

## What is ChiLDREN?

The **Childhood Liver Disease Research and Education Network (ChiLDREN)** is a collaborative team of doctors, nurses, research coordinators, medical facilities, patient support organizations and the National Institutes of Health. The ChiLDREN Network is the amalgamation of the Biliary Atresia Research Consortium (BARC) and the Cholestatic Liver Disease Consortium (CLiC), with the addition of studies on cystic fibrosis liver disease (CFLD). The goal of the ChiLDREN Network is to support the discovery of new diagnostics, etiologic, and treatment options for children with liver disease, and those who undergo liver transplantation. The Network also supports training the next generation of investigators in pediatric liver diseases.

The ChiLDREN Network has clinical sites and research labs in the U.S., Canada, and the United Kingdom. These sites are working together to improve the lives of children and families dealing with rare cholestatic liver diseases. ChiLDREN is funded by the National Institutes of Health (NIH), with additional support from the Cystic Fibrosis Foundation (CFF) and the Alpha-1 Foundation.

## ChiLDREN can help you:

- *Obtain up-to-date information about childhood liver diseases*
- *Stay up to date with new developments*
- *Become aware of clinical research and clinical trial opportunities*
- *Connect with patient support groups*

<http://childrennetwork.org/>

## ChiLDREN's Clinical and Research Centers include:

- **Atlanta** - Children's Healthcare of Atlanta
- **Baltimore** - Johns Hopkins School of Medicine
- **Chicago** - Children's Memorial Hospital
- **Cincinnati** - Children's Hospital Medical Center
- **Denver** - Children's Hospital Colorado
- **Houston** - Texas Children's Hospital
- **Indianapolis** - Riley Hospital for Children
- **London (laboratory facility only)**  
King's College Hospital
- **Los Angeles** - Children's Hospital Los Angeles
- **New York City** - Mount Sinai Medical Center
- **Philadelphia** - Children's Hospital of Philadelphia
- **Pittsburgh** - Children's Hospital of Pittsburgh of UPMC
- **San Francisco** - University of California, San Francisco
- **Seattle** - Seattle Children's Hospital
- **St. Louis** - Washington University School of Medicine
- **St. Louis** - Saint Louis University / Cardinal Glennon Children's Medical Center (Alpha One Antitrypsin Deficiency only)
- **Toronto** - The Hospital for Sick Children

### Data Coordinating Center:

University of Michigan  
Department of Biostatistics  
1415 Washington Heights  
Ann Arbor, MI 48109-2029



## Children Liver Disease Research and Education Network

<http://childrennetwork.org/>

**For more information about ChiLDREN,  
please contact:**

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## Diseases we study

The ChiLDREN Network was developed to support the discovery of new diagnostics, etiologic, and treatment options for infants, children, and young adults with cholestasis, and those who undergo liver transplantation. We are currently studying the following cholestatic liver diseases:

- *Alagille syndrome*
- *Alpha-1-antitrypsin deficiency*
- *Bile acid synthesis and metabolism defects*
- *Biliary Atresia*
- *Cystic Fibrosis liver disease (CFLD)*
- *Idiopathic neonatal hepatitis*
- *Mitochondrial hepatopathies*
- *Progressive familial intrahepatic cholestasis (PFIC)*

## What is Cholestasis?

Cholestasis is a condition in which bile is not flowing properly from the liver to the intestines. Cholestasis is caused by a number of specific childhood diseases, including those listed above. There are several easily identifiable symptoms of cholestasis in children:

- *Jaundice (yellow eyes or skin) is caused by a build-up of bile in the liver and the body.*
- *Pruritus (itching) also indicates a build-up of bile in the body.*
- *Poor growth, another symptom of cholestasis in some children, is caused by poor intestinal absorption of food, which can often lead to vitamin deficiencies.*

There are other symptoms of cholestasis that are related to specific vitamin deficiencies, including:

- *bruising or bleeding (vitamin K)*
- *bone pain or fractures (vitamin D)*
- *problems with balance and muscle coordination (vitamin E)*

## Our Research

The ChiLDREN Network has several ongoing studies focused on children that are diagnosed with cholestasis.

Most of the ChiLDREN studies are natural history studies aimed at acquiring information and data that will provide a better understanding of these rare conditions. Participants will be asked to allow study personnel to obtain information from medical records and an interview, and to collect blood, urine, and tissue samples when clinically indicated, in order to understand the causes of these diseases and to improve the diagnosis and treatment of children with these diseases. All of the information obtained in these studies is confidential and no names or identifying information are used in the study.

For information on all active ChiLDREN studies and how you may be able to participate, please go to Research page of the ChiLDREN website:

<http://childrennetwork.org/research.html>

You can also contact any of the ChiLDREN clinical centers (see list in this brochure) or contact the ChiLDREN Research Administrator (see contact info in this brochure) for more information.

### Funding for the ChiLDREN Network:



## Help when you need it

Patient support groups and advocacy organizations specializing in cholestatic liver diseases are here to help you. These groups are important partners with the ChiLDREN Network, and are devoted to providing support, resources and services for patients and families. These organizations also promote research into the cause, cure, and treatment of cholestatic liver diseases.

### Alagille Syndrome Alliance

503-885-0455

[www.alagille.org](http://www.alagille.org)

### Alpha-1 Foundation

305-567-9888

[www.alpha-1foundation.org](http://www.alpha-1foundation.org)

### American Liver Foundation

800-GO LIVER (465-4837)

[www.liverfoundation.org](http://www.liverfoundation.org)

### Children's Liver Association for Support Services (CLASS)

877-679-8256

[www.classkids.org](http://www.classkids.org)

### Children's Liver Disease Foundation (United Kingdom)

+44 (0) 121 212 3839

<http://www.childliverdisease.org/>

### Cystic Fibrosis Foundation

(301) 951-4422

[www.cff.org](http://www.cff.org)

### PFIC.org

<http://pfic.org>

### United Mitochondrial Disease Foundation

412-793-8077

[www.umdff.org](http://www.umdff.org)