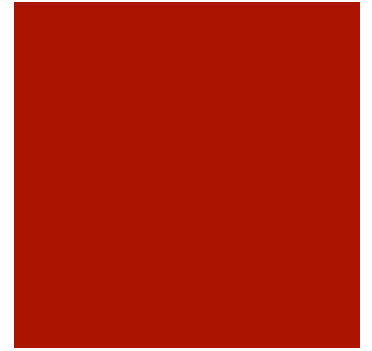


From Public Health Concern to Law: The Legislative Process



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Utah Department of Health

Public Health Concerns



- Access to quality healthcare
- Autism
- Brain Injury and concussions
- Behavioral health
- E-cigarettes
- Congenital Cytomegalovirus



What is Congenital CMV?





H.B. 81 – Cytomegalovirus Public Health Initiative

Utah Legislature – 2013 General Session

CYTOMEGALOVIRUS PUBLIC HEALTH INITIATIVE

2013 GENERAL SESSION

STATE OF UTAH

Chief Sponsor: Ronda Rudd Menlove

Senate Sponsor: Curtis S. Bramble

LONG TITLE

General Description:

This bill amends the Utah Health Code and directs the Department of Health to establish a public education program regarding the impacts and dangers of congenital cytomegalovirus (CMV) infection and the methods of prevention of CMV infection.

Highlighted Provisions:

This bill:

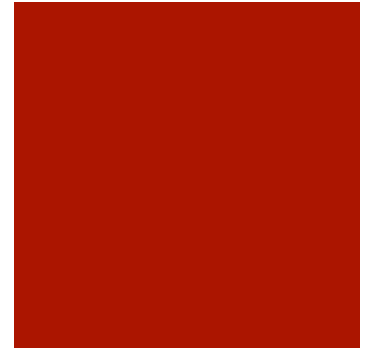
- directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;
- requires the Department of Health to provide this information to:
 - licensed child care programs and their employees;
 - health care facilities licensed pursuant to Title 26, Chapter 21, the Health Care Facility Licensing and Inspection Act;

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1. Directs the Department of Health to create a public education program to inform pregnant women and women who may become pregnant about the occurrence of CMV, the transmission of CMV, the birth defects that CMV can cause, methods of diagnosis, and available preventative measures;

H.B. 81 – Cytomegalovirus Public Health Initiative



2. Requires the Department of Health to provide this information to:
 - Licensed child care programs and their employees;
 - Health care facilities
 - Child care programs
 - School nurses
 - Health educators
 - Health care providers offering care to pregnant women and infants
 - Religious entities providing informal childcare

H.B. 81 – Cytomegalovirus Public Health Initiative



3. Directs medical practitioners to test infants, who fail the newborn hearing screening test(s), for CMV and inform the parents of those infants about the possible birth defects that CMV can cause and the available treatment methods
4. Directs the Department of Health to notify medical practitioners of the CMV testing requirements



Funding for H.B. 81



- One-time funds
- \$4,000 (2013)
- Ongoing funds
- \$30,800 (2013)
- \$40,000 (2014)
- Multiple year requests
- Required coordination between the Department of Health and the Legislature

H.B. 81 – Essential Collaborators

- Department of Health
- Medical Professionals
 - CMV Researchers
 - OB/GYNs
 - Pediatricians
 - Audiologists
- Higher Education
- NCHAM
- Legislature
- Parents

UTAH DEPARTMENT OF
HEALTH



UtahStateUniversity



**Intermountain
Primary Children's Hospital**

The Child First and Always®



THE
**UNIVERSITY
OF UTAH**

NCHAM
National Center for Hearing
Assessment and Management
Utah State University™



Implementation of H.B. 81



- The signing of the bill is just the beginning
- Leadership of state agencies and universities
- Advocacy work
- Follow through by all partners
- Collaboration is key to success

Working with the Executive Branch Health Agency



■ Utah Department of Health

- 130 programs
 - Mostly funded by federal grants (CDC, FDA, CMS)
 - Targeted programs for chronic diseases, epidemiology, child care, emergency medical, facility licensing, laboratory, maternal & child health...
 - Tobacco prevention, Diabetes, Arthritis, Cancer prevention, heart disease/stroke, WIC, Medicaid, etc.
 - Employees are funded by the programs/grants
 - Agency has no resources for unfunded/statutorily required programs

How to Interact with the Agency to Implement a New Health Program



- Route #1: Get the Agency to make a proposal for a new program
- Making the case for a new health program
 - Make a compelling policy case
 - Will rely on the agency to make the arguments to the Legislature
 - Counter negative policy arguments
 - Funding proposal
 - How will you pay for the people, facilities needed to operate the program?

Agency Budget Process



- Budget requests from all parts of the agency
- Prioritization
 - the proposal must compete against other priorities within the Department - mandatory, public health and safety, funding from fees/grants/appropriations
- Governor's budget (competition with all other agencies)
- Legislative budget process (Appropriations Subcommittee, Executive Appropriations Committee, Appropriations Act)

Make a Compelling Policy Case



■ Critical Policy Case

- Evidence based information on the effectiveness of the proposal
- Impact on vulnerable groups (children, disabled, elderly)
- Use actual experience or stories of affected population

■ Financial feasibility

- Show the cost-benefit of the proposal

■ Consider the Politics

- Justify why the government should be the principal actor
- Is there support/opposition the agency should be aware of?

Make a Compelling Policy Case



- Counter Negative arguments
 - Anticipate objections
 - Dispel myths
 - Difficulty treating the infection
 - Celebrate success stories and number of children helped
 - Contact other specialists to monitor the child (hearing, vision, brain function)
 - Prevent transmission
 - Restrict progression through anti-viral treatment
- Address every objection (hopefully before they are made in public)

Make a Compelling Policy Case



- How do you propose funding the proposal?
 - Grant
 - Fees
 - Private contribution
 - Appropriation
- Is the service cost effective?
- Why would this proposal deserve to be funded more than other options being considered by the legislature?

Make a Compelling Policy Case



■ Coalition

- Prepare a respected champion (usually a legislator)
- Bring diverse support together
 - White coats, parents, providers of children's healthcare
- Address the interests/needs of each coalition member (determine if they are appropriate in the coalition or too costly)
- Cultivate an unexpected supporter (Nixon going to China – opposite of expected ideology)

Alternate Routes



- Route #2: Get the Governor to include a new item in the Governor's Budget
 - Directly contact the Governor's Office (by-passing the agency)
 - Not recommended if the Agency does not support the proposal
 - Governor's budget is a starting point for the legislative budget process

Alternate Routes



- Route #3: Get the Legislature to include a new program in legislative appropriations
 - Through legislation (with a fiscal note)
 - Through the appropriations committee
 - Through committee chairs
 - Legislative Champion to make request of the Committee

Overcoming Opposition



- Role of lobbyists and advocates
- Opposition from the Utah Medical Association
- Compromise, amendments, substitute bills
- Moved lead responsibility for follow up with failed hearing assessments to Department of Health in collaboration with medical providers

Overcoming Opposition



- Late session letter opposing legislation from Utah Chapter of the American Academy of Pediatrics
- Delivered during last vote on the bill in the Senate after unanimous votes in House and Senate committees and in floor votes
- Recently published letter criticizing what some see a mandate to tell parents about “available treatments methods”
- Will there be future legislation amending or repealing the provisions of Utah CMV law?

Proposed Legislation in Other States



- Is the Utah CMV legislation and budget success replicable in other states?
- How can proponents increase the likelihood of passing legislation and securing funding?
- Coalition building and preparation
- Strategies for addressing opposition
- Legislation being discussed or moving forward in Connecticut, Illinois, Ohio, Texas

Impact of H.B. 81

- CMV awareness
 - Legislature
 - News/media
 - Required Education
- Individual child and family impact
- Early identification and access to early intervention
- Parents have options



Questions

