around a little bit if it's really just that you didn't click with that provider but you have nothing to lose

9:04

and everything to gain as long as you do it in a respectful way

9:10

thanks jesus thank you thanks elise so um it would be important that um

9:17

your healthcare team has a full understanding of your symptoms

9:23

it's also important to discuss how one was diagnosed some people are

9:29

diagnosed deliberately that is they choose or their parents choose to go ahead and get

9:35

an ultrasound someone else may get diagnosed accidentally

9:40

for example if you've been in auto accident or have some abdominal pain and you go to

9:47

the emergency room you're going to get a cat scan it's hard not to get a cat scan when you go to an

9:52

emergency room and that may show cysts some people are diagnosed because they have back pain

9:58

and they had an mri of their spine and the spine mri may pick up cysts in the kidneys that's another way

10:07

genetic testing is typically not the first thing we do but it may be

10:13

necessary to confirm a diagnosis or to sort out a

10:20

an atypical case so the things that i teach my fellows

10:28

and colleagues to do regarding an approach to someone with polycystic

10:34

kidney disease is to figure out kidney size and we use something called

10:41

the mayo clinic classification which is a way of evaluating kidney size

10:46

as a function of age so if you have large kidneys at a young age say in your 20s or 30s that indicates a

10:54

high risk of progression if you have small kidneys at a young age your risk of progression is lower and

11:00

this is like a crystal bore ball to the future and it's a very important um activity that your your doctor should

11:08

be aware of knowing one's male classification is also

11:14

potentially the ticket to being able to take tolvap then or not or to enrolling in a clinical trial so

11:20

that's really very important abdominal enlargement may be due to kidney cysts it may be due to liver

11:26

cysts symptoms as indicated

11:31

typically related to a kidney and pain in the flanks bleeding infection stones the frequency

11:38

of these and the severity of these should be established by your healthcare team

11:44

other things that may not be so obvious but are important are frequency of urination whether you

11:49

urinate at night whether you urinate more frequently because these have implications as far

11:55

as both kidney disease and other things so if you're a 65 year old man and you're

12:02

frequently urinating it might have nothing to do with pkd it may be related to an enlarged prostate hypertension is

12:09

very important the goals of blood pressure for someone with pkd

12:15

are lower generally than the standard goals for the general population with hypertension

12:20

particularly if you're under age 50. so very important to sort that out

12:25

kidney function is determined by estimating the gfr or the glomerular filtration rate and

12:31

this is typically a function of the level of creatinine in your blood

12:37

and of course the presence or absence of protein in the urine is very important

12:42

typically people with pkd don't have a lot of protein in the urine but if you do have that would

12:49

dictate how your blood pressure uh would be treated

12:54

okay if i could just jump in here for one second that's a big list and i just want to

13:00

make sure that all the patients out there are not looking in that looking at that and saying okay well my doctor has a lot

13:06

to do of course the other side of that coin is that we have to come to those appointments

13:12

knowing some of this information obviously we may not have had our gfr done yet which by the way is just done

13:19

through a blood test we may not know what our mayo classification is but we will learn it

13:24

but a lot of these symptoms and the frequency and how often you've had them and when you last had them etc

13:32

is important information to bring with you and chances are it's best to pop it into your phone or write it down

13:39

and for those who haven't seen the um the talk by dr gordon on the basics of adpkd

13:46

uh that would be a good primer to uh help get yourself ready for your

13:51

appointment so that kind of segues well into the patient perspective

13:57

once you've established your relationship and you've had your essentials all

14:03

examined and you are living your life in the early to mid stages of pkd

14:09

so now we're talking about how am i doing am i doing what i need to what's happened since i last saw my

14:15

doctor am i seeing any other doctors for anything am i keeping up with my nutrition etc

14:22

so there are a lot of things that we can do and i also want to point out to anyone who's new and already feeling

14:27

overwhelmed we do this incrementally we're not going to get it all we're not going to get it all right in the first go-round

14:33

but these are things that can be reminders to you so everyone should have a good blood

14:38

pressure cuff at home and if you need a recommendation on which ones to get because they're better

14:45

you can ask your nephrologist or anyone else on your healthcare team but you should take your blood pressure

14:51

readings at home occasionally during these phases and bring the readings with you because you only get one reading maybe two

14:58

when you're sitting in the doctor's office so have that have that there have again

15:04

in that list what have you noticed anything changing how are you feeling

15:10

if you've gone to see other healthcare providers and there was a whole session on this earlier today which i recommend

15:17

make sure your kidney specialist knows who you're seeing and you're going to have to be the

15:23

quarterback to make sure that different providers are connecting with one another

15:29

if there are important events occurring in your pkd as you know this is a chronic disease

15:36

and so it takes many decades for your pkd to kind of

15:43

reveal itself and the speed of that is not known so it's important to know kind of where

15:48

you are on the trend line are you stable which you very well may be for many many

15:54

years are you on the close end of that earlier on or are you

16:00

potentially nearing that point where you might be declining and some of that will be determined by your symptoms and how

16:06

you're feeling again this is a perfect time to talk about clinical trial opportunities

16:12

i'll i'll keep emphasizing that because no one else can do it if we as pkd

16:20

patients don't and you always want to make sure that you're comfortable and your doctor is comfortable with how often

16:26

you're being seen in their practice thank you judy so

16:33

one very very important thing if the doctor says well there's nothing

16:40

i can do come back and see me when you need dialysis or a transplant you should just

16:45

turn around and walk out the door because there's a tremendous amount of things that must be done

16:54

both for the health of the kidneys but also for the health of your other organs especially your heart

17:00

and i will emphasize heart disease is an important uh cause

17:06

of problems and anybody with chronic kidney disease is at risk of having heart disease and

17:12

heart attacks especially if you have hypertension or if you're overweight so it's it's really important that all

17:19

of these other things are addressed so these top line here supportive care general health measures

17:26

very very important managing hypertension again i mentioned that the goals for

17:32

blood pressure levels are lower in pkd than they are in other chronic kidney diseases especially if

17:39

you're below the age of 50. so as judy mentioned

17:46

obtain a blood home blood pressure monitor one that fits on the upper arm not on

17:52

the finger or the wrist and bring it to your health care provider's office and make sure it's

17:57

giving you accurate reading sometimes they're they're inaccurate uh i would say a

18:03

low to moderate intake of caffeine you know no five cups a day but if you're happy with one or two that's probably

18:11

fine high water intake is very important um for a couple of reasons

18:19

if you have enough water you'll block the secretion of vasopressin which is a hormone that

18:25

makes the kidney progression worse the other feature of pkd is because of

18:31

the cysts the ability of the kidneys to hold on to fluid is reduced so it's easier to get

18:38

dehydrated so for those reasons very important to maintain a high water intake

18:44

typically i advise a mild protein restriction and certainly uh salt restriction in the earliest

18:52

phases of your interaction with your doctor it's important to assess your kidney volume or kidney size and to estimate

18:58

the mayo imaging classification there's an online calculator you just

19:04

google image classification in adpkd and the calculator is right there

19:10

people who are eligible who are at risk of rapid progression uh would be eligible to take tolvap dan

19:16

or jin rq and and this is i think an even more

19:22

challenging area because you may have doctors who are familiar with pkd but who have never prescribed

19:28

to laptop so it's important to poke around the area where you live

19:33

and if your doctor is not willing to consider it even though you might be

19:38

eligible then you need to find somebody who may be willing to prescribe that and and fully educate you

19:44

regarding the risks and benefits uh as as kidney disease progresses

19:51

unfortunately it does progress in many individuals the optimal treatment would be a

20:00

preemptive living donor transplant that is one that takes place prior to needing a start dialysis and

20:08

because pkd runs in families this requires a lot of extended family planning and some of my

20:16

patients when they go to family reunions or weddings or unfortunately funerals they get together

20:21

with their relatives and they kind of figure out um who could give me who could give a kidney to

20:27

to who and obviously if you're affected you can't donate a kidney but these are all things to consider

20:34

again as judy mentioned this is a lot to handle all at once and it's better to bite it off in in

20:40

chunks and to be able to review these things with your your doctor your family your friends

20:47

and perhaps a pkd foundation support group or chapter dr prune can

20:54

you clarify that male imaging classification when someone is given a class can that change

21:00

in their next kidney volume measurement generally the mayo clinic class stays

21:06

stable and it it may

21:12

you know you may be on the borderline between one class and the other and and further the the measures we use

21:20

to estimate the kidney volume for clinical purposes are typically not as accurate as

21:26

research measures so it's it's generally recommended if

21:31

you're a mayo 1a or 1b which are those classes which are not at risk of rapid progression

21:38

you might get your kidney volume remeasured in a few years to determine if your

21:43

class has shifted generally thought to be stable certainly the the more severe classes don't

21:50

regress at least not early on

21:59

so i had a previous slide about kidney care but because pkd is a

22:07

systemic illness there's problems manifestation

22:12

outside the kidneys and if you're seeing a nephrologist who's in

22:18

a major center a major pkd center they can probably handle

22:24

a discussion and appropriate referrals for these other issues if you're seeing a nephrologist who's

22:32

maybe a really good pkd doctor but still may not be an expert in these other areas

22:37

you may need consultations so uh brain aneurysms occur in about 10

22:43

of people with pkd on average but more so in those with a family history of brain aneurysm

22:49

and that requires uh screening with an mra

22:55

we generally advise women to avoid extra estrogen because estrogen can make

23:02

the liver cysts worse and this might involve hormonal contraception

23:07

or post-menopausal hormone replacement therapy and then as i mentioned heart disease

23:14

is an important part of any chronic kidney disease so it's important that measures be taken

23:20

to reduce your cardiovascular risk and this would involve strict control of

23:26

the ldl or the bad cholesterol level a healthy diet and those of you who have

23:32

watched many of the sessions will probably be very confused about what a healthy diet is

23:38

for pkd for example a ketogenic diet is a high fat diet

23:43

and so there there needs to be a lot of consideration as to whether or not that's the right diet for you we know that

23:51

reducing calories and maintaining an optimal body weight is important no matter what stage your disease is and

23:58

avoiding smoking and i should have put getting exercise so all of those things are important for

24:04

a healthy heart and making you

24:09

not get ruled out for a transplant should that be necessary

24:16

judy feel free to dive in at any point uh psycho psychosocial issues are important

24:23

many people with polycystic kidney disease have depression and anxiety uh that

24:30

related to you know they have this disease uh they're obviously appropriately

24:36

worried about what may happen in the future they may feel guilt for passing it on to

24:42

family members to kids and so referrals for counseling

24:49

are certainly should be considered and i would strongly advise connecting with the pkd foundation

24:56

support groups for that i will jump in here for a second with a different hat on which was

25:01

my chapter coordinator hat for all those decades um to say that i have spoken with

25:08

hundreds if not thousands of pkd patients at various points in their journey

25:14

and just having that conversation from time to time is so helpful for people who are feeling

25:20

isolated and alone we are not alone this is a fairly common genetic condition

25:26

and through your chapter you can find people who either have already walked the path or

25:33

dealt with the issues that you're struggling with at the moment or just someone who gets it and sometimes you don't want to talk to

25:39

your family members so reach out and these days as someone said in a prior

25:45

prior presentation i was on today any chapter every chapter is doing something virtual

25:52

and many of them are having these support groups slash conversation sessions so i'm going to

26:00

i have shared um in my profile my email address we will share it again at the end and i

26:06

welcome anyone who just wants to talk to call me i have been down this path

26:11

and just as an aside with dr burns help and guidance saw my way to a very

26:18

successful pre-emptive transplant two years ago thank you for sharing that

26:24

judy dr prong can we go back one slide we have some questions about these non-kidney complications

26:31

could you talk about when you need to involve a new specialist in your care team and what the screening recommendations for these look like

26:38

sure so regarding brain aneurysms um at your initial visit

26:45

with your pkd nephrologist they should ask about your family

26:51

history of brain you know brain aneurysms

26:56

uh strokes brain bleeds uh sudden death this all sounds i'm sure

27:01

pretty depressing but it's important to sort those out and the standard recommendations for

27:08

screening for brain aneurysms have been to screen only those who have a family history of

27:14

aneurysm or bleed i think that these or who have jobs that

27:21

you know if an aneurysm ruptured would put them and others at high risk the rupture

27:27

of an aneurysm in the brain is a catastrophic event possibly leading

27:32

to permanent neurologic disability or even death so it is important that it be thought

27:38

about more recently screening recommendations are such that

27:43

i offer screening to everyone i don't you know i say if if you want to

27:49

be screened it would be reasonable um it's rarely denied by an insurance company if you

27:56

have pkd um so that that's sort of the general approach

28:03

also when i see someone initially i like to get an understanding of whether or not they have liver cysts

28:09

disease and how severe it is so frequently people will come to me with just having had a kidney ultrasound

28:16

which doesn't show the liver and depending on their age and you know other things i might try to get

28:22

a ct scan or an mri of the abdomen or if or if they have small kidneys on

28:29

ultrasound and they're 20 years old i might just be happy to have a an abdominal ultrasound which

28:34

includes the liver so those are you know the main things one screens for

28:41

in terms of cardiac stuff the ldl is just a blood test done when you're fasting

28:47

one one listens for heart murmurs to see if there's any cardiac valve

28:52

issues so those are the the general kinds of screening that's great thank you

29:03

okay uh children and pregnancy um so i'm just going to give general

29:09

guidelines a lot of this is very specific to the ages of children

29:15

in the family history but it's generally considered

29:23

not appropriate to diagnose children who are asymptomatic and aren't

29:30

able to make an informed decision so that is below the age of 18 um

29:37

we don't generally recommend to you know pack your kids in the car and take them all to the ultrasound suite

29:44

there are multiple reasons for that one is that you create a pre-existing condition

29:49

which follows them for health insurance life insurance and disability insurance and their medical

29:55

records the other is you create a disease in a child who was previously

30:01

thought to be healthy now this is in an asymptomatic child and this can medicalize the child

30:08

and can also drive the parents crazy so if the kid is asymptomatic

30:17

and the blood pressure is normal it would be reasonable not to

30:22

do it do diagnosis which would typically be with an ultrasound

30:27

uh if the child has developed high blood pressure or other symptoms

30:32

like abdominal pain or blood in the urine excuse me then a diagnosis should be entertained

30:41

regarding pregnancy any woman who has chronic kidney disease

30:48

with high blood pressure is at risk of having more complications

30:53

during pregnancy and those would include a higher blood pressure

30:58

and a risk of a child may be small for gestational age or being born

31:05

early so those are considerations on the other hand individuals women with well-preserved kidney function and

31:12

well-controlled hypertension can generally be very safely maintained through pregnancy

31:18

and just to be aware that the recommended drugs for high blood pressure

31:23

typically angiotensin converting enzyme inhibitors and angiotensin receptor blockers

31:28

are contraindicated during pregnancy and someone trying to get pregnant

31:35

another issue is reproductive decision making this is very personal and i've seen the

31:41

gamut uh through my practice over many years um

31:46

some people procreate without a second thought recognizing that the chance of of

31:53

each child has a 50 50 chance of having pkd other people choose not to procreate

32:00

to adopt to have semen or egg donors or to do

32:07

pre-implantation genetic diagnosis that's a technique where you do in vitro

32:13

fertilization and only implant the embryos that are unaffected i make no particular recommendations in

32:20

this area these are very personal decisions but this is a range of of options and you should probably meet

32:27

with a genetic counselor even if your doctor is terrific a genetic counselor is probably

32:33

able to better frame these issues for you so i think that's very very

32:40

important judy if i could ask in your experience supporting the community um

32:46

what are your thoughts on um counseling someone whether or not to diagnose their child what's that been

32:52

like for you as a chapter leader well just like the uh concept of

32:59

do we have children or not um it's it's a very personal choice

33:05

and so what i tend to do is to share what i've chosen to do and

33:11

explain why people really just have an opportunity

33:18

to ask the questions that are bothering them but i i

33:24

kind of stand um in dr perham's court on that diagnosis can be

33:30

um far-reaching it can have effects that you need to consider in advance before

33:37

doing it and just you know by way of full disclosure i have two children

33:42

and um they knew all along as they were growing up especially when i sent them

33:48

off to college they knew there was a chance and they learned some of the basic healthy habits

33:54

that's where i let them be until they made the decision to get tested

33:59

when they were older so a very personal decision but one not to be made

34:06

lightly at least not without all the information thank you for sharing that dr prom we

34:12

also have a question about the risks to your kidneys if you are diagnosed with pkd and

34:18

you want to get pregnant are there any considerations there so one of the um so they're both short

34:25

and long-term risks the short-term risk would involve uh worsening of hypertension of high

34:31

blood pressure and um if that was to be severe and and the woman developed

34:40

preeclampsia uh then there's a risk of temporary kidney shut down um or acute

34:47

kidney injury that's generally um not so common if if

34:52

the individual is well managed that is if you're managed as having a high risk pregnancy

34:58

the long-term risks of pregnancy related to kidney function it's thought that four or more

35:04

pregnancies are associated with worse kidney function over the long term

35:11

kidneys work very hard during pregnancy and so it's not unreasonable to think that multiple pregnancies might result

35:19

in and worse long-term outcomes and then again multiple pregnancies are also associated with an

35:25

increased risk of more severe polycystic liver disease

35:30

thank you all right sorry i'm going to advance the

35:37

slides okay judy mentioned participation in

35:42

clinical trials so in the united states and in other countries

35:49

drugs are only approved after they've been tested in humans so even though we can test

35:55

drugs in cells and in mathematical models until they're actually used in humans

36:03

they're not going to be approved by the fda and as judy mentioned

36:11

only people with pkd can participate in these clinical trials of new drugs right now there's

36:18

one medication which has been shown to be effective for slowing the progression of pkd and that's till

36:25

there are other drugs in clinical trial and there was a recent trial of a drug

36:31

called vanglostat in the stage pkd trial which at its interim analysis this is a

36:38

planned analysis was not shown to be working so the trial was stopped

36:43

and this is basically reduces people wasting time

36:49

on a trial where the drug is not effective so again there'll be no new drugs for

36:55

pkd unless patients with pkd participate in clinical trial

37:01

most treating physicians are not involved in clinical trials in the community so they can inform you and refer and

37:08

they can certainly collaborate with the center performing the trial the pkd foundation website has um

37:16

clinical trial listings and there are alerts regarding new clinical trials and

37:22

sometimes geographically targeted emails to

37:29

invite people to participate in clinical trials it's hard to be in a trial these take

37:36

time you have to go to the study center you have to take time off of work sometimes you stay overnight

37:42

in a trial center or a hotel most trials will reimburse for travel

37:48

expenses so at least they take care of that that part

37:56

okay judy so we've talked about a lot of this

38:02

obviously you're as time passes you're progressing with your pkd

38:08

and so at this stage which i'm considering later stage

38:14

you need to understand what the changes are that are happening to you a perfect example of that

38:19

is as your kidney function begins to decline your body needs to adapt

38:27

especially with your diet there are things that the kidneys excrete

38:32

that need to be excreted and when your kidneys can no longer do it like potassium or phosphorus

38:40

you need to learn about how to eat so you can reduce those elements in your system because your

38:47

kidneys cannot get rid of them it's not easy but there are so many resources there so you should be

38:54

thinking ahead of yourself so you can be prepared which means again you should come with

39:00

questions to your visits and dr peron mentioned um you know he and i talked about this

39:07

for years but preemptive transplant was always my goal

39:13

and we managed towards it and that the only way you can do that

39:18

successfully is by coming with your questions and saying okay well my gfr

39:23

is now at x and you know it's moved at this rate what do you think what should

39:28

i start doing and with all the knowledge i had i needed dr perrone to nudge me

39:34

when it was time for me to start looking for a donor and your doctor should be able to do

39:41

that and you should be comfortable accepting that and so that opens all kinds of questions

39:46

what are your options are you thinking about a transplant would it be a deceased owner or a living

39:52

donor what about dialysis what's best for you long conversations with your care team

39:59

um if you're if your kidney health is declining then your participation in whatever

40:05

clinical trial you might be in might be changing

40:10

a lot of talking and considering goes on during this phase and chances are you're going to be

40:16

seeing your provider more often you're going to continue to make

40:22

lifestyle changes um it's it's a that's the one constant is that things

40:27

continue to change but you can do this and you can do it successfully and

40:33

gracefully with the support of a caregiver when you follow these kinds of best practices

40:40

and the foundation is always there for support

40:45

and you should never be reluctant to reach out for the support that you need

40:54

thank you judy um i i think having a a relationship with a dietician who's an

41:01

expert is useful at all stages of pkd

41:07

so getting you know the healthy diet in the beginning and then as as needed

41:16

with severe loss of kidney function and the restrictions and potassium and phosphorus that judy mentioned

41:22

the dietitian will also be able to help you with that i just will jump right back in again

41:27

because i know this is overwhelming i know there's so much information here and i just want to remind people that

41:34

this happens over decades so just keep that in mind you only have

41:40

to bite off what is in the near term ahead of you and it is doable if

41:48

you have the right team around you

41:55

so these are the key takeaways

42:00

find the right care team for you know your numbers uh learn about and participate in

42:06

clinical research ask questions and as judy just mentioned anticipate the next phases of your pkd

42:13

progression seek out the support you need at each stage of your pkd journal

42:18

journey and remember that you have the power to get optimal care in partnership with your health care team

42:23

so you can live your best healthiest life with pkd i feel like i can say that i can i can

42:32

really emphasize that because i've just done it and it is possible and so many of my pkd

42:40

friends and associates have done it too it may not be easy it may feel distressing at times

42:49

keep pushing forward because you deserve the best care that you can possibly get

42:58

so um action steps uh are indicated here the education

43:04

sessions are being recorded and you can review them at pkdcure.org after the conference and of course sign

43:12

up for the registry which informs us about

43:19

[Music] different aspects of pkd how it affects the population

43:25

and possibly help you participate in a clinical trial

43:32

i'm putting my email into the chat and i'm serious when i say

43:38

actually we have it up here oh there it is sorry i forgot yeah um so elise are there

43:45

other i'm not sure where we are time wise are there other questions that uh we can tackle i i haven't been able

43:52

to follow the chat i've been relying on you you've done a pretty good job we are up on time unfortunately

43:58

um but dr perrone and judy have been gracious enough to give you their contact information so if you have

44:04

questions um you can also of course always email the foundation like judy mentioned and we have a lot of support programs

44:10

to help you and to help you navigate your disease journey um sort of thank everyone for joining us

44:16

thank you judy thank you dr perrone we do have a link to a survey in the chat if you please fill that out let us

44:22

know what you thought of this session our next session is called updates from the pkd

44:28

foundation research advocacy and education and that's at 5 45 central time hope

44:33

we'll see you there thanks so much all right thanks and good night

44:57

hello great to be with you on pkd connect now if you're starting to feel a little bit weary maybe your energy is

45:03

dropped a bit rather than going for that fourth cup of coffee or sugary snack to keep you going

45:08

which might put you on a bit of an energy roller coaster where you're gonna get up if you're physically able and move your body

45:13

so you ready we're gonna be starting sitting you're going to put into your tongue muscles you're going to stand on them

45:20

and then you're going to sit back down again if this is no good for you i want you to start just having a gentle little walk on the spot

45:25

otherwise start to reach up here if you can and come on down to bring more of those

45:31

reaching up and down activating your core muscles your glute muscles there

45:37

lifting up come on down one more here great now bring up one heel then the

45:43

other heel and moving through those feet and that's exactly what we're going to do now is

45:48

move through your feet and have a little walk on the spot swing those arms a little bit more than

45:54

perhaps you normally would unless you're really determinedly going somewhere bring those knees up a little bit higher

46:01

and let's go for another count of eight seven yeah swing them out

46:06

four three two and one great push your hand one way

46:12

and the other bring your fingertips back up towards your face now imagine two people you know on this

46:17

event that you're going to give a high five to one way and then the other way save them

46:23

your energy send them your virtual high five let's go a little bit quicker now ready

46:28

push it out there if you tend to do a bit of squat in your

46:35

fitness routine you could do a few now if you're warmed up enough whatever's good for you and your knees and your

46:41

body okay ready to walk it out again let's walk it out

46:46

this time i want you to imagine the ground is quite hot so if you're able to walk a little bit faster maybe you might even like to take

46:53

a little high intensity job whatever is good for you and your fitness and you're just gonna go for it now or just feel free to go back to

46:59

those walks whatever is good we've got four three two and one great just lift one

47:08

knee up bring it back down lift it up and down we're going to punch and punch nice and smooth with

47:14

those elbows bit faster if you've got it now lift up that knee punch it out

47:20

four other side let's do it punching down

47:27

so a nice little gentle twist for your spine here great to get that energy up that heart

47:34

pumping a little bit four three

47:40

let's have a little walk again this time when you walk you're gonna get you bring your arms up then arm down deep breath in

47:48

big round now two more of those really lift those knees up and one more to go this time leave your

47:57

arms up here and we're just going to pull down a little bit just bringing it down

48:03

nice side stretch here that's it two more here

48:10

and one beautiful let's finish with a roll down drop it there have a shake out pull into

48:18

your tiny muscles leave your head down if you tend to get a little bit dizzy when you come up then head on up shoulders back hope

48:24

you've enjoyed that two minute move certainly love being here we do hope to see you on another one very soon bye

48:38

you