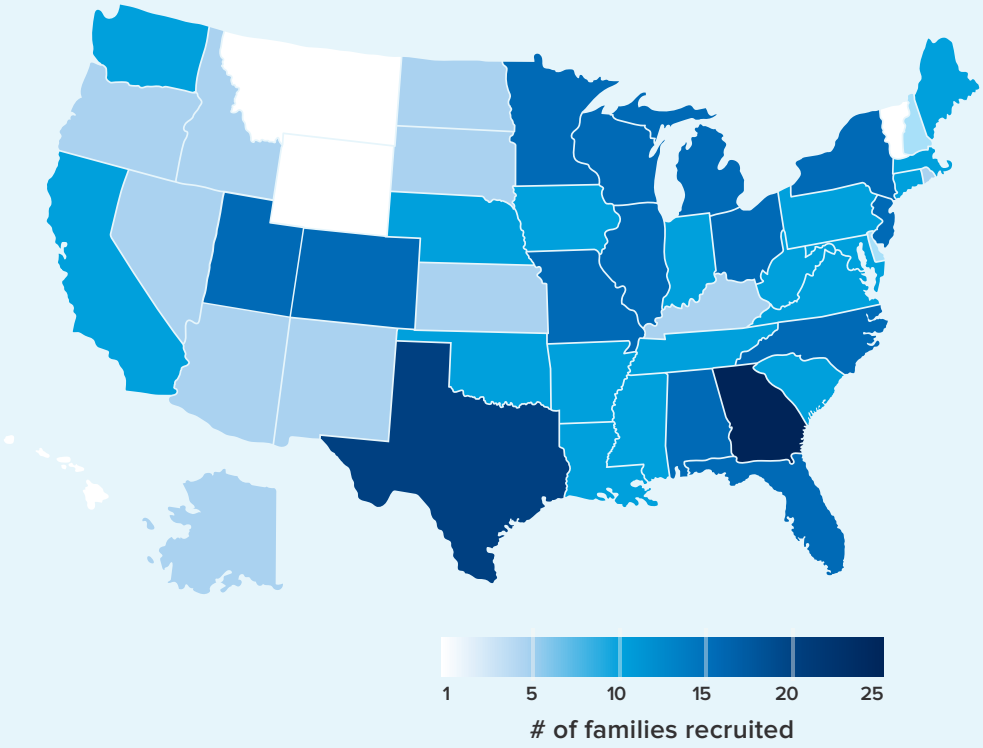
LESLIE LAB • APRIL 2019 • ISSUE 2 • VOLUME 1

EMORY CLEFT PROJECT

ABOUT THE STUDY

The purpose of the study is to understand the different factors that contribute to craniofacial differences, including orofacial clefting. The overall goal of the study is to develop a better understanding of genes related to orofacial clefts and how they interact with the environment, in order to improve treatment, management, and prevention of orofacial clefts.

RECRUITMENT UPDATE



We have now recruited familes in 45 out of 50 states.

We have also recruited international families from Canada, France, Australia, New Zealand, Ireland, Germany and the UK

CURRENT ENROLLMENT

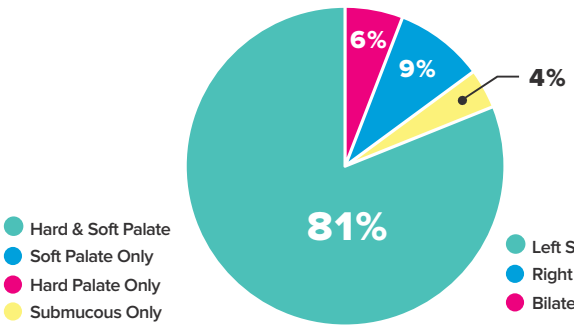
- Over **275** Families
- Over **325** Participants

SAMPLES RECEIVED

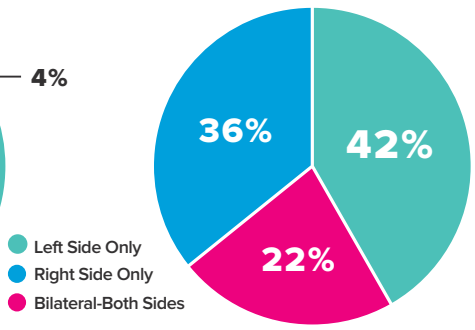
- Almost **400** Samples Returned

(Samples include study participants + families)

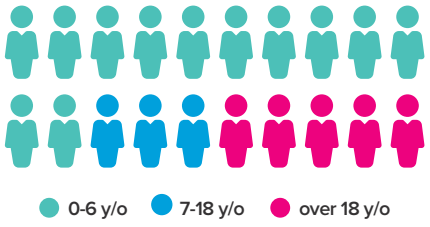
PARTICIPANT CHARACTERISTICS



CLEFT PALATE TYPE



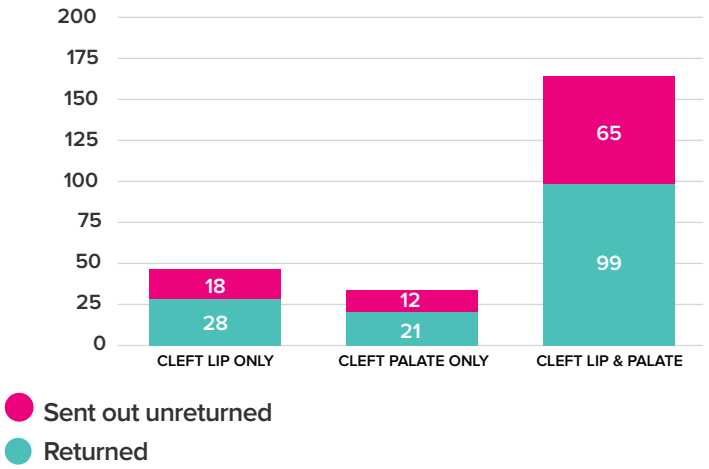
CLEFT LIP TYPE



Ages of participants range from newborn to 72 years old.

SAMPLE COLLECTION PROCESS

SAMPLE COLLECTION PROGRESS



We have been steadily making progress towards our recruitment goals of **200** samples for each cleft type. We have received back about **150** samples from individuals with a Cleft so far, and have sent samples out to almost **100 more!** When recruitment resumes we will be sending out kits to new families, as well as replacement kits to existing families who have not yet returned their samples. Please keep an eye out for study updates!

What's New

We launched our website and social media.

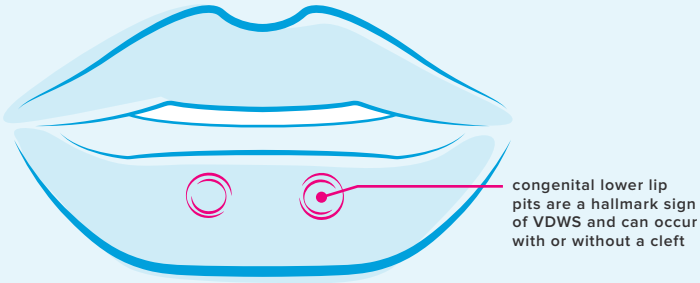
emorycleftproject.org

@cleftproject

@emorycleftproject

On our website you can:

- learn more about our study
- find resources for participants including study materials & demonstration videos
- receive important study updates
- view recent publications & results



A little bit about VAN DER WOUDE SYNDROME...

Van Der Woude Syndrome (VWS) is a rare condition caused by a mutation of the IRF6 or GRHL3 genes. VWS is inherited in an Autosomal Dominant pattern, accounting for ~2% of all clefts, and is estimated to occur in approximately 1 out of every 35,000 people. Affected persons can be born with some combination of cleft lip, cleft palate, and/or lip pits. In some cases a person can have a mutation in these genes but not show any signs or symptoms of the disorder.

COVID-19 UPDATE

The safety of our study participants and study team is our top priority. As a precautionary measure in response to the current COVID-19 outbreak, we are temporarily suspending DNA sample collection from participants, to be resumed at a later date to be determined. We are still actively enrolling study volunteers for remote participation, including online surveys, so if you want to participate, you still can! To find out more about our study, please visit our website at **emorycleftproject.org**