1. **What is Plastic Bronchitis?**

Plastic bronchitis (PB) is an uncommon condition. For reasons unknown, some children with congenital heart disease after surgery leaving them with single ventricle (Fontan) physiology, some adults and children with lymphatic abnormalities, some adults and children with sickle cell acute chest syndrome, some adults and children with influenza, and some adults and children with atypical atopy develop firm airway casts primarily made of mucus but also containing variable amounts of fibrin or polymeric DNA/actin. These casts can completely obstruct the airway and suffocate the patient. This disease was first described by Galen but our interest in mucus clearance disorders allowed us to finally fully describe this disease and develop the currently used classification system.

2. **What are the International Plastic Bronchitis Registry’s specific aims and goals?**

The purpose of the international plastic bronchitis registry is to understand the natural course and long term health outcomes of subjects diagnosed with plastic bronchitis. This provides essential data for identifying best practices and treatments. The secondary aim is to understand the structure of casts and mechanism of their formation.

3. **Who can participate?**

Anyone with a confirmed diagnosis of plastic bronchitis, who agree that their cast(s) and data can be added to the registry, can participate.
4. **How are samples collected?**

PB airway casts are spontaneously expectorated (coughed up) or removed by bronchoscopy and normally discarded. If you participate in the registry, the casts will be placed in normal saline and stored in a freezer until shipment to the Rubin laboratory.

5. **How can samples be shipped?**

All casts are shipped overnight on dry ice to Dr. Rubin’s laboratory at Virginia Commonwealth University. The specimen containers should be placed on dry ice and shipped overnight (Monday thru Thursday) to:

Attn: Dr. Mike Davis  
Dr. Bruce Rubin’s Laboratory  
Bldg: KMSB I, Room: 215  
1217 East Marshall Street  
Richmond, VA 23298  
United States

Please see Collection and Processing Instructions for specific information.

6. **How will other researchers be able to request access to the data/samples contained in the International Plastic Bronchitis Registry?**

Other researchers may contact the principal investigator and/or senior VCU lab staff to request access to the data/samples contained in the registry/repository for future research. VCU investigators may file a usage protocol with the VCU IRB to access the data/samples contained in the registry. Data and sample access will be de-identified.

We have also been accepted to participate in the NIH/NCATS GRDR Program. The NIH/NCATS Global Rare Diseases Patient Registry Data Repository program is building a web-based resource that integrates, secures, and stores de-identified patient information from many different registries for rare diseases, all in one place. Investigators also have the opportunity to search the following webpage [http://rubinlab.pediatrics.vcu.edu/research/plastic-bronchitis/](http://rubinlab.pediatrics.vcu.edu/research/plastic-bronchitis/) for a list of current Plastic Bronchitis casts stored at VCU. The table will list GUID or pseudo GID and how many casts are available for each and will be accessible to anyone visiting the website.

7. **Can one withdraw from the registry?**

To withdraw participants must write to the Principal Investigator: Dr. Bruce K. Rubin. However, participants cannot request their data/samples be destroyed/removed from the registry/repository after they have been linked. Even if patients withdraw, the researchers may still use or disclose health information they have already collected for this study.
8. Who can I contact if I have any other questions?

The study staff named below is the best person to email or call for questions about your participation in this study.

Michael D. Davis, RRT, PhD

Virginia Commonwealth University
Rubin Laboratory

Kontos Medical Sciences Building
1217 E. Marshall Street, Room 215
Richmond, VA 23298
United States

804-628-2793
Michael.D.Davis@vcuhealth.org