

# FAMILY RESOURCES

## LIST OF TRANSPLANT AND DISEASE-SPECIFIC RESOURCES FOR FAMILIES



Families requested a list of disease-specific transplant resources that can help navigate the complexities of the disease and transplant processes and ensure that they are accessing the best possible support. The Starzl Network is not affiliated with the organizations below and does not endorse any of the information provided therein. This information should not replace medical advice from your doctors or medical team.

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## 1. Family Led Resources

### Liver Mommas & Families

- We continue that support beyond the hospital, offering resources on our website for parents and families to help navigate some of the challenges presented by having a child with life-threatening liver disease and liver transplant. Our team members provide individual outreach to families through online support efforts and care packages.
- <https://www.livermommas.org>

### Pressing On

- Pressing On provides wrap-around care to support the entire family. We help uplift and resource all loved ones affected by crisis, including siblings, parents, grandparents, extended family, and community members.
- <https://www.pressingon.org/>

### Transplant Families

- Transplant Families emerged out of a pursuit to inspire and support the community, and a desire for actions to speak louder than words. Established in 2012 as a resource and 2017 as an official 501c3 by transplant parents just like you, we're an organization driven by progressive ideas, bold actions, and a strong foundation of support in the hope to help others. Contact us to learn more and get involved.
- <https://www.transplantfamilies.org/>



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## 2. Liver Disease-Specific Resources

### Alagille Syndrome Alliance

- Our vision is simple – that, as a result of our efforts and in partnership with our stakeholders, all ALGS Warriors thrive in a close-knit community full of loving support, easily accessible resources, and life affirming hope.
- <http://alagille.org/>

### Alpha-1 Foundation (Alpha-1 Antitrypsin Deficiency)

- Support Groups: <https://www.alpha1.org/newly-diagnosed/living-with-alpha-1/support-groups/>
- Kids Guide: <https://www.alpha1.org/Alpha1/wp-content/uploads/2019/09/2016-Version-Not-the-only-Alpha-1-Kids-Guide-to-Alpha-1.pdf>
- Alpha-1 Alphabet Book: <https://www.alpha1.org/Alpha1/wp-content/uploads/2019/09/2014-Version-A-to-ZZ-Childrens-Book.pdf>
- Not the Only Alpha-1; Teenager's Guide to Alpha-1 Antitrypsin Deficiency: <https://www.alpha1.org/Alpha1/wp-content/uploads/2019/09/2016-Version-Not-the-Only-Alpha-1-Teenagers-Guide.pdf>

### Biliary Atresia Research & Education (BARE)

- <https://www.bareinc.org/>

### Crohn's and Colitis Foundation

- <https://www.crohnscolitisfoundation.org/>
- <https://www.crohnscolitisfoundation.org/local-resources>

### Cystic Fibrosis Foundation

- <https://www.cff.org/support#support-resources>

### The Hepatoblastoma Resource Network

- <https://www.hepatoblastoma.org/>

### MSUD (Maple Syrup Urine Disease)

- <https://msud-support.org/>



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### National Organization for Rare Disease (NORD)

- MSUD, Crigler Najjar Syndrome I, Neonatal Cholestasis, Wilson Disease, PTLD (post-transplant lymphoproliferative disorder)
  - <https://rarediseases.org>

### Progressive Familial Intrahepatic Cholestasis (PFIC)

- <https://www.pfic.org/>

### PSC Partners Seeking a Cure (Primary Sclerosing Cholangitis)

- [www.pscpartners.org](http://www.pscpartners.org) (PSC patient and caregiver information and support resources, including links to Zoom support groups, podcasts & webinars)
- <https://www.facebook.com/groups/PSCPclosedgroup> (social media support group)

## 3. Mental Health Resources

### The Child Mind Institute

- The Child Mind Institute is dedicated to transforming the lives of children and families struggling with mental health and learning disorders by giving them the help they need to thrive.
- <https://childmind.org>

### Cosmic Kids

- We use stories, role-play and a good portion of silliness to make yoga and mindfulness fun for kids. We're encouraging them to move and stretch their bodies - and squeezing in breathing, relaxation, and visualization techniques along the way.
- [www.cosmickids.com](http://www.cosmickids.com)

### Heart-Mind Wellbeing

- Heart-Mind Online is for all those who are searching for evidenced-informed resources that educate the hearts of children. This collection of resources builds capacity in individuals and communities to support the Heart-Mind well-being of children, and promotes their positive social and emotional development.
- <https://www.heartmindonline.org>



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### Help Guide

- HelpGuide.org is an independent nonprofit that runs one of the world's leading mental health websites. Each month, millions of people from all around the world turn to us for trustworthy information they can use to improve their mental health and make healthy changes.
- <https://www.helpguide.org>

### The National Child Traumatic Stress Network (NCTSN)

- The National Child Traumatic Stress Network (NCTSN) was created to raise the standard of care and increase access to services for children and families who experience or witness traumatic events.
- <https://www.nctsn.org/>

### Stop. Breathe. Think

- Stop.Breathe.Think gives young people, aged 21 or younger, access to free 1-1 counselling sessions. No wait times and available nationally, we provide vital support to those who need it right now. Stop.Breathe.Think is run by Switch180 charity.
- <https://www.stopbreathethink.org.uk/>

### Trauma Healing

- Dedicated to supporting trauma resolution and resilience through culturally responsive professional training and education, research, and outreach around the globe.
- <https://www.traumahealing.org>

## 4. Other Helpful Resources

### Children's Transplant Book Series

- <https://www.donatelife.net/books/>

Interactive medication alarm app specifically created for transplant patients by medical doctors

- <http://www.transplanthero.com/>



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### 5. Professional Transplant Organizations

#### AALSD (American Association For The Study Of Liver Disease)

- AASLD is the leading organization of scientists and health care professionals committed to preventing and curing liver disease. We foster research that leads to improved treatment options for millions of liver disease patients. We advance the science and practice of hepatology through educational conferences, training programs, professional publications, and partnerships with government agencies and sister societies.
- <https://www.aasld.org/patient-resources>

#### American Society of Transplantation (AST)

- Power2Save Resources - We're on a mission to prove everyone has the power to save a life by supporting organ transplant research.
  - <https://power2save.org/>
- Spanish Resources/Transplant Community Educational Materials
  - <https://power2save.org/community-education/>

#### Be The Match

- Patients depend on Be The Match and our supporters to find a match to save their life. We are here to provide one-on-one support to patients and their families every step of the way along the transplant journey. Our never-ending passion and dedication to save lives through transplant are what drive us to help more patients survive.
- <https://bethematch.org/patients-and-families/>

#### Center for Organ Recovery & Education (CORE)

- The Center for Organ Recovery & Education (CORE) is one of 57 federally designated not-for-profit organ procurement organizations (OPOs) in the United States. CORE partners with more than 150 hospitals and health care facilities to deliver the gift of life by coordinating the surgical recovery of organs, tissues and corneas for transplantation. CORE also facilitates the computerized matching of donated organs, tissues and corneas.
- <https://www.core.org/understanding-donation/living-donation/>



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### Children's Organ Transplant Association (COTA)

- COTA provides information to your community to assure them the funds raised for transplant-related expenses are raised ethically and used appropriately. Because COTA is the administrator of the money raised in your community, these funds are not taxable income and do not jeopardize participation in assistance programs. Additionally, COTA offers each patient fundraising campaign a challenge grant of up to \$5,000.
- <https://www.cota.org>

### Organ Procurement and Transplantation Network/ United Network for Organ Sharing (OPTN/UNOS)

- [https://optn.transplant.hrsa.gov/media/2464/weparentntk\\_optn.pdf](https://optn.transplant.hrsa.gov/media/2464/weparentntk_optn.pdf)
- <https://optn.transplant.hrsa.gov/patients/about-transplantation/>
- <https://unos.org/resources/patient/#LiverIntestine>
- <https://transplantliving.org/community/>
- <https://optn.transplant.hrsa.gov/>



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