

UNIVERSITY OF CALIFORNIA, SAN FRANCISCO CONSENT TO BE IN RESEARCH

Study Title: Describing parent, caregiver and adult perspectives of the long-term impact of Necrotizing Enterocolitis (NEC) on infants and adult survivors.

This is a research study, and you do not have to take part. Jennifer Canvasser MSW from the Necrotizing Enterocolitis (NEC) Society and James Harrison PhD from the Department of Medicine at the University of California San Francisco are available to explain this study to you. If you have any questions, you may contact them directly using their contact details which are provided at this end of this document.

You are being asked to take part in this study because you are a parent, or caregiver, of a child who has been diagnosed with Necrotizing Enterocolitis and have submitted your email address to the NEC Society email distribution list.

In this study, the researchers are doing a survey to learn more about long-term outcomes experienced by infants diagnosed with Necrotizing enterocolitis.

What will happen if I take part in this study?

If you agree to be in this study, you will complete a one-time online survey. The survey asks about the following:

1. Quality of life outcomes experienced by your child due to NEC.
2. Symptoms experienced by your child due to NEC.
3. Your preferences for the types of research and education needed to support infants with NEC and their families.

It will take you about 20-25 minutes to complete the survey.

How will my information be used?

Researchers will use your answers to the survey to conduct this study. Information gathered during this research study will only be used for this study. They will not be shared with other researchers.

Are there any risks to me or my privacy?

Some of the survey questions may make you feel uncomfortable or raise unpleasant memories. You are free to skip any question.

We will do our best to protect the information we collect from you. The survey itself will not include details that directly identify you or your child, such as your name or address. Please do not put this information on your survey. The completed surveys will be kept secure. Only a small number of researchers will have direct access to completed surveys. If this study is published or presented at scientific meetings, names and other information that might identify you will not be used.

Are there benefits?

There is no benefit to you but the survey results may provide information to improve preterm infant clinical care in the future.

Can I say “No”?

Yes, you do not have to complete a survey.

Are there any payments or costs?

You will not be paid for completing the survey. There are no costs to you.

Will I be able to find out the results of this study?

Yes, if you want to receive the results of the study please send us your email or US mail address to Jennifer Canvasser at jennifer@necsociety.org

Who can answer my questions about the study?

You can talk with the study researchers about any questions, concerns, or complaints you have about this study. Contact the study researcher(s) Jennifer Canvasser at jennifer@necsociety.org or James Harrison at 415-502-2008

If you wish to ask questions about the study or your rights as a research participant to someone other than the researchers or if you wish to voice any problems or concerns you may have about the study, please call the office of the Institutional Review Board at 415-476-1814.

CONSENT

PARTICIPATION IN RESEARCH IS VOLUNTARY.

If you wish to be in this study, please check this box