0:00

okay welcome everyone to this very exciting and quite possibly life-changing session

0:07

and i say this because i know firsthand how powerful a preemptive transplant

0:13

panel or session on this topic can be i experienced life-changing

0:21

modalities and goals and a path for myself after sitting in on a pkd conference

0:27

back in 2008 on this very topic and really that's what is making me so

0:34

excited about moderating i thank the pkd foundation for asking me to to

0:39

moderate our panel and to be a part of this program and i truly believe that those of you

0:45

that have signed up that are listening now or listening to a recorded version of this session will uh will

0:54

feel that this is one of the best investments they made in their future i'm living my best and

0:59

longest life and i wouldn't be sitting before you stating that i'm living a great life had

1:06

i not attended that session i wouldn't have been able to bypass dialysis i wouldn't have figured out how

1:12

to find a living kidney donor i wouldn't have been inspired to

1:17

advocate for myself and to secure a better and longer life and so

1:22

i want to give a shout out before we get started to the pkd foundation because they bring such

1:28

incredible content to their constituents myself and others and just because my life was changed

1:34

doesn't mean it needs to stop there i truly believe that many of you will feel the impact of this course as well

1:42

i'd be remiss if i also didn't thank the mentors that i spoke to along the way

1:48

also my donor of course my living donor it took six to find you know the the perfect one

1:54

and also the experts at my transplant center oh my goodness and speaking of experts let's introduce

2:01

our panel to you um first up we have a highly respected transplant surgeon

2:08

from mayo clinic rochester he's also the surgical director of kidney and pancreas of the kidney and

2:16

pancreas transplant program welcome to the program dr dean we thank you for

2:21

joining us today could you briefly tell our audience a bit about you and some of

2:27

the focus that mayo clinic has on preemptive transplantation sure and it's a pleasure to be here

2:33

thanks very much lisa that really and i've been talking to this group for i don't know for this

2:38

convention for seven or eight years now and it's a pleasure to do so the

2:44

you know i think you'll get the message through this session but just in general don't

2:49

believe anybody that tells you you need to be on dialysis before you have a kidney transplant um that's what we hope to convey today

2:57

but and then i think you'll understand through the rest of the session you know how to go about advocating for

3:04

yourself and who to talk to who not to talk to those sorts of things so again pleasure to be here thank you so much and next up

3:11

we have a highly respected transplant nephrologist from the university of nebraska medical

3:16

center i'm a big fan welcome to the program dr miles i'm a big fan because i've seen

3:22

him speak before and he speaks right in tune to preemptive transplantation dr miles can you

3:29

briefly tell the audience a bit about yourself and what you're doing over at unmc

3:34

yeah sure um thanks reese after the introduction and i too would thank the pkd

3:40

foundation for the invitation to be here but also for all they do in terms of patient advocacy um

3:48

some living donation in general is really important for patients with failing kidneys and i

3:56

think that our program tries in a variety of ways and we keep trying to be more

4:02

creative about how to get the message about living donation out into the community

4:08

and in particular trying to promote referral to nephrology practices but also then to

4:15

transplant centers in a timely fashion and then hopefully one of the

4:21

things that will come out of a session like we're having today is what what does timely really mean

4:26

because there are some delays and things you know necessary steps to getting

4:32

through a transplant evaluation have to be taken into consideration when you're

4:37

going through the process so we've tried to engage with the regional nephrology practices

4:45

but we're always looking for better avenues into patient advocacy groups but also

4:52

primary care clinics and other other venues to try to spread this message

4:58

outstanding and you couldn't have said it better timing is everything and to complete our team

5:03

our panel uh we have a living donor nurse coordinator from the university of california san francisco

5:10

and i will say uh helen i caught your session yesterday maybe some of our

5:16

attendees did as well it was outstanding thank you for that

5:21

yeah so yeah please briefly tell us a bit about what you're doing at ucsf and

5:26

about yourself i know the audience would love to know more thank you yes i am a nurse at ucsf

5:33

and i am a living daughter facilitator and we created this position really to try and engage our patients

5:42

from the time that they're referred and really hit home as the importance of living

5:47

donation and definitely you know if we can do a preemptive transplant that is absolutely our goal um so we do

5:55

we i talk to a lot of our recipients all of our recipients hear about living donations throughout their

6:01

evaluation process we also have what we call a living donor champion program

6:07

and it's we recently because of covet of course didn't do it in person we did a webinar which was really pretty

6:14

you know think about this you know we're doing webinars and now we have it recorded so now anyone can look at it any time so

6:22

we're pretty excited and definitely you know we encourage everyone to talk to

6:27

everybody about needing a kidney transplant and thanks for the invitation to be with

6:32

us esteemed group yes yes and education is key too so timing education

6:38

um you know there's so much to learn in this space and i think we all can agree that preemptive transplantation

6:45

offers superior outcomes yet we see it severely underutilized and i think we could all

6:51

agree in in part that's due to a lack of education

6:57

early education patients understanding that they don't have to start as dr dean said you don't have to

7:03

have dialysis first sometimes that can get a little confusing if you look at the it's been an initiative for years called

7:10

fistula first and so in our brain and seems like a lot of the conversations that's happening in the sacred walls of our exam rooms is vein

7:17

mapping dialysis we hear a lot of people are in dialysis and sometimes we think well maybe that's just the easier route

7:24

to go just get hooked up i surely thought that when i didn't know anymore when i didn't know any better

7:31

and while maybe it could be easier to get hooked up it's surely not an easier life to live

7:36

and so we do want to make sure that we are eliminating the confusion and kind of

7:43

bridging the gap between that lack of knowledge and understanding so patients want to know you know curious

7:49

minds uh inquiring minds want to know they want to know more like hey you know why am i not hearing this in

7:55

my nephrology practice so why am i hearing this for the first time at a pkd conference or why am i being able to

8:01

take a deeper dive and see that as a blessing and and take it and run

8:06

the questions that i think many individuals our constituents patients

8:12

are wanting to know more about or what's the evaluation process like and

8:17

when can i enter it and why is it that when i bring it up i'm kind of getting pushback like oh no no

8:23

you're you're too early it's too early to talk about that and what does my gfr have to be and why is

8:29

it that i can contact one center and they're saying well we'll start talking to you at this level of gfr where another one may

8:37

have a different protocol and does their doctor have to refer them can they self-refer these are things

8:44

just like additionally the the living donor situation do i have to have a donor before i even knock on the door of the

8:50

transplant center and if i have more than one donor can more than one donor be tested at the same time so let's start with you dr

8:56

miles if you don't mind can you address some of these questions you're so good at demystifying some of

9:02

these these um really confusing areas and if if you wouldn't mind um taking taking

9:09

over right now and just kind of giving us a feel for what you're doing um at your transplant center yeah yeah

9:15

sure so i mean as a nephrologist and i still see some patients on dialysis i still see some

9:22

patients in you know ckd clinic as well as you know devoting most of my practice time to

9:28

transplantation i i think that one thing i would start with is

9:34

acknowledging that it's really a complex situation so you have a serious health problem that is going to

9:42

be progressive and you're going to have to face a series of decisions

9:47

and try to navigate through that and hopefully with the help of people around you i want to believe that

9:55

primary care providers and nephrology practices are advocating for people's best interests

10:00

but i think one of my one of my points that i would

10:05

would leave people with coming out of a session like today is don't always just assume that everybody

10:12

around you knows all the answers and knows the right path because it is important to be thinking

10:18

about dialysis because it may be a reality and it it is something that obviously lots of

10:23

patients uh will undergo either before a transplant or possibly as their

10:29

destination therapy i do think that practices are remiss in that

10:35

they get they tend to get tunnel vision about dialysis preparation and i

10:40

echo what risa said about remembering that there is also a lot of reasons to be thinking about

10:48

transplantation early in particular with a disease like polycystic kidneys so unfortunately we really don't

10:55

have a cure for this so that at the time of diagnosis

11:00

i think it's likely that people will need to be thinking about these decisions at some point in the future

11:07

so if you get back to like when should you be referred that that is a complicated question

11:13

because it brings into a lot of a lot of different parts of the disease and parts of people's lives generally i

11:20

think gfr's in the 20s are probably very reasonable it takes a while to go through the

11:25

transplant process but also i mean i think we shouldn't forget that people need to be

11:31

sort of wrapping their brain around this this lifestyle change because you know being transplanted is a

11:37

lifestyle change just like starting dialysis would be um whether people need to have a donor

11:44

ahead of time or not i think may differ a little bit transplant center to transplant center

11:49

but i think the patients should begin to have conversations you know you probably are aware of

11:55

initiatives like the big ass big give from nkf that type of thing those conversations

12:01

could be started you know way upstream of of you know getting a gfr of some magical

12:08

number like 20 or something like that so at least the people around you whether their family

12:13

friends coworkers have the concept in mind so so they too have an opportunity to

12:20

think through of what it's going to mean to be evaluated as a kidney donor

12:25

what it might mean to donate a kidney because that that's a big decision for them also

12:30

when i when i let one of the other panelists uh yeah we'll we'll hand the baton over to

12:37

dr dean and tell us a bit of how mayo clinic may either differ or in addition to what was already

12:44

addressed what you might have to add to the conversation all right i think we would agree with

12:49

what cliff said i mean it is it's it's not a cure it's a different disease really

12:54

um it's not called that very often but it kind of is it's a definitely a condition being a

12:59

transplant patient i think you know you don't need to be worried about being evaluated or talking

13:06

to transplant centers when your gfr is 40 but certainly in the 20s is probably

13:12

a good idea um whether or not you i don't i think it's unusual actually

13:18

for folks to come to us with a um you know a list of people who are

13:24

interested in donating a kidney to them uh it's nice that people can and and

13:29

people also have to remember that those are always just potential kidney donors right in fact every kidney donor's

13:35

potential until somebody's throwing a kidney in that's true because donors can choose not to do

13:40

this at any time so i think it's great to get this your story out earlier

13:46

and again people with bkd it's rarely an urgent an emergency that they're

13:52

diagnosed with chronic kidney disease or even normal kidney function and underlying pkd so you do have i mean

13:59

many folks have years to think about this uh it's probably not the only thing they're thinking about when they're

14:04

30 or 40. uh but i do think you know you know people's probably in the back

14:10

of their head their siblings may be either thinking well do i have pkd or am i going to need to be or am i going to be allowed to be a

14:17

kidney donor um so i and so i think that's it's not it shouldn't be a surprise to

14:23

most folks with uh with bkd i the the thought about you know every

14:29

program probably handles a little differently in regards to how many people you evaluate at the same time for donors um

14:36

many programs and partly it's due to insurance issues is

14:41

the recipient candidate usually needs to be approved before you start working up kidney donors

14:47

and that's just often the way it is and it's rare to work up say five or six

14:52

at a time most of the time it's probably more efficient to you might screen and

14:58

the i guess the definition of workup is uh you know how far do you get along that but certainly you can screen quite a few

15:05

potential donors whether it's via phone or via web systems depending on which center you're looking

15:10

at um but the number of donors that are going to come to the center get all the tests

15:16

have a ct scan etc is probably going to be more like one at a time

15:21

but that can generally be done i mean a donor evaluation once they're at a center is usually only

15:27

a few days because they don't need quite as many tests as many recipients do so but yeah i think to echo what cliff

15:35

said the more you're thinking about this the more likely you are to have a potential donor right

15:41

it's people need to know your story and need to know that you need more absolutely uh people need to know our

15:47

story and we have to have the courage to share it and that kind of gives me a license to to

15:53

shoot down to helen now and talk about um ucsf and 400 parnassus uh the reason

16:00

i mentioned the address helen is i was first diagnosed in 1977 at 400

16:06

parnassus and um that's in the days that we were using contrast and um

16:13

you know it's sort of bittersweet i i wanted to know you know as dr dean was saying it's not really a surprise well

16:18

of course it was my hope and i really didn't know so much about the genetics so i you know i was hoping i might

16:25

unfortunately my father passed in his early 40s my brother was on dialysis and has been on dialysis in between two

16:31

transplants the second one is still doing very well um but you know i was hoping that i'd be

16:36

the uh the odd and lucky one out and i still feel like i'm the lucky one because i was able to

16:42

secure a preemptive transplant but as dr dean and dr miles said it's because i started

16:47

early i was also very fortunate at mayo clinic in phoenix to

16:52

start my evaluation at 25 gfr so that gave me a head start because it

16:57

took me two years to find an ideal donor as which was already mentioned you know everybody is

17:04

potential until you're actually sewing it in so helen tell me at ucsf at 400 parnassus

17:10

is there anything that you might want to add to the conversation about um just the assessment the

17:16

evaluation or maybe even any hurdles that some of the living donors experience that surprise

17:23

recipients absolutely and to echo what both

17:28

patrick and cliff are saying it's like you have to talk about it you have to talk about it early you have to talk about it often

17:35

because it's really unusual if someone if you discussed your need for a kidney transplant and someone

17:40

said oh choose me ran through all of the testing and magically you know so it is a process

17:46

and like you said you had six people evaluated i think that's the challenge sometimes is people

17:51

come in and they have one potential donor and they put all of their eggs in that basket and i

17:57

highly encourage people let all of your friends all of your family you know for us we

18:03

our championship program is all about having someone else other than you do the talking because i can only

18:10

imagine i'm you know if i have pkd i need a kidney transplant do i i don't want to be the one who's

18:16

the face of that i want my friends and my family so a lot of times you know for those five other people

18:22

that couldn't couldn't donate to you that was five other champions for you getting the word out

18:29

and so i am always telling people if they can't donate they're now the champion they're now the

18:35

person to be able to talk to everything everyone about this because

18:41

you know there's a lot of myths out there there's a lot of concern and so the more you talk about

18:47

it the more you normalize being a kidney donor you know eventually

18:52

that will you know be a wonderful thing i one of my favorite patients came in and he

18:57

had donated 25 years before to his mother-in-law and now his wife

19:03

needed a kidney transplant and it was just and so talk about a great advocate that here's this person

19:09

25 years later and he's like oh do you want to see my scar and i said no thank you i'm good so i think

19:17

talking early talking often getting the information out and like like we've said you know

19:24

we can test a number of people and again it depends really on your insurance as to how much can we do so

19:31

we have a screening process then we have an evaluation process and it does kind of you know smooth

19:36

things out so that we're testing as many people as possible and and you know making sure that everybody

19:42

understands what's going on you know helen you're reminding me of um you know i talk to a lot of

19:48

do a lot of mentoring for by the way speaking of mentoring if you aren't hooked up with the pkd foundation's peer mentoring program

19:55

please contact them get online and nicole if you would like to put a link in the chat that would be awesome i

20:01

mean there are people that have walked in have walked a mile and crossed the

20:06

finish line and can relay their experiences of how they got there and what their challenges were and

20:13

what they know now what they wish they knew back then that you can glean some of those insights

20:18

um but i'm i'm reminded as as we're listening to you helen about some of the frustration that

20:23

these mentees have shared with me and audience participants and some of my book fans and so forth

20:28

that'll say um gosh you know risa why is it that i'm just so frustrated why is a transplant

20:35

center not telling me about my donor that's in there right now so could you uh perhaps speak to how the

20:42

recipient coordinators cannot really talk about the donor department and so forth it would be great absolutely

20:48

absolutely it is probably one of the you know not knowing i always tell my patients like

20:53

i can't imagine not knowing what's going on not that i'm a busybody but if it's my

20:59

healthcare i want to know what's going on unfortunately because of healthcare privacy i can't tell the

21:06

recipient anything about the donor and i can't tell the donor anything about the recipient now i always remind them they can talk

21:13

to each other so they can tell each other anything that they want but we as healthcare professionals

21:19

cannot share anything with them we can't share with them where they are in the testing process what

21:24

why they couldn't donate you know all of those things that's all healthcare privacy but

21:29

certainly you can tell each other we just can't share that information with you yeah

21:35

important to know because it can be quite frustrating and those that are having a hard time sharing their story

21:40

i'm sure you'd agree helen in addition to what you said you know make sure your champions your advocates the team of individuals that are your

21:47

spokesperson are getting the word out for you but they also it might be easier for them to

21:53

um kind of lean into those potential donors maybe send a group email every now and then hey

21:58

please let us know what's going on because the center is not allowed to pull back that curtain and we'd surely love to know you know if

22:04

there are any updates that we should be aware of because that that's a that's kind of a um a difficult

22:09

situation um but helen since since you've got the floor right now can you tell us a little bit more about

22:16

your program and how you're taking wait listed individuals uh through your donor champion program

22:24

we'd love to hear more absolutely so at our center patients we now have a new

22:30

program where they can self-refer and i think that you know gfr25 is kind of a magic number

22:36

again you know we can we can start but then it's like at what point you

22:42

know will you be transplanted that's gonna be up to your nephrologist uh for us we from the very beginning

22:49

talk to our recipients about the need for a living donor our wait time in california is very long and so

22:56

it is really important that you know you need to get this information out there you need to talk to people

23:02

and so we we discuss with them i will before the pandemic

23:08

when we were doing in-person visits i would go and meet with every one of our recipients during their evaluation now i call them

23:14

on the phone so it's not the same thing but certainly you know we are there and

23:20

as i said we have that education program that we put on and you know the plan is we're going to repeat that

23:25

so that we're always getting out there i personally want to send a message to all of our recipients and say

23:30

have you talked to your donors lately and that will get hopefully the conversation going that do you have a donor because you know

23:38

i can't imagine having to wait the amount of time that you have to wait on a for a deceased donor kidney and

23:45

being that there is different wait times at different centers but we'll

23:50

look to california being probably significantly long uh maybe the coasts uh can be um

23:57

compared there but being that there is a long wait if they are not fortunate enough to find a

24:02

living kidney donor and they are depending on a deceased donor and i should ask all three of you is the

24:10

center repeating tests annually and why don't i start with dr dean do you know if if the person's

24:18

on the list and they're waiting and maybe three four years out they most likely need to repeat evaluation um

24:25

yeah we don't we it depends on the candidate's level of health i would say

24:32

if you're you know 50 years old with polycystic disease on our list and really otherwise quite

24:39

healthy which many folks are another example might be iga nephropathy or some of the

24:44

primary kidney diseases we often don't have them come back to the center necessarily we'll get in touch with them

24:51

and make sure nothing significantly has changed um excellent that's a different story than if you're

24:57

65 with you know diabetes uh heart disease you've had a stroke etc

25:04

so and some of those folks we might even bring back every six months so i but in general you will on a waiting list have some

25:11

sort of contact with your uh center in in some sort of periodic fashion just to make sure that

25:18

and it is important for folks to let us know if something has changed right uh we've called people in for transplant

25:25

and they had an amputation a week ago of their foot or something so um or they

25:30

were in the hospital for or they're in the hospital when we call them so the communication goes both ways

25:35

i think uh very important you know if you do have a significant change in one's health to let the tra your transplant center

25:41

know just so they can respond appropriately and all the more reason to keep ourselves healthy

25:47

um no matter if you're waiting for a living donor or the fourth potential living donor or seventh

25:53

potential living kidney donor we need to keep ourselves healthy i know that in general as you all have mentioned the

25:59

pkd community and our patient population do very well uh with transplant we have less

26:05

comorbidities especially if we're not on dialysis but i know dr miles if i switch back over to

26:11

you i know that you were talking about some interesting rates of deceased donor

26:17

preemptive transplants and so i don't know if you have something to add to dr dean as well as maybe brag a bit about how

26:23

you've got some preemptive happenings with even deceased donation

26:29

yeah i would i would add a couple points to the conversation so um with respect to what helen said

26:36

about you know several donors sometimes needing to go through an evaluation

26:42

when we looked at our own center's experience with that over a course of about a decade the

26:48

average number of donors that was evaluated for someone who eventually underwent a living donor

26:55

transplant was eight which i think blows people's minds because there's all kinds of reasons why someone who contacts a center

27:03

thinking they're going to be a living kidney donor ends up not donating the the best reason

27:08

would be because someone else was a living donor for that individual and that that was included in that number but there's a lot of other reasons why

27:15

people in in so to helen's point is your gfr is drifting down

27:21

it's probably not a good um strategy to just put all your proverbial eggs in one

27:29

potential donor as the as you're being sure that that's going

27:34

to work out coupled to that is then the deceased donor

27:40

issue because if there is only realistically one or two people that could donate to you

27:45

you have to know that they may not be able to or they may not eventually donate

27:50

and so while i do think deceased donation generally should be plan b it still should be the plan ahead of

27:57

dialysis if possible the waiting times in this country are a real problem there just aren't enough

28:03

donated kidneys for the number of people who need kidney transplants that's not likely to go away anytime

28:10

soon unfortunately there's obviously a lot of work being done in the area of organ procurement and

28:15

deceased donation and really important work but such a huge mountain to climb

28:20

so everybody should know that you can begin to accumulate waiting time when your gfr

28:26

touches 20 but you have to be at you have to be registered with a

28:31

transplant center so it differs from dialysis time if you've been on dialysis for a year

28:37

and then go on the waiting list you get credit for that year but if your gfr has been under 20 for a

28:42

year and then you get listed you start that day so you sort of lost an entire year

28:49

so it is true that in parts of the country in california in particular the waiting times are so long that i

28:55

think nephrologists probably patients just kind of say well if i don't have a living donor what's the point

29:01

and there are other parts of the country where where deceased donor preemptive transplantation is a real thing

29:08

i had one of my staff help look this up probably because i'm lazy but uh 14 of our deceased donor transplants

29:15

are done in people who have not yet started dialysis it's amazing nationally it's about four or five percent which is still

29:22

one in 20 so it can happen but it can only happen if people get referred early so i think

29:29

in in the end what we really hope to have patients do is be looking for a living donor or

29:36

several potential living donor candidates but to beginning and getting evaluated and hopefully getting on the waiting

29:42

list in time for them to take full advantage of this this policy which is that you can begin

29:48

to accumulate time when your gfr hits 20. because if it doesn't work out with a

29:54

living donor your preemptive deceased owner transplant still has significant advantages for people

30:00

outstanding excellent points thank you hey nicole i think i'll check in with you do we have

30:06

some questions that we should uh be putting on the table here for our panel

30:11

i do have some good questions um we'll start with this we'll go back to insurance um are insurances insurance

30:18

companies a barrier to preemptive transplant so i think by you know starting evaluations earlier

30:25

is that a concern with your insurance company or is it individual to different insurance companies helen you mentioned something about

30:32

insurance i thought is that am i remembering that correctly yeah um

30:37

i i would never want to say that an insurance company is a a barrier um we do we do check for

30:44

all you know all of our patients obviously you know some kind of insurance was medicare medi-cal or private insurance um

30:52

i don't know that you know if your gfr is in the 40s you probably haven't been referred and

30:58

we we would not probably see you would be my assumption but

31:04

you know i haven't had we haven't had any issues that i know of for getting uh donors tested

31:11

as part of that process before they're before someone's on dialysis i don't know if other gentlemen have had

31:17

any experience with that i would just i i don't think that's as much of an issue as

31:23

uh i mean you know it's not as it has i think oftentimes you know

31:30

people hit a gfr of 25 and then they often think they're going to be at 12 next month

31:35

um it's not usually especially pkd and cliff is obviously more expert in this tonight but it's not

31:42

a precipitous decline it's generally more gradual unless an inner current inner current illness

31:47

happens i mean someone can always get pneumonia and didn't have a abrupt decline but i think there's

31:53

plenty of time usually um especially for folks with pkd um i don't so i don't think the

31:59

insurance companies are barriers uh necessarily it's just they have their way of doing business and

32:05

they're not they're probably not going to pay for an evaluation when somebody's gfr is 40 because you really don't need it

32:12

to be fair i mean you might be at 40 for five more years it so i think it's it's really you know

32:19

it's a balance between you know getting health care of all types

32:24

at any given time versus when it's really needed so i don't see it as a barrier necessarily and you bring up a good point about the

32:31

decline in gfr being slower for those of us uh pkders i though i would say that

32:40

those of us who have seen family members struggle or uh lose the battle um we

32:47

somewhat panic when you get into a certain number base so education once again you know whether

32:52

it's helen or her team partner saying hey let's let's review this and hopefully someone at your outside

32:58

nephrology practice that is um sensitive to these issues of i'll just confess for

33:06

myself i mean many many times i panicked and just looking at my labs would make me panic but i

33:11

didn't realize that you know there would be a little bit of time there nicole i'm going to get back to you

33:18

the pkd patients be evaluated at multiple centers

33:24

sure yeah i would i would take that based on this this concept of you know even if you

33:29

think you know who's going to be your living donor to not you know make the mistake of

33:36

of sort of planning for another eventuality where it doesn't work out

33:42

and so i think so deceased donor waiting times vary across states regions even center to center

33:49

within some some regions and so i think um for those who can because logistically it can be

33:55

challenging to go to multiple centers but for those who can it's it's going to help um if you are

34:03

awaiting a deceased owner transplant yeah it can and i yeah everyone i mean most people in this

34:08

country get health care fairly close to their home uh and that's you know there are a lot of advantages to that but as cliff says

34:15

if you do have the means to at least explore a couple of different centers you don't want to go to two centers in

34:21

the same city for example you wouldn't want to go to ucsf and then

34:26

the one down uh cal pacific i think it's called right right there's just no advantage to that

34:32

um from an allocation standpoint um and even recently i think the policy

34:37

went live in late march of this year allocation changed again uh so you need to understand and it's

34:45

way more than uh you know the the the time allowed for this conference to talk

34:51

about kidney allocation but um you know it generally is

34:56

now it's actually the kidneys are allocated first within 250 miles circle nautical

35:02

miles of the donor hospital um and so where the patient's listed if

35:07

that centers within those 250 miles they sort of get first crack at those kidneys and that's changed since

35:14

you know we see kidneys for example from nebraska that we never saw because they used them all down there

35:20

but now we're starting to get some because we're about 215 nautical miles from there so interesting the geography is a little

35:27

different now than so you just have to work with your nephrologists uh or your transplant center to explore that

35:32

um it's not quite as crazy what's that getting some good corn fed

35:39

kidneys that's what we're used to so it's good but we you guys never used to let them get out

35:44

of nebraska but now we're able to get some of them so but it has changed but there are advantages i think if you're you know

35:52

it's uh the the old framework of opios and donor service areas and regions is a

35:57

little has gone away um and so just work with your team to know you know you know for our patients

36:05

in our area like we're 75 miles southeast of minneapolis there may be a benefit to being listed here rather than

36:11

there because our circle extends to places like milwaukee and chicago where there's doesn't

36:17

so you kind of have to look at the where the centers what you know basically it's population

36:23

based honestly um of course with increasing populations come increasing people that need kidneys so

36:29

there's a it's not always you don't want to necessarily go to a crowded area either i also find that

36:36

those of us that have very enlarged pkd kidneys we may be looking at centers

36:41

that may be more open to uh double nephrectomies i personally had a double nephrectomy at

36:46

mayo phoenix back in 2010 and it was done same day as transplant i know that's rare

36:53

um but i know that when i speak to other pkd patients they're they're wanting to know hey what center

36:59

is a little more open to that and would they be open to that before or after i get my transplant or same day

37:05

as so sometimes that comes into play as well as where's my donor my preferred perhaps best

37:11

looking uh qualifying donor located and if they're across the country you know there may be some consideration

37:18

for location of another center so can i just make one point um about

37:23

absolutely multiple listing it's really important to make sure that your insurance will cover the multiple listing the

37:30

evaluation and thinking about the logistics afterwards you know for us that you see we see and i'm sure you

37:37

guys do too we see patients weekly after they're transplanted so you're going to need to be somewhere

37:42

local and so you need to think about all those things and the other thing i we do have a long

37:48

wait time but we have great outcomes and so that's the thing too that i always caution our patients that

37:54

not only look at how fast but make sure that you're going to get a great outcome so those are just my like hot buttons to

38:01

make sure that our patients know about accidentally some of the work done at one center

38:07

can often be used at another center if you know if you know we get the echocardiogram

38:14

results from ucsf or nebraska will say okay you had your stress test and that's probably okay and you

38:19

don't so just make sure the center is not repeating a lot of things necessarily they may want to do some additional things just

38:25

do just styles of practice but a lot of it can be done um

38:30

you know it doesn't have to all be repeated necessarily right you don't need brand new information on the same echo right right

38:38

excellent and nicole i know we only have a couple minutes left yes we need more time because i've got

38:43

some really good questions um so let me throw two things out that maybe we could answer

38:49

um one if someone needs a dual kidney and liver transplant how would that impact being able to get

38:55

a preemptive transplant and then i also had a question about

39:01

um pain and people pursuing patients pursuing preemptive transplant

39:06

kind of driven by assisting with their pain so how does getting a transplant impact the level of

39:12

pain pkd patient is experiencing pain whoever wants to speak pain pain

39:19

related to their native polycystic kidneys is that anything i believe yeah

39:28

kidney transplant by itself doesn't help that uh usually i mean you know in the short term it

39:33

causes more pain uh in a different part of the body but i you know i think as as uh risa mentioned there are options

39:41

to have the native kidneys removed um you know we've both arizona and rochester here we've

39:48

been pretty active in doing that the same day um before we started doing that we would

39:54

typically take them out at about three or four months after the transplant we preferred not to do it before uh

40:00

mainly because that makes people without kidneys i mean being on dialysis without kidneys is really hard

40:06

even if you're only going to do it for six or eight weeks so i um you know there are many options

40:14

for and each center may have a different style but i don't know that there are that many centers that are totally averse to taking out native

40:20

kidneys the question about the liver with a kidney is a bit more complicated because

40:26

all of the uh waiting time if you will or organ

40:31

allocation is based on the liver um at that point and so um

40:38

that is something that and those scores for those for people with polycystic liver disease

40:43

or what are called appeal scores there's a standard score if the appeal is approved by a national review board

40:50

the uh you get an appealed melt score and meld is a complicated uh system but and so what where that score

40:57

sits kind of relates to where you're going to get a transplant but that score is not the highest melt score it's not the

41:04

lowest either but it's uh somewhere in the you know upper two thirds so it may unless you're going to pursue

41:10

living donor liver transplant followed by a living donor kidney and that gets a little uh logistically interesting

41:18

and people have even used the same donor uh not very often but um we're going to try to do that soon

41:26

not for a polycystic patient but for a liver patient who had her transplant yesterday but

41:31

it get it probably decreases the likelihood of a preemptive transplant yeah just given the liver waiting times

41:41

i think that just it and while nicole was looking up otherwise it's not a failure on anybody's part if

41:46

you don't have a living donor you don't have a preemptive transplant it's nobody's fault um if you've done

41:52

the right things you've gone through you've been proactive i don't want people to come away with it

41:57

being a failure it's certainly the preferred approach i think for most providers most transplant centers and

42:03

recipients probably too but i don't you know i don't want people to come away with a concept that

42:08

i did something wrong or that i've you know i'm gonna die because you know we do see people on

42:13

dialysis for many many years and a year or two of dialysis is

42:18

probably manageable if you had to um you know i we transplanted a girl the other day that

42:23

browned dialysis for 24 years wow i finally decided she want a transplant so i it's not

42:29

um it's not a death sentence i mean i've you can still work you can still be active you can still do things um

42:36

so i don't want this conference to come across as the only way to get a transplant just so people don't you know beat

42:42

themselves up too much i think that's a very good point um risa i

42:47

this i'd like to throw this out there i know we probably have like 30 seconds left um but we do have a break after this and

42:53

um but there you go we could go like a minute over or something sure um so you know maybe we can't

43:01

begin the evaluation until you know a certain gfr um we've had several comments in

43:07

that i read through and so i wondered to helen's point a little while ago um you said have you talked to your

43:14

donors lately or you know something to that effect so if we can't start an evaluation to a

43:19

certain point and we want to be proactive what are things we can do to be talking about

43:24

this idea of a preemptive transplant well ahead of a gfr of you know 20 to 25.

43:35

well first of all i want to say that i do not want to anyone to think that it's easy to talk about needing a kidney transplant

43:42

so we we talk as if it's like oh every day so i want to make sure that people understand that we know that's not an

43:48

easy conversation to have and i think that you know you can't

43:54

you can't always every time you talk to your friends you can't say don't forget don't forget don't forget but i would want you to say and make

44:00

sure that you know maybe in the holiday letter you know thank you so much for all of your

44:06

concerns and your questions about this here's my update so again you're keeping people updated

44:12

as to what's going on and they can think about it to um cliff's point you know

44:18

we want people to think about it and you want to get started thinking about can i be this person's

44:24

donor and that's the other thing is you might actually have to tell people even if you're on dialysis you might

44:30

have to tell people i need a kidney transplant because i've had patients say to me my

44:36

friends know that i need it that i'm on dialysis how come they don't know that i need a kidney it's like well you actually have to tell

44:42

them so i think that you know when you tell your story you have to say

44:47

i'm on dialysis or i'm going to start dialysis which means i need a kidney transplant

44:53

and a living donor is my best option i would just add and i think helen

44:59

mentioned this earlier but but i think having someone and maybe it's a spouse

45:04

or someone in your family who can't donate for whatever reason they can still

45:09

advocate for you and just like sometimes it may be easier to bring it up from that angle to say

45:15

this individual needs a kidney transplant and i'm sort of like acting as an advocate for them

45:23

and especially it's you know if it's someone that's a close family friend or whatever and they can't donate now they're like i

45:30

i failed them i was like no actually you have another opportunity you can do and you can actually say i try because

45:36

this is the thing too especially with spouses that can't donate and they're talking about need

45:42

you know their loved one needs a kidney transplant i tell them you have to tell people i tried and i

45:47

couldn't do it because x because that also speaks to we're not in the transparent world we're

45:54

not going to just take everybody and anybody you have to be in exceptional health you have to have great kidney function

46:00

you have to be for the long term so i think that that speaks to the safety of of the foot thorough

46:06

testing program that we all do you know put our living donors through

46:12

exactly well i sure hope that this program has your uh

46:19

your ideas spinning in your head right now and that you've generated some excitement so because

46:25

maybe you know a little bit more about the path to preemptive transplant we want to make transplant more

46:30

believable and achievable and speak on behalf of the panel i think we all agree that transplant

46:37

should be a choice not a challenge but the only way to really take the barriers down on that challenge is to get with people

46:44

that know more like helen and her program and other programs uh

46:49

across the united states there are some great books one i even authored um there there's just some great tools

46:55

out there and you may not be hearing about these in the sacred walls of your exam room so you know please bookmark this program

47:02

and go back and listen to it again and take those notes and thoughts that you had in terms of what do i do next

47:09

and reach out to nicole if you want to find a mentor that will help you get to the next level

47:14

many of us are are here to help and uh want to see you live a better and longer life

47:19

so thank you all for joining do you nicole do you have some final comments about the survey or

47:25

anything you want to share with them i do really quickly please take the survey the link was put in the chat but

47:31

it's also listed on the agenda for this session so we'd appreciate your feedback

47:37

if you'd like to hang out right here for a few minutes we have a mindfulness break coming up um and then we'll have a

47:43

little bit more time there's actually a 30 minute break but we've used up just a little bit of it to finish up this session so hang out

47:50

here for a mindfulness break and then you can head back over to the platform our next

47:55

session is genetics how your genes impact your family tree and it begins at one o'clock center

48:00

i also would like to thank the panel and risa for moderating this great discussion thanks everyone thank you

48:19

nicole are you wanting us to take more questions just want to get a little more direction from you i think we have a mindfulness break

48:25

coming up so don't stay in this it's supposed to come up right here i think they're supposed to play it

48:31

right here am i right uh tina i don't know if she's still with us

48:38

tina got so excited she's starting to share a story for a friend she's become a champion i am still here

48:44

let me check on that for you um i believe there is a video but i wasn't instructed to share it for this session

48:50

but the next so um stand by let me see what i can find out for you at the last minute yesterday

48:56

okay uh uh let me let me find out for you one second well maybe i don't know we still have some people in here i guess we could take

49:02

another question while we wait um the survey is posted in the link or in the chat here and it's also

49:08

on the agenda page for this session so if you go to the agenda you click on this session you'll see a

49:14

link to it

49:20

did you want me to look for another question yeah that's very exciting i think somebody's taking themselves off

49:26

mute yeah so um do you think that there was like a

49:32

couple key ones that we didn't have a chance or do you think we got to the bulk of them i think we got

49:37

the majority of them somebody did ask though um what happens if you you have a donor

49:44

that wants to donate but you're not quite ready for a transplant oh that's a good question i can take

49:50

that we we work with the national kidney registry and they could donate through the national kidney

49:56

registry as a voucher program so basically you have a you know you would go in

50:02

you would donate and then when your recipient was ready and needed the kidney transplant

50:07

then they would go we put them into the national kidney registry and match them up with someone

50:14

are both of your centers hooked up to the voucher program as well dr miles dr dean dr dean yes and dr miles

50:21

no we actually the voucher nkr um

50:27

a great position as a patient to be in is to have the gfr of 19 18

50:34

but feel well still living your life doing okay and already be listed for transplant and

50:41

have an approved donor because if you're in that position nobody's going to make you go get your kidney transplant tomorrow

50:48

but you you hold the ability then to make it truly an elective procedure when

50:54

you start to really need it and and particularly with a disease like pkd

50:59

they can progress slowly we've had people in that position for years i was like we're not gonna

51:05

we're gonna transplant you until you don't feel good or your labs are starting to get squirrely something like that

51:11

and that that's okay and i people shouldn't be like feeling like they did something

51:16

wrong if they're in that position nicole that that resonates with your personal story

51:23

mm-hmm yeah yeah absolutely i'm sorry i was also looking at the chat so a little bit here's a really

51:30

important question um we'll end with this one this one is definitely not something we've touched

51:35

on before is it more important to get a preemptive transplant from a deceased donor

51:41

if you don't have a living donor than starting dialysis while you try and find a living donor

51:48

well i think those things sort of occur in parallel um you know you're you would be listed

51:55

at a center and then while you're on the waiting list maybe you have a preemptive transplant or

52:02

maybe you find a living donor or neither uh it's really it's kind of the

52:07

fork in the road there i mean but i think they're all kind of in parallel we do see folks that are on the

52:13

list for several years and then three or four years after being listed they'd and on dialysis they

52:20

have a newly found living donor and that's okay that's still probably you know uh it's

52:26

one less person on the waiting list if they receive that living donor kidney so i i think it's all done in parallel if

52:32

that makes sense absolutely not it's not a sequential thing that okay i don't have a printed

52:37

you know that you do all of them at once the other nuance is that you know not

52:43

all deceased donor organs are created equal in terms of what we expect their

52:49

function to be like and so a lot of our patients who are in that exact position

52:54

we'll talk with them and we'll sort of restrict what type of deceased donor sort of i don't know if there's any

53:00

talks about kdpi that kind of thing but we might limit the the the deceased donor waiting list that

53:07

they're actually looking at so if uh i hate sort of good and bad i don't get into that but if like a really

53:14

a donor comes along from the deceased list that we really think should function well for that person give that an opportunity uh otherwise

53:22

wait and try to see what comes out for living donation yeah i think this point's important i mean not all

53:27

deceased donor kidneys are as i mean not all living donors are created equal either

53:34

and there are you know many many to see stoner kidneys at least on paper that

53:39

may work longer than a living donor kidney but you just don't know you know which one is going to come up

53:45

for you unless you restrict your criteria very tightly and most centers probably do that or you

53:50

have people inactive for a while uh while they're work you know if their gfr is 19

53:56

they feel great you know you don't need to transplant if your gfr is 19 and you're feeling great you really don't those are good points

54:03

thank you for taking a few extra questions um the mindfulness break is going to be

54:08

on the main stage after the next general session so that's where you'll find the mindfulness break and

54:14

i think with that we'll say thank you um enjoy your uh slightly shortened break

54:21

um and then we'll see you on the main stage in a little while thanks so much this was wonderful we appreciate it appreciate everyone on

54:28

the panel thank you so much bye-bye everybody