

**FEEDBACK? THIS IS THE FIRST QUARTERLY CBAR NEWSLETTER. PLEASE SEND ANY FEEDBACK, OPINIONS, AND NEWS ITEMS YOU WOULD LIKE TO BE INCLUDED TO ALISON BUTLER AT ALISON.BUTLER@CW.BC.CA.**

## EXECUTIVE NAMED

The CBAR executive was created following the September meeting. The committee is balanced across Canada and has representation from both CAPS & CPHRG. The committee includes:

- Dr. Jean-Martin Laberge, Co-chair
- Dr. Rick Schreiber, Co-chair
- Dr. Najma Ahmed
- Mr. George Anthopoulos
- Dr. Brian Cameron
- Dr. Sherif Emil
- Dr. Carolina Jimenez
- Dr. Steven Martin
- Dr. Natalie Yanchar

## NEW CBAR COORDINATOR

Ms. Alison Butler was hired in February as the CBAR Research Coordinator. Alison brings several years experience in clinical research and administration to the role. She is also the coordinator for the Canadian Pediatric Surgery Network (CAPSNet), providing another synergy between the two networks.

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## ETHICS SUBMITTED

An ethics application was submitted at BC Children's Hospital and is now undergoing minimal-risk review. The application aims to capture 100% of Canadian BA patients. Based on our previous study, we expect to identify 22-25 BA cases across Canada each year. To achieve our goals, it is critical that the registry captures all patients. Following approval, a template IRB form will be created for other sites to follow.

## REDCAP DATABASE NEARLY COMPLETE

The CBAR REDCap database registry was created based on all of your excellent input at the September meeting. After putting on the finishing touches, the database will be ready to go. Access usernames and passwords for individual sites will soon be available to you. Thanks to Victor Espinosa for his fantastic work in creating the database!

Data Collection Instrument	Baseline (1)	Operation (2)	Immediate Post Operative (3)	Transplant (4)	Post Op 1 month (5)	Post Op 3 month (6)	Post Op 6 months (7)	Post Op 12 months (8)	Post Op 2 years (9)	Post Op 3 years (10)	Post Op 4 years (11)	Post Op 5 years (12)	Post Op other (13)	Unscheduled 1 (14)	Unscheduled 2 (15)	Unscheduled 3 (16)	Summary (17)
Demographics	●																
Referral	●																
Tests By CBAR Consultant	●																
Operative Data	●	●															
Immediate Post Operative Data prior to discharge			●														
Post Operative Data					●	●	●	●	●	●	●	●	●				
Post Operative Unscheduled														●	●	●	
Transplant				●													
Summary																	●
Summary Calc																	●

REDCap database event grid showing data collection time-points for each patient

## MEETING REIMBURSEMENT

Hopefully everyone has already been reimbursed for their CBAR Planning Meeting expenses. If not, please contact Alison.

## BARD-BERLIN

The 1st international congress on Biliary Atresia and Related Diseases (BARD) is taking place in Berlin in October, 2014. Visit <http://www.bard-berlin-2014.com/> for more information and to register.

*We appreciate CIHR's support for last September's planning meeting.*

**A big thank you to the C.H.I.L.D. Foundation and the Anthopoulos family, through their donation to the Montreal Children's Hospital Foundation, for their generous support of the CBAR project.**



<http://www.child.ca>

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