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Canadian Biliary Atresia



Registry Newsletter

FEEDBACK? PLEASE SEND ANY FEEDBACK, OPINIONS, AND NEWS ITEMS YOU WOULD LIKE TO BE INCLUDED TO ALISON BUTLER AT CBAR@EHCNET.PHSA.CA.

BA RESEARCH NEWS

A multi-centre clinical trial, called START, found that steroid therapy following hepatoportoenterostomy did not result in statistically significant bile drainage differences at 6 months post-op in biliary atresia patients. However, steroid therapy was associated with earlier serious adverse events. START was a double-blind trial conducted in 140 infants between September 2005 and February 2011.

Bezerra, J.A., *et al.* Use of corticosteroids after hepatoportoenterostomy for bile drainage in infants with biliary atresia: the START randomized clinical trial. JAMA. May 2014, 311 (17):1750-9. doi: 10.1001/ jama.2014.2623.

BARD-BERLIN

Abstracts are now being accepted for BARD-Berlin. BARD-Berlin is the 1st international congress on Biliary Atresia and Related Diseases (BARD) and is taking place in October, 2014. The deadline for abstract submission is August 1. Visit http://www.bardberlin-2014.com/ for more information and to register.

CBAR CONTACT

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RESEARCH ETHICS BOARD APPLICATIONS

The CBAR REB application at BC Children's Hospital was approved and we are happy to announce that we have started recruiting patients! Template consent and application forms were sent out to all participating sites in early May. Kudos to all of the site investigators that are currently working on putting the application through their IRB. For those sites requiring assistance with this process, please contact Alison.

WEBSITE COMMITTEE FORMED

The CBAR website committee was formed and held their first meeting in April. The committee is cochaired by steering committee members Dr. Najma Ahmed and Mr. George Anthopoulos. A warm welcome to new committee members Natalie Williams, founder of Biliary Atresia Awareness and Research (BAAR) and Dr. Jacob Langer, Division Head of General and Thoracic Surgery at SickKids Hospital. Thank you to these individuals for volunteering their time and expertise to the project. Check out cbar.ca to see the latest updates!

CANADIAN CBAR A Namana Katawa A Nama Kat						
Home About Us	News	Abstractors	Resources	Donate	Contact Us	Site Map
For Parents For Physicians REDCap Database		Introduction BILLARY ATRESIA Billary attesia (BA) is a rare pediatric liver disease that manifests exclusively in newbom infants in the first 2-4 weeks of life. BA is the most frequent cause of end- stage liver disease and liverelated death in children (of any age) and the leading indication for liver transplantation in the pediatric population. The severity and rarity of BA mean that new I hawledge and best clinical evidence are best obtained from collaborations enabled by national and international registries. Read more about billiary atresia here.				

REDCAP DATABASE ACCESS GRANTED

REDCap usernames and passwords were sent out to all of the site investigators in March. Thanks to all those who sent their feedback regarding the data collection forms. If you are a site investigator and have not been able to access REDCap, please contact Alison. RED-Cap is almost ready to go and will be totally done by the time sites receive their REB approval. A manual and data collection forms will be sent out shortly.

BAAR SOCIAL MEDIA AWARD



Congratulations to Biliary Atresia Awareness and Research (BAAR) for winning the largest social media award in North America! BAAR was founded by 16-year old Na-

talie Williams, a biliary atresia survivor. She has worked tirelessly over the past couple of years to increase awareness amongst health professionals and new parents about the symptoms of biliary atresia, as well as promoting organ donation. Check out BAAR's awardwinning facebook page here: https://www.facebook.com/ BiliaryAtresia.ca.

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.



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http://www.child.ca/

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