

BACHBank Buzz

The Boston Adult Congenital Heart Disease Biobank Newsletter

ISSUE 2 | MAY 2020

Greetings!

Thank you for your support of the Boston Adult Congenital Heart Disease Biobank (BACHBank). This newsletter provides an update on our progress! This includes how samples are being used and how we are developing new knowledge about adults with CHD. Additionally, we have big news about the future of the biobank and want to give you the opportunity to weigh in.

BACHBank was established in 2012 to improve understanding of and care for congenital heart disease in adults (ACHD) through studying biomarkers.



Updates

We have paused enrolling patients at Boston Children's & Brigham and Women's

As of January 2020, we have paused enrolling new participants or collecting repeat samples from existing participants. Please know we are still very much using the samples and information we have collected to learn about congenital heart disease. We continue to use the biobank to improve risk prediction, and explore mechanisms of disease in ACHD.

What is happening with the collected samples?

A subset of samples will remain at Boston Children's, but most will move to Cincinnati Children's Hospital, where they will be available for future research. All samples sent to Cincinnati will be de-identified. That is, *samples will not include your name or other identifiers, just an anonymous study number that only BCH ACHD researchers can link back to you.*

At Cincinnati Children's, Sasha Opotowsky, the founder of the biobank, will apply expertise in

biomarkers and ACHD to further the biobank mission. ***Our team will continue to use the stored samples as we intended: to improve our understanding of & care for adults with CHD.*** Boston Children's ACHD doctors and researchers will remain involved and will continue to use these samples.

This wouldn't be possible without you!

It goes without saying we could not have accomplished so much without your collaboration. Together, we have already explored the use of biomarkers as clinical tools to assess a patient's risk, and we have made new discoveries about CHD.

We have thought long and hard about this, and we are confident the current plan is the best path to sustain the biobank and enhance research, while continuing to protect your privacy and confidentiality. We hadn't planned to move the samples when we started the biobank or when we consented you for the research, and we want you to know

you have a say in what happens to the samples you contributed. ***Please contact us if you have questions or would prefer your samples not be moved.***

Time & Again

In 2015, we started collecting repeat samples. We now have 493 participants with one redraw, 176 with two and 21 with three. These repeated measurements will help us to better understand how levels of markers change and what this means for our patients.

Biomarker? What's that?

Biomarkers are measurable substances in blood and urine. Examples include cholesterol, glucose and white blood cells. Biomarkers are important in both caring for patients and in research. Biomarkers can help indicate the **risk** and **prognosis** of a disease in a patient and can help **predict** an individual's response to an intervention or exposure.

Contact Information:

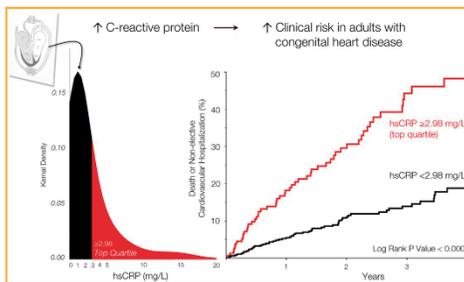
BACHBANK@CARDIO.CHBOSTON.ORG | (617) 355-4347 | tinyurl.com/bachbank

Check out recent findings!

Inflammation: using high sensitivity C-reactive protein (hsCRP) to predict clinical events in ACHD

European Heart Journal. 2018 Sep 7; 39 (34)

hsCRP is a protein made by the liver in response to inflammation. Levels increase to 100-fold with acute infections, but some people have slightly higher levels without any infection. Low level inflammation is recognized as a risk factor for acquired heart disease, like heart attacks and strokes. hsCRP hadn't been studied in ACHD.



We measured hsCRP in the blood of 707 people enrolled in the BACHBank between 2012 and 2016. Mildly high hsCRP (>3 mg/L) was present in about a quarter of patients. Elevated hsCRP was strongly associated with worse functional status, exercise capacity and heart failure, and with comorbidities such as atrial arrhythmia. Those with elevated hsCRP were more likely to have adverse outcomes, such as hospitalization or mortality, even after accounting for baseline clinical status and other diagnoses. Additionally, hsCRP was associated with adverse outcomes for all types of CHD.

Further research is needed to define the role of measuring hsCRP in ACHD, but these results suggest that this widely available blood test may help doctors identify patients at higher risk. This could allow us to make more personalized decisions for each patient. More work is needed to figure out why this marker of inflammation would be so strongly related to what happens to an adult with CHD.

FAST FACTS

1589

CHD participants

690

Repeat draws

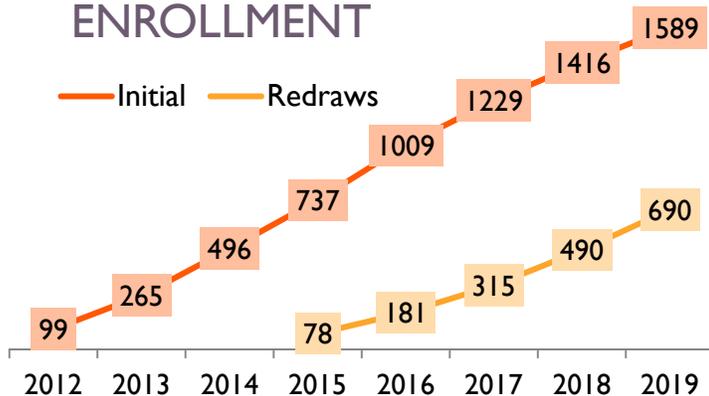
98

Control participants

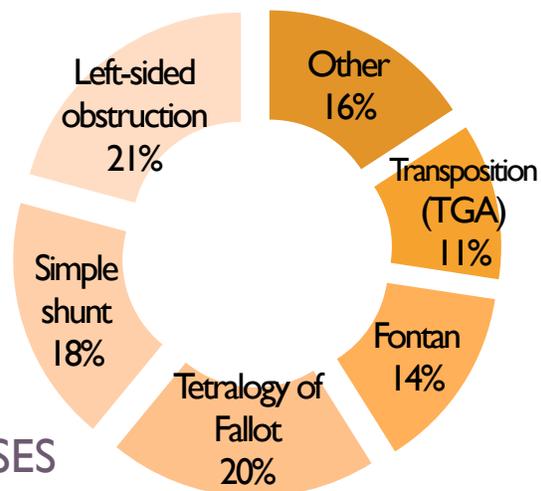


[Click to read the full paper](#)

ENROLLMENT



DIAGNOSES



Thank you!

Together we have created a truly unique and powerful resource to improve our understanding of and care for adults with CHD. Please be in touch if you have any input or ideas to further our partnership.

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



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