

Unlocking Potential: The Importance of Genetics Education for Early Intervention in New England

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nergn

NEW ENGLAND REGIONAL
GENETICS NETWORK



Introduction

Following a boom in direct-to-consumer genetic testing services and the advent of telehealth including telegentics, the New England Regional Genetics Network (NERGN) has recognized the immediate importance of educating a wide variety of health professionals about genetics.

NERGN is a Health Resources and Services Administration (HRSA) funded government program focused on improving health equity of those with genetic conditions. The goal of NERGN's current project is to focus on connecting and networking with Early Intervention (EI) providers regarding genetics education. These providers often have direct experience with individuals with genetic conditions, and their health could be further improved with advanced identification of genetic conditions, as well as being a resource for support of families questioning a genetic diagnosis or with a new genetic diagnosis.

Methods

- Network and connect via email to garner interest
- Creating a "pipeline" of connections through various organization, agency, and personal connections
- Brainstorm ways to utilize advertising in gaining more interest and outreach
- Facilitate training scheduling for interested parties in New England
- Considered accessibility and branding when pursuing outreach activities

Results

6
hour-long
seminars
completed

- Cold-emailed 12 EI professionals with ongoing interest in hosting presentations
- Connected with over 30 EI professionals in total
- 5 trainings scheduled for future dates

2,141
podcast
streams

"I thought [it was] really helpful to hear about the resources available for us as providers and for families we work with. Hearing about the processes of exploring different genetic conditions was a good reminder of the journey many families are going through during the time we work together."

Amber Hewston, DPT
2/6/23 training



Above, DNA Today Podcast logo

Personal Growth

- Learning new pipeline of EI professionals, then expanding that network with more referrals/connections
- Learn process of a HRSA-funded program
- Communicate professionally with all parties involved
- Increased confidence when cold-emailing prospective interested groups
- Creatively brainstormed new avenue of outreach via podcast
- Able to connect with like-minded genetics-gearred individuals, prospective student to share guidance & advice

Conclusions

- Continue to advertise using positive methods with shown workability (ie. poster, podcast)
- Expand reach to other New England newsletters/organizations
- Create trainings & materials in the works for primary care providers- another area we see lacking genetics education to provide for families
- Adding newborn screening recommendations to trainings to increase awareness in this growing area



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Above, Karen Volle, Karina Mancini, and Dr. Elizabeth Humphreys cover photo, LEND Episode of DNA Today Podcast with QR code

References

- Bailey DB Jr. A Window of Opportunity for Newborn Screening. *Mol Diagn Ther.* 2022 May;26(3):253-261. doi: 10.1007/s40291-022-00590-6. Epub 2022 May 4. PMID: 35507129; PMCID: PMC9098569.
- NERGN <https://www.negenetics.org/>
- Dineen, Kira, "LEND Program." *DNA Today*, Jan 6 2023. <http://dnapodcast.com/episodes/2023/1/6/218-lend-program-with-betsy-humphreys-karen-volle-amp-karina-mancini>

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Above, QR Code for NERGN's website

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