It started with a glass of wine...

- 1991 – Reps from the CO Dept of Public Health, University of Colorado and The Children’s Hospital Colorado met to develop a pilot project
- 1992 – Boulder Community Hospital and the University of Colorado Hospital start the first newborn screening programs
- 1995 – Evidence emerges from the UC Boulder demonstrating that infants born in hospitals that screened were identified and starting early intervention by 6 months of age vs. 2 years of age
- 1996 – Lunch with the Chair of the CO Genetic and Metabolic Screen Committee – a Roadmap for universal newborn hearing screening
- 1996 – Hands & Voices is born
- 1997 – Colorado passes legislation requiring hospitals to screen
- 1998 – Christie, Al, et al publish landmark article on the outcomes of children identified early vs. late
- 2008 – Colorado passes legislation requiring insurance to pay for hearing aids for children

EHDI Program Goals 1–3–6 Plan

1. Screen > 95% of the birth population by 1 month of age
   - Refer < than 4% at hospital discharge
2. Diagnose by 3 months of age
3. Enroll in early intervention by 6 months of age
4. States will have coordinated systems of care

Newborn Hearing Facts

- 2 out of 1000 babies will be born with a hearing loss
- 6 out of 1000 children will enter first grade with hearing loss
- Hearing screening in the hospital helps to identify infants with hearing loss
- 50% of the babies with hearing loss are normal and healthy - there was no reason to suspect a hearing problem

2012 Statistics

- Births 65,514
- Screened 63,942 (98%)
- 2,035 (3.1%) of infants referred for further testing at hospital discharge
- 1,525 (75%) have documented follow-up
- 142 confirmed with permanent hearing loss at the average age of 2 months
  - 98 Bilateral
  - 44 Unilateral
Colorado Infant Hearing Advisory Committee (CIHAC)
- Parents
- Consumers
- Educators
- Part C
- Early Intervention
- Audiologists
- Pediatrician
- Family Practice
- Otologist
- Geneticist
- Medicaid
- Hospital representatives

CIHAC Guidelines
- Screening
- Assessment
- Intervention
- Medical
- Parent
- http://www.hcpcolorado.org

The EHDI Model
- Collaboration
- Parent Centered using a medical home approach
- Data Driven
- Evidence Based Practices
- Improving health, social, emotional and educational outcomes for children and their families

Role of Public Health in EHDI Programs
- Using science as a basis for decision-making and action
- Expanding the quest for social equity
- Performing effectively as a service agency
- Making efforts outcome-oriented
- Being accountable

Evaluating the Reach of Universal Newborn Hearing Screening in Colorado
- Initial Screen Results
  - Infants who had 5 minute Apgar scores >7 were 9 times more likely to receive the screen
  - Infants who weighed more than 2,500 grams were 3.5 times more likely to receive the screen
- Rescreen Results
  - Interaction between hospital rescreen rates, mother’s education, race/ethnicity

Evidence Based Practice
- 2007 – Analysis of the EHDI Integrated Data System demonstrates:
  - Infants in the NICU are less likely to receive a newborn hearing screen
  - Infants born in hospitals without audiology support were 36% less likely to return for follow-up
  - Infants born to non-Hispanic mothers were 46% more likely to receive follow-up
  - Infants born to mothers with less than a 12 grade education were 49% less likely to receive follow-up

Importance of data analysis to uncover assumptions
Data Integration

- 1998 – Added screening results to electronic birth certificate (EBC)
- 2000 – Awarded CDC grant to develop a data integration system to track infants from screening through early intervention
- 2010 – The ’greening of EHDI’ – paperless reporting
- 2014 – Adding newborn hearing and blood spot results to the Colorado Immunization Information System

CDPHE – “Resource Central”

- Linking Families to Appropriate Services
  - Screening and evaluation resources
    - Hospitals
    - Audiology
    - Midwives
    - Intervention
    - Schools
  - Colorado Immunization Information System (CIIS) a.k.a. immunization registry
  - Audiology Regional Coordinators
  - Program Brochures – www.cohealthresources.com
  - NBH website - www.Colorado.gov (under construction)

Roadmap for Families

Roadmap: Individualized Information by Hospital or Region

Local EHDI Teams

- Develop Local Parent/Provider Roadmaps
- Includes but not limited to:
  - Hospital Coordinator
  - Audiology Regional Coordinator
  - Parent Guide
  - CO-Hear Coordinator
  - PCP
  - HCP Team Leader
  - Early Intervention Coordinator (Part C)
  - Midwives
  - Local stakeholders

FUTURE DIRECTIONS

- A true integrated data system – i.e. child health profile
- Telemedicine for audiology, early intervention, and genetic consultation
- Increase funding and resources to support newborn hearing screening in Colorado
INTERVENTION: THE “I” OF EHDI
Colorado Home Intervention Program (CHIP)

- All children who are D/HH from birth to 3 years of age and their families have EI providers who have the professional qualifications and core knowledge and skills to optimize the child’s development and child/family well-being.
  - JCIH 2007 Position Statement: Principles and Guidelines for Early Intervention after Confirmation that a Child is Deaf or Hard of Hearing

Early Hearing Detection and Intervention (EHDI)
- The goal of EHDI is to maximize linguistic competence and literacy development for children who are deaf and hard of hearing.
  - All infants screened by 1 month of age
  - Diagnostic eval by 3 months of age
  - Appropriate intervention by 6 months of age from professionals with expertise in hearing loss and deafness in infants and young children
  - “Year 2007 Position Statement: Joint Committee on Infant Hearing”

Transition from Diagnosis to Early Intervention
- Audiologist Confirms Hearing Loss
  - Hearing Resource Coordinator Contacted
    - Contacts CCBs
    - Initiates data management
    - Contacts family

CO–Hear Coordinator: Who we are
- Highly trained professionals; all with M.A. and appropriate professional certification
- Employees of Colorado School for the Deaf and the Blind
- Extensive experience working with families and young children who are deaf or hard of hearing
- Work within a region to provide a statewide coordinated system of referral and intervention services
- Members of the Regional EHDI team

What the Visit Provides to the Family
- Information
- Professional with expertise and experience in childhood hearing and communication development
- Technical support
- Emotional support
- Connections
Collaborative Partnerships are critical!
- The CO-Hear Coordinators maintain collaborative partnerships at both the state and local level.
  - El Colorado
  - CDPHE
  - Child Find
  - Colorado Families for Hands & Voices
  - Pediatric audiologists
  - University of Colorado

Colorado Home Intervention Program (CHIP)
- Program of the Outreach Department of the Colorado School for the Deaf and the Blind
- Statewide, family-centered in-home early intervention program serving families with young children (0-3) who are deaf and hard of hearing
- Data-driven approach to early intervention (FAMILY Assessment)

Service Delivery Model for CHIP
- Community Based
- Multi-Disciplinary Assessment
- Communication Methodology Options
- Transition Support
- Connections with Parents and Deaf Adults
- Technical Assistance from CO-Hears

CHIP
- Individual program to fit family's needs and child's learning style
  - Language development
  - Speech
  - Auditory training
  - Cognitive and play skills
- Utilizes CHIP Parent Manual and other appropriate curriculums
- Family- centered
- Frequency goals determined by the IFSP
- CHIP Facilitators are trained and mentored by the CO-Hear to ensure program consistency around the state.

CHIP Outcome Data: Intervention Making a Difference
- A total of 136 English-speaking children with bilateral hearing loss were assessed as part of the program in the calendar year 2012.
  - 80% had a Language Quotient in the normal range when compared to their hearing peers
  - Additional 9% of the children were in the borderline range on the Expressive Language Scale of the Minnesota Child Development Inventory

Where Do Parents Find Support?
The Parent to Parent Connection

Support, Information, Modeling

PROGRAM CONTACTS

Erica McKiever, Erica.McKiever@state.co.us
Vickie Thomson, Vickie.Thomson@ucdenver.edu
Dinah Beams, Program Coordinator (CO-Hears and CHP) dbbeams@csdb.org
Sara Kennedy, Director, CO Hands & Voices, Sara@cohandsandvoices.org