

Celiac Disease Genomic, Environmental, Microbiome and Metabolomic Study

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

The CDGEMM study enrolls infants aged 6 months or younger who have a first degree-relative (parent or sibling) diagnosed with celiac disease (CD). A child's risk of developing celiac disease is increased by 8-15% over the general population when they have a first-degree relative diagnosed with CD. Participation in the CDGEMM Study provides monitoring for signs of CD throughout childhood AND collects valuable data for research purposes that could ultimately lead to discovering ways to prevent celiac disease!

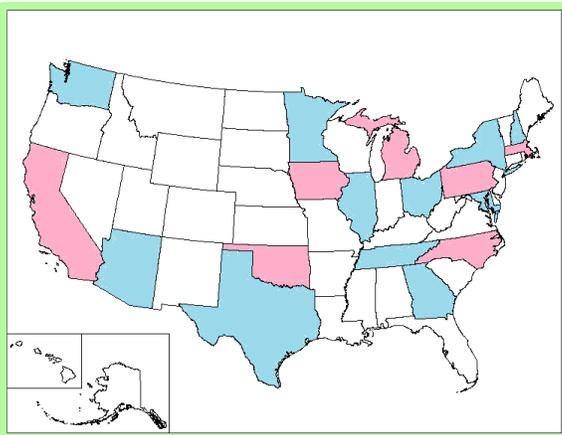
CDGEMM by the Numbers

Since the kick-off of CDGEMM, we have:

- ✓ Enrolled **52 children** in the United States
- ✓ Enrolled **23 children** in Italy
- ✓ Shipped **150** packages of study materials
- ✓ Performed **15** celiac genetic tests

CDGEMM Across the Globe

Many of our participants receive study materials directly to their home by mail, so GEMMs have continued to emerge all over the United States! Check out our updated map to see where in the United States GEMMs are located – any pink or blue states indicate that GEMMs can be found there.



CDGEMM Italia has recruited their first 23 infants across 4 study centers in record-breaking time! Dr. Francesco Valitutti is the physician coordinating recruitment for the Italian branch of CDGEMM. We asked him to share the secret behind Italy's success in conducting celiac disease research. He mentioned that "Italian patients with celiac disease strongly believe in research, largely because they feel part of a project that will make history for celiac disease. The Italian Society of Pediatric Gastroenterology, Hepatology and Nutrition

(SIGENP) is a well-established and successful network for research, while the Italian Celiac Society (AIC) is helping us a lot both regionally and nationally to spread news of the study on social media, websites, and printed newsletters. Families themselves feel part of the network, and there is a lot of commitment to promoting the study locally by outstanding colleagues – both pediatric and adult GI doctors – with expertise in CD." **Che meraviglia!**

CDGEMM in the News

Don't you love a great gluten-free blog? We are lucky to share that many influential celiac or gluten-free bloggers have recently helped spread the word about CDGEMM! You can find a full list of their stories on [this section](#) of our website. Also check out the **#CDGEMM** on Twitter to find some great celiac advocates talking about the CDGEMM Study!



MyKidsFoodAllergies
@kidsfoodallerg

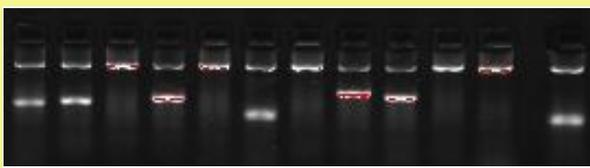
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Can the **#microbiome** predict who develops **#celiac** ? **@CeliacResearch** aims to find out!
[CDGEMM.org](#)

The scientific journal *Nutrients* recently published our paper entitled “Celiac Disease Genomic, Environmental, Microbiome, and Metabolomic (CDGEMM) Study Design: Approach to the Future of Personalized Prevention of Celiac Disease.” In our paper, we discuss the design of the CDGEMM Study and offer insights into how our findings have the potential to pave the way for the future of personalized medicine – particularly in the prevention of celiac disease. You can read the whole paper [here](#).

What do You Mean, “Celiac Genetics”?

Children enrolled in the CDGEMM Study are tested for the HLA DQ2 and DQ8 genes, which are those known to be compatible with celiac disease. Genes are passed from parent to child, providing support for the genetic component of celiac disease. A person must carry at least one of these genes for celiac disease to develop. However, not all people with a celiac-compatible gene develop the disease. In fact, approximately 30% of the general population carries a gene compatible with celiac disease, and only about 1% of the population has celiac disease. So, why perform a celiac genetic test?



This is an example of a result that we might see after performing a genetic test. Each of the lower bands corresponds to a “piece” of the genetic type, which together make up different celiac-compatible genes. This person carries both the DQ2 and DQ8 genes.

Among many others, one of the goals of CDGEMM is to understand how specific genetic types may predict who develops CD. Recent research studies have shown that carrying a specific genetic type, two copies of the DQ2 gene, creates the highest risk of developing CD. In one study, nearly 26% of children from celiac families who had this genotype developed CD by age 10. Right now, a “celiac genetic” test, tells us if your body has the right “tools” to develop CD. Hopefully CDGEMM will teach us

more about what each genetic type means and how to use that knowledge to predict who will develop CD!

Should my child continue to participate in the study if they don’t have “celiac-compatible” genes? The answer to this question is absolutely! It is possible that a child will not carry celiac-compatible genes even if they have a relative with celiac disease. This may occur if only one of the child’s parents carries a celiac compatible gene and the child did not inherit it. These children are among some of the most important participants in CDGEMM because, since they cannot develop celiac disease, they will serve as healthy control patients. These patients are essential to identifying factors that differ between healthy patients and children who go on to develop CD.

What GEMMs are Saying

A parent of a current participant explains why she would recommend participation in CDGEMM to other individuals who have a family member with celiac disease:

“As a mom with celiac disease, I was not sure when to introduce gluten into my children's diets. With each child there seems to be more information available. I want to help other families - and potentially my own children - have the best information about when to introduce gluten to their babies and anything else they can do to reduce a genetically predisposed child's risk of developing CD.”

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! We love to hear what you think!

Keep up with CDGEMM

Don't forget that we are still recruiting GEMMs! Be sure to visit www.CDGEMM.org for more information about the study. We have recently **updated our website** to address additional Frequently Asked Questions and more!

Other ways to keep up with CDGEMM include:

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

Follow our **@CeliacDoc** or our **@CeliacResearch** on **Twitter**



Gluten Dude
@GlutenDude

 Follow

Very cool celiac study being done by Dr. Fasano and crew. Got celiac and an infant? You can help: massgeneral.org/children/resea ... #CDGEMM