

**WHO SHOULD I CONTACT IF I
HAVE ANY QUESTIONS ABOUT
THE STUDY?**

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**THANK YOU FOR YOUR
INTEREST IN THIS STUDY!**

**DO YOU OR DOES SOMEONE
IN YOUR FAMILY HAVE**

**FOCAL SEGMENTAL
GLOMERULOSCLEROSIS (FSGS)**

OR

NEPHROTIC SYNDROME (NS)?

**HELP US TO LEARN MORE
ABOUT KIDNEY DISORDERS
THAT CAN RUN IN FAMILIES**



WHAT IS THE PURPOSE OF THE STUDY BEING CONDUCTED?

Our lab is working to identify the genes associated with kidney dysfunction (especially FSGS and Nephrotic Syndrome) that may run in families.

This condition can occur without symptoms or over time can result in kidney failure. It may be familial, that is passed from generation to generation in the genes (DNA).

We would like to try to find the genes responsible for this condition by analyzing the DNA (genes) in your blood sample.

We hope that this study will lead to better understanding of the genetic changes in problems associated with kidney disease, and that it will ultimately lead to improved treatment of this condition.

You can learn more about our team and our research by visiting our website at www.fsgs.bwh.harvard.edu

WHO IS ELIGIBLE TO PARTICIPATE?

- Anyone with FSGS or NS
- Any family member of an individual with FSGS or NS (even

if they do not have kidney disease themselves)

WHY IS IT HELPFUL TO HAVE FAMILY MEMBERS PARTICIPATE?

Family members share many genes in common. Thus, it is useful to have parents, siblings, and other relatives participate so that we can follow how certain DNA changes are inherited.

This is an important part of determining if a DNA change is related to the development of a specific disease.

WHAT WOULD PARTICIPATION INVOLVE?

- Completing a 2 page questionnaire
- Providing a blood sample
- Providing a urine sample

It is possible to participate through your doctor's office or we can make arrangements for you to have your blood drawn either at our office or at a clinic closer to your home.

In addition, we can coordinate the participation of other family members who would like to help, even if they live in different states.

IS THERE ANY COST TO PARTICIPATE?

No, there's no cost to participants. All materials including prepaid mailers will be supplied to you.

HOW DO I GET STARTED?

If you and/or your family is interested in participating, you can contact Andrea Uscinski, MS, the genetic counselor and research coordinator for this study at 617-525-5885 or by email at auscinski@rics.bwh.harvard.edu

She can explain the details of the study, answer any questions that you or your family might have, as well as help to coordinate your family's participation.

You can also contact Dr. Martin Pollak, the principal investigator of this study and a clinical nephrologist at Brigham and Women's Hospital at 617-525-5840 should you have any questions or concerns.