



Genetic Metabolic Dietitians: Roles and workforce challenges

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Representing GMDI

Presented on behalf of GMDI

- Role of Genetic Metabolic Dietitians in Newborn Screening (NBS)
Long-term Follow up
- Activities in the field of genetic metabolic nutrition
- Current workforce and challenges
- Future needs and plans

GMDI founded in 2005

- Training and professional support
 - Conferences and webinars
 - Clinical practice tools
 - Nutrition Management Guidelines
 - Metabolic-Pro
 - Evidence based nutrition management guidelines
- Networking
 - Conferences
 - Email List-Serv
- Research
- Advocacy and collaboration
 - Reimbursement for medical foods
 - Regional genetic networks
 - Society of Inherited metabolic disorders (SIMD)
 - Parent organizations
 - Others

The mission of GMDI is to provide standards of excellence and leadership in nutrition therapy for genetic metabolic disorders through clinical practice, education, advocacy, and research



Core RUSP Conditions

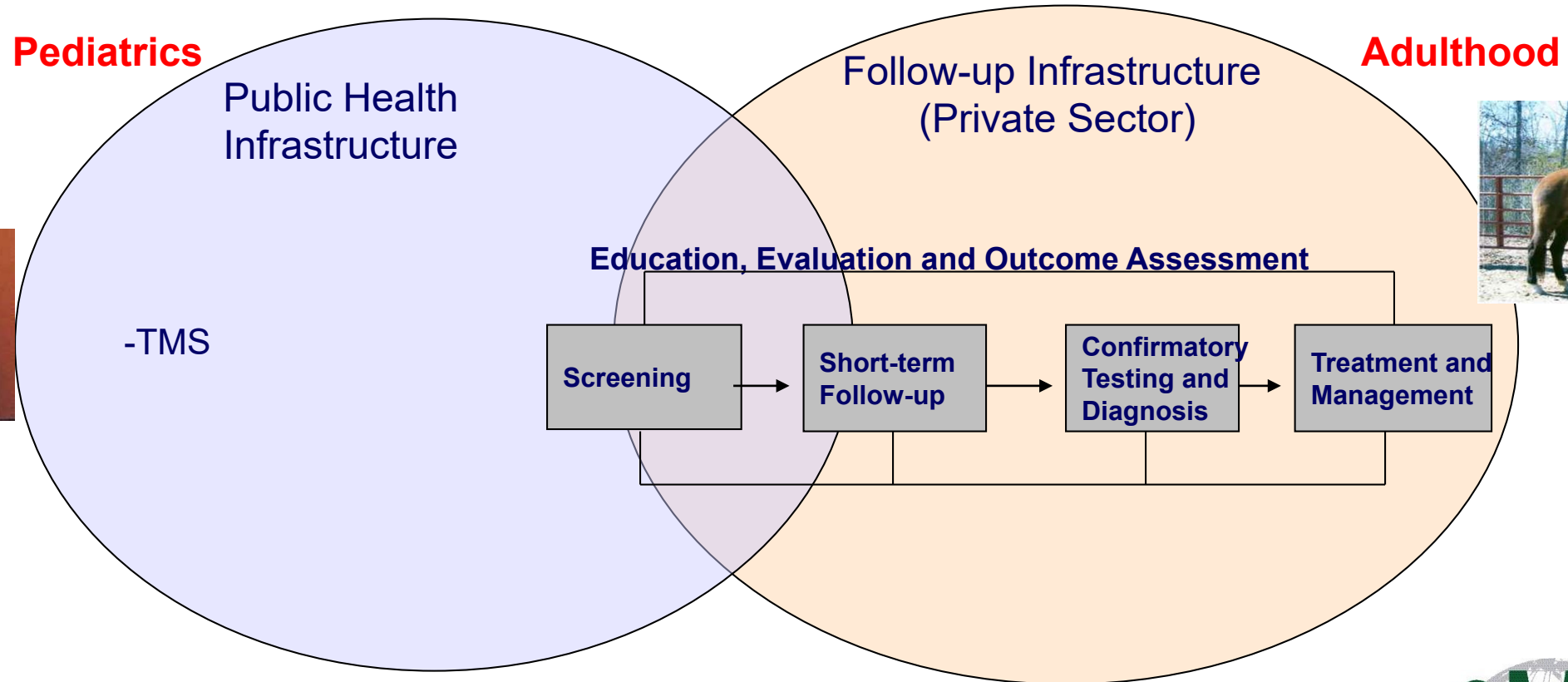
Metabolic Disorders		Hematology	Others
Organic Acidurias	Fatty Acid Oxidation	Amino Acids	
Propionic acidemia Methylmalonic academia (MUT) Methylmalonic academia (Cbl A, B) Isovaleric acidemia 3-Hydroxy 3-methylglutaricaciduria 3-Methylcrotonyl-CoA carboxylase Holocarboxylase synthase def β -Ketothiolase deficiency Glutaric acidemia I	Carnitine uptake defect/carnitine transport Medium-chain acyl-CoA dehydrogenase Very long-chain acyl-CoA dehydrogenase Long-chain L-3-hydroxyacyl-CoA dehydrogenase Trifunctional protein deficiency	Classic Phenylketonuria Maple Syrup urine disease Homocystinuria Tyrosinemia 1 Arginosuccinate aciduria Citrullinemia I	Biotinidase deficiency Congenital adrenal hyperplasia Congenital hypothyroid Cystic fibrosis Classic Galactosemia Pompe Hearing loss Severe combined immunodeficiency MPS 1 X-ALD

Conditions in bold are treated with medical foods and/or single amino acids, amino acid mixtures, vitamins, or other cofactors

Therrell BL, MGM 113 2014

NBS: Comprehensive Long-term follow up

ACHDNC defined the goal of LTFU as assuring the best possible outcome for individuals with disorders identified through newborn screening



Newborn dried bloodspot screening: mapping the clinical and public health components and activities

Alan R. Hinman, MD, MPH¹, Marie Y. Mann, MD, MPH², and Rani H. Singh, PhD, RD³

Successful management of NBS-identified disorders requires:

Immediate initiation of treatment

- *Efficient communication:* NBS coordinator, PCP, family, genetics team
- *Access to treatment:* Expert RDN, coordination of specialty formula

Lifelong diet intervention

- Ongoing *care coordination* (not necessarily reimbursable)
- *Evidence based interventions:* To ensure access to medical food, medications and lifelong care
- *Quality improvement:* Systems evaluations
- *Knowledge generation:* Collecting and documenting data for clinical trials and registries

Trained workforce

Registered Dietitian Nutritionist (RDN) with

- Specialized training in genetic metabolic disorders
- Established networks
 - DME/pharmacy
 - Community providers
 - Schools

Chronic and critical phases, e.g., pregnancy, illness, hospitalizations

Trained Workforce in Nutrition & Genetics: Paving the way to Precision Nutrition in IMDs

Medical foods
specialized formulas



Low Protein
Modified Foods



Regular foods/
Intact protein



Roles and Responsibilities

Clinical and Public Health

- Outpatient, community health, inpatient
- Newborn screening coordinators
- Participation with regional genetic networks
- State newborn screening advisory boards

Research

- Clinical trials and patient registries
- Independent researchers
- Industry-sponsored investigator-initiated protocols

Education

- Patient and family post diagnosis
- Parent organizations
- Academia and medicine

Industry

- Sales and marketing
- Medical science liaisons , educators
- Researchers

Government

- FDA
- NIH

Where do we work?

- University medical center (56%)
- Public hospital/medical facility (20%)
- Private hospital/medical facility (12%)
- Industry (20% list serv members)

How are we funded?

- Hospitals (fee for service, salaried)
- State health departments
- Newborn screening contracts
- Fees for multidisciplinary team visits

Challenges

- Increase trained workforce in this expanding field
- Unmet needs for patient education and nutrition follow-up
- Overburdened care coordination
- Need for clarity in the roles of genetic metabolic dietitians; developing core competencies
- Retaining and promoting skilled dietitians
- Enhancing leadership opportunities
- Independent reimbursement

Underpaid and overworked!

Workforce Issues

- Lack of qualified RDNs
 - Patient care ratio: 133:1
 - Disparity between earnings and responsibilities (30%)
 - Inadequate reimbursement for MNT
 - Mean salary
 - RDN (AND 2019): \$68,600
 - Metabolic RDN (GMDI 2020): \$70,000
 - Genetic counselor (NSGC 2020): \$94,957
 - No standard certification/credential
- Uneven geographic representation
- Limited diversity within the workforce
- Inadequate reimbursement for MNT services
- Time spent on prior authorizations and advocacy for treatments vs. patient care (*from survey >5 hours per week*)

Where do we go from here?

- Support nutrition services and MNT to individuals with genetic metabolic disorders
 - Enhance and diversify the nutrition workforce
 - Increase telemedicine technical support and funding to increase access to services
- Add access to genetic metabolic dietitian and medical foods as quality indicators for NBS programs
- Include nutrition data in LTFU patient registries to generate knowledge and inform practice
- Offer funding/grant opportunities to support training programs and educational activities to prepare current and future workforce
 - ECHO nutrition
 - Web-based curricula
 - Face-to-face workshops
 - Post Master's/graduate fellowships

Thank you!

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GMDI – Genetic Metabolic Dietitians International

<https://www.gmdi.org/>

