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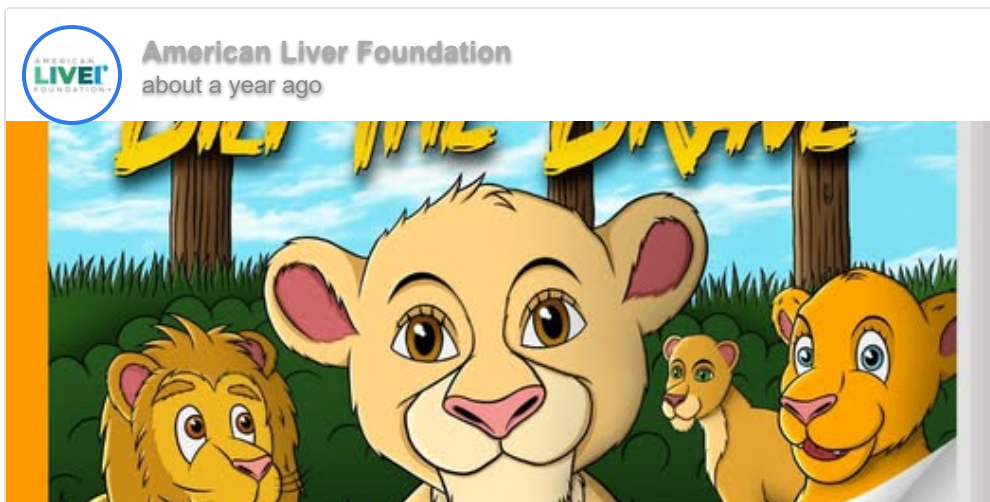
# Bili the Brave Supports Kids With Biliary Atresia

The American Liver Foundation developed the Bili the Brave tool kit to comfort and encourage children living with a rare liver disease.

November 4, 2024 By Laura Schmidt

The American Liver Foundation (ALF) launched an animal-themed tool kit to comfort and support children (<https://www.hepmag.com/tag/pediatric>) with a rare liver disease (<https://www.hepmag.com/tag/liver-disease>), according to an ALF news release (<https://liverfoundation.org/resource-center/blog/american-liver-foundation-launches-bili-the-brave-toolkit-for-children-with-biliary-atresia/>).

The Bili the Brave tool kit (<https://bilithebrave.org/>) was developed to help children and families affected by biliary atresia (BA), a rare liver disease that causes bile ducts to become inflamed and blocked soon after birth (<https://www.hepmag.com/tag/childbirth>). Although rare, BA is the most common cause of chronic liver disease in newborns, occurring in about 1 in every 8,000 to 1 in 18,000 births worldwide, according to the ALF (<https://liverfoundation.org/liver-diseases/pediatric-liver-information-center/pediatric-liver-disease/biliary-atresia/>).

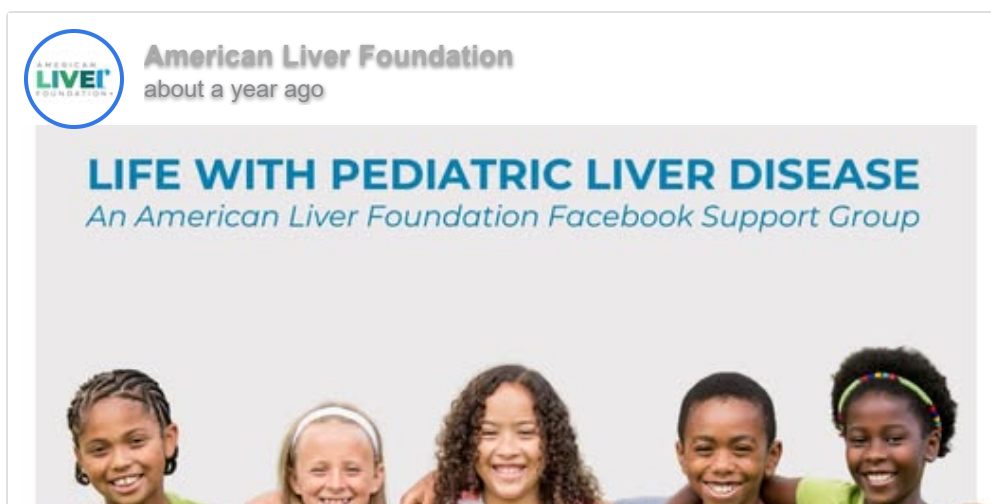


Bili the Brave will be distributed free of charge throughout top pediatric medical centers (<https://bilithebrave.org/participating-childrens-hospitals/>) across the country.

The tool kit includes Bili the Brave, a cute lion with BA that wears a medical bracelet and proudly displays an embroidered scar and bandage to show children that it's normal to experience pain during their BA journey. Kids can squeeze Bili's stomach to hear a recorded clip of real children with BA "roaring."

Symptoms of BA typically appear between two and six weeks after birth. In addition to symptoms such as a swollen abdomen, a baby will experience yellowing of the skin and the whites of the eyes called jaundice. Since other conditions can cause similar symptoms, doctors must perform many tests to diagnose BA; these include blood and liver tests, an ultrasound, X-rays and a liver biopsy.

An online Support Journal for Parents ([https://bilithebrave.org/wp-content/uploads/2024/10/BA-Support-Journal\\_Parents.Final\\_.pdf](https://bilithebrave.org/wp-content/uploads/2024/10/BA-Support-Journal_Parents.Final_.pdf)) features important terminology, information on blood tests used to assess liver function, medical trackers and a daily check-in page for parents in need of self-care.



ALF board member and former Disney Channel executive, Peter Cullen, who helped create Bili, battled autoimmune liver disease and underwent two lifesaving transplants.

“Bringing Bili the Brave to life has been the most rewarding creative project of my life,” Cullen said in the release. “When we created the character description around Bili, it was important to highlight that Bili the Brave is not just a lion with biliary atresia but a lion with a heart full of courage and kindness.”

The tool kit also includes a children’s book authored by (<https://bilithebrave.org/author-and-illustrator/>) Cullen’s daughter, Jennifer Cullen, who grew up seeing firsthand the impact of liver disease. The book also features original artwork by illustrator Nathaniel “Natie” Freson.

“I hope Bili can give children and their families a sense of courage and adventure, breaking down hospital walls and transporting them to a jungle of their own,” Jennifer told the ALF.

Although there is no cure for BA, children can undergo a surgical procedure that replaces the blocked bile ducts outside the liver with a length of the baby’s own intestine, which acts as a new duct.

“Bili’s positive attitude is a beacon of hope for all the young lions out there who share his condition,” Cullen said. “Our hope is that Bili will remind children and parents alike that no matter what obstacles come their way, they can face them with bravery and a smile, just like Bili the Brave.”

For additional resources for adults and educational materials for children, go here (<https://bilithebrave.org/>).

To read more, click #Pediatric (<https://www.hepmag.com/tag/pediatric>). There, you'll find headlines such as "Fatty Liver Disease Is Affecting Children at an Alarming Rate (<https://www.hepmag.com/article/fatty-liver-disease-affecting-children-alarming-rate>)," "Mysterious Children's Hepatitis Finally Has Some Answers (<https://www.hepmag.com/article/mysterious-childrens-hepatitis-finally-answers>)" and "CDC Supports Hepatitis C Testing for Perinatally Exposed Children (<https://www.hepmag.com/article/cdc-supports-hepatitis-c-testing-perinatally-exposed-children#search-query=pediatric>)."