Housekeeping

• This webinar is scheduled to last 1 hour, including Q&A.

• All dial-in participants will be muted to enable the speakers to present without interruption.

• The webinar is being recorded and will be sent via email with the slides, infographic and a brief evaluation survey after the live presentation.

• Questions can be submitted via the chat function at any time during this presentation. We will have a dedicated time to answer questions at the end of the presentation.
Agenda

• Introduction to the Family Center
• Overview of Telegenetics
• Telewhat?! Infographic
• Other Telegenetics & Telehealth Resources
• What Families Need to Know: Provider Perspectives
• What Families Need to Know: Family Leaders’ Perspective
• Questions
National Genetics Education and Family Support Center (Family Center)

Made up of:
- Genetic Alliance
- FAMILY VOICES®
- P2P USA

Funded by HRSA to:
- Help families develop skills to partner with professionals and improve systems of care
- Assist RGNs in partnering with families & family-led orgs
- Assist with outreach to diverse & medically underserved families
- Provide Education & Support
Overview of Telegenetics
What is Telegenetics?

• Appointment with a genetics healthcare provider using:
  • Computer
  • Phone
  • Tablet

• Takes place in:
  • Provider’s office near you
  • Your Home
  • Other settings

• Four main types of Telegenetics appointments:
  • Video conferencing
  • Store and forward
  • Remote monitoring
  • Mobile health
How Does a Live Video Conferencing Visit Work?

• 30 – 60 minute appointment
• Collect medical history and family history
• Local provider may help with a physical exam
• Recommendations for follow-up (e.g. genetic testing)
Why is it Important?

• Improves access to genetic services
• Helps reduce the effects of common barriers such as
  • Distance
  • Time
  • Childcare
  • Mobility challenges
  • Transportation
• Provides significant benefits to families
  • Less distance
  • Less cost
  • Time savings
  • Increased # of available providers
  • More access to early detection
  • Increased patient satisfaction
Telewhat?! Infographic

• Individuals and Families
  • Learn about Telegenetics
  • Prepare for a Telegenetics appointment
  • Share with other families

• Providers
  • Share with Telegenetics patients
  • Share with other providers

• Advocacy and Support Organizations
  • Disseminate the infographic to families
  • Share the infographic on social media
  • Upload the infographic to your website
Additional Telehealth & Telegenetics Resources for Families and Providers
Midwest Genetics Network: Family Video Series
Western States Regional Genetics Network: Family Video

What to Expect From a Telegenetics Visit
Center for Connected Health Policy: Telehealth for Consumers Infographic
COVID-19 Resources
Regional Genetics Networks: COVID-19 Resources

**Telemedicine and Telehealth Resources for COVID-19**

March 25, 2020

With the current pandemic involving the coronavirus, COVID-19, many specialty and primary care providers are transitioning rapidly to utilizing telehealth modalities. We have gathered some of the resources that are available to help medical practices find the information and guidance they need to meet the ever-changing needs of their patients during this time.

If you are just beginning telehealth implementation, one of the best resources is to reach out to the [Telehealth Resources Center (TRC)](https://www.trc.org) that your state belongs to. Ensure which TRC services you, click here to access their [clickable map](https://www.trc.org) and connect directly to the one for your state.

*Telehealth policies are rapidly changing to support activities in response to COVID-19. You may want to sign up to get notices from the HRSA-funded [Center for Commercial Health Policy](https://www.cchp.ucsf.edu).*
National Consortium of Telehealth Resource Centers (NCTRC)
How Patients Can Engage Telehealth

How Can I Start Receiving Telehealth Services?

What Equipment Do I Need?

Is My Personal Health Information Safe?
NCTRC: Telehealth 101 Infographic
Family & Provider Perspectives on Telegenetics
What Families Need to Know: A Provider’s Perspective

Joann N. Bodurtha, M.D., M.P.H.  
Professor of Genetic Medicine  
Johns Hopkins University;  
Project Manager  
NYMAC Regional Genetics Network

Alissa B. Terry, ScM, CGC, LCGC  
Genetic Counselor  
NYMAC Regional Genetics Network

Moderator:  
Allysa Ware, MSW  
Program Manager  
Family Voices
Considerations for Underserved Populations

• Do the faces on your screen reflect the faces in your exam room?
How are things looking?

• Access to Wifi

• Who’s getting the message
How does it sound?

- Availability of interpreter services
- Hospital systems
- F2F network of Cultural Liaisons
The Family Center Can Help!

• Triaging, responding to questions and requests for information

• Linking individuals and families to Regional Genetics Networks
  • Promoting partnership and collaboration

• Connecting individuals and families to family-led organizations
  • Parent to Parent
  • Family to Family Health Information Centers

• Sharing educational materials
  • Webinars
  • Infographics
  • Sites: DiseaseInfoSearch.org, GenesInLife.org and the Advocacy ATLAS
Family Center Regional Guides: Referral to Support and Partnering with Family-Led Organizations

REFERRAL TO SUPPORT AND PARTNERING WITH FAMILY-LED ORGANIZATIONS: A REFERENCE GUIDE

The National Genetics Education and Family Support Center (Genetics Education & Family Support Center) is a companion project to the Regional Genetics Networks (RGNs). RGNs link medically underserved populations to quality genetic services and provide resources to genetic service providers, Primary Care Physicians, public health officials, and families. In many cases though, linking isn’t enough. Individuals and families need direct support and assistance.

The Genetics Education & Family Support Center works to:
1. Assist the RGNs in their efforts to develop meaningful partnerships with families and family-led organizations and reach medically underserved and diverse families.
2. Provide emotional, informational, and navigational support for individuals and families who have, or are at-risk of having a genetic condition;
3. Provide education and resources on genetic conditions;
4. Link individuals and families to services and supports, especially those families in underserved areas;
5. Help families develop skills to partner with professionals and improve systems of care.

The following family-led organizations can help families navigate the system of care system and connect families to the information, resource, and support services they may need. In addition, family-led organizations can partner with RGNs and other families to help build capacity for family leadership and engagement to improve genetic educational materials, services, and programs.
Thank you!