

# Reducing congenital cytomegalovirus infection through policy and legislation in the United States



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**Policy and legislation, backed by accurate science, are viable tools to change behaviour to reduce congenital cytomegalovirus (CMV) infections. Addressing CMV through public policy can provide increased awareness among public health officials, access to existing venues for disseminating information, and much needed funds for awareness campaigns. While some medical professionals and CMV experts oppose public policy and legislation mandating medical practice, most support policies aimed at public education campaigns to provide consumers with accurate CMV education.**

## Changing behaviour through public policy

A woman's risk of becoming infected with CMV and transmitting CMV to her unborn child can be reduced when she practices hygienic precautions<sup>1-4</sup>. However, in the United States, only 13% of women are aware of CMV and only 44% of OB/GYNs counsel women about CMV and prevention measures<sup>5,6</sup>. This article explores the feasibility of increasing CMV awareness and prevention through public policy measures.

There are several policy strategies to promote healthy behaviours<sup>7</sup>. Strategies include:

- Providing information about the desired behaviour (point-of-decision prompts, mass media campaigns).
- Offering incentives/disincentives for behaviour (tax deductions, vouchers).
- Requiring/prohibiting behaviour (vaccinations, screenings).

The behavioural change theory that underlies most public policy is the rational choice model. People assess the choices before them in terms of costs and benefits and then select the choice that

maximises their net benefits<sup>8</sup>. Incentives and disincentives can be very effective. Taxes on plastic bags have been extremely successful, leading to a 90% reduction in the consumption of plastic bags in Ireland<sup>9</sup>. Reports from the World Bank show that increasing taxes on tobacco sales is the single most important step governments can take in reducing smoking<sup>10</sup>.

Governments also provide information to citizens to modify behaviour using the underlying assumption of the rational choice model: if people know that a behaviour and/or activity has adverse consequences they will reduce its incidence or eliminate it. Examples include tackling drinking and driving, HIV, drugs, child safety and smoking<sup>8</sup>.

Public policy also addresses public health issues through required actions. These include required and recommended screening panels conducted for each newborn, regulated by countries, hospitals and clinics, and by each State in the United States.

One public health issue successfully addressed through public policy and legislation is the timely identification of childhood hearing loss. In 1988, the average age in the United States for the identification of hearing loss in children was 2.5 years.<sup>11</sup> As a result of the introduction of the newborn hearing screening, the average age of diagnosis was reduced to 3.9 months.<sup>12</sup>

One of the major contributors to such a dramatic shift in newborn care practice was state-based legislation (Table 1). In 1993, 3% of United States infants were tested for hearing loss at birth. By 2001, 80% were screened<sup>13</sup>.

## Utah's CMV public health initiative

In March 2013, the State of Utah passed a 'Cytomegalovirus Public Education and Testing' law requiring a CMV public health initiative. This law<sup>14</sup> requires:

- (1) The Utah Department of Health to establish and conduct a public education program to inform pregnant women and women who may become pregnant regarding the incidence of CMV; the transmission of CMV to pregnant women and women who may become pregnant; birth defects caused by congenital CMV; methods of diagnosing congenital CMV; and available preventative measures.
- (2) The Department of Health to provide the information to: child care programs; school nurses; school health education

Table 1. Evolution of newborn hearing screening in the United States.

1970	Not recommended, no viable test
1989	Rhode Island Demonstration Project screened 1850 babies
1990	First State law requiring Newborn Hearing Screening in Hawaii
1992	Second State law in Mississippi
1993	Three additional State laws passed; 3% of infants screened
1993 and 1996	Federal grants funded by the US Government to assist hospitals and states to implement Newborn Hearing Screening
1998	712 US Hospitals conducting Newborn Hearing Screening
1999	National Early Hearing Detection and Intervention (EHDI) program established by the US Congress
2001	All 50 States have EHDI programs; 80% of infants screened
2006	Hearing included on the Recommended Universal Screening Panel

Data obtained from <http://infanthearing.org/legislation/>

providers; health care providers offering care to pregnant women and infants; and religious, ecclesiastical, or denominational organisations offering children's programs as a part of worship services.

- (3) If a newborn infant fails the newborn hearing screening test(s) a medical practitioner shall:
- test the newborn infant for CMV before the newborn is 21 days of age, unless a parent of the newborn infant objects; and
  - provide to the parents of the newborn infant information regarding birth defects caused by congenital CMV and available methods of treatment.

Utah's law accomplishes two main objectives that will lead to reduction of CMV infections in mothers and infants. First, it establishes the Utah Department of Health as an authority on CMV and requires the Department to make information available to the public and professionals. The law makes it more likely that women in Utah will receive accurate information about CMV and how to prevent it. The law also contained a fiscal note, dedicating US\$30 000 each year to the CMV public education program.

Utah's law requires CMV testing of infants who fail the newborn hearing screening. By requiring an action on behalf of the parents and the medical provider, the initiative creates additional awareness of CMV, which will lead to CMV prevention as well as appropriate and timely interventions (medical and therapeutical including speech therapy, occupational therapy and physical therapy).

Utah's CMV public health initiative has provided for advertisements in and on public transportation, in publications, and on social media to reach pregnant women and women who might become pregnant. Examples of their outreach can be found on their website, <http://health.utah.gov/cmv>, and their Facebook page: <https://www.facebook.com/CMVUtah>.

## Other CMV legislation in the United States

Following Utah's successful legislation, five additional states have pursued legislation. Four passed legislation in 2015.

- Connecticut passed legislation in 2015 that does not include a public education program, but requires CMV testing for all infants failing the newborn hearing screening<sup>15</sup>.
- Tennessee's legislature did not pass proposed legislation that mirrored the Utah law. Department of Health and medical association officials testified against the legislation<sup>16</sup>.
- Hawaii passed legislation in 2015 requiring a public education program<sup>17</sup>.
- Illinois passed legislation in 2015 requiring a public education program and CMV testing for infants who fail the newborn hearing screening<sup>18</sup>.
- Texas passed legislation in 2015 requiring a public education program<sup>19</sup>.

Parents and professionals have expressed interest in pursuing legislation in additional states in 2016 (personal communication, January to June 2015). It is not unrealistic to expect CMV legislation to be implemented in each of the United States within the next five to eight years.

One key to the successful CMV legislation in Utah was the partnership between policymakers, CMV experts and medical professionals, and advocates including parents and other family members impacted by CMV<sup>20</sup>. Without the input and advice of similar partners in other states including CMV experts and medical professionals, I anticipate it will be difficult to both pass and implement legislation.

## Global CMV policy survey

In 2015, 30 medical professionals with experience studying or treating CMV experts from 24 countries participated in an online survey to assess consensus on statements related to support for potential CMV public health policy. Participants were recruited from participant lists from international CMV conferences and through recommendations from other professionals (S. Doutré and J. Greenlee, unpublished data).

Most CMV experts surveyed support government (74%) or professional (90%) policy requiring pregnant women or women who may become pregnant be counselled about CMV. Experts report they would support government (58%) or professional (58%) initiatives requiring screening of newborns for CMV. If these experts serve as

quality sources of information to policymakers and public health implementation personnel, such policy will serve as an effective tool in increasing CMV education, awareness and prevention.

## Conclusion

While not a singular solution to CMV prevention, public policy can be a tool to increase awareness and prevention by both disseminating accurate information and requiring action by way of CMV testing. Increased agency attention, including via funding, to CMV will increase awareness and education among pregnant women, which may lead to reduction of congenital CMV. In the United States, five states have enacted CMV legislation requiring public education programs, targeted CMV testing or both. I anticipate the number to continue to increase with the support of CMV experts.

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## Biography

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