



Biliary Atresia Support Journal for Parents

A Journal for Parents to keep track of important medical information provided during medical visits including, key terminology, medical trackers and a daily check-in. To learn more visit bilithebrave.org.

Key Terminology

Below are many terms you may be hearing from your child's medical team.

Biliary Atresia A rare disease of the bile ducts that affects infants. In babies with biliary atresia, the bile ducts become blocked soon after birth.

Perinatal biliary atresia - This is the most common type. It appears after birth, most often when a baby is about two to four weeks old.

Fetal biliary atresia - This is less common. It appears while a baby is still developing in the mother's womb

Bile A liquid made in the liver that helps break down fats and other nutrients.

Bile Ducts Small tubes that carry bile to and away from the liver.

Biopsy A medical test commonly performed by a surgeon, radiologist, hepatologist, or an interventional cardiologist. The process involves the extraction of sample cells or tissues for examination to determine the presence or extent of a disease.

Cholangiogram An X-ray procedure carried out by a surgeon in the operating room to identify any blockages in the bile ducts leading from the liver. If the test reveals a blockage, the surgeon will proceed with additional investigation to determine if the child has biliary atresia.

MMP-7 A blood test that looks at a molecule, which is specifically elevated in babies with BA.

Scarring Sometimes called fibrosis, tends to be the early stages of liver damage.

Cirrhosis Extensive scarring of the liver – hard scar tissue replaces soft healthy tissue. Severe scarring of the liver can prevent the liver from functioning well.

Jaundice The yellowing of the skin and white part of the eyes.

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Kasai Procedure A surgical technique used to replace blocked bile ducts outside of the liver with a piece of the infant's small intestine, to act as a new bile duct. The procedure allows bile to drain from the liver into the intestine.

Liver Proteins Albumin, Total Protein and Globulin

Liver Transplant The process of replacing a sick liver with a donated, healthy liver. It may be a whole liver or a piece of a liver.

A variety of blood tests can be used to assess liver function. They include:

Liver enzyme tests (AST, ALT) Elevated levels of liver enzymes can alert physicians to liver damage or injury, since the enzymes leak from the liver into the bloodstream under these circumstances.

Gamma-glutamyl transferase (GGT) The gamma-glutamyl transferase (GGT) blood test may be used to detect the activity of GGT in your blood. If you have liver disease or bile duct damage, GGT may leak into your bloodstream. Having high levels of GGT in your blood may indicate liver disease or damage to your liver's bile ducts.

Bilirubin Bilirubin is produced by the liver and is excreted in the bile. Elevated levels of direct or conjugated bilirubin often indicate an obstruction of bile flow or a defect in the processing of bile by the liver.

Albumin, total protein, and globulin Below-normal levels of proteins made by the liver are associated with many chronic liver disorders.

Clotting studies-prothrombin time (PT) and partial thromboplastin time (PTT) Tests that measure the time it takes for blood to clot may be part of the labs evaluated when diagnosing biliary atresia. Blood clotting requires vitamin K and proteins made by the liver. Liver cell damage and bile flow obstruction can both interfere with proper blood clotting.

Infectious, genetic and metabolic studies Tests on sweat, blood and urine may be done to look for other causes of liver problems that sometimes look very similar to biliary atresia.

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PATIENT MEDICAL TRACKER

Date of Child's Diagnosis: _____

Pediatrician Name: _____

Pediatrician Phone: _____

Hepatologist Name: _____

Hepatologist Phone: _____

Hepatology Nurse Name: _____

Hepatology Nurse Phone: _____

Social Worker/Case Manager Name: _____

Social Worker/Case Manager Phone: _____

Additional Information:

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HOSPITAL VISIT NOTES

DATE OF VISIT

AGE

WEIGHT

BILIRUBIN

STOOL COLOR

_____	_____	_____	_____	_____
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HOME TRACKER

<u>DATE</u>	<u>TIME</u>	<u>PEE</u>	<u>POOP</u>	<u>NOTES (including stool color)</u>
_____	_____	_____	_____	_____
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Additional Notes:

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DAILY CHECK-IN FOR PARENTS

Taking care of an infant affected by Biliary Atresia can be challenging and it's important to also take care of yourself.

A lion's heart is strong and brave, always ready to take on challenges with lots of courage.

Intentions for my day:

Self-care:

Things I am grateful for:

Mood:

Morning:

Afternoon:

Evening/Night:

American Liver Foundation offers support for parents and caregivers:

- Life with Pediatric Liver Disease Support Group on Facebook- facebook.com/groups/alf.ba.families
- Sharing the Journey, an ALF Support Group network for Caregivers - liverfoundation.org/series/sharing-the-journey-an-alf-support-network-for-caregivers
- Caring Connections—an ALF peer-to-peer support program - alf.chronus.com/p/p1

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