



HRSA Perspective

Heartland Annual Meeting
April 30, 2014

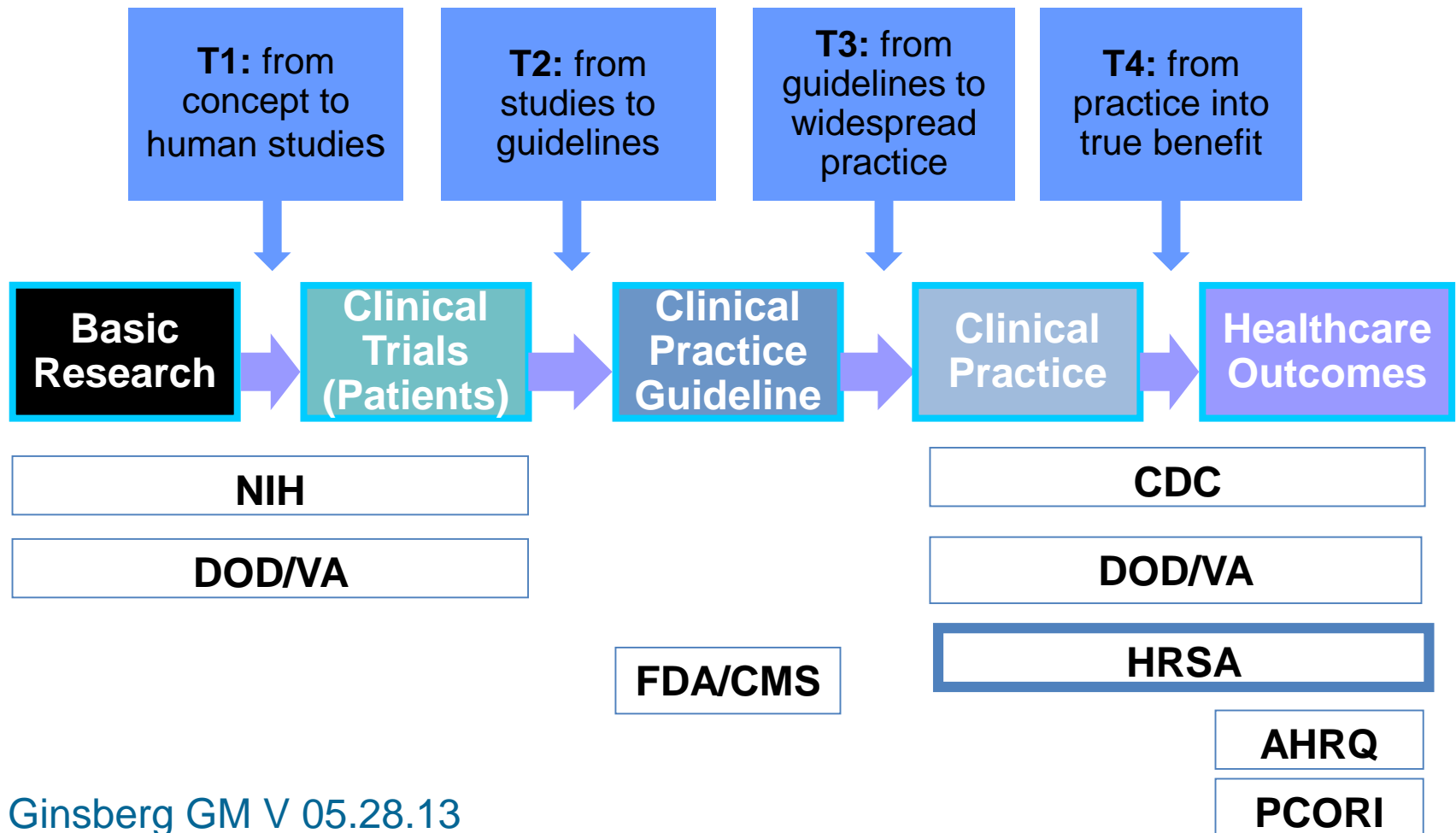
Joan A. Scott, M.S., C.G.C.
Department of Health and Human Services
Health Resources and Services Administration
Maternal and Child Health Bureau
Division of Services for Children with Special Healthcare Needs
Chief, Genetics Services Branch



Translating Genomics to Health



Roadmap of Federal Agencies Along the Translational Pathway



Our Pedigree



The President
Barack Obama



Secretary, HHS
Sylvia Burwell

Acting Administrator, HRSA
Jim Macrea



Associate Administrator, MCH
Dr. Michael Lu



Health Resources and Services Administration (HRSA)

- America's healthcare safety net - HRSA is the primary Federal agency for improving access to health care services for people who are uninsured, isolated, or medically vulnerable.

Maternal and Child Health Bureau (MCHB)

- Provides leadership to improve the physical and mental health, safety and well-being of the maternal and child health population which includes all of the nation's women, infants, children, adolescents, and their families, including fathers and *children with special health care needs*.



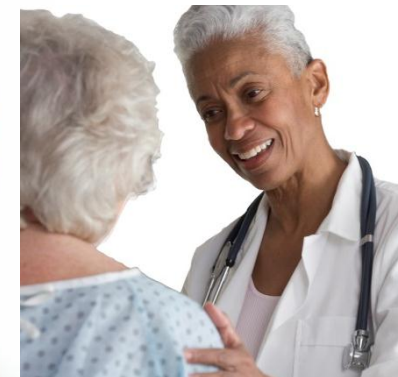
Genetic Services Branch

Vision

Genetic science is intrinsic to the understanding of health and well-being throughout the life course of an individual.

Mission

Provide national leadership to improve, expand, strengthen, and evaluate access to a system of genetic services and the quality of those services for children, youth, and adults across their life course.





Legislative Authority

- **Title V Social Security Act Sec 501:** To provide and promote family-centered, community-based, coordinated care for CSHCN and to facilitate the development of community-based systems of services for such children and their families
- **Title V of the Social Security Act Sec 502(a):** Authorizing funds for Special Projects of Regional and National Significance (SPRANS) for...genetic disease testing, counseling, and information development and dissemination programs
- **Newborn Screening Saves Lives Act of 2008, reauthorized in 2014**

Genomic Medicine

- To optimize the impact of genomics discoveries, advances need to be integrated into activities that directly influence the health of the public

Entry Points into Genetic Services



- Infertility
 - Multiple SABs
 - Family history
 - Carrier screening
 - Prenatal screening/diagnosis
- Newborn screening
- Major/minor malformations
 - Screening for growth, neurocognitive development, autism, hearing, vision
 - Family history
 - Pediatric cancers
- Adolescent and early adult onset degenerative conditions
 - Family history
- Adult onset degenerative conditions
 - Hereditary cancer, cardiovascular
 - Common complex disorders
 - Family history

Prerequisites for Genomic Medicine



- Evidence, value, outcomes
- Genetic services
 - Provider literacy, guidelines, clinical decision support tools to:
 - Identify, test/refer, communicate and use genomic information in treatment decisions
 - Genetic providers
 - Delivery models to reach everyone who needs services regardless of where they live or the family born into
 - Payment
- Systems of care

Six indicators of a well-functioning system

- Families/individuals partners in decision making;
- Comprehensive, coordinated care through the medical home;
- Adequate insurance/financing to pay for needed services;
- Early and continuously for special health care needs;
- Community services are organized for easy use by families; and
- Services to transition to adult health care, work, and independence.

Regional Genetics Service Collaboratives (RCs)

Provide a regional infrastructure of public health genetics to improve, expand, and evaluate access to a system of genetic services and the quality of those services to improve health outcomes for children, youth and adults across their lifespan.

National Coordinating Center - ACMG

1. **NEGC: New England Genetics Collaborative**
2. **NYMAC: New York-Mid-Atlantic Consortium**
3. **SERC: Southeast Regional Collaborative**
4. **Region 4: Region 4 Genetics Collaborative**
5. **Heartland: Heartland Regional Genetics and Newborn Screening Collaborative**
6. **MSGRCC: Mountain States Genetics Regional Collaborative**
7. **WSGSC: Western States Genetic Services Collaborative**





Regional Genetic Services Collaboratives

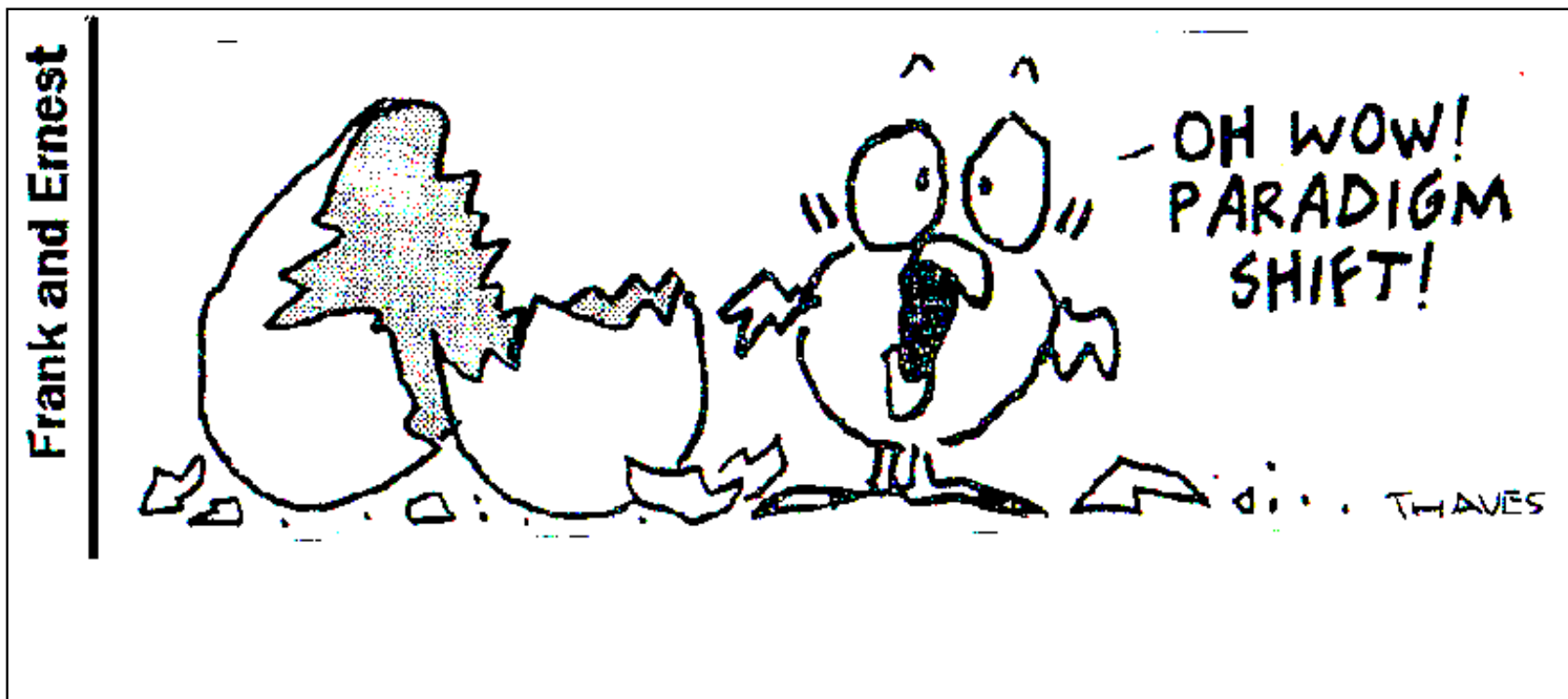
- Develop partnerships to leverage resources and collaborate on solutions
- Identify geographic, population, and funding challenges to accessing genetic services and pose and test solutions
- Pilot projects, data collection related to genetic services
- Development of policy papers and forums to guide the development of services and insurance coverage

How do we evaluate what we're doing?

- What are we doing?
- How well are we doing it?
- Is anyone better off because of it?



New paradigm of regional genetic services?



Going Forward



- What are the gaps that a public health approach can address?
- What are the failures in the market that HRSA can help address?
- Who needs genetic services that aren't getting it?
- What is the needle we are trying to move?
- What will be the impact if we succeed?



Contact Information

Joan A. Scott, M.S., C.G.C
Chief, Genetics Services Branch
301-443-8860
jscott2@hrsa.gov