

GENETICS OF OROFACIAL CLEFT PROJECT

Summer 2021 Newsletter

STUDY UPDATE:



**GENETICS OF
OROFACIAL
CLEFT PROJECT**

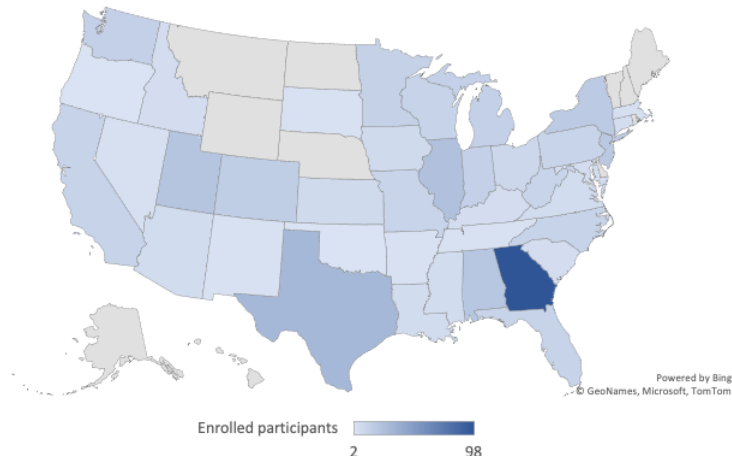
We're re-branding! The Emory Cleft Project is now the Genetics of Orofacial Cleft Project. Our study is still associated with Emory University. We've changed the name to add some clarity as to what our study is all about – the genetics of orofacial clefts. In the next few weeks, you'll see our website and other study-related material updated to reflect this name change. If you have questions about our project, feel free to contact us at cleftproject@emory.edu.

STUDY REMINDER:

Thank you for completing your surveys, sending pictures, and returning your samples to us! If you have not already done so, it's not too late! If you would still like to return your samples or complete your surveys, please contact us.

If you have recently changed your home or mailing address, email, or phone number, please provide us with your updated contact information.

STUDY ENROLLMENT UPDATE:



We have now recruited individuals from 430 families, and have collected 628 samples from 207 OFC families, including individuals with cleft lip and/or palate and their family members. We hope to reach our goal of 1000 samples by the end of 2022- and we are already well on our way to reaching that goal! We have recruited families all over the United States and are still actively enrolling participants to our study, both remotely and in-person. We have also recruited some Van der Woude syndrome families internationally. Here in Atlanta, we are recruiting families in collaboration with several clinicians at the ENT Clinic and the Medical Genetics Cleft Clinic at Children's Healthcare of Atlanta Center for Advanced Pediatrics (CHOA-CAP) and at Emory University Hospital Clinics.

PUBLICATION UPDATE:

The Cleft Palate and Craniofacial Journal recently published a paper written by our study team, which looked at the feasibility of using social media advertising to recruit participants for genetic research of orofacial clefts. Our findings were based on our recruitment experiences with this study since 2019, and from our participant experiences survey that some of you completed. Thank you so much once again for your valuable contributions to our research! A link to the full manuscript is available on our website.

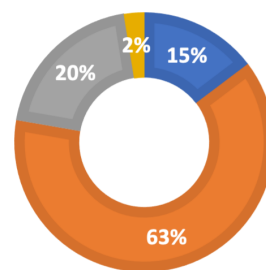
WHAT DID WE DO?



The goal of this paper was to assess the effectiveness of social media advertising through Facebook support groups for research study recruitment. We asked several Facebook support groups for OFCs to post advertisements that include study information, contact information, and a link to an online screening survey. Interested individuals were directed to an online screening survey, and eligible participants were enrolled and completed a series of online surveys. Sample collection was done remotely by mailing kits to the participant's home address. From 313 individuals screened for eligibility, DNA sample kits were sent to 263 individuals. Within 4-5 weeks, 60% of the participants returned their sample collection to our lab. We also distributed a feedback survey to completed participants to gather information about their experiences with the study.

CLEFT TYPES OF ENROLLED SUBJECTS

■ Cleft Lip ■ Cleft Lip and Palate ■ Cleft Palate ■ Other



WHAT DID WE FIND?

We found that this method of recruitment was effective in enrolling a large number of participants from various geographical locations. By simplifying the screening and enrollment process, using online surveys, and allowing for remote collection of samples, we were able to reduce the staff time and costs associated with in-clinic recruitment. While the study population included a variety of OFC phenotypes, participant demographics lacked diversity, particularly in regards to race and ethnicity.

Our feedback survey showed that 41% (or 2 out of 5) of study participants were new to research, suggesting that social media advertising can attract people who may have otherwise not had the opportunity to participate in research. This is a promising finding for using social media recruitment to increase accessibility and availability of research opportunities to more people. Overall, recruitment using social media advertisement was a success that could be modeled in future research studies for orofacial clefts or other rare conditions.



Meet Our Students



KIMBERLY DIAZ PEREZ
DOCTORAL STUDENT

Hello! My name is Kimberly, and I am a rising 4th-year doctoral student in the Leslie lab in the Genetics and Molecular Biology graduate program. I am interested in studying the genetic etiology of complex human diseases. Currently, my work in the lab focuses on dissecting the role of rare genetic variants in non-syndromic orofacial clefts using genetic sequencing of diverse study cohorts.



KELSEY ROBINSON
DOCTORAL STUDENT

Hello! I'm Kelsey, a rising 2nd-year PhD student in the Genetics and Molecular Biology Program. I started my career in veterinary medicine and discovered my love of research while investigating inflammatory brain disease in dogs. Since then, I have dedicated my time to studying the genetic basis of disease. I am working to identify variants that contribute to abnormal craniofacial development resulting in cleft palate.



HAILEY HWANG
MASTER'S STUDENT

Hello! I'm Hailey, a second-year MPH student studying Epidemiology at the Rollins School of Public Health at Emory University. My current interests lie in genetic epidemiology and statistical genetics. I am currently working on creating GCP newsletters. I am also helping to investigate the contribution of rare noncoding variation to the formation of cleft lip with or without cleft palate.

An important part of the Emory Cleft Project's mission is to provide helpful information to our participating families and the greater OFC community.

Please follow us on social media for ongoing study updates!

Website: www.cleftproject.org

Twitter: [@cleftproject](https://twitter.com/cleftproject)

Facebook: facebook.com/cleftproject

Instagram: [@cleftproject](https://instagram.com/cleftproject)

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