

Newborn Screening Longitudinal Follow-up for Congenital CMV in Minnesota

Gina Liverseed, DNP, APRN, PHN | CMV Nurse Specialist

Lexie Barber, MPH | Senior Epidemiologist



Learning Objectives

- Describe the goal and key components of longitudinal follow-up for newborn screening conditions in Minnesota.
- Discuss the planning and implementation of longitudinal follow-up for congenital CMV in Minnesota.
- Identify next steps for longitudinal follow-up activities including data collection.

What is longitudinal follow-up (LFU) for NBS conditions?

- Systematic evaluation to determine how newborn screening is meeting its goal
- Focus: *after* diagnosis of a person with a condition included in newborn screening
- 6 Key Components of LFU at Minnesota Department of Health (MDH) align across all NBS conditions



LFU Case Notification for Congenital CMV (cCMV)

- LFU is alerted of cases by short-term follow-up after confirmation of cCMV infection is received
 - Average age of child when LFU notified is 18 days
- Case details are manually entered from Natus into the Minnesota Electronic Disease Surveillance System (MEDSS).
 - MEDSS also has workflows and reporting functions that allow us to manage and track follow-up activities and analyze data



Connections to Information, Resources, and Services

- Parent(s) or guardian(s) receive a letter and informational booklet by mail from MDH
- Information developed in collaboration with the National CMV Foundation and a workgroup of MN/ND parents of kids with cCMV
- Timing was a key consideration
 - Feedback from parents: earlier is better
 - On average, mailed 11 days after confirmatory lab resulted
- Cost to print/spiral bind is \$18/booklet
- PDF available online
- Translations available: Spanish, Somali, Hmong



Local Public Health Referral

- Connection between family and Local Public Health (LPH) department for their county of residence via direct referral from MDH – utilize an electronic referral process in MEDSS
- LPH nurse contacts the family to complete a nursing assessment which includes up to 5 domains
 - Income
 - Communication with community resources
 - Caretaking/parenting
 - Growth and development
 - Health care supervision



Local Public Health Interventions

- Link to supportive services (Family Home Visiting, WIC, teen parenting, Early Intervention)
- Facilitate connections to medical care by addressing barriers
- Communicate nursing assessment results and special concerns back to MDH via MEDSS
- Option for second visit (their discretion or MDH request)
- LPH departments are reimbursed for visits by CYSHN section

LPH Assessment Data for cCMV

102 children followed by longitudinal follow up	102
90 children have been referred to LPH	90
LPH reached 67 parents/guardians (74%)	67
An assessment was completed for 66 children (1 declined, 9 unable to reach, 14 pending)	66
A second assessment was requested for 22 children	22

Parent Support Pilot Project

- Pilot program for parent-to-parent support in collaboration with Minnesota Hands and Voices (MNHV)
- Families included
 - Have a child classified as "symptomatic" regardless of hearing status
 - Have a child with cCMV and a permanent hearing difference
- Connection between family and MNHV is via direct referral from MDH utilize an electronic referral process in MEDSS
- Contacted by the cCMV parent guide via phone call and are offered 1:1 support
 - Conversations are parent-led
 - List of questions available to parent guide, if needed to facilitate conversation
- Results of phone contact are documented in MEDSS



Parent Support Pilot Project Data

- Very early in the project
- So far, most parents
 - Wonder what they can expect in the future
 - Feel angry that they didn't know about cCMV
 - Appreciate the contact
- Currently planning project evaluation

20 Referrals to MN Hands and Voices



Capacity Building, Systems Evaluation & Improvement

- Sharing information, receiving feedback, providing updates to multiple interested partners
 - EHDI Newborn Hearing Screening Advisory Committee
 - Statewide EHDI meeting
 - Minnesota Hands & Voices
 - Educational Audiologists
 - Statewide Deaf/Hard of Hearing Advisory Committee
 - Local Public Health Nurses
 - Regional Local Public Health Association Directors
 - Follow Along Program staff
 - Statewide Interagency Early Intervention Committee
 - Early Education/Child care providers
 - MDE Part C Coordinator





Public Health Surveillance

cCMV Surveillance

- cCMV surveillance cases
 - Cases that are lab confirmed
 - Positive blood, Urine, or CSF PCR (collected within 21 days of life)
 - MN resident
- LFU is currently following 102 babies identified with cCMV all identified through newborn screening
- cCMV will soon be included on Minnesota's reportable communicable conditions list

REPORT IMMEDIATELY BY TELEPHONE	
Anthrax (Bacillus anthracis)	Middle East Respiratory Syndrome (MERS)
Botulism (Clostridium botulinum)	Orthopox virus (including mpox)
Brucellosis (Brucella spp.) () Cholera (Vibrio choleroe) ()	Plague (Yersinia pestis) () Poliomyelitis ()
Diphtheria (Corynebacterium diphtheriae)	Q fever (Coxiella burnetil)
Free-living amebic infection () (Including at least: Aconthomoebo spp., Naegleria fowleri, Balamuthia spp.,	Rables (animal and human cases and suspected cases)
Sappinia spp.) ()	Rubella and congenital rubella syndrome () Severe Acute Respiratory Syndrome (SARS)
Glanders (Burkholderia mallei) () * Hemolytic uremic syndrome ()	Smallpox (variola) () Tularemia (Francisella tularensis) ()
Measles (rubeola)	Tularemia (Francisella tularensis) Unusual or increased case incidence of any suspect infectious illness
Melioidosis (Burkholderia pseudomallei) () * Meningococcal disease (Neisseria meningitidis) (invasive) () ()	Viral hemorrhagic fever () (Including but not limited to Ebola virus disease, Lassa fever, and Marburg v
REPORT WITHIN O	
Amebiasis (Entamoeba histolytica/dispar)	Leptospirosis (Leptospira Interrogans)
Anaplasmosis (Anaplasma phagocytophilum) Arboviral disease	Listeriosis (Listeria monocytogenes) Lyme disease (Bornelia burgdorferi and other Bornelia spp.)
Borketing but not limited to 1a Crosse encenhalitis eastern equine	tyme disease (Borrelio burgdorferr and other Borrelio spp.) Malaria (Plosmodium spp.)
encephalitis, western equine encephalitis, St. Louis encephalitis, West Nile virus disease, Powassan virus disease, and Jamestown Canyon virus disease)	Meningitis (caused by viral agents)
Babesiosis (Bobesia spp.)	Mumps () Neonatal sepsis ()
Blastomycosis (Blastomyces dermatitidis) Campylobacteriosis (Campylobacter spp.)	(bacteria isolated from a sterile site, excluding coagulase-negative Stophylococcus) less than seven days after birth
Condida auris 🕦*	Stophylococcus) less than seven days after birth Pertussis (Bordetello pertussis)
Carbapenem-resistant Enterobacteriaceae (CRE)	Psittacosis (Chlamydophila psittaci)
Carbapenem-resistant Acinetobocter boumonnii ()* Cat scratch disease (infection caused by Bortonello species)	Retrovirus infections Salmonellosis, including typhoid (Solmonello spp.)
Chancroid (Hoemophilus ducreyi)	Shigellosis (Shigella spp.)
Chikungunya virus disease Chiamydia trachomatis infections	Spotted fever rickettsiosis (Rickettsia spp. infections, including Rocky Mountain spotted fever)
Coccidioidomycosis	Staphylococcus aureus
Coronavirus Disease 2019 (COVID-19)/SARS-CoV-2()*	(only vancomycin-intermediate Staphylococcus aureus [VISA], vancomycin resistant Staphylococcus aureus [VRSA], and death or critical illness due to
Cronobacter soluziokii in infants under one year of age Cryptosporidiosis (Cryptosporidium spp.)	community-associated Staphylococcus aureus in a previously healthy indiv
Cyclosporiasis (Cyclosporg spp.)	Streptococcal disease - invasive disease caused by Groups A and B streptoc and S. pneumonide()
Dengue virus infection Diphyliobothrium latum infection	Streptococcal disease - non-invasive 5. pneumonige
Ehrlichiosis (Ehrlichig spp.)	(urine antigen laboratory-confirmed pneumonia) Syphilis (Treponemo poliidum)
Encenhalitis (caused by viral agents)	Tetanus (Clostridium tetani)
Enteric Escherichia coli infection () (E. coli 0157:H7, other Shiga toxin-producing E. coli, enterohemorrhagic E. coli, enteropathogenic E. coli, enteroinvasive E. coli, enteroaggregative	Taxic shock syndrome () Taxoplasmosis (Taxoplasma gondi)
E. coli, enteropathogenic E. coli, enteroinvasive E. coli, enteroaggregative E. coli, enterotoxigenic E. coli, or other pathogenic E. coli)	Transmissible spongiform encephalopathy
Giardiasis (Giordio intestinolis)	Trichinosis (Trichinella soiralis)
Gonorrhea (Neisseria gonorrhoeae infections)	Tuberculosis (Mycobacterium tuberculosis complex) (pulmonary or extrapulmonary sites of disease, including clinically diagn
Hoemophilus influenzae disease (all invasive disease) () 🕓 Hantavirus infection	disease). Latent tuberculosis infection is not reportable.
Hepatitis (all primary viral types including A. B. C. D. and E)	Typhus (Rickettsia spp.) Unexplained deaths and unexplained critical illness
Histoplasmosis (Histoplasma capsulatum) Human immunodeficiency virus (HIV) infection.	(possibly due to infectious cause)
including Acquired Immunodeficiency Syndrome (AIDS)	Varicella (chickenpox) () Vibrio spp. ()
Influenza (unusual case incidence, critical liness, or laboratory-confirmed cases)	Yellow fever
Kawasaki disease	Yersiniosis (enteric Yersinia spp. regardless of specimen source) () Zika virus disease ()
Kingella spp. (Invasive only)	Zika virus disease ? Zoster (shingles) () (all cases <18 years old; unusual case incidence/complications regardless (
Leprosy (Hansen's disease) (Mycobacterium leprae)	(all cases <18 years old; unusual case incidence/complications regardless
SENTINEL SURVEILLANCE	FOOTNOTES
Diseases reportable through sentinel surveillance are reportable based on the residence of the patient or the specific health care facility. Sentinel surveillance is not statewide reporting.	O submission of clinical materials required. Submit isolates or, if an isolate is available, submit material containing the infectious agent in the following of
	of preference: a patient specimer; nucleic add; or other laboratory materi Call the MDH Public health Laboratory at 651-201-4953 for instructions.
Candidiasis (all invasive disease)	Call the MOR Public Reach Laboratory at 651-203-4953 for instructions. (i) Invesive disease only: isolated from a normally sterile site (e.g., blood, CSF.)
Clostridioides (Clostridium) difficile () Escherichio coli (all invasive disease) ()	fuld).
Stophylococcus aureus (all invasive disease)	In the event of SARS or another severe respiratory outbreak, also report ca of health care workers hospitalized for pneumonia or acute respiratory dis
Respiratory syncytial virus (RSV) Nontuberculous Mycobacteria (NTM), pulmonary and extrapulmonary	syndrome.
contract of the second second participation of a second seco	Also report a pregnancy in a person with Zika; or a person chronically infec with hepatitis 8, HIV, or wohilis.
	 Reportable under the Minnesota Communicable Disease Rules, Chapter 4605-7080 (new disease and syndromes).
DEBARTMENT	
DEPARTMENT OF HEALTH	
O O O O OF HEALIH	TO REPORT
	 For immediate reporting call: 651-201-5414 or 1-877-676-5414.

Next steps

- Determine time points we will be collecting data
- Determine variables we are interested in collecting
- Build database to store the data



Data collection points

- Data abstraction at 6 months those with incomplete short term follow up
 - 20 cases did not complete all elements of diagnostic evaluation
 - Only collecting data not found during short term follow up
- Data abstraction for all cases begin after 1 year start March 2024
- Infant follow up time points requested by CDC SET-NET
 - 2m, 6m, 12m, 18m, 24m, 3years
 - Tentative plan request and abstract data at 15months, 27months, and >3years



Data Elements

- Still finalizing data elements that we will collect
 - Will bring to cCMV consortium for input
 - CDC SET-NET contacts



Proposed Longitudinal Data Elements

- Mortality and cause of death, if known
- Primary and/or condition-specific health care status
- Comorbidities
- Condition specific treatment
 measures (e.g. length of antivirals)
- Hearing status
- Vision status
- Maternal/pregnancy data

- Developmental status
- Referral for developmental delay/concerns or receiving developmental services
- Referral to early intervention
- Educational status
- Currently reviewing SET-NET data dictionary for additional elements to include

Data Sources

- Vital Records
- Medical Records
- Exploring additional data sources
 - Case report forms
 - Family interviews
 - Educational data
 - Maternal pregnancy records



QI project



20

Database

- MDH uses MEDSS for most surveillance programs across the department
- MEDSS is a person centric disease surveillance system
 - Interoperable with newborn screening
 - Able to receive electronic lab reports from private labs throughout the state
- While starting our cCMV surveillance, will use REDCap rather than MEDSS
 - Can build quickly and make changes easily; no informatics or IT support required
 - Will have reports that can easily be imported into MEDSS
- Will eventually transition into MEDSS
 - Used by LFU surveillance/follow up, as well as most other MDH programs



Minnesota Department of Health

Electronic Disease Surveillance System Terms and Conditions of Use. By logging on to the Minnesota Electronic Disease Surveillance System (MEDSS) you

are acknowledging that you are an authorized representative of either the Minnesota Department of Health (MDH) or one of its stakeholders, that you are bound to comply with the agreement signed between MDH and the organization to which you belong, and that you will abide by Minnesota Statutes Chapter 13 and the Minnesota Government Data Practices Act.

If you do not agree to be bound by the terms and conditions, promptly exit this application.



Challenges

- CSTE Case definition was just approved
- Newborn screening and surveillance case definitions are not the same
- Understanding developmental status is difficult only source is health records
- Don't currently have access to all medical records
- Finding mom's record might be challenging
- People move, making it hard to find records





Questions?



health.mn.gov/CMV



Thank You

Gina Liverseed

gina.liverseed@state.mn.us

Lexie Barber

lexie.barber@state.mn.us