

**Action Planning:
Raising Awareness of
Congenital Cytomegalovirus
Among Professionals
and the Public**



Riley and Rachel Greenlee



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 = Cytomegalovirus

- Cytomegalovirus (CMV) is a very common virus
- 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*

Incidence of CMV

- According to the CDC, 1 in 150 children is born with cCMV
- 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*

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*

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

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

How can you catch CMV?

- CMV is a very common virus found mostly in healthy babies, toddlers, and young children
- 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

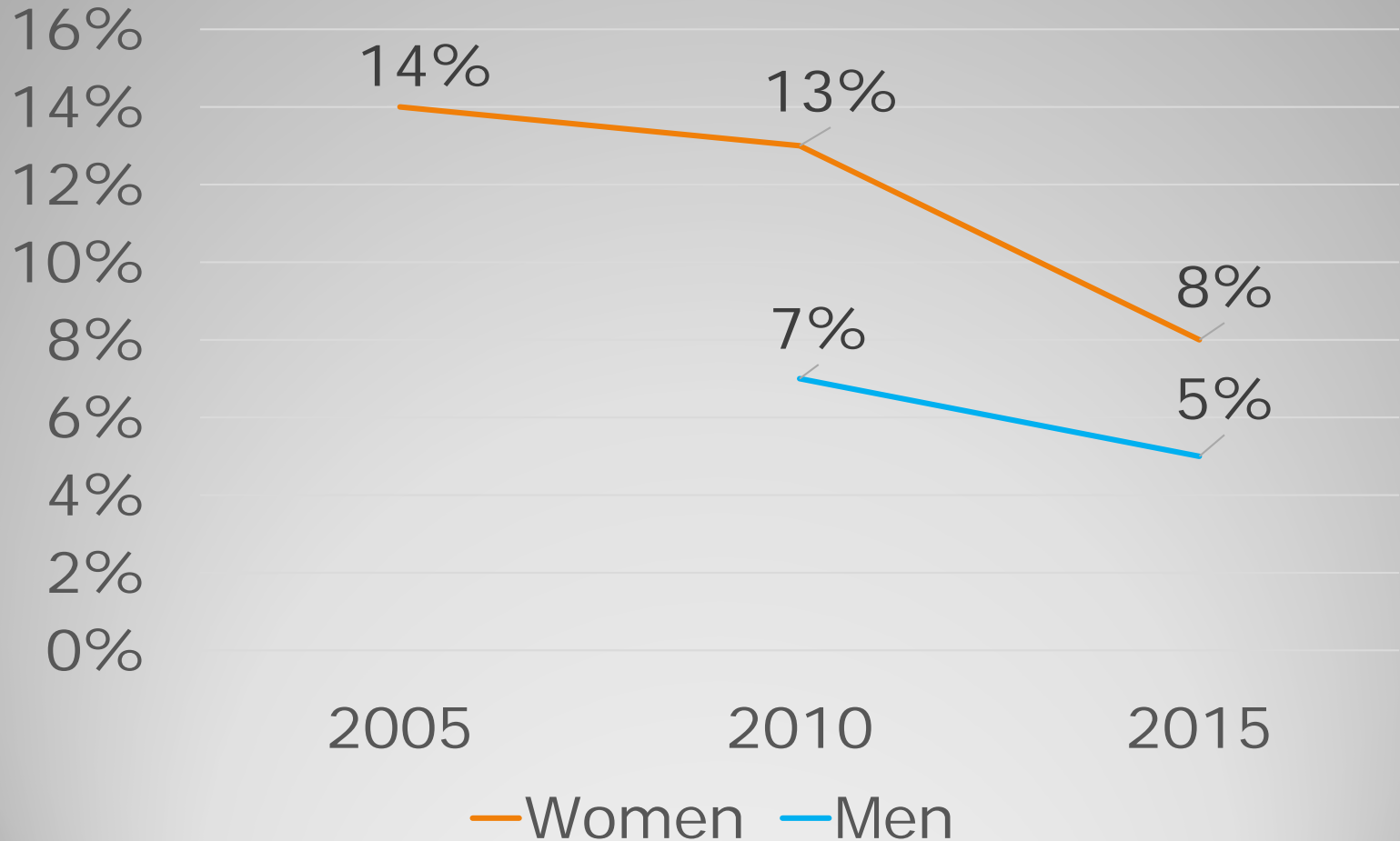
- Wash your hands with soap and water, especially after changing diapers or touching saliva or nasal secretions from a baby or young child
- Avoid kissing babies and young children on the mouth
- Do not share food, drinks, utensils or toothbrushes with babies or young children
- 50-60% of women are at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

Why is CMV a problem?

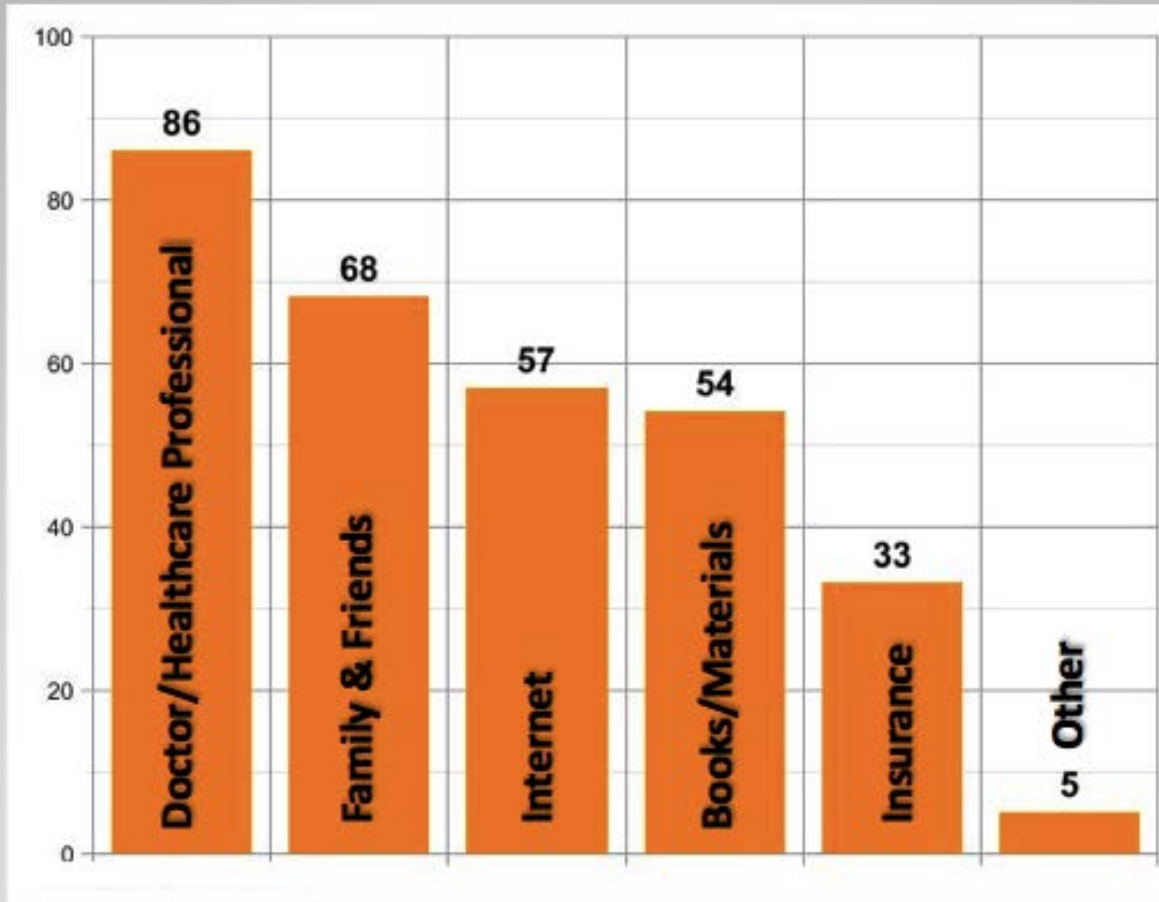
CMV Awareness Research

- 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



Current CMV Messaging

- CDC
- National CMV Foundation
- State initiatives

OVERVIEW PREVENTION CONGENITAL CMV ABOUT US RESEARCH & NEWS RESOURCES GET INVOLVED

Help us raise awareness of CMV!

Share, post, and print our awareness flyers and help educate pregnant women, practitioners, and the public about CMV. Post and distribute flyers in public meeting places, such as OB/GYN offices, pediatrician offices, family practice offices, daycares, preschools, college health centers--anywhere where at-risk populations congregate, work, or socialize.

These flyers provide information about CMV, its effects on pregnant women and babies, and how to prevent congenital CMV infection. They are designed to be easily shared and distributed in various settings.

Cytomegalovirus (CMV) Public Health Initiative

H.B. 81 (2013 General Session) UCA 26-10-10, whose Chief Sponsor was Representative Ronda Rudd Menlove, went into effect on July 1, 2013. This law (Cytomegalovirus Public Education and Testing) directs the Utah 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.

This law also directs 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.

About CMV
 CMV infection during pregnancy can harm your baby. Cytomegalovirus (by the MEG a low yr rus), or CMV, is a common virus that infects people of all ages. Most CMV infections are "silent", meaning the majority of people who are infected with CMV have no signs or symptoms, and there are no harmful effects. However, when CMV occurs during a woman's pregnancy, the baby can become infected before birth. CMV infection before birth is known as "congenital CMV". When this happens, the virus gets transmitted to the unborn infant and can potentially damage the brain, eyes, and/or inner ears.

Every year, more than 40,000 women in the U.S. experience CMV infection during pregnancy.

Navigation: About | FAQs | Testing | Providers | Resources

CDC A-Z INDEX

Cytomegalovirus (CMV) and Congenital CMV Infection

Facebook | Twitter | Plus

Cytomegalovirus (by the MEG a low yr rus), or CMV, is a common virus that infects people of all ages. Most CMV infections are "silent", meaning most people who are infected with CMV have no signs or symptoms. However, CMV can cause disease in people with a weakened immune system and in babies infected before birth. About 1 in 150 children is born with congenital (present at birth) CMV infection.

More >

CMV and Pregnancy

CMV infection can be passed from a pregnant woman to her fetus. Most infants born with congenital (present at birth) CMV infection don't have problems. But CMV infection in a pregnant woman can cause birth defects and, in rare cases, death in infants infected before birth. If you're pregnant or planning a pregnancy, the best way to protect your pregnancy from CMV is to protect yourself.

More >

Trends and Statistics

Congenital (present at birth) CMV infection causes more long-term problems and childhood deaths than Down syndrome, fetal alcohol syndrome, and neural tube defects. In the United States, congenital CMV causes one child to become disabled every hour.

More >

TRANSMISSION

How cytomegalovirus is spread...

CONGENITAL CMV INFECTION

Signs of congenital CMV infection.

What has been done about CMV?

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)
 - Public education program
 - CMV screening with newborn hearing screen fail

CMV legislation – 2017

- Oregon (HB 2754)
 - 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 - UT

- Catalyst - state rep had a grandchild w/ cCMV, legislation
- Lead - EHDI (Stephanie McVicar)
- Funding - legislative appropriation
- Partners - audiologists; physicians; training programs; state/local agencies; pregnancy, women & child health organizations; CMV researchers; CMV families, etc
- Opposition - physicians didn't like mandate, DOH offered support and enlisted their input on process improvement
- Evaluation - surveying to see who has seen messages and materials, ultimate success = reducing CMV incidence
- Advice – assemble medical/scientific advisory panel, create partnerships, utilize student projects, lit review, database system, centralized testing/reporting mechanism, 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 - CT

- Catalyst - legislation, parent-physician advocacy duo
- Lead - EHDI (Amy Mirizzi)
- Funding - unfunded mandate
- Partners – audiologists; birth facilities & midwives; CT AAP/EHDI Chapter Champion (Brenda Balch); CT Children’s Medical Center (ID), Yale-New Haven Children’s Hospital (ID); PCPs
- Opposition - Something is better than nothing vs. education should have come before mandated screening
- Advice – Identify referral sources; talk to ID specialists in your state; estimate additional hours of staff time (x2); it’s more work and more time consuming than predicted (responding to inquiries; developing resources)

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 - MN

- Catalyst - 2014 CMV conference; ID specialists, CMV expert Dr. Mark Schleiss & EHDI coordinator teamed up
- Lead - Dr. Schleiss/DOH (Contact: Kirsten Coverstone)
- Funding - grants (MDH/CDC/Schleiss Univ of MN lab)
- Partners - Univ of MN, Fairview Health, CDC, EHDI Advisory Committee, IDEPC
- Opposition - IRB approval/grant funding process/contracts – takes a long time; professional concern (not all colleagues support CMV universal screening at this time)
- Advice - Patience – if you are going to do something, it is worth taking the time to do it right; try to understand your opposition; learn what elements you need to address to gain their support; be at the table

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

EHDI case study - MI

- Catalyst - 2015 EHDI conference, thinking up a plan
- Lead - EHDI (Debra Behringer), AAP/EHDI Chapter Champion Colleen Berry
- Funding - none yet
- Partners - pending
- Opposition - creating and linking all of the connections in our plan- parents and professional partners, other stakeholders, funding, public awareness campaigns; MCH internal support
- Next steps - possible hospital pilot with EHDI Chapter Champion; Michigan CMV public awareness information; continue to engage partners (parents & professional)
- Advice – share data and plan; start small but start!

What can you do about CMV?

State CMV Activities

- Co-branding of CMV materials
 - Indiana, Massachusetts, Montana, and Ohio



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 la 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 sintomas 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 Messaging

- Read et al, 2008
 - Pregnancy books and popular press contain little, if any, info on CMV
- Levis & Kilgo, 2014
 - Greatest need for web materials
- Thackeray, Wright, & Chipman 2014
 - Content analysis of:
 - 37 pregnancy books (2001-2012)
 - 7 websites
 - Limited CMV information, inadequate information about prevention

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
started!**

CMV Social Media Marketing Plan



essages,
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?



Who is your target audience?

How and where are you going to reach them?



What is your message?

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.			

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

