1/4/22 WEBVTT Genetic Services in Appalachia Session 4 Transcript

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00:09:07.350 --> 00:09:08.760
Kimberly Kelly: Alright, so I’ll ask

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Kimberly Kelly: Anusha or Trupti if they see other people that needs to be admitted if they can go ahead and admit them and I will begin the session if you're ready Alissa.

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00:09:27.990 --> 00:09:29.910
Kimberly Kelly: Okay, so

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Kimberly Kelly: welcome to the fourth session of the webinar series on Genetic Services in Appalachia.

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Kimberly Kelly: We ask that you mute your microphones for the talk and place any comments or questions in the chat.

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Kimberly Kelly: We ask that you not record our session we will be recording this session and providing a transcript on our webinar website and we had a little bit of delay, due to the holiday and some illness,

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Kimberly Kelly: for our third session, but those should be posted by the end of the week, if not in the next day or so.

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Kimberly Kelly: At the end of the session today we’ll ask you to complete an assessment to give us feedback and we sent around for those people that are registered we sent around information on an evaluation for our last session so we ask that you please provide that if you’re able.

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Kimberly Kelly: And, as you know, for this survey this Genetic Services in Appalachia seminar series, our aims include to develop a research agenda for

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Kimberly Kelly: genetic services in rural Appalachia.

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00:10:51.510 --> 00:10:52.290 Kimberly Kelly: Each month

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Kimberly Kelly: we will be having speakers who are working in genetic service provision in medically underserved populations, most of them being in the Appalachian region.

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Kimberly Kelly: And our our ultimate goal is to develop a research focus and to improve the quality of care in genetic services in Appalachia and also you know, to the extent that we can in West Virginia.

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Kimberly Kelly: So we've had three sessions, so far, and those are available on our website, but now I would like to introduce Ms. Alissa Bovee Terry.

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Kimberly Kelly: Ms. Terry is a genetic counselor in New York state and has been working with a federally funded now NYMAC New York Mid Atlantic Caribbean Regional Genetics Network

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Kimberly Kelly: for the past six years. And she will talk to you more about what that is and what exciting opportunities they have for us.

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Kimberly Kelly: Currently, Ms. Terry serves as a project director in telegenetics navigator for NYMAC. Ms. Terry received her BA in biology from Cornell University.

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Kimberly Kelly: and her Masters of Science in genetic counseling from Johns Hopkins University. Ms. Terry has worked in various capacities for the genetic counseling program at the Fair Institute since 2006.

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Kimberly Kelly: So at this time Alissa, if you would like to share your screen, we would be thrilled to learn more about your

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00:12:35.520 --> 00:12:44.220
Kimberly Kelly: NYMAC and the work that you're doing, especially in telegenetics and genetic service delivery to to underserved populations, thank you.

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Alissa Terry: Alright, well, thank you so much for that introduction, I look forward to being with all of you today and sharing some information about our organization.

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Alissa Terry: I do not have any conflicts of interest as Kim just said, I do work under a federal grant from HRSA.

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Alissa Terry: So as you saw, NYMAC stands for New York, Mid Atlantic Caribbean and our region includes 10 states and jurisdictions which I'll discuss further. NYMAC is one of seven federally funded regional genetics networks and we all aim to ensure that individuals, especially from underserved communities, with genetic conditions, as well as their families have access to quality care. You can see the map and the website here. The regions are further supported by the National Coordinating Center at the American College of Medical Genetics and by the Family Center hosted at Genetic Alliance. The system of RGNs collaborates broadly with genetics groups, training programs, and importantly also family and support organizations.

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Alissa Terry: So in a nutshell, what NYMAC does with our grant funding, is to try to improve the genetics delivery system by collaborating with all types of diverse stakeholders to make telemedicine projects, to make it easier for families to get the care they need without travel. And we do education about genetics for both families and professionals and again, all with the aim to achieve access to quality genetic services for people with genetic conditions and their families.

Alissa Terry: And today, we are going to focus on our work around telemedicine and telegenetics. So as I mentioned, the NYMAC region includes 10 jurisdictions, which vary a fair amount in size and makeup. As you can see here, we do have a very long history of working with West Virginia University. So we thank them for their ongoing collaboration. And as we'll see in the next slide, there's a lot of overlap between the NYMAC region and the Appalachian region.

Alissa Terry: So five of the 10 NYMAC states have portions of the state that are considered parts of Appalachia. The other states and Appalachian region are included in some of the other regional genetics networks. So if you're here listening today, and you're not in an NYMAC state, I encourage you to locate your regional genetics network and learn about their similar programs.

Alissa Terry: As we probably all know, one of the biggest challenges in that Appalachian region is the lack of medical providers. You can see here how much of the region is considered to have a shortage of healthcare providers. This is certainly true for the shortages of genetics providers across the region as well.

Alissa Terry: Similarly, if we're all likely pretty familiar with the challenges across the region with poverty, again, you can see the tracking of poverty levels with some of the largest areas of poverty in the Appalachian region. Clearly, these communities will have a more challenging time obtaining adequate health care.

Alissa Terry: The pattern of genetics clinics across the region is pretty stark, with clinics densely located in urban centers near New York City, Philadelphia, Pittsburgh, DC, Baltimore, and Richmond. Well, there certainly are genetics clinics and other parts of the region, many families do have to travel pretty substantial distances to reach them.

Alissa Terry: So the challenges that many families in our region face and getting to a genetics clinic was a big motivation for us to start exploring and supporting telegenetic services about five years ago. The visuals you see here were developed by families in our region to explain telegenetics to other families, you can find the infographic at the link on the slide.

Alissa Terry: When I'm talking about telegenetics, most people think about live video meetings. And that often happens, but sometimes telegenetics happens over the phone. Sometimes records and documents are sent to a provider without a live meeting. And we call that store and forward. And sometimes a doctor will keep track of a person signs and symptoms and send that information electronically for evaluation. And that's called remote patient monitoring. And finally, when communication happens on mobile devices by texting or apps or video messages that's called Mobile Health.

Alissa Terry: With the overall goal being to expand access, we see from studies that telegenetics can improve patient access and reduce cost and wait time and travel. Even before COVID, we were able to see that there were a lot of telegenetics programs in the NYMAC region and a lot of interest in genetics providers. Clearly telegenetics was very important to maintaining care during COVID.

Alissa Terry: But if we're going to think about any kind of telehealth, we also have to look at what resources families have available to them. Telehealth can be a challenge when broadband or cell phone coverage is not good as we see across the region in certain areas. This is really important to keep in mind when you're trying to use telehealth to reach families that already have challenges in accessing care and services.

Alissa Terry: So in 2016, we saw that every NYMAC area had telegenetics at that time. Telephone calls were often excluded at the time from the definition of telemedicine, most of the telegenetics at that time was done by live videos and occurred in a variety of settings.

Alissa Terry: Sometimes it was from one clinic to another clinic so maybe a primary care provider’s office to the genetics office. Sometimes it was from the clinic to the patient at home, which we're seeing more frequently now. Some of this is provided by telegenetics companies. Some of this is provided by the laboratories that offer the genetic testing. And sometimes it happens as I mentioned by providers communicating with each other instead of a patient and a provider working together. And NYMAC has really played a role in supporting some of these clinics and our models of care and we aim to engage with all of them.

Alissa Terry: In the summer of 2020, we explored patterns of telegenetics use across the region and not surprisingly saw there was a big shift from mostly doing in person visit visits to mostly doing phone and video visits during the COVID pandemic. At that time, most providers, about 60% said that they did plan to continue using telegenetics, even post-pandemic.

Alissa Terry: There are always barriers to new models of care. It's interesting to look at what got in the way of providers using telegenetics before COVID as compared to after. We can see in particular that there was a big shift in lack of provider interest, patient interest and time and institutional support being big barriers before COVID,but not barriers after COVID as we all shifted to using telemedicine.

Alissa Terry: NYMAC has aimed to support the providers that wish to use telegenetics in a number of ways. We offer technical assistance, we offer education and training about telegenetics, and we also offer collaborative funding.

Alissa Terry: On the whole, we've seen big successes with our work, we've been able to impact a lot of providers and families with a total of about 20,000 families having been seen by telegenetics in NYMAC supported clinics since 2018.

Alissa Terry: We have provided one on one direct assistance to over 150 providers. We work closely with our partners at the federally funded telehealth Resource Centers, which I'll provide some more detail on later.

Alissa Terry: We also have a telegenetics community of practice. These are providers that we started to identify in 2016, who had a special interest in telegenetics. We try to offer special education opportunities as well as collaboration for these providers and bring them together at our annual virtual meetings each year.

Alissa Terry: We have trained over 80 genetics providers and students in collaboration with partners in the western states network. This training is now fully online and offers free CEUs and CME.

Alissa Terry: And here's some more detail about that training opportunity. If anyone is interested, it was all updated in 2021 and includes 10 modules and a four hour live Zoom meeting. You can email me directly with any questions about that provider training.

Alissa Terry: So in addition to that training, NYMAC offers other educational opportunities related to telegenetics at in person meetings such as NSGC and ACMG. We do a lot of webinars and virtual meetings just like this one, including the annual NYMAC meeting. We post resources about telegenetics on our website, Facebook, YouTube and other locations. So I encourage you to check those out as well.

Alissa Terry: Here are a few examples and links to some of the telegenetics education events that we've done. We do have extensive resources on our website. As you can see on the left, we have some recorded events that are still available. And we also cover telegenetics and all of our annual meetings are meeting last year is fully recorded and available, and this year our meeting will be April 5 and 6th.

Alissa Terry: NYMAC also has a toolkit to support planning a telegenetics program. The online toolkit includes a guide, resources on the website, a factsheet about technology, a progress survey and a introductory webinar.

Alissa Terry: The toolkit is derived from the work that the Heartlands Regional Genetics Network did as well as the California Telehealth Resource Center. We've really boiled it down to seven steps that gives extensive examples and templates for people who are planning. We used a lot of input from our partners at the Telehealth Resource Center and we provide a checklist to help people track their progress.

Alissa Terry: The plan outlines three phases which consists of seven different tasks.The first phase it's really focused on assessing and defining. So you're assessing service needs and environment defining the program model and developing your business case. In the second phase, you're more in development, you're planning your program and your technology. And you're also developing performance monitoring, evaluation and quality improvement metrics. And then finally, the third phase, you're really implementing and monitoring your work. So we spend some time implementing the program and then continually monitoring and improving.

Alissa Terry: We also have a planning checklist to benchmark progress, it's based on the steps in the planning guide. At the beginning, you get basically a baseline score, and then you can track and quantitate progress throughout your planning process. Here are some examples of the progress we saw in clinics pre-COVID, you can see that the trainees that received funding from us made a ton of progress in their program planning.

Alissa Terry: I'm not going to go through each step of the Planning Guide today, you can see notes on each step, the ends of these slides, but I was asked to spend just a bit more time talking about the financial models for telegenetics.

Alissa Terry: So when thinking about the financial models, you really want to include your financial risks and constraints both at the patient site and at the site of the specialist, the genetic specialist. You want to describe the market and the demand for the service and how much uptake you expect. So if the patients really want this, is something that they're interested in and very likely to utilize if it's offered to them. You want to be able to describe all your funding sources. So obviously patient insurance billing options, but also opportunities you have for grants, for direct billing to patients, and through contracts. You want to be able to outline your cost estimates. So there may be some startup technology costs, new operating costs if new staff has to come in.

Alissa Terry: Also any new facilities marketing that you might have to do. But it's also important to note your expected cost reductions. So especially for a program that is going to start using genetics that maybe wasn't doing it before, we see oftentimes, the implementation of this type of genetics program results in better utilization management. With ordering of genetics tests being more appropriate and efficient, and a reduction of errors.

Alissa Terry: You will also want to outline your revenue expectations, what you imagine the program is going to bring in, both in terms of billing for the actual services as well as the downstream revenue to the facility that can result in identifying patients with genetic conditions that need further care after their diagnosis. You want to be careful to project beyond what's going to happen right away and really think about growth in your financial model. And finally, sometimes calculate a return on investment.

Alissa Terry: With all that in hand, it's useful to develop a business report or summary that you can share with your stakeholders. And then to really invite feedback from those people. Some of the resources that we provide in our toolkit related to this are an insurance reimbursement factsheet information about how to calculate a return on an investment, as well as a federal grant Factsheet and a budget template.

Alissa Terry: Some examples of the payment models for telegenetics. This is definitely not an exhaustive list. But obviously many programs do bill insurance for their telegenetic services. This can be done oftentimes by using the professional codes and just using a telemedicine modifier after the code. So there are some CPT codes that can be used, such as 96040 with genetic counselors. This type of billing is often pretty straightforward for physicians and often for PAs and nurse practitioners as well. I will note that genetic counselor billing for telegenetics is often based on how the institution bills for similar in person services, if they offer both.

Alissa Terry: Because genetic counselors are not recognized by Medicare, that means that some institutions do not bill any insurance companies for genetic counseling, even though some private payers would pay those quotes. This typically impacts the way the institution is willing to bill for telegenetics also, and sometimes prompts a review and change of all genetic counseling billing strategies.

Alissa Terry: Facility fee and incident-to billing which are often used for in person care are typically not applicable to telemedicine although sometimes a distance site facility fee is allowed. Some payers will pay an originating site fee. So if a patient comes into a clinic to connect to the genetics provider in a different location, sometimes there's a fee that can be paid to their primary care clinic or Wherever it is they're coming in.

Alissa Terry: And lastly, providers may sometimes assign their billing rights to another site and allow them to do the billing. So there's an occasional situation where your genetic specialist could hand over the billing rights to the primary care office. And that's who would do the billing to the insurance. That's a bit more complicated system, but we do see it used sometimes.

Alissa Terry: So other than insurance reimbursement, another model we see is contract models. This is where the specialist is paid by contract from another group. So this might be an oncology group an MFM group, a cardiovascular group, who pays a genetics group, a genetic counselor, geneticists, in lieu of having them having to employ their own full time staff member as a genetics provider. The group benefits from having better patient outcomes, and gaining eligibility for credential center status. So sometimes Oncology Settings, for example, wants to be credentialed by some of the broader oncology credentialing services and have to have some sort of genetic service available to meet those guidelines.

Alissa Terry: It also helps keep patients local. And as I mentioned before, having genetics involved in some of these specialties really does reduce errors and increase downstream revenue.

Alissa Terry: Sometimes in these contract models, insurance is billed and sometimes that is related to what I mentioned before with assigning the billing rates.

Alissa Terry: And some genetics providers do freelance work under these types of models. And there are a number of telegenetics companies that work under this type of model where the genetics provider is not affiliated with a hospital or institution but does contract work related to other centers that need some level of genetic services but not a full-time employee.

Alissa Terry: In the world of grants, there is a lot of grant funding available right now for telehealth, many telegenetics programs do get started using grant fundings. But we always encourage people to try to plan for sustainability and not be relying on those grants long term.

Alissa Terry: And lastly, patient pay. So sometimes genetics programs really rely mostly on direct billing to the patients. Outside of insurance billing, we do see that happening. It's not the most preferable model certainly is especially in underserved communities, but it is one of the kind of core options that we see telegenetic services using.

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Alissa Terry: So a few final notes about planning,

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Alissa Terry: planning a program can be pretty complex and lengthy or if a pandemic happens, it can happen very fast.

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Alissa Terry: Our planning guide hopes to provide structure, support resources, and a checklist to our genetics providers, we are available to support providers through the process and we encourage our regional partners to contact us for more information.

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Alissa Terry: So lastly, we're happy to be able to provide funding to some groups for telling genetics we're now up to 11 groups, so we have awarded telegenetics funding to.

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Alissa Terry: And we do see big increases in their planning scores and many patients seen by those programs.We have funded or have plans to fund programs in every single one of our jurisdictions and try to make sure that those programs are specifically reaching underserved communities.

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Alissa Terry: And we're lucky to receive great feedback from some other groups, we have worked with.

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Alissa Terry: You can see some of the lovely things that people have shared with us about NYMAC’s support, especially during the transition to tell telemedicine during 2020, so we're really happy to know

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Alissa Terry: that the support that we had provided to our genetics providers and clinics really helped them make that transition more quickly than they maybe would have been able to do, had they not been engaged with us.

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Alissa Terry: So, as I mentioned NYMAC is part of a nationwide system of regional genetics networks and all of those networks provide support for telegenetics.

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Alissa Terry: Here you can see the work that's been done nationally over the past three years.

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Alissa Terry: With regard to telehealth training at the top, education in the middle, and technical assistance on the bottom, so this was happening, not just in our region of NYMAC but across the country with all the regional genetics networks doing this type of support.

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Alissa Terry: And as you can see here, there has clearly been a huge jump in patient's seen by telegenetics in the supported sites across the nation. We're glad to see that a lot of those families are indeed coming from medically underserved areas.

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Alissa Terry: So I also want to make mention of some of the other work that NYMAC does that touches on telehealth in some way.

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Alissa Terry: We are in the process of establishing teams in each of our 10 jurisdictions, these are made up of diverse stakeholders, and we have a great team in West Virginia that some of the people on the call today are in, I think I saw somebody from our Maryland team on today as well.

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Alissa Terry: I thank you guys, for being here. So these are teams that are set up eventually in each jurisdiction to help us understand the key barriers and solutions to improving access to genetics in the state.

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Alissa Terry: So each NYMAC team defines their own local challenges and potential solutions, thus far, our work on the team's has produced an infographic and social media campaign in New York,

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Alissa Terry: and educational program for existing staff that work with families in Virginia, and a family video testimonial project in DC. Some of the NYMAC teams may choose to focus on telegenetics if they deem that to be the most relevant issue to their state at the time.

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Alissa Terry: That work also includes the territories of Puerto Rico and the Virgin Islands. As of 2020 we're working on very similar goals there.

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Alissa Terry: And due to staffing shortages and obvious challenges to traveling for care, a key goal in the territories is also to design a culturally effective model for telegenetics.

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Alissa Terry: So we have been aware that we need to design things pretty differently there than how telegenetics works here, but we're hopeful and we're working closely with some amazing people there to see what we can do to improve access to care and territories.

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Alissa Terry: This is our NYMAC flyer which outlines all the programs that I have talked with you about today, the link is on the side of the slide there you can find it easily on our website as well.

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Alissa Terry: And I just wanted to share a few other notes about really useful resources.

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Alissa Terry: So, as I stated the other regional genetics networks have great resources for telegenetics as well.

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Alissa Terry: The southeast region has a telegenetics work group, the Midwest has some great patient telegenetics videos,

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Alissa Terry: Western states has a huge collection of videos, online resources, and the training program.

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Alissa Terry: The family center has that infographic that I shared earlier, and our national group has a full resource repository that includes these telegenetics products. These are all freely available and I encourage you to explore them.

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Alissa Terry: NSGC and ACMG also have a lot of support and resources for telegenetics both organizations are currently working on publishing recommendations for telegenetics.

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Alissa Terry: They include telegenetics in their education planning and supply a lot of resources, so I encourage you to check there as well.

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Alissa Terry: Some clinics have incorporated other technology beyond telegenetics, including things like chat bots to answer questions, online family history collection tools,

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Alissa Terry: various databases and risk calculators, and even using artificial intelligence and some settings like facial recognition, to predict potential diagnoses so sometimes these

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Alissa Terry: health IT applications are integrated into the telehealth program. Sometimes there's sort of a side project that goes along with both the in-person and the telehealth, but it's been really interesting to see the evolution of these other technology applications in genetics.

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Alissa Terry: It's also key to point out that the family engagement is vital to planning and implementing telegenetics. NYMAC and the other regional networks all emphasize family engagement and were greatly supported by the family support Center.

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Alissa Terry: We have definitely seen that the more the new strategy is informed and tailored by the community, the higher the likelihood of success is. And that's very true for us in our work in the territory as we've noted and doing a lot of work in West Virginia, right now too.

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Alissa Terry: So lastly I'll share some other really good resources for telehealth in general that are not built specifically for genetics, but can still be very instrumental.

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Alissa Terry: So the telehealth resource centers, as I said, are also federal grant funded organizations, they provide assistance, education and information for anyone interested in providing care at a distance.

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Alissa Terry: The Mid-Atlantic telehealth resource center covers Virginia and most of the NYMAC states, but there are different telehealth resource centers that would cover some of the other Appalachian states.

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Alissa Terry: They do offer a number of fact sheets, online resources, office hours, annual meetings, and online forums. And I have the link there that you can either find MATRC if that's your home, telehealth resource center or using their map, you can find yours.

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Alissa Terry: The Center for Connected Health Policy serves as an independent center of excellence for policy, they provide technical assistance to all the other telehealth resource center. So they sort of

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Alissa Terry: keep track of and organize all the state laws and local policies that influence what can and can't be done by telehealth and we're going to take a look at that, on the coming slides because it's ever evolving, as you might imagine.

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Alissa Terry: TTAC is also a federally funded and they kind of keep track of and assess new telehealth technologies so they often review things like if a new

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Alissa Terry: electronic stethoscope that can be used over telehealth comes out they might check it out and do sort of a short video on how it works.

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Alissa Terry: So you can go on there and sort of look at their reviews, their innovation watches, and they provide assistance to organizations that are trying to make purchases or selections in making choices between telehealth products.

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Alissa Terry: So, again telehealth policy can be really important and telehealth resource centers as well as the American Telemedicine Association do a great job of keeping track of those policies.

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Alissa Terry: So just some of the things that can influence the way you build a telehealth program will include state licensure policy.

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Alissa Terry: So typically medical provider needs to be licensed in the state that the family is located, while they're talking to them. that only applies if there is licensure for that profession, so there is no licensure for genetic counseling in some states, including West Virginia.

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Alissa Terry: But for physicians, for example, if they want to talk to a family that is in Pennsylvania, and they, the provider, is sitting in West Virginia, they oftentimes need to have a medical license from Pennsylvania. On the next slide I'll talk a little bit about how that changed during COVID

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Alissa Terry: Similarly, a lot of telemedicine requires credentialing at other institutions if you're going to connect one clinic to another, sometimes your specialist, your genetic specialist has to be credentialed at the other institution.

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Alissa Terry: Medicare has some very specific rules about who can do telemedicine, and how it needs to be done, again a lot of those roles were relaxed during COVID, so we'll talk a little bit about that next slide.

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Alissa Terry: A lot of state Medicaid have their own separate policies, so they don't necessarily align with what Medicare says, they have their own set of rules about both who and how telemedicine can be done.

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Alissa Terry: The private payers may have their own set of rules about what they will reimburse in terms of the codes and the types of providers, some states have specific consent policies that if a family is receiving a telehealth consult they have to

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Alissa Terry: have a specific consent, just for the telehealth visit, so above and beyond the consent that they're providing for treatment.

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Alissa Terry: There are privacy and HIPAA regulations that need to be kept in mind when you're doing telehealth

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Alissa Terry: and fraud use and abuse policies. So certainly something that I say and the Center for Connected Health policy also says, this should never be considered legal advice, but it's useful to keep in mind the various types of policy that would impact a planning process.

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Alissa Terry: So we have seen a lot of policy changes with Covid and the need and demand for telemedicine solutions, so there were changes over time.

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Alissa Terry: In that previous policy, including Medicare, used to require that families that received telehealth had to be located in a rural location.

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Alissa Terry: That has changed, at least temporarily, so that pretty much all patients are eligible to receive telehealth regardless of where they live.

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Alissa Terry: The type of site that the family was in when they talk to their specialist used to be limited by Medicare to only clinical sites, so the patient, could not be at home with a few

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Alissa Terry: really specific exceptions. Again that's changed during Covid, as we all know, a lot of families have received telehealth at home, we don't know what the long term

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Alissa Terry: policy is going to be there, but the previous, as I said, the previous Medicare policy did not allow patients at home to receive telehealth and be reimbursed for that.

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Alissa Terry: The codes that were billable for telehealth used to be much more limited than they have become now during COVID, so when you're thinking about billing codes and

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Alissa Terry: what is happening with the patient from the hospital perspective, there's a lot more eligible codes now.

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Alissa Terry: Similarly, in some situations there were only specific providers that were allowed to provide telehealth so maybe in some places only physicians could do it, and none of the nurse practitioners, PA’s or genetic counselors or anybody else could telehealth

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Alissa Terry: and we've definitely seen that expand.

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Alissa Terry: States oftentimes have specific policies requiring their payers to pay for telemedicine. We've seen that increase over time and that you can check your state on the Center for Connected Health Policy with regard to that.

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Alissa Terry: We've also seen during COVID a relaxing of the rules around HIPAA and consent so

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Alissa Terry: there's no explicit HIPAA policy that's just about telehealth. It's really just about making sure that your telehealth system

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Alissa Terry: maintains the same confidentiality, that you would have in person, but we have seen certainly during the very height of the pandemic,

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Alissa Terry: Doctors much more likely to use their cell phone to do a video call you know, sort of whatever it took to get care to the patient.

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Alissa Terry: So we did see that relaxation happening, I think most people expect it to go back somewhat to be a little more rigid but

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Alissa Terry: I think a lot of expectations are hopeful around continuing to have a little more relaxed rules around these things.

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Alissa Terry: Similarly, I talked about medical licensure on the last slide a lot, I would say most states had very relaxed policies.

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Alissa Terry: At least at certain points during the pandemic with regard to whether or not a provider who's talking to a patient in their state needs a medical license there or not so for pretty long periods of time.

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Alissa Terry: Our providers from Maryland could talk to a family in West Virginia or in Tennessee or wherever the family was without worrying about whether or not they had a license in that state where the family was.

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Alissa Terry: I don't think most people expect that to be an immediately permanent thing, there are some interstate licensure compacts that are being explored that would

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Alissa Terry: make it a lot easier for providers to hold multiple licenses but it's certainly something that you always have to keep your eye on.

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Alissa Terry: If you're talking to a patient in another state, you need to know what the existing current policy is on whether or not you need a license there, and if there is licensure there.

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Alissa Terry: There were some relaxed rules about whether you could prescribe certain medications by telehealth.

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Alissa Terry: As well as around fraud and abuse, we don't really know what the future will look like I definitely rely heavily on the Center for Connected Health Policy.

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Alissa Terry: You can go right to their website find your state find out what's going on, they keep track of policy that is being proposed.

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Alissa Terry: It's important for all of us that are invested in telehealth to play a part in supporting policies that will make things easier for families.

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Alissa Terry: So I think we're all sort of just watching and waiting to see what will become permanent and what might revert back to the way things were pre-pandemic.

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Alissa Terry: So a couple other resources, while I wrap up, I mentioned the American Telemedicine Association before but, here is a link to their website, they also have annual meetings and a lot of resources.

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Alissa Terry: They are a membership-based organization. Some states or regions have telehealth groups that really watch closely and advocate for policies in the state.

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Alissa Terry: The American Medical Association has resources for telemedicine practice as well as the American Academy of Pediatrics specific support resources.

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Alissa Terry: So that's really it for me, I really, thank you for your time today, I encourage anyone in the NYMAC region to please consider joining us, to use our resources, to tell other people about NYMAC.

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Alissa Terry: attend our events, use our website. I encourage you to reach out to us if we can be helpful in your work.

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Alissa Terry: And with that I’m going to thank you for your time today, and I am happy to answer any questions.

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Kimberly Kelly: Thank you for that wonderful presentation and my mind is buzzing and trying to process all of the different sources of information and all the potential directions that we can go in telegenetics.

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Kimberly Kelly: So thank you for that and I’ll also mention that Alissa has been very engaged with us at WVU in trying to learn more about our population needs,

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Kimberly Kelly: and has been doing some work in collecting information and and trying to figure out how to best provide services, genetic services in in our region.

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Kimberly Kelly: And in West Virginia, in particular. So I’ll kick us off with a couple of questions and then anyone else that has questions we'd be pleased to to to feel those.

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Kimberly Kelly: First, knowing your background, and talking to lots of folks in our state and what do you see as the primary challenge for genetic services in rural Appalachia.

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Alissa Terry: It's interesting we, you know as an organization, we have started recognizing that we see three very common themes whenever we talk to any location, that we work with so

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Alissa Terry: So we see themes under the bucket of distance to care,

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Alissa Terry: sort of where you are versus where the closest clinic is and how you get from A to B, even if you're within the same city sometimes those

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Alissa Terry: issues can be really important, so distance to care is one really big one.

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Alissa Terry: We also see issues related to education about genetics so whether the family has sort of enough health literacy, to understand the value, you know if they're if they're recommended to go to an appointment they might,

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Alissa Terry: just it's not on their radar as a priority, and some families do have really important competing priorities.

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Alissa Terry: So we see education barriers, both for the families, as well as some of the providers in the community, so if it's the pediatricians are the primary care providers just maybe not prioritizing

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Alissa Terry: genetics so sort of that education bucket, and then the third is we typically see unique issues

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Alissa Terry: for each underserved community that we look at so, as you said, we've been looking really closely at West Virginia. We Worked last year really closely with Virginia, DC, and New York and every time we have those conversations there tends to be just really specific unique issues that arise

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Alissa Terry: for people in that

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Alissa Terry: specific population. We work with Amish and Mennonite families in Pennsylvania, that obviously have really different barriers to care than

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Alissa Terry: other families. So a lot of the work that we do is really to keep trying to collect experiences and stories from across the state to understand what that is and I don't, you know it's never going to be possible to design

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Alissa Terry: a genetics healthcare system that optimally addresses all of those problems that you know, but I think we can all explore ways to be more flexible in the way clinics provide services,

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Alissa Terry: to participate in community based and provider education, just to raise awareness about genetic services.

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Alissa Terry: You know the issues around bringing providers into the state, I think, is a problem, probably across a lot of the states in Appalachia just not being able to fill genetics provider positions or or fund genetics provider positions is a huge

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Alissa Terry: barrier. And I think a lot of the professional organizations are are trying to provide resources to convince institutions to have more positions for

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Alissa Terry: genetics and I think sometimes the advent of telehealth also allows some of those positions to be filled by people that you know providers that aren't ready to permanently relocate, they can they can still provide some of the services by telehealth so.

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Alissa Terry: I think those are the similar to the other areas of those issues of distance, of issues and underserved populations and education tend to be the biggest things that we try to address.

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Kimberly Kelly: Yeah and I think health literacy is a big one in Appalachia I would agree. I mean

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Kimberly Kelly: And I grew up in more western part of Kentucky, but and my family is from Appalachia, but I never heard of genetic counseling until I went to graduate school and started working with the BRCA mutations. And my family has cleft palates you know, and, you know, had

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Kimberly Kelly: some financial challenges, so I think it is a big issue just knowing that there's someone that can handle these kinds of issues and and

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Kimberly Kelly: So that's something we're also working against. Another question is what are some of the opportunities, you see, for research to improve genetic service delivery in West Virginia and the region. So you talked about some of the other

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Kimberly Kelly: things that are going on and certainly Dr. Falah had talked a bit about her work, but if you can just comment on that.

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Alissa Terry: Yeah and I think

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Alissa Terry: as we're typically not a research research organization we're less tuned in but need to be more tuned in so when we're talking about the solutions that we try to build.

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Alissa Terry: You know, for example, if we're trying to improve the health literacy in a community in a way that would impact the likelihood of a family going to genetics, those are things that can be

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Alissa Terry: tracked and followed, you know if you're going to do some sort of health literacy campaign let's try to find a way to keep track and to measure whether or not that actually improves compliance and families

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Alissa Terry: taking up the referrals that they're given. As you mentioned we've seen

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Alissa Terry: even families that do receive services don't always follow through on the medical recommendation, so I think there's

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Alissa Terry: there's ways to look at interventions in in that arena, what can we do in clinic to remind families to make it more likely that they're going to follow through.

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Alissa Terry: So I think all of these interventions that we talked about, even if it is something as simple as a social media campaign.

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Alissa Terry: We need to be cognizant of finding ways to keep track of whether it's actually working and making an impact because if it does work, you know those are programs that can be expanded more broadly.

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Alissa Terry: If that doesn't make an impact on making it more likely that families are going to get into care, then we shouldn't keep investing money and doing those things.

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Alissa Terry: I mean, I think

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Alissa Terry: there's obviously been work done over the years in demonstrating the value of

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Alissa Terry: having a genetics visit for a family, like you mentioned, you know your family has a history of cleft palate what is the value for them and going to

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Alissa Terry: a visit, but maybe that needs to be studied more specifically in the region, just to be able to demonstrate really concretely why

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Alissa Terry: it brings value to the system and to the family, for them to go to care to sort of convince institutions that it's worth it.

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Alissa Terry: Both to the institution and to the family, a lot of times we do see genetics providers or even genetics clinics being

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Alissa Terry: on paper, looking like they're kind of losing money for the institution, because of the billing situation.

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Alissa Terry: But a lot of places are able to document that there's all these other impacts

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Alissa Terry: on families and downstream with the institution that argue for the value of genetics, so I think for places that are really struggling with

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Alissa Terry: having enough genetics providers or having institutional support for genetics providers may be taking a look again at really documenting and demonstrating why it matters, what impact that has and how it does benefit the institution, even if it's not in an immediate billing cycle.

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Kimberly Kelly: Thank you and does anyone else have any questions for Ms. Terry.

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Kimberly Kelly: And certainly if you have additional thoughts, we have an evaluation and Anusha if you could post that in the chat and we would appreciate your feedback about this, if you have additional questions.

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Kimberly Kelly: You know we're we're working with Alissa lot these days and

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Kimberly Kelly: appreciate the good influence she's had on

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Kimberly Kelly: increasing service provision in our state and it sounds like other regional genetic networks are doing great work in that area as well, and I certainly am indebted to the the progenitor I guess of

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Kimberly Kelly: NYMAC which was MRGN and that kind of that helped me and set on this path, but if there are no additional questions I’ll thank you and we will be in touch.

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Alissa Terry: Thanks so much.

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Kimberly Kelly: Thank you. Oh wait a minute there's something here let's see regarding added value there's one comment from Dr. Kahler.

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Alissa Terry: Oh that's great.

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Stephen G. Kahler, MD: Yep that's that's how you pronounce my name.

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Kimberly Kelly: Well, thank you

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Kimberly Kelly: that’s always encouraging

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Stephen G. Kahler, MD: Yeah of course, the money was spent by genetics and surgery and radiology.

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Stephen G. Kahler, MD: Yeah the income.

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Kimberly Kelly: But yeah the more targeted, we can get in our approach to helping people we're we're not having to you know

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Kimberly Kelly: run a lot of different types of tests and we can kind of zero in that certainly helps too.

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Stephen G. Kahler, MD: Oh that's that saves a lot of people money.

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Alissa Terry: Yeah.

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Kimberly Kelly: All right, well, thank you very much. We appreciate your engagement.

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Stephen G. Kahler, MD: Nice talk, thanks so much.