



HIDDEN HELPERS



Consent Form- Hidden Helpers Focus Groups

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- The focus group session is one hour (60 minutes).

Procedures and Activities- The focus group consist of 12 discussion questions. You can skip any question you prefer not to answer. The focus group has a maximum of 7 participants.

Potential Risks- You risk loss of confidentiality by providing your email address to sign up for a focus group, and by using your first name to sign into Zoom for the group. If you choose to have your camera on during the focus group, you risk loss of confidentiality by being viewed by others in the Zoom session. Another risk is that the 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 survey 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 an anonymous web-based survey. Information on the survey is available [AT THIS LINK](#). Since



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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.

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 a virtual focus group. Four focus



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groups will be held, each with a maximum of 7 participants, for a total maximum of 28 focus group participants.

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.

8. HOW LONG WILL PARTICIPATION IN THE STUDY LAST?

Your participation will consist of participating in one focus group, which will approximately one hour (60 minutes).

9. WHAT ARE THE RESEARCH PROCEDURES?

Participating in the focus group will take approximately one hour (60 minutes). The group will meet virtually, on the Zoom platform, including a maximum of 7 participants and 2-3 members of the research team.

The focus group consists of 12 questions, which will be read aloud by a member of the research team. Participants will take turns sharing their opinions on each question. You can choose to reply, or not, to each question.

Focus group participants will be given a \$25 Amazon e-gift card in recognition of their voluntary contribution of subject matter expertise. E-gift cards will be sent one business day after the focus group.

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.



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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.

You risk loss of confidentiality by providing your email address to sign up for a focus group, and by using your first name to sign into Zoom for the group. If you choose to have your camera on during the focus group, you risk loss of confidentiality by being viewed by others in the Zoom session. Another risk is that the 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.

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

Because focus group and 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.

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

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.

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 a web-based survey as part of this study. Information on surveys 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.



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15. CAN THE RESEARCHERS REMOVE SOMEONE FROM THE STUDY?

Your participation in the study consists of participating in one virtual focus group. Because the audio recording of focus group will not include names, 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?

Focus group participants will be given a \$25 Amazon e-gift card in recognition of their voluntary contribution of subject matter expertise. E-gift cards will be sent one business day after the focus group.

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

18. WHAT INFORMATION ABOUT ME WILL BE USED OR DISCLOSED? (AUTHORIZATION TO USE AND/OR DISCLOSE PROTECTED HEALTH INFORMATION)

Identifiable health information about you will be used by Nemours researchers and may be given to people outside of Nemours for this research. This is done to conduct the research study, to monitor the safety of research participants and for auditing. Federal law requires us to tell you about, and get your approval for, research use and disclosure of health information that includes “identifiers” that can connect the health information to you. (Names, initials, date of birth, addresses, phone numbers, and social security numbers are examples of identifiers.) This identifiable health information is called Protected Health Information (PHI).

Protected Health Information to that will be collected from/about virtual focus group participants includes:

1. Email addresses of individuals who register for a virtual focus group
2. First names of focus group participants- The copy of comments made in the “chat” area in Zoom during virtual focus groups will be downloaded/saved by the research team. All comments made in the chat include the screen names of participants. Participants will be asked to limit screen names to their first name only.

In addition to the two items above, though the focus group protocol includes a caution to participants not to share information that could be used to identify them or members of their family, if they fail to follow instructions the audio recording of focus groups could potentially include identifiable information.



Use of Health Information by Nemours Staff

The health information that will be used within Nemours includes all data collected for this study, as described in this form.

Your identity will be protected as much as possible. Nemours protects your health information by storing records in files or computers that can only be used by authorized Nemours staff.

The people within Nemours that may use this health information include:

- The investigators listed on the first page of this consent form and their staff;
- The Nemours Institutional Review Board (IRB). (The IRB is a group of people that reviews research activities. The IRB is responsible for the safety and rights of research participants), and;
- Nemours internal audit staff.

Identifiable health information will be disclosed (given) to the following individuals or groups outside of Nemours:

- This research is being conducted Nemours and the Elizabeth Dole Foundation. Three individuals from the Elizabeth Dole Foundation are part of the research team: Hannah Hutler Boyd, Lisell Perez-Rogers, and Leah Hellwege. The PHI we collect from focus group participants (see table below) will be shared with these three individuals.

The PHI that will be disclosed (given) to people or groups outside of Nemours for research purposes are listed in the table below:

Type of Identifiable Health Information:	Disclosed:
Email addresses of individuals who register for a virtual focus group	☒
A copy of comments made in the “chat” area in Zoom during virtual focus groups, which include the screen names of participants. Participants will be asked to limit screen names to their first name only.	☒
An audio only recording of the focus group. Researchers will remind focus group participants not to share information during the focus group that could be used to identify them or members of their family. But if they accidentally share identifiable information about themselves and/or members of their families, it will be included in the audio recording.	☒



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Limits on Protection of Privacy and Confidentiality

Only health care organizations have to follow laws and rules about protecting the privacy of health information. If health information containing peoples' identities is given to other kinds of companies or organizations, they are not required by law to safeguard the privacy and confidentiality of that information. Nemours expects these companies and organizations to protect the privacy and confidentiality of research participants, but it is not possible for Nemours researchers to assure that this happens.

Government agencies that may look at records for this research study, including the above health information, include:

- The U.S. Food and Drug Administration
- The U.S. Department of Health and Human Services
- Other agencies of State and local government as required by law