



PFIC.org Newsletter

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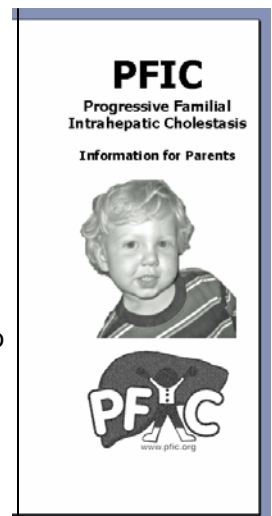
PFIC Pamphlet

Recently Amy Dietrich and myself completed an information pamphlet for PFIC. It is available on-line at PFIC.org, and printed copies are available by request.

I have wanted this pamphlet to exist for so long. I remember when Anna's doctor wrote Progressive Familial Intrahepatic Cholestasis on the marker board as he explained what he thought she had. I tried to copy the name down while holding a fussy baby. I knew then that a PFIC informational pamphlet was needed.

I was so happy when Amy volunteered to help. Besides being Mom to Thomas (pictured on the cover) and Caroline she is also a Pediatrician. Amy did a great job of organizing all the technical information. Many thanks to her for the wonderful work.

Look for the link on PFIC.org that will take you to the pamphlet.



Cholestatic Liver Disease, CLiC

The Cholestatic Liver Disease Consortium (CLiC) is enrolling research participants at a number of centers in CLiC, and information can be found on the CLiC website, <http://rarediseasesnetwork.epi.usf.edu/clic>.

When you visit the CLiC site be sure to register on the Patient Contact Registry. The contact registry provides information for CLiC to contact you and inform you of research studies.

If you have previously registered you should be receiving information on current studies and the enrollment process. The CLiC registry is not a study enrollment form.

Newsletter

Help is needed with the newsletter. Volunteers are needed to help write and edit the newsletter. To volunteer please e-mail Robin PFICII@pfic.org

Chat Night – Tuesday April 15th, 7:00pm CT

Well, folks this newsletter is a short one. It doesn't mean that we all don't have a lot going on, in fact it means just the opposite. I am just too busy to pack all the info in a newsletter, so please join us for Chat Night.

Topics for discussion:

- A monthly set chat time
- The CLiC Studies
- Creating a PBED Parents Guide/Tips for PBED
- The PFIC Store
- A PFIC family get together, and much more.

First time to Chat? Not a problem.

If you have never chatted before it is easy to do. Go to <http://PFIC.org> Click on the Chat button found on the right side of the screen. It will ask you to pick a log on name and text color. You don't have to be a member of the forum to sign onto chat, just sign on and join in.

