

Family Weekend

Frequently Asked Questions

Who can attend Family Weekend?

Anyone impacted by CCM is welcome. Some people attend on their own, while others come with parents, spouses, partners, children, siblings, grandparents, or extended family members. Whether you are newly diagnosed, a longtime community member, or supporting someone you love, there is a place for you here.

I've never attended before. Will I feel out of place?

Not at all. Family Weekend is only in its second year, which means most people attending haven't met each other yet either. This is a community that is genuinely warm, welcoming, and easy to find your footing in. You don't need to know anyone before you arrive, and many people find that the connections they make here are unlike anything else.

Is Family Weekend only for people who are seriously affected by CCM?

Not at all. CCM shows up differently for everyone. Some people attend with significant physical challenges. Others are living with few or no symptoms but carry the weight of a diagnosis that can feel isolating and scary. Whatever your experience looks like, it is valid and it belongs here. This weekend is for all of it.

Can I attend alone, or do I need to bring family members?

You are absolutely welcome to come on your own — and many people do. Whether you attend solo or bring a whole crew, you will find people to connect with. Some attendees bring children, spouses, parents, or siblings. Others come alone and have a great time too.

What about children? Are there activities for them?

Yes, and kids are a real part of what makes Family Weekend special. Children have their own dedicated activities and space where they can meet and connect with other kids who understand their experiences. At the same time, parents have meaningful time to connect with other adults. Throughout the weekend there are also moments when everyone comes together. No one has to choose between their own experience and their child's.

Is the venue accessible?

Yes. Family Weekend is held at a camp that operates year-round as a fully accessible facility, designed from the ground up to welcome wheelchair users and accommodate a wide range of physical needs. If you have specific accessibility questions, please don't hesitate to reach out — we are happy to help.

What is Family Weekend actually like?

Think of it less like a conference and more like a retreat. The weekend is relaxed, informal, and centered on connection — time to meet people who truly get it, share a meal, laugh, rest, and simply be around others who understand life with CCM. Almost every part of the weekend offers two options, so that people with different energy levels, mobility needs, or preferences always have a way to participate that works for them.

What's included with registration?

Registration covers everything you need for the weekend: all meals from Friday dinner through Monday breakfast, lodging for Friday, Saturday, and Sunday nights, and all regular activities. There may be a small number of optional extras — like horseback riding — available for an additional cost, but there is plenty to do and enjoy without them.

Registration is kept affordable thanks to generous donor support through the Alliance to Cure CCM, which subsidizes the cost of the event. Those donations could go toward many things, so we are genuinely grateful for every dollar that makes this weekend possible. If you'd like to support Family Weekend — or the broader work of the Alliance — we would gratefully welcome your contribution.

What if I can't afford the travel costs?

We understand that travel can be expensive, and we do not want cost to be the reason someone misses out. Limited travel assistance funds are available, and you can apply using the link below. If you have questions before applying, you are always welcome to reach out directly.

[Link to financial assistance form]

I'm hesitant to come. How do I know it's worth it?

That hesitation is completely understandable — especially for something new, with people you haven't met. But this is a community built around a shared experience that not many people outside of it truly understand. Family Weekend exists because of how much it means to be in a room full of people who do. One of the things we hear most often afterward is simply: "I'm so glad I came."

Is this event going to happen again?

Yes! Family Weekend is planned to run every other summer, so this year is a real opportunity to be part of something early and growing. The community that shows up helps shape what this gathering becomes. We hope you'll be part of it.

Questions? We'd love to hear from you. Reach out anytime. darla@alliancetocure.org