

# Newborn Screening: Where We've Been and Where (we think) We're Going

A STATE'S PROGRAM PERSPECTIVE;

MICHAEL GLASS, DIRECTOR (RETIRED)

WASHINGTON STATE NEWBORN SCREENING PROGRAM

# Our Usual Business is Actually Quite Unusual

- ▶ Test all babies
- ▶ Find the very few with a hidden 'time bomb'
  - ▶ Assure the right things happen in time to prevent permanent harm, or death
- ▶ We are those babies' first, best... and often last, chance
- ▶ This requires a tightly coordinated, carefully orchestrated system with many key players

# The NBS "System"

- ▶ Appropriate, timely specimen collection
- ▶ Rapid, safe transport to testing facility
- ▶ Precise handling and tracking
- ▶ Robust testing system
  - ▶ High sensitivity
  - ▶ Balanced with sufficient specificity

# The NBS "System" continued

- ▶ Rapid communication of abnormal findings
  - ▶ to- care provider – parents – specialty care
- ▶ Prompt and reliable diagnostic testing
- ▶ Prompt entry into appropriate treatment care
  - ▶ Often life-long

# The NBS "System" - Outcomes

- ▶ When we do it all right:

WE SAVE BABIES!

- ▶ But...
- ▶ Failure at any part of the system can result in tragedy
- ▶ So we must constantly re-assess our unusual business

# Re-assessing NBS:

- ▶ Things we should be Reviewing
  - ▶ How we do things
  - ▶ Why we do them
  - ▶ Our role
  
- ▶ Things we should be Reinforcing
  - ▶ Key values
  - ▶ Core processes



# NBS – Things We Should (or probably will) Review

- ▶ Complacency – public enemy #1
- ▶ Benefits (or harms?) of detecting late onset disorders
- ▶ Benefits (or harms?) of impacts beyond the child
- ▶ Economic evaluations - to include estimating the values of the above
- ▶ Public health's roll in point of care screening
- ▶ U.S. vs. State government roll in screening

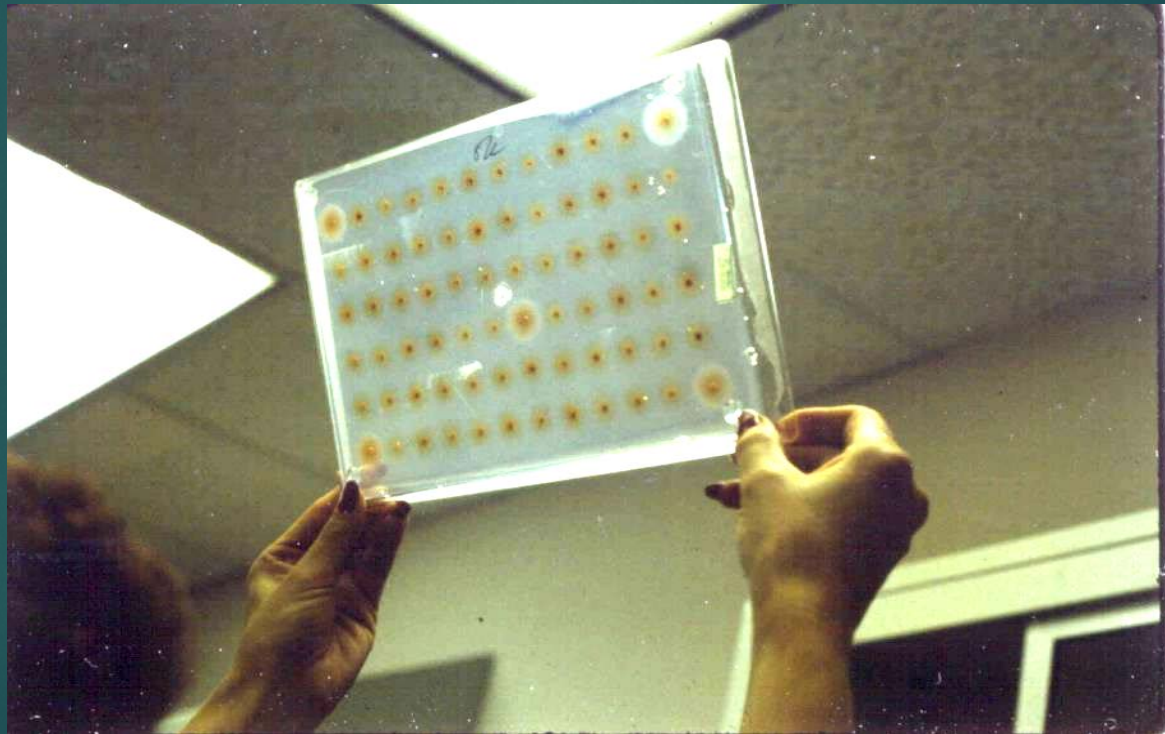
# NBS Things we Need to Reinforce

(according to Mike)

- ▶ Strong flexibility in adopting new laboratory technologies
  - ▶ Our history can be traced through the technologies we've adopted



# In the Beginning



J Clin Invest. 1960 July; 39(7): 1157–1175.

IMMUNOASSAY OF ENDOGENOUS PLASMA INSULIN IN MAN

Rosalyn S. Yalow and Solomon A. Berson

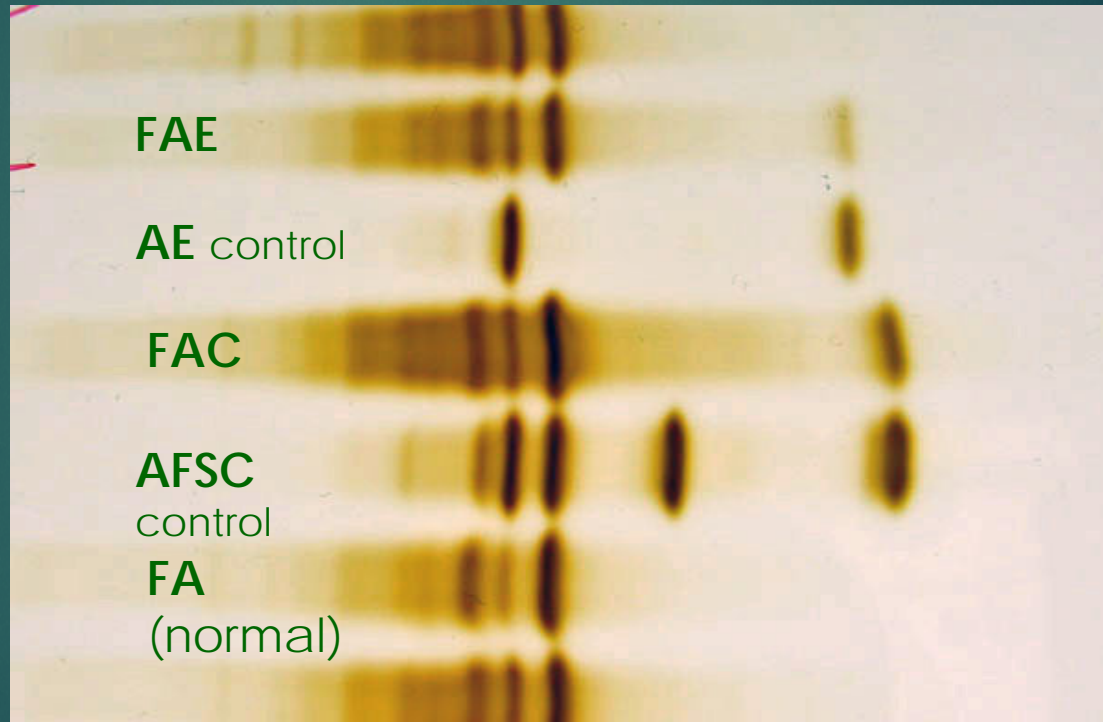
Radioisotope Service, Veterans Administration Hospital, New York, N. Y.

# Multiwell Gamma Counter for RIA



# Isoelectric Focusing (IEF)

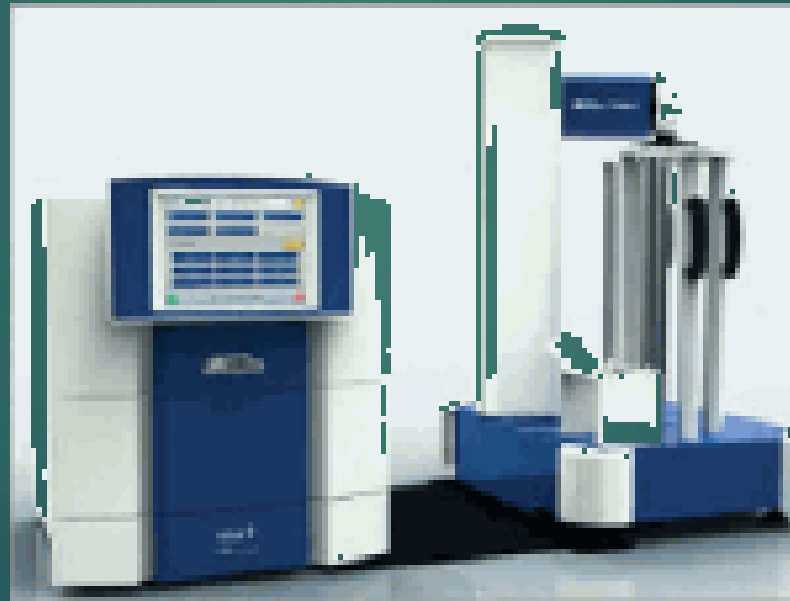
concentrates hemoglobin into distinct bands



# Tandem Mass Spectrometry



# Real Time PCR



# NBS Things we Need to Reinforce

(according to Mike)

- ▶ Strong flexibility in adopting new laboratory technologies
- ▶ Strong collaboration
- ▶ This symposium
- ▶ Key partners
  - ▶ HHS: HRSA, CDC
  - ▶ APHL
  - ▶ Manufacturers
- ▶ Our passion

# Thank You

- ▶ Enjoy the next few days
- ▶ Catch up with old colleagues
- ▶ Meet some new colleagues
- ▶ Learn some new things
- ▶ Then:



Go back home and

**SAVE SOME BABIES!!!**