

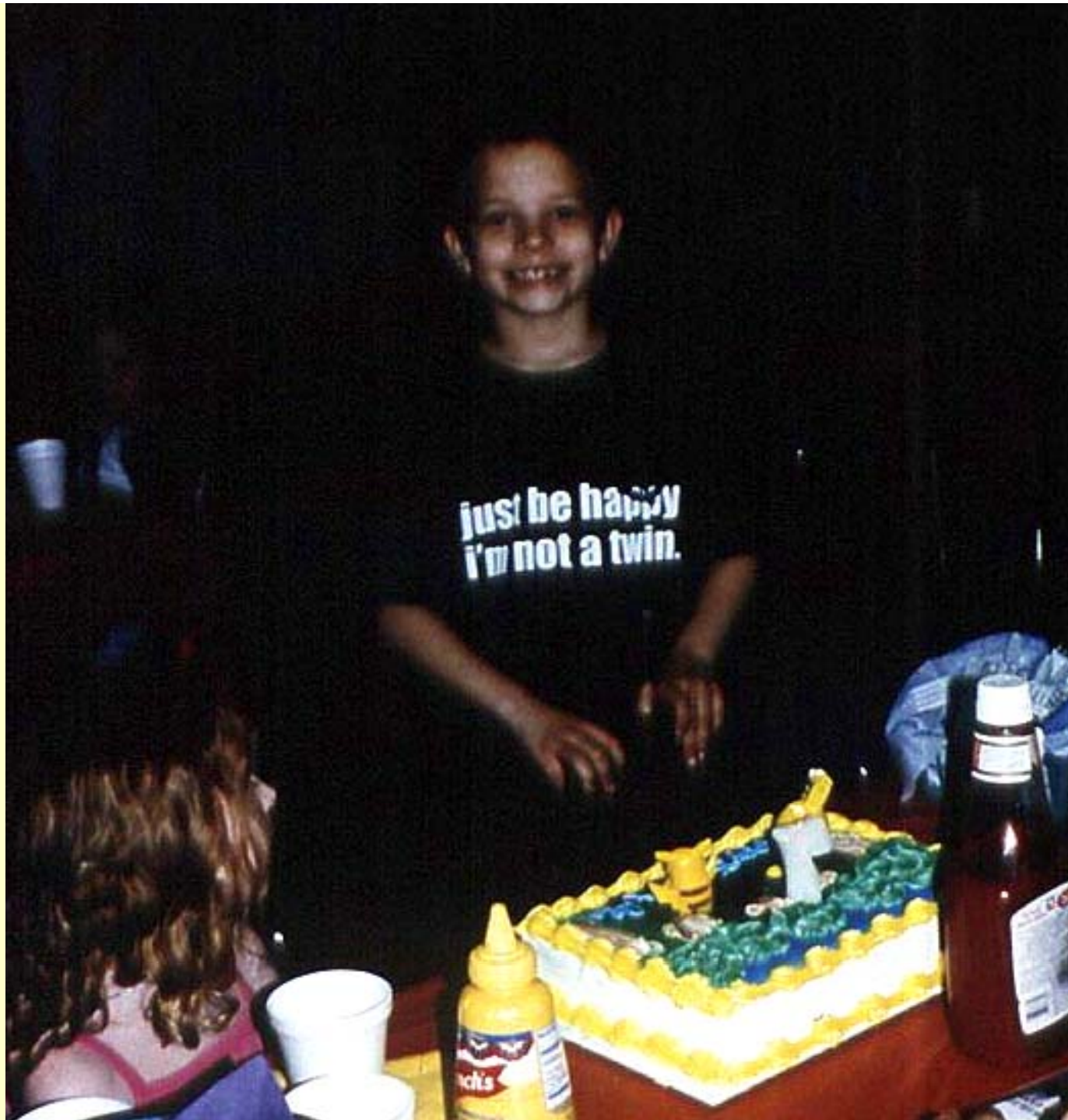
## **Needed Funds and Data Review For an Effective Statewide EHDI Program**

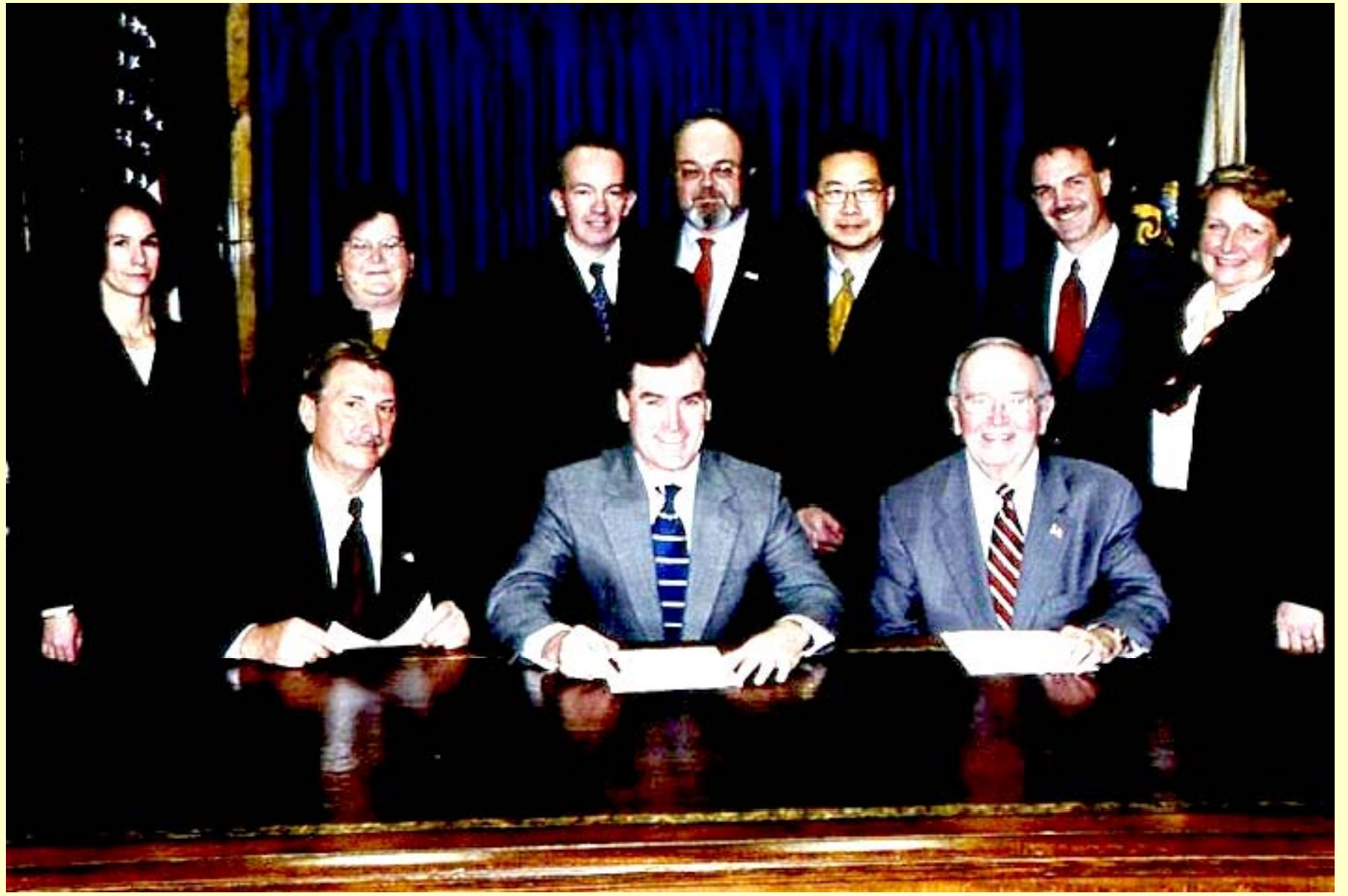
**Louis R. Sieminski, Ph.D. –Advisor, PA Department of Health EHDI Program**





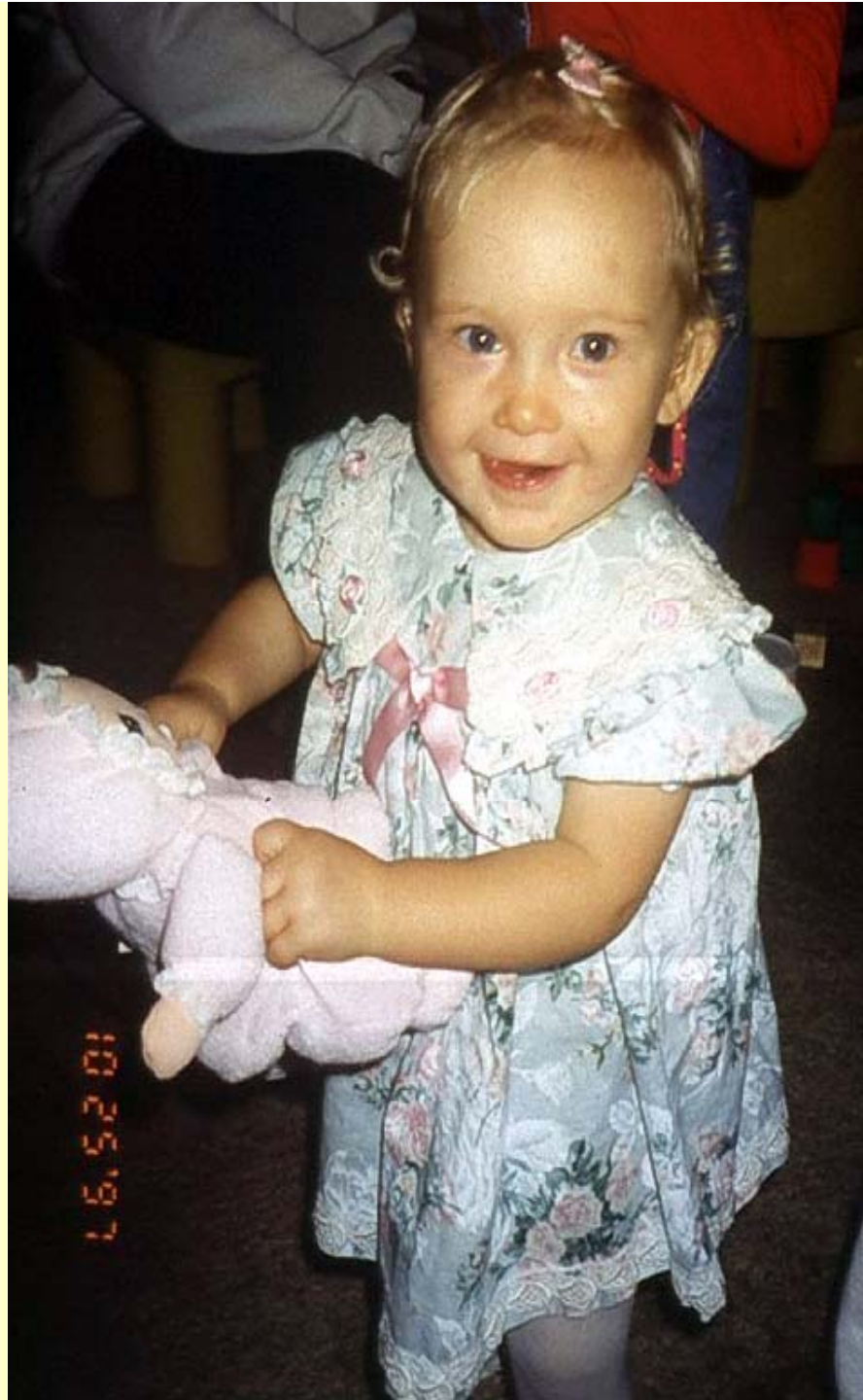






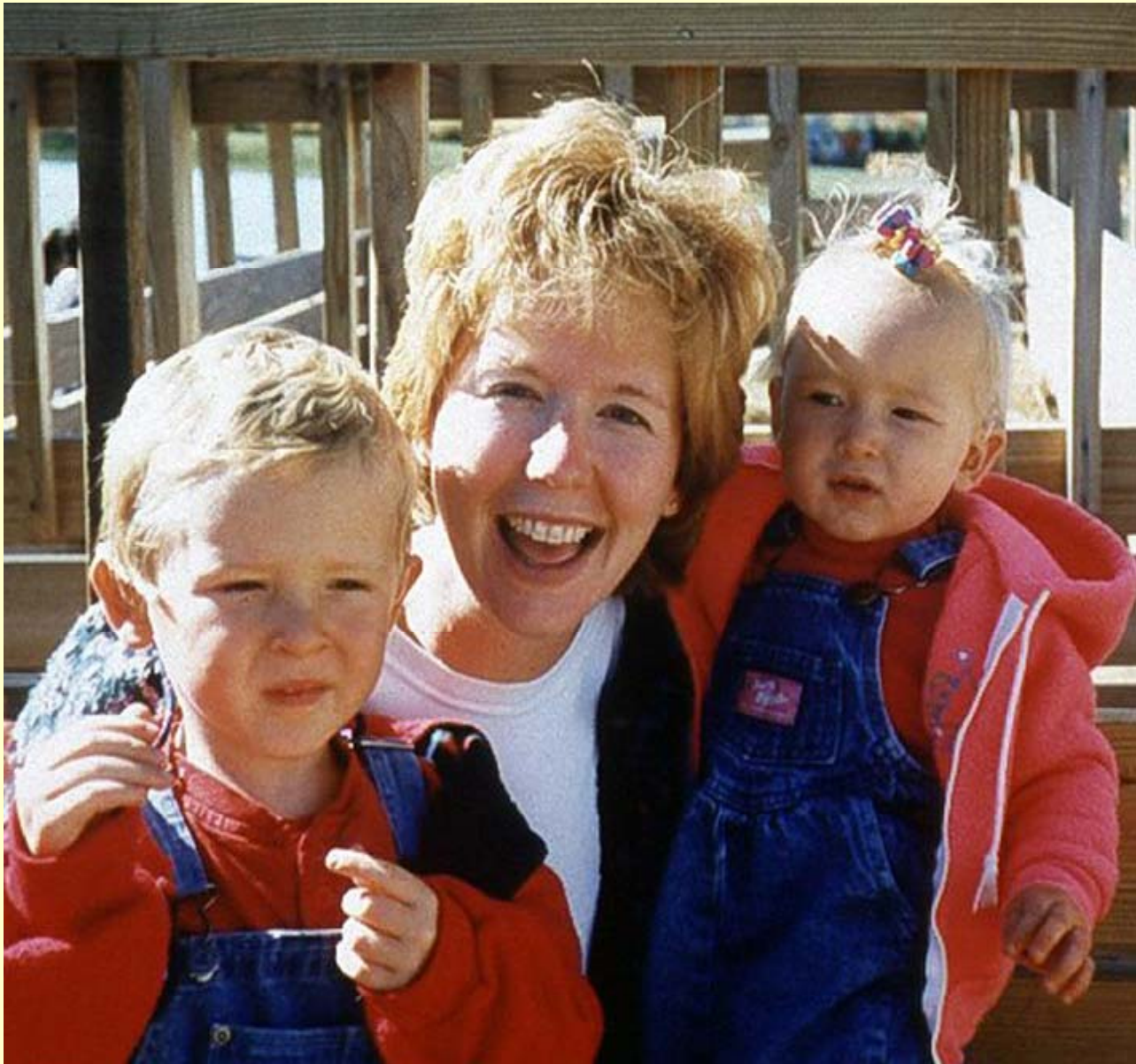






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# Program Goals

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- Screen all newborns by 1 month of age
- Diagnose hearing loss by 3 months of age
- Link the child to intervention by 6 months of age to maximize developmental, educational and communication outcomes
- Provide support and education for families

Remember!! 1 - 3 - 6



# Pennsylvania's Early Hearing Detection & Intervention Program

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- 1999 – began demonstration program in 26 birthing hospitals
- IHEARR Act passed in November 2001
- Statewide program implemented July 1, 2002
- Universal EHDI in all 117 birthing hospitals
- 140,000 hospital births per year
- 3,900 out-of-hospital births per year



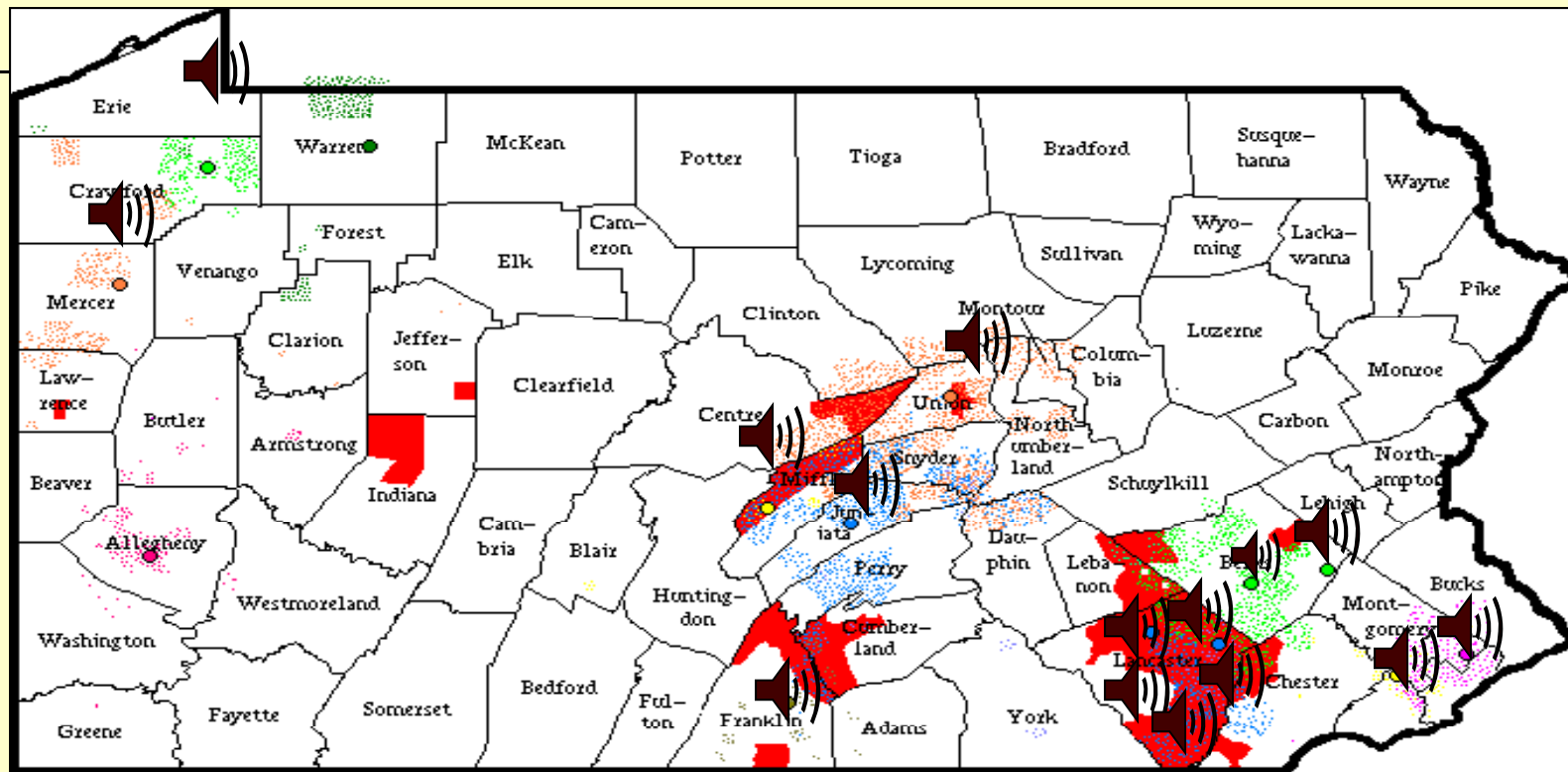


# Out-of-Hospital (OOH) Births

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- Pennsylvania had a total of 3,900 out-of-hospital births
- 1,066 OOH births (32%) occurred at Freestanding Birthing Centers (FBCs); 120 FBC births were to out-of-state residents.
- 2,324 OOH births (68%) occurred in residences, midwives' homes or other locations (the majority were home births).

# PLACEMENT OF PORTABLE ABR SCREENING UNITS



- Pennsylvania's EHDI program has purchased 20 portable ABR units
- The units are currently deployed at the above locations
- Upcoming prospective placement at Pittsburgh FBC





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## Newborn Being Screened by a Midwife in the Amish Community



# OOH Births – How Are We Doing?



41% of Out-of-Hospitals Births are now being screened.

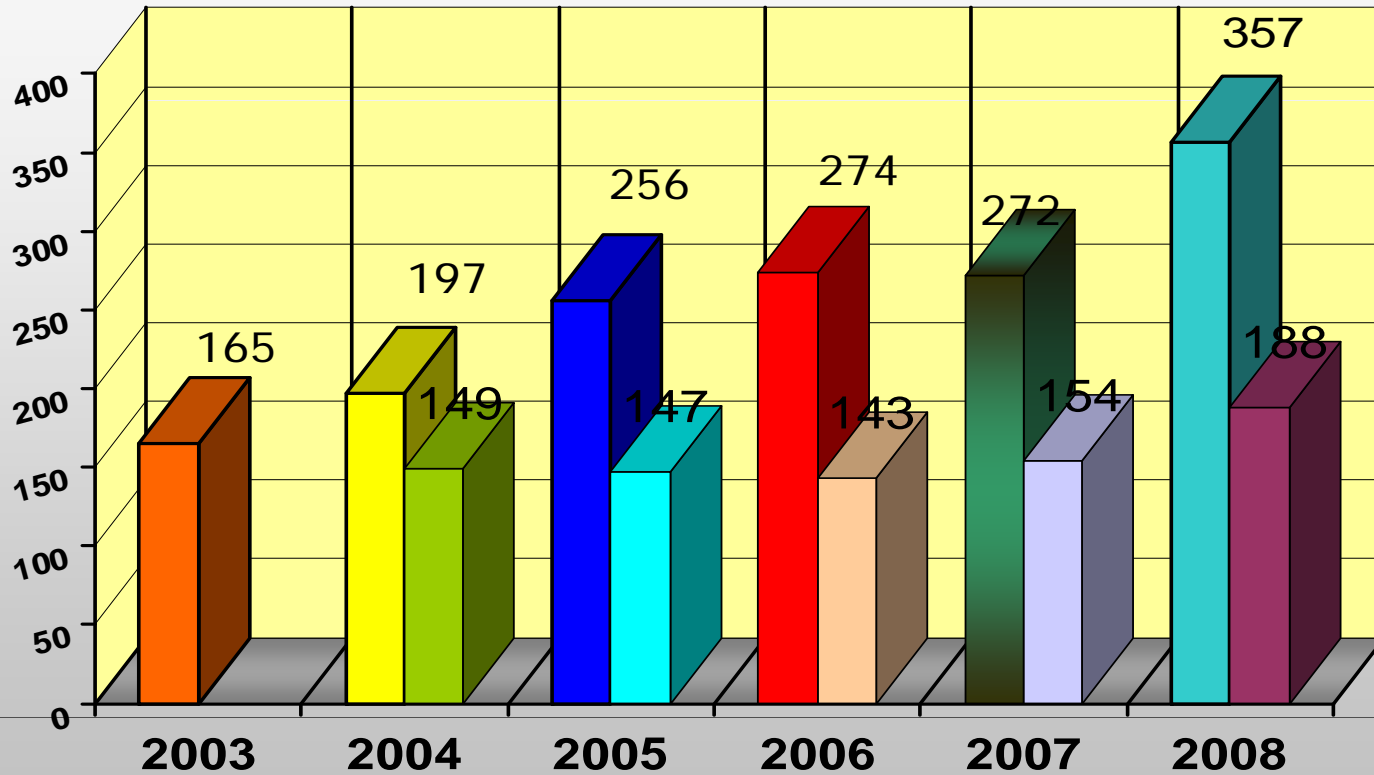
## Summary and Lessons Learned

- ✓ Research is Key
- ✓ Identify and Overcome Barriers
- ✓ Recognize Cultural Diversities
- ✓ Program Requires Investment of Staff Time and Effort
- ✓ Develop Relationships Based on Trust
- ✓ Communications



# PA Newborns Diagnosed With a Hearing Loss

Calendar Year 2003 - 2008



	National	Pennsylvania 2008
Occurrent Births	4,056,618	144,564
Number Screened	3,775,361	142,082
% Screened	94.0%	97.2% (HOSPITAL)
% Not pass, Final	1.8%	1%
# Permanent HL	4,016	187 (175 cond)
Incident of HL	1.2 per 1000	1.3 per 1000
% Loss to F-U	44.8%	6.7%



# Loss to Follow-up

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- Localized area of the state was targeted with high loss to follow up rates.
- 7 hospitals received sole source grant funding



<b>Hospital</b>	<b>2004 Births</b>	<b>2004 Losses</b>	<b>2005 Losses</b>	<b>2007 Losses</b>
<b>1</b>	4926	53	33	15
<b>2</b>	2378	18	28	5
<b>3</b>	2032	65	61	23
<b>4</b>	1399	56	26	14
<b>5</b>	2318	39	13	5
<b>6</b>	4772	18	15	13
<b>7</b>	1995	15	35	20
<b>Total Loss to F-U</b>		<b>264</b>	<b>211</b>	<b>95</b>

Note: 2004 birth information provided by the Bureau of Health Statistics

# National EHDI Programs

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# National statistics That Upset Me

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- ❑ Nationally 4+ million babies born annually
- ❑ 94% screened
- ❑ 6% or 200,000+ not screened
- ❑ Expect 12,000 babies born hearing impaired
- ❑ 4,000 babies were diagnosed
- ❑ 46% babies failing screen are loss to system





# Additional statistics

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- 56.6% no documented diagnosis
- Less than 50% diagnosed by 6 months
- 64% with hearing loss receiving EI
- Most receiving EI after 6 months
- 36% with hearing loss not receiving EI



# My humble opinion

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- 1 ... Hearing screening process needs to be improved
- 2 ... Tracking process must be improved
- 3... Diagnostic follow up must be improved
- 4...Referral and enrollment in EI must be improved
- 5... State EHDI Bills must be improved changed

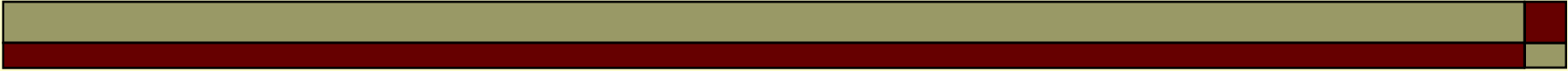


# Hearing screening process

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- ❑ No competency based training
- ❑ Different testing protocols used
- ❑ Most do not use audiologists to test or oversee
- ❑ High percentage of old equipment used
- ❑ Few have backup equipment
- ❑ Method of informing parents





# Tracking process

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- ❑ Majority use paper tracking
- ❑ Understaffed personnel for tracking
- ❑ Data review of individual hospitals not occurring
- ❑ Inner-city hospitals highest percentages lost
- ❑ Needed funds for tracking



# Diagnostic follow-up

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- ❑ Insufficient numbers pediatric audiologists
- ❑ Poor reporting by audiologists
- ❑ Proper diagnostic protocol not followed
- ❑ Inadequate diagnostic equipment
- ❑ Inadequate funding



# Referral and enrollment

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- ❑ Need increased referral and enrollment for hearing impaired
- ❑ Competent EI staff for hearing impaired
- ❑ Increased screening of pre-school head-start
- ❑ Audiologist and medical home referrals
- ❑ Parent to parent involvement



## State EDHI bills

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- ❑ Only 28 of 43 require screening of all babies
- ❑ 29 of 43 require hospitals report data
- ❑ 21 statutes indicate EHDI covered benefit
- ❑ Make-up and involvement of advisory boards
- ❑ Dedicated people with passion and funding

The End

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Questions?