Session 3: Genetic Services in Pennsylvania

61
00:20:24.270 --> 00:20:32.910
Kimberly Kelly: I will go ahead and get started, and we'll watch for more people coming in, as we go along.

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00:20:34.380 --> 00:20:49.110
Kimberly Kelly: Welcome to the third session in the webinar series on genetic services in Appalachia, and we ask that you mute your microphone so the talk in place any comments or questions in the chat box.

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00:20:49.950 --> 00:21:09.300
Kimberly Kelly: While our speakers are talking and there will be time afterwards for discussion. We ask that you not record our session. We will be recording this session and providing a transcript on our webinar website, and we're happy for you to go back and listen to anything that you might have missed.

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00:21:10.350 --> 00:21:20.940
Kimberly Kelly: So if you missed any of the earlier sessions, they are available; so we're happy to have your engagement with that. We also have some evaluations.

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00:21:21.450 --> 00:21:36.870
Kimberly Kelly: If you haven't completed those previously, we would be happy to have you complete the evaluations on the previous sessions, just to give us feedback and also for funders and, as you may be aware, this series has been funded

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00:21:39.000 --> 00:21:49.410
Kimberly Kelly: by the AHRQ the Agency for Healthcare Research and Quality, and they have enabled us to provide this session and also

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00:21:50.520 --> 00:21:57.390
Kimberly Kelly: allowed us to bring in some great speakers from around Appalachia and that are doing work in the Appalachian area.

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00:21:58.530 --> 00:21:58.860
Shenin: <fire alarm>

69
00:22:04.410 --> 00:22:06.570
Shenin: <fire alarm> oh sorry.

70
00:22:08.940 --> 00:22:11.340

Shenin: there's just a warning, playing on my end; disregard that.

71
00:22:14.580 --> 00:22:16.500
Kimberly Kelly: Hopefully, Shenin's

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00:22:18.180 --> 00:22:21.090
Kimberly Kelly: Building isn't burning down and well.

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00:22:23.160 --> 00:22:24.540
Kimberly Kelly: Because that would be terrible.

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00:22:25.710 --> 00:22:37.560
Kimberly Kelly: But yeah so, as you know, our aims include to develop a research agenda for genetic services in rural Appalachian in particular and each month

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00:22:38.040 --> 00:22:47.640
Kimberly Kelly: we will be having and have had speakers who are working in genetic service provision in medically underserved populations of the focus on

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00:22:48.270 --> 00:23:01.260
Kimberly Kelly: research and a research agenda for rural Appalachia and again we will request your feedback at the end, and hopefully be able to get some more information from you.

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00:23:02.880 --> 00:23:17.550
Kimberly Kelly: So I'll introduce you to our speakers Ms. Shenin Dettwyler and Julia Stone, and Shenin received her Master's of Science in genetic counseling from the University of Michigan in 2016.

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00:23:19.170 --> 00:23:34.740
Kimberly Kelly: She has five years of clinical experience and previously worked for the cancer genetics program at Michigan Medicine and University of Pittsburgh Medical Center and so that's how we became involved, and Shenin has has been

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00:23:35.910 --> 00:23:41.220
Kimberly Kelly: One of the folks who was very early in the process and, as we were trying to

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00:23:42.750 --> 00:23:51.780
Kimberly Kelly: figure out how to best address service provision in Appalachia. So we appreciate her continuing engagement.

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00:23:52.740 --> 00:23:53.580

Shenin: happy to be involved.

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00:23:55.560 --> 00:23:59.310
Kimberly Kelly: She recently transitioned to a research focus position.

83
00:24:00.390 --> 00:24:06.270
Kimberly Kelly: at New York University's Langone Pancreatic Cancer Center, and I'm hoping, I said that right.

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00:24:06.690 --> 00:24:07.140
Shenin: Yes.

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00:24:09.060 --> 00:24:09.750
Kimberly Kelly: Julia Stone

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00:24:10.770 --> 00:24:14.580
Kimberly Kelly: will also be speaking, I believe that they're going to

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00:24:18.720 --> 00:24:21.240
Kimberly Kelly: trade off throughout the session.

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00:24:21.630 --> 00:24:32.460
Kimberly Kelly: So I'll go ahead and introduce her as well. Julia Stone received her Master's of Science in genetic counseling from the University of Pittsburgh Graduate School of Public Health in 2018.

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00:24:34.080 --> 00:24:43.410
Kimberly Kelly: Years of clinical experience and prenatal cancer and adult genetics program through the University of Pittsburgh Medical Center to.

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00:24:46.590 --> 00:24:57.960
Kimberly Kelly: Clinical genomics laboratory where she is primarily involved with the workflows there hereditary cancer gene panels and whole exome sequencing so with that.

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00:24:59.070 --> 00:25:05.400
Kimberly Kelly: We, we are very happy to have you join us and we'll turn it over to Shenin.

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00:25:06.270 --> 00:25:12.030
Shenin: Thank you, and should, I share my screen with the slides are we having you advance the slides on your end.

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00:25:14.370 --> 00:25:17.160
Kimberly Kelly: And I would be happy for you to share.

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00:25:17.190 --> 00:25:17.670
Shenin: Sure, Okay.

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00:25:18.960 --> 00:25:22.500
Shenin: Let me get that pulled up then, all right.

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00:25:43.740 --> 00:25:49.380
Shenin: Alright, so just to begin we'll be talking today about genetic services, in Appalachian Pennsylvania.

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00:25:50.250 --> 00:26:03.750
Shenin: Neither Julia I have any disclosures or conflicts of interest and as Dr. Kelly also mentioned, I am no longer with UPMC but Julia is and we also had these slides reviewed by other counselors at UPMC.

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00:26:07.050 --> 00:26:07.410
Hillary Rieger: Right.

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00:26:25.980 --> 00:26:30.270
Shenin: You all, right, Julia could you review the slide please.

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00:26:31.440 --> 00:26:49.170
Julia Stone: Yeah, so we wanted to right off the beginning, give a brief overview of some of the primary service delivery models that are utilized for genetic services in the city of Pittsburgh our discussion today is really going to revolve around

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00:26:50.340 --> 00:26:59.040
Julia Stone: how the clinics work and how the process works for genetic counselors at Magee Women's hospital in Pittsburgh.

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00:26:59.520 --> 00:27:09.570
Julia Stone: But a lot of these models are also used by the other genetics providers within the city so there's there's three main primary service delivery models that we utilize at this time.

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00:27:09.990 --> 00:27:23.970

Julia Stone: The first one, the classic service delivery model or in person visits where patients actually come to the hospital and get to meet one on one with a genetic counselor sometimes those those appointments and involve a position oftentimes they do not.

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00:27:25.800 --> 00:27:38.820
Julia Stone: The second type of service delivery model is a telemedicine model, this was something that we utilized prior to the COVID 19 pandemic and what.

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00:27:39.390 --> 00:27:49.890
Julia Stone: What we had established what was set up was patients could go to UPMC facilities at other hospitals that were not UPMC Magee Women's hospital.

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00:27:50.250 --> 00:28:03.660
Julia Stone: And they would be set up with a video to connect them to a genetic counselor in Pittsburgh and we're going to go through a little bit about some of the sites that we that we work with that do telemedicine.

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00:28:04.380 --> 00:28:20.970
Julia Stone: But the key thing to note with the telemedicine programs are that the clients still have to go to a facility, and they just don't have to make the trip into Pittsburgh. So they might be able to have access to a facility closer to their home.

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00:28:22.350 --> 00:28:35.400
Julia Stone: And then the third type of service delivery model, our video visits and this sounds very similar to telemedicine, they are often used somewhat interchangeably but for our purposes, we do consider them two separate things.

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00:28:35.910 --> 00:28:48.780
Julia Stone: Video visits for something that have become temporarily available to the genetic counseling team due to the COVID 19 pandemic. This allows us to meet with patients directly through

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00:28:49.650 --> 00:29:06.390
Julia Stone: a video app. Basically, they're able to sign on to an app on a phone or a tablet through their MyUPMC, and we are able to sign in and communicate with them via the medical record service. So it's it's confidential; it's HIPAA approved.

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00:29:07.980 --> 00:29:17.100
Julia Stone: And that allows us to meet with with our clients from the comfort of their own home they don't have to go to a separate facility for their genetic counseling services.

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00:29:25.170 --> 00:29:25.800
Shenin: All right.

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00:29:27.510 --> 00:29:32.370
Shenin: The next thing that we wanted to review is where are genetic counseling services available.

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00:29:33.150 --> 00:29:39.540
Shenin: So, given that Julia will be kind of talking about prenatal and I'll be talking about cancer, we thought it would be useful to show that

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00:29:40.110 --> 00:29:44.100
Shenin: there's some overlap between the places where both of these things are available.

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00:29:44.790 --> 00:29:50.280
Shenin: The primary place where both services are available in person is at UPMC Magee Women's hospital.

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00:29:50.610 --> 00:29:58.500
Shenin: And we also have some shared telemedicine sites and again telemedicine denoting that it's a facility where a patient goes and meets with a nurse in person.

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00:29:59.370 --> 00:30:06.240
Shenin: Cancer Genetics has some additional telemedicine sites, and we also have two other in person locations.

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00:30:06.750 --> 00:30:20.280
Shenin: So Hillman Cancer Center specifically in Shadyside is a place where genetic counseling services are also available and once per month, a counselor staffs a clinic at UPMC Passavant and Cranberry which is northwest of the city.

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00:30:24.300 --> 00:30:28.650
Julia Stone: And then for for the prenatal genetics team.

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00:30:29.460 --> 00:30:37.800
Julia Stone: Most most of those appointments right now are seeing either in person or via video visit. Actually there are some telemedicine

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00:30:38.100 --> 00:30:49.140
Julia Stone: sites in contracts that we do still have established, however, that those services largely stopped after the onset of the pandemic and being able to do video visits.

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00:30:49.710 --> 00:31:01.890

Julia Stone: Because understandably clients prefer to if they have the option, potentially meet with with their counselor from home. Of note, these video visits, they were slated to go

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00:31:02.910 --> 00:31:12.660
Julia Stone: To go away, they are part of I believe in the emergency Covid provision here in the state, so they it was something that was supposed to go away in September.

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00:31:12.930 --> 00:31:30.330
Julia Stone: That has been extended, so we are still able to provide these video visits services, at least through March 30th of 2022, and we're still waiting to see whether or not that will be something that we can continue beyond that time.

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00:31:35.130 --> 00:31:49.650
Julia Stone: So we also wanted to take a moment to highlight some of the other genetic services that are available in the city of Pittsburgh. We're not going to go through each one of these in detail. Neither Shenin nor I have been intimately involved with either of these clinics.

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00:31:51.030 --> 00:31:58.350
Julia Stone: But we did want to we did want to let everybody know, although we're going to be primarily focusing on the cancer and prenatal service delivery

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00:31:59.040 --> 00:32:06.120
Julia Stone: models and services here in the city, there's a whole host of other genetic services. The two big ones that I want to highlight

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00:32:06.390 --> 00:32:22.950
Julia Stone: That I think are really unique, we have an ophthalmology genetics clinics and group of genetic counselors that meets with both children and adults for evaluation and in discussion about inherited eye diseases, that's that's not a common

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00:32:24.000 --> 00:32:34.500
Julia Stone: clinic. A couple years ago, I heard, I think there were only 10s of counselors maybe 40 that were practicing ophthalmology genetic services in the country I'm sure that's gone up since then.

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00:32:36.030 --> 00:32:53.100
Julia Stone: But something unique here. And then we also have a physician who's doing, a physician and a team of genetic counselors that are incorporating genetic services into a primary care clinic so they call it a primary care physician medicine clinic and really interested in seeing where

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00:32:54.180 --> 00:32:59.100
Julia Stone: where that kind of continues to go and what comes out of it, because I think that's a really interesting

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00:32:59.700 --> 00:33:14.340
Julia Stone: practice and how to incorporate genetic services into a day to day primary care facility. The one thing that you may notice is not on this list that was included in my introduction, is an adult genetics clinic.

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00:33:14.640 --> 00:33:16.860
Julia Stone: That, unfortunately, is a clinic that

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00:33:16.860 --> 00:33:28.140
Julia Stone: does no longer exist or at least for the time being, we do not have a clinic in the city of Pittsburgh that can accommodate adult patients for general genetic services.

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00:33:28.710 --> 00:33:43.680
Julia Stone: Outside of the specialty services listed on the slide and cancer genetics and prenatal, of course. That is a significant limitation of genetics in the city at this point, and frankly with genetic clinics all over the country and throughout.

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00:33:44.370 --> 00:33:55.980
Julia Stone: Sure mm hmm um it's something that that we're we're working to hopefully get back at at some point, but for right now, we do not have that service here in the city.

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00:33:59.580 --> 00:34:02.430
Shenin: And we also just thought that it would be helpful to show a map

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00:34:02.940 --> 00:34:12.480
Shenin: that kind of connects to the Venn diagrams that we showed earlier, so the services provided by UPMC are unsurprisingly concentrated around Western Pennsylvania.

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00:34:12.870 --> 00:34:19.800
Shenin: Although we do get quite a lot of coverage of like all the Western Pennsylvania from north to south with our different satellite clinics.

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00:34:20.610 --> 00:34:33.660
Shenin: The stars just indicate that there are places where both prenatal and cancer services are available, mostly telemedicine, and then there are a couple of areas where cancer genetics telemedicine services are available as well.

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00:34:34.620 --> 00:34:40.860
Shenin: One thing that is noteworthy is that while we certainly see a lot of people from like Altoona, Johnstown and over.

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00:34:41.310 --> 00:34:48.660
Shenin: And we are also the closest cancer genetics service and potentially the closest prenatal service definitely cancer.

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00:34:48.930 --> 00:34:55.950
Shenin: For people in Eastern Ohio northern West Virginia and sometimes even upstate New York I routinely saw patients that were sort of.

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00:34:56.310 --> 00:35:01.320
Shenin: Within this halo around the border of Pennsylvania, and if you're not close to something like

146
00:35:02.010 --> 00:35:15.690
Shenin: Cleveland or New York City or something like that we did get patients that would drive quite a distance to sometimes even be at one of our satellite clinics Level one at Pittsburgh. So the catchment area that the client services quite a bit larger than the Pittsburgh metro area alone.

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00:35:19.320 --> 00:35:31.620
Julia Stone: Some of the reasons why somebody may be referred for a prenatal or preconception genetics consult, and I make a point to emphasize, we in the prenatal clinic

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00:35:32.190 --> 00:35:43.230
Julia Stone: will see patients both who are pregnant and patients and couples who are considering a pregnancy, but aren't pregnant at that time so both during a pregnancy and before.

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00:35:44.040 --> 00:35:51.120
Julia Stone: We'll see anybody, essentially, who has a higher chance to have a pregnancy with genetic or inherited disorder.

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00:35:51.480 --> 00:36:00.270
Julia Stone: Or anybody who wants to learn more about what their chances might be and what testing options might be available. So some common indications include:

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00:36:01.170 --> 00:36:07.770
Julia Stone: Parental ages parents get older there might be an increased risk to have a child, with certain genetic conditions.

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00:36:08.400 --> 00:36:19.470
Julia Stone: Any personal or family history of the genetic disorder or things in the personal or family history that somebody might be curious as to the chances for them to have a child, with something similar. So, for example,

153
00:36:19.740 --> 00:36:36.180
Julia Stone: birth differences, intellectual disability, autism developmental delays etc. Anybody who's a carrier of a genetic condition, whether that was identified through routine carrier screening during pregnancy or if it's something that they know about

154
00:36:37.200 --> 00:36:40.110
Julia Stone: from prior to a pregnancy or from a prior pregnancy.

155
00:36:41.040 --> 00:36:52.290
Julia Stone: Anybody with a high risk aneuploidy screen result so somebody who's pregnant who's had some sort of blood work completed that's indicated an increased chance for their child to have a chromosome difference.

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00:36:52.710 --> 00:36:58.710
Julia Stone: They'll come and meet with us and we'll talk about what those chances might be in some potential options for next steps.

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00:37:00.060 --> 00:37:10.740
Julia Stone: As well as ultrasound differences, we know many things on ultrasound are sporadic or multifactorial so related to a combination of both genes and nongenetic factors.

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00:37:11.370 --> 00:37:22.830
Julia Stone: But occasionally genetic differences can be related to an underlying oh sorry, ultrasound differences can be related to an underlying genetic predisposition or disorder.

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00:37:23.370 --> 00:37:34.440
Julia Stone: Um one of the things I wanted to highlight here was actually our fetal diagnosis and treatment centers. So this is a group that helps manage pregnancies.

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00:37:34.980 --> 00:37:46.530
Julia Stone: Typically, with complex or significant ultrasound structural ultrasound differences that require extra monitoring during the pregnancy. So things such as heart defects

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00:37:48.540 --> 00:37:56.760
Julia Stone: congenital diapragmatic hernia, ventricularmegaly, etc. that really require a

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00:37:57.870 --> 00:38:09.810
Julia Stone: team effort per management. If a genetic counselor meets with a client and the indication is because of a structural ultrasound difference, we'll make sure that those patients are looped in.

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00:38:10.110 --> 00:38:19.020
Julia Stone: To the fetal diagnosis and treatment centers for their pregnancy management, the routine pregnancy management still goes through their obstetrics provider.

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00:38:19.500 --> 00:38:29.010
Julia Stone: But the imaging and coordination of those imaging consults, neonatology consults to help come up with a birth plan

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00:38:29.550 --> 00:38:40.590
Julia Stone: with the patient and the family. We'll make sure to get patients have been through there and then on the flip side anybody who's referred to the fetal diagnosis and treatment centers.

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00:38:40.980 --> 00:38:52.080
Julia Stone: So if they had an ultrasound difference identified at their you know their home ultrasound department and were referred to the Center for further evaluation and continuation of care.

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00:38:52.470 --> 00:39:03.240
Julia Stone: The first stop is to meet with a genetic counselor so we'll were involved with that clinic in two different ways, but very intimately so and actually one of the coordinators for that clinic is a genetic counselor herself.

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00:39:04.380 --> 00:39:11.340
Julia Stone: And then, a couple of other indications anybody with a history of infertility or recurrent pregnancy loss, something that can be related to the

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00:39:12.180 --> 00:39:20.850
Julia Stone: chromosome or other genetic reason and anybody who wants a more in-depth discussion about testing and screening options that are available before and during a pregnancy.

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00:39:24.570 --> 00:39:29.190
Shenin: And then to go to my area of specialty with cancer genetics so

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00:39:30.090 --> 00:39:37.560
Shenin: one thing to explain structurally about the way that the UPMC cancer genetics clinics are set up is that there is one clinic that primarily sees

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00:39:37.830 --> 00:39:54.300
Shenin: gastrointestinal cancer so colon cancers, pancreatic cancers, etc. And then the other clinic is primarily breast and ovarian cancer, but really serves as everything, other than GI it's just sort of that breast and ovarian are some of the most common indications. So with that preface,

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00:39:55.470 --> 00:40:04.110
Shenin: the cancer genetics program sees patients with either a personal or family history of cancer in some sort of way that is concerning for hereditary predisposition.

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00:40:04.740 --> 00:40:13.590
Shenin: So that can include things like early onset breast cancer defined as any breast cancer diagnosed under 45, colon cancer typically diagnosed under 50,

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00:40:14.340 --> 00:40:27.750
Shenin: renal cancer often anything diagnosed 46 or under, endometrial cancer under 50, melanoma is something that has a strong environmental component, but if you have an early diagnosis or multiple melanomas, we can also see that.

176
00:40:28.590 --> 00:40:40.890
Shenin: I will also say that any there are combinations of those types of cancer that even if it's not necessarily early onset if you've seen multiple individuals with breast, colon, renal cancers things like that

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00:40:41.940 --> 00:40:48.120
Shenin: in a family, or even more than one diagnosis and a person themselves that can also be a reason to come to cancer genetics.

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00:40:49.020 --> 00:40:57.000
Shenin: Ovarian or pancreatic cancer at any age should automatically warrant a referral to genetics, we saw quite a lot of those individuals

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00:40:57.810 --> 00:41:07.680
Shenin: having a prostate cancer that has either metastasized or that is aggressive as denoted by a gleason score on pathology of seven or higher should also be referred.

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00:41:09.060 --> 00:41:17.220
Shenin: There are also certain endocrine tumors or cancers that weren't referral to genetics, and this is not particularly common reason for referral.

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00:41:17.610 --> 00:41:28.230
Shenin: But we would see people that had things like paragangliomas or pheochromocytoma has early onset primary care hyperparathyroidism is also a fairly common indication.

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00:41:30.960 --> 00:41:36.840
Shenin: As something that I alluded to earlier is if an individual themselves has multiple diagnoses of cancer,

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00:41:37.380 --> 00:41:44.820
Shenin: or multiple cancers in the same side of the family, there are certain combinations of cancer diagnoses at certain ages that can warrant a referral as well.

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00:41:45.300 --> 00:41:52.290
Shenin: And we would often see individuals who were coming in, because a relative of theirs had had genetic testing previously

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00:41:52.560 --> 00:42:01.650
Shenin: and had a mutation or pathogenic variant identified and that individual was coming in, for consideration of single site testing or testing for the known mutation in the family.

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00:42:02.490 --> 00:42:11.430
Shenin: We would also, if we found individuals who had a mutation on a panel test, would try to facilitate single site testing for their relatives.

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00:42:13.590 --> 00:42:27.960
Shenin: We get a lot of referrals from a number of different physicians so the waitlist for cancer genetics was often like four to six months out so awareness of the availability of cancer genetics was not really like a problem.

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00:42:29.520 --> 00:42:39.960
Shenin: So a lot of the referrals that we get are from gynecologists. from breast surgeons. that's probably one of the main sources for the kind of regular cancer genetics clinic.

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00:42:41.010 --> 00:42:43.950
Shenin: There is a specialty clinic called the

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00:42:44.970 --> 00:42:58.170
Shenin: BCSCC breast cancer. I'm going to forget what the S about. Essentially, it is a clinic for any woman diagnosed with breast cancer under 50, even though I can't recall the accurate an acronym perfectly at this time.

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00:42:58.590 --> 00:43:10.590
Shenin: And the there is a counselor who's on call every week seeing patients on an urgent basis, and many of the new breast cancer diagnoses are referred by breast surgeons.

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00:43:11.280 --> 00:43:21.000

Shenin: We get some referrals from primary care physicians there were a number of people that were savvy enough to you know ask family history questions and recognize that certain patterns of things should warrant a referral.

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00:43:22.380 --> 00:43:26.940
Shenin: There are also some dermatologists, urologists and gastroenterologists that either

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00:43:28.080 --> 00:43:34.560
Shenin: were knowledgeable and would refer to us, and oftentimes these people were we had kind of had a symbiotic relationship with them.

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00:43:34.860 --> 00:43:43.980
Shenin: Where there were certain providers that we would refer people to for screening if they were found to have a condition or if they were still considered to be at an increased risk for cancer.

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00:43:45.180 --> 00:43:54.510
Shenin: And then we would sort of get referrals from them because of their increased awareness of what to do with these patients that did have some sort of need, based on a hereditary cancer predisposition.

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00:43:58.230 --> 00:44:05.190
Shenin: Oh, this is quite small and unlabeled I am not sure what happened to this slide my apologies.

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00:44:06.360 --> 00:44:08.640
Shenin: There was a better version that had some labels on it.

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00:44:09.240 --> 00:44:18.480
Shenin: Essentially, I was able to get some numbers from the cancer genetics clinic that were current as of about January or February of this year that's the last time that the numbers were pulled.

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Shenin: The graph on the left side is supposed to indicate the total number of patients that have been seen by the cancer genetics program since 2018.

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00:44:28.620 --> 00:44:40.920
Shenin: So roughly 1500 patients were seen back in 2018 and that had increased to about 1661 patients as of 2021. And one note that

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00:44:41.370 --> 00:44:49.260
Shenin: was supposed to be included on this chart was that that number is probably an underestimate, and the rate of growth probably would have

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00:44:49.560 --> 00:44:58.530
Shenin: been even higher, had it not been for the pandemic and a lot of like cancellations, in the early days before the video visits were available and routinely used.

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00:44:59.610 --> 00:45:08.490
Shenin: The smaller chart off to the right is specific to the urgent patients that are seen so once per week, there is a genetic counselor who is on call.

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00:45:08.910 --> 00:45:18.450
Shenin: And their patient volume can be quite high; so most counselors see full time counselors and the cancer genetics program see about 10 patients per week.

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00:45:19.080 --> 00:45:27.090
Shenin: You can have up to about 20 patients lots on an on call week it usually doesn't go quite that high, but I routinely saw like 12-15 patients.

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00:45:27.840 --> 00:45:40.590
Shenin: A lot of brand new breast cancer diagnoses for people that need genetic testing in order to inform their surgical decision making, but we would also see other people like women with ovarian cancer, who were considering initiation of apart inhibitor.

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00:45:41.670 --> 00:45:48.360
Shenin: So this is another thing, where I think the trend would have gone up even higher over time it started out in 2018

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00:45:49.410 --> 00:46:05.790
Shenin: with 423 patients and then I think the actual trend would probably continue to peak beyond that 530. One problem here is that when patients have video visits there's no way to mark them as being urgent versus non urgent so there's almost certainly an additional

210
00:46:06.270 --> 00:46:18.510
Shenin: block that should be added to that last column of video visit patients that were urgent, whereas this one only captured in person urgent. So that alone makes up a pretty substantial portion of the patients that are seen just to give you an idea.

211
00:46:21.570 --> 00:46:36.870
Julia Stone: I can tag on to that and say we weren't able to get those numbers for the prenatal preconception genetics connect, but I can say that each of the the full time counselors in that clinic see anywhere between 15 and 20 patients, a week, on average, so a little bit more than cancer genetics.

212

00:46:38.610 --> 00:46:41.820
Julia Stone: And the team size in 2018-2019-2020

213
00:46:44.370 --> 00:46:46.440
Julia Stone: was around the same, pretty similar.

214
00:46:47.670 --> 00:46:53.910
Julia Stone: So I expect those numbers to be approximately pretty pretty similar.

215
00:46:55.350 --> 00:47:04.680
Julia Stone: So when a client or a patient is referred to a genetic counselor for a prenatal or preconception indication.

216
00:47:05.940 --> 00:47:11.070
Julia Stone: there's a lot of lot of things that we do with that individual or things that we can do with that individual.

217
00:47:11.610 --> 00:47:26.160
Julia Stone: Primarily, the genetic counselors provide a comprehensive reproductive risk assessment, including a family history assessment so in every single appointment we're taking a detailed family health history for at least immediate family members to.

218
00:47:27.210 --> 00:47:32.040
Julia Stone: To see if there might be anything in the in the family that could impact the current or future pregnancy.

219
00:47:33.630 --> 00:47:47.310
Julia Stone: And then of course we take into account anything else related to that particular pregnancy, so any test results that have already been been obtained or screening results any ultrasound any ultrasounds that have taken place, etc.

220
00:47:48.510 --> 00:48:01.500
Julia Stone: We provide pretest genetic counseling about reproductive genetic testing and screening options, and that includes a comprehensive discussion about the benefits risks and limitations of

221
00:48:01.980 --> 00:48:10.740
Julia Stone: of these options, our goal is to make sure that the person in front of us has a solid understanding of exactly what

222
00:48:11.400 --> 00:48:21.870

Julia Stone: the testing and the screening options can and cannot do, what their purpose is, and what what the benefits and also what some of the risks could be. Right, we can

223
00:48:22.530 --> 00:48:32.730
Julia Stone: potentially find things that could impact other family members or that can increase patient anxiety, and pregnancy is already a really stressful time for a lot of people.

224
00:48:34.020 --> 00:48:39.330
Julia Stone: And so we recognize that these screening options aren't for everybody and our goal is to make sure that

225
00:48:40.920 --> 00:48:51.000
Julia Stone: that the patient in front of us has the information that they need to make the most informed decision about how they would like to utilize that that testing or screening, if at all.

226
00:48:52.260 --> 00:49:01.320
Julia Stone: And many, many of the the people that we meet with after having a discussion decide that no these these testing and screening options really aren't for them at that point in their care.

227
00:49:02.820 --> 00:49:11.430
Julia Stone: If somebody does decide to proceed with a test or a screen we do coordinate that and I've been using testing and screening.

228
00:49:12.450 --> 00:49:19.290
Julia Stone: Pretty vaguely but I did provide a list of some of the types of tests and screens that we do help coordinate so aneuploidy screening,

229
00:49:20.100 --> 00:49:31.650
Julia Stone: routine blood work to help assess if a pregnancy may have a higher chance for a chromosome difference, primarily handful of trisomy's and potentially some

230
00:49:33.210 --> 00:49:37.710
Julia Stone: some micro deletion disorders, although that's still very new.

231
00:49:38.760 --> 00:49:45.510
Julia Stone: Routine carrier screening, we talk about routine options versus broader options looking at

232
00:49:46.620 --> 00:49:56.220
Julia Stone: at more conditions, parental carrier typing looking at the chromosomes of the parents, as well as prenatal diagnostic testing.

233
00:49:56.910 --> 00:50:14.010
Julia Stone: So during a pregnancy patients have opportunities potentially to pursue prenatal diagnostic testing through either chorionic villus sampling between 11 and 13 weeks of pregnancy or amniocentesis anytime at or after 16 weeks.

234
00:50:15.480 --> 00:50:30.780
Julia Stone: And so we help schedule those procedures. We're able to actually put them put them on the books and work with our scheduling team and coordinate all of the the testing that may be involved for those kinds of procedures.

235
00:50:31.950 --> 00:50:39.150
Julia Stone: We also have the capacity to help coordinate umbilical cord blood testing at the time of delivery so sometimes.

236
00:50:40.710 --> 00:50:57.600
Julia Stone: Sometimes parents may want additional genetic information, but are understandably uncomfortable with doing a prenatal diagnostic procedure those procedures do come with some risk with every pregnancy, there is some chance of those procedures could

237
00:50:59.550 --> 00:51:06.780
Julia Stone: lead to a complication that could result in a loss of that pregnancy either a miscarriage or preterm labor depending on when it's performed.

238
00:51:07.230 --> 00:51:18.870
Julia Stone: And so, some individuals and couples elect to defer testing until after delivery and if that testing is going to have impact on their baby's

239
00:51:19.980 --> 00:51:29.520
Julia Stone: neonatal care, then we can help coordinate and we work really closely with our neonatologist to help coordinate genetic testing on the umbilical cord blood.

240
00:51:30.270 --> 00:51:37.710
Julia Stone: A lot of times that looks like routine carrier type analysis but that can also include molecular diagnostic procedures.

241
00:51:38.640 --> 00:51:46.860
Julia Stone: And after all the testing is complete them, we also do the posttest counseling so we receive those results we interpret those results.

242
00:51:47.640 --> 00:51:53.880
Julia Stone: Along with the the physician and the physician group that the genetic counselors work with.

243
00:51:54.570 --> 00:52:06.330
Julia Stone: We'll interpret those results and then share those results with the the patient, oftentimes we've set up some sort of plan for how those results are going to be delivered, most of our results we deliver by phone.

244
00:52:07.770 --> 00:52:16.590
Julia Stone: And patients are generally comfortable with that that we do give the option if they prefer to come into to the hospital or to set up a video visit for a results disclosure.

245
00:52:18.600 --> 00:52:26.130
Julia Stone: We can make referrals to appropriate providers so some of the common referrals that we're making our referrals to maternal fetal medicine.

246
00:52:27.510 --> 00:52:36.990
Julia Stone: As well as to the fetal diagnosis and treatment centers in neonatology things like that, we often sometimes make referrals if somebody has a

247
00:52:38.070 --> 00:52:53.730
Julia Stone: child maybe, who has a previous child who has a history of something that could require a genetic evaluation will make referrals to our children's hospital for that child because that could potentially have impacts for the pregnancy.

248
00:52:55.320 --> 00:53:01.560
Julia Stone: One of the the big things with FDTC that I realized I glossed over earlier is we do also have

249
00:53:02.880 --> 00:53:09.870
Julia Stone: an in utero fetal repair team, and so we have performed

250
00:53:10.950 --> 00:53:23.340
Julia Stone: recently a few I say recently over the over the course of the past three to five years, we've had some successful in utero spina bifida repairs, that you can read about online.

251
00:53:23.790 --> 00:53:32.370
Julia Stone: And all for those types of surgeries those patients need to have that one of the requirements is that they do have a prenatal diagnostic procedure.

252
00:53:32.730 --> 00:53:40.200
Julia Stone: And that there have been a normal carrier type and microarray analysis, and so the genetic counselors are actually involved in

253
00:53:40.590 --> 00:53:48.930
Julia Stone: coordinating some of those early steps to to qualify somebody broke procedure like that and we're making sure that if if we're meeting with somebody.

254
00:53:49.200 --> 00:54:05.220
Julia Stone: You know who has a baby with a spinal bifida, for example, that we're we're referring them to the physician and the team to talk about in utero repair options and then through all of this, I mean I've talked a bit about how this can lead to patient anxiety and stress.

255
00:54:06.510 --> 00:54:14.310
Julia Stone: And we we provide a lot of psychosocial support for our clients throughout the process, from start to finish.

256
00:54:14.790 --> 00:54:26.040
Julia Stone: We try to spend a lot of time working with them to make sure that they're getting the right test at the right time, they're understanding their results, and that they feel supported as as they are going through this process.

257
00:54:27.630 --> 00:54:43.860
Julia Stone: And for some of our clients they do utilize the results of genetic testing to make decisions about whether or not to continue a pregnancy. That is a discussion that we have with with our clients as much or as little as they would like.

258
00:54:45.270 --> 00:54:57.060
Julia Stone: And if they are considering going down the path for a potential abortion procedure, then that's something that we do talk about and we make sure that they have the phone number for a family planning team.

259
00:54:58.740 --> 00:55:10.950
Julia Stone: But we recognize that that's a sensitive discussion for a lot of couples and it's definitely not something that all couples elect to do, but it's it's something that we can help support patients and if that's the path that they choose to take.

260
00:55:15.000 --> 00:55:18.090
Shenin: And switching over to cancer genetics again so.

261
00:55:18.840 --> 00:55:31.110
Shenin: Really between the two different clinics that I mentioned earlier we're able to offer services for genetic counseling and germline genetic testing for a broad spectrum of cancer predisposition syndromes, this is just a brief note.

262

00:55:31.830 --> 00:55:34.860
Shenin: Again, mentioning the types of clinics that are available.

263
00:55:35.760 --> 00:55:48.000
Shenin: The first step for patients is pretest genetic counseling and psychosocial support, so what sessions typically look like, are you know going through the personal and family history, highlighting what conditions, if any, are the most

264
00:55:48.360 --> 00:55:55.950
Shenin: likely to be a potential explanation for the family history of cancer and also acknowledging that it's possible that there might not be a genetic explanation.

265
00:55:56.610 --> 00:56:04.260
Shenin: We talked through the different possibilities of genetic testing outcomes and coordinate the test for in person visits that's almost always a blood draw.

266
00:56:05.250 --> 00:56:14.520
Shenin: For the sort of traditional telemedicine visits it's also typically a blood draw. Part of the benefit of having a nurse involved at the facility and the other end

267
00:56:15.180 --> 00:56:20.250
Shenin: is that we have a person there to help sign the consent form and to take the patient for the blood at that visit.

268
00:56:20.910 --> 00:56:30.150
Shenin: Video visits are as I'm sure we're not the only people who have experienced this, it's a little more challenging to either get the patient to go to a blood draw or to

269
00:56:30.780 --> 00:56:40.710
Shenin: get a saliva kit and send it back. A lot of people adapted to that with the pandemic, but there is a little bit of an extra step involved there in terms of getting the sample.

270
00:56:41.430 --> 00:56:52.950
Shenin: And one thing that we often do either at the time of the visit or very shortly after the patient has decided to proceed with testing, is to provide an estimate of cost, so I think a lot of the genetic counselors on the call will

271
00:56:53.760 --> 00:57:08.940
Shenin: be familiar with the patient anxiety associated with the potential cost of cancer genetic testing. There is still this sort of memory that's been either present in patients are passed on through families that testing used to be very expensive so in order to kind of

272
00:57:10.140 --> 00:57:15.480
Shenin: provide that information, and to reduce at least one part of the anxiety, we are able to get cost estimates ahead of time.

273
00:57:16.860 --> 00:57:18.990
Shenin: We often send the test result out.

274
00:57:20.130 --> 00:57:34.410
Shenin: There are different labs that are contracted with various insurances so depending on what type of coverage a patient has that will dictate where their sample goes, although we do have in house testing for the lab that Julia currently works for.

275
00:57:35.430 --> 00:57:43.920
Shenin: And then, when we get those results back again, the majority of results are disclosed via phone, and one of the strengths of the clinic is really interpreting.

276
00:57:44.220 --> 00:57:51.720
Shenin: The genetic testing results in the context of the family history so most of our test results are negative, just just generally how cancer genetics works.

277
00:57:51.960 --> 00:58:00.660
Shenin: But we utilize a number of different risk models, especially for estimation of breast cancer risks and even if a person doesn't have a genetic mutation found.

278
00:58:00.990 --> 00:58:11.940
Shenin: If their risk is high enough, we sometimes still refer them to other clinics, so there is the breast and ovarian cancer detection and early detection and prevention clinic.

279
00:58:12.630 --> 00:58:20.460
Shenin: Which is run by the same medical director, as the cancer genetics program, and that is a clinic where women go if they're estimated to have

280
00:58:20.760 --> 00:58:32.220
Shenin: an increased breast cancer risk, just on the basis of family history alone, but in the absence of a genetic mutation or if a woman has a genetic mutation that puts her in increase breast cancer risk, but is not yet affected.

281
00:58:33.150 --> 00:58:37.680
Shenin: So that's one of the bullet points under indicated referrals to appropriate providers.

282

00:58:39.840 --> 00:58:48.120
Shenin: If a person has a mutation in a gene that is associated with other cancer risks, I feel like we have a really robust

283
00:58:48.420 --> 00:58:55.710
Shenin: network of providers that we can refer people to and that kind of alludes to the symbiotic relationship I mentioned before, that often the people that refer us

284
00:58:56.070 --> 00:59:03.990
Shenin: are also people that we know are knowledgeable and are able to provide the types of screening that our patients need like particular types of colonoscopies.

285
00:59:04.500 --> 00:59:13.740
Shenin: particular types of EUS, there are certain gynecological oncologists that we refer women to to discuss things like preventative self effectimies or hysterectomies.

286
00:59:14.490 --> 00:59:22.260
Shenin: So if a person has a need to have a discussion to reduce their cancer risks, then get a pretty good idea of where to send them.

287
00:59:23.160 --> 00:59:31.200
Shenin: A lot of the specialists are concentrated around Pittsburgh, but even further out in areas like Erie and Altoona, we had identified providers that we're good resources for our patients.

288
00:59:32.970 --> 00:59:38.850
Shenin: And then one other thing I mentioned before, is that we did we do help to coordinate testing for at risk relatives.

289
00:59:39.450 --> 00:59:43.230
Shenin: Julia actually used to staff, a single site clinic that we had once per month.

290
00:59:43.470 --> 00:59:50.430
Shenin: So another thing that people may be aware of is that many genetic testing companies, if you have a positive result identified on a panel.

291
00:59:50.610 --> 00:59:58.170
Shenin: It opens this window of testing for your patients that can range from 90 days to sometimes up to six months some companies really extended that during the pandemic.

292
00:59:59.250 --> 01:00:07.410

Shenin: And in a clinic where we're already scheduling out four to six months, when you suddenly have all these people that need to be seen for a free testing window.

293
01:00:07.710 --> 01:00:13.650
Shenin: Especially if it's a mutation other than BRCA one and two, which typically does not have insurance coverage, that puts some strain on your clinic.

294
01:00:14.220 --> 01:00:29.310
Shenin: But we were able to adapt into the open the single site clinic that required, you know, a copy of the testing report ahead of time, so that we could help to accommodate those patients who were at you know 50- 25% risk for it recently identified mutation in one of their relatives.

295
01:00:30.690 --> 01:00:39.840
Julia Stone: I can add on to that that single site clinic has continued so there are other counselors that are helping to to stop it now, it didn't stop with with my transition.

296
01:00:42.810 --> 01:00:50.790
Shenin: And then, this is just an overview of who do we have that's providing services so Julie, if you wanted to take over the prenatal part first.

297
01:00:51.210 --> 01:00:55.440
Julia Stone: yeah I don't know that we have to go through this in too much detail, but essentially we have one

298
01:00:56.100 --> 01:01:06.480
Julia Stone: physician who oversees all of the genetic counselors and about seven genetic counselors working in in prenatal preconception genetics. Some of these counselors

299
01:01:07.110 --> 01:01:14.010
Julia Stone: work part time in the clinic and do part time with with some other clinics or more managerial things and some of the counselors are full time.

300
01:01:15.720 --> 01:01:18.510
Shenin: Similarly, in cancer genetics, we have one medical director.

301
01:01:19.350 --> 01:01:29.340
Shenin: There are also nine genetic counselors now. There were a couple of growth positions, very recently, to help address the wait times and just the fact that the clinic has expanded to cover so much ground over time.

302
01:01:30.240 --> 01:01:39.090

Shenin: I've also indicated that the last two counselors on that list specifically staff the gastrointestinal clinic, which is a separate but related entity to the cancer genetics program.

303
01:01:39.600 --> 01:01:47.970
Shenin: And then I highlighted two of the nurses that are immune support at the Altoona telemedicine and Hammock clinic in Erie respectively.

304
01:01:48.390 --> 01:02:00.900
Shenin: I also wanted to note at the bottom just for logistics, that we do have administrative support from genetic counseling assistants when I left. We had one that I know of; there were efforts to hire a second. Julia can you comment on how much support we have?

305
01:02:01.710 --> 01:02:09.210
Julia Stone: While two full time genetic counseling assistants and one part-time, who is a one of the current genetic counseling students.

306
01:02:09.210 --> 01:02:18.540
Shenin: And then we have to schedulers as well, so a lot of the tasks of you know, dealing with insurance, packaging up samples

307
01:02:19.020 --> 01:02:28.080
Shenin: fielding patient calls, getting family histories, we get a lot of support from our genetic counseling assistants in that regard so really focusing more on the counseling as a counselor.

308
01:02:29.910 --> 01:02:30.450
Shenin: Um yeah

309
01:02:32.160 --> 01:02:45.270
Julia Stone: So this is an overview of how billing for genetic counseling services and compensation for services work at Magee Women's Hospital I do want to emphasize that this is very specific to our hospital and our institution.

310
01:02:45.780 --> 01:02:51.870
Julia Stone: It does not necessarily apply to other institutions in Pittsburgh or other clinics in Pennsylvania.

311
01:02:52.620 --> 01:02:58.830
Julia Stone: But here at Magee, genetic counselors are not able to bill independently for our services; we are not credentialed.

312
01:02:59.460 --> 01:03:09.810

Julia Stone: With insurance companies, so we cannot bill independently, so all of our consults actually have an authorizing physician who reviews our notes and our orders and signs off on everything.

313
01:03:11.010 --> 01:03:15.000
Julia Stone: There is a CPT code that's available for

314
01:03:16.200 --> 01:03:27.780
Julia Stone: billing for genetic counseling services 96040 that code actually can only be billed from my understanding, if a genetic counselors billing under their own name.

315
01:03:28.170 --> 01:03:38.010
Julia Stone: Which we cannot do here at Magee because we're not credentialed, so what happens is in the system we do tracker charges that 96040 code is a

316
01:03:38.460 --> 01:03:57.870
Julia Stone: a time related code so it's per 30 minutes of service anything under under 45 minutes is considered 30 anything over 45 minutes is considered 60 and that would continue to if you're going over a 60 minute time, although that's pretty uncommon most.

317
01:03:58.590 --> 01:04:16.290
Julia Stone: The cancer cancer appointments are typically about 60 minutes and the prenatal appointments are typically anywhere between 30 to 60 minutes, depending on the indication. So what what we do is in our medical record systems, we use EPIC, the genetic counselor does indicate a charge.

318
01:04:17.580 --> 01:04:33.030
Julia Stone: It's tracked under 96040 for every 30 minutes of time, but that charge on the back end is actually converted into a facility fee, so we are billing a facility we're not billing for our services under a genetic counselor name.

319
01:04:34.320 --> 01:04:53.670
Julia Stone: With the COVID-19 emergency declaration that is allowing us to perform these video visits, it is also allowing us to bill for the video visits in the same way that we billed for an in person consultation. So it's treating those services as if the patient was coming to the hospital.

320
01:04:55.740 --> 01:05:04.470
Shenin: I will say that I have seen this model used in other places we can't like specify, but we thought it would be useful to say like this is something that's done at Magee.

321
01:05:04.950 --> 01:05:13.860
Shenin: It's a model for how genetic counseling can be provided and other places, and this varies from state to state based on licensure laws so just wanted to add that real quick.

322
01:05:14.580 --> 01:05:30.630
Julia Stone: For any genetic counselors who are on the call today who may not know the National Society for Genetic Counseling has an excellent excellent resources on credentialing and billing and coding for genetics and genetic services on their website.

323
01:05:31.890 --> 01:05:35.940
Julia Stone: I actually use that as a bit of a resource when putting together these slides as well.

324
01:05:37.710 --> 01:05:45.840
Shenin: For those traditional telemedicine sites that we mentioned earlier, there are contracts in place for specific sites that are listed here.

325
01:05:46.500 --> 01:05:50.220
Shenin: So the billing works similarly, there is a facility fee.

326
01:05:50.790 --> 01:05:59.040
Shenin: The institution bills for our services, and then a fee is received on that end and so it's a similar but somewhat different service just because of the telemedicine aspect of that.

327
01:05:59.700 --> 01:06:13.770
Shenin: For all other telemedicine sites, our medical director who is able to bill under her own name, unlike a genetic counselor bills for services so just referencing between this slide in the map earlier, you can kind of get a sense of how billing works at different places.

328
01:06:14.730 --> 01:06:17.550
Julia Stone: And, and for the contract these sites actually it is.

329
01:06:19.230 --> 01:06:32.490
Julia Stone: It is a contract I don't think it's dependent on time we don't actually input, a time we don't input separate 30 minute charges for for those consults so it truly is a contract between the two institutions for those services.

330
01:06:35.880 --> 01:06:46.050
Julia Stone: Yup. So quickly we can highlight some of our Community outreach activities, I want to make sure that there's time for for questions this is definitely an area of improvement I would say, for

331
01:06:46.530 --> 01:06:55.800
Julia Stone: both departments, the the prenatal genetics team, they do educational visits with local providers offices every year.

332
01:06:56.190 --> 01:07:07.260
Julia Stone: Primarily obstetrics providers offices, as well as our reproductive endocrinology team, we work very closely with them, they would be the one seeing patients who might be going through

333
01:07:08.130 --> 01:07:18.240
Julia Stone: In vitro fertilization or assisted or utilizing assisted reproductive technologies so a lot of it is geared towards education for local providers, we do also I mean we field.

334
01:07:18.870 --> 01:07:34.350
Julia Stone: students from the local genetic counseling program; we field and work with nurse practitioners, medical students, anybody who might be spending a day or so observing with our genetic counseling team.

335
01:07:36.480 --> 01:07:42.750
Julia Stone: But otherwise there isn't as much by way of community outreach. I think that's definitely an area for

336
01:07:42.930 --> 01:07:44.340
Shenin: for improvement for that team.

337
01:07:44.760 --> 01:07:45.900
Julia Stone: And every opportunity.

338
01:07:46.650 --> 01:07:55.470
Shenin: Similarly, in cancer genetics, there are through the different counselors that staff, the clinic efforts to reach out to the Community several times per year.

339
01:07:56.430 --> 01:08:05.730
Shenin: Some of the different organizations include FORCE, so BRCA carriers, the National Ovarian Cancer Coalition, a survivorship workshop hosted by Magee Women's Hospital,

340
01:08:06.330 --> 01:08:22.950
Shenin: And a virtual education series for the Women's Cancer Center. I have a personal interest in presentation as an education, so I gave quite a few talks during my time at UPMC that you can see, but I will concur with Julia that most of the average that we did was to medical providers.

341
01:08:24.120 --> 01:08:37.620
Shenin: So I often gave talks to things like nurses, different oncologists during tumor board, and some of the surgical fellows in residence and differently gynecology groups.

342

01:08:38.490 --> 01:08:46.890
Shenin: And I think that there is a hope that perhaps educating the providers who make the referrals that there's sort of like a trickle down education.

343
01:08:48.300 --> 01:08:53.790
Shenin: But you know there's certainly additional Community outreach that could be done.

344
01:08:54.570 --> 01:09:09.540
Shenin: And then to address Dr. Falah's question, yes, nine genetic counselors for cancer, and they're the schedulers and the GCA's share scheduling responsibilities so effectively they're sort of like four and a half people that can help with that.

345
01:09:10.860 --> 01:09:16.440
Julia Stone: And the the hereditary GI clinic also has their own scheduling.

346
01:09:16.470 --> 01:09:18.240
Shenin: Correct I forgot about that yep.

347
01:09:20.100 --> 01:09:30.180
Shenin: Okay, and we also just wanted to include a little bit of information on different challenges that are particular to our region of Appalachia. Julia do you want to take the first half, and I can take the second.

348
01:09:30.840 --> 01:09:38.850
Julia Stone: Sure yeah, so I think the very first thing that comes to mind always is barriers to access right, whether that be having to travel.

349
01:09:39.600 --> 01:09:50.250
Julia Stone: From a rural location to see a genetics provider or visit wait time. Shenin alluded to the fact that the cancer team has some pretty long wait times for their services.

350
01:09:51.360 --> 01:09:56.010
Julia Stone: This has been improved somewhat through the availability of video visits.

351
01:09:57.210 --> 01:10:15.570
Julia Stone: However, there are still some barriers to access even with video consults, right. The client needs to have some sort of phone or computer or a tablet that's functional that is up to date enough, it's a current software to be able to utilize the

352
01:10:15.570 --> 01:10:21.300
Julia Stone: application. Has to be a smart device right they also have to have strong wifi.

353
01:10:23.880 --> 01:10:42.480
Julia Stone: So that the video and the audio connect and as well as some level of technical literacy, to be able to troubleshoot when when things aren't going right, especially I think we've all encountered clients who maybe they're not hearing the audio because the audio output is set at

354
01:10:43.620 --> 01:10:59.640
Julia Stone: at headphones or something like that and there aren't any headphones plugged into the device, and if there's no audio, our system actually doesn't have a chat function, unfortunately, so there's not much that we can do by way of troubleshooting without having to call them.

355
01:11:00.990 --> 01:11:09.450
Julia Stone: On their device potentially that they're trying to use for the video consult, so there are still some barriers there in places that can absolutely be improved.

356
01:11:10.350 --> 01:11:18.510
Julia Stone: We've been working to establish more telemedicine clinics over time to try to get some clinics closer to where patients live.

357
01:11:20.370 --> 01:11:38.730
Julia Stone: Like Shenin said the cancer genetics program has hired some more genetic counselor, so has the prenatal genetic program and with the cancer team, the on call counselor is really helpful in getting patients seen in a timely manner when when those results are urgent for

358
01:11:38.820 --> 01:11:47.550
Julia Stone: their treatment, and there's their medical care. For prenatal the way that the clinic is set, they actually don't have very long wait times, which is good.

359
01:11:48.060 --> 01:12:00.480
Julia Stone: Pregnancy doesn't stop, everything is urgent and a pregnancy, so if something's truly urgent we're able to get a patient in typically within 24 to 48 hours, otherwise the standard patient usually within a week yeah.

360
01:12:01.170 --> 01:12:04.380
Shenin: One other thing I'll say before moving on is that I think with the

361
01:12:04.440 --> 01:12:14.820
Shenin: older age of the patient population and cancer genetics, the technical literacy and availability of something that allows you to do a video visit is probably more of a challenge than the typical younger population seen in prenatal.

362

01:12:15.690 --> 01:12:30.750
Shenin: With financial barriers so a lot of the people outside of the Pittsburgh metropolitan area or in more rural areas, there are costs associated with travel, and there are a lot of lower income areas in western Pennsylvania, so when you couple low income with travel distance.

363
01:12:31.800 --> 01:12:41.430
Shenin: You know, it makes it harder to get to your visit. So we've already addressed some of the efforts through telemedicine and video visits do that one thing that helps more than you think.

364
01:12:41.790 --> 01:12:50.370
Shenin: Are parking vouchers at UPMC Magee, I have had patients that are upset that they have to pay $5 to park if it's an extra cost on top of something that's already pretty high effort for them.

365
01:12:51.960 --> 01:12:59.640
Shenin: One thing I mentioned before, too, is that there, there are perceptions that cancer genetic testing still cost $4,000 if it's not covered by your insurance which

366
01:12:59.880 --> 01:13:08.850
Shenin: used to be true decades ago, so we've really tried, through our different efforts in Community and outreach to say it's not that's not quite the deal anymore.

367
01:13:09.120 --> 01:13:15.210
Shenin: Please don't let the cost barrier be what prevents you from making an appointment and getting information to help you and your family.

368
01:13:15.420 --> 01:13:22.200
Shenin: So we do have the ability to do price estimates. There are patient payment plans and out of pocket options and many labs are pretty generous programs.

369
01:13:22.500 --> 01:13:37.500
Shenin: For patient assistance that are income based that like a surprising number of people qualify for it something like if you're within 300% of the poverty line you're testing can be reduced or free, and many labs also have generous options for coverage for Medicare and Medicaid patients.

370
01:13:39.810 --> 01:13:43.020
Shenin: So that covers all the ground that we wanted to go over.

371
01:13:44.040 --> 01:13:52.410
Shenin: Our current contact information there just wanted to highlight again that, even though this talk focuses on UPMC my contact information is a little bit different now with NYU Langone

372

01:13:54.420 --> 01:14:00.210
Shenin: And unless Julia if you if unless you have anything else to say, I think we can open it up for questions.

373
01:14:06.090 --> 01:14:12.000
Kimberly Kelly: All right I think you folks have frozen on my screen I'm not sure if you're able to hear me.

374
01:14:13.170 --> 01:14:14.520
Shenin: I can hear you yes.

375
01:14:16.830 --> 01:14:28.710
Kimberly Kelly: And so, my first question is what are some of the opportunities, you see, for research to improve genetic service delivery in West Virginia and the Appalachian region?

376
01:14:31.620 --> 01:14:33.000
Shenin: Julia would you like to go first.

377
01:14:33.570 --> 01:14:42.810
Julia Stone: Sure yeah some of the things I can think of off the top of my head definitely a research into awareness of genetic services within the area.

378
01:14:44.130 --> 01:14:50.280
Julia Stone: Patients can't get to us if they or their providers don't know that that we better services are out there.

379
01:14:51.600 --> 01:15:02.430
Julia Stone: So definitely some awareness, I would say, research into alternative service delivery models is always it's something that's actively ongoing in the field of genetic counseling I think it's really important.

380
01:15:02.700 --> 01:15:03.270
Julia Stone: Just to go

381
01:15:03.480 --> 01:15:05.070
Julia Stone: additional ways that

382
01:15:06.930 --> 01:15:14.880
Julia Stone: additional ways that we can reach patients, whether that be through creating videos or group consults.

383
01:15:16.080 --> 01:15:24.180
Julia Stone: Maybe group information sessions and an individual one on one coach console but definitely research in regards to service delivery models could be really helpful.

384
01:15:25.740 --> 01:15:37.650
Shenin: I also so there's there's a whole other conference that could be given on the issues surrounding genetic counselors not being Medicare Medicaid recognized providers and how that limits our ability to deliver services.

385
01:15:38.130 --> 01:15:40.890
Shenin: I would absolutely love to see someone

386
01:15:41.460 --> 01:15:50.790
Shenin: retrospectively analyze data from the pandemic, which created this sort of setting where we were able to offer video visits and what did that do.

387
01:15:51.240 --> 01:16:00.960
Shenin: How did patients feel about it? Did were people more able to comply with their visits, because they could have a video visit, even if their kid was sick or even if it was snowing.

388
01:16:01.620 --> 01:16:10.080
Shenin: or and I'm not joking, even if the sheep escape from their field in Altoona like these things are like things that are that some of our rural Pennsylvania population deals with.

389
01:16:11.400 --> 01:16:23.520
Shenin: I would, I would love to see some of the outcomes of that I would be shocked if it was a net negative rather than a net positive, and I would love to see that used as justification to keep being able to offer these services.

390
01:16:24.210 --> 01:16:25.470
Shenin: Because I think that

391
01:16:26.430 --> 01:16:31.140
Shenin: You know it's it's surprising, the number of people that just the distance is too far.

392
01:16:31.350 --> 01:16:42.750
Shenin: They have to drive to McDonalds to get wifi and you know any any little bit that can help the people that it's easy for them to come see us because they have a car and they live close by, I think, are always going to come see us but

393

01:16:43.320 --> 01:16:47.370
Shenin: it's the people that are hardest to reach that need to try and accommodate.

394
01:16:50.550 --> 01:16:50.820
Kimberly Kelly: Did.

395
01:16:53.550 --> 01:16:57.630
Kimberly Kelly: I believe we have a comment comment or question from Dr. Kahler.

396
01:16:58.170 --> 01:17:00.030
Stephen G. Kahler, MD: Kahler, yeah can you hear me all right.

397
01:17:01.140 --> 01:17:01.410
Kimberly Kelly: Yes.

398
01:17:01.980 --> 01:17:11.580
Stephen G. Kahler, MD: I do pediatric genetics, among other things, but also adults and how do you interact with the pediatric genetics team and their metabolic services and what do you do

399
01:17:11.580 --> 01:17:18.210
Stephen G. Kahler, MD: about people with PKU live remotely who are 40 years old, and how does that all interface with the

400
01:17:19.350 --> 01:17:21.570
Stephen G. Kahler, MD: pitch for children's I guess genetics team?

401
01:17:23.280 --> 01:17:37.590
Julia Stone: So I can feel that one, I know the, so the the children's hospital has a general medical genetics clinic they do also have a metabolic clinic and they will see and follow patients

402
01:17:38.070 --> 01:17:43.920
Julia Stone: through adulthood in that clinic. It's one of the few, where they will follow patients into adulthood.

403
01:17:45.360 --> 01:17:46.860
Julia Stone: And they do, they do meet with

404
01:17:47.880 --> 01:17:50.640
Julia Stone: with those patients and it will annually, excuse me.

405
01:17:52.410 --> 01:17:59.040
Julia Stone: The prenatal team and the the pediatrics team are in contact a lot with

406
01:18:00.090 --> 01:18:08.490
Julia Stone: with these families, so if we prenatally identify a pregnancy that has an increased risk to have a metabolic conditions such as PKU.

407
01:18:08.820 --> 01:18:17.700
Julia Stone: With um, not only are we making sure that the neonatologist are aware, but we're making sure that the the genetics team at children's hospital is aware, because they're going to be pulled into that

408
01:18:18.690 --> 01:18:28.620
Julia Stone: that baby's care soon after delivery and vice versa, if they have a child who has been identified, to have a metabolic disorder through

409
01:18:28.800 --> 01:18:40.440
Julia Stone: newborn screening or something like that and they're following that that family they'll then refer the family back to prenatal genetics, to talk about risks in future pregnancies and options for future pregnancies.

410
01:18:41.490 --> 01:18:45.540
Stephen G. Kahler, MD: Yeah that's totally separate world I guess what you've been talking about here today.

411
01:18:46.200 --> 01:18:46.560
Stephen G. Kahler, MD: yeah.

412
01:18:46.830 --> 01:18:53.910
Stephen G. Kahler, MD: Cancer and prenatal genetics are usually some from the pediatric genetics

413
01:18:54.570 --> 01:19:07.770
Stephen G. Kahler, MD: about the other business like cardiomyopathy is that sort of thing mitochondrial disorders of any age, they typically are going to be seen by an integrated service they're very few places where there's a separate genetic service that is not

414
01:19:08.940 --> 01:19:13.890
Stephen G. Kahler, MD: staffed by people with pediatric training or experience so anyhow

415
01:19:15.090 --> 01:19:17.070

Stephen G. Kahler, MD: It’s good to see this, thank you.

416
01:19:17.940 --> 01:19:25.020
Shenin: I’ve got a couple questions in the chat as well, the first one was commenting on the impact of the local genetic counseling training program on staffing.

417
01:19:25.530 --> 01:19:35.250
Shenin: That one's fairly straightforward: most of the people that have been hired in the past years have been new grads from the University of Pittsburgh genetic counseling program.

418
01:19:36.240 --> 01:19:51.720
Shenin: Not all, so I myself came from University of Michigan, and I believe there's been at least two or three other new hires in recent years that are from sort of outside, but a lot of people do kind of want to stay in the Pittsburgh area afterwards so it's probably like 50/50 overall.

419
01:19:52.860 --> 01:19:55.440
Shenin: And then Julia, if you wanted to address the question from Dr. Falah.

420
01:19:56.820 --> 01:19:59.280
Julia Stone: Let me pull up the chat.

421
01:20:01.230 --> 01:20:06.270
Shenin: While you're doing that I will just say that, like the the growth positions have been related to need rather than

422
01:20:06.390 --> 01:20:18.300
Shenin: like the physicians weren't created for like new Grad students, if there were new grads that were applying to jobs that were created to address an existing need then there were always applicants from the program but it wasn't.

423
01:20:19.050 --> 01:20:24.240
Shenin: We don't add positions that often that every new Grad like gets a job.

424
01:20:26.760 --> 01:20:36.420
Julia Stone: But the ability to supervise students as they're going through their training program means that we do have to maintain a certain level of staffing

425
01:20:36.510 --> 01:20:37.620
Julia Stone: to be able to do that.

426

01:20:38.490 --> 01:20:49.440
Julia Stone: So the question was do you think if the genetic counselor can work as an as independent providers and be able to independently bill that could attract a genetic counselor to stay in clinics and decrease their attraction to industry.

427
01:20:49.830 --> 01:20:56.430
Julia Stone: I think this is a really, really thoughtful but really complex question there's there's been a lot of

428
01:20:56.970 --> 01:21:07.080
Julia Stone: research within the genetic counseling community on reasons why genetic counselors leave the clinic space and go on into other opportunities and one of the big reasons is burnout.

429
01:21:08.070 --> 01:21:15.270
Julia Stone: There's genetic counselors do a lot of work, and we care a lot for our patients and tend to go above and beyond.

430
01:21:16.710 --> 01:21:20.850
Julia Stone: And there, there are not currently and

431
01:21:22.170 --> 01:21:34.080
Julia Stone: probably will never be enough genetic counselors to be able to meet with patients and be utilizing those the in person service delivery models, as we utilize them today.

432
01:21:34.920 --> 01:21:40.860
Julia Stone: And so, genetic counselors are stretched oftentimes very thin in the clinic and seeing as many patients as they can.

433
01:21:41.640 --> 01:21:49.380
Julia Stone: Some things that aid in genetic counselor or in reducing genetic counselor burnout are having the staffing to help with administrative

434
01:21:49.920 --> 01:22:10.350
Julia Stone: work, so genetic counseling assistants or other scheduling assistants, billing specialist operation authorization specialists etc. um I do think billing as an independent provider could be beneficial from a reimbursement perspective for hospitals and genetic teams.

435
01:22:12.630 --> 01:22:22.950
Julia Stone: So in that regard that could potentially create funding for these these other services to help with some of the the administrative work.

436

01:22:26.220 --> 01:22:28.950
Julia Stone: Yeah I think that answers that question. Shenin do you want to.

437
01:22:29.970 --> 01:22:30.690
Shenin: The only other comment I'll make

438
01:22:30.750 --> 01:22:36.900
Shenin: that relates to burn out so surprisingly, some people, some people do have emotional burnout you know, they are

439
01:22:37.170 --> 01:22:45.810
Shenin: dealing with cancer risk dealing with the risk to have a child, with condition is all something that can take a toll on a counselor but, honestly, one of the most frustrating that's a burnout

440
01:22:46.440 --> 01:22:53.580
Shenin: that also relates to things on a global scale is we spend so much time thinking about insurance coverage and price estimates.

441
01:22:54.390 --> 01:23:02.550
Shenin: We had a weekly case conference on Mondays, and it was less what is the differential diagnosis for this patient and will this test be covered or not.

442
01:23:03.450 --> 01:23:07.680
Shenin: A lot of "genesurance" counseling to use a phrase from a couple of years ago, so.

443
01:23:08.520 --> 01:23:16.230
Shenin: National changes in what is covered and what is reimbursed, especially for repeated genetic testing when people have only had limited testing in the past.

444
01:23:16.920 --> 01:23:32.310
Shenin: If counselors had to spend less of their time worrying about that, I think that would significantly reduce burnout, but that's another thing that would require national changes in the same way that national changes would be needed to recognition and credentialing so.

445
01:23:38.970 --> 01:23:43.650
Kimberly Kelly: The question related to that, and you can decide how personal you want to be.

446
01:23:44.820 --> 01:23:45.570
Kimberly Kelly: But so

447

01:23:46.590 --> 01:23:50.310
Kimberly Kelly: it seems like using both of you have made some career changes

448
01:23:50.730 --> 01:23:51.060
Shenin: In

449
01:23:51.090 --> 01:23:52.950
Kimberly Kelly: the past few months and

450
01:23:54.000 --> 01:24:17.310
Kimberly Kelly: You know I have been, my family is Appalachian, and you know I've been in West Virginia for 12-13 years now, and you know I don't practice as a genetic counselor and the administrative burden, played a big role in that, for me, but can you, you know, help us

451
01:24:17.850 --> 01:24:24.030
Kimberly Kelly: as we try to retain great folks like

452
01:24:24.120 --> 01:24:27.900
Kimberly Kelly: like you guys in the counseling profession in our region.

453
01:24:29.220 --> 01:24:29.760
Shenin: yeah I

454
01:24:29.850 --> 01:24:31.530
Kimberly Kelly: am Finally, talking about why so

455
01:24:31.800 --> 01:24:34.440
Shenin: my husband decided that he wanted to move to New York City.

456
01:24:34.680 --> 01:24:46.590
Shenin: And that's how I ended up at the Pancreatic Center at NYU. It was nothing to do with the job itself; so I'd hire, this is a joke, but hire people who never want to get married.

457
01:24:49.020 --> 01:25:03.300
Shenin: No honestly like it, UPMC, was a great place to work, and it was just logistical things with my personal life that led me elsewhere; so Julia maybe better poised to answer your question about retention, given that you just switch jobs within the same place.

458
01:25:04.440 --> 01:25:04.920
Julia Stone: Yeah.

459
01:25:06.780 --> 01:25:08.970
Kimberly Kelly: We have trouble retaining faculty members all the time.

460
01:25:12.000 --> 01:25:12.390
Kimberly Kelly: No.

461
01:25:13.470 --> 01:25:15.090
Kimberly Kelly: It’s hard to find

462
01:25:18.360 --> 01:25:21.510
Kimberly Kelly: you know dual earning couples to find.

463
01:25:22.770 --> 01:25:23.910
Kimberly Kelly: jobs in our region, competitive jobs.

464
01:25:27.240 --> 01:25:35.520
Julia Stone: Yeah I can, I can say that the when the position that I have now opened up.

465
01:25:36.690 --> 01:25:49.020
Julia Stone: The thing that attracted me to the position was twofold, one was the ability to impact more patients so through my position in the laboratory I’m helping to generate reports, I’m helping

466
01:25:49.980 --> 01:26:01.470
Julia Stone: to that I participate in weekly discussions about our whole exome sequencing studies and what variants may or may not end up on a report and is it related to a child's phenotype

467
01:26:02.610 --> 01:26:13.260
Julia Stone: and have opportunities to be involved in gene curation and development of new panels and such and in developing a new panel that's something that's going to be offered to

468
01:26:14.040 --> 01:26:23.670
Julia Stone: many, many, many patients who I wouldn't have the opportunity to meet personally, but I know that what I’m doing is having a broader impact on the larger patient population.

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01:26:24.030 --> 01:26:35.610
Julia Stone: I do, I help a lot with this with supporting the the cancer genetics team here at Magee and the prenatal genetic team, especially as we offer more more testing options for the prenatal team.

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01:26:37.020 --> 01:26:42.870
Julia Stone: So I still feel like I'm giving back to to the patients in that way it's just from a different lens.

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01:26:44.310 --> 01:26:47.850
Julia Stone: And if I can say it was something that that level of

472
01:26:48.930 --> 01:26:55.350
Julia Stone: you know procedure and SOP is something that that really fits well with my my brain and my work style.

473
01:26:56.970 --> 01:26:57.690
Shenin: And listen

474
01:26:58.290 --> 01:26:58.530
Shenin: Go ahead Julia

475
01:26:59.130 --> 01:27:07.080
Julia Stone: I was just gonna say there have been other other genetic counselors that have worked in this lab I work with one other genetic counselor currently.

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01:27:07.320 --> 01:27:23.190
Julia Stone: And at the time that I was hired there was not anybody here who had had prenatal experience, so I really wanted to bring that lens into the clinic for thinking for sorry, into the laboratory for thinking about future testing options from from a prenatal perspective.

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01:27:25.050 --> 01:27:28.620
Shenin: One other thought I have just related to retention and keeping people is that

478
01:27:28.680 --> 01:27:37.620
Shenin: in about 2015 or 2016 there was a publication, I believe in the Journal of Genetic Counseling about the creation of career ladders in specific

479
01:27:38.280 --> 01:27:46.710
Shenin: genetic counseling clinics throughout the country and, at the time it was a fairly uncommon thing, but that publication led to the development of career ladders in multiple places so.

480
01:27:48.240 --> 01:27:57.720
Shenin: At all three of the institutions that I've worked at, a career ladder was either in place actively implemented, or was about to be implemented in the near future so.

481

01:27:58.320 --> 01:28:10.530
Shenin: Giving people structure, giving people things to work toward, and then the knowledge that there will be some level of financial compensation when they reach those different levels is a good way to retain things rather than

482
01:28:10.950 --> 01:28:18.480
Shenin: just sort of like you're hired and who knows what will ever happen beyond beyond this, and I think it also it's beneficial from a salary standpoint.

483
01:28:18.810 --> 01:28:32.850
Shenin: But I know the career ladder at UPMC had things like if you published, if you gave a community lecture. So it it helped professionally as well to establish connections with the place where you lived, which I think is also probably important for retention long term.

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01:28:35.100 --> 01:28:52.140
Kimberly Kelly: That's a good point. Yeah and and I don't know how how widely those are implemented, but that is, that is a good idea, and especially you know at our institution, where we don't have as many genetic counselors to consider if you know in building a program having those things in mind.

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01:28:52.770 --> 01:29:04.650
Kimberly Kelly: But I know we're running late and I appreciate you giving us your extra time and for a thoughtful conversation about

486
01:29:04.800 --> 01:29:15.120
Kimberly Kelly: genetic services in our region and I don't see any other questions so I'll thank you again for for a wonderful presentation and a good discussion.

487
01:29:15.480 --> 01:29:34.080
Kimberly Kelly: And we look forward to following up with you in the future and, and of course our next session will be with NYMAC with Alissa Terry will be speaking to us, who I believe Shenin, you will have probably more contact with going forward.

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01:29:35.730 --> 01:29:49.440
Kimberly Kelly: We look look forward to seeing you all next month and learning more about other ways that we can improve our genetic service delivery, so thank you so much Shenin and Julia for talking to us today.

489
01:29:50.010 --> 01:29:50.940
Shenin: Thank you, as well.

490
01:29:52.140 --> 01:29:52.800
Kimberly Kelly: Thanks thanks.

491
01:29:53.400 --> 01:29:53.910
Julia Stone: Bye Everyone.