

National PAP Registry FAQs

What is the purpose of this study?

Currently, there are no routine blood tests available to help identify diseases that cause PAP. The purpose of this study is to evaluate new blood tests to see how well these tests diagnose diseases that cause PAP. We will also create a list of individuals with PAP to enable the distribution of new information, treatment options, and research studies.

Who will be included in this study?

You have received this because you either have PAP or are a relative of someone with PAP. You or your relative may be eligible to participate in this study.

What is involved?

To be in this study, you must give your permission, return a 'Release of Medical Information' form, collect a blood sample from one of your fingertips, and answer some questions.

What are the benefits?

This study is for research purposes only. There will be no direct benefit to you for participating. However, it may provide you with the opportunity to improve knowledge about PAP, to participate in studies to test new treatments for PAP, to participate in studies to understand causes of PAP, and to work with experts in PAP.

Will I get all the facts about the study?

Those interested in participating will be given a consent form that explains the details of the study. The form covers all of the procedures, potential risks and benefits, who to contact with questions or concerns and more. A member of the study staff will review the consent form with participants to ensure all questions are answered. Study procedures will not begin until the participant has signed this consent form.

What are the risks and discomforts of the study?

The risks and discomforts of being in this study relate to routine blood collection and include minor pain, blood loss, and, very rarely, infection or scarring. Completing questionnaires may make you tired. You may feel the questions are too personal. You may skip any questions you wish and may take as long as you want to finish the questionnaires. Being asked to join other studies may be an inconvenience.

What is the pay?

You will not be paid to participate in this study.

Who should I contact for more information?

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