

Celiac Disease Genomic, Environmental, Microbiome and Metabolomic Study

55 Fruit Street (Jackson 14) • Attn: CDGEMM Study • Boston, MA 02114

The CDGEMM Study enrolls infants who have a parent or sibling diagnosed with celiac disease (CD). The risk of developing CD for these infants is increased by 8-25% over that of the general population. Enrolled children are followed from birth until they reach five years of age, including periodic monitoring for signs of CD. A main aim of the study is to track the development of the [gut microbiome](#) by collecting the child's stool samples and watching how the microbial communities evolve over time. We hope to identify a distinct microbial pattern that will allow us to predict who will develop CD before it happens so that we can learn how to prevent it.

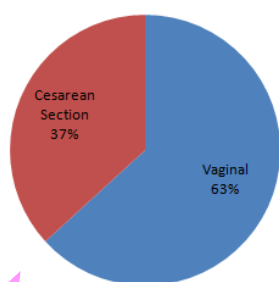
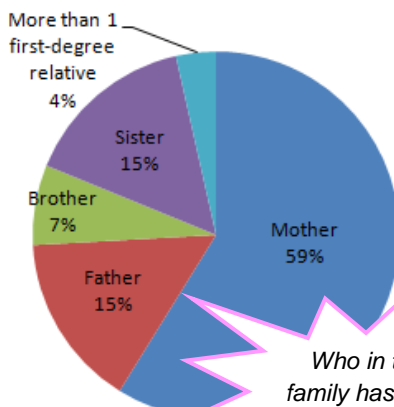
CDGEMM by the Numbers

Since the kick-off of CDGEMM, we have:

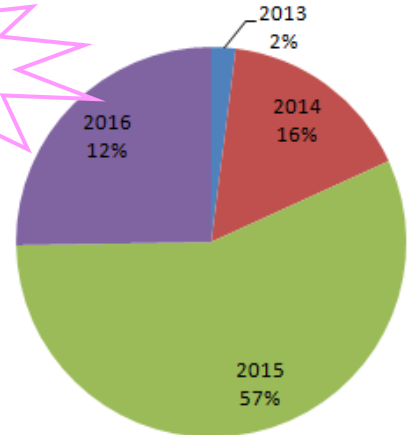
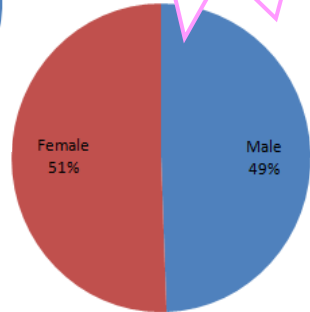
- ☑ Enrolled **60 children** in the United States
- ☑ Enrolled **40 children** in Italy
- ☑ Collected **232 stool** (poop) samples
- ☑ Conducted **98 celiac antibody** tests

The Race to 100

Ambitiously, the CDGEMM Study aims to enroll a total of 500 infants. It is with great excitement that we announce reaching our first big benchmark – the enrollment of the first 100 precious GEMMs! Our study team has certainly learned a lot from the “Race to 100,” and we are excited to continue to expand the study. Some “fun facts” about the babies that make up our 100 include:



When Were Participants Born?



CDGEMM Across the Globe

CDGEMM participants are currently present in **18 of the 50 United States**. Due to this, our study team ships an average of 10-15 sample collection packages per month. Each day, we coordinate with our participant's pediatricians and local lab draw facilities to ensure the CDGEMM experience is as smooth as possible for our remote participants. If you are participating (or want to participate) remotely, simply let our study team know and we will help to coordinate appropriately.

Our Italian study sites continue to experience *exceptional* recruitment!

Current CDGEMM participants are located in 7 Italian provinces situated in the center, south, and north-west regions of the country. We are excited to continue to spread word about the study through the strong patient network established and maintained by the Italian Celiac Society (AIC).



What's New with CDGEMM?

Study forms are smart-phone compatible! If you receive emails to your smart phone, feel free to open the links to your study forms *directly on your phone*. We know life with a small child (or children) is busy, but completing forms for the CDGEMM Study shouldn't add to your stress.

Collected study samples recently? If so, you may have noticed we have increased our lines of communication. All participants receive an email with your shipment's tracking number each time materials are shipped for a sample collection time point. The email also summarizes the samples required at that time so you know what's coming. Additionally, you'll receive a confirmation on the day that study materials are received by our lab – this way, you'll never have to worry about if your child's sample made it to us safely.



Research Coordinator
Stephanie receives a stack of
CDGEMM samples in the lab



Having trouble keeping track of the sample collection schedule? All participants in CDGEMM will receive a personalized calendar at the time of enrollment. This calendar will include projected visit dates and allow you to easily keep track of what is required at each visit. These cute reminders are perfect for hanging on the fridge to ensure you never miss a sample collection time point.



Interested in networking with other CDGEMM participants? Behind each of our enrolled babies is a family living with (at least one individual diagnosed with) celiac disease. We are in the process of planning various events, including online groups and happenings, to help bring members of the CDGEMM community together. Feel free to share your thoughts and preferences for how to build *YOUR* CDGEMM community with our study team!

What GEMMs are Saying

A parent of a current participant says that they would recommend participation in the CDGEMM Study to others because *"this study will better our understanding of the development of celiac disease and help us to respond to our child's needs"* – and we couldn't agree more!

Parents and practitioners alike are encouraged to anonymously submit their comments, criticisms and praise [here](#) for a chance to be featured in our next newsletter. Whether it is good, bad, ugly or glamorous – we want to bring you the best possible CDGEMM and love to hear what you think!

Keep up with CDGEMM

Don't keep up with the Kardashians – Keep up with CDGEMM! Remember that we are still recruiting precious GEMMs. **Consider sharing information about CDGEMM with your friends, relatives and/or patients with celiac disease!** Also, be sure to visit www.CDGEMM.org for more information about the study.

Other ways to keep up with CDGEMM include:

Like us on **Facebook**: Center for Celiac Research

Follow our **@CeliacDoc** or our **@CeliacResearch** on **Twitter** and **#CDGEMM** to join in the conversation

