

Dear Parent and/or Guardian.

Your child has alpha-1-antitrypsin deficiency (ATD) with liver involvement (i.e. cirrhosis and its complications) and has been referred to Robert H. Squires, MD, and the Liver Study team at Children's Hospital of Pittsburgh of UPMC. Your doctor's office contacted us indicating that you are interested in learning more about our Alpha-1 Research Study, which evaluates the effects and effectiveness of carbamazepine (CBZ) on ATD.

Dr. Squires or a member of the study team will call to discuss the Alpha-1 Study and answer your questions about participation. If you chose to participate, your child must first complete the screening visits before they can be enrolled.

What to expect during screening:

- Review of the Informed Consent Form
- Medical History Review
- Physical Exam
- Blood Work

- EKG
- Abdominal Ultrasound
- Liver Biopsy

The screening and future study visits will be done at the Lawrenceville campus of Children's Hospital of Pittsburgh of UPMC, 4401 Penn Ave., Pittsburgh, PA 15224. Driving directions by can be found at www.chp.edu/locations/directions.

Over the course of your child's involvement in the study, Dr. Squires and the study team will also keep your child's doctor informed of his or her progress.

Find more information online at www.chp.edu/liverstudy or contact the Liver Study team at 1-855-428-2281. We can also be reached by email at liverstudy@chp.edu.

We look forward to meeting you and your child.

Sincerely,

Robert H. Squires, MD

Adam Kufen, RN Andrew Chu, MD Kapil Chopra, MD Michael Dunn, MD Philip Orons, MD Shahid Malik, MD James Squires, MD Mitchell Tublin, MD