



**THE UNIVERSITY**  
*of* **NORTH CAROLINA**  
*at* **CHAPEL HILL**

**Recruitment will occur through the following:** National ALS Registry

We are interested in your anonymous participation in a survey of ALS patients. This survey will assess how you were fed as an infant to better characterize potential targets for future research and intervention. Lessons learned from this survey will be used to generate descriptive information on patterns of infant feeding in ALS patients that can inform future research.

**What is the purpose of the survey?**

The purpose of this survey is to look at the prevalence of different infant feeding methods among people with ALS. There is currently no available data to support an association of infant feeding practices and the development of ALS. This is the first survey to investigate such an avenue.

**Who is eligible to take part in this survey?**

You are eligible to take part in this study if you have been diagnosed with Amyotrophic Lateral Sclerosis (ALS).

**Do I have to take part?**

No. To respond to the survey is voluntary. It is up to you to decide whether or not to take part. If you decide NOT to participate, please go on to the next question and answer "No." You will be directed to the end of the survey.

**What will happen to me if I take part?**

If you agree to participate in this research study, you will be asked to complete an electronic online survey. The survey will include questions about how you were fed as an infant. This survey will take approximately 2-4 minutes to complete. There are no other follow-up surveys or procedures.

**What are the possible benefits and risks of taking part?**

You will not benefit personally from being in this research study. Research is designed to benefit society by gaining new knowledge. You may skip any questions you prefer not to answer.

**Will what I say in this survey be kept confidential?**

This survey is anonymous and all the data we collect is completely confidential and stored in a secure database.

**What will happen to the results?**

Results will be disseminated through a peer-reviewed journal article and/or presentation on lessons learned from respondents as a whole.

**Who is organizing the research?**

The Carolina Global Breastfeeding Institute at the University of North Carolina at Chapel Hill

**Please use the link below to access the survey:**

[https://unc.az1.qualtrics.com/jfe/form/SV\\_e1CPT1pgDOfKkT3](https://unc.az1.qualtrics.com/jfe/form/SV_e1CPT1pgDOfKkT3)

**Further information:**

For further information or questions, please contact Karsey Erickson at:  
karseyerickson@gmail.com