

OCDigest

The newsletter of the OCD Family Study
Johns Hopkins University School of Medicine
Department of Psychiatry & Behavioral
Sciences
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The OCD Family Study

The search for causes of obsessive-compulsive disorder

THANK YOU!

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 our progress, as well as other developments in the OCD research.

MAJOR PROGRESS SO FAR

In **Phase 1** (1995-2000), we interviewed over 800 individuals in more than 150 families. Our results indicated that OCD occurs more frequently in certain families.

Relatives of people with OCD are 5 times more likely to have OCD than are relatives of people without OCD. (*Arch General Psychiatry*, 2000).

In **Phases 2 and 3** (2000-2007), we interviewed over 300 families having two or more individuals affected by OCD, and completed the first large genome-wide DNA linkage scan of OCD.

Suggestive linkage signals were found on regions of chromosomes 1, 3, 6, 7 and 15 (*Molecular Psychiatry*, 2006). We are pursuing fine mapping in these regions to narrow the focus in these linkage regions.

In **Phase 4 (2007-)**, we are interviewing and collecting DNA samples from 2000 individuals with OCD and their parents. We will conduct a genome-wide association study to identify even smaller chromosomal regions associated with OCD.

This is an exciting start, but it is IMPORTANT to note that we have not yet found any genes or specific genetic markers for OCD, nor is there any genetic test available for the identification of OCD. See "New in OCD Research," below, for highlights of other findings from the study.

COORDINATOR'S CORNER

I would like to take a moment to thank the members of different support groups around

the country for allowing us to spread the word about our study. I have visited support groups in Erie, PA, Phoenix and Tucson, AZ, Hampton, Richmond and Arlington, VA and Baltimore, MD. I'm looking forward to visiting Portland, OR and Seattle, WA soon. It has been such a delight to meet all of you face to face. If you belong to a support group that would like to have a visit from us, please contact me to discuss this further.

If you have participated in the study and have not provided a blood sample or know of family members who have not provided a blood sample, please contact us to set up a blood draw in your home or location of your choosing. These blood samples are incredibly important to this study! Please don't hesitate to call me with any questions regarding this matter.

If you have already participated in the interview,

and you know of other genetic or psychiatric disorders that run in your family, please let us know.

Thanks to all of you!
Without your participation and time, this project would not be possible.

Krista Vermillion
Research Program
Coordinator

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Do you know of any individuals with OCD?

Please encourage them to contact us. If they qualify, we will explain the study, invite them to participate in a confidential interview about their medical and psychiatric history, and collect a sample of blood.

OCD RESOURCES

The 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 Minneapolis this year, from August 7-9. 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, Dr. Jack Samuels, Dr. Jana Drew, Dr. Margaret Schlossberg, Dr. Janice Krasnow, Ramsay Barnes, and Krista Vermillion from our study team plan on attending the conference and presenting results from the study. Please look for our booth and find out more about the study. We look forward to meeting you in Minneapolis!

NEW FINDINGS FROM OUR FAMILY STUDIES

There are many interesting and exciting research studies evaluating different aspects of OCD. Researchers across the country are trying to better understand OCD through the

study of genetics, treatment approaches, and pharmacological advancements. Here are some highlights from recently published articles from the JHU Family Studies.

Are there subtypes of OCD?

Using a statistical technique called latent class analysis, we found that OCD can be classified into 3 subtypes, based on co-occurring conditions: 1) *OCD simplex class*, in which major depressive disorder (MDD) is most frequent; 2) a *tic related class*, in which tics are prominent; and 3) an *affective related class*, in which panic disorder and mood disorders are prominent (*Psychological Medicine, in press*).

Is hoarding different in men and women with OCD?

We studied correlates of hoarding in 151 men and 358 women with OCD. In men, hoarding was associated with generalized anxiety disorder and tics whereas, among women, hoarding was associated with social phobia, post-traumatic stress disorder, body dysmorphic disorder, nail biting, and skin picking (*Behaviour Research & Therapy, 2008*).

Is the SAPAP3 gene involved in grooming behavior in OCD?

The SAPAP3 gene codes for a protein found in certain neurons in the brain. A recent study found that mice with a deletion of this gene groom themselves excessively. We conducted a family-based association analysis to determine if SAPAP3 is associated with grooming in 383 OCD families. We found that grooming disorders, especially hair pulling

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(trichotillomania) were significantly associated with SAPAP3 in these families. (*American Journal of Medical Genetics Part B, in press*).

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, is a psychiatric epidemiologist and is the project director of the OCD Family Study.

Ramsay Barnes, BA, is a research program coordinator and has primary responsibility for administrative aspects of the study

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

Margaret Schlossberg, PhD is a clinical psychologist who

also 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), 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 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.

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