

Stay Informed: E-Newsletters and E-Alerts

- **Pediatric Transplantation – E-Alert**
 - <http://www.blackwell-synergy.com/toc/ptr/11/6?ai=wj&ui=hytr&af=H>
- **Information for Practice – Social Work**
 - <http://ifp.nyu.edu>
 - gary.holden@nyu.edu
- **Promising Practices News – Pediatrics**
 - <http://www.promisingpractices.net/research.asp>
 - PPN-news@rand.org

Stay Informed

continued

- **United Network for Organ Sharing**
 - <http://www.unos.org/>
- **International Society for Heart and Lung Transplant**
 - <http://www.ishlt.org>
- **Eurotransplant Website**
 - <http://www.transplant.org/>
- **Kaiser Family Foundation**
 - <http://www.kff.org/>

Stay Informed continued

- **American Journal of Bioethics – Weekly News**
 - <http://bioethics.net>
- **Medical News Today**
 - <http://www.medicalnewstoday.com/newsletters.php>
- **Journal Watch – enroll by topic**
 - <http://www.jwatch.org/?q=etoc>
- **Medscape Week in Review - enroll by topic**
 - <http://www.medscape.com/transplantation>

Stay Informed...

- NASW Publications

- <http://www.socialworkers.org/pubs/default.asp>

- PubMedline: US National Library of Medicine and National Institutes of Health

- <http://www.ncbi.nlm.nih.gov/pubmed>

- HealthCare.gov

- Online tool providing information and resources to connect to affordable health care

Just for Kids

□ **Bear Hugs Program**

- Roche
- Teddy bear, storybook, and activities
- http://www.rochetransplant.com/community_support/bear_hugs/default.aspx on-line application
- Or call 1-800-893-1995 for applications

Fund-Raising Organizations*

- **Children's Organ Transplant Association (COTA)**
 - <http://www.cota.org>
- **National Transplant Assistance Fund**
 - <http://transplantfund.org>
- **The National Foundation for Transplants**
 - <http://www.transplants.org>
- **American Transplant Association**
 - <http://www.americantransplant.org>

*Be sure to discuss privacy issues with patient and family

Financial Resources

- **First Hand Foundation of the Cerner Corp.** (any pediatric patient)
 - www.firsthandfoundation.org
- **Lungs for Life** (CF)
 - www.lungsforlife.org (New York State Only)
- **Reach for the Stars** (CF)
 - www.r4stars.org
- **UnitedHealthcare Children's Foundation**
 - www.uhccf.org (16 years and younger)
 - Assistance only for those with commercial insurance

Financial Resources continued

- **CHIN: Spencer's Fund (heart)**
 - www.tchin.org (for members only)
- **Children's Liver Assoc. for Support Services**
 - www.classkids.org
- **Boomer Esiason Foundation (CF)**
 - www.esiason.org
- **Patient Services Inc.**
 - www.uneedpsi.org
 - **Disease specific (includes Alpha1-Antitrypsin Deficiency and CF with pseudomonas Aeruginosa)**

Financial Resources continued

□ **National Kidney Foundation**

- <http://www.akfinc.org>
- <http://www.kidney.org/help/index.cfm>

□ **Cystic Fibrosis Foundation**

- www.cff.org
- www.cysticfibrosis.com

□ **Erika Kate Foundation** (life-threatening heart conditions)

<http://erikakate.org>

Financial, emotional and spiritual assistance

Financial Resources continued

- **Community resources** (state, local) examples:
 - Georgia Transplant Foundation
 - www.gatransplant.org
 - California: Genetically Handicapped Persons Program
 - www.dhs.ca.gov
- **HealthWell Foundation**
 - www.healthwellfoundation.org
 - Check the disease list - Immunosuppression for organ transplant is on the disease list
 - Assistance for meds, insurance premiums and co-pays
- **TRIO** (air travel & scholarships) (any transplant)
 - www.trioweb.org

Financial Resources: Medications

□ Medication

- www.needymeds.com
- www.rxassist.org
- www.pparx.org/Intro.php
 - Spanish <https://espanol.pparx.org/Intro.php>
- www.rxhome.com
- <http://www.freedrugcard.us>
- www.rxhope.com/pap_info.asp
- www.aarp.org/bulletin/prescription/statebystate.html

Financial Resources: Medications

□ **Managed Rx Plans, Inc**

- www.managedrxplans.com

- Private pharmacy – accepts ***most*** insurance as full payment toward prescriptions when deductible is met.

□ **National Alliance on Mental Health (NAMI)**

- www.nami.org

- http://www.nami.org/Content/ContentGroups/HelpLine1/Prescription_Drug_Patient_Assistance_Programs.htm

GENERIC DRUGS - RETAIL

- Be sure to check the current formulary.

Giant Eagle 30 day supply \$4

K-Mart 90 day supply for \$15

Kroger Pharmacy 30 day supply \$4

Target 30 day supply \$4

WalMart 30 day supply \$4; 90 days \$10

Financial Resources continued

- **Milan Foundation (CF)**
 - www.milanfoundation.org/mission.htm
- **Leukemia & Lymphoma Society**
 - <http://www.leukemia-lymphoma.org>
- **North American Grotto – free peds dental care**
 - www.scgrotto.com
- **National Foundation of Dentistry for the Handicapped (NFDH) - adults**
 - www.nfdh.org

Financial Resources: Travel continued

❑ **Angel Flight of America**

- www.angelflightamerica.org

❑ **Corporate Angel Network**

- www.corpangelnetwork.org

❑ **Operation Lift Off** (treatment or wish)

- www.operationliftoff.org

❑ **National Patient Travel Center**

- <http://www.patienttravel.org/>

Financial Resources: Travel continued

□ Airlines

- American 817-963-8118, x4
 - <http://www.americanairlinescenter.com/index.cfm/FuseAction/page/PageID/212>
- Southwest 214-792-4103
 - http://www.southwest.com/about_swa/share_the_spirit/share_the_spirit.html
- Continental Care Force 281-261-6626
 - <http://www.continental.com/web/en-US/apps/onepass/donate/donateMiles.aspx>

Financial Resources: School and Training

- **Vocational Rehabilitation**
 - specific to each state
- **CF Scholarships**
 - <http://www.cfscholarships.com>
- **Creon Family Scholarship Program (CF)**
 - www.solvaypharmaceuticals-us.com
- **Elizabeth Nash Foundation Scholarship**
 - www.elizabethnashfoundation.org (CF)
- **Trio (any transplant)**
 - www.trioweb.org

Financial Resources: School and Training continued

- **George Washington University HEATH Resource Center**
 - www.heath.gwu.edu
 - “Creating Options: Financial Aid for Students with Disabilities” (free resource guide)
- **Federal Student Aid Center**
 - www.studentaid.ed.gov
- **Astellas Transplant (any transplant)**
http://www.astellastransplant.com/events_scholar.php



Financial resources

Education and Training

- Bobby Coulter Rich Scholarship
 - www.psu.edu, Kidney, Penn State
- Dube & Katie Memorial Scholarship
 - www.marshallcf.org, Michigan residents



Financial Resources

□ **Free Gas USA**

- <http://www.freegasusa.org>

□ **Program Grants**

- Children's Miracle Network (CMN), Hospital Women's Aux., Soros Foundation, etc.

□ **Local Civic Organizations & Businesses**

- Shriner's Gifts Committee, WalMart, Builders Care, Habitat for Humanity, Center for Independent Living, etc.

Financial Resources

□ **Cystic Fibrosis Lifestyle Foundation**

- <http://cflf.org>
- <http://www.cflf.org/programs.php>
 - Recreation grants available

□ **Patient Access Network Foundation**

- [www.patientaccessnetwork](http://www.patientaccessnetwork.org)
- Provides financial support for out-of-pocket costs associated with a wide range of drugs, to treat a number of conditions.
- Diagnosis specific; CF included

Financial Resources

□ **National Living Donor Assistance Program**

- www.livingdonorassistance.org
- Up to \$6,000 for donor expenses available based on donor and recipient household income

□ **Angel Food Ministries**

- <http://www.angelfoodministries.com>
- A non-profit, non-denominational organization dedicated to providing food relief for those struggling financially; accepts food stamps

□ **Harvest of Hope**

- <http://harvestofhope.net/our-mission.php>
- Distributes funds to pay for gas, tires, car repairs, rent, utilities, medical services, food, clothing, funeral expenses and educational scholarships for immigrant workers.

Financial Information Resources

□ **Health Insurance Info (Georgetown University Health Policy Institute)**

A CONSUMER GUIDE FOR GETTING AND KEEPING HEALTH INSURANCE for each state and the District of Columbia

<http://www.healthinsuranceinfo.net/>

□ **Kaiser Foundation (State by state summary)**

■ <http://www.statehealthfacts.org/>

□ **US Department of Labor – COBRA**

■ http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.html

□ **Centers for Medicare and Medicaid Services (USA)**

■ www.cms.hhs.gov

Transition Resources

□ **Health Care Transitions, University of Florida**

- <http://hctransitions.ichp.ufl.edu/resources.html>

- Workbooks divided into age groups available for download
- List of websites in credit section of each workbook

□ **Health Care Transitions - bibliography**

- http://biblioscape.ichp.ufl.edu:8001/bw_login.htm

□ **Transition Information and Resources**

- <http://internet.dsc.uic.edu/dscroot/parents/transition.asp>

Education: Transplant Scholarships

- Georgia Transplant Foundation
 - <http://www.gatransplant.org>, Georgia Residents
 - Four separate designated scholarships
 - Recipient, living donor, sibling of recipient, dependent of recipient, parent of recipient
- Gift of Life Donor Program
 - <http://www.donors1.org/patients/resources/jessiesday/>
 - Jessica Beth Swartz Memorial Scholarship- recipients
 - East Pennsylvania, Southern New Jersey, Delaware residents
- Cancer for College
 - http://cancerforcollege.org/CFC_Application.html
 - Cancer patient, cancer survivor and/or amputee
 - (Remember that some cancer treatment results in cardiomyopathy which may require a heart transplant)

Transition Resources

- **Jax HATS – Jacksonville Health and Transition Services**
 - <http://jaxhats.ufl.edu>
- **Adolescent Health Transition Project**
 - <http://depts.washington.edu/healthtr>
- **American Academy of Pediatrics**
 - <http://www.medicalhomeinfo.org/health/trans.html>
- **It's Time to Transition!**
 - <http://www.cdphe.state.co.us/ps/hcp/transition/workbook.pdf>
 - Workbook you can download
- **Finding Our Way Back Home: A National Resource of Promising Transition Practices (Canadian)**
 - http://www.caphc.org/documents_programs/bell/finding_way_home_final.pdf

Advocacy and Resources

- **National Patient Advocate Foundation**
<http://www.npaf.org/>
- **Patient Advocate Foundation**
<http://www.patientadvocate.org>
 - <http://www.patientadvocate.org/index.php?p=533> Pediatric Resource Page
 - <http://www.patientadvocate.org/report.php?p=42> Pick your state
- **Family Voices**
 - <http://www.familyvoices.org>
- **Give Second Chances**
 - <http://www.give2ndchances.org>

Education and Resources

- **Organ Transplants and Donation**
 - <http://www.organtransplants.org>
 - Excellent links section
- **Second Wind Foundation**
 - www.2ndwind.org
- **National Transplant Society: LifeLine**
 - www.organdonor.org
- **US Transplants**
 - <http://www.ustransplant.org/Related.aspx>
- **National Family Caregivers Association**
 - <http://www.nfcacares.org>

Education and Resources

- **Alagille Syndrome Alliance**
 - www.alagille.org
- **Canadian Liver Foundation**
 - www.liver.ca
- **Children's Liver Alliance (Australia)**
 - www.liverkids.org.au
- **Liver Families**
 - www.liverfamilies.org
- **American Heart Association**
 - www.americanheart.org
 - www.americanheart.org/heroes (children's section)

Education and Resources

- **Pulmonary Fibrosis Foundation**
 - [http://www.pulmonary fibrosis.org](http://www.pulmonaryfibrosis.org)
- **Coalition for Pulmonary Fibrosis**
 - <http://www.coalitionforpf.org>
- **Pulmonary Hypertension Association**
 - <http://www.phassociation.org/>
 - Excellent resource link
- **Renal Support Network**
 - <http://www.rsnhope.org> with a link to
 - <http://www.kidneytimes.com/>

Education and Resources

- **Transplant Experience** (Astellas sponsored)
 - <http://www.transplantexperience.com/>
- **Astellas Transplant**
 - <http://www.astellastransplant.com>
- **Transweb**
 - <http://www.transweb.org/>
- **The Gift of a Lifetime**
 - <http://www.organtransplants.org/>
- **American Transplant Association**
 - <http://americantransplant.org>

Education and Resources

- **PBS Online, “NOVA: Cut to the Heart”**
<http://www.pbs.org/wgbh/nova/heart/heartmap.html>
- **An interactive approach to learning how a heart transplant surgery is done**
<http://www.pbs.org/wgbh/nova/eheart/transplantwave.html>
- **Too Young to Be Ill** (free book to download)
<http://www.patientadvocate.org/pdf/pubs/tooyoung.pdf>
- **How Stuff Works**
<http://health.howstuffworks.com/organ-transplant.htm>
- **Bailey’s Heart**
<http://www.baileysheart.com>
Tells the story of a little girl and the Berlin Heart

Sex Education

- **It's Your (Sex) Life: Your Guide to Safe & Responsible Sex**
 - <http://www.kff.org/youthhivstds/1311-index.cfm>
PDF available or order copies
Caution: review and obtain consent from parents if patient is under 18 years old
- **Why do I need a condom?**
 - <http://www.avert.org/usecond.htm>



Death Verifications

- Clarifying rumors of deaths when a patient leaves your Center
 - <http://ssdi.rootsweb.ancestry.com/>