

RRP Research Study

Genetics of RRP Research Study

- *Do you or does your child suffer from Recurrent Respiratory Papillomatosis (RRP)?*
- *Why do some people get the disease and not others?*
- *Why do some run such an aggressive course and others not?*

Dr. Farrel Buchinsky, a pediatric otolaryngologist in Pittsburgh, Pennsylvania, is studying genetic susceptibility to RRP. He is supported by a research grant from the National Institutes of Health (NIH), the state-of-the-art capabilities of the Center for Genomic Sciences at the Allegheny-Singer Research Institute and by the collective clinical experience of the doctors of the RRP Task Force. Now two additional organizations are assisting to publicize the study and to recruit participants: the Recurrent Respiratory Papillomatosis Foundation in Lawrenceville, NJ, headed by Mr. Bill Stern and the International RRP Information, Support and Advocacy (ISA) Center based in Bellingham, Wash., headed by Mr. Michael Green.

If you decide to participate in this important research project, the following will be required:

- A Scope® mouthwash sample from the person with RRP
- A Scope® mouthwash sample from the biological mother
- A Scope® mouthwash sample from the biological father
- A questionnaire that will take between 5 and 10 minutes to complete.

[If either the mother or the father are unavailable then a Scope® mouthwash sample is required from the patient's brothers and sisters who share the missing parent(s). Even if no relatives are available, then we would still welcome your participation.]

Please contact Ms. Marilyn Smith, Research Coordinator or Ms. Mary O'Toole at the Center for Genomic Sciences. You can call us at 412-359-4816 or 888-887-7729, or e-mail us at info@rrpgenetics.org. You are also welcome to discuss this with the staff of the International RRP Information, Support and Advocacy (ISA) Center or the staff of the Recurrent Respiratory Papillomatosis Foundation.

Ms. Smith and Ms. O'Toole will mail a test kit to you; it will contain all that you need to collect the samples. The test is a mouth rinse. It will not hurt. You would then send it back to us at our expense. We will respect your privacy and maintain your confidentiality to the best of our ability.

Please understand that this is a study to help scientists, doctors and patients understand more about RRP. It is not a treatment trial.

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blood specimen
vocal cord wart

RRP Research Study

Father

Mother



Child with RRP



Siblings



We will only need mouthwash from the brothers and /or sisters if either biologic parent is unavailable.

**Principal Investigator:
Dr. Farrel Buchinsky**

For more detailed information on the research study you are invited to contact us or to go to our website <http://www.rpgenetics.org>

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