0:02

okay great yes we're good for that glitch it's always a bit of a problem uh with two screens um

0:07

thank you for uh your patience um i'm going to discuss i was asked to discuss and i'd like to

0:13

thank the organizers for inviting me to the meeting how to how to manage chronic pain it's a very common symptom in people with

0:18

polycystic kidney disease and it may affect some somebody uh transiently or maybe become a chronic

0:25

issue for some patients and generally uh the pain is often related to an

0:31

enlarged and what our pkd foundation colleagues talk about heavy kidneys and a heavy

0:36

liver and there are many medical therapies that can be offered to patients uh and they have to be customized for

0:43

what the problem is for example bleeding cysts hemorrhage into the back of the abdomen

0:49

after a cyst ruptures and kidney stones those are examples of where specific medical therapies are needed

0:56

surgical therapies are often desirable for for problematic single kidney cysts problematic large liver cysts

1:03

and of course when the kidneys become very heavy and patients uh go into kidney failure probably the

1:08

best way to manage their pain is ultimately perhaps to take out the kidneys uh or get to a preempted

1:15

kidney transplant a little earlier and ultimately either before or after the transplant to remove

1:20

the kidney uh the kidneys uh so bilateral nephrectomy is a treatment option and bilateral threatening kidney transplant

1:27

simultaneously has now become treatment option at our center which we've become quite uh proficient at and again stone

1:34

management can center around metabolic management metabolically active stone disease and surgical management of stones

1:42

and so pain is the most common symptom perhaps sixty percent of people and i show this slide of a patient of mine

1:48

with very mild polycystic kidneys he's a a teenager and you would think gosh they don't have

1:53

a lot of cysts in their kidneys their kidneys aren't extremely enlarged but this person actually is debilitated

1:59

by their pain and uh it's an example of someone that needed to go to extreme measures in order to

2:05

control their pain but this is somebody with chronic pain most of most of you that have

2:11

polycystic kidney disease in fact have more problems with acute pain perhaps with a

2:16

urine infection a kidney stone a ruptured cyst can cause pain for several days it can be moderate

2:22

it can be moderately severe it can even require an emergency room visitor or or hospitalization uh bleeding from a

2:30

cyst uh bleeding from a vessel in the polycystic kidney can become an issue and patient can need to be seen urgently

2:37

in the emergency room uh and then of course pain can be due to tumor and tumor does occur in polycystic

2:43

kidneys and therefore if pain is a chronic ongoing issue uh there needs to be a very careful

2:49

assessment for kidney tumor uh the chronic pain often as i said it's

2:54

the enlarged cystic kidneys they cause stretching on the capsule or traction on the pedicle which is the middle of the kidney

3:00

and of course the enlarged liver so the kdigo which is a professional organization of nephrologists and people

3:07

that are interested in various kidney diseases the polycystic kidney

3:13

guidelines from this group recommend that all patients with polycystic kidneys at some point in their life should have

3:20

some form of cross-sectional imaging to look for uh how their liver looks how their

3:26

how their kidneys look and um well there's no set guidelines for how often this should be done they should have at

3:32

least one at one point in their lives at perhaps at diagnosis or a few years into diagnosis

3:38

some assessment of the organ volume and especially if they have pain to try and identify where the pain is

3:44

coming from on the other hand this person here you can see is a young person of mine that has polycystic kidneys

3:50

and in this situation you can see more large plumper kidneys again this person is probably going to have some mass effect they're going to

3:57

have fullness of their flanks they're going to have perhaps some flank discomfort trouble perhaps

4:02

tying their shoelaces this person actually has no pain the person this is why i use this to show

4:07

you that often there's really no correlation between someone with perhaps debilitating pain and someone

4:13

that has no pain at all but large kidneys and so thing is the point i want to make here

4:19

is that cross-sectional imaging may be helpful but often there is a discordance between the amount of pain

4:26

from the organs and the findings on imaging

4:31

so the very classic paper was written by ted simon and dr bajwa an anesthesiologist

4:36

a point i want to make from this paper published in the early 2000s that that

4:43

the pain patterns involved in patients with polycystic kidneys is much the same or you know it's it's

4:49

back pain that patients report in 62 percent abdominal pain leg pain pain down going

4:54

down the leg radicular pain headache is a very common uh symptom uh in in

5:00

in terms of polycystic kidney disease patients and some patients get chest pain and again this may be because the

5:05

cysts are pushing up the liver is pushing up and back pain back pain is quite frequent it can be constant in about a

5:12

third of people it can be daily you may suffer from back pain daily because you've got big huge

5:17

weighty heavy kidneys uh you may get pain once a week from your back pain so as a physician when i as a nephrologist

5:25

when i see a patient we ask about where the pain is where does it go to what kind of pain it is how severe the

5:31

pain is and we can learn about the characteristics of pain which can help us to understand how to treat your

5:37

condition and again the abdominal pain about uh 13 people have this constantly

5:44

all of the time 13 daily uh once a week about 9 so this is these are very common

5:50

symptoms and so pain in the abdomen could be from the kidneys it could be from the liver it could be from something else it could be

5:56

from something completely not related so some of the work in the last 10 years

6:02

comes from some of the larger studies that are done for example the nih hall study described

6:08

some aspects of pain and found that it was an early symptom it inversely correlated with the

6:13

kidney function so as kidney function went down pain tended to be more often more severe

6:20

and they're especially those people with kidney function less than 45

6:27

or stage three kidney disease impacting and quality of life in the tolvaptan study this was an

6:33

industry sponsored study uh they did collect however in over 1800 people the adverse events and

6:39

were able to do some analysis after the clinical trial of the drug was done to look at significant pain related

6:45

adverse events and i'm going to show you some of that data and in in that large study that was done

6:50

about half of the people had had a history of kidney pain um the reprise which was another study

6:56

that expanded the experience of tub after again industry sponsored there seem to be in more

7:02

advanced disease uh in this cohort that with more advanced polycystic kidneys less kidney

7:07

and back pain events and then there's a very significant data from korea that i usually discuss uh showing patients with

7:15

polycystic liver disease and people with very large livers and and in addition they may also have

7:21

very large kidneys the two organs sets together tend to be additive and the risk

7:26

of pain symptoms was five-fold increased when people had a very large liver so it's very important to have a look at

7:33

the liver especially if you're having right-sided pain or abdominal fullness or feeling full

7:39

quickly into a meal because this may be due to symptomatic polycystic liver disease and this is not that common so i don't

7:46

want to scare people that are listening to my talk because people get alarmed when i give this talk

7:52

when they see people with large livers not everybody has that in fact most people have

7:57

do not have a very enlarged liver it's just that some people do and about 16 of patients with pkd tend

8:04

to have symptomatic liver disease and so those patients do need to come to specialized centers uh

8:10

that that can handle uh surgical approaches to alleviate the size of the liver and its

8:16

compressive symptoms and again there was another study uh from japan looking at cross-sectional descriptions of pain so

8:23

there's been quite a bit done and others are studying this uh and funded to study this

8:28

so again what what could be causing the pain well infection so occasionally patients may feel unwell

8:35

have some urinary symptoms and the problem with pkd is that the lower urine infection perhaps cystitis

8:41

or bladder infections presenting with burning or stinging passing urine discomfort over the bladder

8:46

this disinfection can ascend quickly the bacteria go up the urinary tract and one can get infection in the kidney

8:53

known as pyelonephritis which can be a severe infection and can even lead to bloodstream spread

8:58

of this infection and needs to be treated and evaluated promptly but this can be painful and the problem with this is that

9:05

sometimes the cysts can become infected in the kidney on that side and that is another medical emergency

9:12

and those patients really need to be assessed quickly imaging needs to be done and ideally

9:17

uh it should be contrast enhanced damaging to see if there's an infected cyst because sometimes these new drainage

9:24

again uh when patients develop severe acute pain this could be due to hemorrhaging assist enough and that can be in either kidney or a liver

9:31

and then if some cysts are expanding over time patients can report mass effect and that

9:37

can be kind of a fullness symptom pressing on the surrounding kidney tissue or the surrounding muscles of the

9:44

back and then you can get acute expansion of cysts for example a cyst bursting and this can cause acute pain and can be

9:50

quite moderately severe moderate to severe for some people they may need to lie on the couch take a few

9:55

days off work take a lot of fluids get fluids in the emergency room

10:01

and may need moderate pain and pain medicine or even iv pain medicine and again the renal

10:07

capsule is the saran wrap of the outside of the kidney and of course when you have polycystic kidney disease this is under a constant tension so if there's

10:14

shifting of cysts which there always is this can distend the capsule and what's important about the capsule

10:19

it's the capsule of the kidney has a lot of pain fibers in there so it's sensing this pain and so this may

10:26

give a deep type of pain sensation to the individual affected then we see people with kidney stones

10:32

so you can have kidney stones on both or one side these can be either uric acid or oxalate stones and these occur in

10:38

about 20 people and you may be lucky that you don't have passage of a stone but sometimes you can have passage of a

10:44

stone and that's called uratary colic colicky pain so it's a waxing and waning pain that lasts

10:50

minutes or so about 20 minutes and then it fills up it crescendos and then it decrescendos it wanes off as

10:57

the muscle of the ureter is trying to expose the stone if the stone is about to pass now most people can have stones and they

11:04

may not pass or obstruct but if they do then you get this renal colic or uritary colic and it

11:10

can even cause obstruction and then we see patients because of hernias that are a commoner in people

11:16

with polycystic kidney disease one can get complications from a hernia for example incarceration which means

11:23

twisting up perhaps bowel into the hernia the commonest hernias we would see in people with polycystic kidney disease

11:29

would be umbilical hernia so in your belly button near the belly button para umbilical

11:35

hernias abdominal rectal rectus abdominal wall

11:40

hernias are quite common and then inguinal hernias in the groin so they can have passage of bowel

11:47

into the hernia or the out pouching of the of the wall of the hernia and this can lead to

11:53

torsion of the contents and a surgical emergency so polycystic kidney disease is one of

12:00

the most important non-neurologic conditions to cause kidney pain and in the past we've written descriptive

12:06

article about what should be done looking at a flow chart for how it can be handled

12:12

of course simple paint rest but rests laying staying off work getting hydrated

12:17

staying staying hydrated and sometimes a heating pad was sitting

12:22

in the whirlpool one of the patients i'm going to show you today she bought a memory foam mattress other patients tell us they um

12:30

like to sleep in an easy lazy bar chair they don't like to sleep in a bed if they have a lot of chronic pain

12:36

if you have the acute pain you may need to take some time off work uh use these physical measures and then

12:42

simple pain medicines like tylenol uh occasionally a day or two of uh

12:47

[inaudible] the leave advil while it's not recommended to take them long term if you're having acute pain they may

12:54

take the edge off the pain for you another pain medicine that's safe in patients with kidney disease is tramadol

13:02

that that medicine ultra known as ultram is is is is well tolerated in most

13:08

people and it's a response responsive first for moderate pain clonadine is a blood pressure medicine

13:15

traditionally considers a blood pressure medicine but it's an alpha blocker medicine so it has effects on the alpha side of the

13:22

sympathetic nervous system and can block pain centrally and then some patients unfortunately do need to take some low-dose opioid

13:28

medicines like oxycodone hydrocodone hydromarphone um

13:34

and these we would really recommend just to use these sparingly in episodes of acute pain

13:39

and we tried to avoid uh individuals being on these medicines long term

13:45

since they have some physical and psychological dependence associated with

13:50

them can affect alertness and tolerance builds up to the pain

13:56

medicines so the body gets used to the pain medicines and they become no longer affected so we

14:02

try to try to avoid individuals being on these medicines and one of the things we hear a lot from

14:08

patients that come to see is that oftentimes in in smaller hospitals or

14:13

clinics perhaps pain clinics when they don't know of other options for management of pain patients maybe

14:20

prescribe these medicines and without other options being offered

14:26

other options that are offered are quite there's quite a number uh a tens unit electrical stimulation for

14:32

back issues uh associated with large kidneys acupuncture may be helpful but very rarely can we use a spinal cord

14:39

stimulator which would deliver a neuromodulation or we can use a a spinal uh

14:47

opioid infusion that's very rare that we've ever done that but it is an option uh but more more and more we're using

14:54

surgical approaches to decompress cysts that clearly associate with symptoms i'm going to show you some

14:59

examples from the liver and kidney and some examples of denervation approaches that we use

15:05

and not on that slide is that now we have an approved medical therapy in the form of tell that and that

15:11

clearly modulates pain and so my first case here is a 33 year old woman with polycystic kidney disease

15:18

who presented to the emergency room with a two-day history of flank pain on her left side and when she presented there she was

15:24

found to be an acute kidney failure so her creatinine had gone up perhaps her urine up was for low

15:30

a few years ago she had had a similar event when she led into a cyst and so on this visit she was it was

15:35

decided she needed to be hospitalized given some iv fluids and antibiotics and when she came

15:41

to see me her pain had improved since the emergency room physician visit however she was continuing to have

15:47

pain at night and she's a mother with young children and working and this is very inconvenient for her and so you see

15:54

here on the ct scan of her abdomen this is a cross-sectional coronal ct you can see the spine the liver the

16:01

kidneys and you can see in the upper pole of this left kidney here which shows a bunch of cysts growing out of the kidney like

16:07

grapes and this one too that this kidney is considerably much more distorted and correlates with her

16:13

left-sided kidney pain and what's going on here as we try to visualize it here in this imaging again

16:19

i have much more dense files to look at when i see the scan is that this individual this lady is

16:25

having a hemorrhage into a cyst here causing her pain and pushing on everything and uh so this lady was overweight she

16:33

was uh resuscitated in the in the emergency room with fluids and

16:38

given antibiotics for fear that she had infection because often when you have a cyst hemorrhage you can have fever

16:45

as part of the inflammatory response and um she she was able to continue and then

16:51

she was taking some pain meds at night to relieve this pain but she came seeking other options and

16:56

so for this lady we told her to lose some weight get her on the proper diet for polycystic kidney disease patients

17:02

with renal insufficiency and uh we put her on top of that and she was a candidate for twelve acting

17:08

therapy and uh that's where she went so this is a case of the system origin acute system

17:14

rich acute pain first case so now here's another case again this can be

17:19

associated with fever this is some a patient of mine that you can see with a very large liver with cysts in it and

17:25

you can see a kidney here on this part of her of the skin and you can see here around very large cyst in the liver and you can

17:32

see there's a rim around it like an orange and what this is is an infected liver cyst so this person may have

17:38

abdominal pain central abdominal pain they may have fever they may look unwell they may develop acute kidney failure in

17:44

the setting of infection and there are some criteria for diagnosis of the liver cysts for example

17:50

the imaging criteria as shown with this example with the enhancement of the contrast aromasis the

17:56

large cyst the tenderness on examination associated with this finding on imaging

18:01

elevated inflammatory markers and in this case here this person really needs to have this cyst aspirated

18:07

so we can identify the bacteria in the cyst culture the fluid identify the correct antibiotics to be on

18:13

and perhaps treat this person for several weeks and if the cyst infection comes back they need to be

18:18

retreated again or perhaps put on long-term antibiotics and this i'm showing you to you because

18:24

it's an important complication of polycystic liver disease and is frequently missed and patients frequently keep coming back to their

18:30

doctors trying to figure out what's wrong and in fact there's a deep-seated infected cyst

18:35

in a liver and kidney this is an example from the literature that i produced here for this slide showing

18:41

again an infect assist infection in a polycystic kidney and uh picked up with debris in the cyst on

18:48

ultrasound density on the ct scan some enhancement around the edge and heterogeneity or various kind of

18:54

densities on the pixelation on the scan and again in this case it's important to be quickly evaluated and

19:01

in a specialty center like ours we would attempt to drain this cyst because this person

19:07

could quickly decompensate the bacteria could spread to the blood and it's important to remove the

19:13

bacteria and plus from the cyst if there's an infected cyst in the kidney

19:18

now uh we recently published this little review article about

19:23

an approach to abdominal pain in polycystic kidneys and nephrology dialysis and transplantation the

19:28

european journal showing a kind of a workflow for what we would do the person comes in with acute abdominal

19:35

pain perhaps they have fever or not and we look at the vital signs whether they decide quickly whether they need to

19:41

be hospitalized and often in our center and we would encourage uh in other centers that the patient has

19:49

their physician your doctor work with the emergency room physician especially if you've had this

19:56

happen to you several times that you've been to the emergency room with with acute pain and so the nephrologist

20:03

me as a nephrologist i can help the emergency room physician to figure out what's where the

20:09

pain is coming from the line the hypochondria what part of the abdomen

20:14

what are the markers of kidney function make sure urine culture is done get the patient on

20:20

some fluids get the patient to the hospital if they need to be admitted and get the right kind of

20:26

imaging and this is a question the pkd foundation asked me that patients contact them all the time

20:32

asking what kind of scan well it's difficult to say in most cases because everybody has different kidney

20:37

function and but in a situation where we have a potential in cyst infection which is

20:42

life-threatening sometimes we do need that contrast that iodine with a ct scan and of course a ct scan

20:50

is going to be done in a place that has a good ct machine but if you don't have that available to you in your hospital

20:55

it may be an ultrasound but really we like some kind of cross-sectional imaging and a good quality ct scan

21:02

ideally with contrast helps pick things out that might otherwise be missed if contrast was not given

21:08

so um the causes can be not related to the cystic disease at all or it can be stone passage of stone gaston disease it could

21:16

be an acute hemorrhage this can be visualized especially when contrast is given and

21:21

one can decide that based on the hounsfield units or density seen

21:26

cyst infection can it can be readily identified sometimes it can be missed and then sometimes we

21:32

have to rely on other more sophisticated forms of imaging such as pet scan which is particularly helpful in

21:38

liver cyst infection abdominal mri if the hospital or center has that type of scan that's very high high level high

21:44

resolution and in in in more more infrequently we do rely on a nuclear scan that labels the

21:51

white blood cells that can pick up the focus of infection and can help us identify occult infection is a

21:57

cause of pain the treatment involves pain pain management hydration and there's a

22:04

drug called tranoxamic acid i'll show you some cases where that can be used and

22:09

of course antibiotic therapy and dimension drainage from the cyst so this is an example of somebody with a

22:15

kidney stone here this is a ct a stone ct that we do at our center and you can see the hands filled units

22:22

which is the density is compared to the density of the bones in the spine and then we can tell the kidney stone in

22:27

the cyst in the cystic kidney how how dense it is and we can then tell what kind of stone it is is it uric acid

22:34

is it calcium oxalate or is something else and so stones i mentioned are an important cause of acute pain they can

22:41

also cause flank pain chronically they can lead to blood in the urine obstruction infection and sometimes need

22:47

surgical procedures and i'll warn you for those of you that have had these procedures sometimes the treatment may be worse

22:53

than disease because patients come back complaining about the discomfort of the stent the painful lithotripsy or stone

22:59

blasting procedure that they had the painful surgical procedures to retrieve the stone um

23:05

and so in this case actually the management here what was done for this person was

23:10

actually to put the person on out of purine and put them on citrate because they had low urine recitrate

23:15

and they also had a uric stone a uric acid stone here and the stone actually dissolved with medical therapy and

23:21

didn't need a surgical intervention case two a 44 year old man came with

23:27

abdominal pain a few days before he had had gastritis and harsh episodes of vomiting

23:32

because the abdominal and then the abdominal pain subsided but he when he came to the emergency

23:38

room he was having some pain and some tenderness in his left lower quadrant or left lower corner of his abdomen

23:44

and this pain was getting worse and he felt nauseated and sweating so he went to the emergency room

23:49

and his kidney function was was normal and the ct scan again was done to assess

23:55

the situation and they felt that there was a colitis or an inflammation of his descending

24:00

colon he was given some antibiotics put on clear fluids and sent home but then the pain came back on christmas

24:06

eve of course most inconvenient pain occurred and he was now hospitalized for six days

24:12

and again with inflammation he's descending colon now i point out here that patients with polycystic kidney disease

24:18

can get colitis they can get diverticulitis but actually this is what's going on

24:23

this person again you can see is polycystic kidneys very large cysts here in the right kidney

24:28

that are bursting out and you can see preserve kidney here and then you can see here this

24:34

heterogeneous appearance to this cyst down here and you can see that there's some dense materials and this is actually a bleed

24:41

into a cyst okay so this is the initial ct scan but then this is the scan six days later so

24:48

what you see here is that this bleed into this cyst is now extended and it's outside around towards the

24:55

spreading out on the cap around within the capsule of the kidney which you can see here and then there's a the

25:00

extension of the bleed here along the retroperitoneum or back of the abdomen and is pushing on his muscles

25:06

and he's having pain in his lower uh abdomen and his his low back with this so this is

25:13

potentially life-threatening he's having a big bleed into a cyst cyst hemorrhage and a retropertineal

25:19

extension of that bleed and so these patients have to be hospitalized sometimes we have to do

25:24

an angiogram and to try and stop the bleeding or we can give therapies so this this this is another image of

25:31

the same patient you can see that the clot is now much larger this is you can see now the contrast ct you can

25:37

see that the kidneys are lighting up with the contrast you can see the extent of his polycystic disease and you can see we're getting a

25:43

good handle on this large bleeding cyst here uh and he now that has developed into a

25:50

hematoma three you have about 15 minutes left very good so the treatments are can be tranexamic

25:58

acid when there's bleeding like this um he was taking a headache medicine

26:03

excedrin which contains aspirins and this will stop resting him and sometimes we embolize

26:09

and so uh it eventually regressed is showing here so we monitor him

26:14

and then patients that are unstable will do an embolization will block off the blood flow to this

26:20

this bleeding cyst and that's done by interventional radiology and it's an emergency procedure

26:27

so those are the references for those treatments uh i mentioned talvactin as a treatment

26:33

option that modulates pain you've probably seen these data but there was a difference in pain in less

26:40

pain in the top after treated arm of the temple three four so tulvatin is a treatment option for many people

26:47

with pkd so next slide

26:52

again this is just the top acting data and to that trial is over and until that is approved so your nephrologist can get

26:59

you on the treatment but there is a forthcoming licks adapting trial and we did a single patient trial

27:04

of lixidapton in the young lady with the chronic disabling pain and she tolerated this treatment as

27:11

opposed to south afternoon which led to liver abnormalities and so the palladio are planning a large study to

27:19

examine elixivating another uh turvactin-like medication in a global trial to study this in more

27:25

detail and we'll look at pain uh so this is a important summary slide just showing you the treatment options

27:31

that can be done for different different causes of pain from going in with a needle and aspirating assists

27:38

which we don't do very often but sometimes we do as a diagnostic test more often what we do is assist

27:43

aspiration and we put foam into the cyst to treat it and that can be both liver or kidney sometimes we

27:49

go in with keyhole surgery and take out a bunch of cysts this is a day procedure the

27:54

sclerotherapy that's done in the radiology department this is an overnight hospitalization and the procedure we do a lot now is

28:01

foam's clear therapy i'll show you some cases you can do bigger surgeries of course we'll talk about nephrectomy

28:06

nerve blocks are often done uh they can be done as a temporary procedure or a more long lasting one

28:12

liver surgery ablation of the blood flow uh to the liver or to the renal artery to part of the liver to

28:18

reduce the size can be done and is done in some countries more so than than here in the us um and

28:24

then liver transplant for people with very severe polycystic liver disease now this person here case three has huge

28:30

polycystic kidneys you can see here engulfing their whole abdomen very mild

28:36

liver disease little cysts in there and there's a cross section of the of the system you can see that many of them

28:41

have fluid levels in them from the bleeding tenacious material this person we know

28:46

had kidney pain because i he's a case we had so we know he was having pain with these from intermittent

28:51

bleeding cysts and he was on blood thinner or warfarin which didn't help and then he bled into

28:56

assistance can be seen down here and on this so this person has highly symptomatic polycystic livers

29:02

polycystic kidneys that are huge so this person what we offered him in the end as his

29:07

kidney failure advanced after he'd been on top of him for several years he was offered

29:12

a bilateral nephrectomy at the same time as a kidney transplant and this is the procedure that's done at

29:20

our hospital where we can take out the polycystic kidneys both of them uh one or both of them at

29:27

the same time and implant the new kidney transplant in lower quadrant and so this is a big surgery

29:32

um it is safe and feasible at the time of the living donor kidney transplant

29:38

more blood transfusions needed and the patient may need to be observed in our icu overnight other options are uh doing nephrectomies

29:46

after the kidney transplant some which is mostly what we do but we're doing more bilateral

29:52

nephrectomies and simultaneous pre-emptive kidney transplant in our center nowadays so

29:59

um uh i'll go on now to a fourth case bilateral chronic flank pain this man as

30:05

a patient of mine uh chronic stage three kidney failure

30:10

he eventually went on top ten for bilateral flank pain from these polycystic kidneys

30:16

um and then eventually he really was very uncomfortable and he wanted something more definitive

30:21

done for particularly the left kidney so what we did was a denervation procedure which we can do up through the

30:27

groin through the blood vessels so we've done a number of these now um and uh he got relief from that and this is a

30:36

approach that's used in other centers for example the deepak the european group are denovating in some patients with

30:42

polycystic kidney the nerves going into the kidney and so this is called renal denervation

30:47

and they have a kind of a process for that doing temporary nerve blocks first see if that works uh whereas we have

30:54

moved largely to denervation as our primary treatment options for patients with chronic pain where we don't see

31:00

where we can drain cysts or they're not ready to have a nephrectomy yet

31:07

and this is safe we do it it's an overnight hospital stay and so these are the results of their study in the

31:12

netherlands showing that this was safe and feasible and again

31:18

they offer this to patients with other kidney diseases in addition to polycystic kidney disease and they found the pain was improved with this

31:25

procedure they did well and was safe now many patients as i said are only offered

31:31

opioid therapies but i want to point out it's important message of this meeting with patients

31:36

today listening to me is that really there's no sufficient evidence to say that long-term opioid pain medicines

31:42

improve chronic pain at all and we tried to get some other options for our

31:48

patients at our center and so i'm going to move on now to the liver because the liver is an important

31:53

source of pain and often both kidney kidney volume here and liver volume shown here

31:58

as the both organs enlarge the pressure related symptoms causing the pain get more constant and more severe so the

32:05

huge kidney compared with the normal kidney and the huge liver and sometimes this needs removal of some of the liver

32:11

in a subset of patients this person here has severe liver disease as this woman does here often it's a disease more of

32:17

women but we do have men that get it and again this person has an abdominal hernia you can see the symptoms of

32:23

polycystic liver disease again are overlapping with the kidneys uh loss of appetite

32:29

shortness of breath pain in their face back pain abdominal fullness and some of patients are take needing

32:36

daily pain meds and so there are a number of interventions one medical intervention which is an off-label use we have done

32:42

trials with some metastatin analogues and they're very effective but proton pump inhibitors and h2 antagonists can

32:49

help with the potentially some of the secretory mechanisms and then there are surgical approaches

32:55

and so this is a person these are three people here that were in our clinical trials of octreotide and

33:01

on the top of these pictures here you can see the organ volume of the of the of the livers and you can see there's a

33:07

substantial reduction in organ volume in some individuals with very symptomatic liver disease and this is a very viable

33:15

treatment option for those patients although it is expensive we are able to get us in off-label use

33:20

or through the patient assistance programs of the company that makes that drug and

33:25

patients can um uh get it once a month it's an injection and it it slows down the liver enlargement so

33:32

just to point out this paper three years ago that bittery disease can occur so people with polycystic kidneys can also

33:38

get gallstones so if you get pain in your right side uh you should be

33:43

checked out because you have a twofold higher risk of getting gallstones and this is from a chart review in

33:50

oxford in the uk showing uh uh that that fine that there is commonly gallstone problem

33:56

uh from char from chart data and so the people that have large cysts that can be drained we've done sclerotherapy without

34:04

an injected alcohol into the cyst to clean out the cells inside of the cysts that drain and

34:09

make the fluid that fills up again if you don't put something in the cyst these um

34:15

these cysts tend to come back right away immediately so we hear that a lot the patients go to a center and they take the um

34:22

fluid out but they don't put back anything in the cyst so um we show here the spider gram how

34:28

quality of life improved after alcohol sphero therapy and it's very effective but now we've moved

34:33

on to a treatment called foam and this is a woman of my patient of mine we did

34:39

liver and kidney cysts we took out this liver cyst here and then these kidneys a couple of kidney cysts at the foam procedure a day

34:45

procedure then this just did come back because it's very large and she had a laparoscopic or keyhole

34:51

surgery to remove that you see a very nice result and then eventually though she went uh

34:56

with a bouncy kitty failure had both kidneys taken out and a simultaneous living unrelated

35:02

kidney transplant last year and so she's very happy with that result this is another

35:07

uh person who had foam sterotherapy i have a couple of cysts one of my patients here so we targeted these two cysts here

35:13

pressing on her stomach which is this ball this round thing here uh and so this is

35:18

this is just last week when she came back to see me you can see she's had a very effective result from

35:23

phone stereotherapy and she's thinking about doing a few more cysts in the next year or so to help her symptoms

35:30

uh i i was going i don't have time nicole to go back to this but i just wanted to move on in this talk

35:36

now just to show we do we take out a couple of sectors of liver this is a bigger surgical approach for for liver disease

35:43

uh hepatectomy and i had an image of a right side liver uh sectorectomy removal

35:49

uh from k seven and case eight a forty one year old woman where we did a left so we take out the left side of

35:55

the liver to create space and this is the before and this is the after uh for this lady

36:01

who's done well and so in general as we take out about 60 percent of the

36:06

liver with these procedures this needs to be done at a very specialized center a few places around the country are are

36:13

regularly doing this it has a mortality associated with surgery but our results are generally

36:18

very good and patients are very satisfied but you must have two segments of liver that are readily free

36:24

for cystic disease in order to be able to do this type of surgery but it is very effective as shown here

36:31

um we have a 60 reduction in liver volume and i can answer more questions about

36:36

that at the end the toronto group at university of toronto have been doing the phones there

36:41

therapy and published their kidney cyst cases and had a very nice result with reduction

36:47

in organ volume we're also doing liver cases routinely

36:53

and then i'll show you an example but these and these are their cases you can see their pain improves with the uh with this with the

37:00

phone stereotherapy which sticks and blues down this is so they don't come back and we just submitted this abstract to

37:06

the asm showing what a case 10 here where we have somebody with very big large polycystic

37:11

kidneys and they kept coming back wanting more sclerotherapy sessions so we did five

37:17

here the first one the second one the third one the fourth one you can see their total organ volume has

37:22

gone down substantially uh 800 cc's with couple of cysts drained each time

37:28

over a sequential visits for outpatient sclerotherapy so some patients are wanting that they're

37:34

very happy with the result this is somebody that has severe polycystic liberty she asked me to show

37:39

you her image today she's 50. she's waiting for a liver transplant because she has very severe disease

37:45

and as you can see here in her abdomen she has fluid in her belly multiple cysts in her liver and she

37:51

cannot sleep because of the pain she's using tunnel she lies on her back she's the lady that's bought the memory

37:57

foam she has early satiety feeling full quickly because of this mass in her abdomen weight loss

38:03

10 pounds chronic heartburn because the liver is pushing up and so um this is her scan i want to

38:10

show you from 10 years ago so she came to us last year and you can see at this stage she would have actually been a candidate

38:16

for liver resection surgery we could have taken half of her liver away and now she

38:21

regrets not having been referred earlier to our center because she missed that she wanted you to know

38:27

that she missed the window for liver resection surgery and she feels this could have delayed her kidney failure progression if it was

38:33

done back in 2016 a couple of years before and and then that

38:38

resection might have slowed her liver progression and hence her time to liver and kidney transplant and now she's

38:43

waiting for a liver and kidney transplant there are important developments with liver liver transplant and polycystic

38:49

liver disease recently by eunus who have relaxed the criteria to push patients like this lady up and so she's going to

38:56

get a liver transplant in the next month with the changes in the meld criteria so

39:01

the foundation just asked me to discuss with you that they receive a lot

39:08

of comments from patients about how to approach this problem with

39:14

your care providers how to talk about the risks and the benefits of these procedures and when to go

39:19

elsewhere for treatment well uh take home plans you can't just go anywhere not every hospital

39:24

not every clinic is set up for this you need places for their intervention radiologists familiar with this disease

39:30

where there are pain specialists liver surgeons kidney transplant surgeons interventional radiologists that have

39:36

expertise and to look for specialty centers find a supportive medical doctor

39:41

to support you with a good practice nurse that can help you avoid the emergency room avoid opiates

39:47

and if you have to go to the emergency room get your medical doctor or your nephrologist to talk to them there

39:53

while you're there and seek specialty care nice in summary there are many different causes of pain

39:59

uh the studies are there to describe these causes of pain now the imaging is very

40:05

important what you need to know what to look for and there's increasing interest in this

40:10

area improving care there are effective medical and surgical therapies for you and there are alternatives to opioid

40:17

therapies and but multidisciplinary medical teams are needed for this thank you for your attention

40:25

dr hogan thank you so much for this presentation a lot of very helpful information and i

40:31

know that i speak for everyone when i say how much we appreciate it you really answered um and touched on all the questions that

40:40

i was able to pull out of the chat so maybe a final comment to leave us with um what are what are maybe

40:48

symptoms associated with pain that would lead you to um some type of intervention because

40:55

we did have some questions about uh nerve block uh system fornication or de-roofing surgery

41:01

so are there clinical reasons that you would move towards a procedure i think

41:06

yeah i think if it's really impacting on your quality of life you should look for options and not just suffer on i think

41:12

if it's really bothering you or if you're requiring a lot of medicine or you're missing quality time quality time with

41:19

your family or friends because you have to to lay home on the couch or you you're missing a lot of time off work

41:26

you should seek out a specialty center and uh get get looked at and you can bring your

41:31

scans with you we don't necessarily always need new scans you can get your scans now uploaded digitally we

41:37

can look at them and we are doing virtual consoles we can do virtual um consoles with

41:42

people from around the country and look at their scans and discuss what's going on so you don't have to

41:47

spend all that money traveling to a specialty center with with the telemedicine now we can do a

41:52

lot as well so i think you know quite moderate pain uh uh chronic pain uh and then if you're

41:59

having a lot of acute pain episodes if you're passing stones and those kind of things need to be

42:04

checked out thank you thank you very much so i want to take this opportunity to

42:10

thank you dr hogan for being with us today and sharing this information please remember to take the survey

42:15

because we really do want to get your feedback and we appreciate the information you share and we'll use

42:20

it moving forward for other educational opportunities we do have a break coming up our next

42:26

session is clinical studies and adpkd patient registry and that's going to start at 4 pm

42:32

central and i believe if you stay right here we have a quick meditation break and when you

42:38

are ready you can leave this zoom room and head on back to the platform

42:44

to go to the clinical studies and patient registry session so thanks again everyone we appreciate it

42:59

hello wonderful to be with you on your pkd connect if you've been sitting down for a while you might find that your

43:05

body starts to get a little bit tight and achy which can be really distracting to help you get the most out of this

43:10

fantastic event i'm here to give you a little moment to stretch and move my name is lizzy

43:15

from two minute moves and for the next two minutes we're gonna put your oxygen mask on first before assisting others and do

43:21

some chair yoga so you're ready starting in your chair here just going to start by taking a

43:26

look to one side and then look to the other side simple little move just to get your neck out of the same

43:32

position it might have been in for a while stretch it out there ease on into these moves

43:37

and just listen to your body and do what feels good you're just going to drop down a little

43:42

bit towards your toes there and then you're going to roll on up and do a couple of really nice shoulder

43:50

rolls back or you might hear some crunches and some crepes just roll down again

43:55

come on up roll those shoulders back and one more there just release through

44:00

your lower back as you come down there pull into your tummy muscles when you come up two roll backs of your shoulders there

44:07

and we're going to reach one arm up and then the other arm up just start to reach on up nice and

44:14

gently there and let's hold this one and look away from the screen reach up as you breathe

44:20

in and drop those shoulders as you exhale and the other arm up head away from the

44:27

screen big breath in as you reach up and then it's you exhale

44:32

dropping that shoulder now that arm is going to come the outside of the knee you're going to do a gentle little twist

44:37

around if you've got a back of a chair you can hold on to it big breath in drop your shoulders and

44:43

then look around behind you and another nice big breath in and out

44:48

there really lovely twist through your spine take the hand to the opposite knee

44:53

gently does it here as you push into that knee to do a nice little twist if that feels

44:58

okay for your back deep breath in and big breath out

45:05

let's listen up through these hips scoop them up a little bit pull into your tummy muscles as you bring one knee up

45:10

and then the other knee but that was okay for you getting these hips out of the same position they might have been in for a

45:16

while just four more of those and now let's stretch out the back of your legs your

45:21

hamstrings take one leg out bring that toe on up and it feels all right just head on down

45:27

a little bit drop your head for a moment bring that toe up if you want to increase the stretch

45:32

[Music] and then take the other leg out toe up if that's enough for you to stay there

45:38

but if you want to lean forward do that nice big breath in and breath out there

45:45

and it's a little rotation of your feet getting those ankles moving one direction then the other there

45:51

are the foot and then the other direction lastly here rotate through your wrists

45:59

and then rotate through the other way hope you've enjoyed that little two minute move and

46:04

i look forward to seeing you for another one soon

46:12

bye-bye