Adding CMV to EHDI Data Management
Utah HB 81 (2013 General Session)
Cytomegalovirus Public Health Initiative
26-10-10 UCA, “Cytomegalovirus (CMV) Public Education and Testing”

- **UDOH** establish and conduct public education program to inform *pregnant women and women who may become pregnant* about CMV (incidence, transmission, birth defects, diagnostic methods, preventative measures)

- Provide information to: *child care providers, school nurses, health educators, health care providers, religious organizations offering children’s programs as part of worship services*
If a newborn infant fails the newborn hearing screening test(s)......

**Medical Practitioner** shall:

- *Test the newborn infant for CMV before 21 days of age...unless the parent objects; and*
- *Provide to the parents information re: birth defects caused by congenital CMV and available methods of treatment.*
H.B. 81 (2013 General Session) Cytomegalovirus Public Health Initiative (UCA 26-10-10) Sequence of Events

INFANT FAI LS INPATIENT NEWBORN HEARING SCREENING (NBHS)

Hospital must program notifies family that infant's newborn hearing screen and subsequent inpatient re-screening appointment to take place prior to 21 days of age is mandatory regardless of completing the appointment at the scheduled time.

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INFANT FAI LS 2ND (OUTPATIENT)

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TESTING OCCURS PRIOR TO 21 DAYS OF AGE

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Newborn Hearing Screening (NBHS) / CMV

Status Report FAX (1 form with 3 options)

PILOT

Version: August 26, 2013

COMPLETE ONE OPTION ONLY

TO:

CLINIC/HOSPITAL:

FAX:

PHONE:

OPTION 1 (NBHS Program)

PER H.B. 81 (2013 General Session) UCA 26-10-10 Cytomegalovirus (CMV) Public Health Initiative, the following infant who lists you as their Primary Care Physician, has FAILED the INITIAL newborn hearing screen and will require a follow-up re-screen. This follow-up appointment is scheduled as noted. Should you have contact with the family prior to the follow-up date please encourage them to keep the appointment as this should be completed no later than 14 days of age. Otherwise, no action on your part is necessary at this time.

**Notification of failed INITIAL HEARING SCREEN — to be completed by HOSPITAL**

<table>
<thead>
<tr>
<th>Infant’s Name</th>
<th>D.O.B.</th>
<th>Mother’s Name</th>
<th>Contact</th>
<th>Follow-up Appt.</th>
</tr>
</thead>
</table>

OPTION 2 (NBHS Program)

This is to advise the PCP that the following infant has FAILED the FOLLOW-UP (2ND) HEARING SCREENING and is a candidate for congenital CMV testing before 21 days of age per H.B. 81. He/she has also been referred to a pediatric audiologist for a diagnostic hearing evaluation.

**Notification of failed FOLLOW-UP HEARING SCREEN — to be completed by HOSPITAL**

<table>
<thead>
<tr>
<th>Infant’s Name</th>
<th>D.O.B.</th>
<th>Mother’s Name</th>
<th>Contact</th>
<th>Diagnostic Appt.</th>
</tr>
</thead>
</table>

OPTION 3 (Primary Care Provider)

After congenital CMV PCR assay testing has been completed, PCP office should fax this form back to the Hospital NBHS program at the above listed fax # and to the Utah Department of Health Early Hearing Detection and Intervention (EEDI) program at (801) 584-8492.

**Notification of CMV TEST RESULTS — to be completed by PHYSICIAN**

<table>
<thead>
<tr>
<th>Infant’s Name</th>
<th>D.O.B.</th>
<th>Urine (U) or Saliva (S)</th>
<th>RESULT: Pos (+) or Neg (-)</th>
</tr>
</thead>
</table>

If questions, please contact the Utah Department of Health Early Hearing Detection and Intervention Program at (801) 584-8323.
“Notebook” Data: First 6 Months

Babies eligible for CMV testing = 183
# of CMV tests reported back to UDOH = 27
Prior Implementation: Overview

- Risk Indicator Data Entry
Prior Implementation: Overview

- Notes Data Entry
Prior Implementation: Limitations

• Limited Reporting Capacity
• Free text entries make hard to quantify the data
User Requirements: Data Elements

- Studied hard-copy forms currently in use.
- Physician Notices
- CMV Lab Test Results
User Requirements: Ease of Use

• “Up front” on the User Interface
• Consistent with current User Interface culture.
User Requirements: Reporting & Exporting

- Built in Lab Result Report
- Flexible Lab Result filter for existing EHDI-related Reports
- Exporting Functionality
- XML for data exchange with data other systems
Implementation: Data Fields

• Analyzed current system to determine optimal long-term database placement.
• Leveraged HiTrack’s existing tables and code with little system impact.
  • Introduced new Lab Testing types and outcomes.
  • Introduced new CMV specific Recommendation Types.
Implementation: Data Collection

- Iterated User Interface prototypes for Notice data entry.
- Finalized design with users.
Implementation: Data Collection

- Iterated User Interface prototypes for Lab Results.
- Finalized design with users.
Implementation: Reporting

• Iterated Report Design prototypes.
• Finalized design with users.
Implementation: Reporting

- Iterated filter designs for EHDI-related Reports
- Finalized design with users.
Implementation: Exporting

- Existing XML exporting functionality.
- Reviewed new Lab Testing types and outcomes.
Learning Experiences

• Challenge
  • Learned that “Detected” / “Not Detected” terminology is preferred by users over “Positive” / “Negative”

• Solution
  • Flexible system allowed real-time update of the labels with no negative impact.

• Challenge
  • Blood test types were received although the State of Utah prefers CMV diagnosis based on saliva or urine.

• Solution
  • TBD, however, HiTrack allows for customization with little negative impact
Future Work:

• Collaboration with Laboratories
  • Electronic Data Interchange – e.g. HL7
  • Establish Matching Rules
    • Statewide Unique ID
    • Mother Demographics, DOB, etc.
  • Ensure Privacy
• Follow-through data entry in HiTrack by Healthcare providers
  • Web access user interface for providers
CMV Data Management Summary

- Effective Collaboration
  - Involve the User at Every Step
  - Include Knowledge Experts
  - Communicate effectively
  - Know when to upgrade the mode of communication as needs arise.
- Plan for future growth
- Use a data system with flexible database components and features