

Cytomegalovirus Action - CMV Public Health and Policy Advocacy





My CMV Story



Learning Objectives

- Identify key stakeholders for raising CMV awareness through education or screening
- Develop appropriate CMV educational messages for identified target populations
- Learn about existing resources available to help pass legislation and implement educational campaigns and provide examples of successful efforts

What is CMV?

CMV is short for **cyto-megalo-virus**

CMV is common



1 in 150
children are born
with congenital CMV

**Most common virus
transmitted from a
pregnant woman to
her unborn child**



1 in 3

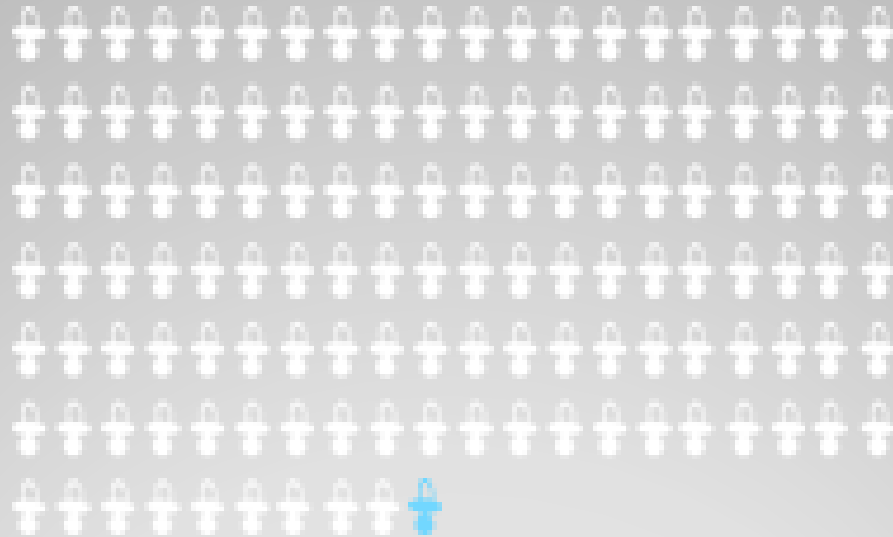
**pregnant women
who get CMV will
pass the virus to
their unborn child**



**More common
than the 29 combined metabolic and
endocrine disorders in the recommended
US newborn screening panel**

CMV = Cytomegalovirus

- Most people who contract CMV will have no symptoms and may not even know that they have been infected
- If a woman gets CMV while she is pregnant, it can cause disabilities in the baby, which is called congenital CMV (cCMV)
- *Many women transmit CMV to unborn babies during a reactivation or infection despite having had CMV in the past*



1 in 200
children are born with
congenital CMV each year

Incidence of CMV

- 30,000 children are born with CMV each year in the U.S.
- Congenital CMV is more common than Down Syndrome, Fetal Alcohol Syndrome, Spina Bifida, and Pediatric HIV/AIDS
- *One study found CMV-positive women were almost 7-times more likely to have a miscarriage than were CMV-negative women*

CMV is short for **cyto-megalo-virus**

CMV is serious

Leading non-genetic
cause of childhood
hearing loss



Every hour, 1 child
is permanently
disabled by CMV



CMV also causes:

Vision loss

Mental disability

Microcephaly

Cerebral Palsy

Behavior issues

Seizures

90%
of babies born
with CMV will
appear healthy
at birth

400
children die
from CMV
every year

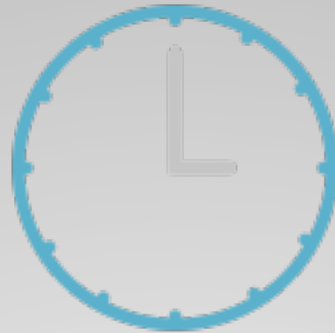


Scientific
research
has found
a connection between
CMV and miscarriage

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FOUNDATION

Babies born with CMV

- Congenital CMV causes hearing loss, vision loss, cerebral palsy, mental and physical disabilities, seizures, and death
- CMV is the leading non-genetic cause of childhood hearing loss
- CMV can cause symptoms when the baby is born or later in the baby's life, long after congenital CMV can be diagnosed by blood lab
- *Half of children with CMV-related hearing loss will have a progressive loss*



1 child

is permanently disabled by
congenital CMV every hour

Congenital CMV Spectrum

Born symptomatic			Born asymptomatic		
Death Miscarriage, stillbirth, infant or child loss	Medically fragile Cerebral palsy, Seizures, Failure to Thrive, Hearing loss, Vision loss	Multiple impairments Cerebral palsy, Vision loss, Hearing loss	Developmental delays Cognitive delays, Learning issues, Feeding and sleeping issues, Vision loss, Hearing loss	Hearing loss Hearing aids, Cochlear implants, Communication and learning issues, Mild vision disorders	None No visible delays or impairments
Severe		Moderate		Mild	

CMV Testing and Treatments

- Pregnant women are not routinely screened for CMV
 - Phase 3 trial of CMV hyperimmune globulin (Cytogam)
- Newborns are not routinely tested for CMV after birth
 - CMV can only be accurately diagnosed less than 2-3 weeks after birth
 - After 3 weeks, baby could have contracted CMV through nursing, exposure to siblings or others who may be shedding CMV
- *States are piloting projects, passing legislation to screen for CMV in newborns who refer*

CMV Vaccines

- In 1999, a CMV vaccine was assigned the highest priority for vaccine development by the Institute of Medicine, along with the flu vaccine
- CMV vaccines are still in the research and development stage
 - Phase 1 candidates - 10
 - Phase 2 candidates – 2
 - Phase 3 candidates – pending
- *Industry cites a lack of CMV awareness for vaccine delay*

CMV is short for **cyto-megalo-virus**

CMV is preventable



Pregnant women who already have young children, or who work with young children, are at highest risk of catching CMV

CMV is found in home and daycare settings



Avoid contact with saliva - Kiss kids under the age of 6 on the forehead instead of lips or cheek



75%
of toddlers have CMV in their urine or saliva in studies at child-care settings



Wash your hands after contact with bodily fluids of kids under the age of 6



Don't share utensils, drinks, or toothbrushes with kids under the age of 6

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How can you catch CMV?

- Up to 70% of healthy children between 1 and 3 years of age may have CMV
- CMV is spread through saliva, urine, tears, blood, mucus, and other bodily fluids
- CMV poses a major risk to pregnant women, especially mothers, daycare workers, preschool teachers, therapists, and nurses
- *CMV can live for 5 minutes in a cracker, 15 minutes on plastic, and 15 minutes on hands*

Reducing Risk of CMV

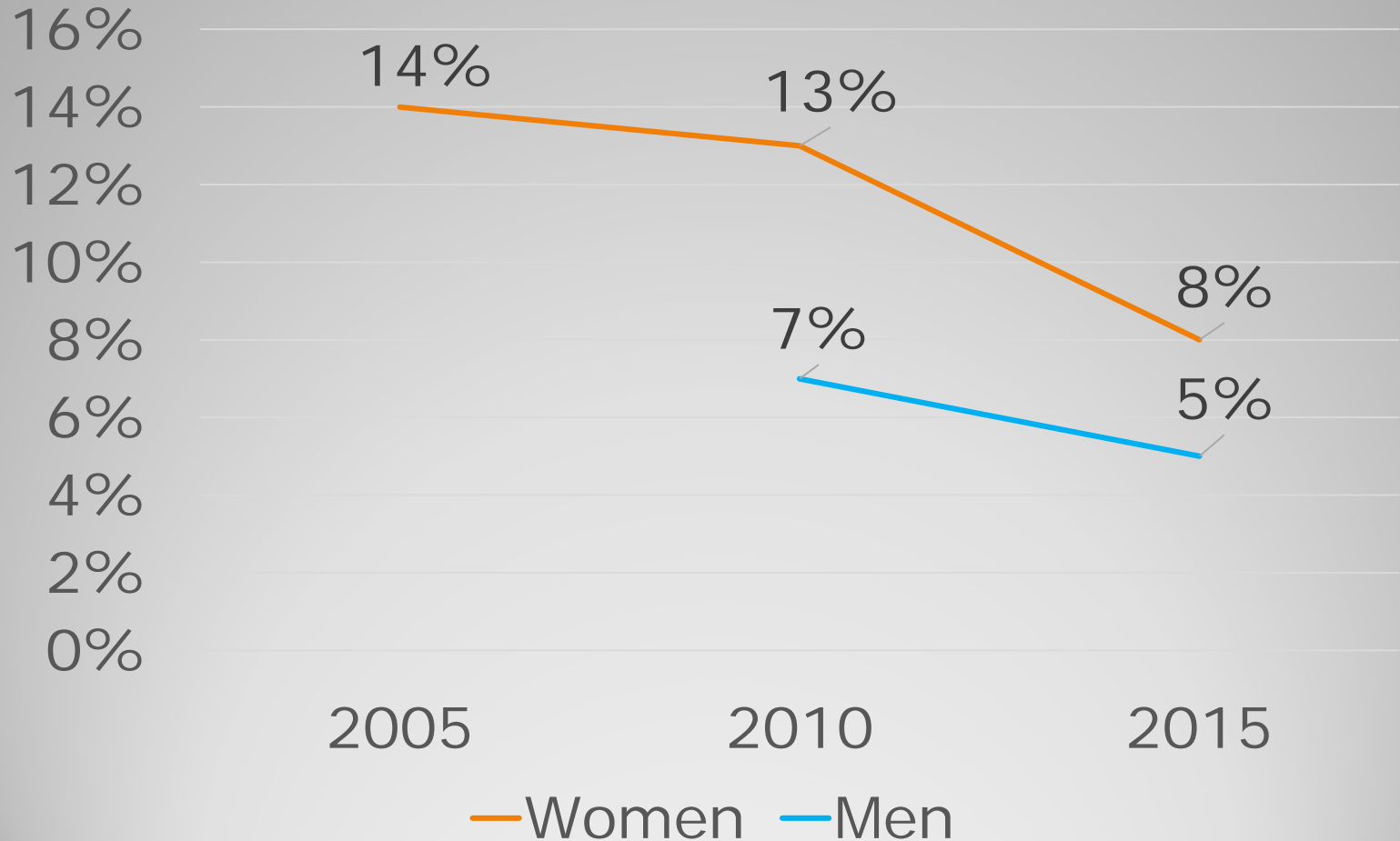
- Wash your hands with soap and water, especially after changing diapers or touching saliva or nasal secretions from a baby or young child
- Avoid kissing babies and young children on the mouth
- Do not share food, drinks, utensils or toothbrushes with babies or young children
- 50-60% of women are at risk for contracting CMV while pregnant
- *"Healthy" children who acquire CMV exhibit no symptoms, can actively shed CMV for years*

CMV Awareness

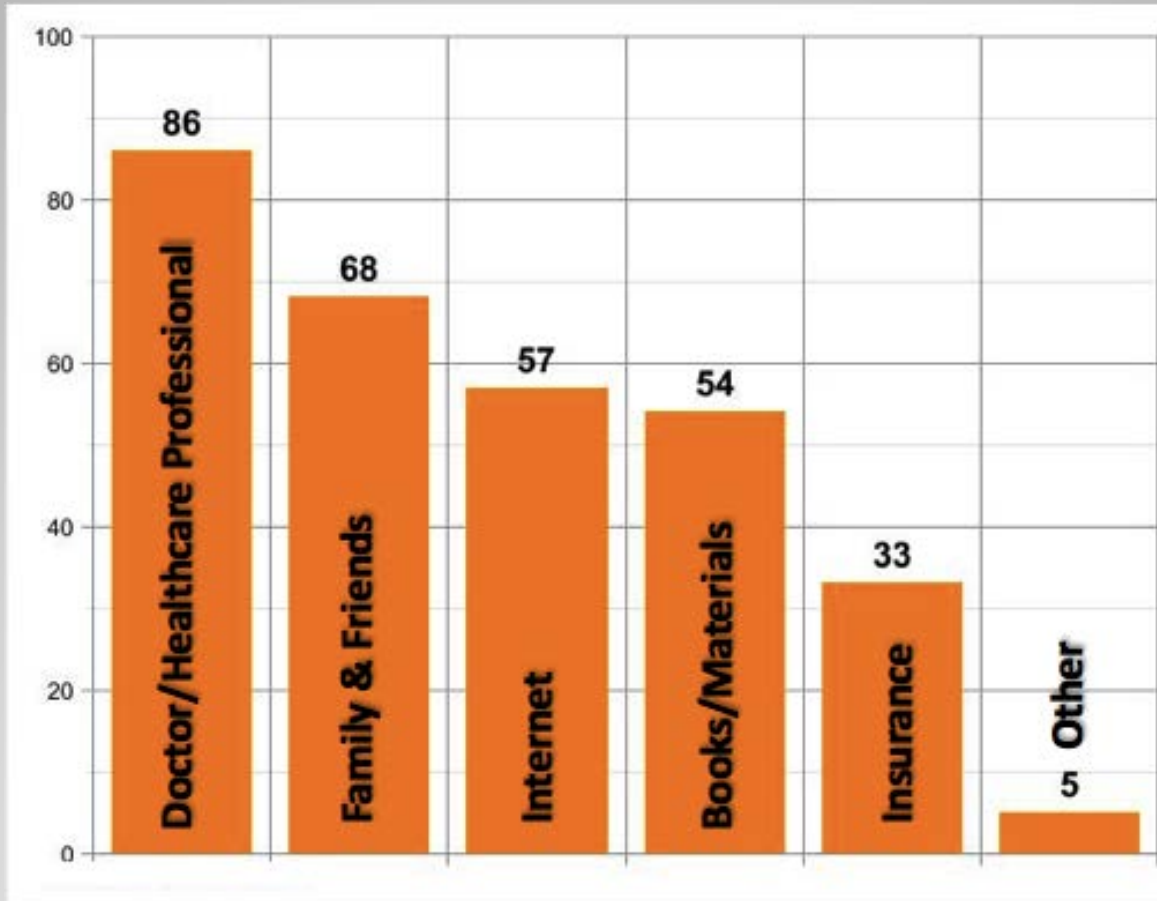
CMV Awareness Research

- HealthStyles TM 2005 (Ross et al., 2008)
 - N=2,656 Women, mailed survey
 - 14% had heard of CMV
- HealthStyles TM 2010 (Cannon et al., 2012)
 - N=4,184 Women and Men, mailed survey
 - 13% of women had heard of CMV
 - 7% of men had heard of CMV
- HealthStyles TM 2015 (Doutre et al., 2016)
 - N=4,127 Women and Men, mailed survey
 - 8% of women had heard of CMV
 - 5% of men had heard of CMV

CMV Awareness Trending



Health Information Preference



What is being done about CMV?

Karen Fowler, UAB

Kim Hill, NC

National CMV Foundation and State Partnerships



ARE YOU PREGNANT?

Learn how to protect your unborn baby from CMV (cytomegalovirus), the leading viral cause of birth defects and developmental disabilities. CMV can result in hearing loss, vision loss, and cerebral palsy.

CMV is an often symptomless virus that is spread through saliva, mucus, and urine. Healthy babies, toddlers, and young children can get CMV from their peers and pass it to their pregnant mother.

Tips to protect yourself and your unborn baby from CMV:

- When you kiss a young child, try to avoid contact with saliva. For example, you might kiss on the forehead or cheek rather than the lips.
- Do not put things in your mouth that have just been in a child's mouth, including food, cups, forks or spoons, and pacifiers.
- Wash your hands after wiping a child's nose or mouth and changing diapers.

Learn more at: www.NationalCMV.org



ESTAS EMBARAZADA?

Aprenda como proteger a tu bebe aun sin nacer de el CMV (citomegalovirus), que es el primer virus que causa el mayor numero de defectos al nacer y discapacidades en el desarrollo, incluyendo perdida auditiva (sordera), perdida de la vista (ceguera) y parálisis cerebral.

El CMV es comúnmente un virus sin síntomas que se transmite a través de la saliva, mucosidades y orin. Los bebes Sanos, niños en edad pre-escolar pueden contraer el virus de otros niños de su edad y contagiar a su madre embarazada.

Algunos consejos para protegerte a ti misma y a tu bebe aun no nacido del CMV:

- Cuando estés en contacto con un niño pequeño, evita el contacto salivar. Por ejemplo, podrías besar en la mejilla o en la frente en lugar de la boquita del pequeño.
- No tomes cosas con la boca que hayan tenido contacto con la boca de algún pequeño incluyendo, comida, cubiertos, vasos o chupones.
- Lavate las manos después de limpiar mucosidades del pequeño (nariz o boca) y después de cada cambio de pañal.

Obtenga más información en www.NationalCMV.org



CMV legislation – 2011

- United States Senate (Res 215)
 - Designated the month of June as “National Cytomegalovirus Awareness Month” in order to raise awareness of the dangers of Cytomegalovirus (referred to in this resolution as “CMV”) and reduce the occurrence of congenital CMV infection
 - Recommended that more effort be taken to counsel women of childbearing age of the effect that CMV can have on their children

CMV legislation - 2013

- Utah (HB 81)
 - Directed DOH 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.
 - Directed medical practitioners to test infants who fail newborn hearing screening for congenital CMV and inform the parents about the possible birth defects that CMV can cause.

CMV legislation - 2015

- Connecticut (HB 5525)
 - CMV screening with newborn hearing screen fail
- Hawaii (HB 782)
 - Public education program
- Illinois (HB 184)
 - Public education program
 - CMV screening with newborn hearing screen fail
- Texas (SB 791)
 - Public education program

CMV legislation - 2016

- Tennessee (SB 2097)
 - Healthcare provider educates at-risk patients

CMV legislation - 2017

- Idaho (S1060)
 - Public education program
- Iowa (SF51)
 - Public education program
 - CMV screening with newborn hearing screen fail
- Maine (LD 87, SP 36)
 - Established a workgroup
 - Report released January 2018
- Oregon (HB 2754)
 - Public education program
 - CMV screening with newborn hearing screen fail

CMV legislation – 2018

- Minnesota (HF 2653 - proposed)
 - Public Education Program
 - Recommendation to consider testing
- California (AB 1801 – proposed)
 - Public Education Program
 - Universal Newborn Screening
- New York (S2816 – proposed)
 - Public education program
 - CMV screening with newborn hearing screen fail

EHDI case study - UT

- Overview - Cytomegalovirus (CMV) public education and testing – legislation with multiple components
 - Public education program to inform pregnant women and women who may become pregnant about CMV
 - Provide information to various groups
 - CMV screening if a newborn infant fails the newborn hearing screening test(s)
- Accomplishments – logo, website, brochures, posters, forms, promo materials, online training modules, mini-documentary, PSAs, social media properties, focus groups, grand rounds, national/state/local presentations, bus/train ads, etc.

EHDI case study - CT

- Overview
 - Newborns who fail a newborn hearing screening are provided a screening test for CMV as soon after birth as is medically appropriate
 - Requires reporting of any case of CMV that is confirmed as a result of this screening to DOH
- Accomplishments
 - Survey assessment of hospital practices
 - EHDI developed resources
 - Added reporting fields to existing Newborn Screening System (EHDI database)
 - EHDI staff responding to numerous inquiries as hospitals revise their internal policies and procedures

EHDI case study - MN

- Overview - MN “Universal Project”
 - Year 1 - Universal testing (consented), methodology & sample comparisons, “Just in time” fact sheet development (parent/provider)
 - Year 2 - Expansion to additional site/s & initiation of general population education efforts
- Goals - Parental acceptance of universal screening, methodology comparison, 2 labs testing dried blood spots (DBS), different methodologies (CDC vs UMN)
- Accomplishments
 - IRB approval from all institutions secured
 - Enrollment has begun
 - Educational information developed

EHDI case study - MI

- Overview - Current scope: Public awareness and professional education, parent story
- Accomplishments - Strategic Plan
- Vision - A new CMV education and screening process for maternal/child healthcare Michigan
- Areas of Focus -
 - Outreach & Awareness
 - Education and Training
 - Access
 - Data & Evaluation

What can you do about CMV?

Public Health Campaigns

- 3 overarching questions of public health campaigns
 - How much funding do you have?
 - What is your capacity?
 - Length (time) of the campaign?



Target Audience – “Who?”

- Considerations: Health needs, resources, demographics, and size of community
- Segment further by:
 - Identifying wants and needs of the segment (what do they like, dislike, fears etc.)
 - Factors that influence their behavior (benefits, barriers, and readiness to change) (review stages of change)
- Include a representative from the target audience in your planning process!

Product – “What?”

- The product may be the idea or behavior change (e.g., educational program, screening, environmental change, self-care programs)
- What is your ask (product)? Must be well defined
- Tailor your ask to your target population

Price – “How Much?”

- Time
- Cost - money, opportunity, energy, social, behavior, geographic structural, or psychological factors
- Barriers that may prevent the consumer from taking action.
- Is there an exchange?
- Is there a benefit?

Place – “Where?”

- Place is where the product can be obtained
 - Ways to reach the consumer and make product available
 - Where consumer puts motivation into action
- What communication channel/s does your target population use?
 - Newspaper, radio, TV, Internet, Social Media
- Does not need to be \$\$\$
- Is your message time sensitive?
- Is your message on-going?

Promotion – “How?”

- Encompasses communication strategies and tactics used to communicate with consumer
- Select effective and efficient methods of reaching target audience
- Make content unique for the platform
 - Use personal stories
 - Help your audience visualize the impact
 - Go to where the conversations are & engage
 - Retweet and use #hashtags

Pilot

- Test! Test! Test!
- Don't develop your campaign in a vacuum
- Iterate as you develop materials and messaging
- Present key elements to get feedback and make modifications
 - Methods
 - Communication
 - Strategies to members of target population
- How big should your pilot be?
- What should be piloted?

**Let's get
to work!**

CMV Social Media Marketing Plan



Target Audience (Who)

Consider: Health needs, resources, demographics, and size of community.

Product (What)

Consider: If your product is an idea, core product, actual product, or a tangible item.



Price (How Much)

Consider: Time, cost (money, energy, geography psychological factors), and benefit.



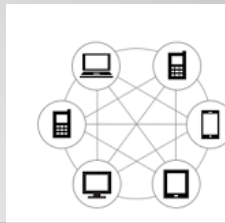
Where (Place)

Consider: Where is your target audience, can you partner with other events/forums, is your message time sensitive or on-going.



Promotion (How)

Consider: Platform, simple messages, and focus on reducing risk.



Pre-testing/Pilot

Consider: Size of pilot and involve your target audience.

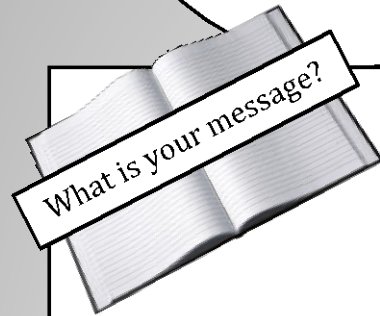


CMVconference.org

Spreading the CMV Message Who, How, Where, What and When?



How and where are you going to reach them?



When?



State Advocacy Strategic Plan

- Section I. Introduction
 - This section should include background information on CMV in general and on the need for increased CMV education in the state.
- Section II. Vision, Mission, and Values
 - This section is a broad overview of the work you hope to accomplish. Mission statements include broad goals like “increasing the number of women in State who are aware of CMV,” “reducing the number of children in State affected by CMV,” etc. The vision should follow through to implementation and not stop at the passage of legislation.

State Advocacy Strategic Plan

- Section II. Vision, Mission, and Values
 - Mission Statement - What is this organization attempting to accomplish? The mission might define patients, stakeholders, or markets served; distinctive or core business; or technologies used.
 - Vision Statement - The term “vision” refers to the desired future state of your team and/or group, where the team is headed, what it intends to be, or how it wishes to be perceived in the future.
 - Values - Value statements are often referred to as “guiding principles” and tells stakeholders and collaborators where the team stands and what they believe in.

State Advocacy Strategic Plan

- Section III. Team Members
 - This section should indicate the members of the team. Roles may be delineated here.
- Section IV. Critical Issues
 - This section should indicate focus of 1-5 year plan.
- Section V. Program Goals and Action Items
 - This section should include your goals as they relate to; accomplishments, actions/activities, and what you will do to address goals outlined, resources needed, timelines, person(s) responsible, and an evaluation (how do you know you have met the goal).

State Advocacy Strategic Plan

CMV ADVOCACY PLANNING TEMPLATE

Strategic Plan

[State] CMV Advocacy Strategic Plan <DATE> to <DATE>

GOAL #1 - <Category>: To ...

Participants: <Names>

Actionable Steps	Who is Responsible	Commentary	Timeline	Evaluation (how will we know it is done)
A.	A.			
B.	B.			

GOAL #2 - <Category>: To ...

Participants: <Names>

Actionable Steps	Who is Responsible	Commentary	Timeline	Evaluation (how will we know it is done)
A.	A.			
B.	B.			

www.nationalcmv.org

Resources

Resources

If you, or someone you know, has been touched by CMV, know that you are not alone. The National CMV Foundation offers parents, families, and professionals valuable information about CMV. Read our blog, download informative literature, share your story, and get your frequently asked questions answered.

Blog

Visit our blog to read up on timely insight around CMV. From industry news to thoughts from experts in the field, we have everything you need to keep yourself informed.

[LEARN MORE ▶](#)

Educational Downloads

Help us raise awareness of CMV—share, post, and print our awareness flyers and help educate pregnant women, practitioners, and the public about CMV.

[LEARN MORE ▶](#)

Parent Stories

Every person touched by CMV has a story. Read personal accounts of families living with this virus, and the efforts people are undertaking to raise awareness for CMV.

[LEARN MORE ▶](#)



**Thank you
for helping us to
#stopcmv**

