2022 NEWSLETTER

A Letter from the Directors

Dear all,

Thank you for your continued involvement in The Women's Health Study: From Adolescence to Adulthood. Your willingness to participate each year is essential to our study's success. This newsletter is your reminder that you will soon be receiving an email with a link to your annual health questionnaire.

We also have important updates to share with you! We have changed our methods of study outreach and optimized the ways in which we keep your information safe. In addition, we have new funding to research the potential impact of COVID-19 on women's health and updates on many of our other research efforts.



Marc Laufer, MD



Stacey Missmer, ScD

You can stay in touch and up-to-date throughout the year by checking our <u>website</u> and <u>Facebook</u> page. You can also find a list of our recent publications <u>here</u>. Please do not hesitate to contact the study team via secure email or phone with any questions or concerns. We are always here to help answer any study-related questions.

Without your dedicated contributions to research on women's health and well-being, we would not have reached Year 9 and achieved so much. We are very proud of all our accomplishments to date, and look forward to another year of working together!

COMITTED TO YOUR PRIVACY-HERE'S HOW

As you know, being able to contact you for health and lifestyle updates every year is what makes our study so powerful. Recently, you may have noticed some changes in how we contact you, to best protect your privacy and confidentiality.

- Some of our study emails are now delivered through a secure email system. These systems require a one-time registration and password creation. For more information and step-bystep instructions, please visit our <u>website</u>.
- Some Redcap surveys will now prompt you to enter your birthdate (MM/DD/YYYY) before you can access your study questionnaire.

Please know that we are working every day to make this study a success and are always here to answer any questions you have. Please feel free to contact us via secure email (as described above) or by phone..



Happy Birthday!

Celebrating your 18th birthday soon? Check your mailbox for a research reconsent form. Please complete it as soon as possible to make sure you do not miss your chance to continue participating in the study.

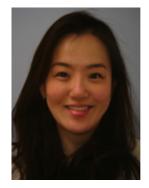
COVID-19 Research

In late 2021, our team was awarded additional research funding from the National Institutes of Health to study the relationship between menstrual health and COVID-19 infection and/or vaccination. Led by Scientific Director, Dr. Stacey Missmer, and Co-Scientific Director, Dr. Kathryn Terry, this study will ask our WHS:A2A participants to fill out short (5 minute) questionnaires two to three times via a REDCap survey. The WHS:A2A participants' years of dedication to this study will allow us to compare compare menstrual characteristics prior and during the pandemic and also before and after COVID-19 infection and/or vaccination to detect any changes that impact our participants' health. The WHS:A2A team was eligible to receive this funding because of Dr. Missmer's current NIH grant "What is Endometriosis?" that seeks to define sub-types of endometriosis that will advance discovery aimed to establish personalized, precision treatment for this condition.

"Anytime we can clarify what people can expect and understand better what the impacts of any changes are, hopefully that will help to decrease vaccine hesitancy,"

- Dr. Stacey Missmer, in conversation with Washington Post regarding the new NIH grant

New Research Staff



Esther Kim, BS, Research Assistant

Esther joined our team in 2021. She is a 2013 graduate of Syracuse University and started her career in television media. Her experience in the communications field was predominantly focused on healthcare and biotech industries. As a research assistant for the Women's Health Study: From Adolescence to Adulthood, Esther is responsible for working with adolescent and adult women enrolled in the study, processing biological samples, and answering any questions that participants and their families may have. Outside of work, she loves to cycle, travel, read, and enjoys classical music and jazz.

NOTE-2 Study is Expanding!

Co-Scientific Director, Dr. Amy DiVasta, was recently awarded funding from the J. Willard and Alice. S Marriott Foundation to expand her clinical trial "Novel Treatments for Endometriosis (NOTE)." This award will allow research staff to expand this ongoing investigation into a multi-site clinical trial that will recruit eligible participants from several hospitals across the United States.

We will continue to enroll participants 15-40 years old with endometriosis-associated pain from Boston Children's Hospital and Brigham and Women's Hospital. More information on the NOTE-2 study is available on our research website.





Esther Kim (left) and Emma Singleton (right) processing and putting away samples in our lab at Brigham and Women's hospital.

"Why can't I receive clinical care from the research team?"

- · Research staff are prohibited from providing clinical advice to study participants. For your safety and wellbeing, it is important that you receive accurate guidance from a clinical provider who is familiar with your personal care. Your clinical provider can be a doctor from Boston Children's Hospital or Brigham and Women's Hospital- just not a research staff member from Boston Center for Endometriosis.
- When we store research data and samples in our WHS:A2A biorepository and database, they are stored with a study ID number, and not your name. Our research is designed to find population-wide answers, not to provide participant-specific support. There are other studies, such as the NOTE-2 Trial, that are designed to test a clinical treatment. While these studies may reveal results that influence future clinical care, even trials cannot determine participant-specific personalized care.
- Our research lens requires that we focus on hypotheses for which we do not yet have definitive answers. It would be dangerous and a human subjects' violation for study personnel to translate ongoing research to any individual's clinical care.

Stay Connected

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WOMEN'S HOSPITAL







