**Health manpower and newborn screening**

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**Why was newborn screening developed?**

- Medical discoveries in 1960’s and after of preventable forms of mental retardation (e.g. PKU, hypothyroidism) and/or improved health in children with early identification (e.g. sickle cell)
- Biotinidase discovered by Dr. Barry Wolf at VCU and available for newborn screening within 5 years

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**What is needed for quality newborn screening?**

- Reproducible accurate test with high specificity (minimizes false positives, retest needs, worry) and high sensitivity (minimizes false negatives, false reassurance)
- Ease of sampling, processing specimens (heel stick blood onto paper card) for 100% coverage
- Economy of scale given incidence of the condition (e.g. biotinidase 1/60,000) to justify public health program
- Effective treatments
- Follow-up programs connecting lab results to clinical care

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**What issues would you anticipate in establishing a public health newborn screening system?**

- Expenses with competing issues/interests
- Mechanisms to connect all newborns in hospitals, home births to lab
- Parental understanding, informed consent/dissent
- Technical expertise to conduct lab tests, quality control, missed specimens?
- Overall responsibility for system
- Doctors, nurses, nutritionists to treat the children
- Primary care providers to interact with the specialists
- Others?

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**What is the overall incidence in Virginia?**

- ~100,000 births annually
- ~7 million population
- For those conditions needing special diets:
  - Maple syrup urine disease ~1/300,000 (~6 in 20 yrs)
  - Phenylketonuria ~1/10,000 Caucasian, 1/2600 Turks (~220 in 20 yrs)
  - Homocystinuria ~1/200,000 (~10 in 20 yrs)
  - Galactosemia ~1/10,000-1/30,000 (~190 in 20 yrs)
- But also have variants, false positive lab tests, adult treatment, other metabolic conditions
- At least 500 children throughout Virginia need daily dietary management for newborn screened conditions

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**What is the Virginia nutritionist workforce?**

- ~300 public health nurses in state
- 2-3 metabolic nutritionists in state, 1 at each medical school (also one in DC)
- 8 medical geneticists in the state who see children with metabolic conditions
- 4 didactic dietetic programs in Va (accredited by the Commission on Dietetic Registration), only JMU and Va Tech offer graduate programs, 7 dietetic internship programs (Tech, UVa, VCU, JMU, VSU, Radford, VDH), no specific programs to train metabolic nutritionists
How is a metabolic nutritionist trained?

- Undergraduate RD (registered dietician)
- On-the-job training (what pays for this?)
- Occasional conferences, sponsored by Ross laboratories and Maternal Child Health Bureau (who pays for this?)
- Small percentage with MPH, Va-LEND training, other graduate degree

Who pays for this?

- No more taxes
- HRSA – identifies and prioritizes manpower needs but Congress, administration allocate and authorize
- State and federal Title V (maternal and child health funding, block grants, state taxes) but also many competing priorities
- Private insurance, public insurance

Whose problem is this?

- Yours if you have a child with PKU etc.?
- Local and state health dept. if in long-term, statewide planning mode?
- Medical schools?
- Private sector (e.g. formula companies, health insurers, etc.)?
- General public?
- Others?

What does the future hold?

- 100's of potential metabolic diseases, not all treatable, may be diagnosed with new technology, tandem mass spec
- Issues of quality control, lab volumes
- Issues of informed consent/dissent
- Options for more tests if you can pay more
- Additional pressures on public health dollars for common conditions, infectious threats, safe water and foods, etc.
- Balancing of individual health concerns in country of ~300 million people
  “It takes a system to help a child.”

Kenneth Pass

Each day in the US more than 15,000 newborns are screened for congenital conditions and inborn errors of metabolism.
Each day, ~14 of these infants are referred for expert medical care for these conditions, and each day these programs improve the health of those children and this nation.