
CMV DADS

A look at Gender, Parenting, and Cooperation within Families Affected by CMV

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AGENDA

1. Introduction
2. Will and Daisy Dautre
3. Ethan and Cora LaPlante
4. Joe and Jane Sweet
5. Survey Overview
 1. Roles of Moms and Dads- Will
 2. Involving Fathers - Ethan
 3. Balancing Time Between Children – Joe
6. Questions

L O G A N , U T A H

DAISY♥DOUTRE

7 Y E A R S O L D



- Middle of three children, Liam (9), Bonnie(4)
- While in utero, ultrasounds detected enlarged ventricles in her brain.
- Within days of birth MRI revealed Germanic cysts consistent with a torch infection
- Newborn hearing screenings:
 - Failed in hospital prior to discharge
 - “passed” 2 week follow-up despite anomalies due to her waking up
- 1.25 years - mild/moderate hearing loss
- ENT referred to another ENT who pulled dry blood spot and confirmed congenital CMV

L O G A N , U T A H

DAISY♥DOUTRE

7 Y E A R S O L D



- My wife, Sara, had years of special education training and was well educated, but we'd never heard of CMV
- Sara pursued information and all avenues of treatment
- We felt like the health system failed us
- Decided to utilize Sara's mom, Ronda Menlove, who was in the Utah legislature to ensure parents had the best chance to receive diagnosis as early as possible
- Rep. Menlove introduced and passed legislation requiring the screening for CMV upon failed newborn hearing screening

W I L L I S T O N , V E R M O N T

CORA ♥ LAPLANTE

2 Y E A R S O L D



- Youngest of two, older brother Jack
- Failed newborn hearing screening, went back for several follow up audiologist appointments, which resulted in a profound hearing loss diagnosis
- CMV diagnosis wasn't determined until about 5 months old by an ENT as a second opinion sought out by parents.
- Parents tracked down blood spot and tested positive for CMV through independent study
- CMV ramifications: Hearing loss and Brain calcifications
- Bilateral CIs right before first birthday

W I L L I S T O N , V E R M O N T

CORA ♥ LAPLANTE

2 Y E A R S O L D



- Mom and Dad split time taking Cora to appointments and meeting with service providers.
- Both parents work full-time, and Cora attends daycare.
- Can be a challenge juggling normal parenthood duties, careers, and appointments. It takes a lot of teamwork to make sure everything gets accomplished.
- Responsibilities all treated equally and play to each other's strengths.

CUMBERLAND, MAINE

JANE♥SWEET

3 YEARS OLD



- Youngest of two, older brother Henry
- Failed newborn hearing screening
 - Profoundly deaf
 - White matter abnormalities
 - Retinal scar
- Insistent that dried blood spot be tested and cCMV diagnosis was confirmed
- Guilt of failure to protect pregnant wife and daughter
- Difficult to differentiate feelings of a male parent w/ female child and any parent with special needs child

CUMBERLAND, MAINE

JANE♥SWEET

3 YEARS OLD

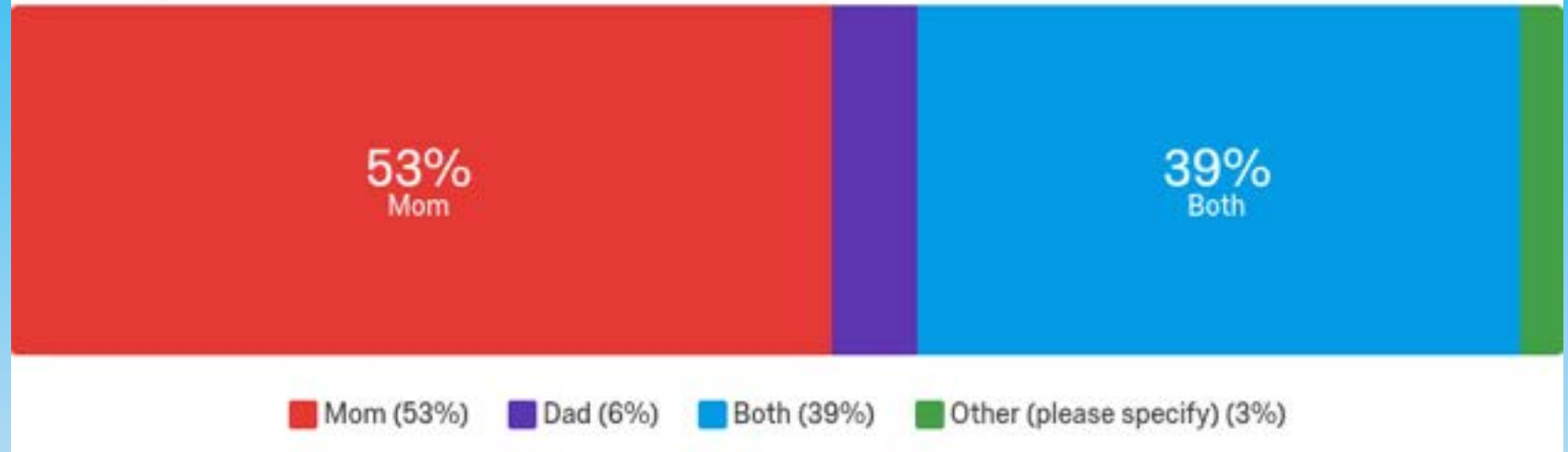


- Wife as prominent “CMV Parent”
 - took lead on doctor’s appointments during maternity leave
 - eventually quit her job and focused on Jane and her development full time
 - developed knowledge of CMV and always took the lead in discussions with doctors, caregivers, etc.
 - Initiated legislative efforts in Maine resulting in ongoing CMV education and screening initiatives with ME CDC

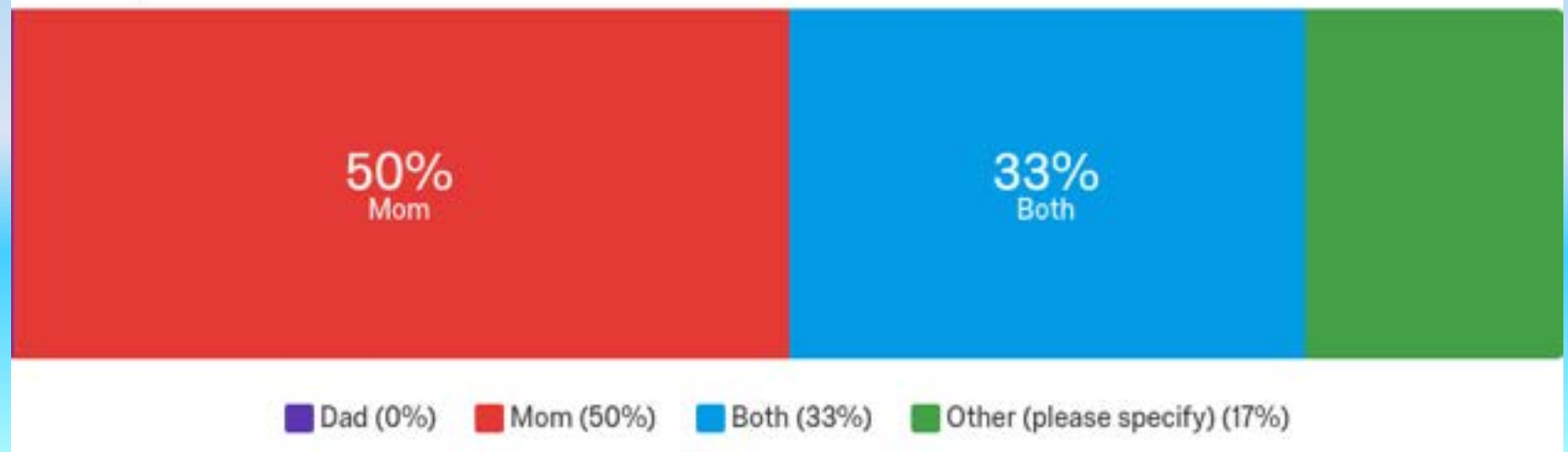
Roles of Moms & Dads

Who is the primary caregiver of your child with CMV?

Mom's responses (35):



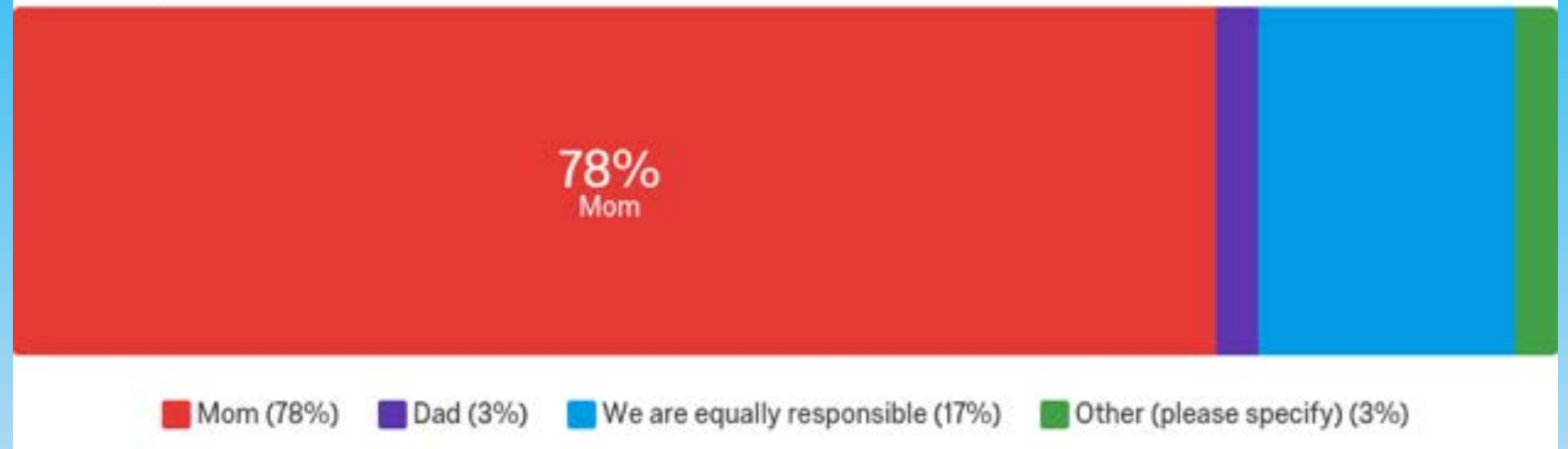
Dad's responses (6):



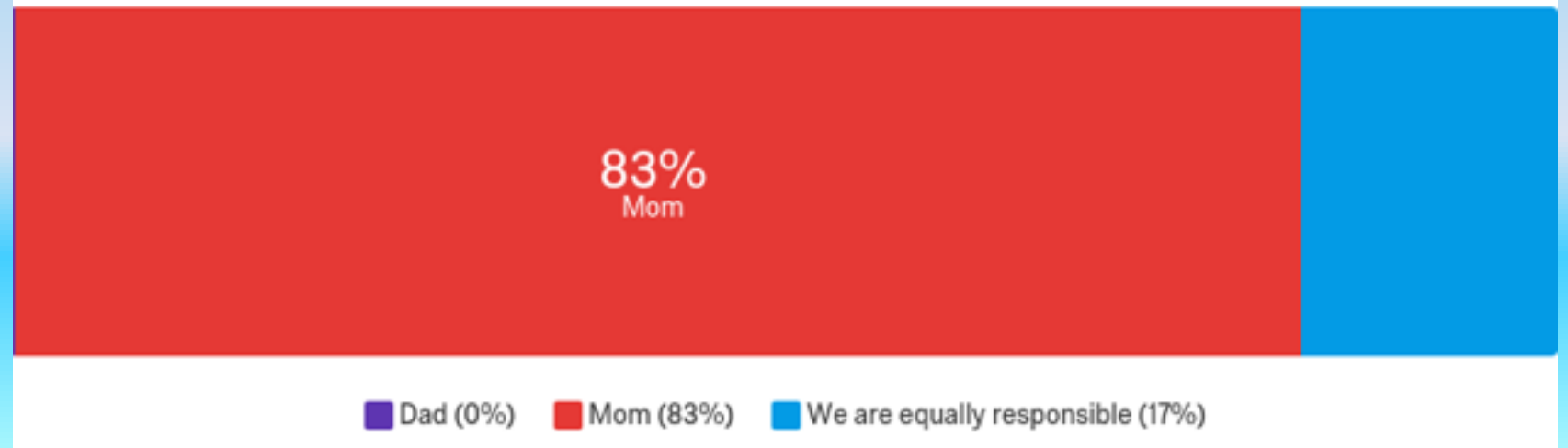
Roles of Moms & Dads

Who is most responsible for taking your child with CMV to the doctor and other appointments?

Mom's responses (35):



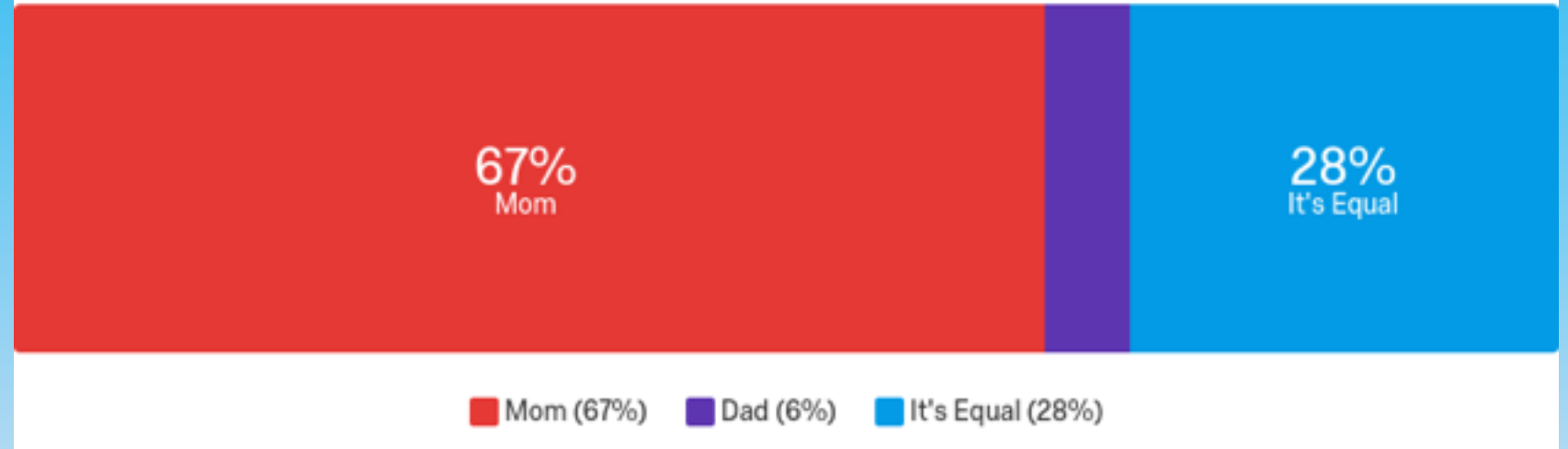
Dad's responses (6):



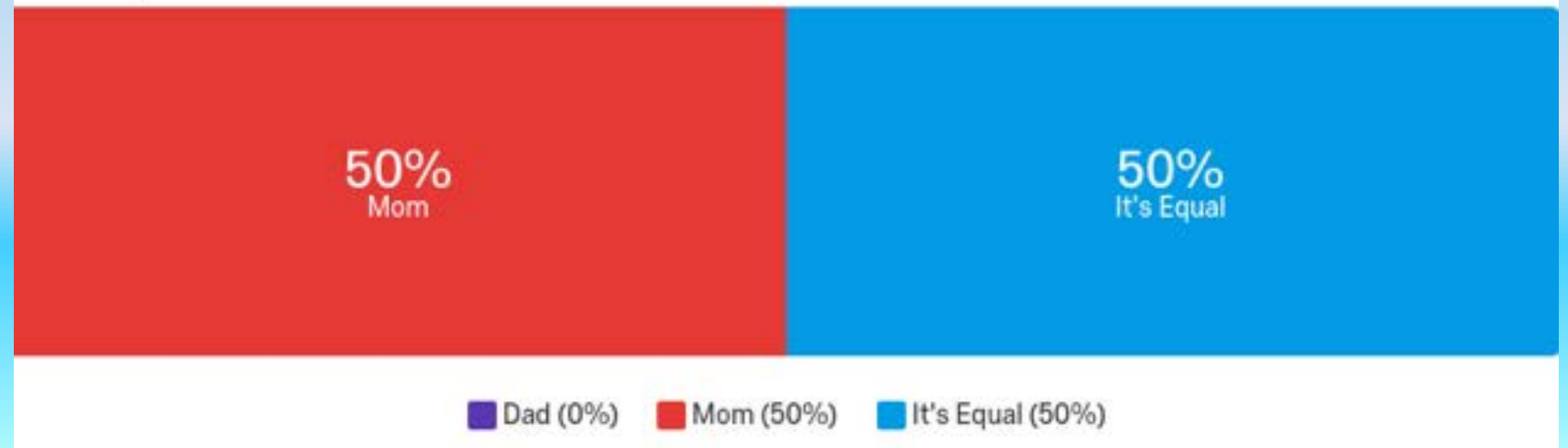
Roles of Moms & Dads

Who has more knowledge of CMV?

Mom's responses(36):



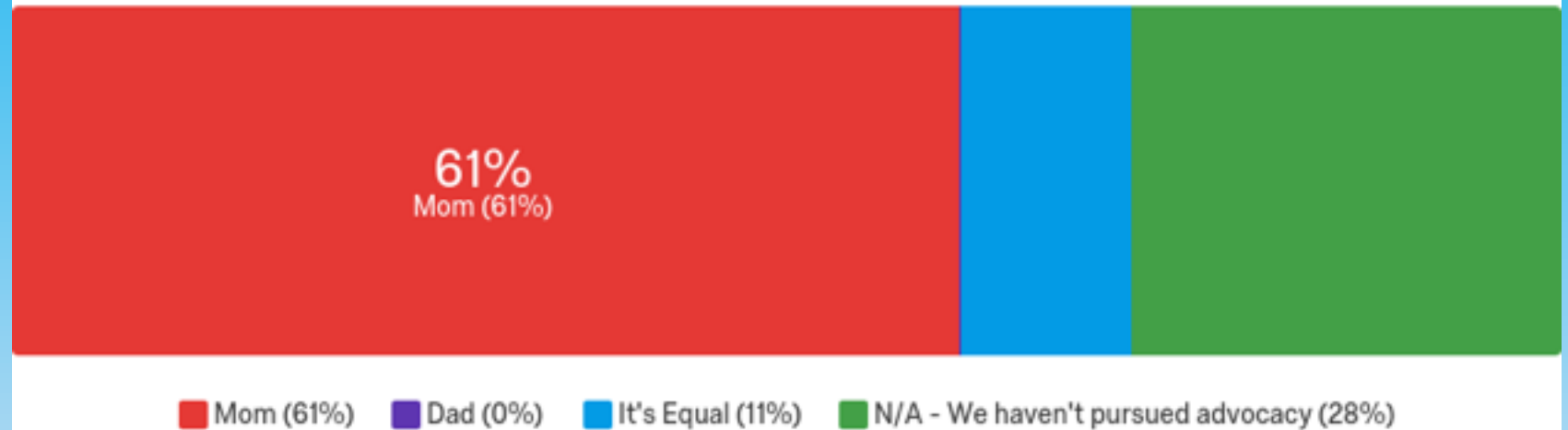
Dad's responses(6):



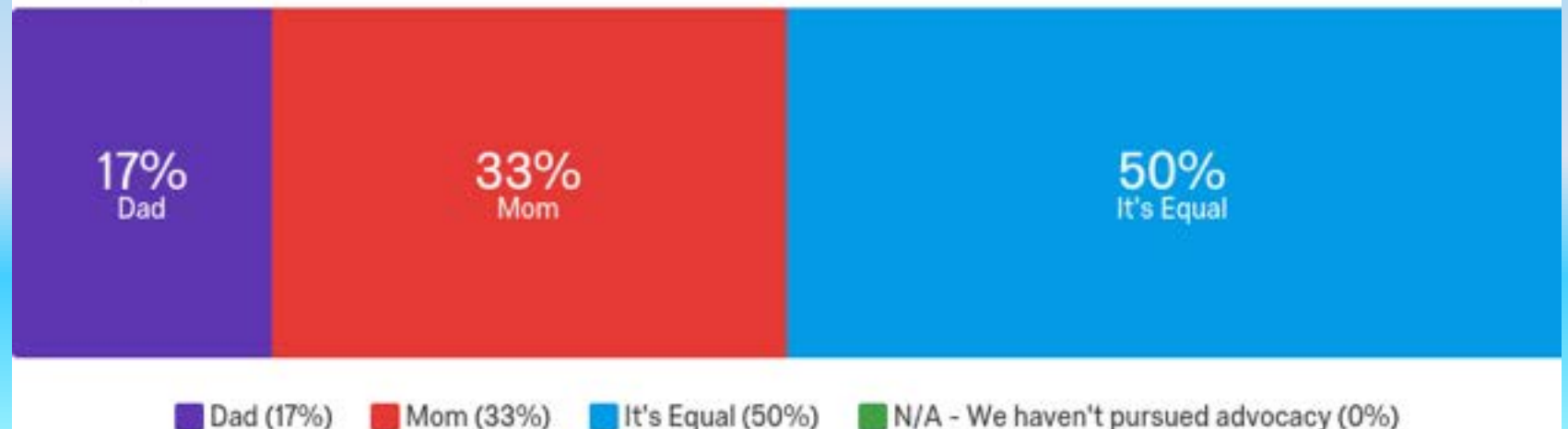
Roles of Moms & Dads

Who was more involved in advocacy if it was pursued?

Mom's responses(36):



Dad's responses(6):



Roles of Moms & Dads

Why was Mom more involved in advocacy?

Note 1: Other responses indicated a combination of more time, drive, and education.

Note 2: 1 Dad stated he was more involved because he had more time due to work schedule.

Moms' responses (28):

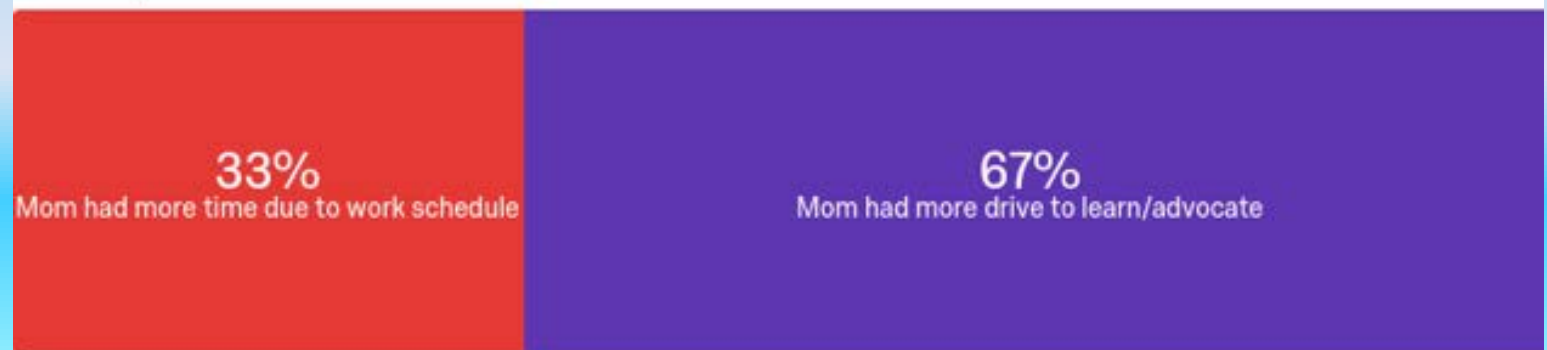


■ Mom had more time due to work schedule (25%) ■ Mom had more drive to learn/advocate (43%)

■ Mom was more qualified through academic and/or occupational experience (18%)

■ N/A: We're equal advocates or I'm in a single parent household (7%) ■ Other (please specify) (7%)

Dads' responses (4):



■ Mom had more time due to work schedule ■ Mom had more drive to learn/advocate

Involving Fathers

Survey Suggestions: “Are there ways for dads to stay more involved?”

What Dads Said:

- Handle some of the PT needs of the child.
- You can take the kids to music class, swimming lessons, etc.
- Push to have a say in the discussion. Stay involved and up to date.
- The only involvement I've had up to this point has been on the periphery due to my wife taking the lead. Finding a specific cause or organization related to CMV is a good first step.

Involving Fathers

Survey Suggestions: “Are there ways for dads to stay more involved”

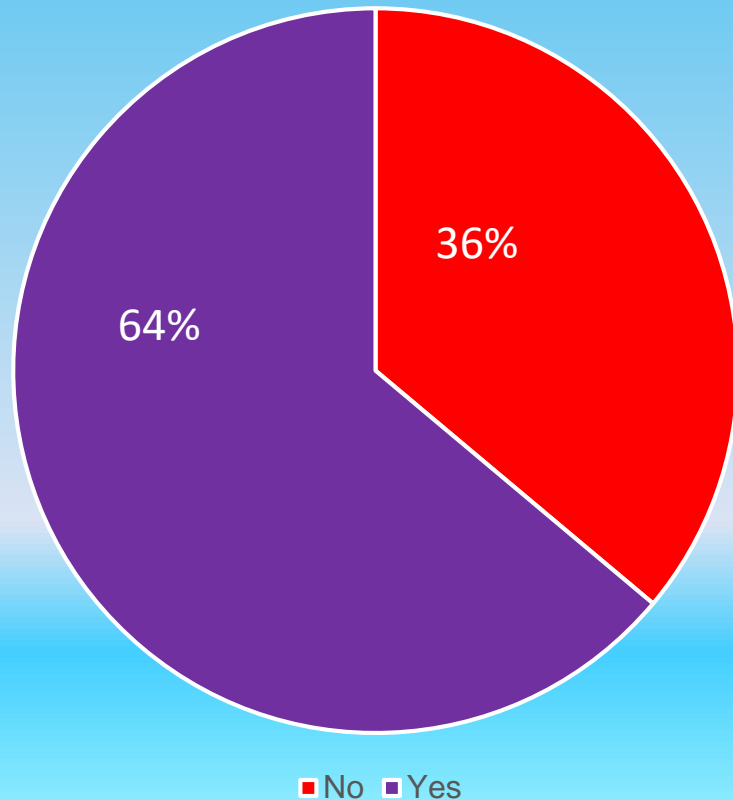
What Moms Said:

- Support Group for Dads
- Care notebook has been helpful for keeping him involved. its like a reference book on her medical appts.
- Being open about any discussion, share any new information and be involved in a parent group for support
- Dad should attend major appointments. When he can't attend appointments, we talk about things we wish to discuss prior to appointment.
- I think the complexity of the schedule and challenges can overwhelm most dads. For us, we've found success in my husband taking a primary role in our daughter's physical exercises, therapy and activities.
- Dads should spend more time reading and learning about CMV. Obviously this doesn't apply to all dads, but it sure seems like you see a lot more discussion, blogs, posts, and information from moms than dads.

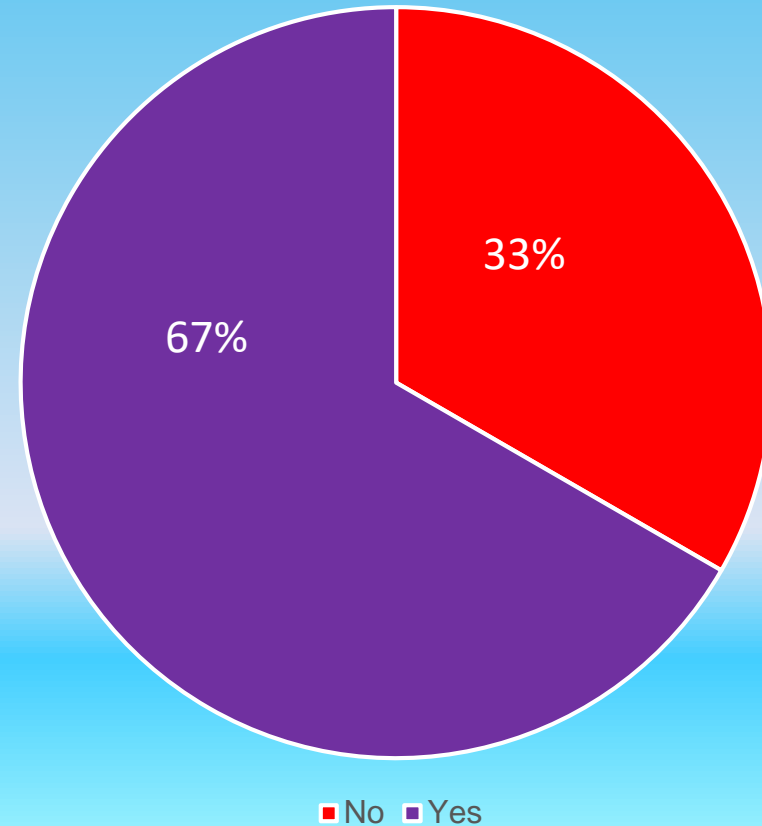
Working with Care Providers

Do Care Providers Treat Dads Differently?

Responses from Moms



Responses from Dads



Working with Care Providers

Survey Suggestions: “What could care givers do differently to involve dads?”

What Parents Said:

- Not default to mom on correspondence and other details.
- Talk to them when in an appointment. We have seen the providers speak to me and sometimes don't even acknowledge he is in the room.
- Have the same sympathy and same understanding that is given to mothers
- I think dads tend to be less involved and spend less time educating themselves... so at appointments moms are asking most the questions and dads play a more passive role. Because they are not as knowledgeable or vocal they get left out on a lot of the discussion.

Balancing Time Between Children

- Concerns both about not spending enough time or isolating one or the other
- Most try and combine activities interacting with all children at once
- Divide and conquer: Parents split time between kids to ensure time with all
- Utilizing therapy/appointment time of CMV child to bond with non-CMV children
- Support different interests of children to dictate together time

THANK YOU!

