THANK YOU!

As we’ve written in previous newsletters, we could not do this research without your help. We are grateful to all who have been kind enough to participate in the OCD Family Study. Without your generous participation, our understanding of this condition would not be possible.

We are sending you this newsletter to help keep you up-to-date on the progress of the study. The goal of the OCD Family Study, which began in 1995, is to identify genetic determinants of OCD.

MAJOR FINDINGS SO FAR

The major findings of the study are that OCD runs in families, is genetically linked to specific regions of several chromosomes, and that genetic variants of the glutamate transporter gene and of several neurodevelopmental genes are associated with OCD.

Although these results are exciting, it is IMPORTANT to note that we have not found for certain that these specific genes cause OCD, nor is there any genetic test available for OCD. See “New Findings”, below, for highlights of the most recent findings from the study.

IMPORTANT REMINDER!

We now are poised to conduct the genome-wide association analyses using all the clinical and genetic information we have collected on nearly 2000 participants to date. In order to have the most powerful analyses, we would like to include as much of this information as possible.

Therefore, if you or applicable relatives have not yet provided a blood sample, please contact us so that we can schedule this as soon as possible.

Also, if you or your interviewed family members have not yet returned the self-completed questionnaires, please do so as soon as possible.

Because this phase of the study will be completing soon, it is crucial that we have this information as soon as possible.

Thank you very much!
COORDINATOR’S CORNER

This has been an exciting 15 years in OCD research, and it has been my pleasure to be involved in this project for all of this time. Getting to know each of you over the years has meant so much to me and I am grateful that I had the chance to become part of your lives, if even for a short while.

Please know that, even though we are completing the data collection for this phase of the study, it does NOT mean that OCD research has ended here at Johns Hopkins. Here are several other studies that are ongoing, or that we are planning on beginning in the near future:

- Johns Hopkins is currently conducting a study designed to understand how specific brain chemicals (neurotransmitters) function in the brains of individuals with OCD. This work is possible because of state-of-the-art brain imaging methods that we are fortunate to have at Johns Hopkins.

- We are also about to start a study about the effects of the menstrual cycle, pregnancy, and menopause on OCD symptoms. This will be a collaborative study with the University of Amsterdam; Valeria Guglielmi, a medical student there, will be conducting the study with us. The study involves completion of a brief online questionnaire. Please see the letter enclosed with this newsletter. Note: you will only have received this study invitation letter if you are an adult (18+) female with OCD.

- In addition, we wish to determine if children in families with OCD have a greater risk of developing OCD, and to identify the early presentation of symptoms.

Do you know individuals with OCD?

If you know individuals with OCD, please encourage them to contact us so that we may explain the studies to them and invite them to participate.

Thanks to each and every one of you for taking the time to teach us so much about OCD.

Krista Vermillion
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FROM THE PSYCHOLOGIST

On behalf of the twelve psychologists who have conducted interviews for the study, I would like to thank you for the great privilege of working with you. Our participants share so much of themselves in telling us about their lives. Every participant’s story is unique and teaches us about the many different ways that OCD intersects with their life experiences and provides invaluable insights for helping others.

FROM THE PRINCIPAL INVESTIGATOR

I would like to express my personal appreciation to all of you who have participated in our study. Our hope is that the knowledge gained from your contributions will benefit all who suffer from OCD. Our foremost goal remains finding the causes of OCD, so that we may develop new and more effective treatments. Although it takes time, we have made substantial progress in understanding OCD, and we are sure that this will accelerate in the near future.
OCD RESOURCES

The International Obsessive Compulsive Foundation (OCF) can provide additional information about OCD. Their website also provides a list of mental health professionals nationwide who treat OCD. You can reach the OC Foundation via their website at www.ocfoundation.org

There are additional websites that have information about OCD. We recommend the following sites to assist you.

- Johns Hopkins OCD: www.hopkinsmedicine.org/ocd
- National Institutes of Mental Health: www.nimh.nih.gov
- The National Alliance for the Mentally Ill: www.nami.org

ANNUAL CONFERENCE

The annual OC Foundation Conference will be held in Chicago this year, from July 27-29. This is the national meeting for individuals with OCD, their families, and mental health providers. See the OC Foundation website for detailed information.

We’ll be at the conference! Dr. Gerald Nestadt will present his annual overview of the genetics of OCD. Please look for his presentation to learn more about the most recent study findings. We look forward to meeting you there!

NEW FINDINGS FROM OUR FAMILY STUDIES

Here are some highlights from recently published articles from the JHU Family Studies.

Is the glutamate transporter gene associated with OCD?
The glutamate transporter gene (SLC1A1) codes for a protein involved in transport of the neurotransmitter, glutamate, in synapses in the brain. Five research groups, including our own, have found that several single nucleotide polymorphisms (SNPs) in, or close to, this gene are associated with OCD. To explore this further, we genotyped 124 SNPs in or near this gene in 1576 participants in 377 families. We found that two SNPs outside of, but near this gene, were associated with OCD, in families with male affected individuals. This finding provides further evidence that this gene may be involved in OCD, although further work is needed to confirm this (Am J Med Genet 2011; 156B:472-477).

Are neurodevelopmental genes associated with OCD?
In the earlier linkage phase of this study, we found that regions on chromosomes 1 and 15 (among others) were linked to OCD. We did “fine mapping” by genotyping hundreds of SNPs in these linkage regions. We found that three SNPs were associated with OCD. Interestingly, these SNPs were in, or near, three genes (PBX1, MEIS2, and NANOG) involved in neural development (Am J Med Genet 2011; 159B:53-60).
MEMBERS OF OUR TEAM

Gerald Nestadt, MD, MPH, Professor of Psychiatry, is the Principal Investigator of the OCD Family Study. He is also the Director of the OCD Clinic at Johns Hopkins Hospital and evaluates and treats individuals with OCD.

Jack Samuels, PhD, Associate Professor, is a psychiatric epidemiologist and is the project director of the OCD Family Study.

Jana Drew, PhD, is a clinical psychologist who conducts interviews for the study.

Janice Krasnow, PhD is a clinical psychologist also conducting interviews for the study.

Krista Vermillion, BS, is a research program coordinator and has the primary telephone contact with the study participants. She is responsible for screening, scheduling interviews, and recruiting new participants.

Ying Wang, MS, is responsible for our website, manages the database, and is involved in the genetic analyses.

Other members of the team:

Dr. Joe Bienvenu, (psychiatrist), Dr. Bernadette Cullen, (psychiatrist), Dr. Fernando Goes (psychiatrist), Dr. Marco Grados, (child psychiatrist), Dr. Kung-Yee Liang, (biostatistician), Dr. Brion Maher (statistical geneticist), and Dr. Mark Riddle, MD, (child psychiatrist).

FUNDING

Our work continues to be funded by the National Institute of Mental Health (NIMH), the James E. Marshall OCD Foundation, and the International OC Foundation. We also collaborate with other research groups at different universities.

Individuals are welcome to make a financial contribution to the study. Checks should be written to the Johns Hopkins University School of Medicine – Dr. Gerald Nestadt Research Account.

CONTACT INFORMATION

We would love to hear from you. Please feel free to contact us with any feedback regarding this newsletter or any questions regarding our study. Also, if you change your address or phone number, please contact us.

NOTE OUR NEW ADDRESS:

We have moved to a new building, across from the famous dome of the Johns Hopkins Medical Institutions:

The OCD Family Study  
Johns Hopkins University School of Medicine  
Dept. of Psychiatry and Behavioral Sciences  
550 N. Broadway, Suite 902  
Baltimore, MD 21205  
Phone: (410) 614-4942  
Email: kvermil1@jhmi.edu or ywang37@jhmi.edu

Or visit us online at www.hopkinsmedicine.org/ocd