



Patient Resources – Comprehensive List

Transportation Resources

[National Patient Travel Center](http://www.patienttravel.org) - (800) 296-1217 - <http://www.patienttravel.org>

The National Patient Travel HELPLINE provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available in the national charitable medical air transportation network. All of the below services are included in the support that the National Patient Travel Center offers.

[Patient Airlift Service](http://www.palservices.org) - (888) 818-1231 - www.palservices.org

Patient AirLift Services arranges free air transportation based on need to individuals requiring medical care and for other humanitarian purposes.

[Lifeline Pilots](http://www.lifelinepilots.org) - (800) 822-7972 - <http://www.lifelinepilots.org>

LifeLine Pilots facilitates transportation for on-going medical treatments, diagnosis and follow-up care through pilot donation of flight expenses and time.

[Air Charity Network](http://www.aircharitynetwork.org) - (877) 621-7177 – <http://www.aircharitynetwork.org>

Air Charity Network™ (ACN) provides access for people in need seeking free air transportation to specialized health care facilities or distant destinations due to family, community or national crisis.

[Angel Flights](http://www.angelflight.com) - (918) 749-8992 - www.angelflight.com

Angel Flights is a non-profit charitable organization of pilots, volunteers, and friends; they arrange free air transportation for any legitimate, charitable, medically related need. Angel Flight primarily serves patients needing transportation to or from the heartland region.

[Angel Flights - Northeast](http://www.angelflightne.org) - (800) 549-9980 - www.angelflightne.org

Angel Flights NE provides air transportation in private aircraft by volunteer pilots so that children and adults may access life saving medical care free of charge. They fly extensively in the Northeast portion of the country.

[Angel Bus](http://www.angel-bus.org) - (800) 768-0238 - www.angel-bus.org

Angel Bus is a nonprofit corporation dedicated to providing compassionate, non-emergency long-distance ground transportation to patients in need who meet financial guidelines.

Financial Resources

[Alcon Cares - Free Eye Care Products Available](#) -

www.alcon.com/en/corporate-responsibility/patient-clinic-inst-assistance.aspx

Alcon Cares, Inc. is a foundation that provides medication to qualified individuals at no charge. The program is open to any private patient of a U.S. licensed healthcare provider who cannot afford their medication and does not have prescription insurance coverage or qualify for local, state or federal prescription programs unless such programs are documented to cause a financial hardship for the patient. Patients should qualify for the income test at 200 percent (two times) the current year's poverty level under the number of persons living in a household.

[United Health Care Children's Foundation Grants for underinsured in the US](#) - www.uhccf.org/apply.html

The United Healthcare Children's Foundation is a 501(c)(3) non-profit charity dedicated to facilitating access to medical-related services that have the potential to significantly enhance either the clinical condition or the quality of life of the child. This “support” is in the form of a medical grant to be used for medical services not covered or not completely covered by commercial health benefit plans.

[Lions Club International](#) - directory.lionsclubs.org

Lions Club International provides financial assistance to individuals for eye care through local clubs. They support sight programs including vision screenings, eye banks and eyeglass recycling.

[First Hand Foundation](#) - https://applications.cerner.com/firsthand/FirstHand_1a.aspx?id=28729

First Hand assists individual children with health-related needs when insurance and other financial resources have been exhausted. First Hand accepts applications from anywhere in the world; applicants must meet stated financial guidelines. Expenses covered include treatment, equipment, vehicle modifications and lodging, food and other expenses for those who must travel for treatment.

[Catastrophic Illness in Children Relief Fund](#) -

www.cancer.org/treatment/supportprogramsservices/app/Resource-Detail.aspx?resourceId=45071

The Massachusetts Catastrophic Illness in Children Relief Fund (CICRF) is intended to provide financial assistance to families with children experiencing a medical condition or disabilities requiring services that are not otherwise covered by a private insurer, federal or state health care assistance, or any other financial resource. In order to be eligible, a family must have expenses related to a child's medical condition that exceed 10% of the family's gross annual income up to \$100,000 and 15% of any portion of the annual family income that exceeds \$100,000.

[The Social Security and Disability Resource Center](#) - www.ssdrc.com

The Social Security Disability Resource Center provides information on the federal disability benefit programs in addition to answering questions about social security retirement benefits and providing resource links on topics such as Medicare.

Support Organizations

[Stevens Johnson Syndrome Foundation](http://www.sjsupport.org) - www.sjsupport.org

The Stevens Johnson Syndrome Foundation was founded by the mother of a BFS patient. The foundation provides support services to SJS patients, family and friends and compiles and distributes information about SJS and adverse allergic drug reactions to the public and medical communities. The foundation offers a helpline, information on local support groups, a newsletter and an active online community discussion group.

[SJS Kids Support](http://sjskidsupport.webs.com) - sjskidsupport.webs.com

A support network for kids suffering the effects of SJS, SJS Kids Support offers a discussion forum, SJS survivor stories, information on SJS events, anti-bullying resources and other patient supports.

[National Keratoconus Foundation](http://www.nkcf.org) - www.nkcf.org

Keratoconus support resources available through the foundation's website include a web-based bulletin board, a worldwide newsletter, an email list-serv, referral lists by state for doctors with expertise in keratoconus, assistance with making personal contact with other keratoconus patients, and information on patient seminars.

[Sjögren's Syndrome Foundation](http://www.sjogrens.org) - www.sjogrens.org

Founded in 1983, the Sjögren's Syndrome Foundation provides patients with practical information and coping strategies that minimize the effects of Sjögren's syndrome. In addition, the Foundation is the clearinghouse for medical information and is the recognized national advocate for Sjögren's syndrome.

[The Dry Eye Zone](http://www.dryeyezone.com) - www.dryeyezone.com

The Dry Eye Zone was founded by a PROSE patient. It is a resource center for people with severe or chronic dry eye who are looking for relief from and treatment of dry eye. It includes a community forum, a blog, a newsletter, a dry eye products shop, and more.

[BMT InfoNet](http://www.bmtinfo.net) - www.bmtinfo.net

Blood & Marrow Transplant Information Network (BMT InfoNet) is dedicated to providing transplant patients, survivors and their loved ones with emotional support and high quality information about bone marrow, peripheral blood stem cell and cord blood transplants. They offer information on choosing a transplant center, help with finances and insurance, a resource directory and also the Caring Connections Program to connect those contemplating a transplant with transplant survivors.

[Dysautonomia Foundation](http://familialdysautonomia.org) - familialdysautonomia.org

The Dysautonomia Foundation is a 501(c)(3) nonprofit public charity that supports medical treatment, research, public awareness and social services for the benefit of people afflicted with FD.

[National Foundation for Ectodermal Dysplasias](http://nfed.org) - nfed.org

The mission of NFED is to empower and connect people touched by ectodermal dysplasias through education, support, and research. Ectodermal dysplasias can cause dry eye, light sensitivity and corneal ulcers, abrasions and infections; as well as other vision defects.

[Care Pages](http://www.carepages.com) - www.carepages.com

CarePages websites are free patient blogs that connect friends and family during a health challenge.

[CaringBridge](http://www.caringbridge.org) - www.caringbridge.org

CaringBridge is a 501(c)(3) nonprofit providing free websites that connect family and friends during a serious health event, care and recovery. A CaringBridge website is personal, private and available 24/7. It helps ease the burden of keeping family and friends informed. The websites are easy to create and use. Authors add health updates and photos to share their story while visitors leave messages of love and support in the guestbook

[Guiding Eyes for the Blind](http://www.guidingeyes.org) - www.guidingeyes.org

Guiding Eyes is an internationally accredited, nonprofit guide dog school with a 50-plus year legacy of providing the blind and visually impaired with superior Guiding Eyes dogs, training, and lifetime support services.

Facebook Organization Pages

[Boston Foundation for Sight](https://www.facebook.com/bostonsight) - <https://www.facebook.com/bostonsight>

[Sjogren's Syndrome Foundation](https://www.facebook.com/SjogrensSyndromeFoundation) - <https://www.facebook.com/SjogrensSyndromeFoundation>

[Stevens Johnson Syndrome](https://www.facebook.com/sjsupport) - <https://www.facebook.com/sjsupport>

[Stevens Johnson Syndrome Foundation](https://www.facebook.com/pages/Stevens-Johnson-Syndrome-Foundation/88253753603) - <https://www.facebook.com/pages/Stevens-Johnson-Syndrome-Foundation/88253753603>

[National Keratoconus Foundation \(NKCF\)](https://www.facebook.com/nkcf.org) - <https://www.facebook.com/nkcf.org>

Facebook Support Groups - *Note- Closed groups are private so that posts can only be seen by members – click “ask to join group” in the top right hand corner of the page to join*

Graft Versus Host Disease Group - <https://www.facebook.com/groups/128127340574867/>

A closed support group with 62 members that include patients, friends and family. Daily posts.

SJS Friends Group - <https://www.facebook.com/groups/sjs.survivor/>

A closed support group with 134 members that include SJS survivors, friends and family. Daily posts.

Stevens Johnson Syndrome Awareness - <https://www.facebook.com/groups/21049136206/>

An open advocacy group with 730 members that include SJS survivors, friends and family. Weekly posts.

Keratoconus Group - <https://www.facebook.com/groups/2581665284/>

An open group with 1,450 members that include keratoconus patients, friends, family and medical providers. Daily posts.

Sjogren’s Syndrome - <https://www.facebook.com/groups/20471766047/>

A closed support group with 312 members that include patients, friends and family. Weekly posts.

Living with Sjogren’s Syndrome - <https://www.facebook.com/groups/Livingwithsjogrensyndrome/>

A closed support group with 209 members that include patients, family and friends.

List-Servs (E-mail support groups)

GVHD: Support group for post-BMT patients- 380 members who posts bi-weekly. To subscribe, e-mail listserv@listserv.acor.org. Leave the subject line blank. Message body should say: "Subscribe GVHD"

SJS/TENS KIDS Support Group: Support group for children and young adults with SJS- 200 members who post weekly. To subscribe: sjskidssupport-subscribe@yahoogroups.com; Yahoo page: <http://health.groups.yahoo.com/group/sjskidssupport/>