

BACHBank Buzz

The Boston Adult Congenital Heart Disease Biobank Newsletter

ISSUE 1 | MAY 2018

Welcome!

Thank you for your support of the Boston Adult Congenital Heart Disease Biobank (BACHBank). This newsletter has been established to keep our partners updated on our progress! This includes how biologic samples are being used and how this biobank is already contributing to our knowledge about adults with congenital heart disease.

What else?

'CONTROL' SUBJECTS

In 2012, we began enrolling healthy participants who do not have CHD to serve as comparison, or control, subjects. These samples will provide a basis for comparison for future analysis of the BACHBank samples. Friends and family members who accompany patients to their clinic appointments are eligible to be controls, too!

A *reminder*: BACHBank was established in 2012 at Boston Children's & Brigham and Women's Hospitals as a resource for ongoing research in circulating and urinary biomarkers, such as proteins, to improving understanding of and care for congenital heart disease in adults. BACHBank is advised by a scientific advisory board with membership including ACHD specialists, patient representatives, cardiovascular biomarker epidemiologists and other experts.

REPEAT DRAWS

In 2015, we began drawing repeat sets of samples from participants about 2 years after their prior draw. Having repeated measurements will help us to better understand how levels of markers in the blood and urine change over time and what this means for our patients.



FAST FACTS

1235

Participants enrolled through 2017

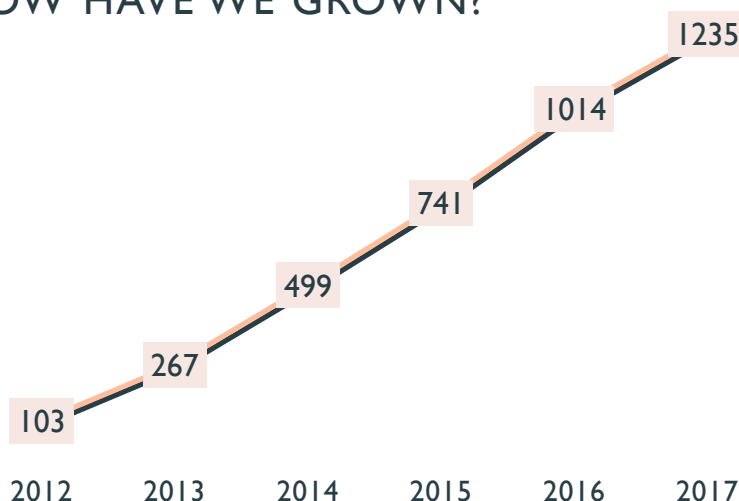
332

Repeat draws

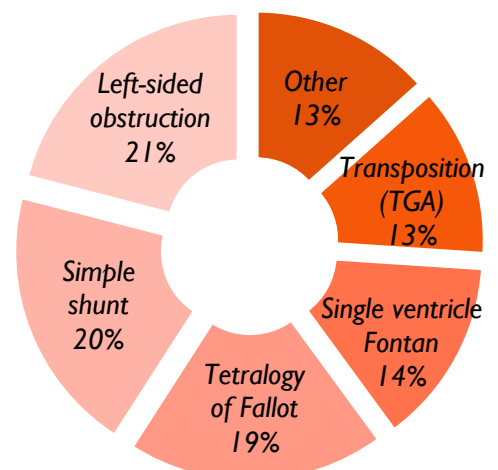
89

Control participants enrolled

HOW HAVE WE GROWN?



Diagnoses at a Glance



Check out a selection of BACHBank publications!

Association of Albuminuria with Major Adverse Outcomes in Adults with Congenital Heart Disease: Results from the Boston Adult Congenital Heart Biobank

JAMA Cardiology. 2018 Apr 1; 3(4).

Increased protein in the urine can be an early sign of more widespread blood vessel dysfunction. As such, the presence of urine protein (albuminuria) is associated with worse prognosis in many diseases. We studied 612 adults with congenital heart disease enrolled between 2012 and 2016, finding increased urine protein in about 1 out of every 6 patients. Those who had this finding tended to have lower oxygen levels, more symptoms, and greater disease complexity. Albuminuria was associated with an almost 5-fold increased risk for adverse outcomes in most patients (those with two ventricles, a “biventricular circulation”).

However, while more than 1/3rd of patients with a single ventricle Fontan circulation had increased urine protein, in that group the presence of urine protein was not predictive of outcomes.

These findings show that increased urinary protein is common and is associated with higher risk for adverse outcome in adults with CHD and a biventricular circulation. It is also common in those with a Fontan circulation, and further research is needed to understand why it isn't associated with clinical course in that group.



[Read More Here!](#)

Design and Implementation of a Prospective Adult Congenital Heart Disease Biobank

World J Pediatr Congenit Heart Surg. 2016 Nov; 7 (6).

Adults with CHD comprise a growing, increasingly complex population. The Boston Adult Congenital Heart Disease Biobank is a program for the collection and storage of biospecimens to provide a sustainable resource for scientific biomarker investigation in ACHD. In this manuscript, we describe a protocol to collect, process, and store biospecimens for ACHD or associated diagnoses. The protocol involves collecting urine and blood. A subset of the blood and urine undergoes immediate clinically relevant testing. The rest are processed and stored in a -80°C freezer as aliquots of plasma, serum, cell pellet, and urine.

Blood is collected in tubes with diverse contents to enable flexible later use. Demographic and clinical data are entered into a database; data on biospecimen collection, processing, and storage are managed by an enterprise laboratory information management system. Between implementation in 2012 and 2015, we enrolled more than 650 participants (aged 18-80 years, 53.3% women). The most common CHD diagnoses were single ventricle Fontan circulation, tetralogy of Fallot, and left-sided obstructive lesions.



[Read More Here!](#)

Did you know?

The BACHBank also enrolled participants at the **Adult Congenital Heart Association** national conferences in 2014 and 2017. Look for us in the Research Room at the next ACHA conference!

Thank you!

We are indebted to you and your ongoing support of this initiative. It goes without saying we could not do this without your contributions. Together, we have started to discover novel insights into understanding of CHD in adults and have already identified new ways for clinicians to assess each patient's risk. Stay tuned and – even better- **please be in touch** if you have any input or ideas to further our partnership.

Financial Support: *The Biobank and its research is supported by Boston Children's Hospital Department of Cardiology, Harvard Catalyst, and the Biobank for Health Discovery. Specific projects and investigators have also received grant funding from Actelion Pharmaceuticals, Roche Diagnostics, Matthew's Hearts of Hope Foundation, and the American Heart Association.*

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