WEBVTT Session 2

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00:00:12.420 --> 00:00:15.000
Kimberly Kelly: I see people in the waiting room, but I can't get to.

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00:00:22.980 --> 00:00:28.470
Kimberly Kelly: Give a few more, there are some folks joining us right now and give them a few more minutes to come in.

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00:02:53.670 --> 00:03:04.470
Kimberly Kelly: All right, I think we've got a nice group here and there may be a few other people trickling in, but I think we've caught

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00:03:05.250 --> 00:03:24.150
Kimberly Kelly: most of the folks that will be joining us today. I would like to welcome you to the second session of the webinar series on genetic services in Appalachia We ask that you mute your microphone for the talk and place any comments that you have in the chat.

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00:03:25.620 --> 00:03:35.820
Kimberly Kelly: We ask that you not record our session we will be recording this session and providing a transcript on our webinar website, so we are happy.

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00:03:36.570 --> 00:03:43.230
Kimberly Kelly: for you to go back and listen and anything that you might have missed or you can.

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00:03:43.920 --> 00:03:53.820
Kimberly Kelly: You know, review the transcript. We're happy that you're participating and interested, and we will do our best to get the information to you.

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00:03:54.630 --> 00:04:07.800
Kimberly Kelly: So, at the end of the session today, we will ask for your assessment and feedback, if you have had a chance to review the previous session and haven't had a chance to

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00:04:08.370 --> 00:04:23.490
Kimberly Kelly: do the evaluation from last month we appreciate you going in to do that. It's just helpful for us to have that data to provide as kind of a summary to our our session.

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00:04:24.450 --> 00:04:34.830

Kimberly Kelly: And also to give us feedback. And so we we did review the feedback from the last one and we've tried to to make those and incorporate those changes going forward.

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00:04:36.120 --> 00:04:37.440
Kimberly Kelly: And I do need to make

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00:04:38.610 --> 00:04:58.080
Kimberly Kelly: a correction, I had pronounced Anusha Sheikh's name incorrectly in the previous session and I did want want to alert you to that. I'm also pleased to know that we have Brenda Harding joining us, and she was very instrumental in.

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00:04:59.190 --> 00:05:03.240
Kimberly Kelly: You know, talking to some of my ideas about

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00:05:04.650 --> 00:05:08.130
Kimberly Kelly: thinking more about genetic services in Appalachia. We had

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00:05:09.150 --> 00:05:24.060
Kimberly Kelly: discussed some different options, so we are appreciative

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00:05:24.630 --> 00:05:37.980
Kimberly Kelly: of the help and assistance and funding from AHRQ. So now, as you know, our aims are to to develop a research agenda for genetic services in rural Appalachia.

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00:05:38.610 --> 00:05:54.030
Kimberly Kelly: And each month we will be having speakers who are working in genetic service provision to medically underserved populations, with a focus on setting a research agenda and rural Appalachia. And so I would now like to introduce our speakers.

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00:05:55.380 --> 00:06:10.980
Kimberly Kelly: Ms. Margaret Au and Ms. Justine Pickarski. Margaret Au is the genetic counselor supervisor for pediatric genetics and metabolism at University of Kentucky Healthcare.

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00:06:11.730 --> 00:06:20.670
Kimberly Kelly: Thus far in her career she's cultivated genetic counseling expertise in a variety of settings, including research, public health and pediatrics.

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00:06:21.180 --> 00:06:25.740

Kimberly Kelly: As part of the pediatric general genetic counseling team at University of Kentucky.

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00:06:26.070 --> 00:06:33.270
Kimberly Kelly: She's privileged to serve as a guide on the diagnostic odyssey and engage in shared decision making with patients and families

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00:06:33.600 --> 00:06:46.050
Kimberly Kelly: being evaluated for a wide range of indications. She completed her master's degree in Genetic Counseling at the University of Cincinnati and Cincinnati Children's hospital, and has a Masters

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00:06:46.440 --> 00:07:02.220
Kimberly Kelly: of Bioethics from the University of Pennsylvania, so a lot of intersectionality a lot of our Appalachian population, also in Ohio and Pennsylvania, and we'll be hearing more about Pennsylvania next month.

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00:07:03.480 --> 00:07:11.730
Kimberly Kelly: So now Justine Pickarski is a licensed genetic counselor at the University of Kentucky Markey Cancer Center

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00:07:12.030 --> 00:07:23.550
Kimberly Kelly: and is responsible for providing programmatic leadership for genetic counseling services at Markey Cancer Center, and she was one of the first people that I spoke to about

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00:07:23.910 --> 00:07:34.140
Kimberly Kelly: putting together a webinar. And so we've been very pleased that University of Kentucky is working with us. She's provided genetic counseling services to

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00:07:36.180 --> 00:07:45.690
Kimberly Kelly: to patients in Kentucky for over 10 years and has helped establish outreach clinics and telehealth services for cancer patients and their families.

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00:07:46.440 --> 00:08:00.570
Kimberly Kelly: So with that I'll turn it over to you, Margaret and if you're able to share screen. I will mute myself, and I will watch for any comments that are coming in to the chat. Thank you.

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00:08:02.970 --> 00:08:05.220
Margaret Au: Excellent. Thank you so much for that introduction.

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00:08:06.270 --> 00:08:08.520
Margaret Au: I believe I am sharing my screen.

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00:08:10.260 --> 00:08:11.880
Margaret Au: Hopefully everyone's able to see it.

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00:08:13.470 --> 00:08:21.150
Margaret Au: So I'll be talking a bit about the general genetics side of genetics and genomics healthcare at UK healthcare.

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00:08:28.380 --> 00:08:33.600
Margaret Au: I am trying to advance my slides, I have nothing to disclose.

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00:08:35.790 --> 00:08:46.710
Margaret Au: And I think you can't talk about Kentucky without talking about counties. Kentucky is a state that's really defined by counties, and I practice in Fayette county.

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00:08:47.760 --> 00:08:57.720
Margaret Au: Which is right there, kind of in the middle it's not technically a county within Appalachia but borders Appalachian counties and

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00:08:58.890 --> 00:09:08.610
Margaret Au: We serve patients really from the Center part of the state to the eastern most parts of the state. The only other pediatric and general genetic clinic

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00:09:09.750 --> 00:09:17.280
Margaret Au: in the state of Kentucky is located in Louisville in the Jefferson county area and

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00:09:18.420 --> 00:09:31.890
Margaret Au: Our clinics generally divide the state in half, with the Louisville clinic providing services to the western part of the state and our clinic providing services to the central and eastern part of the state.

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00:09:35.790 --> 00:09:45.270
Margaret Au: Justine and I also wanted everyone to be aware that the state of Kentucky has established licensure for genetic counselors starting in 2018.

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00:09:45.870 --> 00:09:59.190
Margaret Au: And these are the tasks that we are allowed to perform under our license, getting family histories, medical histories, talking about genetic diagnoses.

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00:09:59.610 --> 00:10:15.750
Margaret Au: Identifying and ordering genetic testing, which is kind of a yes and no situation, because we are not yet recognized by Medicare and Medicaid.

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00:10:16.830 --> 00:10:27.420
Margaret Au: CMS ordering is sometimes tricky and integrating those diagnostic studies, with the personal and family medical histories talking about the implications of genetic diagnoses and results of tests

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00:10:27.930 --> 00:10:39.000
Margaret Au: and providing client centered counseling and anticipatory guidance identifying and utilizing community resources for support and advocacy and documenting our patient interactions.

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00:10:41.760 --> 00:10:50.940
Margaret Au: So now on to the genetic and genomic services at Kentucky Children's Hospital, which is where I practice within the University of Kentucky healthcare.

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00:10:53.970 --> 00:11:02.580
Margaret Au: It is the largest children's hospital in the state that I'm aware of, and we have the largest NICU in the state most definitely.

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00:11:03.420 --> 00:11:21.690
Margaret Au: We offer pediatric specialty services not available in other parts of Central or Eastern Kentucky and care for some of the sickest and most medically complex children in Appalachia Kentucky. So you can see here the volumes of admissions and our capacity.

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00:11:26.130 --> 00:11:32.070
Margaret Au: I notice Dr. Zhang is on, and I did want everyone to know that we have a genomic laboratory

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00:11:32.130 --> 00:11:33.690
Margaret Au: Clinical genomics laboratory

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00:11:33.840 --> 00:11:45.630
Margaret Au: available to us at UK health care, and they are set up to offer a number of genomic tests, including chromosome microarray, Fragile X testing.

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00:11:46.110 --> 00:11:56.280

Margaret Au: A number of Cardiology gene panels like aortopathy panels cardiomyopathy arrhythmia gene panels things like that, as well as clinical exome sequencing.

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00:11:57.870 --> 00:12:09.300
Margaret Au: And our team in pediatrics has partnered with our pathology department to provide some limited genetic counseling support for test utilization management and coordination.

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00:12:10.020 --> 00:12:16.260
Margaret Au: And there is an open laboratory genetic counselor position available if anyone is interested I'd be happy to talk with you.

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00:12:18.750 --> 00:12:27.300
Margaret Au: Our team in the clinical genetic side of things is encompassed by a number of key personnel.

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00:12:28.020 --> 00:12:39.450
Margaret Au: We have a physician geneticists Dr. Stephen Kahler, he is our interim Chief of genetics and metabolism, and works part time remotely from Arkansas about three out of four weeks per month.

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00:12:40.260 --> 00:12:54.870
Margaret Au: And we do have some open physician genetics geneticists positions. We also have three advanced practice nurse practitioners, Paige Matheny, Angela Crutcher and a new hire Kathy Starks I think I can

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00:12:55.650 --> 00:13:02.370
Margaret Au: Let everyone know who she is, as well as three genetic counselors myself, Miriam Bunch and Hillary Rieger.

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00:13:03.870 --> 00:13:09.180
Margaret Au: And then we have a nursing team nurse team leader, a registered nurse

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00:13:09.690 --> 00:13:20.550
Margaret Au: A nurse navigator who primarily works with coordinating the newborn screening results, not just inborn errors of metabolism, but all newborn screens that flag for Central and Eastern Kentucky.

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00:13:21.270 --> 00:13:39.600
Margaret Au: And we are in the process of requesting an additional registered nurse position. We also have two metabolic dietitians and additional support staff, including a patient navigator and two other administrative support staff members, one of whom is designated as a genetic counselor assistant.

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00:13:43.170 --> 00:13:55.500
Margaret Au: The patient population we serve is quite broad, even though we are located within a pediatric clinic in the department of pediatrics we see patients of all ages.

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00:13:56.250 --> 00:14:07.380
Margaret Au: Most of them reside in Central and Eastern Kentucky but occasionally we'll have patients from Western Kentucky sometimes I'll see patients from West Virginia, and I believe my colleagues do as well.

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00:14:08.610 --> 00:14:13.560
Margaret Au: And over half of our patients have some type of Medicaid insurance plan.

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00:14:18.630 --> 00:14:25.740
Margaret Au: We provide services in both in an ambulatory setting and through Inpatient consultations.

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00:14:26.820 --> 00:14:33.000
Margaret Au: For ambulatory appointments we offer telehealth and appointments in-person in our clinic.

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00:14:34.680 --> 00:14:50.220
Margaret Au: Since the pandemic hit, we switched to majority telehealth appointments and have continued that to this day. At this point about 80% of our ambulatory appointments are performed by telehealth.

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00:14:52.080 --> 00:15:02.340
Margaret Au: For Inpatient consultations, most of those are, they're going to go directly to the physician or the nurse practitioner on call.

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00:15:03.540 --> 00:15:21.000
Margaret Au: The genetic counselor may be involved with those to some degree, and we have started to pilot a genetic counselor-only inpatient consultation for children who are coming into the hospital through the child neurology service for epilepsy.

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00:15:23.130 --> 00:15:38.370
Margaret Au: We also provide evaluation and counseling like I was saying, for a broad range of indications basically everything except hereditary cancer indications and prenatal or preconception indications. We also at UK health care

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00:15:39.150 --> 00:15:46.410

Margaret Au: In addition to Justine's team, which she will tell you about soon, we have a prenatal genetic counselor in our ObGyn department.

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00:15:48.000 --> 00:15:57.600
Margaret Au: My team is also involved with providing newborn screen follow-up for infants, who flagged as positive for inborn errors of metabolism.

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00:15:58.710 --> 00:16:07.320
Margaret Au: And as I was saying, we provide some limited genetic counselor support for our pathology department for lab test utilization management.

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00:16:09.090 --> 00:16:19.440
Margaret Au: Since we are located within an academic medical center we have a medical school and a number of other graduate and undergraduate programs.

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00:16:20.220 --> 00:16:38.130
Margaret Au: We do host a number of students in our group, medical students, residents, genetic counseling students, undergraduates, and graduate students. The genetic counseling students are from outside institutions. UK and really any other

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00:16:39.960 --> 00:16:46.230
Margaret Au: institution in Kentucky does not have a genetic counseling training program. There's no such program yet in the state.

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00:16:49.770 --> 00:17:08.130
Margaret Au: So some information about our volume. I think we have been quite successful, and in spite of a number of challenges with pandemic and staffing and have been able to increase our patient and appointment volumes dramatically in the last three years.

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00:17:09.180 --> 00:17:19.710
Margaret Au: It says appointment volume and not patient volume, because our physician or nurse practitioner may have an appointment with a patient, but we have started

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00:17:20.910 --> 00:17:32.910
Margaret Au: Creating a separate appointment for genetic counseling appointment visits if the patient is also seen by a genetic counselor on the same day, and that was really initiated in 2020.

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00:17:33.930 --> 00:17:50.310
Margaret Au: And we also that same year initiated genetic counseling only appointments and these are mostly for disclosure of results or providing pre

test genetic counseling usually for second tier testing like exomes or gene panels.

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00:17:51.780 --> 00:18:00.600
Margaret Au: In 2020 we also hired our third genetic counselor and so that allowed us to increase volumes and as a group initiated telehealth.

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00:18:02.370 --> 00:18:21.420
Margaret Au: In 2021 there were some staffing changes, our physician geneticist at the time relocated to another state, and one of our nurse practitioners retired, and we're now working on replacing them, but even with those challenges we've managed to increase our appointment volumes.

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00:18:25.350 --> 00:18:36.750
Margaret Au: In terms of getting compensated for our services, the majority of this will come from reimbursement for visits, with the physician or the nurse practitioner.

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00:18:37.890 --> 00:18:51.060
Margaret Au: We also do get some funding from the state of Kentucky through a grant for newborn screening for providing follow-up services for individuals or babies in the central and eastern most parts of the state.

83
00:18:52.590 --> 00:18:53.880
Margaret Au: We have tried

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00:18:55.170 --> 00:19:07.140
Margaret Au: billing for genetic counseling, the genetic counselors have tried billing for those services, but we found that there was such a low rate of reimbursement for genetic counselors that

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00:19:08.310 --> 00:19:13.200
Margaret Au: At some point we questioned if it was worth continuing to attempt to billing.

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00:19:14.970 --> 00:19:20.040
Margaret Au: Since such a high percentage of our patients have some Medicaid plan.

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00:19:21.600 --> 00:19:33.360
Margaret Au: Most of those were not getting all of those actually were not getting reimbursed because we're not recognized as providers, genetic counselors as providers, by the centers for Medicaid and Medicare.

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00:19:35.550 --> 00:19:51.030
Margaret Au: So we were also concerned that these patients might be getting some balance bill, and we are at this time not billing for genetic counseling services. We've had some ongoing discussions about other options for billing but haven't yet found a solution.

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00:19:55.080 --> 00:20:07.530
Margaret Au: For our Community outreach activities, these are mostly encompassed by the educational piece that's baked into being part of an academic medical Center.

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00:20:08.370 --> 00:20:25.290
Margaret Au: But a number of my colleagues have given talks to community groups that we you know, often see patients within such as the autism community, the Autism Society of the Bluegrass, and the Down syndrome Association of Central Kentucky or DSACK.

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00:20:27.690 --> 00:20:37.740
Margaret Au: And we have been very busy with genetic counseling students from other programs providing some supervision for those students.

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00:20:39.180 --> 00:20:55.500
Margaret Au: Some opportunities that I see for expanding genomic services within our institution and in the state of Kentucky would be to potentially resume outreach clinics that's not something that we are currently doing.

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00:20:56.520 --> 00:21:21.690
Margaret Au: There has been a long, very I think successful history of geneticists like Dr. Brian Hall traveling out to eastern Kentucky and actually meeting patients where they're at, so I think there's lots of wonderful opportunities there, but we do need the staffing to support those outreach clinics.

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00:21:23.490 --> 00:21:30.990
Margaret Au: We also, I think could provide more services through multi-disciplinary clinics, and there are some areas including

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00:21:32.580 --> 00:21:41.370
Margaret Au: New clinic that's just got gotten off the ground that we've started to be involved with for disorders of sexual development or differentiation.

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00:21:42.660 --> 00:21:54.750
Margaret Au: there's also talk about perhaps starting a Down syndrome clinic that we could be involved in, and there are undoubtedly many other opportunities for multi-disciplinary clinics.

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00:21:56.670 --> 00:22:08.970
Margaret Au: I think the creation of low literacy genomics educational tools within our institution and beyond would benefit our patients a great deal.

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00:22:09.660 --> 00:22:16.680
Margaret Au: Perhaps having videos that they can watch that we can bring in on an iPad or a computer.

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00:22:17.610 --> 00:22:27.960
Margaret Au: Or providing some very general basic written materials would be really helpful, a lot of our patients when they come to us initially,

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00:22:28.620 --> 00:22:44.640
Margaret Au: have a limited understanding of what the role genetics plays in their healthcare so even having something that explain that to them before they are seen before the visit, I think would be helpful and perhaps improve show rates things like that.

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00:22:46.770 --> 00:22:56.940
Margaret Au: I've also been thinking about how genetic counselors might be integrated into other areas beyond genetics and metabolism, in other specialty clinics.

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00:22:57.810 --> 00:23:03.990
Margaret Au: With our Inpatient consultation for child neurology and children with epilepsy.

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00:23:04.770 --> 00:23:15.270
Margaret Au: I've also had some discussions with pediatric primary care about the possibility of integrating a genetic counselor within that sort of practice to

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00:23:15.720 --> 00:23:34.620
Margaret Au: perhaps initiate some of the genomic workup for kids with developmental delay or multiple congenital anomalies. Right now our wait for an appointment in genetics is into the summer of 2022, so perhaps having a genetic counselor

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00:23:36.060 --> 00:23:46.140
Margaret Au: available to some of those clinics, where there might be first year testing that they can you know assist with and make recommendations about, I think could be beneficial.

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00:23:50.550 --> 00:23:54.180

Margaret Au: And that is all I have, so I am going to

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00:23:59.580 --> 00:24:01.290
Margaret Au: stop the share

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00:24:02.550 --> 00:24:03.690
Margaret Au: and hand it off to Justine.

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00:24:09.360 --> 00:24:10.650
Justine Pickarski: Let me get my

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00:24:13.050 --> 00:24:13.590
Justine Pickarski: sharing going.

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00:24:17.430 --> 00:24:32.250
Justine Pickarski: Right so good afternoon I'm happy to be here today and also just want to thank the organizers of this series for inviting me and Margaret to share what's going on at the University of Kentucky.

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00:24:32.760 --> 00:24:40.590
Justine Pickarski: And Margaret's done a great job going over some information about UK and Kentucky and specifically about the general genetics and pediatric world.

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00:24:41.220 --> 00:24:48.600
Justine Pickarski: I'll be sharing our experience at Markey cancer Center and while we have genetic across different specialties at UK,

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00:24:49.200 --> 00:25:04.680
Justine Pickarski: one thing to point out, and that Margaret alluded to is that we are all housed within our own respective departments, and so that I'm at Markey Cancer Center, Margaret's with the Children's Hospital, and then our prenatal genetic counselors house within

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00:25:05.940 --> 00:25:11.790
Justine Pickarski: the MFM clinics there, so we are not one combined group necessarily.

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00:25:14.130 --> 00:25:21.420
Justine Pickarski: So these are my disclosures. I am a consultant for My Gene Counsel, however, that shouldn't impact any of our discussion for today.

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00:25:22.680 --> 00:25:36.480

Justine Pickarski: And you saw this map earlier today with our many counties across Kentucky and those that I have circled in blue are the counties, where there are genetics providers who are available in person, cancer genetic providers.

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00:25:37.200 --> 00:25:48.330
Justine Pickarski: So Fayette County there in the middle again, that's where we practice in Lexington. There are seven genetic counselors across the hospital here in in Lexington who will see patients in person.

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00:25:49.080 --> 00:26:02.610
Justine Pickarski: Kenton county up at the top of the state is near Cincinnati and they have several genetic counselors that are in northern Kentucky. Jefferson County is where Louisville's located so again they have several cancer gc's practicing there.

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00:26:03.690 --> 00:26:09.690
Justine Pickarski: The two counties that are circled that are the farthest west and the farthest east so Davies and Pike county

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00:26:10.320 --> 00:26:17.640
Justine Pickarski: each have one provider. So Davies county in the West is where Owensboro is so that's not technically part of Appalachia.

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00:26:18.270 --> 00:26:23.970
Justine Pickarski: They have one genetic counselor there, and she started about a year ago, and she's the first genetic counselor that they've had there.

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00:26:24.780 --> 00:26:36.450
Justine Pickarski: In Pike county in the Far East, there is a nurse practitioner who goes to that clinic so not a genetic counselor but a nurse practitioner, who has special training in cancer genetics.

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00:26:37.020 --> 00:26:46.590
Justine Pickarski: And she has, she comes I think last I heard it was twice a month, but she goes to that clinic, and she actually comes from the University of Tennessee in Knoxville.

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00:26:47.130 --> 00:26:54.630
Justine Pickarski: So she's been doing that for I think over 10 years so she's provided services to that Appalachian area for quite a while.

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00:26:56.160 --> 00:27:02.280
Justine Pickarski: And then here are circled in yellow that you can kind of see, those are areas that we at Markey provide telegenetic services.

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00:27:02.640 --> 00:27:16.320
Justine Pickarski: So those are sites where the patient goes to the hospital in that county and UK has an agreement with that institution, and we see the patient via telehealth, and we'll talk a little bit more about that in a bit.

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00:27:18.450 --> 00:27:28.200
Justine Pickarski: So a little bit here about Markey Cancer Center, so Markey has been around since 1983, and we are Kentucky's only NCI-designated Cancer Center.

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00:27:28.860 --> 00:27:39.030
Justine Pickarski: We first received that designation in 2013 so it's been a number of years. Since 2017 we've been ranked in the top 50

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00:27:39.480 --> 00:27:49.530
Justine Pickarski: cancer centers by the U.S. News and World Report, so as you can imagine, we're a top cancer Center in the U.S., let alone the state on, so we do have many patients to travel to see us from

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00:27:49.950 --> 00:28:02.730
Justine Pickarski: Across the state or even across state lines; so it’s a wide population that we see. Markey does see over 100,000 outpatient visits each year and in 2020 there were over

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00:28:03.210 --> 00:28:21.780
Justine Pickarski: 34,000 unique patients who were seen, and we have a number of different support services at Markey aside from genetics. So you see those listed there, PT, social workers, financial counseling, and a number of other others that I probably didn't include there but lots of services for patients.

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00:28:24.330 --> 00:28:34.620
Justine Pickarski: Markey has a network of affiliate hospitals, which is the Markey Cancer Center Affiliate Network or MCCAN for short, and this is an affiliation that started in 2006

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00:28:35.220 --> 00:28:46.680
Justine Pickarski: and is now a group of 20 hospitals located throughout Kentucky, and they are shown here on this map. And as you can see they're spread throughout the state, but quite a few of them are in the Appalachian

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00:28:47.220 --> 00:28:52.410
Justine Pickarski: Eastern part of the State. So at Markey we provide cancer specific education and training

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00:28:53.100 --> 00:29:01.920
Justine Pickarski: For these Community doctors and nurses and staff to ensure that they're getting the most up to date cancer information and that's available to providers.

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00:29:02.760 --> 00:29:08.850
Justine Pickarski: Markey also helps to assess these cancer programs in achieving and maintaining Commission on Cancer accreditation.

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00:29:09.720 --> 00:29:18.780
Justine Pickarski: And they also provide services such as genetic counseling that many of these hospitals do not have. These are typically smaller Community hospitals.

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00:29:19.530 --> 00:29:27.420
Justine Pickarski: So we provide telehealth to these hospitals and patients. However, not all of these sites choose to use our telehealth services at UK.

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00:29:28.140 --> 00:29:39.840
Justine Pickarski: And the goal of the MCCAN network is really so that patients are able to get quality cancer care close to home without having to constantly travel several hours to get their cancer care.

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00:29:42.810 --> 00:29:51.270
Justine Pickarski: So this just shows where we get our referrals from specifically for cancer genetics, and this is data from 2020.

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00:29:51.630 --> 00:30:00.780
Justine Pickarski: And you can see here that in the dark blue, almost half of our patients are referred from within Markey so our own oncologist referring patients.

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00:30:01.590 --> 00:30:21.300
Justine Pickarski: About 11% are from these MCCAN sites so that's in that light blue section and then 19% of our referrals in 2020 were, which is that green section. So those are patients who are referred from UK providers, but not specific to Markey so think primary care doctors, ObGyn, gastroenterologist.

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00:30:22.500 --> 00:30:28.560
Justine Pickarski: And then that little 4% in yellow, those are, that’s a smaller community hospital here in Lexington that

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00:30:29.070 --> 00:30:40.290

Justine Pickarski: UK has a partnership with, and then so overall only about 11% or so of our referrals in 2020 were from outside institutions that have no real affiliation with

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00:30:41.010 --> 00:30:54.030
Justine Pickarski: with UK or with Markey. And then that 9% in the gray are self referrals, many of whom are family members of patients that we had previously seen and may have recommended testing for those family members.

147
00:30:57.360 --> 00:31:09.600
Justine Pickarski: So a little background about our team here, so I came to Markey in August of 2016, and at that time I was the only genetic counselor, and we didn't have any dedicated support staff.

148
00:31:10.110 --> 00:31:17.490
Justine Pickarski: And then prior to 2016, Markey had had genetic counselors but had only ever had like one, at a time, and the plan

149
00:31:17.880 --> 00:31:24.990
Justine Pickarski: when I came in was to build more of a program and be able to provide more cancer genetics services to patients.

150
00:31:25.650 --> 00:31:33.930
Justine Pickarski: And so, when I came on, they had been without a genetic counselor for almost a year, so there was a lot of backlog and things to be done there.

151
00:31:34.590 --> 00:31:41.490
Justine Pickarski: And so I came on in 2016, and this is again just a timeline kind of showing what's happened since then.

152
00:31:42.270 --> 00:31:49.230
Justine Pickarski: Within a year, we did hire a second genetic counselor Tara Lucas. That position was already approved at the time that I was hired but

153
00:31:50.010 --> 00:32:06.630
Justine Pickarski: took a little while to get someone to fill the position with staffing issues and a shortage of providers, genetics providers. And then we hired a coordinator and assistant in January of 2018, and then we hired a third genetic counselor in August of 2019.

154
00:32:07.980 --> 00:32:19.890
Justine Pickarski: During the pandemic, there were some staffing changes so then some of our assistant’s duties had changed, and we had a scheduler assigned to

us in July of 2020, and then you can see, we lost the genetic counselor in August of

155
00:32:21.300 --> 00:32:31.230
Justine Pickarski: This or sorry, yes, she left in April of 2021 to pursue a fully remote telehealth position, and then in May of this year we

156
00:32:32.010 --> 00:32:41.610
Justine Pickarski: had one of our nurse practitioners at Markey complete the cancer intensive course through City of Hope so she's primarily using that training

157
00:32:42.000 --> 00:32:52.590
Justine Pickarski: to help run a high risk clinic at Markey and then in July we hired a replacement for the GC that we had previously, earlier this year so Michael Gosky is the third genetic counselor now.

158
00:32:53.190 --> 00:32:58.080
Justine Pickarski: And so, our team is still fairly small so there's just three genetic counselors.

159
00:32:58.710 --> 00:33:13.770
Justine Pickarski: Our scheduler and our coordinator are both shared positions so most of their work is with genetics. I would say over half of what they end up doing is time spent with genetics, but they are shared roles so they're kind of equivalent to one SPE total.

160
00:33:17.160 --> 00:33:25.470
Justine Pickarski: And then, this is a list of all our services that we provide so of course we do ambulatory in person and telehealth consultations.

161
00:33:26.010 --> 00:33:34.770
Justine Pickarski: And we rarely will see patients inpatient and the vast majority of ours are in-person and telehealth consults, and currently over half of our

162
00:33:35.220 --> 00:33:44.580
Justine Pickarski: consultations are through telehealth. Prior to the pandemic only our MCCAN patients were seen via telehealth with those agreements, but COVID has

163
00:33:45.180 --> 00:33:50.580
Justine Pickarski: changed things, and so we are still seeing the majority of our patients through telehealth.

164
00:33:51.480 --> 00:34:02.430
Justine Pickarski: And we, the genetic counselors attend several oncology tumor boards. So there's a number of those throughout the week; there's about nine that us genetic counselors attend that we split those up amongst us.

165
00:34:03.150 --> 00:34:12.720
Justine Pickarski: And then we do review somatic test result for molecular tumor board, so typically there's about 15 or 20 cases that we were review a week.

166
00:34:13.680 --> 00:34:24.630
Justine Pickarski: And many of those are not from Markey. We get a lot that are across the state that outside providers are sending to our molecular tumor board for review.

167
00:34:25.440 --> 00:34:32.940
Justine Pickarski: And we are MCCAN telehealth consultation and we do have a couple of high risk screening clinics that Markey screening clinics,

168
00:34:33.540 --> 00:34:48.330
Justine Pickarski: the GI clinic as it is one that we just started in July of 2020; so that one's pretty new and that's the one that the nurse practitioner has started that clinic, and then we've had a breast, a high risk breast clinic for a number of years.

169
00:34:49.980 --> 00:34:59.130
Justine Pickarski: January of 2020 we started a pediatric cancer predisposition clinic, and this is a clinic that Margaret’s team provide some input on as well, depending on

170
00:35:00.600 --> 00:35:06.060
Justine Pickarski: the patient presentation, but that's the clinic that we've primarily taken on since it's cancer predisposition.

171
00:35:06.930 --> 00:35:15.960
Justine Pickarski: And we're on a number of committees so cancer committees, survivorship committee, our GC’s are on several different, couple different committees.

172
00:35:16.530 --> 00:35:29.820
Justine Pickarski: And then we often get pulled into different research projects and ideas to help provide input or oversee some of those, and lots of education to providers, patients, and students.

173
00:35:32.970 --> 00:35:39.240

Justine Pickarski: So our patient volumes are here and this shows our patient volume since 2017.

174
00:35:39.810 --> 00:35:54.660
Justine Pickarski: These are calendar years so 2021 is not yet complete, and these are data through September either. And these just for our genetic counselors, so I think also different than a lot of the pediatric in general, genetic clinic that all of our visits or GC-only visits.

175
00:35:55.710 --> 00:36:04.380
Justine Pickarski: So as you can see here our volumes have increased over time as we are able to add more genetic counselors and have some more support staff.

176
00:36:05.130 --> 00:36:15.210
Justine Pickarski: And in 2020, we did start seeing all of our patients via telehealth for a period of time, thanks to the pandemic again, as I said, now over half of our patients are still seen

177
00:36:16.080 --> 00:36:23.370
Justine Pickarski: through telehealth, and we're giving patients option of doing either in person or telehealth, and many of them are still choosing to do telehealth.

178
00:36:23.700 --> 00:36:34.590
Justine Pickarski: So they don't have to travel or take off work, and many patients who are undergoing cancer treatment may have lots of other visits and so it's just one less thing they have to come to the hospital for.

179
00:36:36.180 --> 00:36:43.200
Justine Pickarski: In 2020 there were an additional 131 patients, you can see in that light blue.

180
00:36:43.770 --> 00:36:58.320
Justine Pickarski: So those are patients who underwent physician initiated testing through our pancreatic protocol, and those are in 2020 and 2021 there, and in the next few minutes, we'll all talk a little bit more about that specific protocol that we have.

181
00:37:00.510 --> 00:37:09.960
Justine Pickarski: So this physician-initiated testing for our pancreatic cancer patients is an alternative service delivery model that we started in January of 2020.

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00:37:10.710 --> 00:37:22.830

Justine Pickarski: For those of you who are not familiar with a lot of cancer genetics, they do recommend that all patients who have pancreatic adenocarcinoma should be offered germline genetic testing for hereditary cancers.

183
00:37:23.310 --> 00:37:31.110
Justine Pickarski: And this was a guideline change to NCCN criteria that happened in 2018 so kind of in the middle of 2018.

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00:37:31.620 --> 00:37:40.500
Justine Pickarski: And the testing is recommended to be done fairly early in the time of diagnosis and treatment, because the cancer type has high mortality and

185
00:37:40.860 --> 00:37:51.510
Justine Pickarski: the genetic testing can often help determine whether there are specific treatments for the patient, and of course, it can have implications for family members and inform them about cancer risk.

186
00:37:52.770 --> 00:37:59.550
Justine Pickarski: So well, many of our providers were referring these patients, there were a number of patients who were unable to be seen.

187
00:38:00.390 --> 00:38:06.810
Justine Pickarski: Because they weren't able to travel back and forth, or they were too sick or unfortunately, some of them would pass away

188
00:38:07.650 --> 00:38:11.310
Justine Pickarski: between the time that patient was referred, and then the time of their appointment.

189
00:38:12.090 --> 00:38:19.350
Justine Pickarski: So there was one week late in 2019 that I had like five of these pancreatic cancer patients on my schedule and

190
00:38:19.710 --> 00:38:28.620
Justine Pickarski: I didn't end up seeing any of them because they were all too sick to come in for their visit, or had gone home with hospice, or had already passed away, and so that

191
00:38:29.040 --> 00:38:43.230
Justine Pickarski: that week kind of prompted us to really look at our model and come up with a way to ensure that patients were able to have testing done because often they were being referred, but they weren't able to be seen, or have their testing done.

192

00:38:45.120 --> 00:38:56.340
Justine Pickarski: So the genetic counselors along with our medical oncologist and our surgical oncologist, we all worked together to come up with a workflow to help improve the access to germline testing for these patients.

193
00:38:56.940 --> 00:39:05.130
Justine Pickarski: And so, this is the outline that we have that workflow so basically when a patient comes to the clinic if they have pancreatic cancer

194
00:39:05.880 --> 00:39:14.880
Justine Pickarski: the clinic staff give the patient family history questionnaire to complete, it's not as detailed as what our genetic counselors would get, but it does help provide some additional

195
00:39:15.300 --> 00:39:24.330
Justine Pickarski: information to ensure that we're ordering the most appropriate tests for the patient. And then the patient meets with their provider and

196
00:39:24.720 --> 00:39:29.250
Justine Pickarski: the physician or the nurse will discuss the option of genetic testing with the patient.

197
00:39:29.910 --> 00:39:39.930
Justine Pickarski: We created a fact sheet with frequently asked questions, and we ask that the providers use that fact sheet as a guide to help lead the discussion and address questions.

198
00:39:40.770 --> 00:39:53.220
Justine Pickarski: Then the patient is given that fact sheet which has our contact information on it and the patient can decide, then, if they want to do, testing, or if they you know want a more typical pre-test genetic counseling session.

199
00:39:53.970 --> 00:40:04.230
Justine Pickarski: So the genetic counselors are very involved with this process, and we review the family history questionnaire, help coordinate testing and document things in the health record.

200
00:40:04.710 --> 00:40:08.670
Justine Pickarski: And we do contact every patient with the results once they're available so

201
00:40:09.330 --> 00:40:21.270

Justine Pickarski: even if their results are negative, that just allows us to have a touch point with the patient and ensure that all of their questions are answered, and you know, if there's any follow up that needs to be had with family members

202
00:40:21.870 --> 00:40:31.290
Justine Pickarski: we can talk to them about that. If the patient does have a positive test, of course, we typically will try and schedule them for a more detailed consultation to review the results.

203
00:40:31.620 --> 00:40:41.610
Justine Pickarski: And implications for family and those can be done via telehealth or if they're coming back into the clinic we will try and see them the same day that they're being seen at Markey.

204
00:40:44.100 --> 00:40:55.230
Justine Pickarski: So what has the impact of this been, so in 2019 we tested a total of 13 pancreatic cancer patients, again many more than 13 were referred, but

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00:40:55.980 --> 00:41:04.410
Justine Pickarski: They were often not able to be seen, for a number of reasons, so 13 in total. In 2020, which is when we started this

206
00:41:04.920 --> 00:41:18.960
Justine Pickarski: we blew past that low bar of 13 patients within the first month, and we tested 131 patients in 2020. So this process really did improve the number of patients and family members that we were able to impact.

207
00:41:20.160 --> 00:41:33.330
Justine Pickarski: Of that 131 about 40 of those were diagnosed with cancer prior to 2020; so we were picking up, not just the newly diagnosed patients, but some of those that had lived with their disease for several months or years.

208
00:41:34.380 --> 00:41:36.360
Justine Pickarski: And then in 2021 so far

209
00:41:37.590 --> 00:41:52.170
Justine Pickarski: we have, and this is from a couple months ago now, but we've tested 75 patients this year. We do expect this year that we will have a lower number, since we aren't really playing catch up like we were last year with some of those patients who had previously been missed.

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00:41:53.610 --> 00:42:00.510

Justine Pickarski: So now, you can kind of say that our genetics team also includes our surgical oncologist and medical oncologist to some extent, since they are

211
00:42:01.080 --> 00:42:11.190
Justine Pickarski: involved in the genetic testing process more than they historically have been, and we've seen that a lot of the providers have gotten really engaged with genetics and

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00:42:11.640 --> 00:42:18.990
Justine Pickarski: cascade testing and those sorts of things, and you can see here they got a little competitive sometimes about who was testing the most patients so

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00:42:19.500 --> 00:42:25.170
Justine Pickarski: this picture is one of our surgical oncologist Dr. Cavnar and he sent a picture

214
00:42:25.920 --> 00:42:41.640
Justine Pickarski: through email to us, and said "#winning" the day that he had seen a number of pancreatic cancer patients in clinic; so it was exciting to see those providers getting interested in and having a little bit more engagement with genetics.

215
00:42:43.860 --> 00:42:52.110
Justine Pickarski: To talking about the money, so we do bill using the code 96040 code for the patients that we see at Markey.

216
00:42:53.340 --> 00:43:02.670
Justine Pickarski: I think that was all put in place before I came, and they've still always done it, but there is still a low reimbursement rate for services as Margaret discussed earlier.

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00:43:03.600 --> 00:43:14.010
Justine Pickarski: Our MCCAN visits are a little bit different. So these are currently done with institutional billing and something that may change those contracts change and since

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00:43:14.820 --> 00:43:24.900
Justine Pickarski: our telehealth services have changed over the last couple of years since the pandemic. So the current process is that our referring institution is billed a flat fee

219
00:43:25.440 --> 00:43:36.540

Justine Pickarski: per patient. So it tends to be better on our end financially, since it's a guaranteed amount of money and is often more than what the insurance companies would reimburse us.

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00:43:38.370 --> 00:43:43.260
Justine Pickarski: And then another way you could kind of look at reimbursement and not something that we have specifically looked at

221
00:43:43.830 --> 00:43:51.630
Justine Pickarski: UK, but there was a study just recently published in ASCO from the cancer genetics team at UT Southwestern.

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00:43:52.140 --> 00:44:01.410
Justine Pickarski: And with their study they found that one full time cancer genetic counselor would generate 1.49 to $1.86 million in revenue each year.

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00:44:02.310 --> 00:44:08.400
Justine Pickarski: Just looking at screenings and preventative surgeries and things that that would be done as follow up, and this

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00:44:08.820 --> 00:44:21.360
Justine Pickarski: study only will set patients who had BRCA1 or two mutation or Lynch syndrome, so if you think about all the other hereditary cancer syndromes that also need extra screening or even patients who

225
00:44:22.260 --> 00:44:30.420
Justine Pickarski: are high risk just based on family history alone, I think that number would probably go up. So return on investment is quite good, because

226
00:44:31.230 --> 00:44:45.810
Justine Pickarski: 1.49 to $1.8 million is much more than a genetic counselor's salary. It did not account for salaries; so it's not something we've looked at, specifically at UK, but I think it'd be interesting to see what our reimbursement might be there.

227
00:44:48.360 --> 00:44:56.490
Justine Pickarski: And we do some community outreach activities, although being in an academic institution, a lot of our community outreach is within our own UK community.

228
00:44:57.240 --> 00:45:04.650
Justine Pickarski: So we do provide quite a bit of education within UK and within Markey through grand rounds, lunch and learns, and those types of things.

229

00:45:05.520 --> 00:45:18.990
Justine Pickarski: We also give talks for different groups such as residents and fellows. The ACTION program here at UK which I wanted to point out, specifically because it's an interesting group of high school and undergraduate students here at UK.

230
00:45:20.100 --> 00:45:28.710
Justine Pickarski: Pertinent to this talk because it's it stands for the Appalachian career training in oncology so this program gives

231
00:45:29.190 --> 00:45:37.230
Justine Pickarski: these students from Appalachia an opportunity to and to gain some experience in cancer research

232
00:45:37.890 --> 00:45:51.360
Justine Pickarski: and clinical and outreach education experiences so the goal with that program is to help these students from Appalachia be interested in oncology care and hoping that they will pursue a cancer focused career.

233
00:45:52.770 --> 00:46:05.700
Justine Pickarski: And we do quite a few problem presentations for outside hospitals and Markey does conferences every year, they host a few of those and then with our MCAAN hospitals. We provide several

234
00:46:06.180 --> 00:46:10.230
Justine Pickarski: outreach or presentations and educational events for them.

235
00:46:11.130 --> 00:46:24.210
Justine Pickarski: And we do supervise genetic counseling students from other institutions as Margaret said, and then prospective students, so undergraduates or high school students who may be interested in pursuing a career in genetic counseling.

236
00:46:24.810 --> 00:46:35.760
Justine Pickarski: And then we do have presentations for community groups that we've been asked to do; so I've listed a few of those here, and this has been a little more minimal over the past couple years with the pandemic.

237
00:46:38.790 --> 00:46:56.790
Justine Pickarski: Okay, and then our last few minutes, I've got a couple of slides here that Margaret and I had put together about combined observations for patients at UK; so asked Margaret to comment on anything that I may miss on on her end, or things that she are specific to her clinic.

238
00:46:57.990 --> 00:47:12.750

Justine Pickarski: And so, some of the barriers and limitations are here, and I know Margaret had mentioned earlier that previously there were many outreach clinics, which are not currently possible due to staffing limitations.

239
00:47:13.950 --> 00:47:15.960
Justine Pickarski: Many of our families, both in

240
00:47:16.920 --> 00:47:24.240
Justine Pickarski: the cancer in general and pediatrics, travel several hours each way for their appointment, so can take two to three hours.

241
00:47:25.050 --> 00:47:38.640
Justine Pickarski: Definitely a barrier for patients, and telehealth has improved this for many of the patients, although not everyone has access to telemedicine. They may not have broadband Internet or reliable cell phone service so.

242
00:47:39.870 --> 00:47:52.740
Justine Pickarski: We do tend to have many patients to have low or no health literacy especially or no literacy period and especially when it comes to health literacy that can be a challenge in working with some of these patients.

243
00:47:54.510 --> 00:48:05.490
Justine Pickarski: And then, as Margaret also mentioned earlier, they're currently scheduling into summer of 2022. So that can be a challenge for patients to have to wait that long before they're able to be seen.

244
00:48:06.120 --> 00:48:18.600
Justine Pickarski: And again, the low rate of reimbursement for genetic counseling can make it difficult to hire additional staff and to make it a top priority for some of the administrative side.

245
00:48:21.570 --> 00:48:22.050
Justine Pickarski: Anything to add on those Margaret?

246
00:48:24.420 --> 00:48:28.110
Margaret Au: Absolutely, I think the staffing and the reimbursement are connected.

247
00:48:29.430 --> 00:48:41.070
Margaret Au: Unfortunately, but we do have staffing needs beyond just the genetic counseling teams with physicians and for pathology, genetic counselor who wouldn't be billing.

248

00:48:45.480 --> 00:48:49.320
Justine Pickarski: And then anecdotal observations. Margaret do you want to do this one?

249
00:48:49.440 --> 00:49:08.790
Margaret Au: Sure yeah, I had mentioned that a number of our patients and families are unsure of the role the genetics teams and genetic counselors have in their care or their child's care, so perhaps creating some materials for preparing families and patients for visits could be helpful.

250
00:49:10.020 --> 00:49:21.000
Margaret Au: I've practiced in other areas of the country, both coasts and I'm originally from the middle, so what I've noticed about patients here in Kentucky is that

251
00:49:21.840 --> 00:49:31.590
Margaret Au: they are less likely to ask questions of their healthcare providers and maybe more differential to the provider's expertise in the decision making process.

252
00:49:32.940 --> 00:49:45.840
Margaret Au: We in pediatric genetics and metabolism have a high rate of complex patients with multiple medical issues in Justine's area later stage cancer diagnoses, social health issues.

253
00:49:47.490 --> 00:50:04.890
Margaret Au: Kentucky has some of the highest rates of kinship care in the country, so in pediatrics, that means we are seeing children who are not in the care of their biological parents, sometimes in the care of a great grandparent or and an aunt, uncle, cousin or grandparent.

254
00:50:06.060 --> 00:50:16.020
Margaret Au: And what I've also noticed is interesting and Justine probably has, as well, is that many patients' family members are still in the state. Lots of folks

255
00:50:16.440 --> 00:50:24.330
Margaret Au: live in Kentucky their families have been in Kentucky for many generations, which can be helpful in the case of cascade testing.

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00:50:25.320 --> 00:50:39.720
Margaret Au: And patients in general, prefer and report, they are satisfied with their telehealth appointments. Our genetics and metabolism tell healthcare service has consistently received patient experience awards.

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00:50:40.380 --> 00:50:58.560
Margaret Au: So I think this is an opportunity to expand access to genomics and genetic care in Appalachia just a matter of making sure that people have access to the technology so they can they can have a telehealth appointment.

258
00:51:03.960 --> 00:51:05.430
Justine Pickarski: I think that's all we have.

259
00:51:07.500 --> 00:51:10.200
Justine Pickarski: So I think that does leave some time for questions.

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00:51:11.340 --> 00:51:12.210
Kimberly Kelly: Thanks, Ladies.

261
00:51:12.270 --> 00:51:13.140
Justine Pickarski: for discussion.

262
00:51:14.070 --> 00:51:27.330
Kimberly Kelly: I'm going to go ahead and place the evaluation form, and please let me know if you don't see it, and so we appreciate you completing that evaluation form just to give us some feedback and to know

263
00:51:27.960 --> 00:51:42.210
Kimberly Kelly: what you as a participant what your goals are, and you know how we might modify the presentation for the future. I will start us off and just ask one

264
00:51:42.840 --> 00:51:57.540
Kimberly Kelly: question. If you had to pick what is the biggest challenge, do you think, to providing services in Kentucky and Appalachian Kentucky, what would you say would be that the biggest barrier to overcome?

265
00:52:00.300 --> 00:52:01.800
Margaret Au: I can start it's that's alright.

266
00:52:02.550 --> 00:52:04.170
Margaret Au: I think it's having enough

267
00:52:04.770 --> 00:52:18.090
Margaret Au: certified genetics health professionals to provide those services. We have a number of open positions in our area, and I think have a need for positions beyond that as well.

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00:52:18.960 --> 00:52:33.030
Margaret Au: And just recruiting people to come practice in the beautiful state of Kentucky in Lexington and keeping them, retaining staff is really important and challenging.

269
00:52:36.600 --> 00:52:44.400
Justine Pickarski: And I think I'd agree that the access to genetic counselors and even some of the hospitals, like our cancer hospitals that

270
00:52:45.750 --> 00:52:51.390
Justine Pickarski: may not have genetic counselors on site, but even if they can partner with someone to help guide them.

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00:52:51.390 --> 00:52:51.630
Margaret Au: and

272
00:52:51.660 --> 00:52:52.830
Justine Pickarski: You know, like we've seen

273
00:52:53.550 --> 00:53:02.280
Justine Pickarski: I think a lot of benefit from our like physician initiated testing, which we can maybe expand that to other cancer types or something that other other providers can do

274
00:53:02.850 --> 00:53:14.160
Justine Pickarski: while also ensuring that the patients are given access to a genetic counselor, even if it is a phone call or telehealth consult or something like that.

275
00:53:15.540 --> 00:53:15.750
Justine Pickarski: so yeah.

276
00:53:17.820 --> 00:53:19.560
Kimberly Kelly: Do you utilize any

277
00:53:21.450 --> 00:53:28.980
Kimberly Kelly: sort of para professional technical kind of support like genetic assistants or are you using any kind

278
00:53:30.390 --> 00:53:31.560
Kimberly Kelly: of those services?

279
00:53:33.900 --> 00:53:36.330

Justine Pickarski: So I know Margaret you guys have some genetic counseling assistants.

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00:53:38.010 --> 00:53:49.350
Justine Pickarski: Like I said, we have some shared, and they're not, they do something like another counseling assistant type roles, but they're not like interacting directly with patient.

281
00:53:51.420 --> 00:54:01.110
Margaret Au: Yes, we have a genetic counseling assistant, who is primarily involved with scheduling genetic counseling appointments genetic counselor only appointments.

282
00:54:02.250 --> 00:54:15.930
Margaret Au: Monitoring authorizations for genetic testing coordinating lab appointments for genetic tests and triaging incoming patient referrals to genetics and metabolism, thank you.

283
00:54:16.320 --> 00:54:25.740
Kimberly Kelly: Thank you. I see that there is a question from Dr. Falah who is our genetic clinical geneticist/medical geneticist here.

284
00:54:26.160 --> 00:54:39.720
Kimberly Kelly: Can you clarify, you mentioned that one barrier is low rate of reimbursement to genetic counselors but on the other hand, that study showed that the revenue of 1.5 million in revenue by just one genetic counselor?

285
00:54:40.770 --> 00:54:52.080
Justine Pickarski: Yeah so the reimbursement so that's looking at if your billing you know $200 for a genetic counseling visit many times the insurance might pay a percentage of that or none of that.

286
00:54:52.920 --> 00:55:03.570
Justine Pickarski: In that downstream revenue study, they were looking at if a patient has like a BRCA-1 or 2 mutation and need to undergo additional screenings or surgeries it was looking at

287
00:55:04.170 --> 00:55:07.890
Justine Pickarski: revenue the hospital generated from those additional visit

288
00:55:08.820 --> 00:55:21.720
Justine Pickarski: So everybody wants to claim downstream revenue, and I think that some issues that people have run into is like, well the mammography group wants to claim that downstream revenue from biopsies and surgeries and all of that.

289
00:55:22.170 --> 00:55:25.260
Justine Pickarski: But kind of looking at where it initially stemmed was from

290
00:55:26.520 --> 00:55:29.730
Justine Pickarski: a diagnosis of a hereditary breast and ovarian cancer.

291
00:55:31.440 --> 00:55:42.870
Kimberly Kelly: Alright, so we have another question now. Do you think CMS Medicare Medicaid will offer reimbursement for genetic services in the future, genetic counselor services in the future?

292
00:55:44.340 --> 00:55:45.030
Margaret Au: I hope so.

293
00:55:46.890 --> 00:55:57.240
Margaret Au: There is currently a bill that is in the United States Senate, that would recognize genetic counselors as healthcare providers through CMS.

294
00:55:59.040 --> 00:56:02.790
Margaret Au: It's passed the House so we'll see what the Senate says.

295
00:56:03.930 --> 00:56:07.050
Justine Pickarski: I keep saying this is the closest we've been, so we'll see. It's been

296
00:56:08.910 --> 00:56:12.390
Justine Pickarski: something that they have looked at, for years, but we're hoping that

297
00:56:13.890 --> 00:56:15.750
Justine Pickarski: hoping that it will pass this time.

298
00:56:16.890 --> 00:56:24.240
Margaret Au: I believe it would really revolutionize our ability to provide genetic counseling services in the state of Kentucky.

299
00:56:25.380 --> 00:56:28.560
Margaret Au: So I am hopeful that it will pass.

300
00:56:29.010 --> 00:56:38.940

Kimberly Kelly: And it's challenging, right, because it requires a lot of training and yet we're kind of in the middle and

301
00:56:38.940 --> 00:56:56.970
Kimberly Kelly: not necessarily being compensated for that so it's a challenge. I see another question, "Can you explain if there's any disparity in genetic service utilization across Kentucky and how could you how can we bridge a disparity across the state?"

302
00:57:04.410 --> 00:57:15.480
Justine Pickarski: Well, say, from a cancer side of things, so in Kentucky in Lexington we are the farthest East that there's a genetic group, both of providers, and there is one

303
00:57:15.900 --> 00:57:28.020
Justine Pickarski: provider in Pikeville so in East Kentucky, and she provides cancer genetics, but she's only there twice a month, and so I think the Western side seems to have more.

304
00:57:29.310 --> 00:57:46.290
Justine Pickarski: More services across compared to the eastern half, so I think there is some disparity, and I'm pleased to present I think telehealth will, hopefully, I think that has helped a lot, because I know we've seen a lot more patients utilize that and

305
00:57:46.620 --> 00:57:48.240
Justine Pickarski: have it not be such a barrier.

306
00:57:49.770 --> 00:57:55.530
Margaret Au: Yeah I think there are geographic and socioeconomic barriers, and those are

307
00:57:56.610 --> 00:58:04.410
Margaret Au: probably that's my instinct. Some of the biggest disparities and barriers for our patients.

308
00:58:05.730 --> 00:58:19.620
Margaret Au: And I think meeting patients, where they are with outreach clinics or setting up sites where patients can go that are in their communities where they can access to health, like maybe a public health clinic.

309
00:58:21.120 --> 00:58:38.370
Margaret Au: Kentucky has a kind of a centralized service for children. They used to be called the Commission clinics, they are called something else now I

think, but perhaps partnering with those sites and they're usually based out of public health clinics in various counties.

310
00:58:43.470 --> 00:58:52.290
Kimberly Kelly: Definitely that geography, I mean when you're comparing you know the mountains in Appalachia, it looks it looks like it's not very far apart on a map.

311
00:58:52.770 --> 00:59:05.280
Kimberly Kelly: When you're looking at a flat map, but whenever you have these big mountains in your way you know it takes takes longer to get places and people are more spread out so it's challenging. Is it Dr. Kahler?

312
00:59:05.310 --> 00:59:06.600
Stephen Kahler, M.D.: Kahler.

313
00:59:06.900 --> 00:59:07.800
Stephen Kahler, M.D.: Can you hear me all right?

314
00:59:08.040 --> 00:59:22.530
Stephen Kahler, M.D.: Yes, good yeah it's Kahler. I work with Margaret. What a nice bunch of talks. I wanted to say a couple of things, one of them is that the same areas that are hard to get to by road, are also hard to get to by Internet.

315
00:59:23.670 --> 00:59:34.560
Stephen Kahler, M.D.: So it hasn't really improved. It's improved how we can plan to see people, but the connections to Harlan and places like that have been sometimes very challenging.

316
00:59:34.920 --> 00:59:50.400
Stephen Kahler, M.D.: People may not have Wi-Fi in their home, and they sit in their car to get a better signal, but that's not so good either. That's a kind of accessibility issue for the mountains that's more than just the roads. The other thing I wanted to mention is that there's a growing

317
00:59:52.680 --> 01:00:01.440
Stephen Kahler, M.D.: plain people the Amish, Mennonite, and such around Hopkinsville, Pembroke and the physician as Dr.

318
01:00:01.950 --> 01:00:16.710
Stephen Kahler, M.D.: I guess, his name is Mark. He's working with Holmes Martin who created a clinic for special children's stress for Pennsylvania, and I've been in touch with him about how can we help out that community with what we know how to do.

319
01:00:18.060 --> 01:00:27.060
Stephen Kahler, M.D.: The clinic in Pembroke is relying on lab services from Vanderbilt with the newborn screening, which is how we first encountered

320
01:00:27.660 --> 01:00:37.560
Stephen Kahler, M.D.: what was going on there is done in Kentucky. So the patients are Kentucky citizens, and we will help take care of them in Lexington and elsewhere, so that's that's another

321
01:00:38.760 --> 01:00:40.350
Stephen Kahler, M.D.: area of genetic

322
01:00:41.430 --> 01:00:48.840
Stephen Kahler, M.D.: patients that are going to be getting better service, now that I've established connection with Holmes Morton and

323
01:00:49.740 --> 01:01:01.530
Stephen Kahler, M.D.: he's very good. He's still based in Pennsylvania, though, so this is another where we will have plenty to do. And as a final thing out of that when he was in Strasbourg, they set up a

324
01:01:02.460 --> 01:01:17.010
Stephen Kahler, M.D.: plain people genetic panel, basically all the mutations for all the disorders, that are known in the community is one test. And it's not very expensive, and he says for whenever you see somebody from that community if you can check the parents

325
01:01:18.600 --> 01:01:29.910
Stephen Kahler, M.D.: he'll know exactly what the children might have and what the possible combinations might be by just checking the parents, and then you can start working. From there, you've already eliminated all the things they might not have; so you can focus on the things they might.

326
01:01:30.990 --> 01:01:31.320
Stephen Kahler, M.D.: Thanks.

327
01:01:32.250 --> 01:01:50.310
Kimberly Kelly: Thank you. Yeah when I trained at Riley Children's, we worked with the Amish Community some there, and it really is a very unique population with unique needs. So we appreciate your outreach to that community. I see a question.

328
01:01:51.090 --> 01:01:54.330
Kimberly Kelly: From Alissa Terry, who is from an NYMAC.

329
01:01:55.110 --> 01:02:09.690
Kimberly Kelly: Which is one of our regional genetics groups. “Have you tried telehealth using local telehealth equipment sites. Can be local clinics public libraries, etc, to help families with no devices or broadband?”

330
01:02:13.200 --> 01:02:14.850
Justine Pickarski: that's how our MCCAN sites

331
01:02:15.180 --> 01:02:25.080
Justine Pickarski: kind of operate. That the patient goes to the the clinic and is seen there, but those are the only patients that we see that way, the rest of them are seen

332
01:02:27.000 --> 01:02:30.960
Justine Pickarski: usually kind of Zoom while through our Epic platform now but

333
01:02:32.520 --> 01:02:36.240
Justine Pickarski: we have that's the only places we've done that I don't know if Margaret team has

334
01:02:37.440 --> 01:02:38.220
Justine Pickarski: anything like that

335
01:02:39.030 --> 01:02:48.270
Margaret Au: You have not, but I think that is certainly an option for patients who don't have access to technology or broadband service.

336
01:02:49.020 --> 01:03:00.480
Margaret Au: The Commission clinic that I had mentioned before, does provide services in that way that genetics is not involved with the Commission clinics at this time, but I know our child neurology service

337
01:03:01.140 --> 01:03:12.810
Margaret Au: performs telehealth in that manner. The patient will come to the public health clinic in their county or the nearest county, and they'll see the child neurology provider by telehealth from there.

338
01:03:18.900 --> 01:03:22.020
Kimberly Kelly: All right, thank you, I think that's the end of our questions.

339
01:03:22.020 --> 01:03:33.510

Kimberly Kelly: And we're at the end of the hour, and I would like to thank our our genetic counselors and clinicians at University of Kentucky and our

340
01:03:34.020 --> 01:03:53.790
Kimberly Kelly: genetic counselor supervisors Margaret and Justine for a wonderful talk, both of you, and also for a nice discussion. And so again, we appreciate your feedback and learning more about setting a research agenda for research in the

341
01:03:53.910 --> 01:03:56.700
Kimberly Kelly: Appalachian area and how we can best service

342
01:03:56.910 --> 01:04:04.950
Kimberly Kelly: our population. So again, thank you very much to our speakers, and thank you all who have attended today, we appreciate it. Bye

343
01:04:06.450 --> 01:04:06.930
Margaret Au: Thank you.