

## WHAT ARE THE POTENTIAL BENEFITS TO PARTICIPATION?

Your participation is completely Voluntary. If you decide to participate in this study:

1. You will be helping the researchers answer public health questions relevant to your child's health and access to services.
2. The data obtained may help to guide future policy regarding the type of care children should receive.

Do you have questions?

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Long-Term Follow-Up Pilot Project  
financially supported by the Georgia  
Department of Public Health.

## Long-term Follow-Up Pilot Project



## WHAT IS THE LONG-TERM FOLLOW-UP PILOT PROJECT (LTFU)?

Emory University has developed a public health tracking system for the long-term follow-up of newborns with a positive newborn screening of metabolic and endocrine conditions.

The Long-Term Follow-up System (LTFU) is a project designed to collect information on the health of children with specific diseases identified through the Georgia Newborn Screening.

Currently, we are piloting the Long-term Follow-up project (LTFU) on patients with a positive newborn screen for Very-Long-Chain acyl-CoA Dehydrogenase Deficiency or (VLCAD), Medium-Chain Acyl-CoA Deficiency or (MCAD) and Severe Combined Immune Deficiency or (SCID) .

We hope to expand the project and include other conditions in the near future.

## WHO CAN PARTICIPATE?

Children with a positive newborn screen for:

- Very-Long-Chain acyl-CoA Dehydrogenase Deficiency or (VLCAD).
- Medium-Chain Acyl-CoA Deficiency or (MCAD).
- Severe Combined Immune Deficiency or (SCID) .
- Children receiving care in Georgia.
- Children born January 1st, 2017 to present.

## WHAT DOES MY PARTICIPATION INVOLVE?

Your family will be asked to do the following:

- Conduct an interview that lasts about 15 minutes.
- Agree to conduct the interview once a year.
- Give us permission to obtain medical information on your child specific to the condition.

## HOW WILL YOU PROTECT MY PRIVACY?

- The information we gather is kept confidential.
- Personal information about you will not be available to anyone outside this project.
- We will never use your name in any report or publication.
- We have firewall protection in our electronic systems.

## WHAT WILL YOU DO WITH THE FINDINGS?

- We will make recommendations to the department of public health and to the providers that deliver care to your family.
- We will publish our findings to share knowledge.