

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 that naturally live in the intestines 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 **142 children** in **32 of the 50** United States
- ☑ Enrolled **130 children** in Italy
- ☑ Enrolled **15 children** in Spain
- ☑ Collected **819** poop samples
- ☑ Conducted **335** celiac antibody tests

Exciting Pilot Analyses

In our last update, we mentioned that the first pilot analysis was underway using stool samples from a subgroup of participants. Our study team identified a small subgroup of children who had stool samples from three different time points: 7-15 days after birth, 3 months, and 4-6 months of age (all samples before solid foods have been introduced). This subgroup included children who are at high and standard risk (based on the presence of either DQ2 and/or DQ8 genes) for developing celiac disease, as well as a few infants who do not carry either the DQ2 or DQ8 gene and thus are not at risk of developing celiac disease. Further, the children were stratified based on birthing delivery mode (vaginal or caesarean section), feeding type (breast or bottle fed), and antibiotic exposure.

Since this initial pilot analysis began, we have identified and included several more children who fit the criteria for this specific analysis. We have now included children not just from the United States, but also from our collaborating sites in Italy. While all the same time points and objectives, it adds a new dimension with the examination across possible geographic differences. With samples being collected and shipped around the world for analysis, it is exciting to share that preliminary data shows that our data collection and analyzing techniques are feasible.



In addition, there are now a few children in the study, from both the United States and Italy, who have gone on to develop celiac disease. While early detection, due to the routine blood work as part of the study, is a benefit of this study, we are now able to analyze samples from before and after the development of celiac in these children. Several of their samples from all study time points collected, along with matched controls (based on gender, age, genetic risk, delivery mode, etc.), were included in this analysis. This includes samples from not only before/after the development of the disease, but also before the introduction of solid foods into their diet. While currently a small subgroup, it is the beginning of a major goal of this study: *identifying a distinct microbial pattern that will allow us to predict who will develop CD before it happens.*

In both analyses, we hope to learn if there are differences between the developing microbiome in these infants. We are excited to share full results of this research with you all soon!

Who's Talking about CDGEMM?

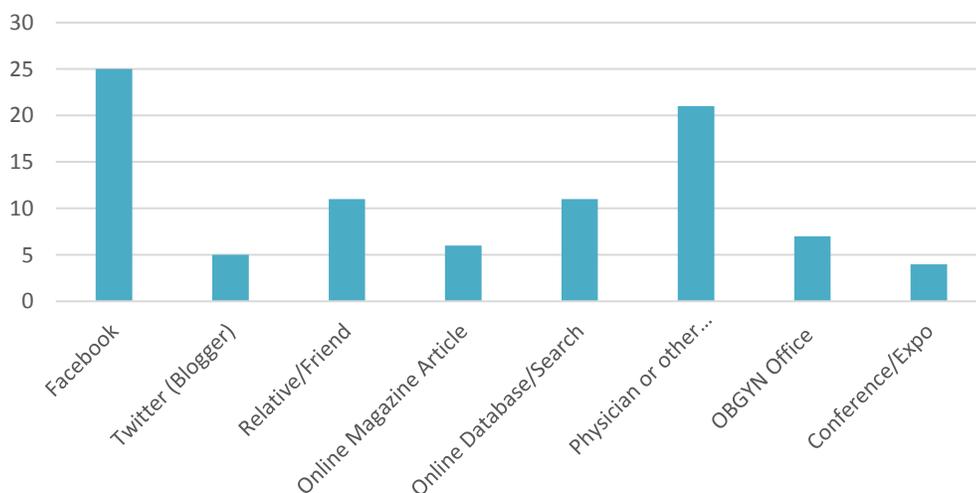
Dr. Maureen Leonard was featured on the Gluten Free Guide Podcast at Children's National Medical Center. She discusses not only celiac disease, the microbiome and genetics, but also the CDGEMM study and what it involves. She focuses on the goals of the study and how we hope to prevent celiac disease by looking at samples from these infants at risk. Click [here](#) to check out the full podcast.

Several online bloggers and websites recently helped spread the word about CDGEMM through postings on their social media accounts. [Gluten Free Easily](#) published an article on their website and Facebook page that outlines in detail who is eligible, how to enroll, and mentions a few FAQs. [FindATopDoc](#) also wrote about the study and notes what factors we are examining and hope to identify. [Beyond Celiac](#) has been very helpful in sharing information and updates about CDGEMM, and posted a recent update on their social media accounts. Click on the links to see the complete articles. We continue to be very appreciative to everyone who takes the time to discuss, share, and write about the CDGEMM study!



Help us reach 200 US GEMM's

As demonstrated above, a lot of our recruitment and promotion for the CDGEMM study has come from online sources, such as Facebook, Twitter and online blogs. Social media is a powerful source when it comes to spreading information. We were interested in how our current families found out about the study, so we asked them a brief survey. Below you can see the wide-range of answers we received, emphasizing that all outlets can be beneficial in finding GEMMs to help us make history.



We are still recruiting precious GEMMs for the CDGEMM Study. **Children aged 6 months or younger who have a parent or sibling diagnosed with celiac disease are eligible to participate.**

If you have an online blog or social media account and want more information to share with your followers, be sure to visit www.CDGEMM.org or send us an email at cdgemm@mgh.harvard.edu.