#### **CMV Conference 2014**

Salt Lake City Utah September 26-27







### **Planning Committee**

2014 CMV Public Health and Policy Conference

Jim Bale
Michael Cannon
Sara Doutré
Mandy McClellan
Ronda Menlove

Stephanie McVicai

**Albert Park** 

**Lenore Pereira** 

Alyson Ward

**Karl White** 

Abstracts Due Monday

∕September 29th<sup>№</sup>

#### **OVERVIEW**

SUBMIT ABSTRACTS A

WHO SHOULD ATTEND

REGISTRATION

SCHEDULE & PRESENTATIONS

**EXHIBITS & ADVERTISING** 

**SPONSORSHIPS** 

STAKEHOLDERS' MEETING

**AWARDS** 

HOTEL INFORMATION

**PAST & FUTURE MEETINGS** 

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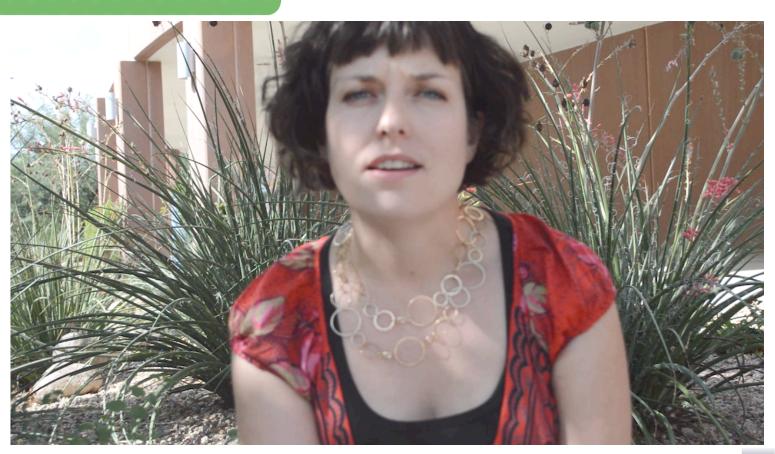
#### 14th ANNUAL EARLY HEARING DETECTION & INTERVENTION MEETING

March 8 - 10, 2015 · Louisville, KY



#### 2015 Early Hearing Detection & Intervention Meeting

Submit an Abstract for the 2015 EHDI Annual Meeting





# What Do People Know About CMV? What Can We do About It?

Rosemary Thackeray, PhD, MPH Department of Health Science Brigham Young University

#### Session Objectives

- Identify levels of CMV awareness among various groups
- Locate best sources of CMV information on CMV websites or books
- Name three ways to engage in social media conversations about CMV

### What We Know

#### U.S. Women



- Pediatric outpatient clinic
- OB/gyn clinic
- •Medical students and staff
- Students at student union building
- ■N = 643
- ■22% had heard of CMV

#### U.S. Women

- •Mail survey
- -N = 2,656
- ■14% had heard of CMV

#### Pregnant Women in France

- Obstetric clinics
- ■N = 362
- ■60% have heard of CMV
- ■72% knew how to prevent infection



# Pregnant Women in Singapore





- Specialist outpatient clinic at Singapore General Hospital
- N = 200
- 20% heard of CMV
- Most common sources of information
  - the workplace- 50.0%
  - newspaper or magazine- 22.5%
  - None informed by their obstetrician

#### U.S. Men and Women

- Nationwide mail survey
- ■N= 4,184
- ■13% of women aware
- ■7% of men aware



# Pregnant Women in The Netherlands

- •20 midwifery practices
- ■N = 1,097
- ■12.5% heard, seen or read about
- Knowledge was low or incorrect

#### Japanese Pregnant Women

- Kobe University Hospital
- ■N= 343
- ■18% aware
- 77% no knowledge of transmission
- ■85% no knowledge of prevention



#### **U.S. Medical Students**

- •Medical school
- -N = 422
- ■34% of year one students
- ■100% of year 2 students



#### Summary

- Low awareness
  - ■13 to 22%
- Exceptions
  - •2<sup>nd</sup> year medical students
  - France
- Specific knowledge lower than awareness



### **Child Care Providers Study**

#### Rationale

- Child care facilities are primary locations for the spread of infectious and other communicable diseases
- Child to parent transmission (Pass et al 1986)
- CMV can stay on absorbent surfaces (Stowell et al 2012)
- Women associating with or having close contact with young children are at risk for contracting CMV
- There is no literature about CMV awareness among child care providers

#### **Child Care Licensing Options**

- Hourly
  - not on a regular schedule
- Residential
  - 1-8 children in the home
- Licensed Family
  - 1-16 children in the home
- Child Care Centers
  - 5 or more children, <u>not</u> at the provider's home
- Out of school time programs
  - non-residential setting for school age children 5-12 years

#### Sample

- •Licensed family (n = 796)
- Residential certificate (n = 118) providers
- Simple random sampling
  - 451 selected
    - estimating a proportion, within 5% points
    - response rate of 60%
    - finite population correction

#### Methods

- •Mail survey
- Dillman Total/Tailored Design
- ■Response rate = 68.4% (N = 306)

#### Questions

- Awareness of viruses, parasites, bacteria (1)
- Sources of information (3)
- Awareness of how to prevent spread of disease in child care settings (7)
- •CMV knowledge and source of information (5)
- Demographics (12)

#### Sample Demographics

- Female
- White (86%)
- Age
  - 21.4% <35 years of age
- •Education
  - 69.8% high school or some college

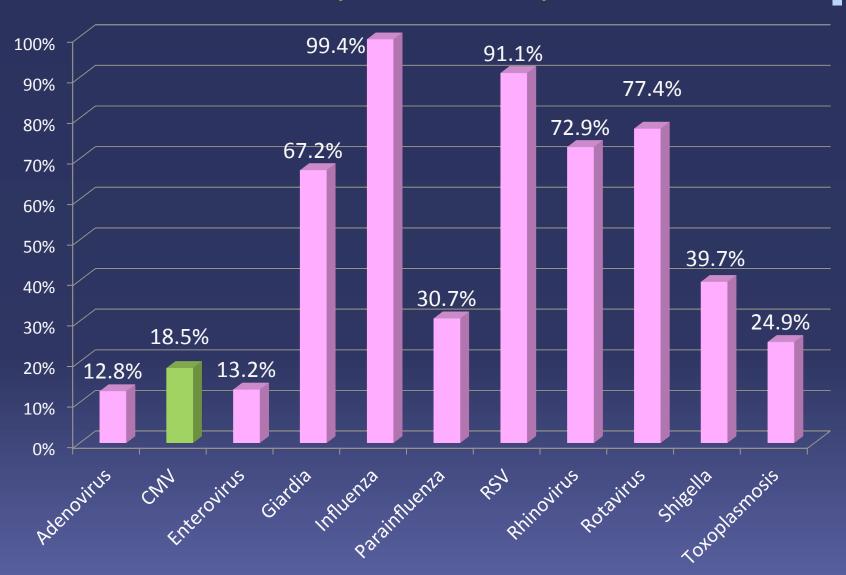
#### Sample Demographics

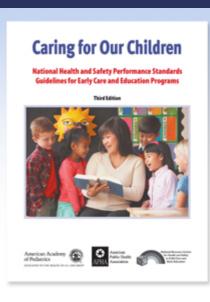
- Household income
  - ■<\$25,000 per year 13%
  - **■**>=\$65,000 32%
- Pregnancy
  - ■97% ever pregnant
  - ■8.3% current
- ■72% no children under the age of 5

#### Child Care Experience

- ■63% a child care provider for >10 years
- •36.6% employed at least one other staff member
- •All age ranges of children

#### Aware of Viruses, Bacteria, Parasites





#### Caring for Our Children

National Health and Safety Performance Standards
Guidelines for Early Care and Education Programs
3rd Edition

National Resource Center For Health and Safety in Child Care and Early Education

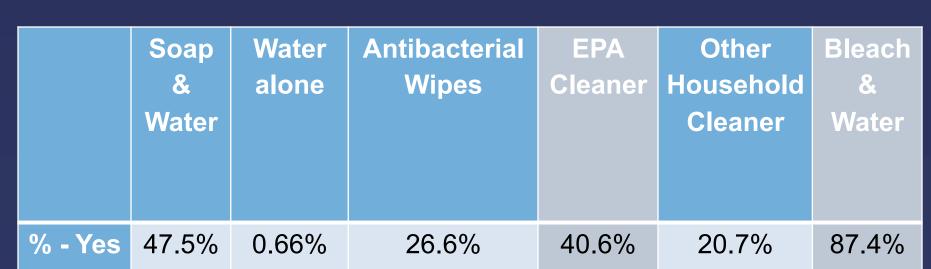
### **Disinfect Diapering Surface**

	Soap & Water	Water alone	Antibacterial Wipes	EPA Cleaner	Other Household	Bleach &
					Cleaner	Water
% - Yes	21.1%	0.33%	71.7%	48.3%	16.4%	93.8%

# Disinfect Surfaces When There is a Spill of Blood or Blood-Containing Bodily Fluids

	Soap & Water	Water alone	Antibacterial Wipes	EPA Cleaner	Other Household	Bleach &
					Cleaner	Water
% - Yes	21.9%	0.66%	45.0%	54.2%	19.2%	90.9%

## Sanitize Surfaces Such as Cutting Boards Prior to Food Preparation



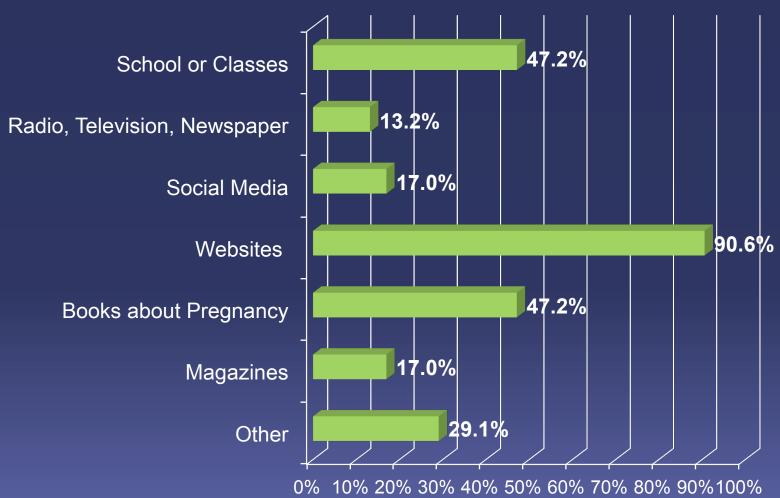
# Sanitize toys that children have placed in their mouth or have been soiled with bodily fluids

	Soap	Water	Antibacterial	EPA	Other	Bleach
	&	alone	Wipes	Cleaner	Cleaner	&
	Water					Water
% - Yes	37.3%	0.66%	49.3%	41.2%	19.1%	92.8%

## Likelihood to clean hands using soap & water or hand sanitizer (gel)

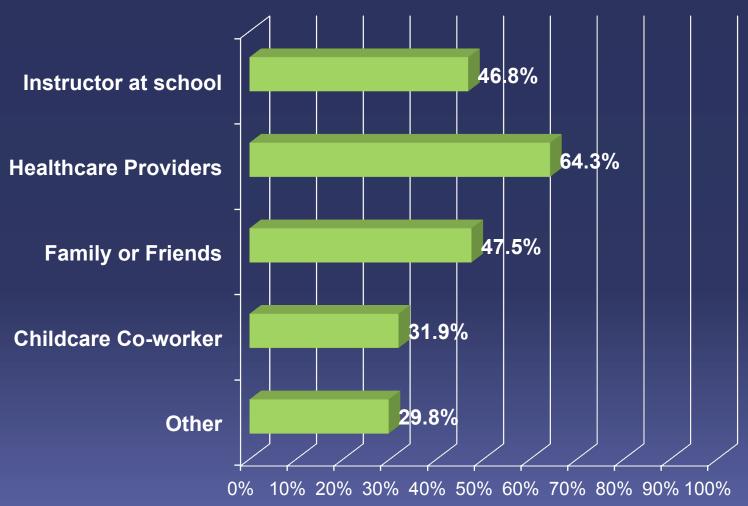
	Extremely <u>un</u> likely	<u>Un</u> likely	Neutral	Likely	Extremely likely
Before serving food	2.29	.33		2.29	95.10
Before changing diapers	10	23	14	16.33	36.67
Before blowing your nose	18.33	34	20.67	9.33	17.67
Before wiping a child's running nose or drool	15.33	36	18	12	18.67
After serving food	5.57	7.21	4.92	13.11	69.18
After blowing your nose	1.96	.65	.98	6.54	89.87
After changing diapers	2.62	.66			96.72
After wiping a child's running nose or drool	2.61	.65	.33	5.23	91.18
After going to the toilet	2.61			.65	96.73
After handling children's toys	5.28	12.87	24.42	20.46	36.96

#### Sources of CMV Information

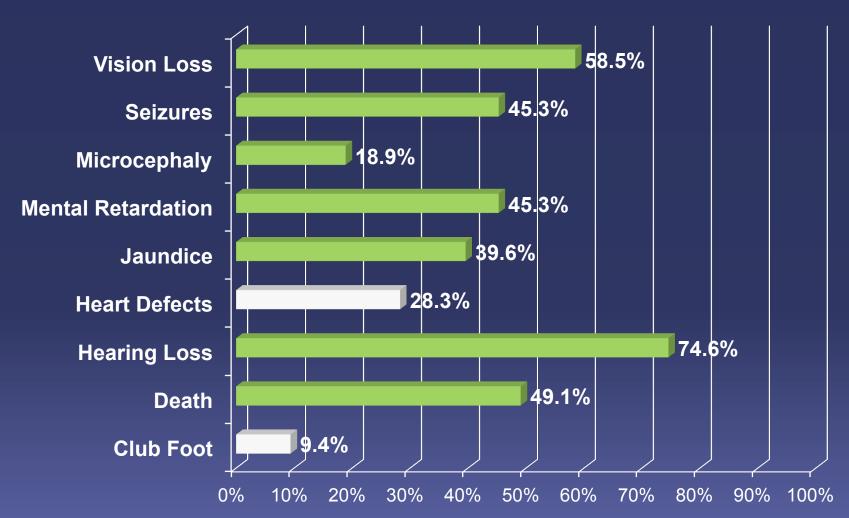




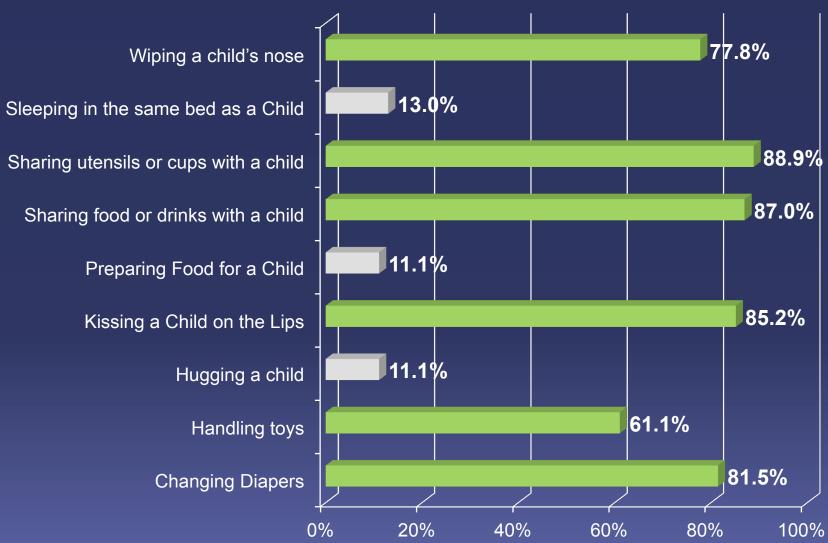
#### Sources of CMV Information



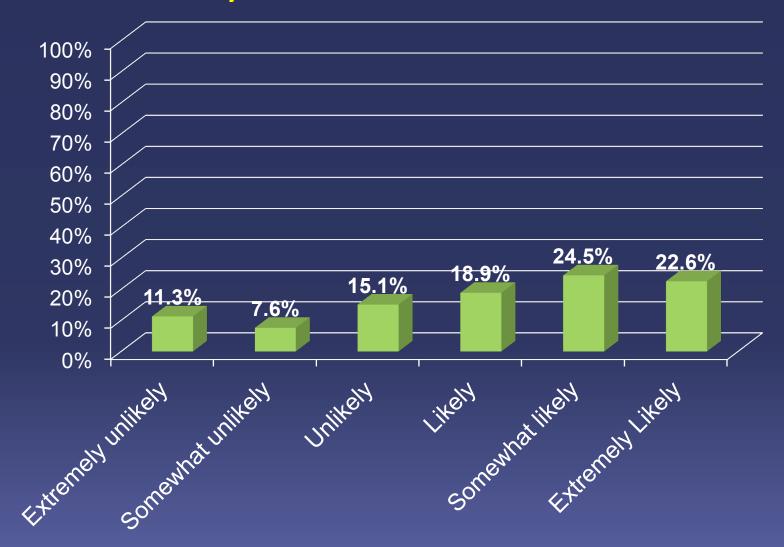
#### Awareness of What is Caused by CMV



### Awareness of How You Come in Contact with CMV



# Likely You Will be Exposed at Child Care Facility



### Conclusions

- Overall awareness similar to other populations
- Knowledge varies
- Perceived risk is low
- Communication
  - Website = key channel
  - Training classes
- Child care "centers" may employ higher risk group



# Reference Books and Websites

Thackeray, Wright, & Chipman, *Maternal and Child Health Journal*, 18 (3) 2014

### Rationale

- Women seek pregnancy information from
  - health care providers
  - the internet
  - discussion forums
  - family members
  - books
- •Read and colleagues (2008) suggested that pregnancy books and the popular press contain very little, if any, CMV information

### Methods

- Content analysis
  - 37 pregnancy reference books 2001-2012
  - 7 websites

- Two Coders
  - inter-coder agreement 85.4-95.4%
- Subject matter experts review

- General coding categories
  - CMV description
  - Transmission
  - Prevention

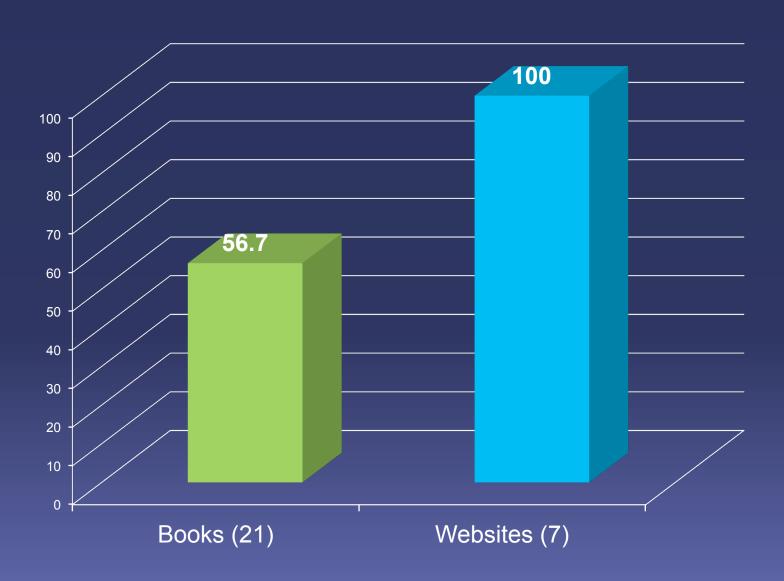
### Methods

- Accuracy
  - % of women with antibodies before pregnancy
  - % who will get infection
  - % of maternal infections that lead to fetal infection
  - # born with CMV
  - # of deaths
  - # with permanent disabilities
  - likelihood of transmission with a reinfection

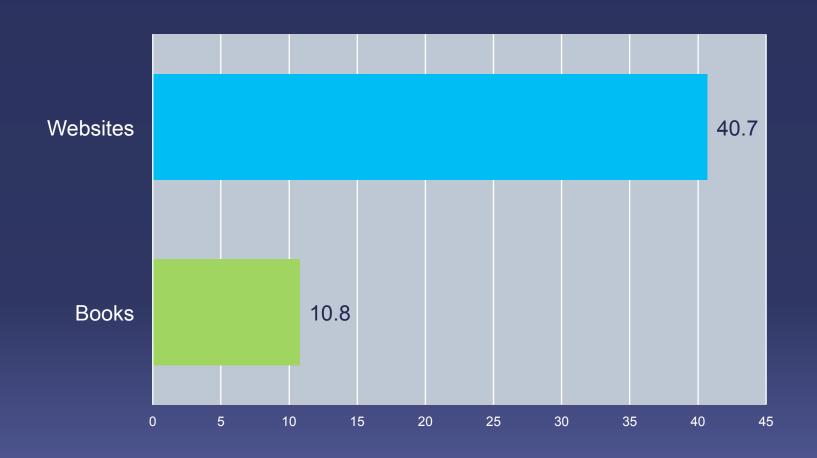
### Methods

- Compared CMV with
  - toxoplasmosis
  - listeriosis
  - group B strep
  - HIV
  - Down syndrome
  - fetal alcohol syndrome
  - spina bifida

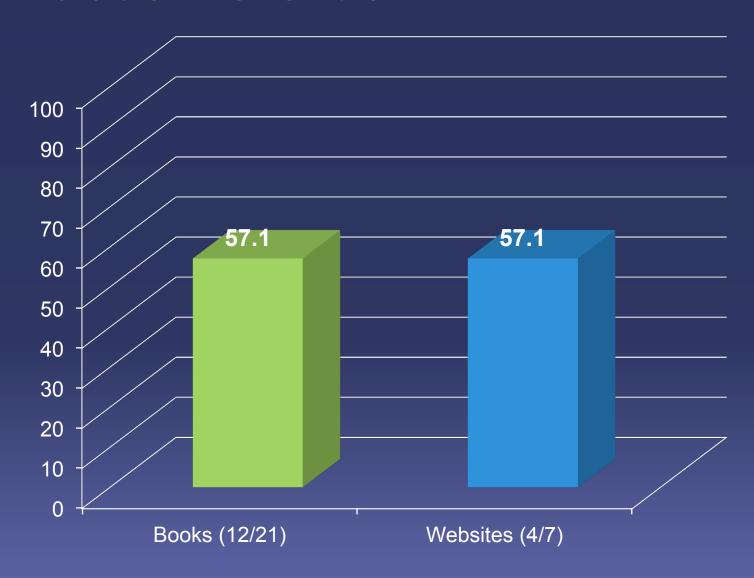
# Include CMV



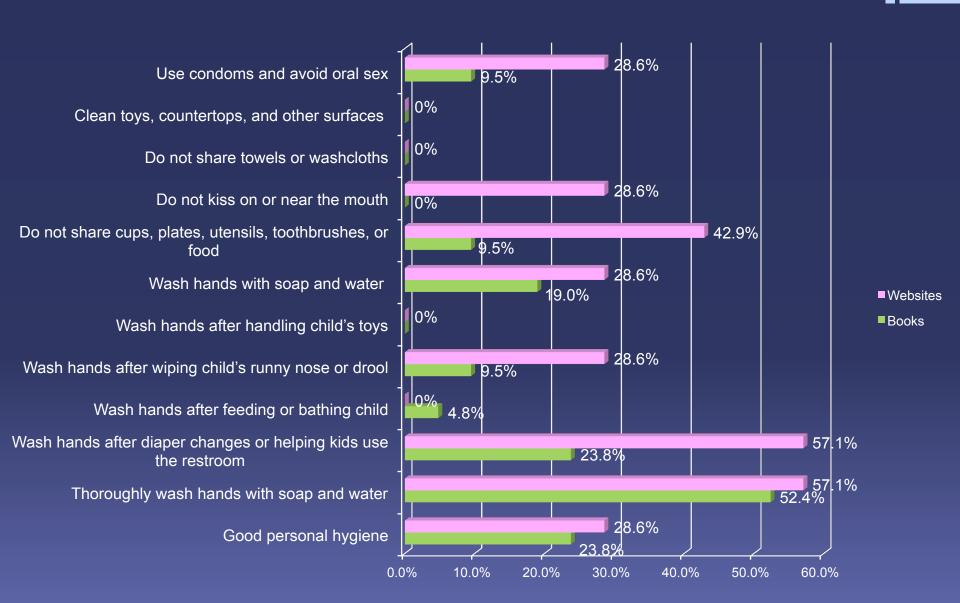
### Number of Sentences about CMV



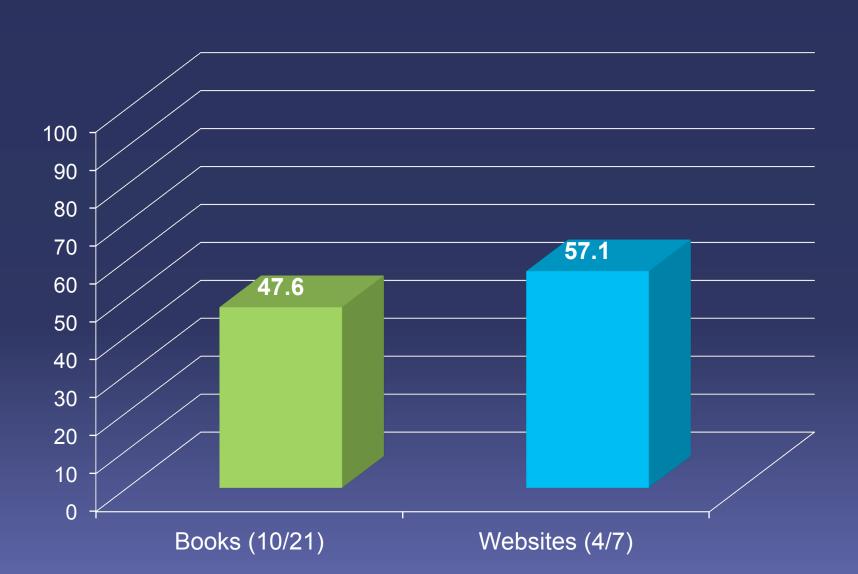
# Include Prevention



### What Preventive Measures?



### Risk Factors for Maternal Infection



## Transmission



### Inaccurate Info About

- % of maternal infections that lead to fetal infections
- # of children who have permanent disabilities
- the chance of developing CMV immunity

### Conclusions

•Limited CMV information, though not statistically different from other infections or birth-defects.

•Inadequate coverage given to prevention of CMV transmission may contribute to CMV remaining a continued leading cause of birth defects in the United States.





# WHO?



# WHAT?

No.

Maddie's Mission @Maddies\_Mission · Sep 12

#Pregnant women should follow these steps to protect their unborn baby from the leading viral cause of disabilities.

Maddie's Mission

### 3 SIMPLE STEPS TO AVOID CMV DURING PREGNANCY

- Do not share food or drinks with a toddler. No more "one for mommy and one for baby."
- Avoid contact with saliva when kissing a child under 6 years old.

  Instead, of kissing on the lips, for instance, kiss on the forehead and add a hug.
- Wash your hands often with soap and water for 15 20 seconds especially after changing diapers, wiping noses or drool, and







# WHERE?

# WHEN?

- On-going
- Need strategic communications plan
  - What, when, where, who
- Does not need a lot of resources







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# Facts & Prevention (Cytomegalovirus :: The Silent Virus that Women Need to Know About)

by Guest Blogger on June 30, 2014 in Babies, Motherhood, Pregnancy, Preschoolers, Toddlers

Today's series is composed of four women brought together by the most unfortunate circumstances. They all have one thing in common...Cytomegalovirus {CMV} has significantly changed their lives. However, their individual experiences resulting from this awful virus are vastly different. On this last day of National Congenital Cytomegalovirus Awareness Month.





Congratulations and thank you to Katie Igoe and her "Together We Can" team for hosting their annual event this weekend in New York! With almost 200 attendees, they raised over \$21,000 for Stop CMV!



#### National Health Observances

National Health Observances (NHOs) are special days, weeks, or months dedicated to raising awareness about important health topics.



#### 1-30 June

National Congenital Cytomegalovirus Awareness Month

Stop CMV - The CMV Action Network P. O. Box 62214 Sunnyvale, CA 94088-2214 (209) 712-9929

email@stopcmv.org

www.stopcmv.org &

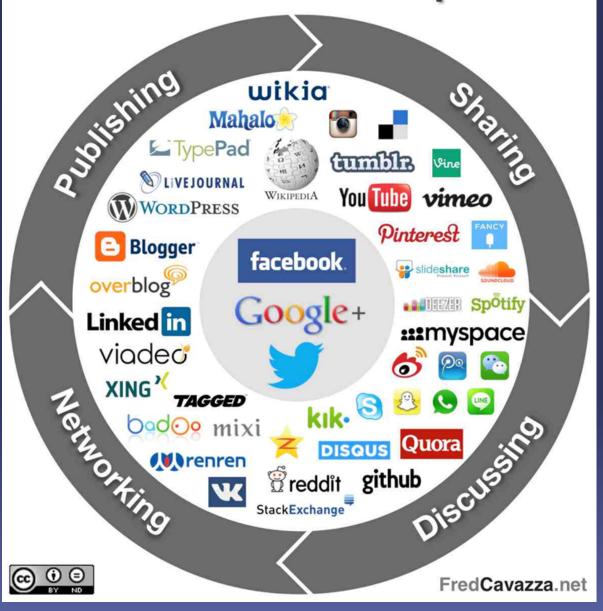
Materials available

Contact: Janelle Greenlee

### Social Media Defined

"Activities, practices, and behaviors among communities of people who gather online to share information, knowledge, and opinions using conversational media. Conversational media are web-based applications that make it possible to create and easily transmit content in the form of words, pictures, videos, and audios."

### Social Media Landscape 2013



Home > Help Fight ALS

#### Share Drint

#### THE ALS ICE BUCKET CHALLENGE

# Thank you for the outpouring of support.



WHAT IS ALS?

WHAT WE DO

DONATE



WIKIPEDIA
The Free Encyclopedia

Main page

Contents

Featured content

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Random article

Donate to Wikipedia

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Interaction

Help

Article

Talk

# Summer of Monuments

### Ice Bucket Challenge

From Wikipedia, the free encyclopedia

The **Ice Bucket Challenge**, sometimes called the **ALS Ice B** dumping a bucket of ice water on someone's head to promote lateral sclerosis (ALS) and encourage donations to research. August 2014.<sup>[1][2]</sup> In the US, many people participate for the A



Jon Fortenbury Contributor

FOLLOW

I cover health, autism and the human struggle with disease.

full bio →

Opinions expressed by Forbes Contributors are their own.









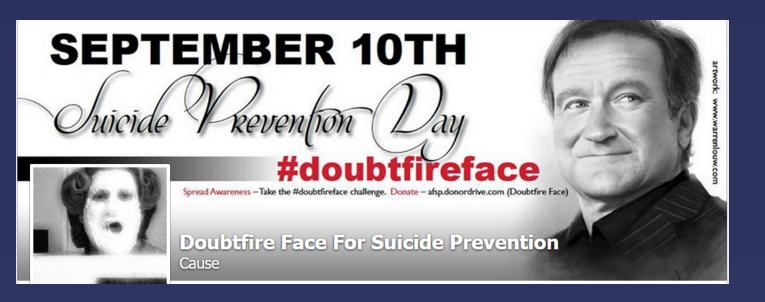
PHARMA & HEALTHCARE

9/01/2014 @ 4:14PM 8,272 views

# Has The Ice Bucket Challenge Changed Healthcare Fundraising Forever?

+ Comment Now + Follow Comments

There's no shortage of Ice Bucket Challenge knockoffs. From giving rice to the needy to taking a pie to the face for suicide prevention, many are trying to start a challenge that will echo what the ALS Association received from the Ice Bucket Challenge in one month, which as of Aug. 29 was \$100.9 million from over three million donors. That level of fundraising success in such a short period of time is unprecedented, for ALS Association or anyone, and everyone with a passionate cause is trying to reach it.



### How to participate?

#RiceBucketChallenge

- 1 Pickup a bowl of rice from your kitchen
- (2) Go to the nearest needy person and give it to them

#RiceBucketChallenge
Are you up?

picture and post it on facebook with hash tag #RiceBucketChallenge

Rice Bucket Challenge 🕢

Community ds and ask them to take up the challenge

Timalina

About

Dhoto

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#### Ice bucket craze faces cream pie challenge

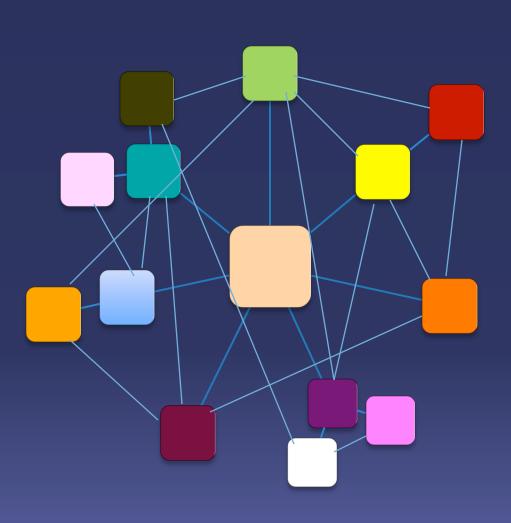
Published: 11 Sep 2014 13:30

MOVE over Ice Bucket Challenge — there's a new craze coming to Scotland.



BRAVE: Kane fought until the end

In aid of Childhood Cancer Awareness Month, social media users are preparing to 'Get Whipped' by having a cream pie thrown in their face.

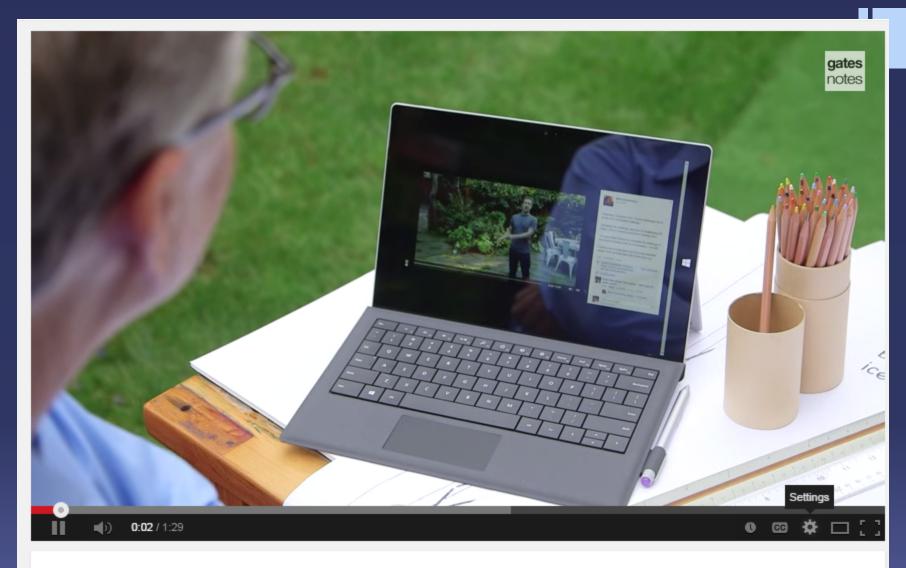




### Amy August 24 at 7:24pm 🐰

I'm so happy I got tagged! I tagged the world! Donate to www.alsa.org or another charity of your choice. Such a fun way to bring awareness to a horrible disease. Thinking of my friends Lisa and Debbie who lost their moms to ALS. — with Julene and 40 others.





Bill Gates ALS Ice Bucket Challenge



SNACKS SNACKS

"Less and less users are interested in publishing, all they are looking for are snackable content to share in order to start quick conversations and social interactions."

Fred Cavazza



## 10,000 Stories in 10 days

Help us add 10,000 grandma stories between 9/20/2014 and 9/30/2014.



Family Tree

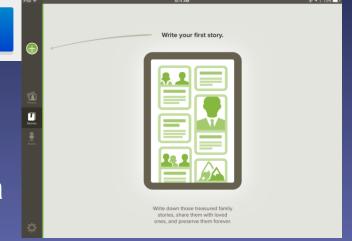
## What Makes Your Grandma Special?

#MeetMyGrandma. If you could share one story you love about your grandma, what would it be?

Sign in now to share

**10336 Stories** 

and counting...



#MeetMyGrandma



Jill Sep 22

My grandma was my inspiration for becoming a journalist. She wrote for a Kansas newspaper; I grew up wanting to do that too. #MeetMyGrandma



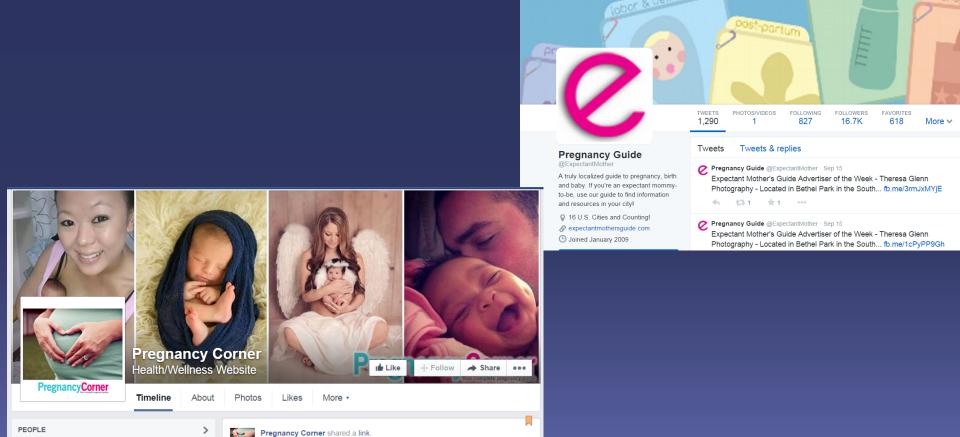
- 59 likes
- Grandma Lindblom is awesome cause she always has dum dums and we ways drank nesquik chocolate milk complete with a straw and she ways gives us &2 dollar bills for our birthdays and she always made me say please and thank you no matter what! I love her for all those reasons! Grandma Francis is the bomb dot com cause

## #MeetMyCMVchild

"Content is the fuel to conversation, it is a valuable investment you cannot avoid."

Fred Cavazza

# Go To Where The Conversations Are Happening



Yesterday 🚱

#TeamNatural vs #TeamMeds

1.081.632 likes

mother's guide

# Make Your Posts Specific and Meaningful



If you haven't already, why not donate to a charity close to Kimberley's heart and celebrate the birth of Bobby 🚭 🍑 👚 uk.virginmoneygiving.com/team/kimberley...

## **Engage in Conversation**

#### Answer their questions or comment on their post



Is it harder to get pregnant after a CMV affected pregnancy I've been trying for a few months and with my first 2 pregnancies I was pregnant the first time I tried. Does having a CMV affected pregnancy affect your fertility or ovulation at all?

Like · Reply · September 5 at 7:26pm

#### Give thanks



CMV Action UK retweeted



Mad As A March Hare @Bonkers PR · Aug 9

@cakesphotoslife Thank you for your support of @cmvactionuk Just letting people know of simple practices to reduce risk is so important







View conversation



CMV Action UK @cmvactionuk · 4h

Thanks @EssexBaby for your Wash Away CMV Campaign post. Every little helps. Action #cmv #cmvaction shar.es/11hQIG via @sharethis

## Make Content Unique for The **Platform**



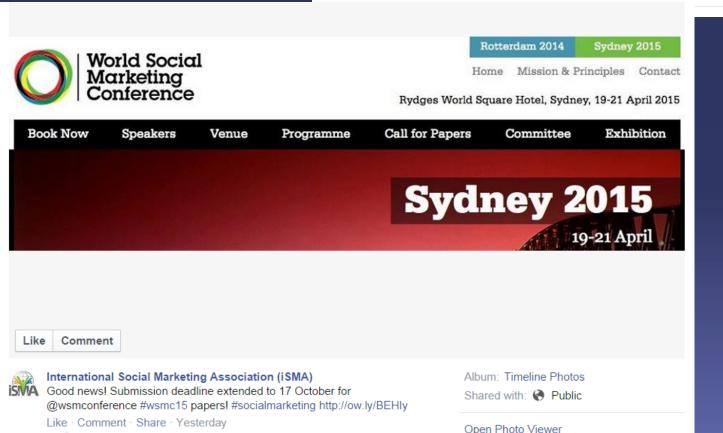


Social Marketing @isma org · Sep 18

Good news! Submission deadline extended to 17 October for @wsmconference #wsmc15 papers! #socialmarketing... fb.me/3zEpwNl8x

Expand

◆ Reply ★ Retweet ★ Favorite ••• More



## Posts with Compelling Information or Opinion



Sharyn Rundle-Thiele @rundlesr · Sep 18

Back pain, poor posture, leg cramps, tense muscles? Here's something you can do about it! Inkd.in/bqGKkmf

Expand





◆ Reply ★ Retweet ★ Favorite ••• More



craig lefebvre @chiefmaven · Sep 18

During infectious disease outbreaks, behavioral changes account for 80-90% of economic losses.

#socialmarketing nytimes.com/2014/09/18/wor...

☐ View summary













Maddie's Mission retweeted



CDCChronic @CDCChronic · Sep 16

Sept. is #InfantMortality Awareness Month. Sign up for @mytext4baby - just text BABY to 511411, go.usa.gov/yRaB

Expand











## Posts that are Personal

Maddie's Mission @Maddies\_Mission · Aug 26 Met with @RepJohnZerwas to discuss the importance of CMV legislation in Texas! Women deserve to be educated about CMV

View more photos and videos

### **Retweet Others**

Maddie's Mission retweeted

March of Dimes NY @MarchOfDimesNY · Sep 16

We're bringing awarenss to #InfantMortality. #Retweet to help us honor all of the #babies who left us too soon.









## Use Hashtags

- #cmv
- #stopcmv
- #cmvconference

### Conclusion

- Awareness is low
- There are lots of audiences to talk to
- •Messages need to be
  - Specific, actionable
  - Personal
  - Sharable
- Social media is one way to have that conversation, but not the only way.

rosemary\_thackeray@byu.edu