

Frequently Asked Questions

What is a virtual conference?

This year we will be providing educational sessions, research updates and peer to peer connections via an online and mobile platform. This means you will be able to watch the presentations and connect with other families on your computer, tablet, iPad or phone. The program will be similar to what you are used to seeing at our in-person conference. In addition to research updates there will be sessions on newborn screening, drug development and seizure management, as well as other topics important to the GM1 community. We will also have scientific posters and ways for you to connect with sponsors and researchers.

When will the conference be held?

The conference will take place on various dates in September.

How do I sign up?

A link to the conference registration page will be available mid-May, and this link will also be on all our social media pages and website (curegm1.org).

Do I need to download an app to access the virtual conference?

No, you can fully participate in the conference from your computer! If you prefer to participate from your phone or tablet you can download the app from your App Store. Each person who has registered will receive information on how to use the app or web portal. All the conference information will be available within both.

Is there a fee to attend conference?

No, there is no fee for families to register for conference.

Is this relevant to me if my child who suffered from GM1 passed away?

Absolutely! You can help by attending and honoring your child's legacy while supporting patient advocacy and other families.



Frequently Asked Questions

Will there be a webcast or recording made available to those who cannot attend?

We will post the videos on the Cure GM1 Foundation YouTube channel following the conference.

Will I be able to understand the presentations if I am a patient and not a scientist?

The talks are specifically intended to be presented to patients. This year, the focus is much less on science and more on the patient community.

Is this conference open to GM1 families outside of the United States?

Yes, the conference is open to anyone across the world. We are excited for this opportunity to bring together families that would not generally be able to meet in person.

Will I still get to connect with other GM1 parents?

Yes! There will be opportunities to connect via chat in groups as well as one on one through the conference app and website.

Can my extended family join the conference?

Yes, we would love to have any extended family join who are interested.

Will there be research updates?

Yes, similar to our in-person conference we will be providing research updates.

Will the sessions be recorded for us to watch later? Yes! Some of the content will be recorded and available for up to one year through the app or the website.