

# A Regional Approach for Developing a State Newborn Screening Program

## *Recipe for Success*



**Sylvia M. Au, M.S., C.G.C.**  
**Hawai`i Department of Health Genetics Program**

# History of Hawai`i Newborn Metabolic Screening Program

- ❖ State follow-up program started at DOH in 1986
- ❖ Program reviewed by NBS “SWAT” team in 1989
  - Recommended centralizing laboratory functions
- ❖ Genetics needs assessment done in 1993
  - Recommended centralized laboratory functions and development of user fees with special fund

# History of Hawai`i Newborn Metabolic Screening Program

- ❖ Snapshot of NBMS Program in 1995:
  - State follow-up program funded by state general funds
  - 4 local laboratories doing screening for 18,000 births per year
  - Screening for only PKU and congenital hypothyroidism
  - Last state in nation to screen for only two disorders



**State Budget Crisis in late 1995**



# Timeline

1/17/1996  
Legislation  
Introduced

6/1/1996  
Legislation  
Passed &  
Signed by Governor

7/1/1997  
Regional  
Program  
Implemented



12/1/1995 - 5/31/96  
Pass Legislation

6/1/1996 - 7/1/1997  
Implementation Activities

12/1/1995

7/1/1997

**19 Months!!**

# Legislative Efforts

- ❖ Allow DOH to designate disorders included in screening panel
- ❖ Give authority to DOH to convene Community Panel to determine screening panel, feasibility of centralized testing laboratory and set the fee
- ❖ Authorize **user fees** to be charged to hospitals via collection kit purchases
- ❖ Create **special fund** for NBMS fees
- ❖ Allows fees to be used to support state NBMS follow-up program, education, services for indigent patients, etc.

# Legislative Efforts

- ❖ DOH administrative support
- ❖ Family/Organization support
- ❖ Medical Community support
- ❖ NBMS Advisory Committee support
- ❖ Governor's support
- ❖ Legislative support
- ❖ Media support

# Implementation Efforts

- ❖ Get agreement from NBMS Community Panel on:
  - disorders for NBMS panel
  - feasibility of a centralized testing laboratory
  - NBMS fee
- ❖ Develop and pass administrative rules
- ❖ Develop laboratory RFP and contract

# Implementation Efforts

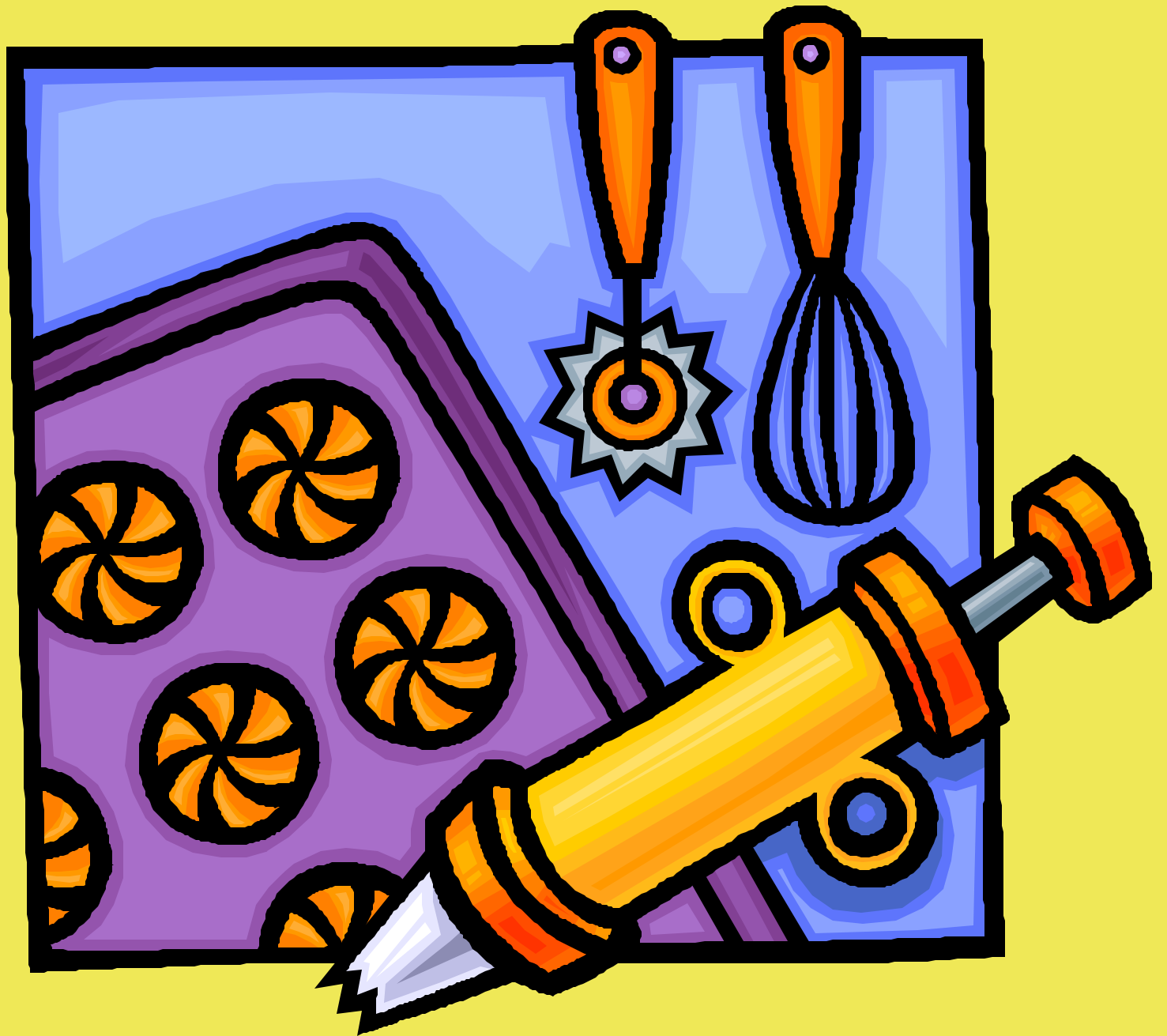
- ❖ Develop contract with Federal Express for all statewide birthing facilities
- ❖ Develop and complete educational activities
- ❖ Develop and implement collection kit sales
- ❖ Develop fiscal controls for program

# Program Overview

- ❖ Blood spots on collection kits sent overnight to the OSPHL via FedEx
- ❖ OSPHL does laboratory testing and data entry
- ❖ Results downloaded from OSPHL to HI NBMS program each weekday
- ❖ Mailers sent by OSPHL to providers
- ❖ HI NBMS program provides follow-up on missing repeat screens, abnormal screens, and confirmatory testing

# Program Overview

- ❖ Significant abnormal results called and faxed to NBMS program
- ❖ NBMS Program confirms PCP and fax results to PCP
- ❖ OSPHL clinical consultants call primary care provider with abnormal results
- ❖ Confirmatory testing done by OSPHL under our contracted fee until diagnosis is confirmed
- ❖ Families referred to local endocrinologists or metabolic clinic for clinical follow-up



Success leads to....

More Legislation  
Mandate Coverage for  
Medical Foods

# Expanding NBMS

- ❖ Exploring expanding NBMS panel beginning in 2000
- ❖ Invited to be part of HRSA funded California MS/MS Pilot Project
- ❖ NBMS Advisory Panel supported pilot project
- ❖ Pilot project began March 1, 2002
- ❖ Awarded HRSA funding to do a multi-state study on the FELS issues surrounding expanding NBMS

# Expanding NBMS

Beginning in April 2002:

- ❖ Oregon State Public Health Laboratory decides to move to MS/MS screening
- ❖ Laboratory options and pilot results presented to NBMS Advisory Committee
- ❖ Unanimous decision to increase NBMS fee, expand NBMS panel using MS/MS, and keep screening mandatory

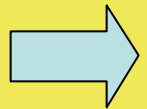




- ❖ Pediatric geneticist leaves the state
- ❖ Hospital closes metabolic clinic

# Crisis Motivates Action

- ❖ Collaborative relationship developed among hospitals, DOH, and UH School of Medicine



## **HAWAII COMMUNITY GENETICS**

- ❖ Contract with Stanford Medical Center Division of Medical Genetics for clinical genetic services
  - 24/7 telephone/e-mail coverage
  - 1 week per month in-person clinics
  - Telemedicine capabilities

# Expanding NBMS using MS/MS

- ❖ Revise and pass administrative rules
  - Important for fee change
- ❖ Modify contract with OSPHL
- ❖ Educational activities for providers, consumers, hospital staff
- ❖ New collection kits, provider manuals and brochures
- ❖ Upgrades to software

**Statewide Expanded NBMS  
Implemented  
September 1, 2003**

# Future Activities

- Web-based data and follow-up system integrated with NBHS Program
- Expansion of Hawaii Community Genetics
- Continue research on additional disorders for NBMS panel
- Improve and continue educational efforts
- Help Guam and the other Pacific Islands improve their NBS programs

# **Recipe for a Successful Regional NBMS Program**

- **1 ton of optimism, drive, determination and energy**
- **1 handful of dedicated staff members**
- **2 cups of administration support**
- **10 cups of family, provider, organization & legislative support**
- **Dash of crisis**
- **1 cup of an experienced regional laboratory**
- **1 cup of a reliable transport system**
- **3 cups of a clinical follow-up team**
- **Generous dose of money**
- **Laughter to taste**

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[www.hawaiiigenetics.org](http://www.hawaiiigenetics.org)