

LIFE WITH CANCER®

Resources for Pediatric Oncology Patients and Their Families

There are numerous resources and support programs available to help you and your family cope with the cancer diagnosis and treatment journey. Resources commonly referred to are listed below. Please contact your hospital or outpatient social worker for information and eligibility requirements for these and other resources to meet your particular needs.

Web-based Information and Educational Resources Regarding Diagnoses and Treatment

- ❖ www.curesearch.org --- by the Children's Oncology Group, information on all diagnoses, late effects, survivorship.
- ❖ www.chemocare.com --- descriptive information about every aspect of chemotherapy, managing side effects, etc.
- ❖ www.nci.nih.gov --- National Cancer Institute, latest information regarding treatment, clinical trials, research.
- ❖ www.clinicaltrials.gov --- National Institutes of Health sponsored website.
- ❖ www.beyondthecure.org --- Sponsored by the National Children's Cancer Society, information on survivorship, advocacy, school issues, insurance, building your own treatment summary, etc.

Books and Videos

- ❖ "Why Charlie Brown, Why?" (for children); "The New Normal" (for parents) excellent videos.
- ❖ Living With Childhood Cancer: A Practical Guide to Help Families Cope, by L. Woznick and C. Goodheart, available through Life with Cancer®.
- ❖ Candlelighters---www.candlelighters.org---provides free books on request including: Childhood Leukemia: A Guide for Families, Friends, and Caregivers; Childhood Cancer: A Parent's Guide to Solid Tumor Cancers; Childhood Cancer Survivors: A Practical Guide to Your Future (N. Keene & W. Hobbie); Chemo, Crazyness & Comfort, My Book about Childhood Cancer, (practical advice for children 6-12, easy to read text); and Educating the Child with Cancer, all by Nancy

- Keene; Childhood Brain and Spinal Cord Tumors (Shiminski-Maher, Cullen, Sansalone); The Amazing Hannah, (also available in Spanish), picture book for pre-schoolers, 1-5, showing real life treatment situations; Oliver's Story: For Sibs of Kids With Cancer, for 3-8 year old siblings, answers questions and offers constructive ways on how sibs can offer support.
- ❖ *Starlight Starbright Children's Foundation*---www.starbright.org--- books, videos and games for children and teens coping with cancer, chemotherapy, returning to school.

Support Groups and Programs

- ❖ *Life With Cancer*---www.lifewithcancer.org--- Monthly Calendar of classes, support programs and events, plus website with several topics translated into multiple languages. For registration for children's programs, contact Children's Program Mgr @ 703-698-2536:
 1. Sibling Support Days, 8 times per year including many Monday school holidays and during the summer
 2. Teen Activity Group---different venues such as bowling, mini-golf, eating out
 3. Kids with Cancer Days---all day activities for the child undergoing treatment, sometimes combined with Sibling Support Days
 4. Pediatric Oncology Parent Night---monthly programs for parents with different speakers/topics co-sponsored by the Leukemia and Lymphoma Society and DC Candlelighters
 5. Individual and family counseling
 6. Survivorship conferences and educational programs for teens and young adult survivors of childhood cancer---offered yearly
 7. Young Adult Support Group---20 +
 8. Numerous classes open to parents and adults on stress management and complementary therapies
 9. Parent Bereavement Group---monthly support group, 2nd Thursday of each month
- ❖ *D.C. Candlelighter's of the Metro Area*---offers financial assistance (up to \$250), gift bags for newly diagnosed families; parent to parent and monthly support groups; "teas" in the pediatric oncology clinics and hospital; books and resources published by the National

- Candlelighter's organization. Contact Lisa Tignor, 703-590-4134, dccandlelighters@gmail.com; www.dccandlelighters.org.
- ❖ *Leukemia and Lymphoma Society*---"First Contact Program" matches children/parents via phone for support; contact 703-960-1100 X231.
 - ❖ *SuperSibs*---www.supersibs.org---1-866-444-SIBS---honors, recognizes, supports brothers and sisters with free gifts, newsletters, programs, resources for parents, college scholarships for sibs.
 - ❖ *Songs of Love*---www.songsoflove.com, 1-800-960-SONG---provides personalized songs on child's own CD written and performed by talented artists with input from the child's life.
 - ❖ Help with design of free personalized websites:
 1. Care to Share Cancer Connection, www.nationalchildrenscancersociety.org
 2. Caring Bridge, www.caringbridge.org
 3. Care Pages, www.inova.org, select Inova Fairfax Hospital for Children.

Financial Resources

- ❖ SSI---Supplemental Security Income under Social Security for children who meet disability and family income criteria. Provides a monthly benefit and automatic link to Medicaid. Social Security Administration Hotline 1- 800-772-1213.
- ❖ *National Children's Cancer Society*---provides financial help to eligible families with transportation reimbursement, meals, health insurance premiums if there has been a loss of employment, expenses and lodging at treatment centers away from home, some costs of bone marrow searches for transplant, and other categories of assistance. Requires Social Work referral, application, liquid assets less than \$5,000, copies of bank statements.
- ❖ *Leukemia and Lymphoma Society*---provides \$150 per year for out of pocket chemotherapy and other drug expenses and mileage assistance; offers co-pay assistance for some diagnoses, www.lls.org/nca
- ❖ Local charities (*Pediatric Oncology Fund, Teardrops to Rainbows, The Quadrino Foundation, Special Love, Inc, Steven Greenwood Foundation affiliated with the Ronald McDonald Charities, Growing Hope, & DC Candlelighters*) provide emergency assistance with various household

- and non-medical expenses. With exception of Growing Hope, each request requires a social work referral. Maximum grant requests range from \$500 - \$1,500. Contact Social Worker for more details.
- ❖ *National Foundation for Credit Counseling*, 1-800-388-2227; www.cccs.org. Local financial care centers, free or low cost. Also see *Consumer Credit Counseling Services*, many local offices @ 800-747-4222; *Northern Virginia Family Services*, 703-385-3267 (Fairfax), 703-490-3646 (Prince William); or *Virginia Cooperative Extension*, 703-324-5369 (Fairfax).
 - ❖ *College Scholarships for Cancer Survivors*---see comprehensive lists on www.curesearch.org or www.I'mtooyougforthis.org

Camps and Retreats/Special Events

- ❖ *Special Love, Inc.*---www.speciallove.org. 1-888-930-2707. Sponsors summer camp for patients 7-17, Brass Camp for brothers and sisters, Fantastic Friends camp, weekend getaways for parents and the whole family; teen, ski, and young adult weekends; numerous other activities throughout the calendar year at the 4-H facility in Front Royal Virginia, newsletter.
- ❖ *Believe in Tomorrow*---www.dreamsurfer.org---sponsors local beach and mountain retreats and special "adventures" for the whole family.
- ❖ *Camp Friendship*---www.cjcf4kids.org---sponsored by the Carol Jean Cancer Foundation, located in Maryland; several week long camping sessions per year plus several other programs for siblings, teens, and parents.
- ❖ *Children's Oncology Camping Association International (C.O.C.A.)*, www.coca-intl.org, provides information on pediatric oncology camps throughout the country.
- ❖ *Growing Hope*---local Foundation which sponsors annual Peds Oncology Picnic (Spring), trips to the Circus (Ringling Brothers in March, Big Apple Circus in Oct.), and King's Dominion (Sept.), support for the annual Holiday Party, and many other activities in the clinic setting. www.ourgrowinghope.com
- ❖ *Teardrops to Rainbows*---local Foundation which co-sponsors annual Holiday Party "extravaganza" in December, with gifts for the entire family, gift bags and blankets for newly diagnosed families, and

supports renovations and amenities on the hospital unit, in the outpatient clinic and at Life with Cancer (teen lounge),
www.teardropstorainbows.org

Special Wishes

- ❖ *Make-A-Wish Foundation*---www.wish.org---grants wishes for travel, meeting celebrities, spending sprees, etc. for any child with a life threatening illness, 2 ½ -17.
- ❖ *Children's Wish Foundation International*---www.childrenswish.org---grants first and "second" wishes (on a limited basis).
- ❖ *A Special Wish Foundation, Inc.*, www.spwish.org, grants wishes to children up to age 21.
- ❖ *Kids Wish Network*, www.kidswishnetwork.com, 3-17, may grant "second" wishes if more than 3 years have passed since child received first wish.

School Issues

- ❖ Homebound instruction---Schools are mandated to provide teachers for homebound instruction, grades 1-12 in core subjects. Requires medical documentation and the commitment of a parent to be present during scheduled teacher visits. Many teachers will make hospital visits as well. Social worker or hospital teacher will make referral.
- ❖ Home schooling---an option for parents who wish to provide the instruction themselves. Contact National Home Education Network @ www.nhen.org for information, group listings, newsletter.
- ❖ IEPs/504 plans---many children treated for cancer will need evaluations for special education and/or accommodations following treatment due to physical and/or learning difficulties.
- ❖ *Child Find and Early Intervention Programs*---out patient and home-based developmental evaluations and therapies (physical, occupational, speech, cognitive) for infants through pre-schoolers with disabilities or suspected delays. Contact social worker for appropriate referral.
- ❖ School Re-Entry---excellent web resources for information on late effects, school re-entry, advocacy include: www.children-cancer.org; www.cancersourcekids.com; www.cancer.org (ACS website); www.ldonline.org; (provides comprehensive and interactive

- guide to learning disabilities for parents, students and teachers); www.leukemia-lymphoma.org (sponsors teleconferences and workshops on school re-entry); www.candlelighters.org; www.starbright.org
- ❖ Annual "Back to School Conference"---sponsored by the Leukemia and Lymphoma Society of the National Capital Area for parents, teachers, principals, school nurses, hospital and clinic personnel on all aspects of school re-entry. Appropriate for all diagnoses, K - 12. Usually held in November.
 - ❖ *Hope Cam*---"free" laptop computer (for 12 months) and high speed internet video link-up to child's classroom. Started by local peds oncology parent to help homebound children/teens stay connected to friends and teachers; contact Jen Bond at 703-620-2555, ext 110 jbond@hopecam.org; www.hopecam.org
 - ❖ *Parent Educational Advocacy Training Center*---(PEATC) statewide and local organization dedicated to providing information and guiding parents through the IEP process, denials and appeals---703-923-0010.

Wigs and Hats

- ❖ *Hip Hats*---www.hiphat.com---partial (breathable) wigs made of real hair that can be worn with caps matched to girl's hair color, length and texture. Financial assistance available to help with purchase.
- ❖ *Wigs for Kids*---www.wigsforkids.org---needs physician referral.
- ❖ *Locks of Love*---www.locksoflove.org---provides hairpieces to children younger than 18. Accepts hair donations.
- ❖ *Hair Club for Kids*--- www.hairclub.com/hc_for_kids. 1-800-269-7384.

Transportation To and From Treatment/Other Treatment Centers

- ❖ *American Cancer Society*---volunteer drivers provide rides to chemo and radiation appointments (only). 1-800-ACS-2345.
- ❖ *Logisticare*---rides to doctors, clinic/hospital appointments for Medicaid eligible children, 1-866-386-8331.
- ❖ *Corporate Angels*---www.corporateangelnetwork.org---provides free air travel to treatment centers using empty seats on corporate jets. Open to all cancer patients, bone marrow donors who are ambulatory and not in need of medical support while traveling.

- ❖ *AirlifeLine*---www.airlifeline.org---free air travel on private planes to treatment centers anywhere in the U.S., using pilots who donate their services to the angel flight network. Patients must not be in need of medical support in-flight.
- ❖ *National Patient Travel Center*---www.patienttravel.org---arranges air medical transportation to any specialized treatment center for diagnosis and treatment, regardless of financial need. Based in Virginia Beach.

Employment/Insurance Help and Advocacy

- ❖ FMLA---Family Medical Leave Act---provides up to 12 work weeks of unpaid leave to care for family member with a serious illness without threat of loss of employment. Contact employer or Dept. of Labor website @ www.dol.gov/esa/whd/fmla.
- ❖ *Patient Advocate Foundation*---1-800-532-5274---
www.patientadvocate.org--- provides assistance with insurance problems and works to resolve coverage and benefit issues.
- ❖ COBRA---federal act which allows continued health insurance coverage due to loss of job, job relocation or reduced work hours on a temporary basis (18 months) at the employee's expense. Contact EBSA Hotline @ 1-866-444-EBSA with questions.
- ❖ HIPPA---federal act designed to protect access to health insurance when starting a new job or changing jobs, or when buying individual coverage if you lose coverage under an employer group plan. Contact State Insurance Commissioner or Centers for Medicare/Medicaid website @ www.cms.hhs.gov/hippa.
- ❖ "Pro Bono" (free) Legal Help---for those diagnosed with leukemia, lymphoma, and other blood disorders through the *Leukemia and Lymphoma Society*, National Capitol Area; 703-960-1100, X231.

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