



REGISTRY NEWSLETTER



Welcome!

Welcome to the latest issue of the International PPB/*DICER1*/OTST Registry newsletter! The International Pleuropulmonary Blastoma (PPB)/*DICER1* Registry was formed in 1988 and since its inception has grown to more than 1000 participants from 47 states and 49 countries. The Registry's mission is to improve outcomes for children and adults with PPB, Sertoli-Leydig cell tumor (SLCT), and other *DICER1*-related conditions. The International Ovarian and Testicular Stromal Tumor Registry was formed in 2011 and since its inception has grown to more than 204 participants from 36 states and 14 countries.

One of our goals is to share the latest findings with the individuals who make this research possible. As some amazing families have taught us, knowledge is power and every journey matters! With that in mind, we're sharing the latest Registry research findings from the 6th International PPB/*DICER1*/OTST family meeting held virtually last August. Thanks to the Registry Patient/Parent Advisory Board for their insights and contributions to last year's event. You'll find a link to the first session from the family meeting [here >>](#)

Thank you for sharing your journey with us to advance research for these rare tumors!

With warmest regards,

Kris Ann Schultz, MD

Registration Open for 7th Annual Family Meeting

Our next Family Meeting will be held virtually on August 4th. The meeting will coincide with the 2022 Pine Tree Apple Tennis Classic Tournament held August 4th-7th. Please click the button below to register and we will keep you updated by email as more information is available. If you are interested in serving on the 2022 Advisory Board to help plan the topics and event, please indicate your interest on the form. We look forward to seeing you!

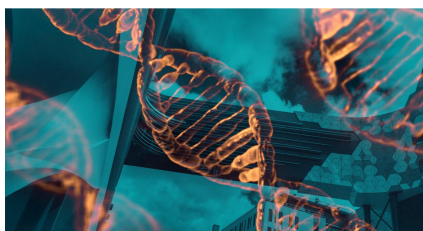
[Click to Register](#)



What is PPB?

Pleuropulmonary blastoma (PPB) is a lung tumor seen primarily in children. The name “pleuropulmonary blastoma” means that the tumor is thought to originate in either the tissue covering the lungs and inside surface of the chest cavity (“pleura”), or in the lung tissue itself (“pulmonary”).

The word “blastoma” refers to the appearance of the tumor under the microscope. There are four main types of PPB: Type I, Type II, Type III and Type IV PPB. Each of these types of PPB may be linked to variation in a gene called *DICER1*. [Keep reading >>](#)



What is *DICER1*?

Research from the Registry has shown a link between PPB and a gene called *DICER1*. *DICER1* is a gene which encodes a protein, DICER, which impacts gene expression and has downstream effects on cell proliferation. In studying PPB, we have learned that nearly all PPB tumors are characterized by variation in the *DICER1* gene. [Keep reading >>](#)

DICER1 Testing and Surveillance Guidelines Available

In the late 1980s, two children, a brother and a sister, were both found to have unusual appearing lung tumors, which we now recognize as PPB. With this sentinel observation, PPB research—and the PPB Registry—was born. In 2009, Registry researchers in conjunction with several families, found a genetic link between *DICER1* and PPB in families. While most individuals with *DICER1* gene variation are healthy, there is an increased risk for PPB and certain ovarian, kidney, thyroid and brain tumors.

Testing and surveillance guidelines are available and are helping to detect tumors in their earliest and most curable form. Please click the link below to request a copy of the *DICER1* testing and surveillance guidelines.

[Request the Guidelines](#)

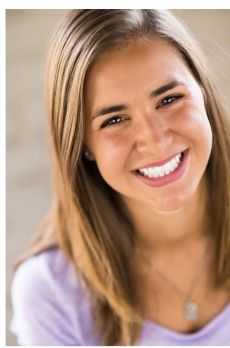


Ways to Get Involved

We can find a cure for PPB, SLCT and other *DICER1*-related cancers if we all work together. This includes clinicians, pathologists, geneticists, radiologists, laboratory scientists, coordinators, philanthropic volunteers and donors—and most of all, patients and families.

Each research advancement in this area has been made possible by the generous sharing of clinical information and tissue and blood samples from individuals and/or their family members. To contribute clinical information and/or blood/tumor samples, please consider enrollment in The International PPB/*DICER1* Registry. [Learn more >>](#)

Meet the Research Team!



First Row: Anne Harris, MPH, Clinical Research Specialist, Alexander Nelson, BS, Research Associate, Paige Mallinger, MS, Clinical Research Coordinator, Kris Ann Schultz, MD, Principal Investigator
Second Row: Anna Dybvik, BS, Clinical Research Associate, Nicole Frederickson, BA, Clinical Research Associate, Melissa Abraham, BA, Clinical Research Associate, Yoav Messenger, MD, Co-Principal Investigator

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