



## The International Pleuropulmonary Blastoma Registry

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January 2011

Dear PPB Families,

We are pleased to announce that the PPB Registry Team has formalized a collaboration with Dr. Christian Kratz, an Investigator at the National Cancer Institute, (NCI) Clinical Genetics Branch (CGB) in Bethesda, Maryland. We are very pleased that Christian and his team at the CGB are willing to share their genetics expertise with us as we work to better understand the genetics of PPB and related conditions. The study represents an expansion of the current PPB genetic study in which many of you already have already participated. If you are already participating in the PPB Registry and/or PPB genetic study, we invite you to consider enrolling in this study as well. If you haven't yet enrolled in the PPB genetic study, enrollment in the NCI study will accomplish the same task as we have joined research teams and resources.

The primary goal of this study is to collect information that will help us understand what causes PPB. Who is at risk and at what risk? And what is the best way to screen for PPB and associated conditions? This study seeks to enroll all blood relatives of children with PPB. This may help us understand why some children in a family get PPB while others do not. And hopefully by putting these clues together we will also make progress on learning what makes PPB grow and what will make it stop.

The NCI/CGB study focuses on the families of individuals with PPB and related conditions. If you agree to participate, Dr. Kratz and his team will ask you to:

1. Complete a new, updated family history questionnaire
2. Ask each blood relative to enroll and to complete a new personal medical history questionnaire providing detailed medical information about him/herself
3. Give permission for us to obtain medical records documentation on reported medical conditions.

Please excuse us that some of this information collection may seem redundant. It is very important that we obtain the information in a systematic fashion. The CGB team will provide you with everything you need to make your enrollment easy. Please note that your participation is totally voluntary and that you will be provided ample information to make

an informed decision for you and for those you are a guardian for to participate in all phases of the study.

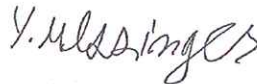
**To enroll in the new study, or to learn more about the study, please contact the CGB referral nurse, Stephanie Steinbart, at 1-800 518-8474 or e-mail her at stephaniesteinbart@westat.com at your earliest convenience.** (Stephanie is employed by Westat, which is the support services company to the CGB of the National Cancer Institute.) Stephanie will ask you for basic family history information over the phone and we do apologize in advance because it may be information you've already provided to the Registry. She will also ask for your contact information and then prepare the first package of new consent forms and family history questionnaire to be mailed to you.

We appreciate your support of PPB research. We are making progress thanks to the many families who share their time and hope with us in this effort. Again to enroll, we urge you to contact the CGB Referral Nurse, Stephanie Steinbart using her toll free number 1-800-518-8474 or e-mail her at stephaniesteinbart@westat.com. Of course, you are also welcome to contact us with any questions or concerns you might have.

Respectfully,



Dr. Ashley Hill



Dr. Yoav Messinger



Gretchen Williams, BS