



Consent Form- Hidden Helpers Survey

You have been asked to consent to be in a research study. This form explains the research, your rights as a research participant, and any responsibilities that you may have as a result of your participation. You should understand the research study before you agree to be in it. ***You should save a copy of this form for your records. Read this form carefully. You may also talk with your family or friends about it. A research team member will answer any questions you have before you make a decision.***

1. Study Title: Data Collection Regarding Hidden Helpers

Key Information for You to Consider

Voluntary Consent- You are being asked to volunteer for a research study. It is up to you whether you choose to participate or not. There will be no penalty or loss of benefits to which you are otherwise entitled if you choose not to participate or discontinue participation.

Purpose- to collect information that will help Coalition members create trainings and other resources for health care providers. Our goal is for health care providers to better understand and support the social, emotional, and mental health needs of Hidden Helpers - the children and youth impacted by the care needs of a wounded, ill, or injured veteran.

Duration- Completing the survey is expected to take 10-15 minutes.

Procedures and Activities- Your participation includes completing a survey consisting of 12 questions and 6 demographic items.

Potential Risks- The greatest risk of participating in the survey is that questions will trigger unpleasant memories or emotions related to previous interactions with health care professionals who didn't understand the needs and realities of military caregiving families and children. A copy of focus group questions is available [AT THIS LINK](#) so you can review them before deciding if you agree to participate.

Potential Benefits- Because survey responses will be used to develop trainings and resources for health care professionals, your family and/or other military caregiving families in the United States may benefit from better interactions with health care professionals as they become better able to understand and meet the needs of military caregiving families.

Alternatives- Input from military caregiving families is being collected through this survey and through virtual focus groups. Information on virtual focus groups is available [AT THIS LINK](#). Since participation in the survey and/or focus group is voluntary, you have the option not to participate in either.

2. WHO IS IN CHARGE OF THE STUDY?

If you have a question, complaint, or problem related to the study, you can call the investigators anytime at the numbers listed below.



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Principal Investigator: Kate Blackburn, Nemours Children's Health; 302-650-2328
Co-Investigator: Allison Gertel-Rosenberg; Nemours Children's Health; 302-298-7602

3. WHO SHOULD RESEARCH PARTICIPANTS CONTACT ABOUT THEIR RIGHTS?

If you have questions about your rights as a research participant, what to do if you are injured, if you would like to offer input or obtain information, or if you cannot reach the investigator or want to talk to someone else who is not involved with this research, you may contact the persons listed below.

Chairperson, Nemours IRB at 302 690-8728
Director, Nemours Office of Human Subjects Protection at 302-298-7613
Email address: NOHSP@nemours.org

4. WHAT IS THE PURPOSE OF THE STUDY?

This survey is being conducted by members of the Hidden Helpers Coalition, an initiative designed to uplift the voices of military caregiver kids, better understand the unique challenges they face, and enhance the support services available to them. The purpose of this survey is to collect information that will help Coalition members create trainings and other resources for health care providers. Our goal is for health care providers to better understand and support the social, emotional, and mental health needs of Hidden Helpers - the children and youth impacted by the care needs of a wounded, ill, or injured veteran.

5. WHO IS SPONSORING OR PAYING FOR THE STUDY?

Nemours Children's Health is paying for costs associated with this study.

6. WHO CAN BE IN THE STUDY?

Participants must be:

- Parents/guardians of a child (or children) living in a military caregiving home
- Fluent in English
- Age 18 or older

7. HOW MANY OTHER PEOPLE WILL BE IN THE STUDY?

Through this study, researchers are holding virtual focus groups and conducting a web-based survey. You are currently reading the consent form to participate in the web-based survey. For the web-based survey, we project that 30 or fewer individuals will participate- although the SurveyMonkey platform will not limit to how many people can participate.

For the virtual focus groups, there will be a maximum of 28 participants (4 focus groups with a maximum of 7 participants in each one).

8. HOW LONG WILL PARTICIPATION IN THE STUDY LAST?

Your participation will consist of completing one web-based survey, which should take approximately 10-15 minutes. There is no follow up of any kind.

9. WHAT ARE THE RESEARCH PROCEDURES?

Completing the web-based survey should take approximately 10-15 minutes.

Participation is voluntary. You can stop answering at any time. There are no required questions; if there's a question you don't want to answer, you can skip it.



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The survey is anonymous. Your answers cannot be traced back to you. You will not be asked to share any personal information or information that could be used to identify you.

This research project includes virtual focus groups and a web-based survey. The research team includes 2 individuals from Nemours Children's Health and 3 individuals from the Elizabeth Dole Foundation. Members of the research team will have access to an audio-only recording of focus groups and a copy of the chat for each group, as well as email addresses of individuals who sign up to participate in focus groups. The research team will also have electronic copies of completed surveys.

Summarized data from focus groups and surveys will be shared with the project team working to develop trainings and resources. The project team includes additional individuals from Nemours Children's Health and the Elizabeth Dole Foundation as well as individuals whose organizations are part of the Hidden Helpers Coalition. Summarized data will be used in reports and recommendations shared with members of the Hidden Helpers coalition and the general public. No identifying information about focus group or survey participants will be shared with the project team or included in summary data, reports, recommendations, or any other documents created as part of this research project.

10. WHAT ARE POSSIBLE RISKS OF BEING IN THIS STUDY?

Any research has some risks (things that could make you sick, feel uncomfortable, or hurt). The risks with the most chance of happening to someone in this study are listed below. Also, there is a chance of other risks that almost never happen, or unknown risks.

The greatest risk of participating in the survey is that questions will trigger unpleasant memories or emotions related to previous interactions with health care professionals who didn't understand the needs and realities of military caregiving families and children. A copy of the questions is available [AT THIS LINK](#) so you can review them before deciding if you agree to participate.

There are no known privacy or confidentiality risks since this is an anonymous web-based survey.

11. WHAT ARE POSSIBLE BENEFITS OF BEING IN THIS STUDY?

Because survey and focus group responses will be used to develop trainings and resources for health care professionals, your family and/or other military caregiving families in the United States may benefit from better interactions with health care professionals as they become better able to understand and meet the needs of military caregiving families.

12. WHAT HAPPENS IF A PROBLEM OR INJURY RESULTS FROM THE RESEARCH PROCEDURES?

Nemours will assure that you receive treatment, if needed, for study-related injuries. Neither Nemours nor the study doctor has a program to pay for medical care provided to treat the injury. If you have health insurance, it may, or may not, pay for the cost of treatment resulting from a study-related injury.

If your insurance does not pay, or if you do not have insurance, you understand that you may be responsible for paying for the cost of treatment.



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13. IS BEING IN THE STUDY VOLUNTARY?

Being in this study is totally voluntary. Anyone who takes part in the study can stop being in it at any time.

14. WHAT OPTIONS ARE AVAILABLE OTHER THAN BEING IN THIS STUDY?

- You can refuse participation in this study.
- Input from military caregiving families is also being collected through virtual focus groups as part of this study. Information on virtual focus groups is available [AT THIS LINK](#). Since participation in the survey and/or focus group is voluntary, you have the option not to participate in either.

15. CAN THE RESEARCHERS REMOVE SOMEONE FROM THE STUDY?

Your participation in the study consists of completing one anonymous survey. Because the survey is anonymous, researchers are unable to remove anyone from the study.

16. WHAT ARE THE COSTS OF BEING IN THIS STUDY?

The only cost of being in this study is time lost; we anticipate that it will take 60 minutes to participate in a virtual focus group and 10-15 minutes to complete a web-based survey.

17. WILL I BE PAID FOR BEING IN THIS STUDY?

You will not receive payment or incentives with a cash value (gift card, etc.) for participating.

No arrangement exists that would allow participants to share in any profit generated from this study or future research.