

KIM: Hello, everybody. I'd like to welcome you to the NF Network webinar series. We are very fortunate tonight to have Dr. Kaleb Yohay, associate professor of neurology and pediatrics and director of the comprehensive NF Center, which I believe is the largest NF clinic from NYU Langone Health Center.

Tonight we're going to be talking about life hacks, tips, tricks and ideas that he has learned from working with the NF community for the last 20 years. Sometimes the little things can make a big difference in the quality of life for people living with NF.

Dr. Yohay and I talked about this, oh, last fall, and really glad to see it coming together. Thank you very much for joining us tonight.

DR. YOHAY: Well, thank you so much for having me, and also thanks for the conversation that led to this. We were sitting next to each other at the DoD programmatic review, and this idea came out of that conversation.

Yeah, and I just wanted to have the opportunity to sort of talk through a lot of the things that I've learned over the years from my patients and from talking to patients on a daily basis. We see about 800 patients a year with NF. We see kids and adults and patients with NF1, NF2, and schwannomatosis. And in all of these many conversations over the last 20 years, hopefully I've learned a few things that might be relevant for some of you.

I don't think every hack will be useful for every single person, but hopefully each one of you can come away with something that you find helpful or interesting or useful.

And also at the end of the talk I've added a link so that if you have hacks of your own or ideas of your own that you want to share, it can be left on a bulletin board type that I have, and we can sort of pull all those together. I don't know what we'll do with them in the end, but maybe it will get distributed in one way or another.

So living with neurofibromatosis obviously has its challenges and has its ups and downs, and so my goal tonight is to just talk through some of these ideas that hopefully can make day-to-day living possibly a little bit better.

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As I was putting this talk together, it sort of naturally fell into two sort of chapters, and one is navigating your way through the healthcare system, internet, school, things like, sort of more general ideas and tips. And then the second half will be talking about managing specific symptoms of neurofibromatosis and tips and tricks and managing those symptoms.

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So I'm just going to start off with one of the things that comes up in almost every clinic appointment in conversation, which is both the good and the bad of the internet when it comes to Neurofibromatosis. I think most people who have been living with NF either themselves or a family member with NF has had the experience of going on to Google, typing in neurofibromatosis and finding, you know, a picture of NF that isn't really the complete picture but one that tends to be the more sensational, just because those are the images and the pictures of NF that get the most clicks and so rise to the top of any Google search.

So I've also found that over the years it's gotten a little bit better, but there is a lot of misinformation about neurofibromatosis on the internet, both on websites as well as in chat rooms and boards, but even the websites that one might think would have good, reputable information is often wrong.

So I think most of us know that places like Wikipedia are not necessarily always accurate. And I recently went on Wikipedia and read about NF and found that indeed there are a number of inaccuracies in that site.

So I recommend to my patients really sticking with reputable websites. Obviously NF network has a great website, as does the Children's Tumor Foundation. And one that maybe not as many people know about, the one that I find really helpful for people who are interested in learning what's going on in the world of clinical trials for NF is [clinicaltrials.gov](http://clinicaltrials.gov).

This is a terrific website that allows you to search for all clinical trials that might relate to neurofibromatosis just by typing in neurofibromatosis or, even more specifically, NF1 or NF2 or schwannomatosis.

And then you can even narrow it down further by looking for trials that are open right now or for a specific symptom or for a specific age group. And it can really give you a nice idea of what's going on in the world, especially right now when there are so many -- well, so many for NF, but so many trials that are underway and getting started right now. So it's an exciting time to be in the field of NF.

So these aren't the only sites to go to, but these are ones where you can be confident that the information you are getting is accurate and up-to-date and good. A lot of clinics are a good place to look for websites as well. So a lot of clinics will have their own independent website.

I particularly like the Washington University. It's the newest website. That's a really good one to look for. It has a lot of excellent brochures and information that they have available for their patients.

Another good trick on the internet is to -- if you want to stay up-to-date on what's happening, you can go to Google and set a Google Alert for any word or combination of words that you want, and basically Google will search the internet on a constant basis and every day if you want or every week will

shoot you an email that tells you all of the times that something gets mentioned.

So if you want to know about neurofibromatosis type 1, you type in your neurofibromatosis type 1, and you'll get a blast from Google letting you know that something has come up into the World Wide Web, and you can stay up to date on all the latest things that are happening.

Some people really want to delve deeper, and a good trick for getting to really delve into the science of neurofibromatosis a little bit further is Google Scholar. Google Scholar maintains many scientific papers that otherwise are difficult to access. So if you belong to a university, you can access all of these journals for free. On the internet it's more difficult.

But Google Scholar will tell you which articles are available for free and which ones you can access immediately, and you can download them as PDFs. So it's a good way to stay up to date on the science.

And another sort of interesting and sometimes difficult conversation that we have on a regular basis, but I think a really important tip, is that, you know, kids -- if you have a child with NF, NF1, NF2, schwannomatosis, at some point they are going to look up NF on their own and on the Internet. And just like all adults and all parents of kids with NF have done before them, they will be confronted with the same pictures and sort of biased stories of NF that we all see.

And so it's really important to have an explicit conversation with kids before that happens, just to arm them with the information that the internet is a filter for the worst-case scenario of everything, and that not all the information they read will be accurate, and a lot of the information will be confusing.

I think we've probably all had the experience of going online and reading from something on NF and it really not being clear if we're talking about NF1 or NF2 or both. And that can -- as you can imagine, that would be even more difficult for a kid.

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So the next couple of tips and tricks that I have are really ways to make the most out of your appointment. I should have said this before, but obviously I'm a physician, and I take care of people with neurofibromatosis. This talk is definitely weighted towards the medical aspect of life with NF. That's the viewpoint I'm coming from.

So a lot of what I'm talking about today in addition to symptoms are also about interacting with and navigating through the healthcare system and through doctor's appointments.

So a doctor's appointment can be more useful if you come in prepared and if you know what you want to talk about and you want to know what you -- sort of what things are on your priority list to make sure that your doctor addresses. It's good to have an idea of that ahead of time.

One thing that happens a lot of the time is that something comes up at home -- a new bump, a new symptom, a new movement, something that's different -- and by the time you get into doctor's office, that thing, that symptom, that whatever, has disappeared and you're left just describing your memory of what that looked like to the physician.

So if something comes up, you're not sure what it is, take a picture of it. Put it on your phone. Leave it there until the next time you come to the doctor. Take a video, if there's something that would be helpful from a video, and bring that with you to your appointment. It can make a huge difference for us as clinicians in helping to figure out what's what.

I know not everyone goes to an NF center for their care, but for people who have a main NF doctor, it can be really helpful to directly connect your primary care physician to your NF doctor. Primary care physicians, in general, they want to know more about NF.

They're limited by time. They are limited by the amount of information they have about NF. But your NF provider should be willing and able to talk to your primary care physician, if your primary care physician has any questions. And that can make your healthcare certainly more well rounded if your primary care physician knows your NF doctor and knows a little bit about NF.

It should be kept in mind that most primary care doctors in their entire career will see about 10,000 people. So what that works out to be is for NF1, they'll maybe see their entire career three people, four people with NF1, and maybe nobody with NF2 or schwannomatosis.

So they are operating out of a place where their knowledge of NF is really remnant of some lecture that they got probably 10 years before, 20 years before, and really may not have a whole lot of up-to-date information.

And you can really help out by making that connection as easy as possible, either connecting people by email or providing phone numbers and asking both doctors what the best way to connect the two people are.

So this is one of the very first tips that I ever learned about, which is that as a patient, you are your own best advocate, and you are going to do a great job of educating your healthcare providers about NF.

The reason I got into NF was the very first family I took care of with NF as my own patients were a family with NF2, and the mom of these two kids with NF2 educated me about NF like nobody's business. She wanted me to know everything there was to know and how to navigate the system and how to pick

the right surgeons and how to pick the right time for surgery. And I learned so much from her that has carried through to my care today.

And so it isn't your job as patients to know everything about NF, but you can teach your providers things about NF that they won't read about in any books. So I just want us to remind everyone that that's a really key thing to do. And it there's a really good trickle-down effect. So if you educate one provider, they'll teach somebody else, and more will get out there about NF, and care will improve.

I do want to say if you try to educate your providers about NF and you meet resistance, if they don't seem interested in learning, if they don't want to hear about NF, that may not be a provider that you want to stick with. And, you know, clinicians who take care of people up with NF, take care of any chronic disease of any kind, they really should be willing and able to learn.

Another really important tip is to actually ask your healthcare provider what the best way to reach them is. It isn't always the main number. I can't speak to everyone, obviously, and everyone's office is going to be a little bit different, but like when a patient tries to call me -- I work in a big academic medical center, and phone calls actually get routed to a call center a thousand miles away, which is not an efficient way to directly reach your healthcare provider.

So it's important to ask what the best way is. Sometimes it's phone, sometimes it's email, and sometimes it's through the patient portal. But find out what way your provider wants to be reached, and you're more likely to get answers more quickly that way.

Another little trick, if you are getting a test done, blood work or a scan, these days most doctors work with electronic medical records, and those test results will come back to them through the electronic medical record. But it doesn't always happen right away and they don't always get pinged in such a way that they know that the test has been done.

So if you want to get results quick, your best shot is actually to call, just to sort of remind the doctor that something has been done. And then when they call back, they will have looked at the results, and you'll get the results sooner.

One important thing I've learned from that very first family that I mentioned before is that you should really keep a copy of your own records. And we'll talk more about that in a little bit. It can really make a big difference in your ability to sort of get all the information to the right people when it's needed. So if you get a lab report or a scan report, you should definitely hold on to it.

And I sort of alluded to this before, but these days electronic medical records are being used by most systems. And I will say that the patient portals are really making a huge difference in terms of being able to access

information quickly. So if your provider uses EPIC, you should sign up for MyChart, if they use AllScripts or any of the other electronic medical system medical records. I highly recommend signing up for the patient portals.

Sometimes it's a little bit of a pain in the neck to get it working in the first place, but once you get it working, it just -- it helps so much with getting information, both from you to your doctors and also from the doctors to you.

But I will say one downfall for this is that sometimes people get so used to sending messages to their doctor through these patient portals that they sort of assume that it's like a -- you know, like just a text chat or Facebook or email. But everything you send to your doctor through your patient portal is part of your permanent record.

So, you know, it's not a terrible thing, but I've got a patient who is a math teacher and he knows that my son loves math, and so every now and then he wants to send me a math problem for my son to work on. And when he sends it through the patient portal, that math problem then becomes part of his medical record. Which, again, not the worst thing in the world, but maybe not something you necessarily want to do on a regular basis.

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When you go to your doctor, you usually have questions. And I think many of you probably have experienced that when you get there, you sometimes forget what those questions are. Or you leave the piece of paper at home that had all the questions.

So for those of you who use smartphones, which I suspect maybe most of you, if not all of you, I'm going to have a bunch of apps in this talk. So hopefully many of you are technologically savvy and are interested in using these tools because they really can be very helpful.

But the Note functions in iPhones and other smartphones can be really helpful. A lot of times you can even speak your questions into your phone and create a reminder list or a question list that you can just add to whenever you think of something. And you won't forget to bring your phone to the appointment, so you'll have those questions with you when you go.

So I already talked about how to reach your doctor, signing up for the patient portal, and I just want to show here a picture of the patient portal for EPIC, which is what we use at NYU. And you can ask for prescriptions, you can send messages. And it really is a very direct way to reach your doctor and be able to communicate with them directly.

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So sometimes with NF there's difficulty communicating in the doctor's office. For patients with hearing impairment or with -- who are bilingual,

multilingual, or may not speak English, as well as another language, it is always your right to request for interpreter services.

So for any visit at any major institution, they are going to have access to interpreters, whether that's a live interpreter or a video interpreter or at least a telephone interpreter.

So if you feel like you need help with translation, either through American Sign Language or another language, it really is your right to get that service provided to you at the time of your appointment.

That being said, it's really important to request it ahead of time. So this comes up with our NF2 population a lot. There aren't that many American Sign Language interpreters available at any given time, and so the earlier -- you know, if you know when your appointment is going to be, and when you schedule your appointment, you should tell the schedulers right then that you are going to need an interpreter so they can request it ahead of time. You know, it's probably worth checking in again about a week or so before your appointment to make sure that interpreter is available.

So a lot of places will default to using a telephone interpreter or a video interpreter, and it's much better in terms of quality of communication to have someone live and in-person interpreting. So if you are in need of an interpreter, you may not always get it, but you should always specifically request the live interpreter. You're more likely to get one that way.

For patients with hearing impairment, one of the things that has totally changed my life as a provider, and I know has made a big difference for a bunch of my patients, are transcription application. So apps that you can download onto your phone that will transcribe as you're speaking.

And my favorite, which I was taught about by a patient of mine, is called Ava. There are others that are good. Other people use Live Transcribe and Dragon. There's a bunch of them.

The really nice thing about Ava is that you can connect with somebody else. So I -- so if a patient of mine comes in who has hearing impairment and I want to speak with them, I can talk -- our phones can get connected, and I can talk into my phone, and it will -- the transcription and the typewriting will come up on their screen. And then when they talk into theirs, it comes up on mine.

And so it allows the most natural conversation I've ever had with any transcription program and really has made such a big difference, particularly with the NF2 population. And works on the NF1 patients that have some hearing impairment as well.

And, again, as I mentioned before, educate your providers. So if there's a particular app that you think works best, let them know. And like I said, I

learned about Ava from one of my patients, and I've been using it on an almost daily basis ever since.

I should mention Ava is -- I can't remember exactly how many hours -- I think it might be five hours of transcription a month for free, and then there's a subscription, a paid subscription after that. But I think many people are very happy to pay for the subscription. I don't think it's too expensive. And then five hours of transcription is actually pretty good, and many people may not need more than that.

Another good idea is to save the transcription after your appointment so you can go back and look at your entire conversation. So I actually do that as well as a provider. I will print out that transcription, and I will enter into the patient chart so that I have a record of our entire conversation.

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All right. Moving on to record keeping. So, you know, I think for a lot of people, not just people with NF, but for a lot of people who have medical issues that may be longstanding or chronic or recurrent, it's really important to keep what's called a personal health record, a PHR. A personal health record is your own record of your health, and it's a place to keep all of your own data.

And the reason why this is so important is if you are going to see a new provider, a subspecialist, or if you end up in the emergency room for some reason, if you have a personal health record, it will save so much time and effort in terms of communicating all of the information, which is sometimes quite complicated to your new provider.

There are online personal health records that people can subscribe to, but I actually think a hard copy that you can carry around is better, or maybe doing both of them together. And I know that that is something that people are working on, even people who may be listening to this phone call. But the online services may not be always as good as the hard-copy versions right now.

You should always keep copies of your own scans and reports of your scans. And we'll talk about this more in a minute, but I don't know if you know this, but when you ask for a copy of a scan on a CD, it doesn't always have the radiologist's interpretation.

And it's really helpful for other providers to have both the scan and the report together. So if you can get a printed copy of the report, you should keep that with the CD ROM of the scan so you can give them both together.

One of the most helpful things that I've seen patients do is write out a timeline with dates and locations of major health events. So for patients who have a more complicated history, with several surgeries over time or multiple scans, it's really helpful to be able to sort of write that down,



either just as a list so every time something happens you just add something to the bottom of that list, or as a timeline, or any other thing you want to, to set it up. But it really is a handy reference for yourself as well as for your healthcare providers.

When you come with a hard copy to the doctor's office, the doctor is going to want some of those records. And they can take them from you and then walk down the hall and put them on the copy machine and copy them. But you don't want to spend 10 minutes of your 30-minute appointment having your doctor making copies. So come with copies that you can give away. So you have your own copy that you always keep, but then make Xeroxes so that you can give them to whoever might need them.

And it's also helpful to send copies ahead. If you can mail them in or email them electronically so they're in your electronic medical record before you even get to the appointment, that can be helpful. But I would still say bring paper copies because you never know if it actually gets scanned. It sometimes it takes months for records to actually get scanned in. So you might send it in in January, and it might not be till your next appointment in June that those records are actually visible to your doctor.

And also, to be quite honest, it's much faster to look at paper records than it is to try to pull up scanned records on the computer. So your doctor will appreciate it if there are both electronic copies as well as paper copies.

Then finally I also suggest keeping a doctor directory. People with NF almost always end up seeing several different types of subspecialists, and it can be confusing sometimes. And so it's nice to keep on one page or two pages just the name, telephone number, and contact information for each doctor and what sub specialist they are, just to help keep all that information at your fingertips and organized and to remind yourself who's who, but also to allow whoever you're seeing to have the contact information for whoever else they might want to reach out to to talk about your care.

On the bottom there, I just included a link to a nice blog that describes how to build a personal medical record. So I think that it's worth taking a look at.

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All right. So segueing in to getting scans and imaging done. So, you know, one of the unfortunate realities of living with NF is that most people at some point in their life will have to get an MRI scan or some other kind of medical imaging. And so it's important to be able to hack your way through this in a way that makes the most of it.

It's also important to know which scans are better for what. Your doctor should know that, but sometimes, especially doctors who aren't as familiar with NF, they may make mistakes. And so it might be worthwhile to just have

a little bit of information so that you know what scans might be useful for what things.

So in general, for someone with NF1, NF2, or schwannomatosis, if your doctor is going to be looking for a tumor or something related to your NF, other than bone problems, an MRI is going to be better than a CT.

A CT is sort of like a 3D or fancy x-ray. It uses x-rays, and x-rays are really good at looking at bones. So if someone needs to look at your spine or the bones of your limbs or something like that, or your skull, a CT is going to be better than an MRI. But like I said before, for tumors and soft things, MRI is better.

Sometimes it's hard to even remember or know which scans you've had in the past. And it's good to know that if you are getting a scan in something that's shaped like a doughnut, that's a CT scan. If it's a tube that you slide into, like we see in the picture here, that is an MRI scan, not a CT.

It's also really important, especially for people with NF1, to know that CTE uses x-rays. So one of the things that we've learned about NF over time, particularly NF1, is that people with NF are a little bit more susceptible to radiation than other people. And so it doesn't mean that you can't ever get an x-ray, but it does mean that if there's a choice to either get one or not get one or to get something else instead, it might be worthwhile getting something that doesn't use radiation.

So CT uses radiation, MRI uses no radiation. So if some aspect of your neurofibromatosis needs to be followed with repetitive scans, this applies to NF2 as well, then getting an MRI on a regular basis is quite a bit safer than getting a head CT or some other CT on a regular basis.

So this is an important thing to know. You know, a lot of people don't like getting MRIs because you do have to slide into that tube and you have to lie there and it's noisy and you can't move. And so a lot of companies have tried to get around that by creating technology that makes it a little bit easier. So they've come up with these fancy MRI scans, you'll see them listed as open MRI or standup MRI.

And I have to say it looks like a great idea, right? It looks so much better than being slid into that tube. Unfortunately, it's -- the pictures that you get from these standup and open MRIs are just not good enough for neurofibromatosis. They may be fine for some things, but for NF you really need detailed scans that are good quality, and you just can't get the quality that you need for the -- with that type of scanner.

So I often have patients that are quite disappointed by this particular fact, but it's the reality. And maybe the technology will get better down the road, but for now it just isn't there.

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KIM: Dr. Yohay? Can we interject a question here really quick?

DR. YOHAY: Yeah, of course.

KIM: So we (indiscernible) question, and it says -- they want to know your feelings about the possible effects of accumulation of a contrast in the brain after repeated MRI scans.

DR. YOHAY: Yeah, so that's a relatively new issue. So gadolinium is the dye that we use in MRI scans. It's a little bit different than the dye that's used in CT, and in general is considered to be much more safe long term than the dye used in CT. But what we are finding is that people who may get 20, 30, 50 or more scans in their lifetime, some of that dye, the gadolinium that's used for MRI doesn't get excreted through the body and actually sticks around.

As far as we know so far, there are absolutely no side effects of having a little bit of this contrast that's left over, and there have been no reports of any problems as a result of it. So can certainly understand why it would be a concern. And, you know, I think it's always reasonable to ask your providers, if they're ordering a scan: Do we need to get gadolinium? I'd rather not do it if we don't have to have it.

And the truth is that if you -- if your provider knows a good bit about NF, for certain types of tumors, you don't need gadolinium. So neurofibromas and schwannomas and NF2 light up really well on a particular sequence called STIR, S-T-I-R. So that might be something you can educate your providers about if they don't know about it already and let them know that that might be able to be used instead of getting contrast.

That being said, there are definitely going to be times where contrast is necessary. And usually the risk of contrast I consider to be so extremely low that it's worthwhile getting contrast if it's going to be helpful.

KIM: We have another question here, Dr. Yohay, and they want to know if it's really necessary to image NF1 tumors with contrast.

DR. YOHAY: Yeah, so along the same lines. I don't think that it's always necessary. For a lot of the brain tumors, it's really helpful; but for the peripheral tumors, it's not as helpful.

KIM: Thank you.

DR. YOHAY: So, yeah, that's good questions. So another really great trick is to -- when you're scheduling an MRI, particularly for a child or for an adult that doesn't like to get an MRI, ask if your facility has an MRI with a movie-compatible scanner. So a lot of facilities will have one or -- you know, they may have multiple scanners, but maybe only one or two will allow you to watch movies or listen to headphones while you're in the scanner.

And particularly for kids, this can be a lifesaver. You know, you put on their favorite DVD during an MRI, and suddenly it becomes much easier to lie really still. And it's really important to lie still. So it's like taking a photograph. If you're moving around, the MRI quality is not going to be as good.

So maybe a favorite movie, but maybe one that's not so exciting that they're jumping all over the place. But you can bring your own DVD or your child's favorite DVD so that they are -- so that you know that there'll be something there that they're interested in.

Another trick that some of my families use is using a meditation app, and I'll list one of those later on, or an app that makes ambient sounds. So there are a bunch of apps these days that people use for meditation or to drown out sounds around them, and you can play that through the headphones and drown out all the noisy jackhammer sounds that the MRI machine makes.

If MRIs make you claustrophobic and you need to have one -- I mean, a significant number of people just really can't tolerate being in that small space, or sometimes it's just not comfortable, if you have back pain or limb pain and you're asked to lie still for a long time, that sometimes just isn't possible -- it is fine to ask your doctor ahead of time for medication.

But you have to ask at the time that the MRI gets scheduled. So you can ask for a dose of Valium or a dose of Xanax or Ativan, one of those types of medications in the class of benzodiazepines. Or even Benadryl for some people.

But a key thing to do is to get a couple of extra doses, and if you've never tried one of those medications, make sure you try it some weekend before the MRI, on a day that you don't have a lot planned, not just for fun, but because sometimes people actually react the opposite way to two medications. And you don't want to take a Valium for the very first time you're getting an MRI and it turns out that it makes you really anxious and jittery. So try it out at least once before the day of the scan.

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This is a book that I discovered really recently that I love, and it's a great thing to read to your kids if they are going for MRIs. It's called "The Donut That Roared! A Child's Guide to Surviving an MRI." They have a website, and you can also buy this on Amazon. And it's just a really nice way to introduce MRIs and what to expect for kids that are going to get them.

There are also child life specialists at most big centers. So child life are specialists in working with kids to help them get through studies and medical procedures. So if you are interested in looking into that, just make sure that when the MRI is getting scheduled, that you talk to your doctor about

potentially working with somebody, even before the scan, so that they can talk through what it's like to get an MRI with your child.

A lot of times, especially little kids, they'll need to get medication to lie still for the scan. So they'll need sedating medication with an anesthesiologist. And there are some smaller centers that will do that, but I highly recommend, just for safety's sake, going to a place that sees a lot of kids. So a kids-friendly hospital. So either a pediatric hospital or at least a hospital that has a good pediatric department.

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When you get a scan, I don't know -- a lot of people don't know this, but when you are at the scan on the day of, while you're there, the tech, the person who is actually pressing the buttons and running the computer and getting the images, can right then and there print out all of the images on a CD and give you that CD as you're leaving.

But you have to ask for it. They won't give it to you unless you ask for it. And they pretty much have to give it to you if you do ask for it. So if you are getting a scan, every single time you should ask them to print it out on a disk. You should have it in your hand before you leave the facility. That way you have a copy that you can keep forever, you can pass along to any doctors that might need it. And that can save a lot of time and hassle later on.

But the reality of medical record departments and radiology departments, if you request later on, if you remember that -- if it turns out down the road you need a copy of the scan and you didn't get it the day of, you have to fill out a form, send it to the radiology department.

And I would say only about half the time you may actually send it out, and then the other half of the time they usually send it to the wrong place. So it's better to have a copy in your own hot hands.

KIM: Dr. Yohay, can I -- a couple of questions right here. This one would be a question that I have myself for my daughter. So how long do you recommend that we keep the copies of those scans? At what point do you think we can kind of go through our files and get them out.

DR. YOHAH: So, you know, they take up so little room, my short answer is: Never. I just today was looking at some scans from 2004 to compare to more recent scans. So even really old scans can be helpful.

If they don't work anymore, if they don't load anymore, toss those. But I would keep the rest. You know, I was also going to say that you should get a CD binder like this, and it can hold hundreds of disks in a very compact space and easy to carry with you, easy to store, doesn't take up much room, and keeps them organized so that when you go to the doctor's office, you can find whatever it is that you're looking for.

KIM: I appreciate that, thank you. And now I'd like to read this question for you. It says: My son has a bowed tibia, and the ortho said that the plan is to brace it and do x-rays every six months and make sure that the bone stays bowed at the same degree until he reaches adulthood. Is an x-ray every six months reasonable?

DR. YOHAY: Yeah, so different types of scans and x-rays have different amounts of radiations. And a plane bone x-ray has very low radiation. So in a situation like that, if this wasn't necessary, I would say, you know, skip it. But in a situation like that, that is something that I would absolutely support doing.

KIM: Okay, thank you. Again, I'd like to read this next question: How valuable is it to get a full body MRI early in life to have a baseline and to know where the tumors are lurking, and will insurance ever cover this procedure?

DR. YOHAY: Yeah, that could be a talk all by itself, and that's sort of a work in progress. Right now we don't know the answer to that. We don't know how helpful whole body MRIs are in terms of predicting tumors that are going to be problematic or predicting cancer risk. I suspect that over the next few years, particularly as new drugs are developed for treatment of neurofibromas, where in the past we didn't have any treatments, that whole body scans probably will become standard of care.

I don't know when that will happen, and I don't know what age that will be, but it probably will be in childhood, maybe as soon as kids can do it without sedation. But we're not quite there yet, and it's something that we as a community are trying to figure out. There have not been good studies yet done.

And insurance, insurance has been a lot better about covering them recently. And actually this is a tip that I had, didn't put in the talk, but one that I -- it's probably more for healthcare providers than for patients, but one of the ways I get MRIs -- whole body MRIs covered is you have to do what's called a peer-to-peer.

So if you do a whole body MRI and they don't cover it, you have to talk to the insurance company, to one of their doctors. And I'm happy to get on the phone and talk to them and say: Oh, yeah, that's fine, I don't have to do a whole body MRI, but I would then just like to get permission to do the left hand, the right elbow, the shoulder, the neck, the whole spine, the brain, and then -- oh, yeah, and the right thigh.

And at that point they usually say, oh, yeah, maybe just go ahead and get the whole body MRI, because that turns out to be a lot cheaper than all of the other scans that I would have ordered. So maybe you can educate your providers to do that as well.

Just one more thing about CD ROMs and MRIs. You can use your home computer to burn copies, and it's good to -- again, to leave a copy with a doctor so they can keep it and hold on to it. I have hundreds of these binders in my office, but we also upload our scans up into the medical record.

(Next slide.)

All right. Just moving on to school and education, and just to keep an eye on time on this, I can move a little bit quicker through some of this. But there's a typo here, but so ignore that, but this is one of the things that I talk about with my patients a lot.

You don't ever have to tell a school about a diagnosis of neurofibromatosis. There's no law that you have to tell, disclose the diagnosis. There's no medical emergency that the school needs to be aware of around NF in general, unless your child has seizures or something like that.

So you should really think about whether or not you want your child's teachers and school to be aware of the diagnosis. And the reason why I say that, it's not because there's any stigmas necessarily about NF itself, but teachers and educators will go through a lot of the same process that a new parent who learns NF does, and they'll go online and they'll read about NF. And

They might start to assume a lot of problems that may not be actually present for that particular child.

They may assume that there are going to be learning disabilities. They assume that there's going to be attention deficit disorder or behavioral problems, or whatever they happen to read, and that may color the way that they educate your child, the kind of information they provide to your child. And they may -- it sometimes has a negative effect.

So in general, I advise my families to, you know, really only talk about the diagnosis of NF with their teachers and school if there is some potential benefit. And that main benefit is if your child does need any kind of services, having a medical diagnosis of any kind can help get those services paid for and covered by insurance or be obtained through the school system.

So a lot of kids with NF will at some point benefit from getting educational testing and neuropsychological testing. So educational testing sort of gauges where your kid is in terms of grade level. And then neuropsychological testing is testing that better explains how your child's brain learns best, what the weaknesses and strengths are in terms of their learning style.

The way things are set up in the United States, getting this kind of evaluation, at least getting the majority of it done, is a right that every student has. So you can -- if you write a letter to your school, if they say they aren't going to do testing and can't do testing, you can write them a letter, and they have to do testing.

You have to know your rights, and your school has to provide you with a written copy of your rights if you ask for it. And that can be very helpful in writing your own letter back to them to make the request for testing.

And then, you know, it can be tricky knowing what the testing is going to include and how much to include. But basically it's probably best to get as much included as you possibly can. And so you should always ask for basically getting as much done as they can do.

And once the evaluation is done, it's really important to have a team meeting with the teachers and the testers so that you can talk through the results. And you'll get a lot more information by meeting with them in person.

You can also always request that a full intelligence measure be given. So they won't do this automatically. So an IQ test can be very helpful in understanding sort of where your kid's strengths and weaknesses are, what the potential is for educational services, et cetera. So you should always request that as being part of the core testing.

School evaluations, though, will never provide you with a medical diagnosis. So if you're hoping to get a school evaluation because you're concerned your child might have ADHD, they will never give you a formal diagnosis of ADHD.

(Next slide.)

To do that, you have to go through private testing. And sometimes parents do decide to go through private testing and -- because it often does give a more complete report and can give formal diagnoses which sometimes is helpful. The downside of these is that they're often not covered by insurance. But again, a medical diagnosis, so telling them ahead of time that your child has a diagnosis of NF, it's much more likely to be covered by insurance.

But you should also plan way ahead for these tests because it can often take months to get them scheduled, and then it can take months for the report to be written. So if you need some information for school, you know, if you like want something to happen in grade 3 and your child is in grade 2, you want to get that process started, probably in -- around Christmastime to be able to make sure that you have all the results of that testing back in time to influence how things are set up for the next year.

(Next slide.)

All right. Helping kids take medication. Unfortunately a lot of kids with NF need to take medicine, either for attention deficit disorder or headaches or something else, and it can be a real trick. One of the tricks that I have used a lot with my patients, you know, some liquid medicines, particularly for little kids, tastes really terrible.



If there's a compounding pharmacy in your area -- there usually is, you just have to look it up online or on Yelp and specifically look for a compounding pharmacy -- these are pharmacists that can actually add new flavoring to any medication or even take a liquid and make it into a pill or take a powder and make it into a liquid. They can change the form of many different medications and make it much more palatable.

It's also helpful to hide medications in soft solids, like applesauce. It's better to do it in solids than just to put it in a drink because you don't always get all the medicine in a liquid, but you can be much more sure that everything is getting in using applesauce.

Unfortunately there are some pills that you just can't crush. And most medicines that are extended-release, so like Concerta, which is an ADHD medicine, you can't crush it because then it won't be extended-release anymore, and you'll get all the dose all at once. So if you're crushing medicines, just make sure it's not extended-release medicines.

Another trick I've used with my families is practicing swallowing pills with mini M&Ms. Kids are much more willing to practice over and over and over using mini M&Ms than they are with medicine, obviously, and probably a lot healthier than using many Concerta pills.

And for kids who really have a hard time, who gag a lot, this has been really helpful for a lot of our patients. It's called an Oralflo cup. There are other brands out there, but this is one that I know works. And it's just a cup that's specifically designed to sort of trick kids into swallowing pills. You put the pill in that little tube, and you put a drink in there, and they just drink from it, and it goes right down. It's pretty cheap as well. Amazon.

(Next slide.)

For many adult patients, older patients, teenagers with NF, taking medications is a daily part of living with NF, and also some -- you know, can be hard to remember, especially things like vitamin D where you should be taking that every day, but you may not remember it.

So one idea is to put your medications near something you do every day. If I really want to remember to take a medicine, I actually put a little pill bottle in my bag of coffee beans because I drink coffee every day. Refrigerator is another way to do it.

The hack that I have come up with for my patients is what I call the toothpaste tube trick. All you need for this is your medicine, a travel tube for Advil or Tylenol that you empty out, some electrical tape, and your toothpaste tube.

Everyone remembers to brush their teeth twice a day, right? So if you take this Advil tube, you empty it out, fill it up with your medication, tape it

to your toothpaste. Every time you take your toothpaste tube out to use it, the pills rattle and it'll remind you that you're due to take your medication. It's impossible to forget to take it this way. If you don't take it this way, it's just because you don't want to. Which is okay.

Another trick is to use apps to remember to take your medicine. There are a number of really good ones. These are two that I like. Round Health is a very simple one. Medisafe is a little bit -- has a little bit more functionality, little bit more complicated. So just depends on sort of what you're looking for. But both worth trying out, and both are free.

(Next slide.)

Pill boxes are fantastic for helping you to remember to take your medication. Find ones that lock; otherwise they will open up on you and spill, and then you'll be scrambling around in your bag to try to find your pills.

The bottom one is one that you can actually take each day out. So you can take it with you to work, if you take medicine during the day, or to school. And that's another really nice thing to have convenience-wise.

And then I'm the medical person at the NF camp in Virginia, and one -- and we have all our kids come, and they need to take medications throughout the camp. When you send your kids to camp, pre-fill a pill organizer that locks and then write their name all over it with Sharpie, and it'll make the medical people's lives a lot easier, and it'll make it much more likely that your kid will get the medications they need when they need it.

(Next slide.)

All right. I'm definitely running behind, but we'll keep going. And, Kim, you just tell me when -- if we're going to long and we need to stop, okay?

KIM: Okay, we will, but we still have (indiscernible) line. So let's just keep going as long as you're willing. We appreciate it.

DR. YOHAH: Okay. So the next section is just managing symptoms of NF.

(Next slide.)

For pain, which is a common issue in schwannomatosis, NF1, NF2, consider treatments beyond just taking pills. So acupuncture has actually been shown in a number of studies to be as effective as most pain medications and doesn't have any significant side effects other than your pocketbook. Unfortunately it's not covered by insurance very often. But if it is, it's great.

There's something called biofeedback which can also be very helpful. There are biofeedback centers in most cities. These are places that can teach you how to manage blood pressure, heart rate and, by doing so, allows you to

actually decrease pain and also ADHD symptoms, and there are studies that show its benefits as well. Mindfulness/meditation also can be very helpful with pain.

Do you guys know what TENS units are? TENS units are like -- they look like a little old-fashioned iPod, and they can put out a little electric current through pads that you can put on painful areas, and it just runs a gentle electric current through there. And it can be very helpful for painful nerves and muscles.

And insurance will usually cover that 100% if you get a prescription from your doctor. Even if you don't know if it'll work, you can get one for free and try it out and see if it is helpful.

Heat and ice can be helpful for painful tumors or nerve pain. Physical therapy. I can't recommend physical therapy enough for pain. It really does a great job for many types of pain.

That's a little bit out of order, but I should have put that before. Heat and ice can be great for pain, but you -- especially with plexiform neurofibromas, you do not want to use something that's too hot or too cold. The skin overlying a plexiform neurofibroma is often a little bit thin, a little bit delicate, and you're more likely to give yourself a little bit of a burn, either an ice burn or heat burn. So just be careful.

The picture on the right there, some of you probably know what that is. It's one of the classic hacks that you'll see on the internet, but it's the rice sock. So if you take some uncooked rice and pour it into a sack, tie that sock up with a knot on the end, put a little lavender oil or something like that on the sock, and then put your sock in the microwave for one minute, you have a fantastic heating pad that you can put on your neck or any sore muscles or joints. The heat lasts for a long time and, I think it works better than any heating pad I've ever bought.

(Next slide.)

For pain, a lot of times people are using Tylenol, Motrin, Advil, things like that. And it can be really a lifesaver in many ways, but if you're using it more than three times a week, it can cause what's called rebound pain, which is pain that actually makes things worse over the long term. So try not to -- if you're using medications more than three times a week, you should be talking to your doctor about other types of medicines that might be safer to use that frequently.

This is a pet peeve of mine and an important thing to know. A lot of pain medications, like Excedrin and over-the-counter migraine medicines, they include caffeine, and caffeine is a big culprit in causing rebound pain. So it can work wonders temporarily, but if you're using it more than a couple of times a week, you will make your headaches or other pain worse in the long run. So it's just something to keep in mind.

This is an important one if you have hand or foot pain. There's a small type of benign tumor that almost no one has ever heard of called the glomus tumor, and it can cause excruciating hand or foot pain that's temperature sensitive. And it's something that most doctors, even NF doctors, won't know to look for.

But people with NF1 are much more likely to get these tumors than other people, and they're really quite common. And if you have one, you can see it on an MRI. You can see that little white dot at the tip of this person's finger. That's a little glomus tumor. And you can have a little procedure just in the office to have that taken out, and pain can sometimes just magically disappear after those tumors are removed. So it's a good thing to be aware of and to let doctors know about.

Migraines are common for people with NF. Many people don't realize that a lot of vitamins have been shown to be as effective as migraine medication in preventing headaches. So vitamin B2 and magnesium are both as useful as almost any other of migraine medicine and very safe and very cheap.

(Next slide.)

If you have pain or headaches, it's really important to keep track of the pain, especially when you're starting a new treatment or trying a new medication. You can use a calendar or print out a diary and just keep track of things. It's really important because our brains are really bad at remembering how pain was and -- so this gives a more accurate representation of how things are actually going.

(Next slide.)

And there are also some great apps that you can download that also help keep track of pain. This is two that I like. The one on the left is Migraine Buddy, which is really designed for migraines. The one on the right is Manage My Pain, which can be used for any type of pain and allows you to print out diagrams of how your pain has changed over time that you can either email or print out and take to your doctor for your appointment.

(Next slide.)

We're finding out more and more, and I've been finding from my patients in particular that sleep can be a big issue, particularly for NF1 patients, trouble falling asleep or waking up in the middle of the night. And so the first step in fixing this is something called sleep hygiene, but the number one thing to try to fix is getting off your screens an hour before bedtime.

The light from our screens activates a gland in the brain called the pineal gland. And actually the pineal gland doesn't operate exactly normally in people with NF1. The pineal gland makes melatonin, and people with NF1

actually make less melatonin. So get off the computer screen, get off your phone an hour before bedtime, and especially for kids.

You can help relax using a meditation app, and also good for MRIs, the one I like a lot is called Headspace. It has a lot of free material but also has a subscription service as well. But it has lots of like sleep sounds and sleep-specific meditation. It can be really helpful. My 13-year-old daughter uses it every single night, and she loves it.

And melatonin can really be a lifesaver for some people, both adults and kids with NF. It can be used in low doses. It's very safe. It's not addictive. And it can replace some of the melatonin that is not there in many people with NF1. It's also really helpful for kids who are on stimulant medications for ADHD for sleep.

It works best if you take it about an hour or two before bedtime. If you take it right when you want to go to sleep, it probably isn't going to work as well for you as taking it beforehand.

(Next slide.)

All right. Hypotonia. So almost all kids with NF1 have relatively low muscle tone. Muscle tone is sort of how stretchy your muscles. And kids with low tone can have several -- you know, can impact several things. One is core strength can be weakened with it. Posture can be affected. So a lot of young kids with NF in particular sort of keep their belly out and their back swayed, and they sit with the -- in a W position or have a little bit of trouble getting up from a sitting position.

And building core strength is the best way to help correct that, to correct posture, to correct motor coordination, and to correct the low tone. The number one activity, if you can get your kids to swim a lot, swimming is great strength training for your core. Horseback riding also. Karate is very good.

(Next slide.)

So swimming, horseback riding, karate, yoga. And then playground activity. So a really good one is actually doing crab walking. So getting on -- having a child race by doing the crab walk, as you see in this picture, it's a really good core strengthening exercise. So these are good ways to get your kids to work on their core strength.

(Next slide.)

Hypotonia, or low tone, can also result in a lot of foot issues. So flat feet and ankles that turn out. So many kids in our clinic complain of achy legs or they fatigue easily or their feet hurt at the end of the day. And it's largely because the feet are just too flat. And when the feet are flat,

they have less spring, and it really affects overall energy a tremendous amount.

If your child has flat feet or if you have flat feet that has -- that's not too bad, you can go to a sporting goods store. If you go to the drugstore and you get Dr. Scholl's, those probably aren't going to be good enough. You have to spend probably in the \$20 to \$40 range at a sporting goods store and get a good pair of running insoles with arch support. And they can make a huge difference in energy level, decreased pain, and speed of walking.

And you can also go to a physical therapist or a podiatrist who can actually do molded inserts. Those can be really expensive. So you should look to see if your insurance will cover it before going down that path.

There's also for kids who have sort of slouchy posture because of their NF, there are some new smart tools out there. This one's called Lumo Lift. This is actually something, it's a magnet that you wear on your shirt, and every time you slouch forward, it buzzes and reminds you to sit up straight. And there are studies that show that for people with hypotonia and bad posture, these can be really helpful in improving posture long term.

And they work better than other things. Sometimes you'll see posture shirts or other things that are designed to hold shoulders back and posture up, and it probably doesn't work as well as these smart devices. These smart devices are a little expensive. The Luma Lift is about \$140 right now.

(Next slide.)

Itching is really common in NF. We don't exactly know why, but we think it may have to do with invisible little neurofibromas that may be growing on tiny little nerve fibers. Kids in particular can benefit by having lots of moisturizer applied. So fragrance free, good quality moisturizer at least twice a day, especially in the wintertime.

If that doesn't work, especially if your kid is itching particularly at bedtime, just using one dose of Tylenol or Motrin may be enough to help them get to sleep. You can get a herbal medicine called quercetin, which is available in most health food stores, that I've had a number of patients tell me about and have had really good luck with in terms of decreasing the itching of their neurofibromas or of their skin. Very safe. Not very expensive.

And for people with really severe itching, you should tell your doctors about it. A lot of people -- a lot of times people don't even mention it to their doctors because they don't even realize it's related to their NF. But because we think it's because of irritation of nerve endings, it actually responds really well to a to a nerve medication called gabapentin. So for some people who have really bad itching, we'll use gabapentin as a treatment.

(Next slide.)

For people with NF2, balance is often an issue as the vestibular schwannomas grow. Physical therapy can be very helpful for balance, but you should look for physical therapists that specialize in something called vestibular rehab. Most rehab centers will have programs these days, but sometimes you need to request specifically to be put into those programs, and they can really help with balance and gait.

(Next slide.)

Another issue that comes up with NF2 and balance is that sometimes with NF2 it's really hard to do what's called the tandem walk, which is putting one foot right in front of the other and walking. It's also known as a drunk driving test. And we've had patients that were, you know, stopped for speeding and they're asked to do the drunk driving test, and they fail, not because they're drunk, but because they have NF2.

And so for our patients, we provide them a letter, similar to the one I have up here, that they can keep in the glove box with them all the time so that if they do get pulled over, it can explain to that police officer why you are failing the drunk driving test even though you're not drunk.

This may seem unlikely, but when it happens, it's a lifesaver. Or at least a big -- it can eliminate a lot of hassle.

(Next slide.)

So for hearing impairment, one thing that a lot of people haven't heard about is something called cued speech. Most people know about sign language. Sign language is great and a really important thing for the deaf community, but it's hard to learn. And if you learn it but you don't have anyone to use sign language with, it doesn't help you too much.

Cued speech is a much faster to learn process. It actually helps lip-reading. It's actually hand signals near a person's mouth that help a lip reader read lips more accurately. And you can do weekend workshops that are put out by this group called the National Cued Speech Association.

Their website lists all the workshops around the country and also teachers that you can hook up with in your area. And you can have a whole group go and learn over the course of the weekend about cued speech so that for the person with NF2 who's having difficulty hearing, if their entire family goes with them, then everyone can use cued speech together, and it can be a really big help.

SoundCheck is another interesting app to use. It's not the greatest, but it's helpful to follow hearing. So if you get this app, it'll actually record what your hearing levels are in both ears, and you can follow that over time so you can get a sense of whether or not things are getting worse.

And NF2 patients should ask for a dose pack -- it's called a Medrol dose pack, which is a box of steroids to keep at home in case you have sudden hearing loss or sudden balance issues. It can be corrected really quickly sometimes with just taking a few days' worth of steroids which can reverse some of the sudden hearing loss. So definitely worth talking to your doctor about.

(Next slide.)

A lot of people are going to take supplements of one kind or another. We get asked questions about this all the time, and I'm fully supportive, but you do have to tell your doctor because they do interact with other medications.

And you need to educate yourself about them and choose wisely. It's really hard to educate yourself about supplements because they're not regulated the same way medications are and so the quality varies. When you go to the health food store, you don't really know which ones are good quality, and some of them are actually rice powder. A study came out -- many studies have come out that showed that a lot of medications aren't what they purport to be.

So this website I have here is called [consumerlab.com](http://consumerlab.com). It's a fantastic website that actually analyzes supplements and tells you which ones are of good quality, which ones are not, and it ranks them and keeps updating all the time. The only downside is that it is a subscription service. You have to pay to use ConsumerLab. It's not very much, but I don't remember off the top of my head how much it is.

Labdoor is a free service that also analyzes supplements. They're not as good at keeping up, and they don't have as many supplements that are evaluated. But if you don't want to spend any money, this one is a good option also.

Let's see. A lot of people today take turmeric. Turmeric has been talked about for prevention of tumor growth, skin tumors, other things. If you are going to take turmeric, just make sure that you take a brand that contains piperine or you can eat it with -- take it with a high-fat meal, and that increases availability in your body. If you don't take one of these forms, it's just a waste of money because the levels that you get inside your body are not high enough to be useful.

If you take fish oil, you have to store it in the refrigerator. Fish oil actually goes bad if it's left on the counter and actually doing the exact opposite of what you want it to do. So always store it in the fridge. Probiotics also you need to store in the fridge. Even ones that say you don't need to, you probably should. In general with supplements, if you're going to take supplements, take them with meals. They tend to work better with food.

(Next slide.)



All right, I think this is the last slide. For cutaneous neurofibromas and cafe au lait spots, one thing that I remind my patients on a regular basis, if there are neurofibromas that you want to have removed for one reason or another, it's really important that you let your doctors know that those neurofibromas are painful.

Painful neurofibromas are much more likely to be covered by insurance in terms of having them removed rather than ones that are being removed for, quote/unquote, just cosmetic reasons. We all know that it's more than just cosmetic when you have many neurofibromas on your skin.

But insurance companies don't necessarily do it that way. But painful neurofibromas, they will often pay for their removal. So just keep that in mind as you describe your neurofibromas and as your doctors place the orders for referrals to surgeons for having them removed.

Once you have a diagnosis of NF1, the number of cafe au lait spots you have doesn't matter anymore in terms of severity. So a lot of times people get concerned that more spots are coming up might mean that the disease is getting more severe, but that's not the case.

There aren't any proven ways to prevent neurofibromas yet, but there are a few things that they're -- you know, there's some data that might be helpful. So one is avoiding high-dose progesterone. So like Norplant or other progesterone-only birth control can actually cause skin neurofibromas to grow.

Regular use of vitamin D may decrease the number of cutaneous neurofibromas. There are a couple papers that suggested that. It's not totally clear if that's true. But vitamin D is good for bone health. And people with NF have low vitamin D levels in general, so worth taking for almost everybody with NF1.

There are couple of things. So turmeric might slow the growth or even shrink some skin tumors. So that's part of why I think it's so commonly used in the NF population. And then there's a medicine called Ketotifen which has been talked about for a long time. Vic Riccardi, who was one of the original NF doctors out in California, has been talking about using Ketotifen for a long time to prevent tumors. And there's some data that suggests that it might be helpful in some people.

It's not available in the U.S., but you can get it delivered to the U.S. through online pharmacies in Canada, and there are some compounding pharmacies here in the U.S. that will have it available as well. But it can take a little while to get it, but once you get it going, pharmacies are usually happy to get it in.

(Next slide.)

So I've gone way over, and I hope that's okay. But, you know, like I said at the very beginning, you know, I'm a physician. I take care of people with NF. And I've met thousands of people with NF, and I've learned a lot about NF, but I don't have NF. So there's a lot that I don't know, and there are a lot of things that we could all learn from each other in terms of ways to live your very best life with NF.

So if you have tips or tricks or hacks that you want to share, you know, if we have time for questions now, feel free. And then also you can go to -- I have a blog site that I haven't really updated very much, but maybe this will help spur me to do that. But go to thenfdoc.com, and you can leave comments and suggestions about your own life hacks that you've come up with during your life.

All right. Thank you very much, and I hope that some of this was helpful for some of you.

KIM: Dr. Yohay, that was amazing. Deb and I are sitting in the office here. We have two pages of notes. We've been doing this for many, many years, and we learned so much tonight.

There are some questions that are still on here, but I think that we can address most of them through the office. They're NF related. There is one gentleman on here, Sam, who's asked a few questions, and so I would like to just give just one last question and answer one of his in particular.

He says he's 50 years old. He's had several tumors removed, sound like skin types of tumors. He's got cafe au lait spots. At 50 years old, he does not have the diagnosis of NF, but he himself is suspicious of that, and he's wondering if at his age he should see an NF specialist.

DR. YOHAY: A hundred percent the answer is yes. The -- even adults with NF, even with mild NF, there are certain things that we have to keep an eye out for that your primary care physician might not be aware of. So blood pressure issues that can be caused by a growth on the adrenal gland, that's something that regular doctors might not be looking out for.

Women with NF in adulthood we screen for breast cancer starting at an earlier age and using different tests than we do for women without NF. So it's important to be aware of that, and not all primary care physicians would be aware of that.

Having access to all the latest updated information about new treatments. There are at least two or three medications that are in the works, in the pipeline now for treating cutaneous neurofibromas that hopefully within the next couple of years may potentially have some benefit.

So, you know, by being connected to an NF clinic or an NF provider, you'll find out about things that might come along that will be of great help. So absolutely I think that it's worthwhile.

KIM: And I know I said one, Dr. Yohay, but I would like to do a stretch, one more. Let's do two.

DR. YOHAY: Okay.

KIM: He just wants to know the name again of the medicine from Canada that you mentioned.

DR. YOHAY: Oh, Ketotifen.

(Previous slide.)

K-e-t-o-t-i-f-e-n.

(Next slide.)

KIM: Okay, thank you. And then we will wrap it up. I'd like to just read one from Mary Ann for you. She says: Thank you for letting us know about the right to get a copy of your MRI scan before leaving the imaging facility.

Tons of thanks to you tonight, Dr. Yohay. This has just been an amazing webinar with lots of information that we've learned. I know I want to go back through this presentation again and get more information. So you will get copies of it emailed to you, and it will also be posted on our website. It just takes us a day or two to get that up and back out to you. And then you'll receive it. Well, thanks again, Dr. Yohay, for spending the evening with us.

DR. YOHAY: My pleasure. Thanks very much. Thanks, everybody.

KIM: Bye-bye.

DR. YOHAY: Goodnight.