

Child Neurologists and Newborn Screening

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Disclosures

- Site PI for Novartis-sponsored clinical trials in gene therapy for spinal muscular atrophy



Outline

- About child neurologists and the Child Neurology Society
- Workforce challenges to keep up with new discoveries and treatments
 - Need more child neurologists
 - Need more child neurology subspecialists – neuromuscular disorders, inherited white matter disorders
- Innovative solutions to addressing shortages, challenges and gaps
 - COVID response
 - Telehealth guidance
 - Improving recruitment

Child Neurology Society

- The Child Neurology Society (CNS) was founded in 1972 with an initial enrollment of 223 members
- CNS membership today is 2268 and it exists to serve the academic, research and practice-based needs of child neurologists
- National Office – St. Paul, MN
 - Roger Larson, Executive Director



Child Neurologists

- Training: Five-year post-graduate residency:
 - Two years training in pediatrics
 - One year in general “adult” neurology
 - Two years in pediatric neurology
 - Additional years in subspecialty training—epilepsy, neurophysiology, neuromuscular disorders, movement disorders, etc.
- Today, there are over 70 university-based child neurology training programs enrolling over 150 candidates yearly in the United States and Canada
 - In 2000, there were 58 programs and approximately 80 positions

Workforce is Growing! *(But Not Enough)*

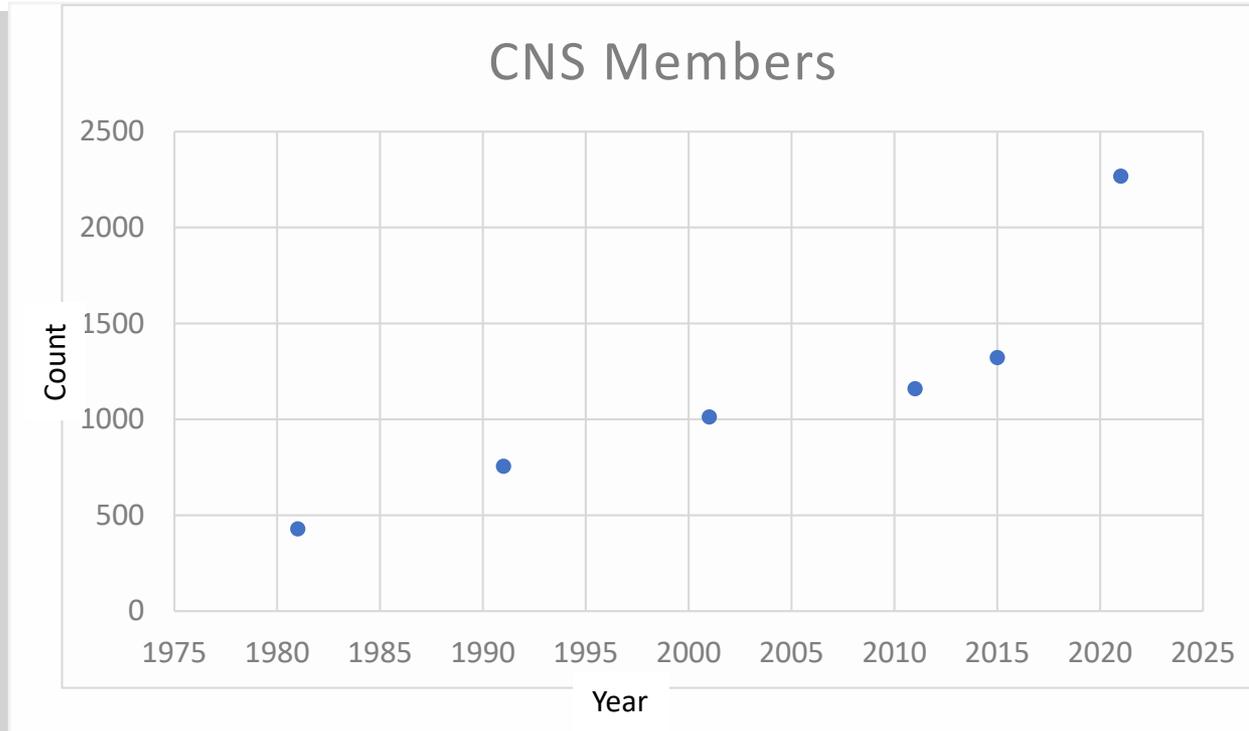


Chart values cited in Kang PB, et al. Neurology 2016;87:1384 and personal communication, Philip Pearl, President of CNS



Scope of Activities

- Recent decade has seen dramatic growth in medical knowledge of neurological disorders, including genetic mechanisms and novel treatments
- There are increased opportunities for subspecialty training which are becoming more important as standards of care become closely tied to having specialized experience
- Even a community-based, general child neurologist will likely see rare conditions with some regularity and will need to keep up on new treatments
- The complexity of our patients means that we routinely engage with other specialists and services. We care for our patients in a multidisciplinary world filled with therapists, geneticists, genetic counselors and more

Workforce Challenges

- More child neurologists are needed to keep up with the new innovations and heightened expectations of our field
 - Replace an aging workforce
 - Improve recruitment of new trainees. The number of residency applicants to child neurology programs and residencies has not increased over the years

ERAS 2016	ERAS 2017	ERAS 2018	ERAS 2019	ERAS 2020	ERAS 2021
383	381	336	312	329	353

- Compensation has not been as good as adult neurologists or other pediatric subspecialists since we tend to spend more time with patients
- Child neurologists tend to work in larger urban areas so patients may have to travel longer distances to see us

Guidance and Innovative Solutions

- Use of multidisciplinary telehealth
- Making the most of in-person visits by increasing care coordination
- Outreach clinics

From CNS

- Ethics Statement in COVID19 Era
 - Graf, Epstein, Pearl: *Pediatr Neuro* 2020
- Change of Practice for Infantile Spasms
 - Grinspan et al, *J Child Neurology* 2020
 - Grinspan et al, *Annals of Neurology* 2020
- Tele-neurology Examination
- Re-opening of Practices
- Statement on Institutional Racism
 - Pearl et al, *Annals of Neurology* 2020

Creation of clinical care guidelines for rare conditions

- SMA Newborn Screening guidelines
- X-linked adrenoleukodystrophy guidelines

Child Neurologists and NBS

Spinal Muscular Atrophy (SMA)

- Child neurologists are the primary specialists who see infants with SMA identified by state NBS programs
- Child neurologists led the efforts to define appropriate natural history studies that then could be used in clinical trials.
- We recognize the importance of multicenter collaborations
- We have been energized by the benefits of SMA NBS; we are eager to be involved in other NBS programs
 - Neuromuscular disorders – e.g. Pompe disease
 - Leukodystrophies – e.g., X-linked adrenoleukodystrophy

And my thanks to

Margie Ream – what great ideas!

Adam Wallace

Questions?

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