



CMV Global Network

Community Engagement to Improve Prevention and Treatment of Congenital Cytomegalovirus Infection

Laura Gibson, M.D.

Adult and Pediatric Infectious Diseases and Immunology
University of Massachusetts Medical School
Worcester, MA, USA



Congenital CMV Network Development

Concept

Rationale

- Expansion of advocacy efforts led by families of affected children
- Limited opportunities for engagement of all stakeholders

Goals

- Build a partnership of stakeholders
- Create a global network to ***support collaboration*** and ***accelerate progress***

Approach

- Community Engagement Forum in Austin, TX (September 2016)
- Network development activities



Congenital CMV Network Development

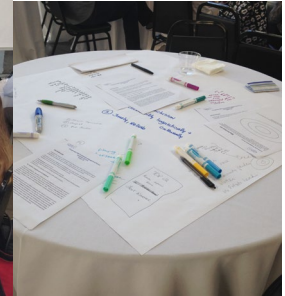
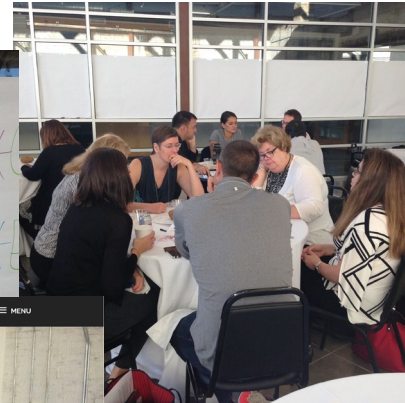
Community Engagement Forum

CTA Architects Engineers
Austin, TX Sept 2016



* Resource of cutting edge information
* Provides different perspectives
* Organized structure for easy access

* Responsive
* Supportive
* Informative



CMV
Community Engagement Forum
CMV Network: Visualization Group Exercise

01 Write down the key adjectives that would describe a successful network
collaborative, transparent, creative, mission driven, respectful, staffed, funded, cross-cultural, easy to implement, available, sub-matter experts/knowledge/expertise, strong communications, pleasurable, outcome driven/time box



① Balanced Inclusion
② Accessible - technically, linguistically, culturally
③ Reliable



• Diverse stakeholders are represented and engaged.
• Politically savvy, responsive, and nimble.
• Maintains a current, relevant knowledge base germane to clinical practice.



04 Who (person, type of person, organization or type of organization) would need to be connected with the CMV Network to make it most useful? Make a list.
Parents, non-profit org., federal org., grandparents/extended fam., home visiting/CHD/childcare, state org., researchers, clinicians, health care prov., pharma, drug, policy, market



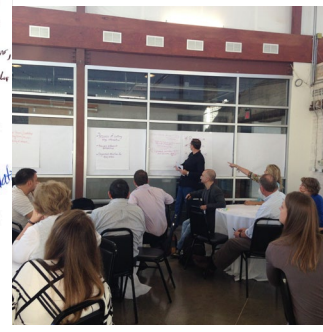
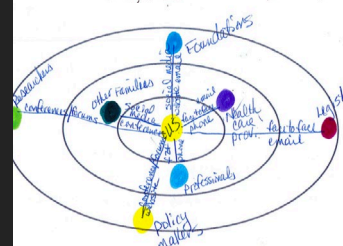
CTA for CMV: Applying design-thinking to a social challenge

By: Travis Edwards
29 November 2016

At CTA, we facilitate and participate in many, many charrettes. There is almost no problem that can't be addressed by gathering with our colleagues, getting into our right brain, and collaborating to find a solution. We do this all the time when designing for the built environment. However, we don't as often have the occasion to solve social challenges using design-thinking.

In September, CTA Austin had the privilege to facilitate a unique charrette for attendees to this year's CMV Conference. Cytomegalovirus (CMV) is an all-too-common, yet not widely known, infection affecting expectant mothers and their babies, leading to deafness, blindness, and myriad other tragic side effects in children.

Who (person, type of person, organization or type of organization) would need to be connected with the CMV Network to make it most useful? Make a list.
ED, marketing, private & ENT, nurse practitioners, public health, family practitioners, child care providers, school health programs, researchers, industry, Early Intervention, EMT, media





CMV Global Network

Vision, Mission, and Guiding Principles

Our **vision** is elimination of congenital CMV infection.

Our **mission**:

- 1) To serve as a platform that joins congenital CMV stakeholders into a ***global collaborative partnership*** focused on accelerating progress in awareness, prevention, patient care, and research
- 2) To ***enhance and accelerate*** the work of stakeholders by providing core services that support their goals



CMV Global Network

Vision, Mission, and Guiding Principles

Guiding principles motivate our interactions and activities:

Inclusion and equity

All whose lives and/or work include congenital CMV infection are welcome. The network benefits from diverse experiences and perspectives, so all partners are equally respected and valued.

Accessibility

Partners have access to information through many entry points, and are invited to participate actively in the network.

Transparency

Operational activities of the network or its committees are available for review and feedback by all partners.

Service and responsiveness

Leaders directly serve and encourage participation of partners in working toward their local or overall network goals. Bi-directional communication between leaders and partners should be respectful and timely.

Sustainability

The network makes decisions and takes actions that ensure progress over time, particularly in areas that require longitudinal efforts.



CMV Global Network

Network Development Team: Partners in the design process

Common themes

- *GLOBAL PERSPECTIVE*
- Don't duplicate efforts
- Database and discussion forum

Current activities

- Website (www.cmvglobalnetwork.org)
- Governance
- Establish nonprofit
- Funding

Format

- Monthly conference calls
- Working groups focus on single tasks
- Shared drive for documents and resources



CMV Global Network

Website



[Login](#) | [Register](#)



[HOME](#)

[ABOUT US](#)

[CONTACT US](#)



CMV is the most common viral infection that infants are born with in the United States.

[Find out more](#)



News and Events

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Clinical

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Research

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Family Support

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Advocacy and Legislation

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Public Health and Policy

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Resource Libraries

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout



Network Directory

Lorem ipsum is a pseudo-Latin text used in web design, typography, layout