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## **SUMMARY EXPLANATION OF RESEARCH**

Penn State College of Medicine

Penn State Health

Title of Project: Food and Ehlers-Danlos Under Pandemic Conditions (FED-UP)

Principal Investigator: Jane R. Schubart, PhD

Address: Department of Surgery, Penn State College of Medicine, Hershey, PA

Telephone Numbers: Weekdays: 8:00 a.m. to 5:00 p.m. (717) 531-1262.

You are being invited to volunteer to participate in a research study. Research studies include only people who voluntarily choose to take part.

- The aim of this study is to gather information from people with Ehlers-Danlos syndromes to understand how the COVID pandemic has impacted their ability to access food and the dietary changes as a result of the pandemic.
- The study involves completion of an online survey questionnaire about access to food and dietary practices pre-pandemic and currently.
- The questionnaire is estimated to take approximately 30 minutes.
- No personally identifiable information will be collected, and no health information can be traced to you.
- There is a risk of loss of confidentiality if your information or your identity is obtained by someone other than the investigators, but precautions will be taken to prevent this from happening. The confidentiality of your electronic data created by you or by the researchers will be maintained to the degree permitted by the technology used. Absolute confidentiality cannot be guaranteed.
- You will not benefit from taking part in this research study. Medical science may gain further understanding of the impact of the pandemic on persons with Ehlers-Danlos syndrome, their access to food, and impact on their diet and health.
- You do not have to participate in this research. Taking part in the research study is voluntary. Your decision to participate or to decline the research will not result in any penalty or loss of benefits to which you are entitled.
- You may print this consent form for your records.

If you have questions, complaints or concerns or believe you may have been harmed from participating in this research, you should contact Dr. Jane Schubart at (717) 531-1262. If you have questions regarding your rights as a research subject or concerns regarding your privacy, you may contact the

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research protection advocate in the HMC Human Subjects Protection Office at 717-531-5687. You may call this number to discuss any problems, concerns or questions; get information or offer input.

Your completion of the questionnaire implies your voluntary consent to participate in the research.