

WEBVTT

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Kim Kelly: If I think Anusha can continue to let folks in I will go ahead and start.

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Kim Kelly: So, welcome to the fifth session of the webinar series on genetic services in Appalachia. We ask that you mute your microphone for the talk.

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Kim Kelly: And place any comments or questions in the chat box until the end of the session, and then there will be opportunities to ask questions, then.

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Kim Kelly: we're happy that you're joining us, we ask that you not record our session. We will be recording this session this time, and

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Kim Kelly: we will provide a transcript on our website. We had a little technical issue on our last one, and so we are working to get that added to our website soon.

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Kim Kelly: So be looking for that, and we'd be happy to have any comments or questions about that too, and we have an evaluation for that session that we will be sharing, so that we can get more feedback.

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Kim Kelly: So we will ask for feedback at the end of this session, as well, and so we hope to post that in the Q & A. We appreciate your feedback, whatever it might be, because this is information to our funders about your thoughts and also, as we try to construct a research agenda.

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Kim Kelly: As you know, our aims include to develop a research

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Kim Kelly: agenda.

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Nadia Falah:

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Kim Kelly: So we appreciate you joining us if you wouldn't mind muting your phone or your zoom, then we will proceed.

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Kim Kelly: So each month we're having speakers working in a variety of genetic service provision to medically underserved population, with a focus on rural Appalachia.

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Kim Kelly: And so now I'd like to introduce our speaker Dr. Rebecca Kronk. Dr Kronk is the associate dean of academic affairs at Duquesne University School of Nursing in Pittsburgh.

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Kim Kelly: She is a pediatric nurse practitioner and has her PhD in developmental psychology. Her clinical career has focused on children with a range of developmental and genetic conditions.

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Kim Kelly: She helped establish the fragile X Center at Children's Hospital of Pittsburgh at UPMC.

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Kim Kelly: This achievement affected inter professional practice and education in the Children's Hospital in Pittsburgh, and this interdisciplinary center is internationally recognized as part of the fragile X International Clinic Consortium.

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Kim Kelly: Dr. Kronk has served as the President of the International Society of Nurses in Genetics from 2020 to 2021, so she is just finishing her work there.

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Kim Kelly: But she continues to be active in that group. She was recently awarded an R25 grant from the National Human Genome Research Institute of the National Institutes of Health.

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Kim Kelly: To improve nurses literacy in genetics and genomics to benefit their research, clinical practice, and teaching in order to improve patient healthcare outcomes

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Kim Kelly: particularly those from underrepresented communities. And so I was sharing with Dr. Kronk that her perspective is a much needed addition

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Kim Kelly: to our webinar and I am excited to learn more about the field of nursing genetics and what Dr. Kronk has working on in particular so I'll turn it over to Dr. Kronk now thanks.

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Becky Kronk: Thanks Kim. That was a nice introduction, I just want to make sure that everybody sees the full slide not the split slide. You see the full side, okay that's great.

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Becky Kronk: So I'm grateful to be here and I'm grateful to be able to share, our collective knowledge and experiences with one another.

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Becky Kronk: I've been able to attend a couple other of these noon time sessions, and I really benefited from them all, so I hope that today's presentation also benefits you, and I always like a conversational style so anytime anyone wants to interrupt me I'm happy to respond.

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Becky Kronk: So today I've divided up the presentation into two parts, and so the very first part, I really want to concentrate on the role of nurses in genetics,

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Becky Kronk: and explore the competencies for the registered and the advanced practice nurse, and also to examine the present state of genetics and genomic nursing education programs.

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Becky Kronk: And also to introduce you to some professional organizations and learning opportunities that continue to promote genetic and genomic development in the nursing profession.

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Becky Kronk: And then, secondly, which is my second passion, I really want to talk about the intersection of nursing genomics and disability.

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Becky Kronk: I want to discuss health disparities of people with disabilities, particularly in relationship to genetic conditions

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Becky Kronk: and explore this disability belt of complex diseases that occurs in Appalachia, and it results in these multiplex

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Becky Kronk: phenotypes, and then lastly to not only discuss I think the nurses' role, but the interdisciplinary role of health outcomes of people with disabilities as it relates to known conditions. So it sounds like a lot, but we'll get there.

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Becky Kronk: I wanted to start with this quotation by Connors and Schorn, and it was actually an editorial in the Journal of Professional Nursing.

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Becky Kronk: And I'll read it to you because I think it's really important, it states that nurses must be prepared in the fundamental genetic and genomic content to meet population health needs.

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Becky Kronk: To understand the molecular and genetic basis of disease treatment modalities, and the recognition of therapeutic response is an imperative

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Becky Kronk: for quality nursing care. It is crucial that nurses receive extensive formal and ongoing continued education in genetics and genomics, and so I think this really lays the groundwork of

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Becky Kronk: the basis of all the efforts that we're trying to make in this profession to include genetic and genomic content.

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Becky Kronk: To improve health outcomes for the people that we serve.

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Becky Kronk: So I wanted to kind of review where this all originated, so the inclusion of Genetic Competencies and undergrad nursing has been recommended since around 2006.

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Becky Kronk: There was a consensus panel formed by the American Nurses Association and, I want to say, roughly 30 other institutions of learning or

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Becky Kronk: other nursing organizations came together, and they published this "Essentials of Genetic and Genomic Nursing."

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Becky Kronk: And it was a list of competencies, and then in 2008, it was revised and they added some specific outcome indicators which I think were really helpful, and the fact that it gave especially nurse educators the opportunity to think about what these competencies would look like in practice.

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Becky Kronk: And then in 2011 this very similar group, including the American Nurses Association came together and created the "Essential Genetic and Genomic Competencies for the Graduate Nurse."

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Becky Kronk: And both of these publications stem from the first publication, which I have over there "The Genetics and Genomics Nurse Scope and Standard of Practice."

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Becky Kronk: That very first publication came out around 2006, 2007, and it was a joint effort between the American Nurses Association and the International Society of Nurses in Genetics.

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Becky Kronk: And we developed a scope and standard practice for The Genetics and Genomics Nurse, this was updated in 2007, and we are actually working on another update beginning right now in 2022

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Becky Kronk: because things have changed so rapidly.

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Becky Kronk: What I really find important about all these publications, is that the overarching goal has been to make genetics more mainstream and approachable.

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Becky Kronk: You know, for all nurses in practice. We don't want nurses to think or be limited, that you know genetics is just connected to rare disorders.

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Becky Kronk: Or that it's a special realm but that there's knowledge of genetics and genomics is necessary and routine care across any setting.

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Becky Kronk: That involves this personal relationship between a client and a nurse, and that recipients of genetic nursing practice can be individuals, families or communities for entire populations.

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Becky Kronk: And we can, you know, involve or treat people at any stage of life, whether they're pre-symptomatic or at risk, whether we just determined that they are susceptible to a specific disease.

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Becky Kronk: Or that they just need genetic information and education and help with genetic literacy.

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Becky Kronk: So just briefly some of the essentials of The Genetics and Genomics Nurse, and this is the RN The pre-licensure, you know the basic licensure for nursing.

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Becky Kronk: They've divided these components up into professional responsibilities and professional practice, and I just highlighted the sub domains under each one of these competencies.

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Becky Kronk: And these competencies reflect the minimal amount of genetic and genomic knowledge and skills that's expected by every nurse.

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Becky Kronk: And these publications on the genetic and genomic competencies like I said earlier, are also helpful to guide you know nurse education and implementation of learning experiences to help the next generation of nurses in the workforce.

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Becky Kronk: I have to say, you know from experience I started a standalone genetics course here at Duquesne University in 2014.

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Becky Kronk: And it was for the undergrad nurses and initially, and I think this happens even to this day, you know the nurses, I mean the students, they sort of think you know 'why do I need a genetics, another genetics course? You know, I've had biology. I've had pathophysiology.'

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Becky Kronk: Sometimes even the second degree students who have had you know degrees in biology previous to coming to nursing school would say you know why do I need this course, why is it important.

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Becky Kronk: They have to say, based on I based the course here at Duquesne on these competencies and so it really helps them, you know bridge that

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Becky Kronk: theory to practice gap, right? Like I can learn about inheritance, or how to do you know, a history

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Becky Kronk: or perform a three, you know, generation chart, but what does that mean as a nurse and caring for an individual?

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Becky Kronk: So because of these competencies we do a lot of reflections, we do a lot of case studies, and we demonstrate like why genetics and the nurse make a difference.

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Becky Kronk: And I hope that that helps you see, you know and honestly, you know I have them do impressions at the beginning of the course.

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Becky Kronk: And you hear a lot of this negativity. At the end of the course, I will hear things like 'this has changed my practice; this has really changed my life.'

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Becky Kronk: You know even personally they ha'en't thought about some of the ways that

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Becky Kronk: genetics can be incorporated, you know into you know ethical situations, religious situations, thinking about the health literacy of their patient.

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Becky Kronk: They can do referral activities by the end of this course, things that they wouldn't normally get in a biology or pathophysiology course, so I think that that makes a pretty profound difference, and they see that by the end.

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Becky Kronk: And then I also, just providing some again domains of the Genetic and Genomic Competencies for the nurse with the graduate degree, and of course these build on those core RN competencies that are it for the undergraduate.

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Becky Kronk: But we know that those nurses with graduate and doctoral degrees interface more with treatment and translation of genetic and genomic advances in clinical care and are increasingly asked to provide the leadership and practices and in education and research.

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Becky Kronk: So that we know that you know APN, advanced practice nurses, they have a more broader scope of practice with more advanced training so myself as a pediatric nurse practitioner, you know the Fragile X clinic know is able to you know, do everything that

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Becky Kronk: you know my colleagues did who were also from the medical profession know is able to interview and diagnose and order treatments and interpret

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Becky Kronk: test results and offer some counseling and referrals so

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Becky Kronk: those are the competencies for the graduate nurse.

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Becky Kronk: So let me just say that you know, there have been many challenges, though, to adapting a uniform approach to genetics and genomics and the nurse and to prepare nurses in their in academia.

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Becky Kronk: You know many schools of nursing, you know some of the barriers have been that you know faculty don't feel qualified

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Becky Kronk: to teach genetics and genomics, and I can totally understand that right.

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Becky Kronk: A lot of times nursing curricula and many of you and pharmacy and other healthcare disciplines know that that curriculum is already packed with a lot of content so.

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Becky Kronk: You know, how do we put in a standalone course? So some undergraduate programs or graduate programs will spread the information throughout courses, so you just get a smattering of genetics and genomics.

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Becky Kronk: And then there are some postdoc and graduate programs that receive some T32 grants to advance the training of nurses and genomics. I gave an example here of the University of Pittsburgh, and then the University of Washington has a T32 in the Omics and Symptoms Science.

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Becky Kronk: And then Vanderbilt University has a genetics fellowship for family nurse practitioners, so we don't have a very uniform approach, but there are some really strong programs out there to address again this

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Becky Kronk: theory to practice gap and many of us get our experiences, you know post graduation, and many of these funded opportunities.

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Becky Kronk: In my introduction, we mentioned an R25 that I recently received, but it was really quite an important milestone for both Dr. Laurie Connors and myself.

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Becky Kronk: To both receive R25's this past year, and you know it's very nice to for the National Human Genome Research Institute to recognize the important work of nurses.

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Becky Kronk: And to also see the importance of preparing nurses to in this era of genomics. So Dr. Connors is from Vanderbilt she has an R25.

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Becky Kronk: And the acronym is TIGER it's called Translation and Integration of Genomics

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Becky Kronk: is essential for doctoral nursing, and it's a five year grant, and it's to increase the capacity and capability of doctoral nurses and the translation and integration of genomics. And then my grant is a little bit different in the fact that it does

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Becky Kronk: address graduate level nurses, doctoral level nursing faculty and students, but it is to improve the nurses' genetic literacy and genomic science literacy.

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Becky Kronk: Mine's setup and much of a way that you know I I want nurses, without any genetic background to be able to think, 'oh, I can take this course and learn some basics about genetics and increase my own literacy' and also be encouraged to take a next step in their genomic journey.

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Becky Kronk: And then we also want to focus on the underrepresented minorities, because many times in genetics and genomics in research

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Becky Kronk: we have many minority groups that aren't represented, and so you know, one of my goals was to bring that to the attention of many nurses and, hopefully, their work will start to involve underrepresented minorities.

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Becky Kronk: So that's a little bit about the basics of education with genetic and genomic nursing, but there are quite a few professional organizations

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Becky Kronk: that offer continued education and recognition as a genetics and genomics nurse, so the Nurse Portfolio Credentialing Commission offers certification as a clinical genomic nurse or as an advanced clinical genomics nurse.

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Becky Kronk: And these particular nurses provide services to patients with or at risk for inherited disease and many of them work in specialty areas such as oncology, cardiology, neurology, pediatrics, and I think even in one of the very first found a

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Becky Kronk: noon time

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Becky Kronk: presentations but there was some talk about the genetic services at WVU and the nurses there and how they actually take the I think it's the City of Hope

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Becky Kronk: Course, the oncology course for genetics, but this is this, these are the nurses that I'm talking about. They specialize in certain areas that really focus on genetic conditions, and they're able to be credentialed.

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Becky Kronk: One thing that NPCC is also working on is a credential for genetics nurse educators, and I'm very excited to see that coming in the future.

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Becky Kronk: Um the other organizations, one of them most familiar with and I've been with ISONG for

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Becky Kronk: many years. And this organization was started in 1988, and we have around 350 plus members and from all over the world, and I've listed quite a few of the countries where our members reside.

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Becky Kronk: And this organization is really to support nurses from any field but are interested in genetic and genomic education, leadership opportunities, research opportunities, or maybe just want to learn more about genetics for the clinical practice.

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Becky Kronk: And every year, we have an ISONG conference, and the past two years, of course, we've had it online, but it is just a great opportunity for us to connect and provide educational webinars and

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Becky Kronk: research and clinical opportunities to our members.

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Becky Kronk: And then the Omics Nursing Science and Education Network, ONSEN for short,

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Becky Kronk: And I put a little video here that if you want to go to that on your own. It's just a YouTube video that talks a little bit more about this really wonderful resource.

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Becky Kronk: It is a group of nurses who were interested in Omics in their program, and they created this resource network, and it's open again to all,

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Becky Kronk: all healthcare providers, but it is really you know it originated with this nurse science community.

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Becky Kronk: And it was to enable collaboration and mentoring and access to training opportunities across institutions, so they do provide resources for training, common data elements support, and exploring partnerships in research.

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Becky Kronk: And some of you may be familiar with the Human Genome Institute, which is the Inter-Society, Coordinating Committee for Practitioner Education in Genomics. That's quite a mouthful, but this is an interdisciplinary group

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Becky Kronk: that includes over about 200 Members from different professional organizations and societies and the NIH and

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Becky Kronk: since its inception, it provides a forum for discussion and in-person meetings to detect develop resources for genomics education and webinars and mainly the goal is to improve the genetic genomic literacy of healthcare providers from many different

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Becky Kronk: disciplines, and it's you know it's a very, very exciting group and does a lot of good work, and again I put a little YouTube video there for your own future reference.

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Becky Kronk: And then the very last organization; which is an international one, this is called G2NA it was established in 2017 and what I wanted to do was just promote genomics healthcare

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Becky Kronk: and make it again very accessible to any nurse, you know internationally. And its mission is to support nurses to realize their full potential so integrating genomics

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Becky Kronk: across nursing practice to improve health care for all, and this is a very, another really good website that provides webinars, publications, and a list of other genomic nursing societies that worldwide that nurses can become involved with.

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Becky Kronk: So, before going into part two, I just was wondering, is there any comments or questions about the first half of my presentation that anyone might

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Becky Kronk: like to share.

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Becky Kronk: Well we'll move on to part two of

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Amy Dameron: Can you hear me.

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Becky Kronk: Now we can.

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Amy Dameron: Okay, my name is Amy Dameron I work with GeneDx, and we have a team of about 30 nurses who do clinical records abstraction for us, so this is

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Amy Dameron: this kind of piques my interest. Um are you able to send out some additional information on the

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Amy Dameron: the courses that you mentioned, the online courses that will be available.

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Becky Kronk: Oh yeah.

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00:33:25.590 --> 00:33:26.760

Amy Dameron: Okay, great. Thank you.

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Becky Kronk: I can yeah I can talk to Kim, I can send her or Anusha could send it out, but I'll give the links to both of those and that can be sent out.

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Amy Dameron: Okay. Thank you so much.

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Becky Kronk: Sure.

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Becky Kronk: Um so at this intersection of disability and genetics I'm hoping that this kind of brings it home right, the whole purpose of I think Kim's grant and

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Becky Kronk: here is to think about Appalachia, and the specific needs of the people in that area and the service that's needed there and to bring some attention.

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Becky Kronk: And, and maybe even talk about some ways to address some some issues and barriers there.

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Becky Kronk: So I think there's this really important alignment between disability and genetics, you know I say disability affects all age groups, cultures and ethnicities.

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Becky Kronk: And so, does genetics right, I mean we can drill down to more specific types of conditions, but overall genetics effects all age groups, cultures and ethnicities.

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Becky Kronk: And whether it's a single gene, a chromosomal disorder, or complex disorder, essentially every genomic disorder can be a primary disability.

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Becky Kronk: Or it has the potential to result in some form of disability, so I think there's these great parallels between between these two health conditions, right.

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Becky Kronk: And for those that may I'm just going to you know again tip of the iceberg here, you know, over a billion people worldwide

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Becky Kronk: live with a disability, so that's about 15% of the world's population, and it truly is the largest minority group in the world.

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Becky Kronk: And yet they are three times more likely to be denied health care, four times more likely if to access health care, but be treated poorly. And just to give an example worldwide, there's about 75 million people that need a wheelchair, but only 5-15% have access to one.

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Becky Kronk: And disability is on the rise, and if I was in a classroom, I'd say to you what are some reasons why you think it's on the rise.

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Becky Kronk: But you know, in the essence of time, you know, one of the reasons, I'll give you a few. You know we have an aging population, so, in some ways it's inevitable, the longer you live, the more likely, you are to probably have either an acute or chronic disability.

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Becky Kronk: People are living longer, with chronic diseases which tend to have lend itself to disabilities. We have more survivors of violence and trauma.

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Becky Kronk: And we also have higher survivors of prematurity, all because you know we have better treatments that, we have better treatments and and so survivorship lasts, you know we have higher rates of survivorship, but disability also comes with those higher rates at times.

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00:36:51.150 --> 00:37:05.250

Becky Kronk: And the one thing I really want to pull out and again this is, I want you to be thinking also about Appalachia here right. People with disabilities, on the whole experience higher rates of poverty.

216

00:37:06.690 --> 00:37:14.490

Becky Kronk: 32% of people with disability compared to 11% of people without disability live in poverty.

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00:37:16.290 --> 00:37:19.200

Becky Kronk: There are lower rates, of employment rates.

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00:37:20.970 --> 00:37:28.260

Becky Kronk: You know 14% of people with disabilities are employed compared to 76% of those without disabilities.

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00:37:29.340 --> 00:37:31.380

Becky Kronk: They receive less education.

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00:37:32.640 --> 00:37:44.100

Becky Kronk: I think only about 20%, in 2016, this is a statistic from there 20% of people with disabilities have less than a high school education.

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00:37:45.750 --> 00:37:54.210

Becky Kronk: They have unequal access to health care services, you know women with disabilities have lower rates of mammograms and pap tests.

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00:37:54.780 --> 00:38:07.740

Becky Kronk: Even getting on a scale to be weighed, is almost non-existent at times and adults with disabilities, you know or have, there's higher rates of health risk behaviors, right.

223

00:38:08.670 --> 00:38:23.250

Becky Kronk: There's higher smoking rates, higher obesity rates, we have higher rates of diabetes and cardiovascular disease, and people with disabilities. So you can see how this kind of creates the perfect storm.

224

00:38:24.660 --> 00:38:31.500

Becky Kronk: There's a greater risk of exposure to violence, and you know when I read the statistics on this, I'm just like blown away.

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00:38:32.700 --> 00:38:49.200

Becky Kronk: You know, people with disabilities are three times more likely to be experienced violent victimization—those are things like rape, robbery and assault, and as a child, they're 1.5 times more likely to be abused.

226

00:38:50.610 --> 00:39:06.570

Becky Kronk: And then there's this high risk of unintentional injury. One other thing that's not on this slide that I think it's really important is to think about you know there's a lack of emergency planning, which is a major safety issue.

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00:39:09.630 --> 00:39:23.280

Becky Kronk: For example, there were about 38% of people who were not evacuated during Hurricane Katrina because either they had mobility disability or were caring for someone with that disability.

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00:39:24.660 --> 00:39:35.490

Becky Kronk: And then I think it's really important, if you think about how this perfect storm happens, you know, if you're a minority from a racial or ethnic background plus have a disability.

229

00:39:35.820 --> 00:39:51.450

Becky Kronk: You have this health disparity amplifying phenomena, but I want you to keep this in mind as we talk about Appalachia region because I to think that there's this amplifying phenomenon that we need to pay attention to.

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00:39:54.660 --> 00:40:07.470

Becky Kronk: So the Disability Belt is this geographic distribution of people on disability in rural areas of Appalachia, the deep South and along the Arkansas-Missouri border.

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00:40:08.490 --> 00:40:15.210

Becky Kronk: And it covers much of this Appalachia region, so I'll just show you this map here.

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00:40:17.250 --> 00:40:35.040

Becky Kronk: So, according to the Appalachian Regional Commission, there's a percentage of people receiving disability benefits in this area that's higher than the national, so about, and these darker areas, you know that's the highest levels of disability.

233

00:40:36.210 --> 00:40:55.920

Becky Kronk: Overall, that area in Appalachia's about 7.3% higher than the United States, and where there's about 5% of people on disability benefits, but there's these five Appalachians sub regions that report higher percentages and like I said, those are those really dark blue areas.

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00:40:57.990 --> 00:41:11.250

Becky Kronk: And central Appalachia has a particularly high figure, it's about 13.9% and then there's other more distressed areas around 13.6% right.

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00:41:11.700 --> 00:41:24.270

Becky Kronk: So I just really want you to pay attention to these darker areas and where you see these darker areas of people who are those higher rates of people on disability benefits okay.

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00:41:26.070 --> 00:41:33.840

Becky Kronk: So if we move to the next slide again there's same areas where there's these higher rates of cancer.

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00:41:39.690 --> 00:41:52.380

Becky Kronk: And just real quickly, you know when there was a survey done in '89 to '95, the cancer mortality rate in Appalachia was only 1% higher than the rest of the US.

238

00:41:52.860 --> 00:42:14.940

Becky Kronk: By the time this map came around in 20. So this was map done in between 2008 and 2014 cancer mortality rates rose to be 10% higher than the rest of the US, so gigantic jump right, from 1% higher to 10% higher.

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00:42:16.530 --> 00:42:20.430

Becky Kronk: Again this looks almost like the exact same map, doesn't it, if I go back.

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00:42:23.220 --> 00:42:33.780

Becky Kronk: But now we're talking about heart disease, you know again, in 1989 to 1995 heart disease mortality rate in Appalachia was 10% higher

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00:42:34.290 --> 00:42:49.290

Becky Kronk: than the rate and United States, overall, but by time 2008 to 2014 rolled around the rate was 17% higher than the national rate so there's this growing disparity.

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00:42:53.070 --> 00:43:00.480

Becky Kronk: And then diabetes kind of start to see a little bit lighter areas, but again got this dark concentration, some of these areas.

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00:43:02.640 --> 00:43:13.290

Becky Kronk: And then, and I just want to say that in all five sub regions in Appalachia they report higher diabetes prevalence than the national figure, the central

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00:43:14.460 --> 00:43:31.980

Becky Kronk: area, right here of Appalachia has a 13.5% and North Central has a 12.8% report, and I think, overall, the US has a 9.8%.

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00:43:33.600 --> 00:43:45.780

Becky Kronk: And then just looking at the lifespan approach you know down here in the southern region, we have some really darker areas, but again, some smattering here, you know West Virginia,

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00:43:47.280 --> 00:43:49.140

Becky Kronk: Central and North Central.

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00:43:53.280 --> 00:43:55.290

Becky Kronk: The Appalachian region,

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00:43:57.990 --> 00:44:07.230

Becky Kronk: it says here with a rate of 7.1 infant deaths per thousand births, the infant mortality rate is 16% higher in the Appalachian region.

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00:44:08.460 --> 00:44:10.500

Becky Kronk: It's really kind of mind boggling isn't it.

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00:44:16.290 --> 00:44:24.540

Becky Kronk: And to support some of this data I you know, there was this really interesting research, study done by McDaniel's and colleagues in 2019.

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00:44:26.280 --> 00:44:38.400

Becky Kronk: And it looked at this description of the causes and the rates of childhood epidemiology, childhood disability and the Mississippi Delta and the Appalachian regions.

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00:44:40.290 --> 00:44:57.870

Becky Kronk: And you know talk about using the data from the US census, and they looked at disability rates across all types, any type, ambulatory self care, hearing, vision and cognitive, and these rates were all higher in this Mississippi Delta and Appalachian regions.

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00:45:00.000 --> 00:45:06.300

Becky Kronk: And you know most rural associated economically-disadvantaged areas were within the Mississippi Delta.

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00:45:07.650 --> 00:45:15.510

Becky Kronk: That had the highest rates in the United States, so some things to think about you know what this may be due to.

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00:45:16.200 --> 00:45:24.120

Becky Kronk: You know these authors proposed that you know, there's certain parental lifestyle behaviors like alcohol consumption and smoking

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00:45:24.870 --> 00:45:41.070

Becky Kronk: during pregnancy may contribute to this lack of access to health care services, leading to prenatal infections and low birth weight and then exposure to environmental toxins may all contribute to these higher rates.

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00:45:44.370 --> 00:45:57.240

Becky Kronk: And I just again want to point out that when you think about this health disparity and these amplifying effects, you know you add poverty into this mix of disability and

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00:45:58.410 --> 00:45:59.160

Becky Kronk: and high

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00:46:00.840 --> 00:46:07.800

Becky Kronk: disease rates, you know we're seeing that you know this area also has higher rates of poverty.

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00:46:11.760 --> 00:46:31.470

Becky Kronk: In 2018 the number of Appalachian residents living below the poverty poverty line was higher than the national average in every age group, except over 65 and those with the largest disparity was among 18 to 24 year olds, and they were three times higher

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00:46:32.670 --> 00:46:35.640

Becky Kronk: in poverty than the rest of the United States.

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00:46:38.220 --> 00:46:43.890

Becky Kronk: And then, not to overwhelm you with more statistics, but then you think about these health risk behaviors that

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00:46:44.730 --> 00:46:52.500

Becky Kronk: again go into this amplifying phenomenon, you have this level of physical inactivity, smoking prevalence,

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00:46:52.860 --> 00:47:04.920

Becky Kronk: and obesity prevalence. And you can see, you know, in the worst quintiles that you know 43% these are counties now, 43% of the counties have report

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00:47:05.430 --> 00:47:27.960

Becky Kronk: these high physical inactivity rates, 189 counties, 45% of the 420 counties in the region report smoking prevalence and again the obesity prevalence is very high in 126 of the 420 counties in the region.

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00:47:32.670 --> 00:47:50.250

Becky Kronk: So I think it was interesting to think about you know the genetics of all of this, you know, and what are the residents of this rural Appalachian area think about genetics research and again this study by Fullenkamp done in 2012 you know looked at

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00:47:51.900 --> 00:48:03.360

Becky Kronk: genetic literacy, genetic understanding and residents in this area and I thought it was interesting that they asked participants about their perception of genetic research and environmental health.

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00:48:04.020 --> 00:48:10.650

Becky Kronk: And what I think was one of the really key takeaway messages, maybe not so much the individual items here,

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00:48:12.270 --> 00:48:19.650

Becky Kronk: But with each one of those you know, the majority of people agreed with some of these phrases right.

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00:48:20.310 --> 00:48:25.950

Becky Kronk: But what was interesting was the difference, I think, between I need to know more or disagree.

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00:48:26.490 --> 00:48:44.760

Becky Kronk: You know there wasn't this dichotomy is like, I agree, I don't agree, it really pulled out that there's some genetic information lacking among individuals in this area, you know, there was a lot of response here about I need to know more.

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00:48:46.440 --> 00:48:54.090

Becky Kronk: And maybe some of the highest responses, if we look at it a little bit more closely were with about cigarette smoking

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00:48:55.170 --> 00:49:07.680

Becky Kronk: and also environmental exposures. So you know it shows to me that this you know and again the authors very much say the same thing that the interaction between environmental exposures

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00:49:08.100 --> 00:49:15.660

Becky Kronk: and genetics as a disease catalyst warrants further environmental genetic research but also warrants further

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00:49:16.050 --> 00:49:32.790

Becky Kronk: education, you know, this really stands out to me how important it is for us as healthcare providers to identify areas that people want more information about and maybe need to have you know

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00:49:34.230 --> 00:49:41.490

Becky Kronk: their literacy in those areas be improved and have access to some education around that.

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00:49:44.310 --> 00:49:57.480

Becky Kronk: So you know we can lay all this out and I, and I think it was really enlightening for me to even prepare this talk and learn a lot, but then I always think to myself what next, you know, I can look at all this data, I can look at all these things and

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00:49:57.840 --> 00:50:10.590

Becky Kronk: I'm one person, so you know how does, how can this change. You know I love these these noon time talks because I think it's just increasing awareness and has motivated us to think about these things more.

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00:50:11.070 --> 00:50:24.780

Becky Kronk: But I really think that it takes some thought about adapting a certain framework with individuals and communities where we can have multiple entry points to make a change or make a difference.

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00:50:25.200 --> 00:50:33.150

Becky Kronk: Um so just bear with me here, I know we're probably a little per quarter till, and this will probably take another five minutes or so.

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00:50:33.600 --> 00:50:46.560

Becky Kronk: But I'm just going to kind of give you a framework and take this framework and walk it from the individual to the community and think about you know what we can do as next steps, or as nurses.

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00:50:47.790 --> 00:50:54.480

Becky Kronk: So I don't know if anybody's familiar with this framework it's called the international Classification of Functioning Disability and Health.

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00:50:55.050 --> 00:51:07.260

Becky Kronk: But I was a trainee and a LENDDD program. a Leadership Education and Neuro Developmental Disabilities back in my master's program, and I was really kind of trained, many years ago

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00:51:08.130 --> 00:51:17.910

Becky Kronk: in this classification system and it just spoke to me and I, and I always think about this this when I'm when I'm thinking broadly.

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00:51:18.420 --> 00:51:32.790

Becky Kronk: So this ICF, for short, it's a descriptive way of capturing health and health related states. It's always focused on health, rather than the disease, that condition, or the disorder.

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00:51:33.180 --> 00:51:45.720

Becky Kronk: It's not a medical model. It's like a social, you know, social biological model, and it's part of the World Health Organization, a whole system of

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00:51:47.220 --> 00:51:58.410

Becky Kronk: of international classifications, like the ICD 9s and 10s and things like that, but what I love about this is that all this interaction.

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00:51:58.920 --> 00:52:07.230

Becky Kronk: So you could take a health condition, and you can think about how it, you know affects the body function or structure.

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00:52:07.710 --> 00:52:13.830

Becky Kronk: But you can think about the activities of daily living that this health condition might impact.

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00:52:14.430 --> 00:52:24.450

Becky Kronk: And you can think about how that health condition might impact participation, and I really like that there's a difference between an activity and participation.

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00:52:24.780 --> 00:52:36.990

Becky Kronk: You know, you might have an individual who, 'yeah I can use utensils' and feed themselves, but does that translate to participating in an evening out with friends at a restaurant? That's participation.

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00:52:37.920 --> 00:52:44.190

Becky Kronk: And then you have to think about these contextual factors like personal factors and environmental factors.

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00:52:46.140 --> 00:52:51.180

Becky Kronk: And then there's all of this interaction right so again bear with me here.

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00:52:52.560 --> 00:53:04.740

Becky Kronk: There was this sample about a health condition like breast cancer and I just picked this one, because you know it can have a genetic component to it, but you can see that the health condition was

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00:53:05.790 --> 00:53:20.430

Becky Kronk: breast cancer, post-mastectomy, they give you a list of body structures and functions here that were affected, and this gives you a list of activities here of daily living.

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00:53:22.080 --> 00:53:28.410

Becky Kronk: This gives you an insight into this person's ability to participate in employment and fitness.

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00:53:29.070 --> 00:53:37.770

Becky Kronk: And it also gives you some environmental factors, this person happens to have a supportive family structure and a work environment and good health insurance.

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00:53:38.220 --> 00:53:52.170

Becky Kronk: And they seem highly motivated and have financial stability and a strong, self-advocate but that could be very different right, and I've had individuals that I've worked with that have very different personal and environmental factors.

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00:53:52.710 --> 00:54:02.910

Becky Kronk: But what I like about this: let's just say that this person, you know, wasn't highly motivated or maybe needed um you know didn't have support at work.

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00:54:04.410 --> 00:54:15.570

Becky Kronk: Or needed some help with finding an exercise that they are able to do, I mean each one of these boxes there's a way for us to intervene.

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00:54:16.110 --> 00:54:26.160

Becky Kronk: And you're not like tackling everything all at once, but you're working with the individual and you're you know, there are just these different openings that can make a difference, a small difference.

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00:54:26.490 --> 00:54:40.140

Becky Kronk: If I make a small difference here, it may impact her participation or her ability to do activities if I make a small personal change here, it could change all of these other boxes as well.

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00:54:41.460 --> 00:54:48.690

Becky Kronk: So when I think about this and I just think about this when we think about a community, and it may be one of those

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00:54:49.860 --> 00:54:54.240

Becky Kronk: you know areas of Appalachia, it might be one of those

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00:54:55.980 --> 00:55:13.470

Becky Kronk: smaller communities, you know, can we look at that community and think about the health condition of that community? Can we think about the structures and functions which I would think are the schools, the medical facilities, the businesses are they present, not present, right?

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00:55:14.520 --> 00:55:26.130

Becky Kronk: Can we look at the activity levels of the people who are in that community whether the you know number sick days, missed days of work, what is school attendance like?

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00:55:26.640 --> 00:55:40.200

Becky Kronk: And then do those activities, you know translate to participation in that community, what are the employment rates, the graduation rates, is there opportunities for people to engage in sports or park usage?

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00:55:41.130 --> 00:55:53.850

Becky Kronk: And then you can think about the environmental factors, many of which we talked about already, what are the poverty levels? There's the rates: its genetic conditions, disability rates, the economy, accessible transportation.

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00:55:54.360 --> 00:56:06.120

Becky Kronk: And then the personal factors, you know the one article was talking about the literacy of those in the environment. Is there a safety, is their resiliency in the community, what are the neighborhoods like?

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00:56:07.080 --> 00:56:15.150

Becky Kronk: And although this is, you know about genetics and genomics the disability, you know, I think it captures all of those

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00:56:15.960 --> 00:56:23.640

Becky Kronk: health conditions, but if we you know if we go into a certain area can we make a difference in any one of these blocks

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00:56:24.240 --> 00:56:30.870

Becky Kronk: that will eventually improve the health condition of the community, and I just think that it's possible.

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00:56:31.290 --> 00:56:46.320

Becky Kronk: I think, as we see these statistics and these statistics may not be very inspiring and they may be sort of depressing, I think that we have to think about a way to make a difference and, for me, this is one way to conceptualize that.

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00:56:48.930 --> 00:56:55.320

Becky Kronk: So that was the end of my discussion or my presentation so I'm happy to think about

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00:56:56.760 --> 00:57:01.830

Becky Kronk: ideas or reactions or anything helpful that I can be.

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00:57:04.830 --> 00:57:15.630

Kim Kelly: Well, thank you so much for a wonderful talk, and I, you know, have a lot of ideas going through my mind, but I'll go ahead and kick us off here with a question.

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00:57:16.650 → 00:57:27.480

Kim Kelly: You know, you talked about a lot of issues that were problematic in Appalachia, and what would you say is the primary challenge for genetic services in rural Appalachia?

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00:57:28.500 --> 00:57:28.800

Becky Kronk: Hmm.

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00:57:30.900 --> 00:57:46.560

Becky Kronk: You know two things come to mind right, I think, accessibility to services right, and genetic literacy, I think, genetic literacy is huge, you know health literacy genetic literacy, however, wherever you want to begin with that.

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00:57:47.100 --> 00:57:57.660

Becky Kronk: I'm just being able to you know given people an opportunity to be able to say, 'yeah I'm interested in this, but I don't understand it,' you know or

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00:57:59.250 --> 00:58:10.050

Becky Kronk: how many times to you know we were talking earlier about Fragile X and the phenotype of Fragile X for both males and females has changed a bit right.

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00:58:10.770 --> 00:58:24.930

Becky Kronk: So how do you explain that to someone who's saying you know I have, I have a daughter, who just can't seem to understand something, or I have a mother in law, who has tremors and her cognition's you know, reducing and

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00:58:25.410 --> 00:58:39.900

Becky Kronk: and, just to be able to think, 'oh, this could have a genetic component,' and that doesn't have to be scary is, I think a really big obstacle, whether it's in Appalachia or just across the board right.

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00:58:45.570 --> 00:58:57.000

Kim Kelly: So as we think about a research agenda, what do you see, as some of the opportunities for research to improve genetic service delivery in West Virginia and our region.

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00:58:58.470 --> 00:59:09.720

Becky Kronk: Yeah I think just you know those two studies that I just brought up I think it's really interesting to you know delve even further into this environmental, genetic

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00:59:11.370 → 00:59:27.030

Becky Kronk: interaction, I think that that would be really important and also you know again. From my own perspective, I think, just understanding the impact that genetics has on everyday functioning for people.

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00:59:29.160 --> 00:59:36.030

Becky Kronk: And then you know just really again, interventions that can be improved, the healthcare of individuals.

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00:59:40.440 --> 00:59:41.580

Kim Kelly: Great. Thank you.

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00:59:42.810 --> 00:59:45.600

Kim Kelly: Anyone else have questions that they would like to ask.

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01:00:00.690 --> 01:00:04.620

Kim Kelly: I had a Brazilian roommate and one of the expressions that they had was

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01:00:06.930 --> 01:00:11.130

Kim Kell': 'turn out the light' and whoever wants it will take the piece of cake, you know.

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01:00:12.210 --> 01:00:13.290

Becky Kronk: That's funny yeah.

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01:00:14.070 --> 01:00:14.730

Becky Kronk: I just don't

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01:00:14.880 --> 01:00:15.150

Becky Kronk: know.

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01:00:16.590 --> 01:00:21.630

Becky Kronk: You know I've just hopefully you know just provided some food for thought, you know.

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01:00:23.340 --> 01:00:27.960

Kim Kelly: It looks like we have in our chat there.

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01:00:30.210 --> 01:00:38.610

Becky Kronk: I think that's a great question, you know what types of community-based interventions can nurses participate in that make a difference in a wide scale basis.

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01:00:40.710 --> 01:00:45.210

Becky Kronk: You know I really think you know the community efforts that we make

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01:00:47.970 --> 01:00:52.320

Becky Kronk: on any level, you know I mean I lots of things that pop into my head.

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01:00:53.460 --> 01:01:07.020

Becky Kronk: But just I think having a presence, you know, in a community is really important, and, as in any community, I think that takes some time to build trust.

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01:01:08.280 --> 01:01:21.870

Becky Kronk: And I also think one of the most important things with community-based interventions, is to have this engagement with the community so that we're understanding what their needs are right and that where it's

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01:01:22.590 --> 01:01:34.320

Becky Kronk: you know it sounds rather simple but it's got to be there, the communities agenda that we're addressing and not our own agenda. I mean, we see these statistics, we see all these needs, but

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01:01:34.770 --> 01:01:48.870

Becky Kronk: you know I remember and starting to this is minor but I remember starting the Fragile X clinic, and one of the first things we did was we had a forum with some families who were part of the clinic.

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01:01:50.040 --> 01:02:00.990

Becky Kronk: And we said to them tell us what your needs are, and I was shocked, because my needs about the clinic were very different than their needs, and one of the very first things they said to us was

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01:02:01.350 --> 01:02:14.040

Becky Kronk: we need a dentist referral, you know we need who can understand our children and their anxieties and have the patience, as well as the competency to care for them.

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01:02:14.430 --> 01:02:25.350

Becky Kronk: And you know, finding them a dentist was not my top priority, but the fact that they said that to us, and then we went and researched, you know and had good referrals for dentists,

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01:02:25.890 --> 01:02:32.970

Becky Kronk: that helped build trust with those families, and it really made a difference in their support of the clinic

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01:02:33.210 --> 01:02:49.320

Becky Kronk: and trusting us on other things. So you know those community based interventions, I think the most important thing is to be present and to really understand from the community what the needs are, and yet it may not be our top priority, but we'll get there alright

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01:02:51.990 --> 01:02:52.950

Becky Kronk: I hope that helped.

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01:02:53.040 --> 01:03:01.710

Kim Kelly: And I think that's so true about the Appalachian, the rural Appalachian population, in particular, because there is some

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01:03:02.970 --> 01:03:07.230

Kim Kelly: I guess concern that they may be seen in a bad light or you know.

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01:03:08.280 --> 01:03:17.940

Kim Kelly: People have prejudices against people from Appalachia, and I think getting buy-in to really help people open-up, it's so important.

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01:03:27.150 --> 01:03:28.380

Becky Kronk: Thank you I'm glad.

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01:03:30.150 --> 01:03:31.380

Kim Kelly: Are there other questions.

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01:03:34.110 --> 01:03:40.590

Meg Glenn: I have more of a comment than a question, but I am a genetic counseling assistant, I actually work with Amy at GeneDX.

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01:03:41.010 --> 01:03:49.500

Meg Glenn: And I grew up in Kentucky, which is a very largely rural state and I don't know if you have any other Kentuckians on the call, but I have very limited experience

357

01:03:50.130 --> 01:03:58.200

Meg Glenn: with nursing specifically as opposed to you know, working with nurses, so it's great to hear about all the advancements that are being made within nursing

358

01:03:58.770 --> 01:04:04.860

Meg Glenn: considering genetics, specifically. I used to work in a low-cost, free clinic in rural Kentucky.

359

01:04:05.430 --> 01:04:14.580

Meg Glenn: And a lot of people would come to that clinic, even if they had insurance just because they were so familiar with the nurses that work there, We didn't have an MD we just had

360

01:04:15.540 --> 01:04:27.840

Meg Glenn: just, had nurses that were fantastic, and I think it's great to see that that is being focused on within nursing, as opposed to just trying to you know shoehorn in genetic counselors and MD's.

361

01:04:30.750 --> 01:04:33.690

Becky Kronk: Thank you so much, I'm glad that that was helpful.

362

01:04:40.740 --> 01:04:57.690

Kim Kelly: All right, so we're coming to the end of our time, and I would like to take this opportunity to thank Dr. Kronk for a wonderful presentation, and I'm sure we're all, we all have ideas that we're thinking about and ways

363

01:04:58.770 --> 01:04:59.700

Kim Kelly: to

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01:05:00.930 --> 01:05:16.050

Kim Kelly: incorporate and work more with you know genetic services and nursing services, and we appreciate the efforts from from Dr. Kronk and folks like her, who are

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01:05:16.800 --> 01:05:25.620

Kim Kelly: really going into communities and identifying these, especially in our Appalachian community and

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01:05:26.400 --> 01:05:36.030

Kim Kelly: so Anusha has posted an evaluation survey in the chat and we will be most appreciative if you would go in and give us feedback

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01:05:36.390 --> 01:05:49.680

Kim Kelly: about this session. And we also have other sessions, that we would appreciate your feedback about so thank you so much, and next month we'll look forward to a

368

01:05:50.340 --> 01:06:03.750

Kim Kelly: conversation with Dr. Graves who is doing some work, research work with a medically underserved population in genetic services, so thank you again, thank you, Dr. Kronk and thank you all for joining us.

369

01:06:04.530 --> 01:06:05.190

Becky Kronk: Thank you.

370

01:06:05.280 --> 01:06:06.030

Becky Kronk: Bye bye.