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Genetic Counselors and Newborn Screening: Roles, Activities and Future Challenges

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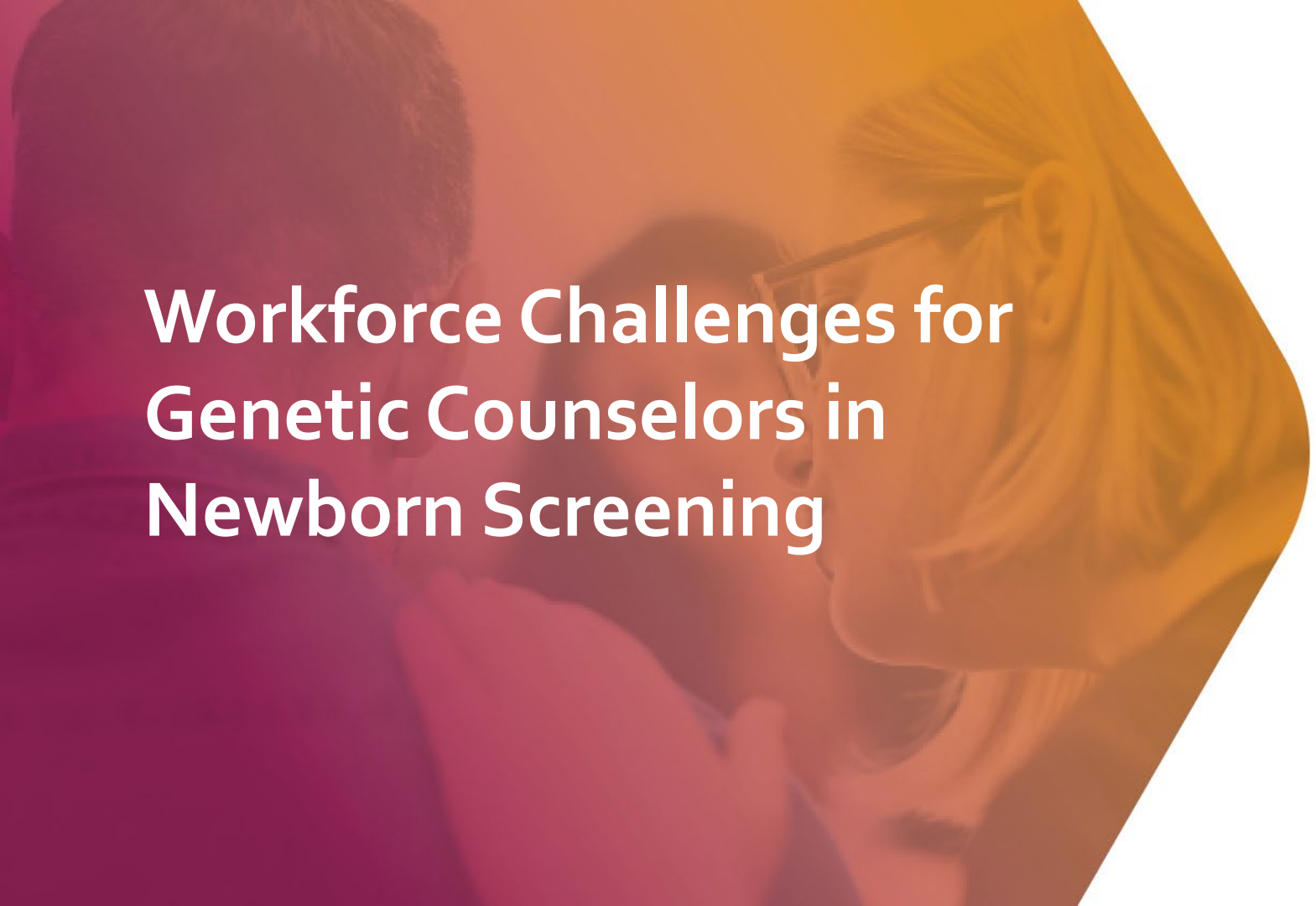
Genetic Counselor Roles in Newborn Screening

Genetic Counselors in Newborn Screening

- Number of GCs currently involved in NBS is unclear
  - 2020 NSGC Professional Status Survey lists <10 GCs who consider NBS to be their primary work setting and <10 who work in public health.
    - Likely an undercount of EOE by Genetic Counselors in NBS
    - Many positions are not “Genetic Counselor” positions within state or federal position classification systems
- Individuals trained as Genetic Counselors fill many roles within and related to Newborn Screening Programs and patient follow-up
  - Federal Genetic Services/Child Health Programs/HRSA
  - Federal Regulatory/Advisory/ACHDNC
  - Regional Genetics Networks – project directors, leadership
  - State Genetic services programs/coordinators
  - State Newborn Screening Advisory Board Members
  - NORD/Genetic Alliance/other non-profits that support families of those identified through NBS/Advocacy groups
  - Patient and professional NBS education
  - *Laboratory liaisons
  - NBS data management/reporting, QI/QC
  - *Clinical Service provision – short- and long-term
  - Clinical research/clinical trials for new therapies – natural history studies, coordinators of trials
  - Industry – MSLs, advocacy, education, marketing



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Workforce Challenges for Genetic Counselors in Newborn Screening

Challenges

Increasing Workforce Needs

- Need for educators for families, professionals, existing NBS workforce
- Need for knowledgeable informants to work with families “in waiting” – depending on state screening protocols, families may have to wait for molecular results and may have many questions while waiting
  - Addition of Pompe and MPS1 has already significantly increased need for individuals knowledgeable about the disorders and the molecular genetics/genomics of the conditions and this will continue
- Managing cascade testing as new conditions that have later onset variants are added. e.g. Pompe, ALD, SMA , others in time
- Diversity of providers to serve a complex and diverse population seeking care
  - Impacts public health and post-screening workforce
  - Racial, ethnic, language, gender
- Need for individuals knowledgeable about clinical trials for conditions on the RUSP

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Challenges

Increasing Workforce Needs

- Need for competitive compensation commensurate with training, experience and skills, in both public health and clinical care
  - Lack of defined positions for GCs in public health
  - Need for entry level and retention considerations
  - Need for promotion opportunities/“job ladder”
  - Lack of a defined civil service positions for GCs
  - Programs are under-resourced
  - Limited # of MD geneticists to do the follow-up work

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Challenges

Compensation

- NSCG PSS data – caveats: may not be capturing the GC NBS workforce, N is small, gov't positions not clarified (State vs. Federal)
- Salary Data by Primary Area of Practice:

	N	Mean	Median
Newborn screening	5-9	$84,635	$80,896
Public health	5-9	$90,774	$81,000

- Salary data by employer work setting:

	N	Mean	Median
Gov't Organization or Agency	36	$91,801	$85,225

- In comparison to overall profession:

	N	Mean	Median
All who reported salary info	2,331	$97,976	$89,489

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Genetic Counselor Activities in Newborn Screening: present and future solutions

Present and future solutions: more educators

- Increasing prenatal NBS education for families
  - discussion of screening throughout pregnancy can integrate inclusion of NBS screening education in the prenatal GC setting
  - Innovative solutions for NBS education – chat bots, iPhone aps, videos developed or in development
- GCs providing “molecular 101” training for existing NBS workforce/follow-up staff
- HI parent fact sheets and new videos all done by GCs in conjunction with specialty care providers. Project of the Western States Regional Genetics Network
  - www.newbornscreening.info

Present and future solutions: families in waiting

- GCs working with families “in waiting” –
  - Families have expressed frustration that notifying provider isn’t always knowledgeable
  - GCs have the training/expertise to deliver “high anxiety” news
  - Inclusion of molecular results in some states in first notification requires explanation for families
  - Inclusion of disorders with broad phenotype leads to need to assess risk and immediacy of referral
  - Coordination/planning with PCP if s/he chooses to inform

Present and future solutions: Advocacy

- Support for families
  - Resource referrals - not all clinics have a nurse or social worker; GCs often fill multiple roles
  - Genetic counseling
  - Cascade screening – time consuming
  - Care coordination
- Other
  - QI: dialogue with NBS system team to decrease false positives
  - Coordination of delivery of quality clinical follow-up data to state programs

Present and future solutions: additional knowledgeable providers

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- Exponential growth of number of GC programs in the last 5 years
  - Now 55 total programs
  - Student enrollment increased by 52%, average program size increased by 7% - limited by availability of clinical rotation sites.
  - Profession growth rate – over 100 % in the last 10 years
    - Expected to continue
  - Increases in metabolic and NBS curriculum content in some programs.
  - Longstanding focus on Public Health in U. Pittsburgh program

Present and future solutions: Diversity

- JEDI (Justice, Equity, Diversity, Inclusion) external assessment by Exeter group followed by development of a 5+year organizational plan to be implemented with the 2022-2025 strategic plan, and ongoing
- Working with ASHG, ACMGG, NHGRI on Genomics Workforce Diversity Initiative
- Minority Genetic Professional Network – support and mentor minority students into the field and support those already in the field. (800 members). Initiative of the Western States Regional Genetics Network

Present and future solutions: Compensation

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- NSGC legislative efforts to increase access to genetic counselor services – first bill introduced 10/23/2108
- H.R. 2144 – focuses on GC reimbursement for services from Medicare and CMS, including direct reimbursement
  - Downstream effects
    - hospitals can bill for GC services, allowing for hiring of more GCs due to direct revenue stream
    - Allows for more private practice GCs
    - May encourage other covering entities to reimburse GCs – especially private payors

Supplemental Materials and credits

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Thanks

Thanks to the following genetic counselors for contributing ideas and information:

- Amy Gaviglio
- Dawn Peck
- Sara Reichert
- Sylvia Mann
- Joan Scott
- Also NSGC – Meghan Cary, John Richardson

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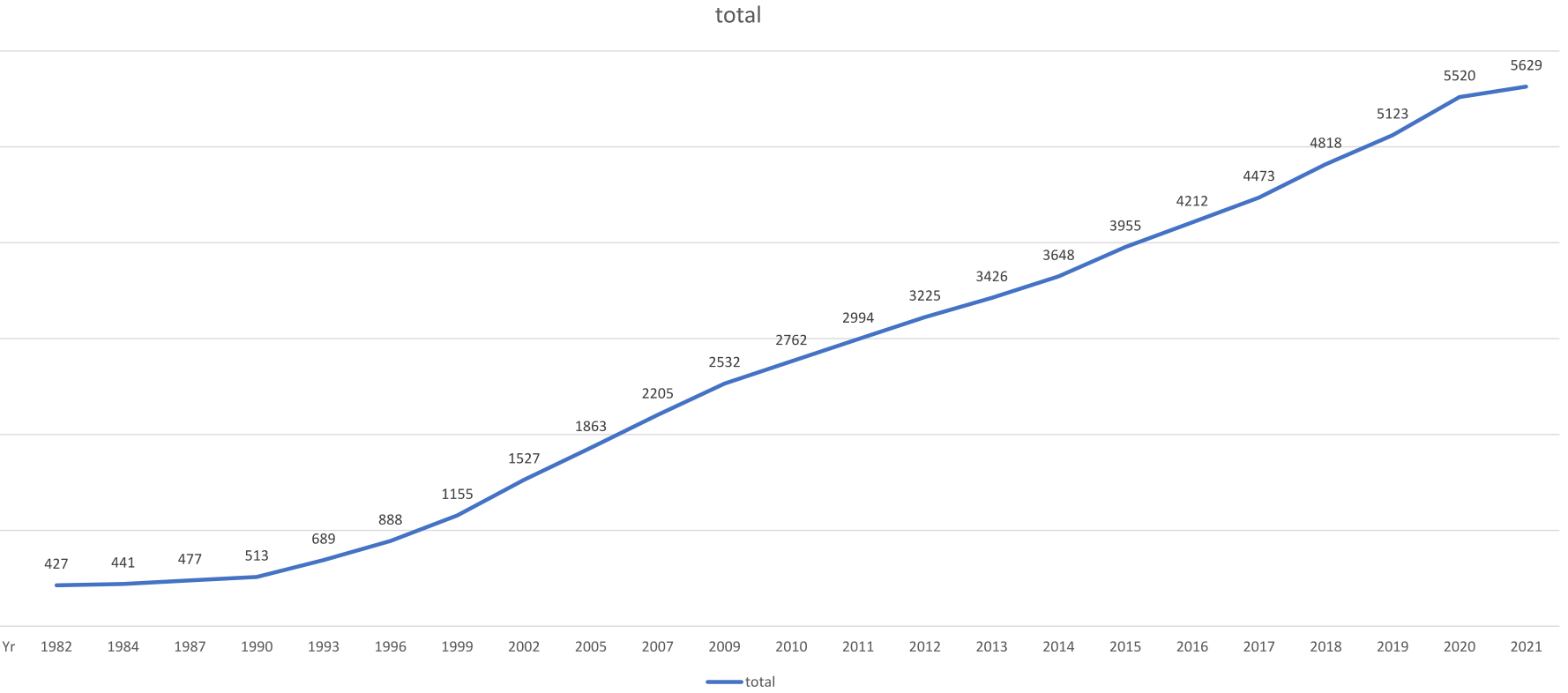
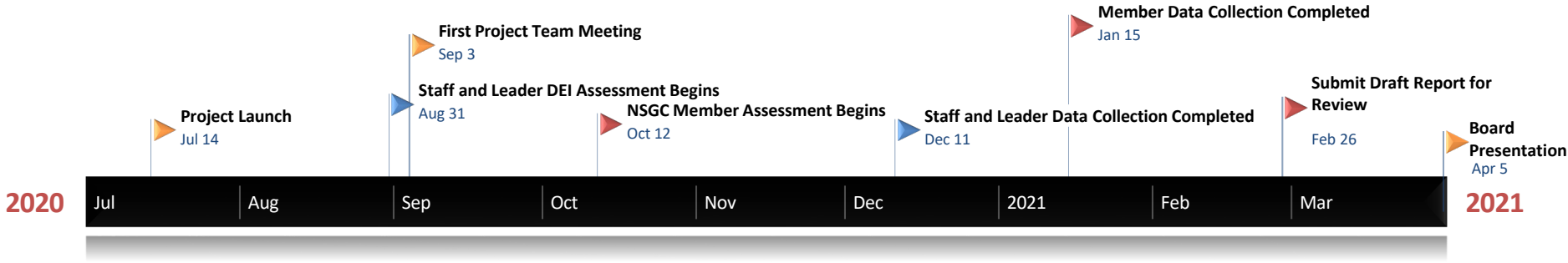
ABGC Diplomates by Year – 4-21-2021



NSGC DEI Assessment Project Timeline
The Exeter Group



Sep 21 - Oct 16	Confirm Societies/Organizations to Benchmark
Sep 21 - Oct 16	Identify Quantitative Staff, Leader, and Member Data for EG to Review/Analyze
Aug 31 - Sep 25	Identify Policies, Processes, and Procedures for EG to Review
Sep 7 - Nov 27	EG Completes Benchmark Research and Environmental Scan
Nov 30 - Dec 18	Conduct Interviews with NSGC Stakeholders
Nov 30 - Dec 11	Launch Staff and Leader Survey
Oct 12 - Oct 30	Launch DEI Member Survey
Nov 2 - Nov 13	Analyze Member Survey and Submit Focus Group Questions to NSGC for Review
Facilitate Virtual Member Focus Groups by Diversity Dimensions	Dec 7 - Jan 15
Analyze Focus Group Data and Identify Emergent Themes	Dec 14 - Jan 22
Analyze Member Survey Results	Nov 2 - Jan 22
Integrate Findings from Staff and Leader Qualitative and Quantitative Data Analyses	Dec 14 - Feb 26
Presentation to NSGC Board and Stakeholders	Apr 1-30

Updated 9.9.20

https://www.newbornscreening.info/wp-content/uploads/2021/02/X-ALD_Male.pdf

GENETIC FACT SHEETS

Other Disorders

Screening, Technology, and Research in Genetics is a multi-state project to improve information about the financial, ethical, legal, and social issues surrounding expanded newborn screening and genetic testing –

http:// www.newbornscreening.info

Disorder name: X-Linked Adrenoleukodystrophy Acronym: X-ALD

- What is X-ALD?
- What causes X-ALD?
- How is X-ALD inherited?
- What are the symptoms of X-ALD in males?
- What is the treatment for X-ALD in males?
- What happens when X-ALD is treated?
- Is genetic testing available?
- What other testing is available?
- And more plus video: https://youtu.be/gRoTOcaRRn4

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