

10/5/21 First session:

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00:19:04.650 --> 00:19:07.920

Kimberly Kelly: Good morning, I hope you can hear me.

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00:19:13.350 --> 00:19:14.040

Jessica Eloise Pugh: morning.

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00:19:16.890 --> 00:19:17.760

Kimberly Kelly: So.

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00:19:18.840 --> 00:19:39.210

Kimberly Kelly: For today, and we'll give folks a few more minutes to join in, because we're individually admitting each person. And there seems to be quite a flow still of people joining us; so I'm so happy that you all are joining us today and care about this issue.

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00:20:28.350 --> 00:20:31.620

Kimberly Kelly: So we'll just give it a couple more minutes for folks to join.

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00:22:26.100 --> 00:22:38.910

Kimberly Kelly: Okay I'll go ahead and start, and as people will trickle in as we get going. And if they missed any part of this, we hope to have a transcript and ...

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00:22:39.570 --> 00:22:50.790

Kimberly Kelly: Audio recording and video recording, so we will proceed. First of all, let me welcome you to our webinar series on genetic services in Appalachia.

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00:22:51.150 --> 00:23:05.820

Kimberly Kelly: It's a cause that's very near and dear to my heart, and I appreciate you all caring about this issue and wanting to learn and discuss more about genetic services in Appalachia.

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00:23:06.540 --> 00:23:24.090

Kimberly Kelly: I think you know it's an area that is very challenging, and I appreciate those folks who are out there, providing service to our communities.

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00:23:25.680 --> 00:23:41.820

Kimberly Kelly: So we ask that you mute your microphone and at the end, we can all have a discussion and, but if you have any questions or comments you are feel free to put those in the chat session, and we can ask questions at the end.

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00:23:43.650 --> 00:23:54.660

Kimberly Kelly: So, to begin I'll provide a brief overview, and then we'll have Dr. Falah to talk about genetic services that we provide through WVU.

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00:23:55.110 --> 00:24:05.790

Kimberly Kelly: And we are doing our best to try and figure out the complicated health system in West Virginia

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00:24:06.240 --> 00:24:19.050

Kimberly Kelly: And all the different people who are providing, and so we're still working our way through that. So this is an evolving process, and we appreciate your patience, as we identify additional individuals.

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00:24:20.010 --> 00:24:27.930

Kimberly Kelly: So I will start, and then after we're both finished, there will be a brief evaluation that we would appreciate.

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00:24:28.410 --> 00:24:39.030

Kimberly Kelly: That you would complete just to give us some feedback on areas of interest for you, and things that we might do better, things that we might think about moving forward.

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00:24:39.570 --> 00:24:58.830

Kimberly Kelly: So I'll begin with genetic services in Appalachia, and we're very happy to be funded through the Agency for Healthcare Research and Quality, who have been very supportive of our efforts to increase access to health care services in West Virginia.

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00:25:00.270 --> 00:25:01.320

Kimberly Kelly: And throughout the country.

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00:25:09.300 --> 00:25:12.660

Kimberly Kelly: I have no conflict of interest to disclose.

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00:25:14.340 --> 00:25:23.280

Kimberly Kelly: Just to tell you a little bit about our planning Committee, I am a Professor in the School of Pharmacy and the Cancer Institute.

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00:25:23.970 --> 00:25:31.470

Kimberly Kelly: My training is in behavioral science, so I have training as a social and health psychologist.

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Kimberly Kelly: And also did some work in cancer control. In addition, I have a degree in genetic counseling, but I don't practice as a genetic counselor. So my main function is research and teaching.

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00:25:45.270 --> 00:25:59.550

Kimberly Kelly: And Dr. Falah who will be talking later today, is an Assistant Professor in Pediatrics and the Cancer Institute, and also we're joined by Dr. Virginia Scott, better known as Ginger.

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Kimberly Kelly: And I don't think she'll mind me telling you that. She is a Professor and Director of Continuing Education in Pharmacy, so she's our expertise in conducting webinars. This is a new thing for me, so I appreciate all the guidance from her.

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00:26:18.450 --> 00:26:21.690

Kimberly Kelly: And also, we have two graduate assistants who are helping us.

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00:26:22.770 --> 00:26:32.280

Kimberly Kelly: Anusha Sheikh and Trupti Dhumal who are in Public Health and the School of Pharmacy Health Services and Outcomes Research programs, respectively.

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00:26:34.530 --> 00:26:45.780

Kimberly Kelly: So, for those of you who don't know, I'm sure many on this call, are very familiar with the Appalachian region, but some are surprised.

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Kimberly Kelly: I think people have maybe a stereotype about what Appalachia is and then I've known people who are doing Appalachian research. They look at the map and suddenly realize that they are in fact from Appalachia.

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00:27:03.090 --> 00:27:13.590

Kimberly Kelly: So it's a thirteen state region from New York to Mississippi, and it is designated by county at the federal level. So it's geopolitically defined.

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Kimberly Kelly: It has approximately 25.7 million residents, so there are a lot of people in Appalachia. About 10% are rural.

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00:27:25.110 --> 00:27:39.720

Kimberly Kelly: And some who are living in Appalachia don't identify as Appalachian, and some people who live outside the Appalachian region identify as Appalachian.

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00:27:40.050 --> 00:27:57.810

Kimberly Kelly: So although there are these geopolitical definitions, at the individual level, there is some variability about especially people who are new to Appalachian may not identify as Appalachian, or from some of the border areas at the edge of Appalachia.

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Kimberly Kelly: Some of the things that you probably are familiar with the Appalachian region, it has health care professional shortages, there are some educational disparities and with less education, has limited high quality broadband.

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Kimberly Kelly: And for those of you who are from flat states, there's special challenges to providing broadband in mountainous areas, and we have that. We also have fewer providers than perhaps some other areas that are in mountainous ranges.

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00:28:35.310 --> 00:28:44.700

Kimberly Kelly: It's a very diverse region, as you can see, stretching from New York to Mississippi. There's a lot of different kinds of people in Appalachia.

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00:28:45.360 --> 00:29:09.570

Kimberly Kelly: And also, if you look at the, so the first map is of Appalachia and the regions of Appalachia, and we're coming from you, mainly from the central Appalachian region.

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Kimberly Kelly: And then, if you look at rurality in the Appalachian region, which is the green and the red, the green area, the darkest green is the most rural.

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00:29:16.140 --> 00:29:31.980

Kimberly Kelly: The lighter green areas are non-metro, and then the red areas are the metro areas. So they're more city, but, as you can see in the central Appalachian region, we have a lot of rural counties.

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Kimberly Kelly: So our aims with this session overall and for the entire webinar series include to provide an overview of current models of genetic service delivery in the rural Appalachian region and barriers to care provision.

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Kimberly Kelly: So we know that there are many challenges just geographically getting to people. You know, broadband isn't easy.

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Kimberly Kelly: It's not easy to drive in some of the areas. So there are a lot of people who have limitations to getting genetic services. So how are we delivering services? So there's the physical limitations and also the economic and educational limitations.

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Kimberly Kelly: Aim two is to provide prevention potential resources for genetic services delivery in the rural Appalachian region.

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Kimberly Kelly: And we are pleased to have NYMAC joining us, and we have folks that are from other regions as well. Also we have the immediate past president of the International Society of Nurses in Genetics.

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Kimberly Kelly: And aim number three to establish a list of priorities of future genetic services research in the rural Appalachian region.

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Kimberly Kelly: And so we will have a wrap up including Dr. Graves from Georgetown University, who's doing some exciting work in a different population than we work with in Appalachia, but to reach medically underserved individuals.

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00:31:09.900 --> 00:31:19.590

Kimberly Kelly: So our schedule, we meet every Tuesday, first of the month, so October 5th, November 2nd, December 7th and so on.

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Kimberly Kelly: And we'll be talking about services in West Virginia, Kentucky Pennsylvania who have large populations of rural Appalachians.

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Kimberly Kelly: Also, we'll get some information from NYMAC on telegenetics, That's the New York Mid-Atlantic Region and Caribbean. And also genetics nursing, genetics outreach, and of course, our wrap up. So this is how our aims and our schedule correlate.

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Kimberly Kelly: So as a part of our process, we ask that you register.

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Kimberly Kelly: So even if you receive the link for this conversation from someone else, we ask that you go in and register. That just helps us know a little bit about the people that are participating and what your interest in the Appalachian region is.

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00:32:17.580 --> 00:32:24.480

Kimberly Kelly: As far as our registrants, I think we had about 60 when I last checked.

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Kimberly Kelly: Most of our registrants are healthcare providers. So as we move forward through our sessions, we're hoping to bring in more patients, as well as community members and caregivers.

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Kimberly Kelly: But we've been really pleased with the engagement of healthcare providers in our region, and we'll continue throughout the series to reach out to them.

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Kimberly Kelly: We will have some time for discussion, and we will be recording the sessions, just so that we understand that we don't miss anyone's contribution.

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00:32:58.710 --> 00:33:11.400

Kimberly Kelly: And we want to thank you for being engaged throughout this, and I will provide a link for an immediate follow up after each of the sessions.

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00:33:12.330 --> 00:33:24.240

Kimberly Kelly: It's five or six items just to see how you liked it and any feedback that you want to give us just so that we know that things that we can improve, and we want to try to get better with each additional session.

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00:33:24.840 --> 00:33:44.370

Kimberly Kelly: And then at the end of the series, we will send you an overall evaluation to your email. So we appreciate all of your feedback, and this also helps with our funder, and if we decide to pursue any research areas in the future, then we have additional information.

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Kimberly Kelly: So that is a general introduction to the session, and now I'll move on to Dr. Nadia Falah.

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Kimberly Kelly: She is an assistant professor in the Department of Pediatrics Division of Genetics and Metabolism at West Virginia University.

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Kimberly Kelly: She is board certified in Medical Genetics and Genomics and is a fellow at the American College of Medical Genetics. She serves on the West Virginia advocacy Council for Rare Disease. I'm sorry, advisory council.

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00:34:28.290 --> 00:34:32.460

Kimberly Kelly: So with that I will stop my share.

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00:34:33.570 --> 00:34:36.750

Kimberly Kelly: And Dr. Falah, if you can share, I will turn it over to you.

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Nadia Falah: Hello, everyone. Good afternoon. Thank you so much for being here today, helping us navigating or determining some limitations about providing the genetic service in West Virginia.

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Nadia Falah: Today I'm going to talk about, present my team regarding the genetic service that is provided through West Virginia University.

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Nadia Falah: I have no conflict of interest to disclose.

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Nadia Falah: First, I want to start off where we are and where we practice. We're mainly located in through the Department of Pediatrics West Virginia University, WVU Medicine in Morgantown.

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Nadia Falah: And our offices are at the Health Science Center. We do see patients, mainly in Ruby Memorial Hospital and the outpatient clinics. We're moving to the new Children's Hospital this upcoming year, probably January of 2022 or February.

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Nadia Falah: So, in terms of genetic clinics that we have, we do have a general genetic clinic where we see patients. A variety of diagnoses.

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Nadia Falah: All ages: from 0 to 99. We do the newborn screen throughout the state, and Dr. Narumanchi covers that with a metabolic dietitian. We do have a metabolic clinic that we follow up with these abnormal newborn screens.

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00:36:47.520 --> 00:37:07.860

Nadia Falah: And specifically, for that. We also participate in the Multi-disciplinary clinics. An example of them is a Cardiogenetic clinic, which is established a year, a year ago, collaborating with a cardiology team. We also participate in the cleft lip and palate clinic.

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Nadia Falah: Since I started here, we integrated our service to the Cancer Institute, and we do have a cancer clinic (cancer genetic clinic) that is three days of clinic a week. There we just provide service to the cancer-related questions or concerns.

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Nadia Falah: WVU Medicine also has a genetic counselor that is based, with the OB team, and she provides prenatal counseling, non-invasive prenatal testing, and genetic testing, just for OG/Gyn patients.

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00:37:56.700 --> 00:38:07.950

Nadia Falah: So the Department of Genetics at WVU Medicine is the only genetic division throughout the state; although, there are some people who provide genetic services.

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Nadia Falah: That outside of this department, including, as I stated earlier, the genetic counselor through the OB/Gyn department.

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Nadia Falah: As well as we do have some mid-level providers with some genetic expertise, who provide genetic service through the Cancer Institute.

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Nadia Falah: In addition to that, we do have a geneticist who's also a neonatologist that provides a unique service to those babies that are born with possible genetic problems. A direct access to genetic service through NICU.

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Nadia Falah: So these are the names of the providers at the WVU Genetic Department: and the Department Chief is Dr. Narumanchi.

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Nadia Falah: We have Dr. Burke. She is affiliated with the Department of Genetics, as well as neonatology, providing the services in both locations. The third one is me, and now we have Jenny Wilkins.

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Nadia Falah: She is our metabolic dietitian where we help with the, well, she helps with them, providing the services for newborn screen and metabolic conditions.

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Nadia Falah: Mrs. Peron, she is a nurse practitioner who joined our practice, about a year ago, started learning a lot about genetics. She is doing a great job and practicing along with or closely with the Department chief, Dr. Narumanchi.

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Nadia Falah: The genetic service or the names of the providers who actually have a training in genetics are me and Mrs. Yoho she's a certified genetic counselor Dr. Narumanchi and Dr. Burke.

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Nadia Falah: We all are board certified in genetics and have the training for providing the genetic counseling.

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Nadia Falah: We also have other genetic professionals who provides genetic counseling that are in the Cancer Institute. Basically, cancer patients require a lot of genetic testing and follow-up.

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Nadia Falah: So we have Mrs. Jordan, Likar and Hall, as well as Mrs. Moran, who all provide genetic testing genetic counseling and they received a special training through the City of Hope,

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Nadia Falah: where they have special education in genetics and cancer prevention, screening recommendations for example Lynch Syndrome and the BRCA mutations related to hereditary breast and ovarian cancer syndrome.

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Nadia Falah: Of course, our staff, they do a great job helping us with the service, and I don't think that we can do the service without them.

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Nadia Falah: We have Paige, who has helped us develop the cardiogenetic clinic.

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Nadia Falah: Specifically, obtaining or understanding the referral type and pulling up patients with the diagnoses that have both genetic and cardiac finding where they have two referrals.

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Nadia Falah: So she helped us with that implementation.

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00:41:36.810 --> 00:41:45.960

Nadia Falah: Nicole Matthews, she's basically doing a lot of authorizations coordinating genetic testing throughout the state, which is a challenge work, especially with the insurance limitations that we have. Navigating the cost of the testing and taking it to the patients.

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Nadia Falah: As well as coordinating genetic testing through the difficult region where laboratory may not be there, or patient compliance will be less.

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Nadia Falah: Karen Murray, she is our administrator manager, Jessica and Holly they both are social workers.

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Nadia Falah: They do a lot of help with calling patients with results, obtaining help through a family tree, as well as sometimes they go with, travel with the providers to help them, collecting information to be put in the medical records. We have Catherine Turner; she is doing a lot of scheduling. She is the secretary of the department.

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00:42:45.990 --> 00:42:57.900

Nadia Falah: So I mentioned the earlier that we are located in Morgantown, but we have Dr. Narumanchi and Mrs. Peron. They both travel for the outreach clinic, which is a very challenging way of providing service.

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00:42:58.590 --> 00:43:03.840

Nadia Falah: They travel twice or once a week for multiple locations and provide service to the outreach clinics.

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Nadia Falah: We also have the outreach telemedicine,

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Nadia Falah: where we have two locations in Martinsburg, as well in Summersville. We have nurse practitioners, who see patients there and we communicate via telemedicine to help them with making the decision, providing information to the patient.

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00:43:23.580 --> 00:43:33.690

Nadia Falah: After Covid, and as you all know that we have an easier way or easy to, or we started to provide Telegenetics through a video visit, as well as through a telephone visit at some point,

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00:43:34.980 --> 00:43:47.700

Nadia Falah: especially for those who do not have access to technology,

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Nadia Falah: or poor Internet connections, telephone visits could be also an alternative, and again we started doing this service after Covid-19 started.

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Nadia Falah: So I, as I stated, that the outreach clinics are one of the most important things that we do here. I basically don't travel, but my colleagues, specifically Dr. Narumanchi and Mrs. Peron, they travel to multiple locations.

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00:44:17.010 --> 00:44:31.500

Nadia Falah: Charleston is one of them. I think that we have had some issues lately, but we did in the past couple of years, through CAMC Women and Children. They go to Regional Medical Center in Summersville.

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Nadia Falah: In Parkersburg, they have a clinic in Mid-Ohio Valley. In Wheeling, we have the Wheeling hospital, which is now part of WVU medicine.

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Nadia Falah: We also go to the Huntington Hospital, located in Pediatrics suite, And in Martinsburg to the Pediatric Specialty, as well as I mentioned earlier. through the telemedicine, where we collaborate with a nurse practitioner providing these kinds of services.

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00:45:05.070 --> 00:45:17.370

Nadia Falah: Who supports the Department of Pediatric or Genetics? Basically, we're supported by West Virginia University, as well as we do receive funding from the West Virginia Bureau of Public Health,

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Nadia Falah: Office of Maternal and Child Health. There are sometimes, some private contributions that can add, as a resource to our office or to our department.

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Nadia Falah: Testing that we provide. We provide as any other genetic departments, we offer all the genetic testing to our patients,

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Nadia Falah: newborn screen to cancer syndrome cardiomyopathy panel, whole exome sequencing, genome sequencing, familial testing, carrier screening panels.

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00:45:55.770 --> 00:46:13.410

Nadia Falah: Technically, or physically, we do have some issues, offering some testing due to interest limitations, but overall we do the same as everybody else throughout the United States, offering all variety of genetic testing with up to date technology.

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00:46:16.320 --> 00:46:27.330

Nadia Falah: Now, how do we get the other health care providers to know about, that we exist or how we get a referral.

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Nadia Falah: Through other health care providers, telling them that we are here.

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00:46:34.320 --> 00:46:44.370

Nadia Falah: We can provide genetic service to patients who are actually needing it, especially that with complex disorders, sometimes as healthcare providers, primary care may not know that there is a need for a referral.

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00:46:45.090 --> 00:46:57.000

Nadia Falah: So we provide Grand Rounds throughout West Virginia University to the Department of Family Medicine, to the Cardiology Team,

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Nadia Falah: As well as outside of the hospital, just to kind of you know, spread education about the genetic disorders, which patients could be referred to you. Meetings and workshops, they also could be helpful.

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00:47:16.650 --> 00:47:26.940

Nadia Falah: And providers may get to know about our services through those meetings and discussions.

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Nadia Falah: Websites and media where we advertise about our services through the Children's Hospital, as well as magazines. The genetic services staff, where we communicate with others regarding testing referrals, and you know, our availability to help them if they need a genetic service.

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00:47:49.560 --> 00:47:51.270

Nadia Falah: And patients also.

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00:47:52.800 --> 00:48:06.810

Nadia Falah: Having patients to be aware of the service that exists, as well as to be aware that if they need genetic services, that is important, and they get informed, number one, through the referrals.

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00:48:08.130 --> 00:48:15.240

Nadia Falah: When the primary care doctor kind of thinks about a possible genetic etiology, then they refer them to us to educate them about what it is.

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00:48:15.480 --> 00:48:26.850

Nadia Falah: And it's not a surprise that many of our patients come to see us, and say, 'I don't know the reason why I'm here today.' And we have to educate them about the service, what we can offer, what genetic testing we could give them, and how it could help them manage their disorder.

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00:48:27.720 --> 00:48:38.070

Nadia Falah: Now websites and media, I think that they play an important tool in our hospital.

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Nadia Falah: WVU Medicine also put our names out there as well as magazines and things like that through the waiting room for patients to be aware, about the rare disorders and the genetic services that can be provided.

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00:48:53.190 --> 00:48:55.260

Nadia Falah: We also have sometimes distributed genetic educational material to patients,

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00:48:56.760 --> 00:49:05.730

Nadia Falah: And we recommend sharing it with other family members, second degree relatives, first degree relatives.

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00:49:06.120 --> 00:49:20.100

Nadia Falah: Just to educate them about what could be possibilities, and for them to come to this genetic clinic for the awareness.

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Nadia Falah: Also some support groups, including the Mountaineers of Hope, they do some podcasts as well as information to the patient regarding the rare cancer syndromes related to the genetic service.

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00:49:32.070 --> 00:49:39.000

Nadia Falah: And let them know about our services that are existing in West Virginia, to the West Virginia University.

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Nadia Falah: One of the important topics about us as a provider, how we can keep up to date with the information. The genetic field is evolving and information is updated every year.

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00:49:51.930 --> 00:50:03.030

Nadia Falah: So I see that as a challenge, and an important concept that genetic providers do that are practicing anywhere, not just in Appalachia to be up to date with the information.

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00:50:03.390 --> 00:50:15.540

Nadia Falah: So we keep up our education through the maintaining of certification, attending seminars, conferences, we go to conferences ACMG, ASHG.

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Nadia Falah: We review a lot of genetic materials, even within when the patient comes to see us, again, the entire guidelines change every year, the recommendations could change every year as well.

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Nadia Falah: The recommendation of testing gets up to date or changes, so we do team review. We have the entire guideline; we use some Apps to help us with the diagnoses.

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Nadia Falah: At the City of Hope, providers have intensive cancer genetic training, and now we have many providers who are physician assistants who participated in this type of training

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Nadia Falah: And help them be more experienced in the genetic service.

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00:51:03.270 --> 00:51:07.800

Nadia Falah: We also, as a genetic provider, we educate other staff regarding

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Nadia Falah: If there is, if they have any questions or if they do not understand the genetic results, so we go and educate them and work with them closely to provide the best genetic service throughout the state.

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00:51:25.590 --> 00:51:36.810

Nadia Falah: So we see everybody, all diagnoses, all ages. Most our patients are White-Caucasian.

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00:51:38.040 --> 00:51:50.250

Nadia Falah: We do have a lot of Medicare or state insurance. So we have a very unique population that could be different. I used to practice in Florida; so it's kind of a different kind of population here.

182

00:51:52.380 --> 00:52:13.230

Nadia Falah: I kind of created this summary, requested from our administrative staff, to help me put together the number of patients that we saw and, interestingly, that in 2018 to 2000 from July of 2018 to June of 2019 we have 2772 patients, and that's throughout the whole state.

183

00:52:14.370 --> 00:52:34.950

Nadia Falah: The following year, which you can see that the number has decreased to 1984 patients, and that's probably because of Covid, decreased the number of visits, although we switched it to telegenetics, but that still did not compensate for or made it even closer.

184

00:52:36.300 --> 00:52:49.860

Nadia Falah: Now for last year, which is July of 2020 to June of 2021 we have 2654 patients in total, and those are the total number of patients again throughout the state.

185

00:52:50.580 --> 00:52:59.940

Nadia Falah: This is the rough estimate numbers because they do not include the inpatient consult, and we can see that there are some differences here.

186

00:53:00.360 --> 00:53:08.970

Nadia Falah: Again, because of some changes or some numbers that were not added in the next in this table.

187

00:53:09.630 --> 00:53:23.190

Nadia Falah: Now here we asked about the location, the number of patients that we see per location and, as you can see, in the middle here, that the majority of our patients are seen at the POC in Morgantown.

188

00:53:23.910 --> 00:53:42.540

Nadia Falah: We have about a 1000 per year in 2018 through 19 and then through 19 to 20 we are around 1000 per year, but then in 20 to 21 we almost doubled our number of patients that we see.

189

00:53:43.320 --> 00:53:59.940

Nadia Falah: These numbers, they only include the Department of Pediatrics Genetics. It does not include other providers who provide genetic services, including the physician assistants in the Cancer Center, as well as Mrs. Yoho, who is a genetic counselor at the OBGyn.

190

00:54:00.990 --> 00:54:24.660

Nadia Falah: Now you can see that we have some issues, especially with the challenges with the service in Charleston at this point; so, we did not provide any in the past year. We have similar numbers in Summersville, 172 for first year, 157 2019 to 20 and 177 in the 2020 throughout 21.

191

00:54:27.450 --> 00:54:38.880

Nadia Falah: And as I stated earlier, that nurse practitioners joined us a year ago, and she is doing a lot of outreach with Dr. Narumanchi, the Chief of the Department of Genetics.

192

00:54:43.260 --> 00:54:52.320

Nadia Falah: And I also asked to look at the coverage or financial coverage for our patients.

193

00:54:53.730 --> 00:55:15.930

Nadia Falah: And as you can see that there is a Medicaid is a major part here, compared to a commercial insurance, we have the PEIA and Medicaid; those are the numbers, those are the percentage of the patients' coverage for our visits in the past three years.

194

00:55:20.220 --> 00:55:25.260

Nadia Falah: So what are our limitations at this point, I think that we are very small team.

195

00:55:25.830 --> 00:55:39.690

Nadia Falah: We are trying to hire an additional geneticist. We had Dr. Hummel in the past. She retired a year ago, and we are trying to hire another geneticist who can help us with providing the genetic service.

196

00:55:40.290 --> 00:55:54.480

Nadia Falah: We also have difficulty hiring a genetic counselor. We kept losing them in the past years, and because of the competitive pay by the industry that took our genetic counselors.

197

00:55:55.050 --> 00:56:14.550

Nadia Falah: There is the funding that is supporting the department is basically requiring a lot of travel, which is once a week throughout the state, so the travel requirement may have kind of decreased our chance of having the genetic professionals' recruitment.

198

00:56:15.690 --> 00:56:36.120

Nadia Falah: We do have, we are now providing Telegenetics, which is a great tool for providing Telehealth to or providing genetic service to a rural areas. However, there are some challenges with the Internet connections; a lot of the population or a lot of people, they do not use the technology.

199

00:56:37.260 --> 00:56:45.930

Nadia Falah: And compliance also plays an important role in our limitations of patient coming to the visit or patients coming

200

00:56:47.370 --> 00:56:52.200

Nadia Falah: And following up with testing after it is recommended

201

00:56:53.400 --> 00:56:54.150

Nadia Falah: In the clinic.

202

00:56:55.860 --> 00:57:06.750

Nadia Falah: So what we're looking for, we're looking to expand our service throughout West Virginia in general and developing more roles to the genetic assistant.

203

00:57:07.350 --> 00:57:20.790

Nadia Falah: Adding a genetic counselor or genetic professional, genetic counselor assistants could also be helpful.

204

00:57:21.450 --> 00:57:30.600

Nadia Falah: We really hope to change a lot of policies for genetic services that are provided in West Virginia, including licensure to genetic counselors.

205

00:57:31.410 --> 00:57:42.990

Nadia Falah: As well as a coverage by insurance companies, especially West Virginia Medicaid; they cover the service, they cover the genetic testing, which could ease a lot of what we provide.

206

00:57:44.160 --> 00:57:55.050

Nadia Falah: Implementation of a new educational program specifically on educating primary care doctors or mid-level providers who are located mainly in the outreach about the prevention of the cancer syndromes.

207

00:57:55.500 --> 00:58:01.080

Nadia Falah: Now a lot of patients with Lynch Syndrome or BRCA mutations

208

00:58:01.890 --> 00:58:17.460

Nadia Falah: They are out there in West Virginia, and you know, traveling two hours, three hours to Morgantown could be a hassle for them.

209

00:58:18.690 --> 00:58:32.370

Nadia Falah: So educating primary care doctors, mid-level providers in their locations about the updated guidelines, health screening, and having those patients following up there in a couple, three, four years, and then come back to see us as needed, that could also a potential role to improve the services.

210

00:58:36.270 --> 00:58:38.040

Nadia Falah: I think that's all.

211

00:58:39.210 --> 00:58:48.600

Nadia Falah: I hope that I provided you with an overall review about what we do in the Genetics Department here in West Virginia and if you have any questions, I'll be happy to answer.

212

00:58:50.220 --> 00:58:54.930

Kimberly Kelly: So I'll kick off with a couple questions

213

00:58:56.550 --> 00:58:57.060

Kimberly Kelly: While we're waiting for questions to come in.

214

00:58:58.680 --> 00:59:06.150

Kimberly Kelly: First of all, what do you see is the primary challenge for genetic services in rural Appalachia?

215

00:59:07.230 --> 00:59:07.410

Kimberly Kelly: If you had to pick one.

216

00:59:07.590 --> 00:59:13.140

Nadia Falah: Access, patient access to a genetic service, I think that's the number one.

217

00:59:14.400 --> 00:59:25.020

Kimberly Kelly: Yeah, and I noticed that we had some folks from the high-risk group at, I believe Cabell Huntington, join us so we're glad that they were able to join us.

218

00:59:25.650 --> 00:59:38.130

Kimberly Kelly: They work with the high-risk cancer population, I believe in the southern part of the State.

219

00:59:39.150 --> 00:59:51.510

Kimberly Kelly: So we're happy to you know talk about, you know, how we can bridge the gap throughout the state and make sure that you know, whoever is providing the service where they are have access to services, right?

220

00:59:52.320 --> 01:00:02.400

Kimberly Kelly: Okay, the second question is what are some of the opportunities, you see, for research to improve genetic service delivery in West Virginia and in our region?

221

01:00:05.820 --> 01:00:17.880

Nadia Falah: Um I think that if you talk about research in general, I think that we needed to do more quality improvement in the genetic service that is specifically implementing better referrals,

222

01:00:18.990 --> 01:00:21.420

Nadia Falah: Understanding from the genetics,

223

01:00:22.620 --> 01:00:34.980

Nadia Falah: Understanding from primary care doctors, are we receiving all the referrals that are needed?

224

01:00:36.270 --> 01:00:39.570

Nadia Falah: Challenges with, if a patient is diagnosed with a genetic disorder, do we see a screening recommendation that are given?

225

01:00:41.100 --> 01:00:55.740

Nadia Falah: So more of implementing referrals, education, as well as collaboration between primary care doctors in different locations.

226

01:00:56.160 --> 01:01:10.500

Nadia Falah: They always vision that we do have kind of like sub-sites where, though, we have a genetic professionals who are or genetic providers who are interested in genetics and have a direct communication with us here.

227

01:01:11.790 --> 01:01:23.130

Nadia Falah: Also, hiring a genetic counselor in some locations could be also helpful, especially now with the remote services that we can offer, it could help that.

228

01:01:25.590 --> 01:01:41.490

Kimberly Kelly: All right, thank you, and so, if anyone has a question, we're not being barraged in the chat, so if you want to unmute yourself and ask a question, or you can type it in, if you're feeling shy, we'd be happy to discuss.

229

01:01:42.540 --> 01:01:56.460

Kimberly Kelly: Or if you just want to, you know, make a comment you don't necessarily need to have a question specifically. If you have any comments about, you know, what your challenges are in Appalachia, especially thinking about West Virginia.

230

01:02:23.130 --> 01:02:24.330

Kimberly Kelly: All right.

231

01:02:25.410 --> 01:02:31.410

Kimberly Kelly: So I think folks are a little quiet today, and hopefully you'll have some - I'm sorry.

232

01:02:32.760 --> 01:02:52.200

TaraChandra Narumanchi: I just wanted to take a moment to we've got some folks from the State on, and I wanted to recognize the contribution from the Office of Maternal Child Health. For 30 years, they have been providing support to the Division of Genetics here at WVU.

233

01:02:53.850 --> 01:03:03.480

TaraChandra Narumanchi: Basically, they underwrite a good portion of our budget and give us the ability to travel to patients, as I'm sure most professionals across Appalachian know.

234

01:03:04.200 --> 01:03:15.150

TaraChandra Narumanchi: One of the biggest burdens is just at the expense of getting to the clinic and the distance.

235

01:03:15.660 --> 01:03:30.060

TaraChandra Narumanchi: So West Virginia, 30 years ago, was very forward thinking in getting professionals to the patients, and which is why we have a series of locations across the state where, we go, and we try and see 20 to 30 patients per visit, per clinic and make ourselves available to them.

236

01:03:31.200 --> 01:03:46.260

TaraChandra Narumanchi: Rather than yeah, obviously there is a limitation there, based on the number of providers, we have

237

01:03:47.790 --> 01:04:04.830

TaraChandra Narumanchi: But it is certainly for many patients the ability to even have enough gas money to get to their local clinic is sometimes a huge burden, so I just wanted to recognize the state and their concern and care for the citizens of West Virginia.

238

01:04:06.060 --> 01:04:14.760

Kimberly Kelly: Yeah it's, it's amazing you know the difficulties that our population is dealing with and trying to bridge that gap is a challenge sometimes.

239

01:04:15.270 --> 01:04:32.220

Kimberly Kelly: And you know it's a challenge for people working with all different populations who are medically underserved that have issues as far as maybe educational attainment,

240

01:04:33.330 --> 01:04:41.940

Kimberly Kelly: Or you know familiarity with health professional services. I mean, there are plenty of folks that we encounter who really haven't had, you know, don't go to the doctor once a year.

241

01:04:42.570 --> 01:04:51.210

Kimberly Kelly: And I think some of us take that for granted, especially as healthcare professionals.

242

01:04:51.840 --> 01:04:58.980

Kimberly Kelly: But there are folks out there who have unique challenges, and I think that's one of the big challenges for rural Appalachia is just physically getting to them.

243

01:04:59.700 --> 01:05:16.350

Kimberly Kelly: And you know I'm hopeful that our broadband access will increase, but there will still be challenges for broadband in our population even whenever we get good-quality broadband throughout the state.

244

01:05:17.640 --> 01:05:20.250

Kimberly Kelly: So thanks for noting that.

245

01:05:23.910 --> 01:05:40.320

Kimberly Kelly: All right, well if there's no other questions, then we will wrap up for today, and we look forward to seeing you in our next session.

246

01:05:41.790 --> 01:05:43.740

Kimberly Kelly: I'm going to put our information in the chat box.

247

01:05:45.810 --> 01:05:47.280

Kimberly Kelly: And I will send it by email as well for you to provide us some feedback.

248

01:05:48.930 --> 01:05:54.600

Kimberly Kelly: And I'll do that right now.

249

01:05:56.640 --> 01:05:57.150

Kimberly Kelly: And I appreciate it, it's only about six questions.

250

01:05:58.500 --> 01:06:10.920

Kimberly Kelly: So if you can go into that link and complete some feedback, and we will also email this, if you're not able to access it right now, but I'll give you a few minutes to look in the chat.

251

01:06:15.750 --> 01:06:27.000

Kimberly Kelly: But thank you again, we appreciate your participation, and we will look forward to seeing you next month. And we will continue to get out the word.

252

01:06:27.630 --> 01:06:40.110

Kimberly Kelly: And hopefully bring in more folks who have an interest in genetic services in Appalachia; And with that I will end. And follow up by email. Anyone else have anything else, that they would like to say?

253

01:06:41.700 --> 01:06:56.310

Kimberly Kelly: <From chat: So the meeting next month, is it the same as this one?> The format will be similar, but the University of Kentucky will be talking about their genetic services, and so we can have a larger conversation between the States about some ideas that we might have to reach the rural Appalachian population.

254

01:06:56.970 --> 01:07:16.770

Kimberly Kelly: So each month we will have a different focus but the overall webinar series is on genetic services in Appalachia so, thank you Jessica for your note.

255

01:07:18.480 --> 01:07:28.380

Kimberly Kelly: All right, and so I will wrap up here and we will look forward to hearing from the folks at University of Kentucky next month. Thanks a lot.