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# RESOURCES TO HELP CHILDREN, ADOLESCENTS, AND YOUNG ADULTS WITH CANCER

### Advocacy / Legal

### **C-Change**

202-756-1600

http://c-changetogether.org/

Mission is to eliminate cancer as a public health problem; focuses on advocacy, strategic initiatives and research.

### **Children's Cause for Cancer Advocacy**

202-304-1850

http://www.childrenscause.org/

A long, healthy life for every child with cancer. Advocacy for research, resources, and support.

#### Fetaweb

http://www.fetaweb.com/

Parents, advocates, educators and attorneys visit FetaWeb.com to learn effective advocacy skills.

#### **Livestrong Young Adult Alliance**

855-220-7777

http://www.livestrong.org/site/c.khLXK1PxHmF/b.2661399/k.71A4/Young\_Adult\_Alliance.htm

Information and advocacy for young adults with cancer in order to promote research and improve survival rates. Highlight the unique features of the AYA cancer experience with the goal of improving treatments and outcomes.

### **National Hospice and Palliative Care**

1-800-658-8898

http://www.nhpco.org/

Advocates for improved care at the end of life and resources to improve the assistance given by other organizations. Also, offers education and conferences about quality end-of-life care to patients and families.

### Wrightslaw

http://www.wrightslaw.com/

Up-to-date information about special education law and advocacy for children with disabilities

### **Air Charity Network**

877-621-7177

http://www.aircharitynetwork.org/

Provides transportation to patients traveling for treatment.

### **American Cancer Society (ACS)**

1-800-ACS-2345

http://www.cancer.org/

The American Cancer Society is a nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives, and diminishing suffering from cancer through research, education, advocacy, and service.

### **American Childhood Cancer Organization**

855-858-2226

http://www.acco.org/

Our mission is to provide information and support for children and adolescents with cancer and their families, to provide grassroots leadership through advocacy and awareness, and to support research leading to a cure for all children diagnosed with this life-threatening disease.

### Angel Flight East (AFE)

215-358-1900

http://angelflighteast.org/

The mission of Angel Flight East is to provide free air transportation to qualified patients and their families by arranging flights to distant medical facilities, delivering supplies to disaster areas, and reuniting families during desperate times.

### Century Ambulance Service, Inc.

904-356-2828

Brandon.carter@casjax.com

http://www.casjax.com/

Medical transportation and non-medical transportation. Residence and healthcare facility-based transport.

### **Child Cancer Fund**

904-396-4223

http://www.childcancerfund.org/

Dedicated to providing emotional, practical, educational, and financial support to families of children battling childhood cancer. Core programs include a Child Life Specialist position at Nemours Children's Specialty Care, Financial Assistance program for non-medical household bills, provides doctor recommended materials, and a family retreat weekend.

### **Childhood Leukemia Foundation**

1-732-920-8860

https://www.clf4kids.org/

Offers free support services to kids with childhood leukemia across the united states. These services range from support binders, baskets full of toys, or even IPad so a child can keep connected with family members.

### **Childhood Cancer Society**

http://www.childhoodcancersociety.org/

To provide comfort and love to patients battling a childhood cancer through support and gifts.

#### **Children's Brain Tumor Foundation**

866-228-4673

https://www.cbtf.org/

To improve the treatment, quality of life and long term outlook for children with brain and spinal cord tumors through research, support, education and advocacy to families and survivors.

### Cleaning For a Reason

877-337-3348

http://www.cleaningforareason.org/

Provides free housecleaning for women that are going through cancer. Offers cleanings once per month for four months while they are undergoing treatment.

### **Community Hospice of Northeast Florida**

904-407-6500

http://www.communityhospice.com/

Provides compassionate guidance and care to help those with advanced illness and their families to live better and improve quality of life.

### **Crazy Sexy Cancer**

http://crazysexycancer.com/

Documentary film of a 31-year-old woman diagnosed with a rare incurable cancer and films the story her life. Taking a seemingly tragic situation and turning it into a creative expression.

### **Corporate Angel Network**

914-328-1313

http://www.corporateangelnetwork.org/

Provides free flights to cancer patients that are going to their treatments on corporate jets.

### CureSearch

800-458-6223

http://www.curesearch.org/

Represents the Children's Oncology Group (COG) and the National Childhood Cancer Foundation (NCCF). Supports lifesaving research and helps raise awareness of the importance of cancer clinical trials. Provides online information on types of childhood cancer and treatments.

### **Emmanuel Cancer Foundation**

908-322-4323

http://www.emmanuelcancer.org/

The Emmanuel Cancer Foundation is New Jersey's oldest free, in-home, counseling and support agency. ECF provides services to any New Jersey family whose child has been diagnosed with cancer.

#### **Friends of Karen**

914-277-4547

http://www.friendsofkaren.org/

Dedicated to providing emotional, financial and advocacy support to children with life-threatening illnesses and their families. Serves children from birth to 21 who are diagnosed with any life-threatening illness and living in the New York metropolitan area, including all of New York City (Bronx, Brooklyn, Manhattan, Staten Island, Queens), Long Island (Nassau, Suffolk), Westchester, Rockland, Putnam, Dutchess, Sullivan, Orange and Ulster Counties, northern New Jersey (Bergen, Essex, Hudson, Passaic, Union), and Fairfield County, Connecticut.

### Gilda's Club South Jersey

609-926-2699

http://www.gildasclubsouthjersey.org/

A place where men, women and children living with cancer, together with their families and friends, can join with others to build social and emotional support as a complement to medical care. Free of charge and nonprofit, Gilda's Club offers support and networking groups, lectures, workshops, and social events in a nonresidential, home-like setting.

### **Give Hope Foundation**

https://givehopefoundation.org/407-961-9973

Provide support to children and families in Central Florida who are battling childhood cancer and have a unique combination of medical, emotional and financial needs.

### **Gabriel House of Care**

904-821-8995

http://www.gabrielhouseofcare.org/

Provides affordable long-term lodging for cancer patients and caregivers who come from outside of Jacksonville to receive cancer treatments at area hospitals and clinics.

#### **Hope Lodge**

800-227-2345

https://www.cancer.org/treatment/support-programs-and-services/patient-lodging/hope-lodge.html Sponsored by the American cancer society, the hope lodge offers free housing for cancer patients undergoing treatment so that guests can focus on getting well.

### **Hugs of Hope**

229-561-0840

http://hugsofhope.org/

Provides social, emotional, spiritual, educational, and financial support to families affected by pediatric cancer in Lowndes county and South Georgia.

Hyundai Hope on Wheels: Helping Kids Fight Cancer

https://hyundaihopeonwheels.org/

Mission is to find a cure for childhood cancer one handprint at a time.

#### Jacksonville Children's Commission

904-630-3647

http://jaxkids.org/

An organization that provides comprehensive afterschool programs, mentor sessions, health and nutrition programs, and resources for healthy parent lifestyles. This is an all-encompassing resource for families in the Jacksonville area.

### The Jimmy Fund

http://www.jimmyfund.org/

Supports the fight against cancer at Dana-Farber.

### Lance Armstrong Foundation (LAF)

855-220-7777

http://www.livestrong.org/

Inspires and empowers people affected by cancer. Helps people with cancer focus on living. Believes unity is strength, knowledge is power, and attitude is everything. Provides the practical information and tools people with cancer need to live life on their own terms. Serves its mission through advocacy, public health, and research.

### **Learning Disabilities Association of America**

412-341-1515

http://www.ldanatl.org/

Started by parents, the association offers parents information on learning disabilities, negotiating the special education process, and helping your child and yourself. Includes an online training course about the Individuals with Disabilities Education Act (IDEA).

### The Leukemia & Lymphoma Society (LLS)

The Information Resource Center (IRC)

800-955-4572 (Mon-Fri, 9 AM to 6 PM EST)

http://www.lls.org/

Committed to providing information, support, and guidance to people living with blood cancers and to the health professionals involved in their care. The Society provides ongoing educational programs, printed materials, and videos for children, parents, and educators. Services include the IRC, a call center staffed with social workers, nurses, and health educators who offer callers up-to-date, accurate disease-related information. Includes a network of chapters throughout the United States and Canada. To locate a chapter near you, visit the website or call the toll-free number.

#### Mattie's Mission

912-338-0623

http://Mattiesmission2013@gmail.com

Offers financial, spiritual, and emotional assistance to families directly affected by childhood cancer. Located in Waycross, Georgia.

### National Association of Hospital Hospitality Houses, Inc

800-542-9730

http://www.nahhh.org/

Provides lodging and support services to patients, families and their loved ones who are receiving medical treatment far from home.

#### **National Cancer Institute**

1-800-4-CANCER

http://www.cancer.gov/

Provides general cancer information. Includes the latest cancer research news and help for finding clinical trials.

### The National Children's Cancer Society

314-241-1600

https://thenccs.org/

Provides financial and in-kind assistance, advocacy, support services and education

### **National Coalition for Cancer Survivorship**

877-622-7937 (toll free)

http://www.canceradvocacy.org/

Advocates at the federal level for quality cancer care and empowers cancer survivors by providing credible and accurate patient information such as the *Cancer Survival Toolbox* (Available at: http://www.canceradvocacy.org/toolbox/)

### **Center for Parent Information and Resources**

http://www.parentcenterhub.org/

Provides resources regarding testing accommodations for individuals with disabilities.

#### **Real Time Cancer**

709-579-7325 (REAL)

http://www.youngadultcancer.ca/

An initiative of Young Adult Cancer - Canada

Online community and information on Montreal Retreat, all geared toward ages 15-30

### **Ronald McDonald House Charities**

212-639-0100 (RMHC of the New York Tri-State Area)

http://www.rmhc.org/

RMHC offers three core programs:

Ronald McDonald House - provides a home away from home for families of seriously ill children receiving treatment at nearby hospitals

Ronald McDonald Family Room - extends the comfort of the Ronald McDonald House into the hospital by providing a place to enjoy a meal, talk with other parents and relax

Ronald McDonald Care Mobile - brings cost-effective, high-quality medical, dental and health education services directly to underserved children in rural and urban areas across the globe

### Starlight Starbright™ Children's Foundation

310-479-1212

http://www.starbright.org/

Creates innovative, media-based programs that help seriously ill children and teens better cope with their disease — and enhance their quality of life. Offers free CD-ROMs and online communities of information and support for kids and parents.

### **Still Strong Foundation**

https://stillstrongfoundation.org/

The Still Strong Foundation currently supports families with children being treated at certain hospitals with financial assistance: Rent, Mortgage, Utilities, Bills, Childcare and Travel Expenses to and from the hospital.

### **Tom Coughlin Jay Fund Foundation**

1-866-538-6331 (toll free)

http://www.tcjayfund.org/

Mission is to help families tackle childhood cancer by providing comprehensive financial, emotional and practical support. Target population is children and young adults, ages 0-22 years old that are currently undergoing treatment. Serves families who are permanent residents of the following:

- North Florida Alachua, Baker, Bradford, Clay, Columbia, Duval, Flagler, Nassau, Putnam, St. Johns, or Union Counties
- South Georgia Camden, Charlton, Clinch, Glynn or Ware Counties
- The five boroughs of New York City (Bronx, Brooklyn, Manhattan, Queens, & Staten Island)
- New Jersey Bergen, Essex, Hudson, Middlesex, Passaic and Union Counties

#### Tomorrows Children's Fund

551-996-5500

www.tcfkid.org

Provides financial, educational, and emotional support as well as social work and psychological services

### The Ulman Cancer Fund for Young Adults

888-393-FUND (888-393-3863)

http://www.ulmanfund.org/

Addresses areas of cancer support, advocacy, and education for young adults dealing with cancer. Connects young adults affected by cancer. Offers financial assistance through grants and college scholarships.

#### The Valerie Fund

973-761-0422

https://www.thevaleriefund.org/index.php

Mission is to provide support for the comprehensive health care of children with cancer and blood disorders

#### Wellness House

630-323-5150

http://www.wellnesshouse.org/

A house located Hinsdale, IL that provides support and programs for anyone impacted by cancer. They offer counseling, support groups, and fun family activities at no cost to the participants.

### Camps, Retreats, and Activities

### Art with a Heart

904-306-0390

http://www.artwithaheart.info/

Provides personalized fine art experiences that enhance the healing process for patients and their families.

### **Big Sky Kids**

406-586-1781

http://www.eaglemount.org/

Outdoor adventure camps (skiing, rafting, etc.) in Montana

Ages 5-23

### **Camp Boggy Creek**

352-483-4200

www.boggycreek.org

Year-round camp serving children with serious illnesses throughout Florida. Offer week long summer sessions for children and family retreat weekends for the whole family

### **Camp Courage**

http://www.camp-courage.org/

An outdoor summer camp for children with cancer ages 10-18.

### Camp Happy Time – The Valerie Fund

973-761-0422

https://www.thevaleriefund.org/index.php

A one week overnight camp experience for any child aged 5- 21who has or has had cancer, regardless of where they are treated

### Camp-Mak-A-Dream

406-549-5987

http://www.campdream.org/

Year-round conferences and camps (free of charge) for different adolescent and young adult categories (for teens, siblings, 2+ years out of treatment, etc.), ages ranging from 6-25. In Montana

#### **Camp Safe Haven**

800-727-1889

http://www.havenhospice.org/campsafehaven.aspx

A camp created by haven hospice that helps children, teens, and families to help cope with the loss of a loved one

### **Camp Sunshine**

207-665-3800

http://info@campsunshine.org

A year-round program that provides support and joy to children with life-threatening illnesses and their immediate families. Based in Casco, Maine.

### **Christina Phipps Foundation**

904-233-6162

http://info@christinaphippsfoundation.com

A foundation that offers free yoga classes for cancer patients and survivors in Jacksonville.

### **Deliver the Dream**

1-800-687-3732

http://www.deliverthedream.org/

A foundation that provides three day retreats for families with a child that has a serious illness or who have recently lost a child.

### **Dreams Come True**

904-296-3030

http://www.dreamscometrue.org/

Offers once in a lifetime trips to children with life threatening illnesses in the Northeast Florida and Southeast Georgia area.

#### For Pete's Sake

267-708-0510

http://takeabreakfromcancer.org/about-us/

Free, one week excursion for the survivor (24-50) and their main caregiver

#### **First Descents**

303-945-2490

http://www.firstdescents.org/

Free, one week outdoor adventure (kayaking, hiking, rafting, rock climbing) for young adults (18+) with cancer

### Friends of Jaclyn Foundation

1-855-486-3653

http://info@friendsofjaclyn.org

Aims to improve the quality of life for children battling pediatric brain tumors and other childhood cancers by pairing them with local high school and college sports teams. Based in New York Area.

#### **Halo Keepers**

http://www.halokeepers.org/

904-657-6982

Make personalized yarn wigs for patients while going through treatment.

### In the Pink

904-372-0029

http://www.jaxinthepink.com/

Provide free services, such as wigs, lymphedema sleeves and more to those who qualify.

#### **Kids Together Against Cancer**

904-742-2916

http://info@ktacjax.com

A team of oncology social workers that comes together to provide workshops and fun activities for children ages 5 to 17 to attend. Provides 5 week workshops, monthly meetings, and One-on-One sessions with social workers.

### **Live for Today**

904-273-4590

http://www.live-for-today.org/

Provides young adults, between the ages of 18-35, to experience life adventures, everyday experiences, member support, and healthy living.

### **Make-A-Wish Foundation of America**

800-722-WISH (9474) (toll-free)

http://www.wish.org/

Grants the wishes of children with life-threatening medical conditions to enrich the human experience with hope, strength and joy

#### **Next Step**

617-864-2921

http://www.nextstepnet.org/

Workshops and retreats year-round for teens and young adults with cancer and blood disease

#### **Nighthawk Ranch**

http://www.nighthawkranchcolorado.org/

A ranch-style summer camp for children with cancer ages 10-18.

### On the Tip of the Toes Foundation

418-543-3048

http://pointedespieds.com/en/index/

Adventure camps in Canada

### **Shining Stars Foundation**

http://www.shiningstarsfoundation.org/

Events, adventures and social outings for children with cancer ages 8-18.

### Sky High Hope Camp

http://www.skyhighhope.org/

A summer camp for children with cancer and their siblings 8-18.

### Special Love, Inc.

888-930-2707

www.specialove.org

Offers Year-round camps in Virginia and Maryland for ages up to 25

#### Visit Jacksonville

904-798-9111

http://www.jaxhealthcenter.com/patients

Local expert for local accommodations, dining, things to do and additional resources during your treatment.

### **Vs Cancer Foundation**

984-444-9141

http://info@vs-cancer.org

http://www.vs-cancer.org/

Provide any team, any athlete, any community, the ability to help kids with cancer.

### Wapiyapi

http://www.campwapiyapi.org/

A summer camp for children with cancer and their siblings ages 6-17.

### Wigs for Kids

440-333-4433

http://www.wigsforkids.org/

Wigs for Kids is a nonprofit organization providing hair replacement solutions for children affected by hair loss subsequent to medical conditions or treatment procedures.

### **Educational Programs**

Welcome Back: Facilitating the school experience for childhood cancer survivors.

http://www.onehealth.ca/r alberta nwt/video conferences/E101126-HOA.pdf

This live professional education program is held in every chapter of The Leukemia & Lymphoma Society especially for schoolteachers, nurses, social workers, guidance counselors and administrators.

### **South Florida Cancer Association**

http://www.sflca.org/

Provide cancer-related information, assistance, and support to the undeserved communities of South Florida.

#### Office of Early Learning

866-357-3239

http://www.floridaearlylearing.com/

Offers VPK Specialized instructional services for children that our four years old and have disabilities. Offers services other than the traditional VPK programs.

#### Six-Step Screening

610-258-3763

http://EVA@sixstepscreening.org

http://www.sixstepscreening.org/

Early stage oral cancer is often painless and goes undetected. Every dental checkup should include a six-step screening.

#### **Wyzant - Tutoring Services**

312-646-6365

www.wyzant.com

An easier way to connect people who need to know with the experts that can teach them.

### **External Support Groups**

### Alicia Rose "Victorious" Foundation

856-784-0615

http://www.victoriousfoundation.org/

ARVF provides activities, programs and events that enhance the quality of life for teens with cancer and other life-threatening illnesses. Successfully partnered with 99 children's hospitals in 37 states throughout the country, funding 62 Teen Lounges and providing over 12,000 Teen Kits to critically-ill children.

### **Cancer Care for Young Adults**

1-800-813-HOPE (4673)

http://www.cancercare.org/get help/special progs/young adults.php

Counseling and group support, as well as financial resources, for people in their 20s and 30s

### **Family Nurturing Center of Florida**

904-389-4244

http://www.fncflorida.org/

Provides classes for parents to create more health relationships for the whole family.

### **Parents with Hope**

904-285-1130

http://Jaxque@pontevedravalley.com

A support group for parents suffering from the loss of a child. Meets the first Tuesday of every month in the Ponte Vedra area.

#### Share

636-947-6164

http://www.nationalshare.org/

Offers support groups for those that have experienced the death of newborn.

### **Young Empowered Survivors**

303-477-2161

http://www.youngempowered.org/

For women diagnosed before 45 years' old Meet once a month Based out of Boulder, CO

### **Financial Assistance, Insurance & Prescriptions**

#### Andrew McDonough B+ Foundation

302-563-8389

Assitancebepostive.org

http://bepositive.org/

Offers financial assistance nationwide to families who are going through cancer diagnosis.

#### Andre Sobel River of Life Foundation

310-276-7111

http://info@andreriveroflife.org

Provides financial assistance to single parent families with urgent everyday expenses. Provides support nationwide. Examples include advocating for airline tickets, buy a wig for a teenager going through chemotherapy or pay for ballet lessons for a neglected sibling.

### Caleb's Crusade

239-896-8786

http://www.calebscrusade.org/

Supports advocacy, raises awareness for childhood cancer, and directly funds local families in the southwest Florida area.

### **Cancer Care**

800-813-4673

http://www.cancercare.org/

Provides financial assistance to those that are currently undergoing cancer treatments as well as paying for Co-payments.

### **Catastrophic Illness in Children Relief Fund**

1-800-335-FUND (3863)

609-292-0600

http://www.state.nj.us/humanservices/cicrf/home/

A financial assistance program for New Jersey families whose children have an illness or condition otherwise uncovered by insurance, State or Federal programs, or other source, such as fundraising

### **Children's Cancer Cooperative**

843-832-8167

http://www.childrenscc.com/

A South Carolina non-profit corporation established in 1999 to support the medical and associated costs for treatment of indigent children in the state of South Carolina.

#### **Family Reach**

973-394-1411

http://familyreach.org/

Provides urgent assistance to families that are fighting cancer. Family reach can cover costs such as mortgage, rent, transportation, utilities, and medical expenses.

### Go 4 The Goal

http://www.go4thegoal.org/

Mission is to improve the lives of children battling cancer by providing financial support, developing and implementing unique hospital programs, funding innovative research, and granting personal wishes. Based in the New Jersey area.

### **Healthwell Foundation**

800-675-8416

http://www.healthwellfoundation.org/

Helps with insurance copays, premiums, and out of pocket costs for a wide variety of cancers.

### IronMatt

201-337-3525

http://www.ironmatt.org/

To raise the awareness and funds necessary to overcome pediatric brain tumors and to help the affected children and families.

#### Johnathan Cancer Fund

315-423-7747

http://www.jonathancancerfund.org/

An organization that provides financial assistance and fund management for families of children through eighteen years of age suffering from cancer who are being treated in Onondaga County.

### **Nicki Leach Foundation**

904-716-5394

http://www.nickileach.org/

Provides high school and college age students, ages 16-25, with cancer the opportunity to enjoy normal or extraordinary activities they may not be able to afford. Funding for car expenses, clothing, and college costs as well as some special funding opportunities.

### **NJ Family Care**

1-800-701-0710

http://www.njfamilycare.org/default.aspx

NJ Family Care is a federal and state funded health insurance program created to help New Jersey's uninsured children and certain low-income parents and guardians to have affordable health coverage.

### **Partnership for Prescription Assistance**

1-888-477-2669

https://www.pparx.org/

Helps qualifying patients without prescription drug coverage get the medications they need for free or nearly for free.

#### **Patient Advocate Foundation**

1-800-532-5274

http://www.patientadvocate.org/

A national non-profit organization that seeks to safeguard patients through effective mediation assuring access to care, maintenance of employment and preservation of financial stability. Serves as an active liaison between patients and their insurer, employer and/or creditors to resolve insurance, job retention and/or debt crisis matters relative to their diagnosis.

#### RX 4 NJ

888-793-6764 (RXFORNJ)

http://www.rx4nj.org/

Rx4NJ is a program that connects qualified, low-income people with discount prescription drugs, direct from the pharmaceutical manufacturer.

### **United Healthcare Children's Foundation**

1-855-698-4223

http://www.uhccf.org/

provides grants for families with children that have medical needs not covered or not fully covered by their commercial health insurance plan.

### For Families/Friends of Those With Cancer

### **Cancer Support Community**

888-793-9355

http://www.cancersupportcommunity.org/

Provides free psychological and emotional support to cancer patients and their families.

### **Forever Jaiden Foundation**

904-405-8385

http://www.foreverjaiden.org/

http://info@foreverjaiden.org

A foundation that provides resources for siblings that have a brother or sister with cancer. Provides birthday parties, tutoring sessions, awards, and mock interviews.

### **Grief Haven**

310-459-1789

http://www.griefhaven.org/

Provides support for the loved ones that have lost a child in the process

#### **Imagine**

908-264-3100

http://www.imaginenj.org/

info@imaginenj.org

A free year-round children's grief support center that serves NJ children age 3-18 and young adults 18-30 who are grieving the death of a parent or sibling, or who are living with a parent of sibling with a life-altering illness.

#### Momcology

http://www.momcology.org/

Support community for mothers and primary caregivers of children who have been diagnosed with cancer. Provides retreats for moms to relax.

### **Partnership for Parents**

831-422-3002

http://partnershipforparents.net/

A support network and online guide for parents of children with serious illnesses

### **Pediatric Oncology Resource Center**

http://www.acor.org/ped-onc

A website for parents, friends, and families of children who have or have had childhood cancer

#### Super Sibs

866-333-1213

http://www.supersibs.org/

Support for siblings of those living with cancer, geared toward younger adolescents and children

**Too Young To Be Ill...A Practical Survival Guide for Caregivers of Children and Young Adults** – a publication of the Patient Advocate Foundation

Available at: http://www.patientadvocate.org/pdf/pubs/tooyoung.pdf

Provides information and resources on disability, insurance, access to care, medical records, financial issues, respite care, early intervention, fertility and survivorship

### **Young Cancer Spouses**

http://www.stupidcancer.org/ycs/discussions

Sharing information, support, and experiences with young spouses through online forums (through the Bulletin on website)

### **Information and Education**

#### 2 b me

1-800-395-LOOK

http://www.2bme.org/

Information on the physical and social changes that one may go through, includes look good feel better for teens

Band-Aides and Blackboards - Stories from the Front

### http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/stories.html

Features stories from children, teens, and siblings about living with serious illness

### **Beyond the Cure**

314-241-1600

http://www.beyondthecure.org/

Information for survivors of childhood cancer, including insurance, fertility, psychosocial, education, advocacy, employment, and healthy living information

#### Cancer Resource Guide of North Central Florida

http://www.cancerresourceguidencf.org/

Provides cancer patients, survivors, caregivers, and counselors with resources, networking opportunities, education, and financial support opportunities.

### **Cure Search for Children's Cancer**

800-458-6223

https://curesearch.org/

Provides information about childhood cancers, treatment options, research, and coping resources. This is a holistic website that offers information about questions a parent or child would have about cancer.

#### **Family Caregiver Alliance**

1-800-445-8106

http://www.caregiver.org/

Provides a variety of free online resources for family caregivers.

### Florida Department of Health

850-245-4444

http://www.doh.state.fl.us/family/cancer/index

The Bureau of Chronic Disease Prevention and Health Promotion, Comprehensive Cancer Control Program provides information and resources for individuals regarding cancer and related topics.

### **Hospice Foundation of America**

800-854-3402

http://www.hospicefoundation.org/

The caregiving resource page on their website offers practical tools, reading suggestions, and tips on caregiving for persons near the end of life.

### Kidshealth

http://kidshealth.org/

Provides information for parents, kids, and teens about children's health and development.

## **Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers** – published by Cure Search

http://www.survivorshipguidelines.org/

Provides guidelines for the screening and management of late effects related to cancer treatment, Intended for healthcare providers

### **Remembering Our Babies**

http://www.october15th.com/ http://robyn@october15th.com Provides information about how to cope with the loss of a newborn and how to create events in memory of a child.

#### **Silent Grief**

http://chinton@silentgrief.com

http://www.silentgrief.com/

Provides information, chat boards, and resources for those that are grieving from the loss of a child.

### **South Florida Cancer Association**

786-319-6912

http://www.sflca.org/

Provides financial assistance to pay for screening or treatment and insure that cancer patients have reliable transportation to and from treatment. Also provides cancer related information and promotes public awareness of cancer.

### Still Standing Magazine

http://stillstandingmag.com/

Offers information and stories from others that have experienced the loss of a child. Gives new information and perspectives to parents who are experiencing the same thing.

### **National Association for Home Care and Hospice**

202-547-7424

http://www.nahc.com/

Offers educational materials and information on agencies, hospices, home care aide organizations and medical equipment suppliers.

### National Cancer Institute: Caregivers, Family & Friends

1-800-4-CANCER

http://www.cancer.gov/cancertopics/coping/familyfriends

Information to help caregivers cope while caring for a loved one with cancer, and also features resources that help individuals with cancer cope with the illness.

### **New York State Psychological Association**

http://www.nyspa.org/

Provides a good source of information for those that are dealing with grief from a miscarriage.

### **Northeast Florida Cancer Control Collaborative**

http://www.nefloridacounts.org/index.php?module=Tiles&controller=index&action=display&alias=NEFCCCPro vides additional resources for families in northeast Florida who are fighting cancer.

### **Teens Living With Cancer**

585-563-6221

http://www.teenslivingwithcancer.org/

Sponsored by Melissa's Living Legacy Foundation. Offers teens a place to get cancer facts, connect with others, and share stories of hope and inspiration.

### University of Texas at Austin – K-16 Education Center

1-866-361-UTHS

http://www.utexas.edu/cee/dec/k16/

Distance education program serving Texas students who want or need an educational alternative; similar programs may be available in other states.

### **Vital Options International**

1-818-508-5657

http://www.vitaloptions.org/

Information and resources for young adults (ages 17 through 40s)

### **International & Location-Specific Resources**

### Brendan Borek High Tides Memorial Fund, Inc.

609-967-0100

http://brendansfund.org/

A pediatric cancer fund for the residents of Cape May County, NJ. Services range from professional counseling and advocacy programs to financial and material assistance.

#### Canteen

http://www.canteen.org.au/

Information and support for Australians ages 12-24

### Children's Chance

803-254-5996

http://www.childrenschance.org/

Provides financial assistance for families who have a child with cancer in South Carolina as well as counseling and art programs.

### Footprints in the sand foundation

212-546-6293

http://www.footprintsfoundation.org/

Provides financial assistance to families living in the Rockland and Bergen counties in the New York area.

### Oceans of Love – For Children With Cancer

1-800-368-4385

http://oceanoflove.org/

Dedicated to helping Ocean County, NJ children with cancer and their families. Provides financial and emotional support.

### Rosepetals

1-973-239-0072

http://www.rosepetals-hospice.org/

Dedicated to assisting terminally ill children, and children with all types of illnesses and their families through hospice counseling and assistance with like choices in the New York and New Jersey areas that are experiencing serious illness.

#### **Teenage Cancer Trust**

http://www.teenagecancertrust.org/

UK site that offers awareness, education, conferences, support networks, etc.

With focus on building teenage unites (13-24) in UK hospitals

#### **Teen Impact Program**

323-361-4660

Support groups, retreats, and mentoring programs for ages 6-25 Based out of the Los Angeles Children's Hospital

### The Gold Hope Project

http://goldhopeproject.com/

This organization works to pair families with a child that has cancer with a photographer to provide a photography session for free.

### **Online Forums/Support Groups**

#### **Bite Me Cancer Cares**

https://www.facebook.com/groups/bmccares

A Facebook group for teen cancer patients only.

#### **Cancer Hope Network**

800-552-4366

http://www.cancerhopenetwork.org/

Provides support to cancer patients and their families by matching them with trained volunteers who have undergone and recovered from a similar cancer experience.

### **Group Loop**

1.888.793.9355

http://www.grouploop.org/

Sponsored by The Wellness Community. Provides online support, information, and resources for teens with cancer and their parents.

### **Huffington Post**

http://www.huffingtonpost.com/claire-mccarthy-md/helping-families-dealing-with-cancer b 3910052.html An article about the Do's and Don'ts of helping a family who is dealing with cancer. It talks about what the family is facing and how friends can play a positive role in the family's life.

### I'm Too Young for This!

877-735-4673

http://stupidcancer.org/directories/yaorgs.shtml

Online forums, plus resources and information for every need (financial aid, counseling, retreats, etc.) Most comprehensive list of resources for adolescents and young adults
List for retreats/camps in every state

#### **Prepare to Live**

http://www.preparetolive.org/

Online videos/clips, support groups, stories

### **Planet Cancer**

512-452-9010

### http://www.planetcancer.org/

An online community for young adults affected by cancer.

#### Re-Mission

http://www.re-mission.net/

Videogame and online community

#### Starlight Children's Foundation

310-479-1212

https://www.starlight.org/ourwork

An online community for chronically ill teens and their siblings

### **Vital Options TeleSupport Cancer Network**

818-508-5657

http://www.vitaloptions.org/

An organization that facilitates a syndicated cancer talk show linking callers with patients, long-term survivors, family members, physicians, researchers and therapists.

### Scholarships, Financial Aid, & Career Info

### **Cancer and Careers**

http://www.cancerandcareers.org/

Resources and information for working women with cancer

#### Caps Fund, Inc.

845-331-8986

http://www.capsfund.org/

To assist families financially in dealing with the complications of cancer.

### **Hardest Hit Fund**

https://www.treasury.gov/initiatives/financial-stability/TARP-Programs/housing/hhf/Pages/default.aspx Hardest Hit funds may vary from state to state, but often help with mortgage payment assistance.

### Surviving and Moving Forward: The SAM Fund for Young Adult Survivors of Cancer

617-938-3484

http://www.thesamfund.org/

Helps support young adult cancer survivors in the transition from high school to college. Offers financial assistance through grants and scholarships.

### Sexuality, Fertility, Pregnancy

### Fertile HOPE

877-236-8820

http://www.livestrong.org/we-can-help/fertility-services/

Resources and information for cancer survivors faced with infertility

### **Pregnant with Cancer**

1-800-743-4471

http://www.pregnantwithcancer.org/

Support (connects women together) and resources for women diagnosed with cancer while pregnant

### **Site-Specific Resources**

### **A Caring Hand**

212-229-2273

http://www.acaringhand.org/

provides outreach, group programs, and consultations for family members that have lost a child in the New York area.

### Lymphoma Australia

https://www.lymphoma.org.au/

A website dedicated to uniting Hodgkin's Lymphoma patients throughout Australia

#### Children's Brain Tumor Foundation

866-228-4673

http://cbtf.org/cms/

Support, education, and advocacy for children with brain and spinal cord tumors to improve treatment, quality of life, and long term outlook

#### Club

812-430-6379

http://www.colonclub.com/

Raises awareness for colon cancer using unique techniques (such as the colossal colon)

### **Kisses for Kyle**

267-210-1489

http://www.kissesforkyle.org/

Helps families in the Philadelphia region by providing financial assistance through gift cards and local business services.

### **Kyle Feel Peace**

http://www.kylepeasefoundation.org/

Helps families in the Philadelphia region by conducting seminars, providing stress reduction techniques, and providing special activities.

### **Living Beyond Breast Cancer**

855-807-6386

http://www.lbbc.org/

Empowering women affected by breast cancer through offered programs and services

#### Making Headway Foundation Inc.

914-238-8384

http://www.makingheadway.org/

Offers support and care through professionals for children with brain and spinal cord tumors before, during, and after surgery

#### MaleCare

http://www.malecare.com/

Information and (support group) resources for men affected by prostate/testicular cancers

### **Pop Smear**

978-744-5300

http://www.theyellowumbrella.org/

Raising awareness for cervical cancer through advocacy and concerts

#### **Rethink Breast Cancer**

416-920-0980

http://www.rethinkbreastcancer.com/

Information, research, support, news and prevention

### **Rolling to Recovery**

812-430-6379

https://colonclub.com/rolling-to-recovery/

Resource for young adults with colon cancer

### **Sean Kimerling Testicular Cancer Foundation**

212-986-0892 ext. 5

http://www.seankimerling.org/

Information, events, focus on prevention and awareness

### **Sharsheret**

866-474-2774

http://www.sharsheret.org/

Young Jewish women living with breast cancer

Information, forum, events

### Tamika and Friends

866-595-2448

http://cervivor.org/

Cervical cancer and HPV

Awareness, events, support

### Young Adults Surviving Glioblastoma

https://www.facebook.com/pages/Young-Adults-Surviving-Glioblastoma-

YASGcom/103156533117037?sk=wall

For young adults with glioblastoma (most aggressive form of brain cancer)

Online forums and chats

### **Young Survival Coalition**

877-972-1011

http://www.youngsurvival.org/

Women 40 and under with breast cancer Advocacy, education, online support

### **Zane Beadles Parade Foundation**

http://zanesparade.org/

Started by the Jacksonville Jaguar player, Zane Beadles, and works to support Brent's Place in Aurora Colorado, the UF Proton Therapy Institute in Jacksonville Florida, and the Ronald McDonald House in Salt Lake City, Utah. The foundation works to creates new experiences for pediatric cancer patients.

### **Statistics**

Childhood Cancer in New Jersey, 1979-2005, Cancer Epidemiology Services, New Jersey Department of Health and Senior Services

Available at: <a href="http://www.state.nj.us/health/ces/documents/childhood\_cancer\_report.pdf">http://www.state.nj.us/health/ces/documents/childhood\_cancer\_report.pdf</a>
Cancer incidence and mortality data from 1979-2005 for NJ children up to 19 years of age.

National Cancer Institute: SEER: Cancer Epidemiology in Older Adolescents and Young Adults <a href="http://seer.cancer.gov/archive/publications/aya/aya\_mono\_complete.pdf">http://seer.cancer.gov/archive/publications/aya/aya\_mono\_complete.pdf</a>
Epidemiology for different types of cancer

Statistics for ages 15-29

#### **Treatment & Quality of Life Research**

### **CURE Childhood Cancer**

http://curechildhoodcancer.org/

CURE focuses entirely on children's cancer efforts and funds the work of some of the best and brightest scientist in the field of pediatric cancer.

### **Commission on Cancer**

312-202-5085

http://www.facs.org/cancer

Dedicated to improving the quality of life for cancer patients through standard-setting, prevention, research, education and the monitoring of comprehensive research.

### **Hope Lab**

650-569-5900

http://www.hopelab.org/

Research and innovative solutions for chronic illnesses to improve health and quality of life for young adults Remission Game: www.re-mission.net

### **Books and Pamphlets**

To obtain a copy of these materials, go to <u>www.LLS.org</u> or call the telephone number provided. If only a publisher is listed, you can obtain a copy through your local bookstore.

#### For children and teens

*Henry and the White Wolf*, by Tyler and Tim Karu. A book to help children going through the process of hospitalization or chemotherapy.

**The Human Body: An Illustrated Guide to its Structure, Function, and Disorders** — big, colorful book that helps children learn about their bodies. Useful tool for classroom presentations. Available from DK Publishing Inc

**The Jester Has Lost His Jingle** by David Saltzman — a story about finding laughter and happiness inside oneself to help get through challenging times such as a cancer diagnosis.

Useful tool for classroom presentations. Published by Jester Books.

Planet Cancer: The Frequently Bizarre Yet Always Informative Experiences and Thoughts of Your Fellow Natives by Heidi Di Adams and Christopher Schultz.

**What Is Cancer Anyway? Explaining Cancer to Children of All Ages** by Karen L. Carney — in simple terms, provides basic information about cancer in a reassuring way. Published by Dragonfly.

### For parents and teachers

The Leukemia & Lymphoma Society offers disease specific informational booklets about: Acute Myelogenous Leukemia (AML), Acute Lymphocytic Leukemia (ALL), Chronic Myelogenous Leukemia (CML), Lymphomas and other blood cancers. All are available at www.LLS.org.

**100 Questions & Answers about Your Child's Cancer** by William L. Carroll. Published by Jones & Bartlett Publishers, Inc.

**Baby Dust** by Deanna Roy: Based on the stories of dozens of real survivors, this is a tribute to the strength of mothers who must endure the impossible loss of a baby.

**Cancervive Parent's and Teacher's Guide for Children With Cancer** — explains social and academic challenges childhood cancer survivors face and outlines strategies for successful school reintegration. Available from www.cancervive.org.

*Childhood Cancer Survivors: A Practical Guide to Your Future* by Nancy Keene, Wendy Hobbie, and Kathy Ruccione. Published by O'Reilly & Associates, Inc.

*Childhood Leukemia: A Guide for Families, Friends & Caregivers* by Nancy Keene. Available from www.LLS.org.

Coping with Childhood Leukemia and Lymphoma is available from www.LLS.org

**Competing with Cancer,** by Shannon Miller. Available as a free eBook at <a href="http://www.shannonmillerlifestyle.com/">http://www.shannonmillerlifestyle.com/</a>

**Educating the Child with Cancer: A Guide for Parents and Teachers** by Nancy Keene. Available from www.candlelighters.org.

Footsteps Through Grief by Darcie D. Sims

Healing a Parent's Grieving Heart by Alan D. Wolfer

*I Didn't Miscarry, she Died* by Michelle Walters: A creative expression of what it is like to lose an unborn child and heal from such a loss.

*In Company of Angels: A Memorial Book* by Casey Shay Press: A book to record each moment during pregnancy for parents who have lost a baby. Important part in the healing process

**Learning & Living With Cancer: Advocating for your child's educational needs**. Available from <a href="http://www.lls.org./">http://www.lls.org./</a>

*Living With Childhood Cancer: A Practical Guide to Help Families Cope* by Leigh A. Woznik and Carol D. Goodheart. Published by the American Psychological Association.

Our Child Has Cancer: What Do We Do About School? by Carla Woyak. To order, call 602-300-0831.

Our Children, Our Hearts by Emily Laitmon

The Other Side of Grief by Darcie D. Sims

**Pictures of My Journey** is a coloring book & activity book for children with cancer. Available from <a href="http://www.lls.org./">http://www.lls.org./</a>

**The Stem Cell Transplant Coloring Book** is for children with blood cancer who are coping with having a stem cell transplant. Available from www.LLS.org

**Young People With Cancer — A Handbook for Parents**. Available from <a href="https://www.cancer.gov">www.cancer.gov</a>.

**Three Minus One** by Sean Hanish: A collection of intimate stories and artwork by parents who have lost a child to stillbirth, miscarriage, or neonatal death.

**Why Do Bad Things Happen To Good People** by David Arnold: A simple tool that teaches readers that the suffering, distress, and frustration they have encountered are not outside the assistance of God's grace.

When the Bough Breaks by Judith R. Bernstein

### **Videos**

Back to School: Teens Prepare for School Re-entry. Available from http://www.starbright.org/.

Emily's Story: Back to School After Cancer. Available from <a href="http://www.cancervive.org./">http://www.cancervive.org./</a>

*I'm Still Me*. This videotape for young school aged children features Susan Linn and her puppets talking about childhood leukemia and the fears and concerns of classmates of the child.

*Making the Grade: Back to School After Cancer for Teens*. This is an 18-minute documentary where teens discuss returning to school after having been diagnosed with cancer. Available from <a href="http://www.cancervive.org/">http://www.cancervive.org/</a>.

Why, Charlie Brown, Why? This videotape for young school-age children features Charlie Brown characters reacting to a classmate's diagnosis of leukemia. Available in English and Spanish from <a href="http://www.lls.org./">http://www.lls.org./</a>

With a Little Help From My Friends- Living with Leukemia and Lymphoma. This 21-minute documentary is for middle-school-age students. Available from <a href="http://www.lls.org./">http://www.lls.org./</a>