0:10

all right i think we're right on the right on the start time so let's get started with our session

0:16

um welcome everybody my name is nicole harr and i'm going to be your hospitality host for this session you

0:23

have joined us for talking about pkd patients and caregivers share experiences talking with friends and

0:28

family before we get started just a reminder you can type your questions into the

0:34

chat and we will address some questions throughout maybe or at the end we'll see how that goes

0:41

we do ask you to keep your microphone muted i'll just make sure that everybody has good audio

0:47

i am really excited to introduce our panel to you i'm not going to tell you uh very much about them because i'm

0:52

going to let them do that but we have with us ann bartels, laura macklin ed and

0:58

kathy mcvay and nancy kaminsky is also with us and she's going to be our moderator for this

1:03

session so nancy it is my pleasure to turn this over to you

1:08

thank you nicole my name is nancy kaminsky and i am a pkd foundation

1:14

volunteer with the pittsburgh chapter i'm also a pkd patient and a transplant

1:21

recipient with a multi-generational family history of pkd our panel this

1:28

afternoon is here to talk about how they've shared their story of pkd with family or friends there's no right

1:36

or wrong way it's a very individual thing for a long time i didn't tell my story

1:43

my kids always say i came out of the closet about it it's very individual and very personal

1:51

and none of us are experts but we hope to help you find your own way to share your story

1:57

and talk to family and friends about pkd i'd like to start our discussion with

2:02

ann bartels who says she has always been very open about pkd

2:08

and hi so i'm going to start with saying i'm not a public speaker so please be kind

2:16

um pkd has been in my family as far as three generations back that i can

2:21

find out um my mother was diagnosed first she had it she knew she had it for

2:28

probably 20 years before her mother was diagnosed and so i think i heard another family saying that

2:35

and then she was probably diagnosed when i was about 10 years old and so we always

2:43

talked very openly about it you know we didn't want my mom didn't want us to be scared about it so it was something that we talked openly

2:49

we talked about it at the dinner table we talked about it when her cysts would pop

2:55

and she'd be in bed on antibiotics for a couple days and so she always raised us which i'm

3:02

following her lead as treat us as we have it and hope that we don't

3:08

and so my sister was diagnosed probably in her 20s my brother was

3:14

diagnosed also in his 20s and i really thought i had dodged the bullet i had a child at

3:20

30 and then i had my second child at 32 and my blood pressure went out of whack and i got tested and i had it

3:26

and so i was the last child that got diagnosed so my mom had three

3:32

children four of us got it and so i was a young mom with two kids

3:38

and i my kids have been raised with it unfortunately i lost my mom when my

3:43

first born was 10 months old and so he never really got to know her but i just raised my family the same way

3:50

i talk about it with my friends i talk about with my family i talk about it with anybody who will listen my coworkers

3:56

i'm not ashamed of it it's something that we have to deal with and grow with

4:02

i don't consider it a death sentence at all i'm living a very life and full life i

4:09

continue to work full time i continue to take care of my kids i'm married and so if anyone's willing to listen i'm

4:15

willing to share my share my story with them and so my sister

4:22

was transplanted probably about eight years ago and so she had to get a liver transplant

4:28

and a kidney transplant my brother is trying to get on the list i'm on the list for kidney transplant

4:34

and a liver transplant because it affected um our livers also unfortunately but i think it's very very common

4:40

and so i'm living life on the list everybody knows about it my boss knows about it my kids know

4:46

about it my friends and family know about it um we're all just kind of hoping

4:51

for my day to come um i'm kind of raising my kids they have not been tested

4:58

i am not stopping them from getting tested i'm not encouraging them to get tested i'm just raising them as they have it

5:06

um i'm discouraging the high energy drinks the high salt intake meals

5:13

but yeah it's just a very open book at our house it's never been anything that we've hidden it's never been anything that

5:21

we've even tried to hide and so that's just how i live

5:29

thanks dan our um next people on the panel to speak are ed

5:36

and kathy mcvay and they're here to share with us the shock they experienced when they found

5:43

out that their daughter had pkd kathy and ed thank you nancy

5:49

hi can everybody can you hear us yes okay good thanks uh

5:56

kathy and i are active in the uh milwaukee chapter of the pkd uh and we were asked to

6:03

join this panel because our daughter has a d pkd

6:10

she was diagnosed seven years ago when she had just graduated from college

6:16

and it was quite by accident she had been having some internal issues the doctor was actually looking

6:22

for an ulcer and discovered that she had pkd

6:28

to the best of our knowledge we had no family history of it the only thing in hindsight is that she

6:36

had been being treated for high blood pressure which we always thought was odd um but

6:44

we never jumped to a conclusion so um that's basically how we got started with

6:51

uh with it and how we came to uh the knowledge that she had a spontaneous

6:57

uh mutation so um we were shocked

7:04

uh we were in disbelief we were scared um we felt helpless

7:11

and um at that point and we do we do have another child we

7:16

have a son who's a couple of years younger than her but as a family we decided that we

7:23

would uh try to learn everything we could um that's not too scientific over our

7:29

heads but we learned everything we could about the disease and if you plan on telling

7:36

people about your diagnosis you're going to want to know some things about it because they're

7:41

going to ask questions they're going to ask a lot of questions and so we turned to a nephrologist and

7:49

the most helpful thing was the pkd foundation the people in the milwaukee chapter

7:54

have been incredible in helping us understand and learn a lot about pkd

8:02

so yeah um so once once we decided that we

8:09

would learn as much as we could and of course nicole and everybody in the

8:16

pk day foundation office in kansas city are just an amazing resource as is the

8:22

website but we decided that we would start with our family media family and we we did tell

8:30

them in a one-on-one situation wherever possible uh at the very least a

8:36

phone call but we did try to do it in person one-on-one

8:44

so we did that and then we really let meredith direct uh our

8:50

daughter direct whether or not she wanted to discuss it with friends

8:56

extended acquaintances neighbors things like that employer employer and she was had made the

9:02

decision that she was 100 percent comfortable with being open talking about it

9:08

trying to learn as much as we could maybe helping others that had it as well so um once she

9:14

decided that we we started visiting one on one with

9:21

extended family and extended friends and neighbors and so we we did sort of extend the

9:28

circle out and whenever we talked to people we tried to do it one-on-one so we could answer their questions there

9:35

they always wanted to know uh what's this mean for meredith and how

9:40

can i help um and it's very touching

9:45

that you know people that you know really want to help you when you come across something that's as important

9:53

you know in your life as this big change was in our in our lives for our family

10:00

so with that we uh we really started because of their everybody would

10:06

say what can we do is there a way we can help we had people say can we donate a kidney

10:12

it's pretty amazing and touching

10:18

and and that moved us forward into doing more fundraising so we've been really

10:24

active in raising funds for the walk every year

10:29

yeah the walk has been a lot of fun for us we've had family friends

10:34

pretty big groups come and join us 20 30 40 people one year

10:39

and we've been successful in in helping uh

10:48

with the fundraising uh for research and we've helped people that we didn't know had pkd

10:57

so now what we do when we talk with people is we try to keep them updated on the

11:02

progress the things we learn about at meetings and at conferences like this so we hope one

11:09

day to be able to share the news that there's been a cure found

11:14

so great thank you ed and kathy um and how is meredith

11:22

doing now very well good good

11:27

okay um our next speaker is laura macklin and laura was diagnosed in her 20s

11:35

and with her diagnosis came fear for her future which i think a lot of us can probably relate

11:41

to us she will share with us how she became an open and honest advocate for research laura hello everyone

11:49

and thanks for joining i'm going to share my screen so you have some more fun images to look at besides me

11:58

so i think we should be sharing

12:03

now you can hopefully see my little cutie patootie this is our son miles um this is probably when he was four and

12:10

um i was obviously diagnosed and i shamelessly used him um for fundraising in the walks and um

12:18

putting stickers on him as you can see in any swag i could put on him to share my story um so i'm gonna these there'll be some

12:24

slides running through here of just some um as i talk about my history here um i'll start that in a moment but um i

12:32

was diagnosed uh like they said in my early twenties my father uh we've traced it back to my

12:37

grandfather and my father um by a routine sort of physical found out he had it so by that time

12:44

he was well married and um that we have four kids in our family i was the youngest of four and me and my

12:51

older sister both have pkd and my other sister and my brother do not

12:57

so i i was nervous i was scared i was in a serious relationship um i didn't know if the uh my uh my

13:05

boyfriend at the time marcus would want to stay with me and and have kids and all these things kept running

13:11

through my head of course and so i was scared so i dove in straight head first and tried to learn as much as i could

13:17

i am thankful i'll skip ahead a little bit we have been married for 25 years and have our beautiful son

13:22

so he did stick around thank goodness um and he has been my supporter along the way 100

13:28

along with my family um so i have been in a healthcare family and i've always heard about

13:34

advocating and speaking up for yourself so i think that is in my dna as an individual

13:39

but i will selfishly say that i did this for me i needed to be a part of the foundation

13:45

the pkd foundation i am truly honored to be in a city like seattle where there is a lot of kidney

13:51

um research going on with the kidney research institute um with northwest kidney centers and

13:57

i've just dived head first into that so that that's kind of going from early

14:02

on to now but i needed to talk about it i needed people to be aware i needed to meet others and so social

14:09

media i needed some mental and emotional peace of mind and i had to be careful with social media because you can't believe

14:16

everything you see but i wanted to share my story with others and so that people knew so that they

14:21

could they could see me who for who for who i was what i was going through because as we all know

14:27

our disease isn't very physical sometimes you could look at me and not know anything is wrong but i could

14:33

be having a really horrible day because of my pkd and so i thought it was necessary for me

14:38

to share that story i'm going to start my slideshow so you can see some more pictures

14:45

and i believe it became very important um for advocacy so i would speak anytime

14:51

and anywhere so this is at a conference um that we had i set up tables at local places this is

14:56

all from the pkd foundation this is at a walk at a local kidney walk

15:02

in our baseball field here this is just information at any event that i could share and talk

15:07

to people about and so this became my thing the walk is huge and so we always

15:15

held a walk for every year in seattle here i think we've had as much of three or

15:20

four hundred people and i'm gonna pause on this uh picture hopefully it stops so my father

15:26

is the inspiration my father turned 84 i think dada if you're listening

15:32

uh this past week but in his mid-80s my father does not have a transplant and has been never been on dialysis

15:39

and he is living the healthiest life he runs every day he as you this is a few years ago but he

15:45

looks just like this and he's amazing and so that is inspiration for all of us and i tell people that story all the

15:52

time um that it's very important to know that we all um do this differently i've proceeded

15:58

through this differently i also my sister who's about six years older than me um

16:03

did have to have a transplant and that happened in um uh in her 40s and so i was

16:10

convinced that i was going to also be able to have a preemptive transplant and the the good news there was my brother

16:16

was the donor so my sister got a pre-emptive transplant she's 14 or 15 years now post-transplant and

16:22

doing fantastic she runs she uh she rides 100 mile bike rides up into the mountains of colorado she swims

16:29

on a master swim team she's a poster child for kidney health um so very lucky but i was convinced

16:35

that then that would be me next so my 40s come along i'm now 51

16:41

and nothing i am sitting at stage four renal failure with giant cysts on my liver i am

16:47

uncomfortable i am tired i don't like to exercise as much as i used to

16:52

i'm sad i get anxious i'm depressed and i want to transplant and i can't get

16:58

it because i'm just not quite there yet so these are the emotions that i have gone through from my 20s to my 50s

17:05

and just trying to do everything i can to let people know how i feel without

17:13

becoming too down on the situation i'm going to continue the slideshow here so this is

17:19

my family um participating in one of the walks my lovely parents my son miles here and his teens i

17:26

believe me and my husband marcus and my niece sarah always had family at the walks i live in

17:32

seattle um i've been the seattle chapter coordinator for five or six years now my parents live in iowa

17:38

so have really had a great support with um folks coming to support us in the walk

17:44

which has been fantastic this is my son's um high school

17:49

basketball team and so again as community awareness and speaking out my we've made sure that people know that

17:56

miles might have the disease he has not been tested but we are advocates for it so the kids came out this is his like i said high

18:02

school basketball team and friends and they earned community um points uh service points for their

18:07

graduation requirements and so bringing out again teenagers who had no idea what this is and i found out

18:13

the next day after this walk this picture was taken that a lot of the kids wore their t-shirts to school and

18:19

um it was just amazing i was like and you know they're just a great group of kids we're very lucky and very

18:24

supportive because again we don't know if miles has it or not similar to ann's story i do

18:31

5k runs or walks and i always wear my npk t-shirt i wear buttons on my coat when i um out

18:37

on the link light rail i post on social media anything that i can to let people know i went to olympia and

18:45

advocated for northwest kidney centers and i often take all the great paraphernalia

18:52

and information like this and bring this um to social media and let people know

18:57

but one of the best things that i've ever done in the last five or more years and i think there's a couple people on

19:02

the call today is uh the pkd coffee chats we used to do these in person and now we do them virtually uh due to

19:08

covet and i think the virtual has actually been much more productive in some ways but we meet every single month

19:14

for one hour sometimes two on a call like this and we talk to each other and we just talk we talk about our

19:21

problems our issues we taught we share good things and bad things and it's just a very safe space

19:26

and the foundation had set this up for us and uh they logged us in and we just talked so i highly recommend any other

19:33

chapters out there or if you don't know get involved with one or join our seattle one we can do this virtually so you don't

19:39

have to live in seattle to join our seattle chapter and then lastly um i just want to sort

19:44

of wrap up um uh with one more photo because my son just turned 25 i'm sorry 21. oh

19:52

my gosh i just 21 this last tuesday he's happy he's healthy bought his first drink on his own and um

20:00

i do this for him i speak for him i hope there'll be a cure one day but i'll do everything in my power to make sure that

20:06

research and funding is possible to find a cure

20:11

there you go thank you laura that's a great story you have you've

20:17

been quite the advocate and um i like the idea of the the group the

20:23

monthly meetings with your group i think that's something we could use here in pittsburgh

20:29

um i think we're going to go to questions at this point

20:34

uh nicole can you help me out with that

20:46

you're on mute nicole i am so sorry there we go can you hear me now yes yes

20:52

thank you i'm sorry it's amazing that that still happens after so many zoom calls sorry about that um

21:00

i'm seeing some comments um in the in there not in the chat but not specific questions but

21:06

um one kind of uh i think theme came up we talked about

21:11

support uh and kathy mentioned that when they talk about pkd with their friends and

21:18

neighbors and things like that a lot of people want to know first of all how is meredith doing and second how can we help

21:25

and i'm just curious if any of you would want to comment about how you've built a a support network

21:34

and how that helps you feel comfortable about talking and sharing your pkd journey with others

21:41

anybody want to jump in on that yeah i can say a few words um it's

21:47

always been really important to share uh family and friends and um talk about openly about uh pkd

21:55

there's some of my family members so besides my intern my immediate family i described i had an aunt who died of we didn't know at the

22:02

time but was pkd she had an aneurysm and her daughter has pkd and then she has two kids that we don't know if they

22:08

have it and so it's there's there's some that will speak about it and openly and some that won't but i feel like

22:15

um you have to be somewhat open or connect with somebody who is just for that awareness and

22:22

um and if we don't talk about things we're not going to know to how to help and so i think that's

22:29

where it's a strong power within me to say we need that research we need that money if

22:35

you follow any of these research and studies and use your own family even

22:41

to help the researchers you know there's places we can donate our pkd kidneys once we do get a transplant and lucky

22:47

enough there are places that are doing studies i am donating my my urine and my dna blood and every

22:53

other other thing that i can donate to help with studies as well and i think all of that is really

22:59

important for our friends and family to know that there are options out there there's possibilities and we can't just um kind of sit back we

23:06

have to be our own advocates especially for something like this that a lot of people have never even heard of

23:11

and there's so many of us suffering i would say nicole sadly

23:17

one of the things because it's not in our family and meredith was a spontaneous mutation

23:24

i you know ed's family is more involved in sharing the story my family not so much

23:31

um and we really would love that for them to to share it more and and try to reach

23:38

out to people um and let them know because as laura says it's

23:44

you know it's not very it hadn't been heard of a lot

23:51

i'm going to jump on the bandwagon in regards to the studies i have been involved at ku med center

23:57

for i guess 20 years and so as soon as i got diagnosed my nephrologist referred me over to the

24:04

university for pkd studies and so i've kind of used it as a way to

24:10

help find a cure my goal has always been to find a cure so my kids don't have to deal with this disease it's also uh the

24:18

pkd walk the kansas city walk i haven't i think i've missed one because i was in a wedding

24:23

um but for the last since they started i've been involved in the pkd walk and so we bring a huge group my aunts my

24:30

uncles my cousins we all come out of the woodwork we all get matching t-shirts um yeah we we try to be very very

24:39

involved but i agree with laura we need to get in with the universities that are doing testing and i it's kind of almost free

24:46

healthcare at the same time you know i get my labs done for free i've gotten mris for free and so it's a

24:53

win-win so you get to track your disease with the leading researchers out there and you

25:00

get to help find a cure very well said um we have a really good

25:06

question and i want to get to that but i just point out that what i've heard from all of our panelists

25:12

i think is having a support network and how that has been helpful to you um and also

25:19

a lot about getting involved and how that helped and educating yourself and being a voice

25:25

for your children no matter what their age as they've grown so

25:30

those are three things that i heard quite a bit um that have been helpful to all of our panelists but i do want to ask this question and

25:36

see if we have some responses so we have um an adp kitty patient

25:43

that's young doesn't have symptoms basically very healthy and not really

25:48

having any issues right now and sometimes she feels weird about talking about pkd because there's

25:54

nothing wrong with her right now so any tips about how to talk about it without coming across

26:00

as being matic such a great question

26:06

anybody have thoughts to share what age we're talking about she says

26:13

young i can i can give it a go um

26:19

hi i'm greg um i'm 27 and i've been coming to terms with my pkd for many

26:25

years i've known since birth essentially and it is it is really strange to

26:31

either choose to kind of hide your pkd or to face it head-on and really it changes

26:39

day-to-day conversation to conversation um to be fair though the threat of

26:45

kidney failure is something to cause drama of you're that that is something worthy of concern

26:52

and i i'm not sure it is hard to bring it up but

26:57

in the right company i don't just i think it people it does sink in that that is

27:02

something that is very threatening to my livelihood in my life

27:08

um i am at work i'm gonna take this call but i i'm not sure i don't i ask the same

27:13

question to myself a lot so i'm interested in more conversational well you take don't we want you to take your call but thanks

27:18

for jumping in so that brings up a question too because i think he said something really important

27:24

it changes you know from conversation to conversation so how how has that been in our

27:30

panelists experience as far as you know maybe did you kind of work up to feeling more comfortable about

27:36

talking about it or did you feel comfortable all you know all at once like how does how did you react with in that way

27:43

i think for me i um it started out really it was a slow progression but i also

27:50

want to just jump to the the high school students in my son's school because he doesn't have it but we found

27:57

out through what we did that one of the kids at the school did have it he wasn't willing to come and

28:02

talk about it but there was an instant connection we're like wow this is a small school too a graduating class

28:08

of less than 80 kids and we found out that this other boy had um pkd as well and so

28:14

i think it was just the um openness and then also um talking slowly about you know just

28:20

good health this is i eat healthy because i exercise because and oh yes i'm doing

28:25

this because i have this kidney condition that there is no cure for but i need to be the best that i can be

28:31

and so maybe turning it into nutrition and exercise and sports and what you do or or anything that um you know drinking

28:37

a lot of water and all the things that we know are good as you're young maybe that turns into a really general

28:43

conversation about health in general and how important it is to talk about it

28:48

that's a very good point laura thanks for sharing that any other episode on that i think nicole

28:55

that um it does change when i was in my 20s um and 30s

29:02

i didn't have any symptoms i didn't have any problems and so i got involved with the walks

29:09

and i raised funds by talking about my mom who had pkd and two of my three brothers

29:16

who had been transplanted and sometimes people asked me if i had it and sometimes they didn't if they asked

29:23

i was honest i said that i had it but that i was not having any problems at that time

29:31

and that sort of got me through that early stage once i hit my 50s and started to

29:38

go into renal failure then i found i had to talk about it a little bit more but it was kind of a gradual

29:47

i think it depends sometimes on where you are how willing you are to talk about it

29:54

i think that makes sense we had a comment to someone said finding someone who has pkd to talk to has also been helpful

30:01

which is what we've been talking about when you get involved and maybe go to the walk or go to you know one of our

30:07

chapter meetings and meet others that helps as well it helps you to talk about what your experience is did you guys find that to

30:14

be true i think the walk is a great first way to get involved

30:22

you can kind of go anonymously and meet people and see how you feel about things we went to

30:28

the walk for many years before i began volunteering and really got involved with the chapter

30:36

in our chapter meetings we have also um people have participated and they may have logged in not turned on their video and just

30:42

listened there's no requirement to say anything and then maybe by the third meeting they're starting to open up or

30:48

maybe they've connected with somebody that has like for me the pld conversations are really crucial right

30:54

now because i'm finding more and more issues with my liver cysts my liver function is 100 my kidneys

31:00

aren't but i have more issues with my liver and having those conversations with people has been really helpful for me

31:06

now that i'm in my 50s and other things are happening with my body and i'll just say it perimenopause is

31:11

sticking in there and now there's all these other issues that are um coming up and i don't know if it's my kidneys it's my liver

31:18

it's my something else and so you know you meet all these people and you can meet

31:23

one-on-one after the chat and and just connect and every single month we meet somebody who

31:29

has said this has helped them in some way so i just think that is that connection point when you're comfortable

31:34

that you'll find that completely in your heart it'll feel really good to talk with people

31:40

in the milwaukee chapter we have people all over the map with people that are you know transplant

31:46

patients we have one guy that's double transplant because his first kidney failed

31:51

um you know we have people that are you know high functioning like meredith

31:56

spontaneous you know um mutation and then some people that have a long family history and

32:02

and all these different experiences some that are until vapton it's just incredibly helpful um

32:10

to hear what they have to teach us and i'd say the last thing to that young

32:15

person that had the question after you first tell everybody

32:21

um you'll know the people that want to learn more and which ones are comfortable learning

32:28

more so you'll you'll kind of feel your way through how much to talk about it

32:36

that's a good point i think you were talking that one side of your family talks about it more than the other

32:41

and so maybe you lean in you know to the side that talks about a little bit more and then as you find others that want to

32:49

talk about it it kind of makes it easier to talk to those people but we did get a question

32:54

so do you have suggestions on garnering a support network for someone like myself who has a small family

33:01

um and she's an only child which i can relate to i'm an only child as well how do you share your story when you've

33:07

got a small family maybe you're an only child you really aren't starting with your family

33:13

good question co-workers perhaps yeah i was going to

33:20

say the same co-workers i invited my co-worker cohorts in different jobs to the walk

33:25

and i started telling my story that way um uh different uh my son was younger the pta

33:31

you know lots of different kid activities and again i would just wear my shirt and there's a shirt that the foundation

33:37

used to sell and i don't call if we still do it says ask me about pkd and it was in big letters on the back of

33:43

my shirt and i would just walk around of festivals and whatever my daily activity and just wear my shirt and you'd be surprised i had

33:49

people come up to me and either ask and said oh my gosh i have pkd and so you know it was just being kind

33:57

of comfortable with that in myself and um and trying to connect people and i would sometimes just throw my i'm

34:03

since i'm a volunteer i'd have little business cards and i would put those in my bag and hand those out but it's it's just that baby steps and

34:10

and then at domino effects all of a sudden you'll meet one and two and five and or someone might have a

34:15

kidney problem that's not pkd but you still connect because of dialysis or whatever and there's lots of renal failure out

34:22

there that's not just pkd and so combining those um networks together was really helpful for me as

34:28

well i would also say um occasionally i post something on my facebook page

34:34

like a little fun fact or something um and see if you get any hits on that

34:40

that's a great point i've done that the foundation again has always little images and i'll either take them from social media and or

34:47

forward them and say the same thing because they are they're they're nice cartoon-like images and they're fun facts and

34:53

um and then people are interested and they want to help out or they want to ask questions

35:00

so just so you know there's a lot of comments here um that people are really appreciative

35:06

of all of you for sharing your stories and being so open and honest and it's helping uh you know it's helping others

35:14

feel more open wanting to share um there's just a lot of great comments

35:20

if you can uh multitask which i'm not fantastic yet obviously because i'm

35:25

stammering around a little bit um you could take a look at some of these because they're really good uh if people want to connect in the

35:33

um the forum chat areas you can click on our names i believe and you can connect with us and if you

35:40

want to ask us questions or join other um things or i've already had a lot of people ask me about the seattle chapter

35:46

and what i do and the things that i've been doing and um and some of the other advocacy things so please feel free to

35:53

reach out that's awesome i was getting ready to mention that to say you know please go over to the attendee tab

35:59

and find people you know that you want to connect with especially those that you might be um communicating in these chats with you

36:05

know i see a lot of people communicating with you know with other people that are in this session so that's a great way to

36:11

find someone you know that um also shares some of your same experiences

36:16

um i just wanted to see if we had any more questions um there's some questions about jobs

36:24

nicole yeah i just saw that and i was going to the same place what how how do you feel about addressing

36:30

that how do you feel about sharing your ekt story and journey at work

36:38

i can speak from rick for meredith um it it is a concern right it's it's a

36:44

it's one of those scary things that you don't know what the outcome will be so i can't say

36:51

do it or don't do it you'll have to feel your own way through that but

36:56

for her situation her companies have so far been

37:01

incredibly supportive one of the companies she when she was

37:07

working at kohl's corporation in milwaukee it was so easy to to talk about it

37:12

amongst her co-workers because if she could get five co-workers

37:18

to join the walk would have 500 bucks and each employee would get

37:26

credit allotted to them for community service and kohl's put a

37:32

lot of emphasis on that pretty unique i think but um

37:37

it's a real positive so if you're just gonna have to feel your way through

37:44

your company and see how it feels to to either talk about it or not but you i

37:51

think you'll know after a while it's important if you do start

37:57

to have as much knowledge as you can i agree i didn't bring it up to my

38:02

employer day one once i got closer to my employer and

38:07

i've been blessed by having a wonderful employer that um you know going to doctor's

38:14

appointments hey i'm going to run up to the doctor i got her under my nephrologist you know and kind of bring it in that

38:19

way uh kind of bring it in slowly but yeah i definitely didn't bring it up in the job interview yeah i mean

38:26

yeah that's right yeah i don't think any of us did

38:31

no i think for me also part of it was just making sure that my

38:36

um my manager so i my screen here i do work at seattle children's hospital but i'm

38:42

not clinical i work in the design side of the hospital and i have been fortunate this is the last four years

38:48

and they are very supportive but i felt it was necessary for some of my co-workers and my manager to know i

38:54

can't sit for more than 30 minutes without being uncomfortable so i have a sit stand desk they've made

38:59

accommodations if needed um i get to go outside and take walks i can do things um

39:04

and sometimes i'll sit in the back of before covet i would stand in the back of a room at a comp at a meeting an in-person

39:11

meeting because i needed to stand up and i just needed people to know that i'm not being strange or odd it's just

39:17

it's more comfortable for me so those are when i started talking about it more but i didn't do it on a

39:22

day-to-day basis it wasn't about oppor me or this is going to be bad it was just i needed people to know that this is why i

39:28

was doing what i was doing but i agree not day one it's not necessary it's just like any other

39:33

health issue you need to keep it private to a certain extent um but there's there's avenues

39:39

that you can share yeah let your good work define you first

39:45

absolutely and then you'll find the opportunity to talk about it

39:50

right i think nancy said in the beginning you know everybody's different and you have to do what you're

39:56

comfortable with maybe i'm saying it a little bit differently but i remember that you said that so there is a comment here maybe we have

40:02

a couple more minutes so we can address this it's hard to share with uh work

40:08

and friends because i don't look sick so they don't believe it's real has that

40:13

been a an issue that's come up for any of our panelists i i think you need to be able to explain

40:21

why you do look fine but what's going on again that's that whole issue of

40:27

educating yourself so that you can explain it to other people

40:32

and i think once you explain it people do understand that a little

40:38

better i think it was harder to um explain as i

40:43

was in my 30s and maybe my 40s and it's little easier now as i get older

40:48

and i'm not sure why that is but um yes because you don't i mean nine times out

40:55

of ten no one's gonna say something's wrong and realize how when i say i'm on stage four renal

41:01

failure everyone just kind of was what you know there's just nothing physical about me that says that um

41:07

unless you know me on day to day so it's it's just one of those it's another

41:12

edge way to educate to say yes there's diseases inside we don't know what people are going through and it's a good lesson in life to learn

41:19

about any kind of disease we don't know what's happening inside everybody so when you approach people be kind you

41:24

don't know so i think pkd runs in that same gamut you just don't know and so be kind

41:31

that's good advice mm-hmm i think that also goes back to what was

41:37

shared about um you know know about pkd you know educate yourself so that when you have

41:43

these conversations because you know people are going to ask questions they're going to want to know more

41:49

it's just our nature and so that arms you with with information so that you can keep

41:54

the conversation going any last-minute thoughts from any of our

42:00

panelists for me i just want to say be an advocate for yourself i listened to a couple

42:06

couple chats earlier yesterday or this morning and um the amount of information that we

42:11

have to keep control over whether it's a nephrologist a general practitioner for me my gyn

42:17

with my i had a recent scare with being severely anemic and talking to

42:22

all my physicians and keeping that information in my repertoire so to speak and sharing

42:30

with my physician so that they made sure that they had all the information to help me so important please don't count on your

42:36

own clinical people to feel like that they will have your best they'll have your best interest

42:42

don't get me wrong but that they have all the information that you have to bring that to all your physicians and

42:47

they need to talk and um i've had a couple scary incidences in the past six months where they weren't talking or i had to

42:53

encourage them to talk so that's my piece of advice for moving forward with your own health

42:59

as well as just being an advocate and don't be afraid to say anything

43:05

i hear a lot of pkd um patients use the word uh warrior you know as far

43:11

as well as advocate i hear that a lot and see it on social media so i think that's what you know don't be

43:18

afraid talk to others get your information get involved maybe that's why that's a word that's

43:24

used a lot anybody else have a last-minute uh comment before we end this session

43:32

[Music] thank you all it was great yeah

43:39

thanks, thank you thanks for having us absolutely um i just want to take

43:45

um the opportunity to say thank you to each one of you for um you know taking the this

43:51

opportunity to share your story and help others and sharing your experience we're getting quite a few thank yous in

43:58

the chat now some hearts i didn't know you could do that that's cool i want to learn how to do that later

44:05

so thanks all of you for joining us um and i hope this has been helpful as you navigate conversations moving forward

44:12

uh nancy thanks for moderating our session i do want to remind everyone to take the survey we'd love to get your

44:18

feedback and our next session uh starts at 2 45 it's a breakout so you can go back to

44:24

the agenda and pick out which session you'd like to go to next and you're gonna have about 10 minutes i

44:31

believe before that starts so thank you all so much thanks everybody enjoy being here

44:48

bye-bye

45:28

you