

# What CMV Families Want You to Know – Professionals, Family, and Friends.

From the families themselves

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CMV Parent Guide By Your Side – Kentucky Hands & Voices

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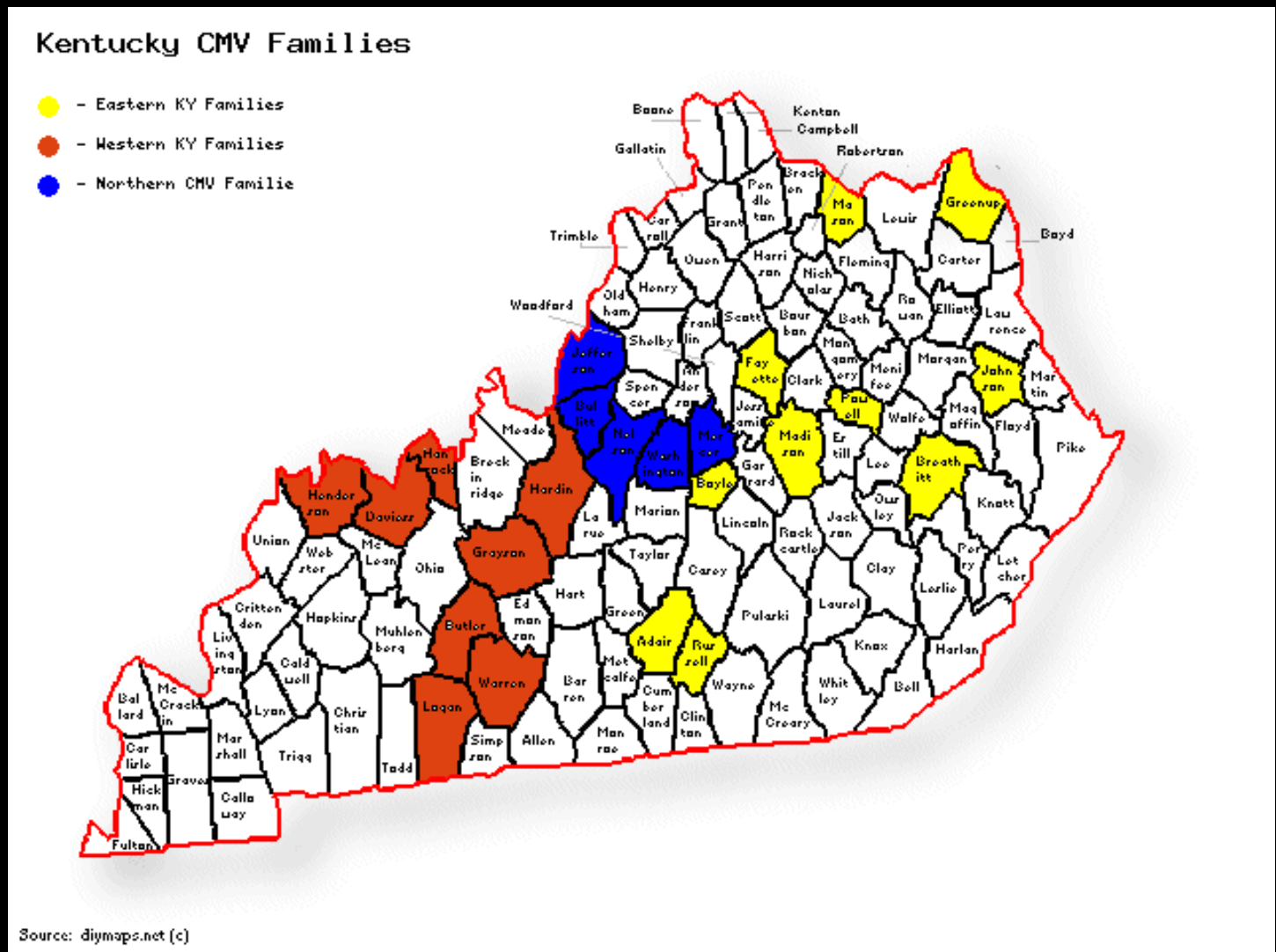
# What CMV Families look like



- All races
- All ages
- All social economic
- All geological regions
- All genders
- All religions
- All ethnic orientation
- Single mothers with multiple children
- Two parent families
- Single dad families
- Adoptive families
- Grandparents raising grandchildren
- Families with multiple disabilities



- 42 Families
- 7 CMV Angels
- Ages 1 - 31yrs
- Most under 13yrs
- 23 counties



# What cCMV Families Need

1. To not only be heard, but also to feel heard. We are used to being told everything, but not many stop and ask. We have a lot to share, if you will take a moment to ask.
2. To not be blamed for our child's diagnosis. The fact that this disease is contracted by us and given to our child means we already feel guilty. Please take a moment to tell us that it was not our fault. Most have never heard those words.
3. To be valued as a treatment team member. We sleep and breathe this child. I guarantee we have a few things to offer the treatment team. We might can teach you something.
4. To answer our questions honestly and be given helpful information. Please don't tell use to google CMV! Send us to the National CMV Foundation. The handouts are free have them in your office.
5. To see our child as a whole person not merely their diagnosis. Many of our children have lots of complex medical issues. We see specialist routinely that only look at that one area of concern. Not many stop and look at our child as a whole.

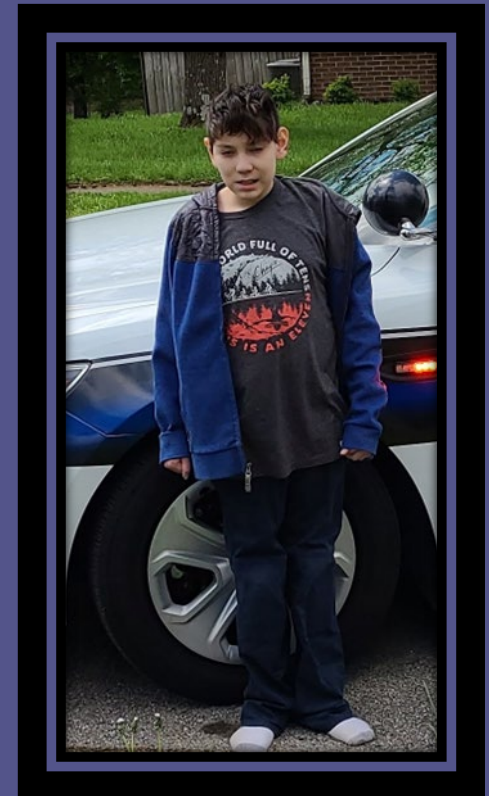
“Until you have a kid with special needs you have no idea of the depth of your strength, tenacity, and resourcefulness.”



# How to Address the Needs of cCMV Families

1. Please be brutally honest. We deal with cold hard truth everyday. Truth is the only way we can wrap our head around it.
2. Please use compassion. We struggle with the things we must put our children through. We are trying.
3. Please give us options, when there are options to be had. Much of our child's medical needs are beyond our control and we don't get many options.
4. Please address us in person, but also give it to us in writing. We often very overwhelmed and we are only able to hear every other word. This is important information that we will need later. Please understand and offer us a summary.
5. Please educate yourselves about cCMV before you treat our child. We are all about educating people about CMV, but it is a big relief when that person is not our medical professional.

“Parents who have children with special needs hear about all the things that they need to do better, improve, change...more than any other parent. It's about time that they hear the things that they do right.”



# Good Relationship with cCMV Families Professionals

1. Show interest in our home lives, since that is where our child spends the most of their time. We don't expect you to be BFFs, but we want to know you care.
2. We may totally geek out and come in with all kinds of diagnosis and possible treatments for our child. Please don't shoot us down! We love our child, and we are desperate to help them.
3. Share pieces of your life, if possible. We sometimes feel very vulnerable spilling all of our stuff for you. It can help, if we can see you as human too.
4. Please don't count our child out too soon! Their prognosis might not be good, but we still have hope and faith. Don't rip away the faith we are holding. Tell us the truth but acknowledge that miracles do happen.
5. Please don't ever shame us for having to make very difficult decisions. We are often in a position, where there is no good decision. Please understand that we have to make the choice we can live with. We will be the ones to live with it.

*“Parents of children with special needs create their own world of happiness and believe in things that others cannot yet see.”*



# Good Relationship with cCMV Families

## Non - Professionals

1. Invite us to the cooks and the play dates! We are still a family, and we have a child. Just because our child has medical concerns doesn't mean we don't want to be included. If we are unable, we will let you know.
2. When you know life is hard, such as hospitalization, sickness, or even new diagnosis. Don't say, "I'm here if you need anything". We hear that so often that we write it off. If you truly want to help, give us real choices – Would you rather I cooked a meal, cleaned your house, or babysat your children so you could go to dinner.
3. Please be very flexible when scheduling with our family in mind. Life has taught us the hard way that plans change. We don't aim to put people out, but our child's health must be our top priority.
4. Please be our friends. Life often demolishes our social lives due to health concerns, doctor's visits out of state, and the daily medical routines. We will not be the best of friends, but stick with us, if you can.
5. Learn how to love our child! Learn what makes them laugh and what catches their eye! Learn how to hold them. It takes a little more work, but it will mean the world to us.

“Being a special needs parent means celebrating strengths, choosing to believe there is sun behind the clouds, and never ever giving up.”



## What the families are saying:

“When you don’t know the answer, tell us that, but be willing to help us find the answer.”

“I wish we were told that with early interventions, our child could have a quality life.”

“Don’t discount me because I’m not in the medical field.”

“I stay up at night researching things I can do for my child.”

“The doctors only ask about my medical child. They don’t ask about my other children or how our home life is going.”

“My child lost an eye due to CMV. Doctors that did not read the charts first came in and asked what we had done to our child’s eye.

They made us feel like garbage”

“Let us know CMV is not uncommon!”

“Validate that something is going on with our child and be willing to try multiple paths to get an answer.”

“Know my child’s name before you come in our room.”

“I educate people everyday about CMV. Don’t make me have to educate you too.”

“Let us know about CMV during pregnancy”

“It is very frustrating to be discounted or not heard as he is with me 24/7 and I know him and his medical journey better than anyone”

“Sometimes I need to cry.”

“I have other children.”

“Educate yourself about CMV! We need you to be the professional”

“You can educate me, but don’t accuse me of harming my child”

“Let us know there are other families and other children. Let us know we are not alone”

“Please remember my child is not a majority or a minority. My child has cCMV, but they are uniquely themselves.”

“Validate my feelings”

“Tell me it is not my fault”

“Please don’t tell me my newborn will never walk or talk or be able to do anything.”



## Advice from the professionals:

“ Make the parents feel that they are not alone.”

“Don’t limit a child’s potential based on diagnosis.”

“Listen to the family”

“Learn about the family and what are their biggest struggles. This will help in connecting them to resources.”

“See the child as a whole child and not just symptoms of the aftermath of the damage done by the virus.”

“Please be education and informed about cCMV”

“Make sure they are receiving early intervention and they are being seen by infectious disease, audiology, and pediatric ophthalmology.”

“Don’t assume there are other specialist and that they will address an issue you are seeing. Be sure this issue has been addressed and is being followed. If not, help make the referrals for the family.”

“Interact with the child.”

“Connect families with other CMV families and with CMV organizations.”

“Kindness can go a long way.”

“Ensure that families understand what you are conveying to them.”

“Create an environment where families feel free to ask any and all questions. If you don’t have the answers, help them to find the answers.”



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If you or someone you know is a parent of a child with cCMV feel free to reach out to me or send them my way! I will help them find the support and services they need an answer any questions they may have. Feel free to share my contact information.

You can order free CMV materials including brochures and posters from the National CMV Foundation. You will find an order form on their website. Also if you need assistance in order materials, let me know and I will gladly help you out.