

# “REMEDIES FOR SORROW” Book Study

Author Megan Nix

Created 2023



*This discussion guide is put together for the purpose of supporting the Minnesota Statewide Early Hearing Detection & Intervention (EHDI) Representatives as they participate in reading the book, “Remedies for Sorrow”.*

## Part 1 - Weeping

During our Statewide EHDI Meeting we will have time for discussion, in smaller groups, around Part 1 “Weeping” from the book. There are 4 sections in our discussion guide. Your group might choose to focus on one section, a few sections, or cover all the sections. Do whatever feels most helpful for your group. The sections are: [Reflections](#), [Resources](#), [Quotes and/or Facts](#), and [Actions Steps](#).

### Reflections:

***Pick 3-5 of the following questions to reflect.***

1. This section takes the reader through Anna’s birth and the process of getting the initial diagnosis. The author seeks honesty, talks about anxiety, guilt and uncertainty as she searches for information and clues. What do you think the author wants you to understand and learn from this part of their story
2. How might the first part of Anna’s story been different if her family hadn’t had the support or resources that were described? How can we support equitable access to interventions for all babies with cCMV?
3. On page 20 and 21 she notes the impact of the environment in the doctor’s office on her experience and feelings. When looking at the pictures of the children on the walls she noted the lack of hearing aids, walkers, wheelchairs and glasses. What connections might be made to how educational environments impact families? How does your program ensure that they are creating as welcoming of an environment as possible?
4. On pages 23-24 Megan writes, “It’s only when you’re facing a diagnosis of congenital CMV (when the information is nine months too late) that you begin to learn about the disease - a condition the medical world has contested disclosing to pregnant women for the last seventy-some years.” Many families that enter early intervention might know nothing about their child’s diagnosis. What can we do to support families who are still learning about their child’s diagnosis?
5. “We don’t always say something’s hard when it’s happening.” (page 34) Families often have many things they are juggling, working though, learning about, etc... How can we as practitioners learn to recognize and respect whatever stage of their process they are in? What supports and/or resources can we offer? What language might we consider using?

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6. We learn that CMV can manifest with visible symptoms or the baby can look fine but exhibit progressive symptoms over time and the spectrum of those symptoms are broad. The nature of CMV might result in a great deal of uncertainty and anxiety as the progression unfolds. How can early interventionists support families in “guarding their imagination” (page 57) as they seek information about their child’s diagnosis? How might we support them through the uncertainty? Some children do not have physical signs of CMV...how does this impact early interventionists and working with children?
7. On page 48 Megan writes, “I can feel she’s concerned and listening. I will look for this audible compassion in every provider we see.” How do we as early interventionists show our compassion? What does this look like, sound like, and feel like?
8. “Lynne tells me not to believe any predictions placed upon Anna’s life.” (page 57) Might this be similar for early interventionists? How can we check ourselves from only believing predictions and leave expectations open-ended?

## Resources:

*Which resources have you utilized before?*

*How was a resource helpful?*

*Which resources do you plan to explore more?*

- ★ [Megan Nix on her Memoir Remedies for Sorrow and risks of cCMV](#) - 2 minute YouTube video
- ★ Podcast from the National CMV Foundation titled “[Meet Megan Nix, CMV parent and author](#)” – 45 minutes
- ★ [Minnesota Department of Health EHDI](#)
- ★ [Minnesota Department of Health CMV and Congenital CMV](#)
- ★ Minnesota Department of Health [Congenital Cytomegalovirus Information for Families and Caregivers](#)
- ★ [Early Hearing Detection and Intervention National Technical Resource Center](#) (EHDI NTRC)
- ★ [National CMV Foundation](#)
- ★ [Marlana VanHoose](#) (mentioned on page 50)

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## Quotes and/or Facts from Part 1 Weeping:

*Which quotes really resonate with you? Why?*

*What additional quotes from the book were impactful for you as you were reading?*

- ★ “Hearing loss is the most common irregularity in infants from birth - and frequently a sign of systemic disease.” (page 7)
- ★ “All former stability has undergone a silent but seismic shift.” (page 13)
- ★ “I can’t handle anything but honesty at this point.” (page 21)
- ★ “In America, around 40,000 babies are born each year with CMV, of whom 6,000 to 8,000 will end up with lifelong disabilities. Children disabled by congenital CMV outnumber children disabled here by any other congenital condition or disease, including down syndrome, spina bifida, cystic fibrosis, and pediatric HIV.” (page 25)
- ★ “And the percentages seem to silence a harrowing fact: that 100% of babies born with CMV have the potential to end up with permanent delays.” (page 25)
- ★ “Congenital CMV is the leading cause of birth defects and developmental delays in the US” (page 26)
- ★ “I realize it might feel like a summer of saying no, but maybe it isn’t. Maybe it’s a season of learning a different yes.” (page 55)
- ★ “Guard your imagination” (page 57)

## Action Steps:

Take a few moments to reflect on any possible action steps you are considering. This might include your own personal growth, ideas for supporting children and families, and sharing back with your colleagues.