

Newborn screening and follow-up of children with endocrine disorders: current successes and challenges

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Wisconsin Newborn Screening (NBS) Panel

Hemoglobinopathies (5)

- Beta Thalassemia Major
- Hemoglobin S-Beta Thalassemia
- Hemoglobin SC Disease
- Hemoglobin E-Beta Thalassemia
- Sickle Cell Disease

Organic Acidemia (12)

Example: Proponic Acidemia

Other Disorders (5)

- Biotinidase Deficiency
- Galactosemia
- Cystic Fibrosis
- Severe Combined Immune Deficiency (SCID)
- Spinal Muscle Atrophy (SMA)

Fatty Acid Oxidation Disorders (12)

Medium Chain Acyl-CoA Dehydogenase Deficiency (MCAD)

Amino Acid Disorders (11)

Example: Phenylketonuria (PKU)

Endocrine Disorders (2)

- Congenital Adrenal Hyperplasia
- Congenital Hypothyroidism

Wisconsin Newborn SCREENING PROGRAM

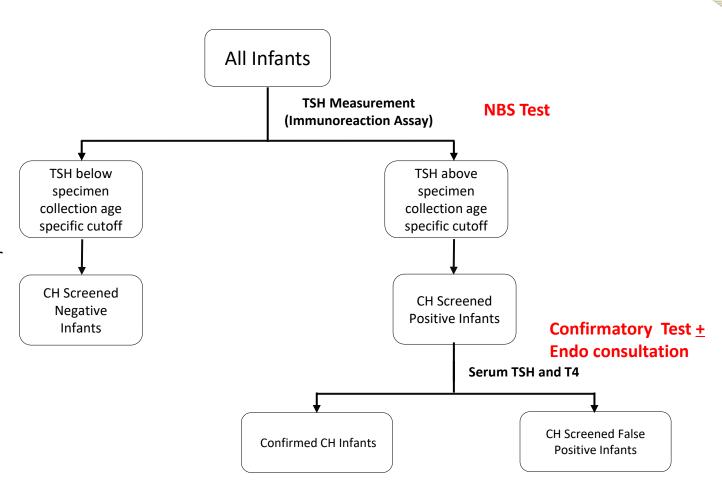
Babies are covered by the umbrella of Wisconsin's Newborn Screening Program

NBS for CH in Wisconsin



Congenital hypothyroidism

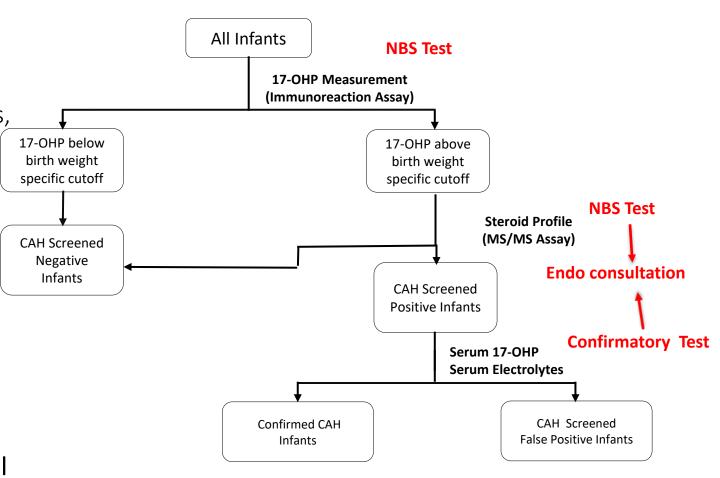
- ~ 1:2000 live births (~35/year WI)
- Most common preventable cause of cognitive disability
- NBS TSH predominant
- Continuum of severity –
 permanence established by 3y
- Therapeutic objective FT4 upper normal, TSH lower normal
- Follow-up
 - Lab q3-6 months
 - Frequent dose adjustment
 - Ped Endo visit 1-2 x/year
 - Telemedicine adaptable



NBS for CAH in Wisconsin

Congenital Adrenal Hyperplasia (210HD +)

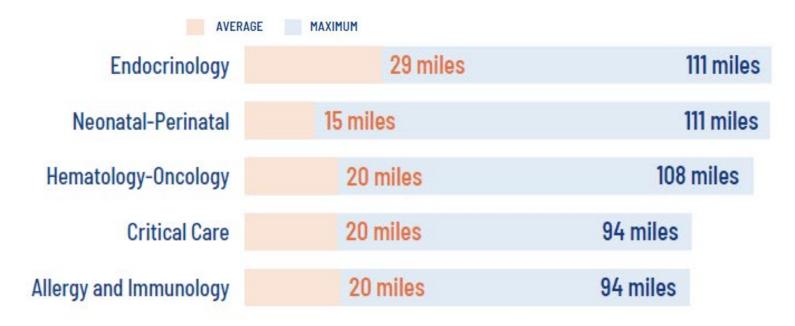
- AR, ~1:10,000-15,000 births
- Cortisol <u>+</u> aldosterone deficiency, female genital and CNS virilization
- Pre-NBS salt-wasting adrenal crises, sex mis-assignment
- NBS filter paper 170HP ——
- High false positive -> second tier strategies evolving
- Treatment cortisol and mineralocorticoid replacement
- Follow-up
 - Lab, PE, growth monitor q3-6m
 - Frequent stress-dose management for illness/injury
 - Puberty complex psychosexual and medical management





Specialty care for children with CH and CAH: shortage and maldistribution of pediatric endocrinologists

HOW FAR DOES A CHILD IN WISCONSIN NEED TO DRIVE FOR PEDIATRIC SUBSPECIALTY CARE?



Ten states have fewer than 1 PE per 100 000 children





NOTES FROM THE ASSOCIATION OF MEDICAL SCHOOL PEDIATRIC DEPARTMENT CHAIRS, INC.



Sustaining the Pediatric Endocrinology Workforce: Recommendations from the Pediatric Endocrine Society Workforce Task Force

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What Evidence Raises Concern about the Future Pediatric Endocrinology Workforce?

Dwindling recruitment:

- Total PE fellows declined from 254 (2012) to 243 (2018)
- Applicant/position = 0.7 -> 41/108 positions unfilled (2020)



Declining recruitment to Pediatric Endocrinology

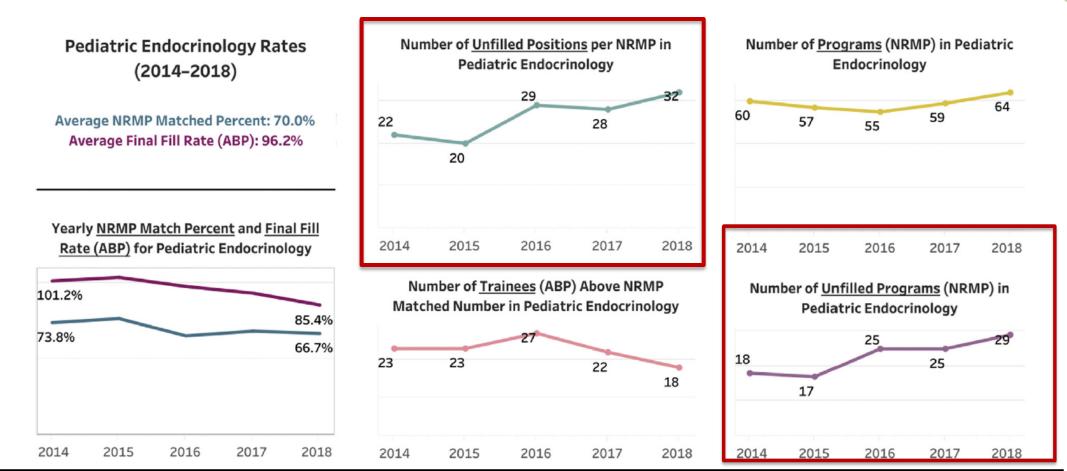


Figure. Pediatric endocrinology fellowship match and program fill rates from 2014 to 2018. Source: National Resident Matching Program (NRMP) data and American Board of Pediatrics (ABP) data; https://www.abp.org/content/comparison-abp-data-nrmp-match-data.





Dwindling recruitment:

- Total PE fellows declined from 254 (2012) to 243 (2018)
- Applicant/position = 0.7 -> 41/108 positions unfilled (2020)

Declining and under-diverse current workforce

- Aging 21% >60 years old
- Early career 80% female (many part-time)
- URM 23% of trainees, 5.5% black

Growing patient population

- Increasing T1DM and (especially) T2DM and obesity-morbidity
- Transgender, cancer survivors, retained complex young adult pts

Synchronous trends— \downarrow fellowship recruitment, \uparrow patient numbers -> shortage of trained pediatric endocrinologists



What Factors and Perceptions Threaten the Pediatric Endocrinology Workforce Pipeline?

Lack of early subspecialty exposure and mentorship

- Not required medical school rotation
- Typical 3rd year residency exposure post-career decision

Financial concerns

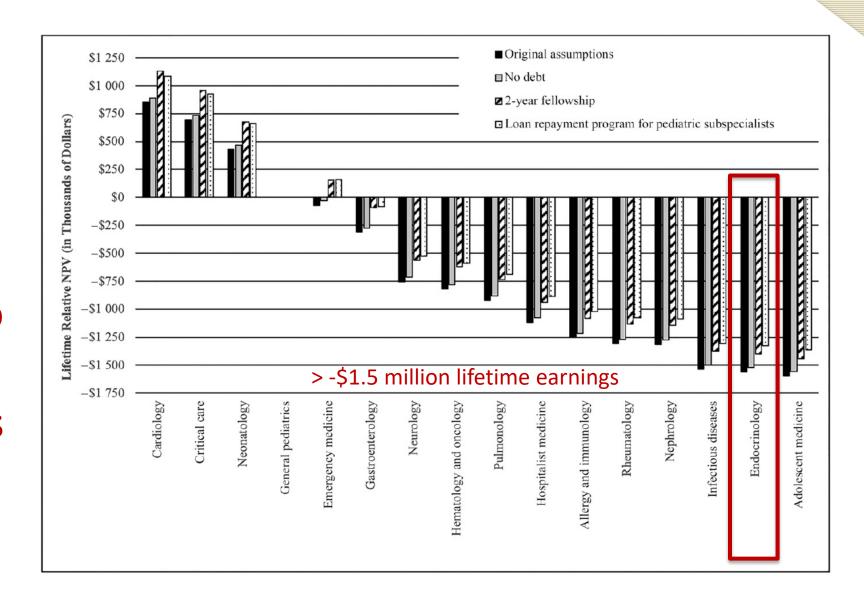
- Medical student debt (averaging \$232K) dissuades additional training
- Relatively low average salary of PE

Negative professional QOL perceptions

- Personal/professional life boundaries perceived unpredictable for PE
- Competition from shift-scheduled specialties (e.g. hospitalist)

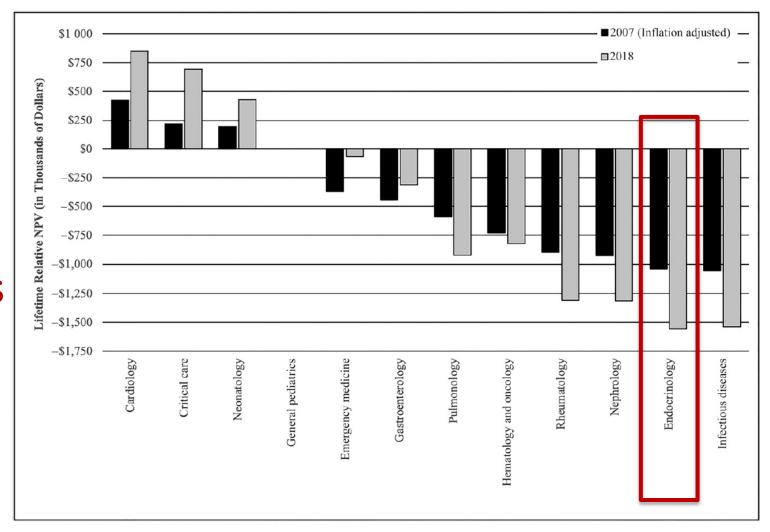


Lifetime earnings of pediatric specialists compared to general pediatricians





Pediatric endocrinology: largest relative decline in lifetime earnings among pediatric specialists 2007 -> 2018

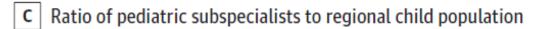


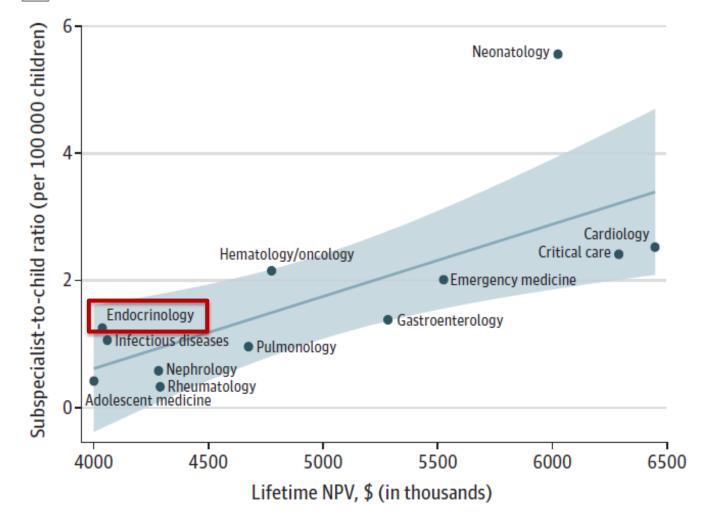


Lifetime earning potential

predicts:

- distance to subspecialists
- # subspecialists per regional pediatric population
- increase in # specialists/population growth
- fill rates for fellowship training spots







What Efforts Are Needed to Increase the Numbers and Diversity of the Pediatric Endocrinology Workforce?

Increase early positive exposure to Pediatric Endocrinology

- Outpatient subspecialty exposure in core rotations
- Emphasize exposure to enthusiastic fellow and faculty mentors
- ACGME/CoPS/APPD support for early residency exposure to nonprocedural subspecialties
- Professional society medical student recruitment initiatives





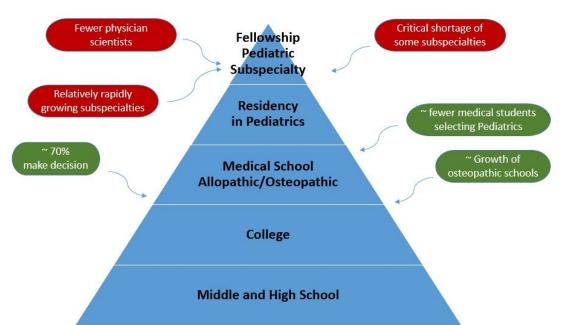
Lessening barriers

- Financial
 - Expand loan forgiveness for work in underserved areas and lower-paid specialties
 - Fund a targeted Loan Repayment Program for non-procedural specialties
 - Implement shared-care models that value non-procedural PE expertise
- Duration of training
 - Re-evaluate 2 year program and modify if deemed appropriate
- Perceived lifestyle detractors
 - Expand utilization of care extenders
 - Embrace technology to improve work/personal life balance



Pediatrics 2025: AMSPDC Workforce Initiative

Workforce Pipeline



Objective: attract trainees to undersubscribed pediatric subspecialties:

- Change medical education paradigm
- Early exposure and marketing
- Address economics
 - Lessen financial burden
 - Equalize Medicare and Medicaid revenue streams
 - Equalize compensation

Steps to ensure follow-up for endocrine disorder NBS

- Early life close collaboration with NBS program
- Recruitment to strengthen viability of the PE specialty
- Assistance from care extenders (PA, NPP)
 - Effective for CH >> CAH
 - Private practice >> academic institutions
- Adult medicine collaboration/early transition
 - Limited necessity for CH
 - CAH transition complicated and thus far not satisfactory
- Technology (propelled forward by COVID-19)
 - Improves patient access (>50% CH follow-up visits)
 - Does not address provider shortage



Thank you for this opportunity to present