

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 **122 children** in **27 of the 50** United States
- ☑ Enrolled **108 children** in Italy
- ☑ Enrolled **10 children** in Spain
- ☑ Collected **604** poop samples
- ☑ Conducted **236** celiac antibody tests

[CDGEMM Families Get Social](#)

After months of planning, the CDGEMM Study Team recently held its first event for local families who are enrolled in the study. The party took place here at Mass General Hospital in June 2017, where study participants and their families enjoyed delicious gluten-free food, arts and crafts for the kids, and even a photobooth with unlimited pictures! Local food vendors donated gluten-free items and helped to make this event a huge success! [Lantana Hummus](#) provided small packets of gluten-free pita chips and several different flavors of hummus. [Something](#)



[Sweet Without Wheat](#) (located in Woburn, MA) provided everyone's favorite donut holes. [Twist Bakery and Cafe](#) (located in Millis, MA) provided an assortment of gluten-free breakfast scones, muffins, cinnamon rolls, etc. Needless to say, the food was one of the best parts! However, getting to spend time meeting families, including all of the adorable GEMMs and their siblings, as well as the opportunity to update everyone on the status of the study

was extremely rewarding for our study team. Thank you to everyone who attended the party, and to all our GEMM families across the country and the world who continue to help us make history for celiac disease. We are excited to hold more events in the future!

While local participants were able to attend the event in June, we wanted to give all families across the country the opportunity to talk with our study team. Thus, in January 2017, the CDGEMM study team hosted their first live video chat on YouTube. Dr. Maureen Leonard (study doctor) and Pam Cureton (clinical dietitian) were live to answer questions about the study, celiac disease, and the gluten-free diet.

Check out the full video chat here:

<https://www.youtube.com/watch?v=WoORy9DIXKQ>



Pilot Analysis Underway

The first pilot analysis for the CDGEMM study is currently being conducted using stool samples from a subgroup of participants. The small subgroup includes infants 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. We are interested in comparing the different microorganisms found in the infants' stool samples based on four categories: genetic risk for CD, birthing delivery mode (vaginal or caesarean section), feeding type (breast or bottle fed), and antibiotic exposure. All of the stool samples were collected at three separate time points: 7-15 days after birth, 3 months of age, and between 4 and 6 months of age. With this analysis, we hope to learn whether or not there are differences between the developing microbiome of all infants born via c-section or vaginal delivery, as well as differences between all infants based on their genetic risk for celiac disease. We are excited to finalize and publish results from this pilot analysis, and hope to share some information with you in the near future.



It Takes a Team

We are officially recruiting participants for the CDGEMM Study in the United States, Italy, and *now* also in *Spain*! Our goal is to recruit a total of 750 infants from these three countries, and we are just about a third of the way there. With recruitment on the rise, our study team works hard to ensure that all sample materials are shipped out and processed in a timely manner. Every week, we ship out an average of 8-10 sample collection packages to families all across the country. Every day, we help 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.

What happens to samples that are collected and shipped back? When sample packages are received here at Mass General Hospital, they either contain samples of a child's blood and stool or a stool sample alone, depending on the study time point. All stool samples are stored in our freezers until future analysis. Our study team then processes the blood samples, including separating the blood into its components, and uses a small portion of the sample to perform antibody testing for markers of CD. These results are shared with families so that they are aware whether or not their child is showing signs of celiac disease. At the 12-month study visit, we also perform genetic testing and again share these results with the family so that parents have better idea of their child's risk of developing celiac disease. *Check out our January newsletter for more information on genetic testing:*

<http://www.massgeneral.org/children/assets/pdf/cdqemm-january-2017-newsletter.pdf>

Between study recruitment, sample collection and sample processing, it certainly takes a team to make sure that the study runs smoothly, and that all sample collections are as easy as possible for our participants!

Help us reach 200 US GEMM's

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. **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.