

## Family Resources

Please feel free to use any of these resources. If you find more resources that you would like to share with other families please contact us at [events@childcancer.org](mailto:events@childcancer.org) and we will add it to our list of resources. We hope you find all the information you need to be prepared for the journey ahead of you.

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## **Childhood Cancer Facts:**

### **Incidence:**

- Currently, one in every 330 children in the United States develops cancer before the age of nineteen. The incidence of cancer among children is increasing. Each school day, enough children are diagnosed with childhood cancer to empty two classrooms!

(According to [www.ChildCancer.org](http://www.ChildCancer.org))

### **Survival Rate:**

- Depending on the type of cancer and the development upon diagnosis, the ACS estimates that approximately 2,300 children will die from cancer in the year 2000. The number of children diagnosed with cancer in the U.S. each year puts more potential years of life at risk than any single type of adult cancer. (According to [www.ChildCancer.org](http://www.ChildCancer.org))

### **Causes:**

- Largely unknown. Currently, there are no established guidelines for childhood cancer prevention. (According to [www.ChildCancer.org](http://www.ChildCancer.org))

### **Description:**

- Childhood cancers are mostly those of the white blood cells (leukemia's), brain, bone, the lymphatic system and tumors of the muscles, kidneys and nervous system. Each of these behaves differently. Cancers in very young children are highly aggressive and behave unlike malignant disease seen at other times of life. The median age for childhood cancer is six. Children frequently have a more advanced stage of cancer when they are first diagnosed. 80% of children show that cancer has spread to distant sites in the body when the disease is first diagnosed. (According to [www.ChildCancer.org](http://www.ChildCancer.org))

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### **Current Treatment Options:**

- A child with cancer must be diagnosed precisely and treated by clinical and laboratory scientists who have expertise in the management of children with cancer. Advances in treatment have been made in some childhood cancers; however, many cancer types offer very aggressive treatments with lower survival rates. Many treatments include: several rounds of chemotherapy, tumor removal, radiation therapy, bone-marrow-transplantation, and various clinical procedures. (According to [www.ChildCancer.org](http://www.ChildCancer.org))

### **Cancer Facts/Statistics:**

- Each school day, 46 children are diagnosed with cancer. (According to [www.Candlelighters.org](http://www.Candlelighters.org))
- One in 330 children will develop cancer by age 20. (According to [www.Candlelighters.org](http://www.Candlelighters.org))
- Each year in the U.S. over 12,600 children are diagnosed with cancer. (According to [www.Candlelighters.org](http://www.Candlelighters.org))
- Although the 5 year survival rate is steadily increasing, one quarter of children diagnosed with cancer will die 5 years from the time of diagnosis. (According to [Candlelighters.org](http://www.Candlelighters.org))
- Cancer remains the number one disease killer of America's children - more than Cystic Fibrosis, Muscular Dystrophy, Asthma and AIDS combined. (According to [www.Candlelighters.org](http://www.Candlelighters.org))
- 80% of children have metastatic disease at time of diagnosis as compared to only 20% of adults. (According to [www.Candlelighters.org](http://www.Candlelighters.org))

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- There are currently more than 270,000 childhood cancer survivors in the U.S. (According to [www.Candlelighters.org](http://www.Candlelighters.org))
- Late effects of childhood cancer treatment are common in survivors, and approximately one-third are moderate to severe. (According to [www.Candlelighters.org](http://www.Candlelighters.org))
- Worldwide, 160,000 kids are diagnosed with cancer each year. (According to [www.StBalricks.org](http://www.StBalricks.org))
- Childhood cancer kills more U.S. children than any other disease – more than AIDS, asthma, diabetes, cystic fibrosis and congenital anomalies, combined. (According to [www.StBalricks.org](http://www.StBalricks.org))

## **Sibling Information & Tools:**

- SuperSibs: provides tips, conversation starters, and support systems for parents to use with siblings of a child with cancer.  
[www.supersibs.org](http://www.supersibs.org); (866) 444-SIBS
- The Sibling Support Project: the only national effort dedicated to the interests of over six million brothers and sisters of people with special health, mental health, and developmental needs.  
[www.siblingsupport.org](http://www.siblingsupport.org); (209) 297-6368
- Gilda's Club Worldwide: creates welcoming communities of free support for everyone living with cancer - men, women, teens and children - along with their families and friends. Our innovative program is an essential complement to medical care, providing networking and support groups, workshops, education and social activities.  
[www.gildasclub.org](http://www.gildasclub.org); (888) GILDA-4-U

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- Cancer Care: CancerCare is a national nonprofit organization that provides free, professional support services for anyone affected by cancer.

[www.cancercare.org](http://www.cancercare.org); (800) 813-HOPE

## **Fun For Kids:**

- Squirrel Tales: Resources for parents and kids on how to communicate and stay busy in the hospital.

[www.squirreltales.com/parents/creative.html](http://www.squirreltales.com/parents/creative.html)

- Children's Hospital: Games to play in the hospital.

[www.childrenshospital.org/arthur/li\\_games\\_more\\_en.html](http://www.childrenshospital.org/arthur/li_games_more_en.html)

- American Brain Tumor Association: An excellent site with medical explanations geared for children. It also contains word games.

[www.abta.org](http://www.abta.org)

- Band-aids and Blackboards: This Web site is designed for children of all ages, and is divided into categories for children and teens. The focus is how to deal with medical problems of any kind. The site contains helpful hints for parents, teachers and other professionals.

[www.lehman.cuny.edu/faculty/jfleitas/bandaides](http://www.lehman.cuny.edu/faculty/jfleitas/bandaides)

- Brave Kids: The site has contests, games and stories. It also has message boards in Spanish or English.

[www.bravekids.org](http://www.bravekids.org)

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- Kids Cancer Network: provides "a dose of hope™" for kids and their families isolated by the rigors of childhood cancer treatment by providing activities, resources and ways to share their story.

[www.kidscancernetwork.org](http://www.kidscancernetwork.org)

- Look Good, Feel Good: This Web site for teens deals with appearance issues, as well as relationship and emotional issues.

[www.2bme.org/2bMe.html](http://www.2bme.org/2bMe.html)

- Starlight Starbright Children's Foundation Coping with Chemo: A Web site for young adolescents, it features a video on how to discuss your diagnosis with friends.

<http://chemo.starlightprograms.org>

- Teens Living With Cancer: This Web site gives medical explanations, advice on talking to peers and family and many other emotional-support ideas for teenagers. In English and Spanish.

<http://teenslivingwithcancer.org>

- The Captain Chemo website: This is an interactive comic strip/game that also teaches children about cancer and treatment.

<http://www.royalmarsden.org/captchemo/index.asp>

- The Songs of Love Foundation: This organization provides personalized songs for children and teens facing tough medical, physical or emotional challenges, free of charge. These one-of-a-kind compositions are created by professional songwriters and can be done in almost any language and musical style.

[www.songsoflove.org](http://www.songsoflove.org)

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- Starlight Children's Foundation and Hollywood Video
- Brings mobile movie nights and game tournaments to hospitals and sent kids to their Video Starlight Site in Portland. Look at websites for more details.

[www.hollywoodvideo.com/communityspotlight](http://www.hollywoodvideo.com/communityspotlight)

[www.starlight.org](http://www.starlight.org)

## **Travel Information & Resources:**

These organizations provide airline flights for patients that need to travel for medical reasons.

Also note: One parent reports that if you contact the airlines for medical issues they will let you have the cheapest rate for the airfare, meaning even though you are leaving tomorrow, they will give you the same discount as though you did a 30 day advance ticket.

- Air Lifeline
- Air Charity Network

800-446-1231

800-549-9980

<http://aircharitynetwork.org>

The Air Charity Network 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.

- Air Care Alliance

800-296-1217

[www.aircareall.org](http://www.aircareall.org)

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The Air Care Alliance is a nationwide league of humanitarian flying organizations whose volunteer pilots are dedicated to community service. This site will introduce you to us and to all the groups we list whose volunteers perform public benefit flying for health care, patient transport, disaster relief, environmental support, and other missions of public service.

- Angel Flight, Inc. People Flying People in Need

918-749-8992

[www.angelflight.com](http://www.angelflight.com)

Angel Flight is a non-profit organization of pilots and other volunteers dedicated to serving the community by arranging free private air transportation for medical patients who cannot afford to utilize normal, commercial transportation. Angel Flight also provides services to blood, organ and tissue banks. Angel Flight is a member of Air Care Alliance, a group of 37 organizations providing similar services throughout the United States. These groups are coordinated through a toll-free service (NPATH) that helps individuals in need find assistance in their area.

- Angel Flight at NIH

301-451-9646

[www.angelflightatnih.org](http://www.angelflightatnih.org)

For patients in medical and financial need who need to travel to the NIH Clinical Center in Bethesda, Maryland.

- Cancer Air Flights

[www.gwccs.org/flights.html](http://www.gwccs.org/flights.html)

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Lists a number of organizations that assist cancer survivors and their caregivers with transportation to and from treatments.

- Children's Flight of Hope

919-466-8593

[www.childrensflightofhope.org](http://www.childrensflightofhope.org)

Children's Flight of Hope provides free, private air transportation to and from medical facilities for children in need. "With our organization-owned aircraft and crew of experienced volunteer pilots, we transport children and their families to and from hospitals throughout the eastern United States. We seek to ensure that children in our service area (North Carolina) are not denied access to medical treatment at distant facilities due to either financial need or a medical condition that precludes travel via ground or commercial aircraft."

- Continental Careforce

Bob Jack at 1-281-261-6626.

Has a contract with Memorial Sloan Kettering Cancer Center for reduced or free airline tickets.

- Corporate Angel Network

1-914 328 1313.

[www.corpangelnetwork.org](http://www.corpangelnetwork.org)

Free flights for cancer patients and their families. Private jets used by corporations that have empty seats, free flights. No financial requirements. One of many advantages is low risk of exposure to contagious illness because just a few people are on plane.

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- Delta AirSky Wish at United Way

1-800-892-2757 ext. 285, Christina Walker

Free flights, no financial requirements. Difficult to get into as often short on miles.

- Hope Flight Foundation

510-427-3956

[www.hopeflightfoundation.org/Welcome.html](http://www.hopeflightfoundation.org/Welcome.html)

Hope Flight Foundation provides dependable, free air transportation for children who need critical medical treatment at facilities far from their homes. Flights to children's healthcare camps and 'make-a-wish' flights are also provided.

- Lifeline Pilots

309-697-6865

[www.lifelinepilots.org](http://www.lifelinepilots.org)

LifeLine Pilots is a private, non-profit organization that provides people in medical and financial distress with access to free air transportation on small (4-6 seat), private aircraft for health care and other compelling human needs.

- Mercy Medical Airlift

1-800-296-1217

[www.mercymedical.org](http://www.mercymedical.org)

(MMA) is a non-profit organization dedicated to serving people in situations of compelling human need through the provision of charitable air transportation. MMA is

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totally supported through charitable giving and the services of volunteer pilots and office assistants.

- Midwest Express Miracle Miles

Natalie Fuerst at 1-414-570-3644

One free flight, thereafter flights are discounted. No financial requirements.

- Miracle Flights for Kids

(800) -359-1711 or (702) 261-0494

[www.miracleflights.org](http://www.miracleflights.org)

Transporting children to medical treatment since 1985.

- National Patient Air Travel HELPLINE

1-800-296-1217

[www.patienttravel.org](http://www.patienttravel.org)

Provides information about all forms of charitable, long-distance medical air transportation and provides referrals to all appropriate sources of help available through the Angel Flight America Network. Once NPATH, now also known as

- Northwest Airlines, Kid Cares program

1-612-726-4206

[www.nwa.com/corpinfo/aircares/about/kidcares.shtml](http://www.nwa.com/corpinfo/aircares/about/kidcares.shtml)

The Northwest Airlines KidCares medical travel program provides air travel to children age 18 and younger who are unable to receive treatment in their home area. Those with financial need have priority.

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- TWA Operation Liftoff

[www.operationliftoff.com](http://www.operationliftoff.com)

Providing special trips to children who are facing life threatening illness. Free flights, no financial requirements. Operation Liftoff provides air transportation for children with a life threatening illness for a wish trip or treatment trip.

## **Camps:**

- OKIZU: is committed to the continuing support of the childhood cancer community through its Oncology and Siblings camping programs, Family weekends, Bereavement programs, and Teen and Young Adult programs.

Located in Novato CA.

[www.okizu.org](http://www.okizu.org); (415) 382.9083

- Children's Oncology Camping Association International: Strengthens the international community of camps for children with cancer and their families through networking, advocacy, education and other resources.

65 camps located throughout the US, Canada, Australia, New Zealand and Europe.

[www.coca-intl.org](http://www.coca-intl.org); (515) 669-4580

- American Cancer Society (American Cancer Society Summer Camps): the 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.

[www.cancer.org](http://www.cancer.org); (800) ACS-2345

- World's Greatest Camp:

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providing year-round recreational and social activities designed to foster supportive relationships for pediatric cancer patients and their families.

Located in Orange County, CA.

[www.ocf-ocf.org](http://www.ocf-ocf.org); (949)855-1972

- Camp Summer Sault: American Cancer Society, in collaboration with Campfire USA, Long Beach Cancer League and other donors and volunteers has provided a summer day camp experience free-of-charge. Five-day day camp for children with cancer aged 6 to 13 and their siblings. Leadership experience for teenagers aged 14 and older.

Locate in Long Beach, CA.

(310) 437-0791 or (562) 933-8600

- Camp Jornada Foundations: This is a free camp for children faced with cancer and they also offer a year round support network.

[www.campjornada.org](http://www.campjornada.org)

- Camp Sunshine: Families of cancer patients may apply to attend a week-long camp at no charge.

[www.campsunshine.org](http://www.campsunshine.org)

- Kids camp.com: Lists oncology camps by region and state.

[www.kidscamps.com/special\\_needs/cancer\\_oncology.html](http://www.kidscamps.com/special_needs/cancer_oncology.html)

- Special Love, Inc; 540-667-3774

[www.speciallove.org](http://www.speciallove.org)

- First Descents; 970.845.8400

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First Descents provides whitewater kayaking and other outdoor adventure experiences to promote emotional, psychological and physical healing for young adults with cancer.

[www.firstdescents.org/cms/](http://www.firstdescents.org/cms/)

## **KRM Family Caring Bridge Pages:**

Caring Bridge: A CaringBridge website helps keep loved ones informed during difficult times. In return, family and friends give patient and caregiver support through guestbook messages. Every free, personalized CaringBridge website includes: [Patient care journal](#) to update family and friends, [Guestbook](#) for messages of love, & a [Photo gallery](#)

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

## **Chat Rooms, Message Boards, & Networks:**

- Cancer Kids: a web-based organization which began in 1997 with one simple goal-to help children with cancer tell their stories to the world.  
[www.cancerkids.org](http://www.cancerkids.org)
- Kids Cancer Network: provides "a dose of hope™" for kids and their families isolated by the rigors of childhood cancer treatment by providing resources and ways to share their story.  
[www.kidscancernetwork.org](http://www.kidscancernetwork.org)
- Care Flash: Free personal websites for sharing health updates, information and well wishes with friends and family during illness.

[www.careflash.com](http://www.careflash.com)

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- Care to Share Cancer Connection: An Internet support network for people who have been affected by childhood cancer. This is a place to share experiences, offer encouragement and learn from others. It is moderated by parents and social workers.

[www.thenationalchildrenscancersociety.org/forums](http://www.thenationalchildrenscancersociety.org/forums)

- Association of Cancer Online Resources: This site offers information and support through discussion groups on a variety of topics and disease specific areas.

[www.acor.org/support.html](http://www.acor.org/support.html)

- Cancer Hugs: This Web site's purpose is to help you understand how online support can aid you and your loved ones cope with cancer. The information within this site is intended to assist people living with cancer and their loved ones by sharing their trials and tribulations with others that are dealing with the very same life experiences.

[www.cancerhugs.com](http://www.cancerhugs.com)

- Cancersurvivors.org: This chat room allows you to search by topic and has a variety of topics including Adult survivors of childhood cancer and parents of childhood cancer patients. They also have a weekly general chat session.

[www.cancersurvivors.org](http://www.cancersurvivors.org)

- OncoChat: Online peer support for cancer survivors, families and friends.

<http://cancer.about.com/gi/dynamic/offsite.htm?site=http://www.oncochat.org>

- Teens Living With Cancer: This discussion board is for teens with cancer and their families. You do not have to register to post messages on this monitored site.

[www.teenslivingwithcancer.org](http://www.teenslivingwithcancer.org)

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- 4YOUth List: This is an online-support mailing list for young people (12-21) with cancer, who may be on or off treatment.

<http://listserv.acor.org/archives/4youth.html>

- Cancer Kids: A Web site dedicated to children with cancer. This is a place where they can share their stories. It also has a ‘memorials’ section.

[www.cancerkids.com](http://www.cancerkids.com)

- Childhood Cancer Web Ring: Join this free service to click from one online-support home page to another without use of a search engine.

<http://orgchem.colorado.edu/webring/index.html>

- Cancer Care: Offers information and online-support groups.

[www.cancercare.org](http://www.cancercare.org)

- National Brain Tumor Society: The site contains a chat room as well as conference schedule for brain tumor patients and their families.

[www.braintumor.org/GeneralMenu](http://www.braintumor.org/GeneralMenu)

### **Free Services (Wigs, etc.):**

- Cancer Fund of America is a non-profit organization set up to help cancer patients, hospices, and other non-profit healthcare providers by way of sending products free of charge directly to them

[www.cfoa.org](http://www.cfoa.org)

- Cure Today Magazine; a free magazine that is a guide for every stage of cancer.

[www.curetoday.com](http://www.curetoday.com)

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- Free Wigs for Kids with Cancer

[http://hair.lovetoknow.com/Free\\_Wigs\\_for\\_Cancer\\_Patients](http://hair.lovetoknow.com/Free_Wigs_for_Cancer_Patients)

- Locks of Love; provides hairpieces to financially disadvantaged children in the United States and Canada under age 18 suffering from long-term medical hair loss from any diagnosis.

[www.locksoflove.org/apply.html](http://www.locksoflove.org/apply.html)

- Children's Art Project: through worldwide sales of young cancer patients' original artwork featured on seasonal note cards and gift items, the project has funded more than \$24.5 million to programs that benefit cancer patients and their families. Each year, the project offers Holiday, Everyday and Valentine collections of note cards and gift items.

[www.childrensartproject.org](http://www.childrensartproject.org)

- Wigs 4 Kids provides custom-fitted, age-appropriate wigs which are individually cut and styled and services at no cost to kids and their families and accepts donations from caring individuals, companies and organizations. Wigs 4 kids provides an environment where a child can feel at ease. Each child learns important practical skills to help them through this difficult time.

[www.wigs4kids.org](http://www.wigs4kids.org); 586-772-6656

- Pantene Beautiful Lengths

[www.beautifullengths.com/en\\_US/index\\_home.jspp](http://www.beautifullengths.com/en_US/index_home.jspp); 800-945-7768

- Childhood Leukemia Foundation: This site offers a range of free services, including kid-friendly hats with human hair, gift baskets, gift cards, financial aid and sponsorships to pediatric-oncology summer camps.

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[www.clf4kids.org](http://www.clf4kids.org)

- Heavenly Hats Foundation: Donates brand-new hats to more than 160 hospitals across the U.S. and to individuals in need. Hats are shipped at no charge.

[www.heavenlyhats.com](http://www.heavenlyhats.com)

## **Financial Assistance Resources:**

### **Links to Local Food Banks**

- [www.cafoodbanks.org/list.htm](http://www.cafoodbanks.org/list.htm)
- [www.placer.ca.gov/Departments/hhs/Managed%20Care/~/\\_media/hhs/hhs%20%20%20managed%20care/documents/Food%20Resources%20of%20Placer%20Co.ashx](http://www.placer.ca.gov/Departments/hhs/Managed%20Care/~/_media/hhs/hhs%20%20%20managed%20care/documents/Food%20Resources%20of%20Placer%20Co.ashx)
- [www.roseville.ca.us/civica/filebank/blobdload.asp?BlobID=10004](http://www.roseville.ca.us/civica/filebank/blobdload.asp?BlobID=10004)
- [www.ncidc.org/food/CNFNP.html](http://www.ncidc.org/food/CNFNP.html)

### **Links to Financial Sources**

- Helps Single Parent Families  
[www.andriveroflife.org](http://www.andriveroflife.org)
- California Children's Services: helps pay for medical care if you qualify.  
[www.dhcs.ca.gov/services/ccs/Pages/default.aspx](http://www.dhcs.ca.gov/services/ccs/Pages/default.aspx)
- Children's Cancer Community: provides support groups, cancer survival kits, scholarships, a cancer library, family assistance, special events and activities for families.  
[www.hopeforcancerkids.org](http://www.hopeforcancerkids.org)

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- National Children’s Cancer Society: We serve as a financial, emotional, educational and medical resource for those in need at every stage of their illness and recovery. In the United States, we ease the financial burdens that accompany major illness; give crucial support and comfort; and address the challenges of survivorship.

[www.children-cancer.org](http://www.children-cancer.org)

- Clayton Dabney Foundation for Kids with Cancer: Provides financial assistance for families when their child is diagnosed with cancer. The criteria and application, which must be completed by a professional, are online.

[www.claytondabney.org](http://www.claytondabney.org)

- First Hand Foundation: Assists children with health problems by providing financial assistance for medical needs.

[www.cerner.com/firsthand](http://www.cerner.com/firsthand)

- NeedyMeds: This web site offers information regarding financial assistance for pharmaceuticals.

[www.needymeds.org](http://www.needymeds.org)

## **Health Insurance & Legal Information**

- American's Health Insurance Plans: This site provides links to many of the nation’s primary health care plans as well as current information relating to health care policy.

[www.ahip.org](http://www.ahip.org)

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- Blood & Marrow Transplant Information Network: Offers attorney referrals for patients who have insurance disputes. The site also allows patients to link with survivors who can provide emotional support.

[www.bmtinfonet.org](http://www.bmtinfonet.org)

- Health Care Choices: This site provides information on where to get insurance, what to do if claims are not paid on time and getting a second opinion for cancer. The information does not cover every state.

[www.healthcarechoices.org](http://www.healthcarechoices.org)

- Health Hippo: This site offers legal information on everything from drug approval to social security.

<http://hippo.findlaw.com/hippohome.html>

- HealthWell Foundation: This site helps patients afford the medical treatment they need.

[www.healthwellfoundation.org](http://www.healthwellfoundation.org)

- National Coalition for Cancer Survivorship: This site gives up to date policy information on issues that are important to cancer survivors.

[www.canceradvocacy.org](http://www.canceradvocacy.org)

- Patient Advocate Foundation: Offers financial advice and free legal consultation about insurance.

[www.patientadvocate.org](http://www.patientadvocate.org)

- Patient Access Network Foundation: Assisting patients who cannot afford the out-of-pocket costs associated with their treatment needs.

[www.patientaccessnetwork.org](http://www.patientaccessnetwork.org)

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- Patient Services Advocate: Helps people who live with certain chronic illnesses or conditions subsidize the cost of health insurance premiums.  
[www.uneedpsi.org/CMS400Min/index.aspx](http://www.uneedpsi.org/CMS400Min/index.aspx)
- U.S. Department of Health and Human Service: U.S. government site which provides information on Medicaid and Medicare complaints.  
[www.hhs.gov/](http://www.hhs.gov/)

## **Grief/Bereavement Support:**

- Facing Bereavement: This website was formed to offer a unique reference point on facing and dealing with bereavement. It has up to date articles and newsletters written by professional journalists and experts.  
[www.facingbereavement.co.uk/aboutoursite.html](http://www.facingbereavement.co.uk/aboutoursite.html)
- Growth House, Inc.: This site contains a large search engine that covers information on palliative care, including death and grief. It also offer tips on finding a support group, funeral planning and a chat room with drop-in conversations and scheduled programs.  
[www.growthhouse.org/death.html](http://www.growthhouse.org/death.html)
- Hospice Net: Offers information on grief, saying goodbye, pain relief and many other topics dealing with death. On the site, readers may also locate the nearest hospice center.  
[www.hospicenet.org](http://www.hospicenet.org)
- Kidsaid: This site provides a safe place for kids to share and help each other cope with grief.  
<http://kidsaid.com>

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- M.I.S.S.- ( Mothers in Sympathy and Support): This site has inspirational poetry, articles and information for professionals. It also offers families a way to communicate their story and share with others who are also suffering through grief.

[www.misschildren.org](http://www.misschildren.org)

- The Compassionate Friends: This organization offers brochures, conferences, sibling chats, cyberfriends and pen pals to people suffering the loss of a child.

[www.compassionatefriends.org](http://www.compassionatefriends.org)

## **Index of KRM's Newsletters:**

[Archive of Past Newsletters](#)

## **Helpful Books, Articles, and Videos:**

### **SIBLING RESOURCES:**

- Drums, Girls, & Dangerous Pie
- Hi! My Name is Jack
- Life Isn't Always a Day at the Beach
- A Day with Dr. Waddle
- What is Cancer, Anyway? Explaining Cancer to Children of All Ages
- Chemo Crusader and the Cancer Fighting Crew
- Kathy's Hats; A Story of Hope
- Little Tree; A Story for Children with Serious Medical Problems
- Little Tree; A story for Children with Serious Medical Problems
- Kids Tell Kids What It's Like to Have a Brother/Sister with Cancer

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## GENERAL RESOURCES:

- Sammie's New Mask: A Coloring Book for Friends of Children with Cancer
- Friend-O-Meter Ruler
- The Mountain You Have Climbed: A Teen's Guide to Childhood Cancer Survivorship
- The Mountain You Have Climbed: A Parent's Guide to Childhood Cancer Survivorship
- Patient & Family Newsletter
- The Beyond the Cure Cancer Survivor Treatment Summary
- Voice of Hope Newsletter
- Help, Hope, Believe N.C.C.S. Informational Brochure

## **Medical Resources:**

- American Academy of Pain Management: Discusses the Patient's Bill of Rights and has information on locating a pain clinic.  
[www.aapainmanage.org](http://www.aapainmanage.org)
- American Brain Tumor Association: The site offers a primer on brain tumors, as well as a guide to clinical trials.  
[www.abta.org](http://www.abta.org)
- American Cancer Society: The site offers a tool to assist in deciding treatment options and questions to ask your doctor. It also contains descriptions and guides for the main forms of cancer treatment. This is a bilingual Web site.  
[www.cancer.org/docroot/home/index.asp](http://www.cancer.org/docroot/home/index.asp)

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- American Medical Association: The Web site has a search tool for registered doctors by name and by specialty. You can also access abstracts of JAMA journal articles.  
[www.ama-assn.org](http://www.ama-assn.org)
- American Society of Clinical Oncology: The site offers an explanation of clinical trials, as well as a guide for finding an oncologist. It also contains information on all types of cancer, resources and coping strategies.  
[www.asco.org/portal/site/ASCOv2](http://www.asco.org/portal/site/ASCOv2)
- Bonetumor.org: This Web site is geared towards the medical community with information on bone tumors. In English and Italian.  
[www.bonetumor.com](http://www.bonetumor.com)
- Cancer Consultants: This site offers the most up to date news clippings on cancer treatments.  
<http://patient.cancerconsultants.com>
- Cancer News: This site offers all of the latest news on cancer and cancer treatments through news articles.  
[www.cancernews.com/default2.asp](http://www.cancernews.com/default2.asp)
- CenterWatch Clinical Trials Listing Service: This Web site answers questions about clinical trials currently being conducted at major medical centers.  
[www.centerwatch.com](http://www.centerwatch.com)
- Chemo Care: Scott Hamilton's chemotherapy site offers chemo information for cancer patients and their families, caregivers and friends. Outlines all you should know about chemotherapy and cancer treatment.

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[www.chemocare.com](http://www.chemocare.com)

- Chemotherapy.com: This website provides chemotherapy treatment information for patients and caregivers. It includes helpful information on types of chemotherapy, resources, and questions to ask your doctor, and insurance and tax tips.

[www.chemotherapy.com](http://www.chemotherapy.com)

- Children's Cancer Fund: This Web site reviews some of the current research being done on childhood cancer.

[www.childrenscancerfund.org/new/index.asp](http://www.childrenscancerfund.org/new/index.asp)

- Children's Oncology Group: A National Cancer Institute-supported clinical trial cooperative devoted exclusively to childhood and adolescent cancer research. Members are listed on the Web site.

[www.childrensoncologygroup.org](http://www.childrensoncologygroup.org)

- Columbia University Integrative Therapies Program: This Web site offers information regarding an integrative therapies program for children with cancer as well as summaries of the most current scientific literature. On this site you can also find detailed information about the various CAM clinical services offered, as well as sources of cancer education and news.

<http://integrativetherapies.columbia.edu>

- Cure Lymphoma Foundation: The site offers information specifically on lymphoma including clinical trials.

[www.lymphoma.org/site/pp.asp?c=chKOI6PEImE&b=1573289](http://www.lymphoma.org/site/pp.asp?c=chKOI6PEImE&b=1573289)

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- EPA Office of Children's Health Protection: Offers statistics on childhood cancer, plus environmental concerns.

<http://yosemite.epa.gov/ochp/ochpweb.nsf/content/whatwe.htm>

- Eye Cancer Network: An educational Web site that covers diagnosis and treatment of ocular tumors, eye cancer and orbital disease for patients and their families.

[www.eyecancer.com](http://www.eyecancer.com)

- IntelliHealth: Offers easy to understand descriptions of all types of childhood cancer along with information on symptoms, prognosis, treatment and nutrition information.

[www.intelihealth.com/IH/ihtIH/WSIHW000/408/408.html](http://www.intelihealth.com/IH/ihtIH/WSIHW000/408/408.html)

- Leukemia and Lymphoma Society of America: The site offers disease and treatment information for leukemia and lymphoma patients and their families. On-site questions and answers.

[www.leukemia.org/hm\\_lls](http://www.leukemia.org/hm_lls)

- Medical Matrix: This is a free directory of medical sites reviewed by professionals. Users must join in order to access the information.

[www.medmatrix.org/reg/login.asp](http://www.medmatrix.org/reg/login.asp)

- Medicine Net: This site offers descriptions of diseases, treatments and side effects.

[www.medicinenet.com/script/main/hp.asp](http://www.medicinenet.com/script/main/hp.asp)

- MedLine Plus: This user-friendly Web site provides information and links about cancer diagnoses, pharmaceutical information and also abstracts and journal articles. It is updated frequently and has some sources in Spanish.

<http://medlineplus.gov/>

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- National Brain Tumor Foundation: The site offers support and education for brain tumor patients and their families and allows users to e-mail questions to a nurse specializing in brain tumors.

[www.braintumor.org/GeneralMenu/](http://www.braintumor.org/GeneralMenu/)

- National Cancer Institute: This section details information on cancer clusters and who to contact if you think you may be living in one.

[www.cancer.gov/cancertopics/factsheet/Risk/clusters](http://www.cancer.gov/cancertopics/factsheet/Risk/clusters)

- National Coalition for Cancer Survivorship: This site has an excellent step-by-step guide on researching specific diagnoses.

[www.canceradvocacy.org](http://www.canceradvocacy.org)

- National Foundation for the Treatment of Pain: This site offers up to date legislative work on pain control and a library of pain related information. You can send pain related questions to the site, as well as financial questions about treatment.

[www.paincare.org](http://www.paincare.org)

- Oncology Inc: Through registration you can find a clinical trial that matches your needs. The database of trials is not complete.

[www.synovate.com/healthcare/expertise/gom.jsp?item=mcs](http://www.synovate.com/healthcare/expertise/gom.jsp?item=mcs)

- Pain Foundation: Offers ideas on advocating for yourself with your doctor as well as pain management ideas.

[www.painfoundation.org](http://www.painfoundation.org)

- ScienceKomm's MedBioWorld: This is one of the largest sites for Medical journals online.

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[www.medbioworld.com](http://www.medbioworld.com)

- Steve Dunn's Cancer Guide: Offers guidelines on doing your own research, tips for clinical trials and details on specific types of cancer.

[www.cancerguide.org](http://www.cancerguide.org)

- The Childhood Brain Tumor Foundation: Offers an updated selection of articles relating to brain tumors and treatment.

[www.childhoodbraintumor.org](http://www.childhoodbraintumor.org)

- The Sun Protection Shop: This site has photographs of melanoma and describes warning signs of skin cancer.

[www.sunprotection.com.au/](http://www.sunprotection.com.au/)

- U.S. Food and Drug Administration MedWatch: This site is a medical products reporting site. It has the latest on approvals and concerns.

[www.fda.gov/medwatch/index.html](http://www.fda.gov/medwatch/index.html)

- University of Pennsylvania Cancer Center: This site offers thorough diagnosis definitions and treatment information. Also offers symptom management ideas.

[www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)

## **Nutrition Resources:**

- American Institute for Cancer Research: The site offers information on nutrition including recipes for cancer patients.

[www.aicr.org/site/PageServer](http://www.aicr.org/site/PageServer)

- Arbor Nutrition Guide: This is a comprehensive nutrition site with links to many nutrition websites.

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[www.arborcom.com](http://www.arborcom.com)

- Cancer Nutrition Center: This site offers basic nutrition information.

[www.cancernutrition.com](http://www.cancernutrition.com)

- IntelliHealth: This excellent website offers a range of information with complex to simple answers to nutritional needs questions. Readers can also email questions to "Ask the Expert".

[www.intelihealth.com/IH/ihtIH/WSIHW000/408/408.html](http://www.intelihealth.com/IH/ihtIH/WSIHW000/408/408.html)

- Oncolink: This web site contains simple tips for cancer patients as well as scholarly articles. It contains information on nutrition and cancer prevention and nutrition during cancer treatment.

[www.oncolink.upenn.edu](http://www.oncolink.upenn.edu)

## **Scholarships:**

- UC Davis Cancer Center Healing and Performing Arts Program Courses (916) 734-0823
- Children's Cancer Community

[www.hopeforcancerkids.org/Hope\\_for\\_Cancer\\_Kids\\_by\\_the\\_Childrens\\_Cancer\\_Community/Memorial\\_Scholarship.html](http://www.hopeforcancerkids.org/Hope_for_Cancer_Kids_by_the_Childrens_Cancer_Community/Memorial_Scholarship.html)

- National Children's Cancer Society

[www.children-cancer.org/NetCommunity/Page.aspx?pid=489](http://www.children-cancer.org/NetCommunity/Page.aspx?pid=489)

- Beyond The Cure Scholarship

[www.beyondthecure.org/about/scholarship-story.html](http://www.beyondthecure.org/about/scholarship-story.html)

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- American Cancer Society; 800-227-2345

College scholarships to survivors in various states.

[www.cancer.org/docroot/NWS/content/NWS\\_5\\_1x\\_College\\_Scholarships\\_for\\_Cancer\\_Survivors.asp](http://www.cancer.org/docroot/NWS/content/NWS_5_1x_College_Scholarships_for_Cancer_Survivors.asp)

- Andre Sobel River of Life Foundation; 310-276-7111

An award of \$5,000 and honorable mentions of \$1,000 are given to United States citizens who are survivors and under the age of 21. This is an essay competition.

[www.andreriveroflife.org/rules.htm](http://www.andreriveroflife.org/rules.htm)

- Brain Tumor Foundation for Children, Inc.; 404-252-4107

Financial assistance and scholarships for survivors of pediatric brain tumor or spinal cord tumors. Applicants must be Georgia residents.

[www.braintumorkids.org](http://www.braintumorkids.org)

- Cancer Federation, Inc.; 951-849-4325

[info@cancerfed.org](mailto:info@cancerfed.org)

P.O. Box 1298

Banning, CA 92220

Scholarships are for biology majors interested in research. The scholarships are to various colleges and universities.

- Cancer Survivors' Fund; 281-437-7142

The mission of the organization is to provide scholarships and assistance for medical expenses to those diagnosed with cancer, receiving treatment for cancer or in remission,

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to give them a new purpose and meaning in life. The application and criteria are both online.

[www.cancersurvivorsfund.org](http://www.cancersurvivorsfund.org)

- Carti (Dennis J. Jungmeyer Scholarship); 800-482-8561, Ext. 616

Scholarship is limited to people treated at the Central Arkansas Radiation Institute.

[www.carti.com](http://www.carti.com)

- Carolyn's Compassionate Children; E-mail: [childrecc@aol.com](mailto:childrecc@aol.com)

Carolyn Rubenstein, 22-year-old Duke University graduate, founded this nonprofit in 1999. This is the fifth year of the scholarship program for childhood cancer survivors. A college-scholarship committee selects recipients based on personal character, financial need, successful completion of high school and community service. Awards are \$1,000 to be used for college education.

[www.ccscholarships.org](http://www.ccscholarships.org)

- Financial Aid Information Page

This is a comprehensive guide to getting scholarship information but is not exclusive to cancer patients. It offers you a free search as well as basic financial information.

[www.finaid.org](http://www.finaid.org)

- Hawaii Children's Cancer Foundation; 808-528-5161

The scholarship is for young adult survivors of childhood cancer who were treated in the state of Hawaii.

[www.hccf.org](http://www.hccf.org)

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- Jay's World Childhood Cancer Foundation Inc; 516-889-0583

The scholarship is awarded to a person who has been cured of cancer, in remission or able to attend college while in treatment and must be a resident of New York.

[www.jaysworld.org/html/scholarship.cfm](http://www.jaysworld.org/html/scholarship.cfm)

- Jeff Apodaca Celebration of Life Scholarship; 505-272-1333

Awarded to pediatric cancer survivors who were treated at one of the University of New Mexico Hospitals and who are attending a New Mexico college or university.

[www.jeffapodaca.com/scholarship.html](http://www.jeffapodaca.com/scholarship.html)

- Jonathan Jackson Cancer Survivors Scholarship; 888-375-8117

Awarded to cancer survivors and current cancer patients from North Carolina by the Mount Airy Community Foundation.

- Michael A. Hunter Memorial Scholarship

Two \$5,000 scholarships are awarded to leukemia patients or children of a non-surviving leukemia patient.

[www.oc-cf.org/NetCommunity/Page.aspx?pid=310&srcid=289](http://www.oc-cf.org/NetCommunity/Page.aspx?pid=310&srcid=289)

- National Collegiate Cancer Foundation; 717-215-0943

One-thousand-dollar competitive awards are given based upon four criteria: financial need; quality of essay and recommendations; displaying a 'will-win' attitude; and overall story of cancer survivorship.

[www.collegiatecancer.org/content/view/18/58/](http://www.collegiatecancer.org/content/view/18/58/)

- Pacific West Cancer Fund

320 Andover Park East, Suite 275

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Seattle, WA 98188

Stephanie Cunningham, Donald Traver (fund administer)

The fund has no Web site, but the financial-aid office at any college or university should be able to provide information on this scholarship.

- Patient Advocate Foundation; 800-532-5274

This site has criteria and a downloadable application for a \$5000 annual scholarship for cancer survivors.

[www.patientadvocate.org/index.php?p=69](http://www.patientadvocate.org/index.php?p=69)

- Pediatric Brain Tumor Foundation

The foundation offers scholarships for brain tumor survivors.

[www.pbtfus.org/survivors/education/scholarships/](http://www.pbtfus.org/survivors/education/scholarships/)

- SCAPON Childhood Cancer Survivor Educational Scholarship; 909-558-8400

Recipient must be diagnosed with cancer before age 21 and a resident of Southern California. The award is given through the Southern California chapter of the Association of Pediatric Oncology Nurses (SCAPON).

[www.scaphon.org/scholarshipinfo.htm](http://www.scaphon.org/scholarshipinfo.htm)

- Scholarship Resource Network

Offers a free search for scholarships with a database of more than 8,000 programs.

[www.curesearch.org/resources/resource.aspx?ResourceID=374](http://www.curesearch.org/resources/resource.aspx?ResourceID=374)

- Special Love, Inc; 540-667-3774

Recipients must be past and/or current recipients of programs sponsored by Special Love, Inc. in the Mid-Atlantic region.

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[www.speciallove.org](http://www.speciallove.org)

- Stephen T. Marchello Scholarship Foundation; 303-886-5018

Awards up to 2500 in scholarships to one or more survivors of childhood cancer. The application can be found online.

[www.stmfoundation.org/scholarships.html](http://www.stmfoundation.org/scholarships.html)

- SuperSibs!;866-444-7427

This site has criteria and application for two \$5000 scholarships to be given to siblings of childhood cancer survivors.

[www.supersibs.org/programs-and-services/scholarship-program-main.html](http://www.supersibs.org/programs-and-services/scholarship-program-main.html)

- The Ashley Foundation, Inc.; 301-694-6414

The criteria and application are available at this site. The scholarship is for Maryland residents.

[www.theashleyfoundation.org/scholarship.html](http://www.theashleyfoundation.org/scholarship.html)

- The Ryan Mullaly Second Chance Fund; 609-737-1800

Candidates must be United States citizens who were diagnosed with cancer between the ages of 13 and 20.

[www.ryans2dchancefund.org](http://www.ryans2dchancefund.org)

- The SAMFund

On-line inquiry about grants and scholarships. The SAMFund assist young adults transitioning into the adult world by providing financial assistance.

[www.thesamfund.org/grants-scholarships.html](http://www.thesamfund.org/grants-scholarships.html)

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- The Susan Fund, Inc; 203-226-4145

Scholarships for Fairfield County, CT residents who have been diagnosed with cancer.

[www.thesusanfund.org](http://www.thesusanfund.org)

- The Ulman Fund For Young Adults; 888-393-3865

This site offers scholarship information specific to cancer survivors.

[www.ulmanfund.org](http://www.ulmanfund.org)

- Tim & Tom Gullikson Foundation; 1-888-GULLIKSON

Scholarships for brain tumor patients/survivors and/or children of brain tumor patients/survivors.

[www.gullikson.org](http://www.gullikson.org)

- Young Cancer Survivor Scholarship Program; 800-877-1710, Ext. 221

Sponsored by the American Cancer Society. The information and application for the renewable \$1000 scholarship for Michigan and Indiana residents is on the ACS Web site.

[www.cancer.org/docroot/COM/content/div\\_CA/COM\\_11\\_2x\\_Young\\_Cancer\\_Survivor\\_Scholarship\\_Program\\_2007-2008.asp?sitearea=COM](http://www.cancer.org/docroot/COM/content/div_CA/COM_11_2x_Young_Cancer_Survivor_Scholarship_Program_2007-2008.asp?sitearea=COM)

- Jay's World Childhood Cancer Foundation Inc.

The site offers one of the first scholarships to children who have been diagnosed with cancer. The application is online.

[www.jaysworld.org](http://www.jaysworld.org)

**Support, Advocacy, & Important Resources:**

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- American Cancer Society

The site provides a resource search engine based on your zip code.

[www.cancer.org/docroot/home/index.asp](http://www.cancer.org/docroot/home/index.asp)

- Association of Cancer Online Resources

This Web site offers access to mailing lists and unique Web sites. It offers support groups in Spanish and English.

[www.acor.org](http://www.acor.org)

- Brandon's Foundation, Inc.

Assists in fund-raising to support cancer research and aids families that have had to relocate out of state for outpatient treatment for their child.

[www.geocities.com/mbyccf/home.htm](http://www.geocities.com/mbyccf/home.htm)

- Cancer Fund of America

A nonprofit organization that offers medical supplies nationally. The Web site lists available supplies.

[www.cfoa.org](http://www.cfoa.org)

- Cancer Hope Network

Offers one-on-one support for cancer patients by attempting to link them with a volunteer with a similar diagnosis.

[www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

- Chai Lifeline

Offers support services, school and community education, counseling, recreation

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programs, and bereavement services. This site is especially for Jewish children and their families.

[www.chailifeline.org](http://www.chailifeline.org)

- Children with Leukemia

This Web site offers information to parents on how to discuss a cancer diagnosis and the basics of treatment with others. It was designed by a parent who lost a daughter to leukemia.

[www.jlsfoundation.org/index.htm](http://www.jlsfoundation.org/index.htm)

- Children's Cancer Association

This site offers a comprehensive national directory of resources.

[www.childrenscancerassociation.org](http://www.childrenscancerassociation.org)

- Children's Brain Tumor Foundation

This Web site offers excellent tips and information to parents on topics such as supporting their child during a hospital stay, finding a second opinion, the treatment team and supporting your child after the operation.

[www.cfoa.org](http://www.cfoa.org)

- Cure for Lymphoma Foundation

Offers patient-to-patient support via telephone, e-mail or letters. It also has a \$500. grant for quality-of-life expenses not covered by insurance. The application is online.

[www.healthywomen.org/resources/healthservices/nationalorganizations/dbnationalorgs/cureforlymphomafoundation](http://www.healthywomen.org/resources/healthservices/nationalorganizations/dbnationalorgs/cureforlymphomafoundation)

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- Joe's House

Cancer patients and their advocates are provided a national online directory of lodging accommodations near their hospital.

[www.joeshouse.org](http://www.joeshouse.org)

- Leukemia and Lymphoma Society of America

This site offers back-to-school information, locations of support groups and a resource center.

[www.leukemia.org/hm\\_lls](http://www.leukemia.org/hm_lls)

- MyLion.org

This Web site offers helpful information on pediatric cancer and service/learning projects designed to help kids battling cancer and their families.

[www.mylion.org](http://www.mylion.org)

- National Dissemination Center for Children with Disabilities; 800-695-0285

Contains information on each states vocational and educational programs as well as federal government contact information.

[www.nichcy.org/Pages/Home.aspx](http://www.nichcy.org/Pages/Home.aspx)

- National Cancer Survivors Day Foundation

National Cancer Survivors Day is the world's largest cancer-survivor event. It's celebrated on the first Sunday of June. Information about the event, as well as a free celebration-planning kit, is available from the Foundation.

[www.ncsdf.org](http://www.ncsdf.org)

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- National Respite Locator Service

Lists respite services for every state, including contact numbers.

<http://chtop.org/ARCH/National-Respite-Locator.html>

- R.A. Bloch Cancer Foundation

This organization links people who have the same cancer diagnosis. The Web site also has helpful information on getting a second opinion.

[www.blochcancer.org](http://www.blochcancer.org)

- Ronald McDonald House Charities

This site has guidelines and Ronald McDonald House locations across the country.

<http://rmhc.org>

- Stand Up To Cancer

Stand Up To Cancer is a charitable services fund of the Entertainment Industry Foundation that is raising awareness in the battle against cancer and raising money for research to find a cure for cancer. This site provides lengthy resource lists for cancer advocacy, support, and cancer centers as well as governmental and research organizations.

[www.standup2cancer.org](http://www.standup2cancer.org)

- The Never-Ending Squirrel Tale

Offers suggestions to parents on everything from diet choices to how to decorate the hospital room. It also has a chat room for families.

[www.squirreltales.com](http://www.squirreltales.com)

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- The International Cancer Alliance for Research and Education (ICARE)

This nonprofit organization provides user-friendly cancer information to each patient (and to their physicians) on an on-going, person-to-person basis. It has several online-support groups.

[www.icare.org](http://www.icare.org)

- The Kelly Davidson Pediatric Cancer Foundation

The organization provides a "care kit" of educational materials specific to the 11 types of pediatric cancer.

<http://kellysteam.googlepages.com>

- The Ulman Cancer Fund for Young Adults

This site offers education, support, resources and prevention tips to young adults affected by cancer.

[www.ulmanfund.org/Default.aspx](http://www.ulmanfund.org/Default.aspx)

- The Wellness Community

Provides free services, including professionally led support groups, educational workshops, stress-management and mind/body classes, nationwide in a homelike, community setting.

[www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)

- University of Pennsylvania Cancer Center

Offers questions and answers on various topics, including sexuality, fertility, psychosocial issues and coping.

[www.oncolink.com](http://www.oncolink.com)

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- Candlelighters

Provides information and awareness for children and adolescents with cancer and their families, to advocate for their needs, and to support research so every child survives and leads a long and healthy life. They are the largest publisher and distributor of free childhood cancer books in the country.

[www.candlelighters.org](http://www.candlelighters.org)

- CureSearch

CureSearch National Childhood Cancer Foundation is dedicated to raising private funds for childhood cancer research for the Children's Oncology Group, the world's largest cooperative cancer research organization.

[www.curesearch.org/resources](http://www.curesearch.org/resources)

- Childhood Cancer Guides

<http://childhoodcancerguides.org>

- American Cancer Society-American Cancer Society Summer Camps

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.

[www.cancer.org](http://www.cancer.org) (800) ACS-2345

- American Society of Pediatric Hematology/Oncology; (847) 375-4716

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ASPHO is a multidisciplinary organization dedicated to promoting optimal care of children and adolescents with blood disorders and cancer by advancing research, education, treatment and professional practice.

[www.aspho.org](http://www.aspho.org)

- Beads of Courage; 520.331.1984

Beads of Courage is a resilience-based intervention designed to support and strengthen the protective resources in children coping with serious illness. Through the program children tell their story using colorful beads as meaningful symbols of courage that commemorate milestones they have achieved along their unique treatment path.

[www.beadsofcourage.org](http://www.beadsofcourage.org)

- Webbugs

This site is for children, parents, siblings and friends. It discusses everything from school reentry to late effects of treatment to stories from patients and their families.

<http://webbugs.wustl.edu>

- Cancer Care; (800) 813-HOPE

CancerCare is a national nonprofit organization that provides free, professional support services for anyone affected by cancer.

[www.cancercare.org](http://www.cancercare.org)

- Parents Against Cancer, Inc.; (562) 943-5626

This web site to keep you in touch with things happening both in the hospital and in the outpatient setting. It is also a channel to find out about many of the events and people that you care about. PAC has available the L.I.S.A. fund to provide *emergency* assistance to

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families. Provides funds for such things as busses to camp, refreshments at functions, etc. Maintains a resource library on the hospital floor with pertinent information for our families and much more.

[www.parentsagainstcancer.com](http://www.parentsagainstcancer.com)

- Children's Cancer Community: provides support groups, cancer survival kits, scholarships, a cancer library, family assistance, special events and activities for families.

[www.hopeforcancerkids.org](http://www.hopeforcancerkids.org)

## **Survivorship:**

- Beyond the Cure

The N.C.C.S.-sponsored Web site contains information regarding all aspects of cancer survivorship. It also allows the survivor or family member to create a personalized risk assessment specific to diagnosis and treatment.

[www.beyondthecure.org](http://www.beyondthecure.org)

- Cancer Survivors Network

After joining, members may participate in public and private chat with other cancer survivors.

<http://csn.cancer.org/>

- Cancer Survivors Online

Offers ideas on dealing with the medical community and treatment, subscription to an e-mail list of services and support through sharing stories online.

[www.cancersurvivors.org](http://www.cancersurvivors.org)

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- Cancer-Survivors IRC Chat Channel

An online chat room for cancer survivors. The site posts survivors' biographies set to the audio background of "I Will Survive."

<http://aoma.com/cs/>

- Cancervive

This web site is maintained by a childhood cancer survivor. It contains educational material for survivors.

[www.cancervive.org](http://www.cancervive.org)

- Dana Farber Cancer Institute

This Web site discusses current survivorship research being done at Dana Farber, as well as discusses cancer prevention and risk factors.

[www.dana-farber.org/pat/surviving/childhood/default.html](http://www.dana-farber.org/pat/surviving/childhood/default.html)

- FertileHope

This organization meets the profound needs of patients whose medical treatments present the risk of infertility. The site explains what treatments may affect fertility, as well as preventative steps to take prior to treatment.

[www.fertilehope.org](http://www.fertilehope.org)

- The George Washington University Heath Resource Center

A national clearinghouse for post-secondary education options and outcomes for individuals with intellectual disabilities.

[www.heath.gwu.edu](http://www.heath.gwu.edu)

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- National Cancer Survivors Day (NCSD)  
(The NCSD Foundation's National Cancer Survivors Day is the world's largest cancer-survivor event. It is celebrated on the first Sunday of June. Information about the event, as well as a free celebration-planning kit, is available from the Foundation.  
[www.ncsdf.org](http://www.ncsdf.org)
- National Coalition for Cancer Survivorship  
Lists the national programs related to cancer survivors. The web site is in Spanish and English.  
[www.canceradvocacy.org](http://www.canceradvocacy.org)
- Outlook - Life Beyond Childhood Cancer  
Offers current survivorship information and hot survivorship topics. It has valuable information on topics like insurance and fertility and links to personal Web pages of survivors.  
[www.outlook-life.org/index.pl](http://www.outlook-life.org/index.pl)
- The Brain Tumor Society  
Stories of long-term survivors of childhood brain tumors.  
[www.tbts.org/GeneralMenu/](http://www.tbts.org/GeneralMenu/)
- The Children's Cause  
This site offers updates on national policies that affect research, healthcare and services for pediatric-cancer survivors.  
[www.childrenscause.org](http://www.childrenscause.org)

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- [Wrightslaw](#)

Updated and accurate information on special education laws.

[www.wrightslaw.com](http://www.wrightslaw.com)

## **Transplant:**

- A Parent's Guide to Cord Blood Banks

An excellent guide to public and private cord blood banks.

<http://parentsguidecordblood.org>

- American Cord Blood Program

This site gives basic information about cord blood transplants and how to be a cord blood donor.

<http://acb.tacticom.com/home.html>

- Blood & Marrow Transplant Information Network

This site has an excellent drug database where you can get detailed descriptions of drugs and their side effects. You can also search for transplant centers by disease or type of marrow transplant needed.

[www.bmtinfonet.org](http://www.bmtinfonet.org)

- BMT Support Online

This is an online-support organization with a chat room for people with an interest in bone-marrow transplantation.

[www.bmtsupport.org](http://www.bmtsupport.org)

- Children's Cancer Web

Offers basic information on various types of transplants, as well as links to several bone-

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marrow registries.

[www.cancerindex.org/ccw/](http://www.cancerindex.org/ccw/)

- Children's Organ Transplant Association

Offers fund-raising guidance to families who need to raise money for transplants. It has some emergency funds available.

[www.cota.org](http://www.cota.org)

- Cord Blood Donor Foundation

This site offers valuable information on how to find a private cord blood bank where you can store cord blood for family members, as well as basic cord blood-transplant information.

[www.cordblooddonor.org](http://www.cordblooddonor.org)

- Cord Blood Guide

This Web site offers cutting- edge information on the science of stem cell research.

[www.storkin.com/2006/12/cord-blood-guide.php](http://www.storkin.com/2006/12/cord-blood-guide.php)

- My Friends Care Bone Marrow Transplant Fund

The organization provides assistance for individuals who are fund-raising for medical and non-medical expenses associated with bone-marrow transplants.

[www.myfriendscare.org](http://www.myfriendscare.org)

- National Cancer Institute

Offers very detailed information regarding transplant and possible side effects.

[www.cancer.gov](http://www.cancer.gov)

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- National Foundation for Transplants

This organization assists families with fund-raising for the cost of transplants not covered by insurance and has links to most major transplant centers in the United States.

[www.transplants.org](http://www.transplants.org)

- National Marrow Donor Program

This site answers basic questions on bone marrow transplant and donation. It is an international bone marrow registry.

[www.marrow.org](http://www.marrow.org)

- National Transplant Assistance Fund

This organization aids in raising money for transplants and related expenses.

[www.transplantfund.org](http://www.transplantfund.org)

- The Bone Marrow Foundation

This nonprofit organization offers financial support to families experiencing bone-marrow transplantation at one of its affiliated hospitals. The site provides basic information about bone-marrow transplants.

[www.bonemarrow.org](http://www.bonemarrow.org)

## **Wish Foundations:**

- Children's Hopes & Dreams Foundation

The site does not accept referrals, but the organization grants wishes for seriously ill patients and also matches pen pals.

[www.helpingnow.org/kidskare.html](http://www.helpingnow.org/kidskare.html)

- Catch-A-Dream; (662) 325-8149

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You can refer a child on their website. Catch-A-Dream grants once-in-a-lifetime outdoor experiences to children 18 years old or younger who have a life-threatening illness.

<http://catchadream.org/index.html>

- Imus Ranch/Imus Ranch Foods; 505-421-4687

This is an authentic working cattle ranch in New Mexico where children with cancer can come for a free cowboy experience. All proceeds from the sales of Imus Ranch foods go to support the charitable work.

[www.imusranchfoods.com](http://www.imusranchfoods.com)

- Make-A-Wish Foundation

This site offers information in Spanish and English. Wish referrals can be made online.

[www.wish.org/?sourceID=05GOMAD1124](http://www.wish.org/?sourceID=05GOMAD1124)

- Starlight Foundation

This is a wish-granting foundation that also provides media entertainment in certain hospitals.

[www.starlight.org.uk/](http://www.starlight.org.uk/)

- Sunshine Foundation

Grants wishes to children suffering from terminal or chronic illnesses throughout the country and the world.

[www.sunshinefoundation.org](http://www.sunshinefoundation.org)

- The Silver Lining Foundation

This is a link to Andrea Jaeger's foundation, which provides a weeklong camp in the

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mountains for children with cancer.

[www.silverliningfoundation.org](http://www.silverliningfoundation.org)

- Wishing Well Foundation USA

Grants wishes to terminally ill children between ages 3 to 18. Online application.

[www.wishingwellusa.org/HOME.asp](http://www.wishingwellusa.org/HOME.asp)

## Glossary of Cancer Medical Terms

***Abscess***—An abscess is an area in the body's tissue that is filled with infection and surrounded by inflammation.

***Absolute neutrophil count (ANC)***—ANC refers to the percentage of the total white blood cell count that is made up of cells called neutrophils. Neutrophils are particularly important because they defend our bodies against infection.

***Acute lymphocytic leukemia (ALL)***—ALL is a disease in which large numbers of malfunctioning lymphocytic (infection-fighting) blood cells are made by the body. It is most often diagnosed in children. Signs of the disease include fever, pale skin, loss of appetite, fatigue, bone pain, and recurrent infection.

***Acute myelogenous leukemia (AML)***—AML is a disease in which the bone marrow produces white blood cells that cannot carry out normal function. Signs of the disease include bleeding gums, anemia, fatigue, fever, bone pain, and repeated infections.

***Adenocarcinoma***—Adenocarcinoma is a cancer that develops in the glandular tissue of the body.

***Adjuvant chemotherapy***—Adjuvant chemotherapy is chemotherapy given after surgery, when there is no visible cancer but there is a risk that there are still cancer cells left in the body.

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***Allogeneic bone marrow transplant***—An infusion of bone marrow or stem cells from a donor.

***Alopecia***—Alopecia is hair loss. Chemotherapy and sometimes radiation may make patients lose some or all of their hair during treatments. The most common area involved is the head, although other body hair can also be affected.

***Analgesic***—A medication that relieves pain.

***Anastomosis***—A surgical joining of two body structures (e.g. blood vessels or intestines), which allows flow from one to another.

***Anemia***—Anemia is a lower-than-normal number of red cells in the blood. Red blood cells are important because they carry oxygen from the lungs to all other cells in the body. Shortness of breath, fatigue, and weakness are signs of anemia.

***Antibiotic***—An antibiotic is a medication used to fight germs or bacteria that cause infection. Chemotherapy can make patients more at risk for infection. Antibiotics are given to treat an infection.

***Antiemetic***—An antiemetic is a medication used to stop or help prevent nausea and vomiting, common side effects of some chemotherapy.

***Autologous bone marrow transplant***—During an autologous bone marrow transplant, patients' own bone marrow or stem cells are given to them after they have received high-dose chemotherapy.

***Axilla***—The axilla is the area under the arm or the armpit.

***Bilirubin***—A substance that is formed when red blood cells break down. It becomes part of bile, which is produced by the liver. A buildup of bilirubin can cause jaundice. Bilirubin levels are often tested to monitor liver or bile duct function.

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**Biological therapy**—A type of therapy that stimulates the immune system to help fight cancer. Biological therapy also may be used to lessen side effects of treatment. It may be referred to as *immunotherapy*.

**Biopsy**—Removal of cells from the body to see if they are cancerous. A doctor examines the cells under a microscope, comparing them to normal cells. Techniques to remove cells include:

- *Fine needle aspiration (FNA) biopsies* use a needle attached to a syringe to withdraw cells from a tumor. When a slightly larger needle is used, it is called a *needle core biopsy*. Sometimes doctors use an ultrasound or a computed axial tomography, or CT, scan to view the tumor and assist them with needle placement.
- During an *excisional biopsy*, a surgeon removes an entire tumor. During an *incisional biopsy*, only a small amount of tumor is removed. Both of these procedures involve a surgeon cutting through the skin. Sometimes the surgery requires general anesthesia, and sometimes it can be done by simply numbing the area to be cut (local anesthesia).

**Bone marrow aspiration**—Removal of cells from the bone marrow. The doctor usually takes the sample from the hip bone after numbing the area. In a *bone marrow aspiration*, the doctor uses a small needle attached to a syringe to remove a few cells. In a *bone marrow biopsy*, the doctor uses a larger needle to remove a small amount of bone and marrow. Patients usually feel some pressure during either procedure and sometimes feel uncomfortable. It is helpful to try to remain as relaxed as possible during the procedure.

**Bone scan**—Bone scans use nuclear medicine imaging to spot cancer in the bone. A radioactive substance is injected into a vein and is attracted to areas of cancer, and then the radioactivity is recorded by a special camera as a picture. There is a phenomenon called "normal physiological

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uptake," which may vary from individual to individual. Also, previous trauma or fractures can elicit a positive signal as well.

***Brachytherapy***—Brachytherapy is radiation treatment inside the body, placed as close to the cancer as possible.

***Bronchoscopy***—A bronchoscopy uses a bendable fiber-optic camera to view the throat and lungs. In most cases, the patient is sedated and a local anesthetic is sprayed or swabbed over the mouth, tongue, and throat. Biopsies and secretions are collected during the procedure. Your throat may be sore after the procedure.

***Carcinogen***—A carcinogen is anything that causes cancer. Carcinogens can be physical, chemical, or viral, but many are not known.

***Carcinoma in situ***—A cancer that has not spread to other parts of the body or invaded nearby tissue. Carcinoma in situ, an early form of cancer, is highly curable.

***Chemotherapy***—The use of drugs to destroy cancer cells. A person on chemotherapy may take one drug or a combination of drugs. Most often these drugs are given by vein using intravenous (IV) infusion. Some can be taken by mouth or given in a shot.

***Chronic lymphocytic leukemia (CLL)***—CLL is a disease that makes immature lymphocytic cells. Unlike in acute lymphocytic leukemia (ALL), these cells can carry out some of their normal functions. As a result, chronic leukemia gets worse gradually.

***Clinical trials***—Tests of new and promising ways to treat cancer. The goal of all clinical trials is to find better treatments to fight cancer. Clinical trials can test new surgical procedures, radiation therapies, and drugs.

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- *Phase 1 clinical trial*—The stage of drug development when the investigational product is first researched in humans and when drug safety is determined. Usually a small number of healthy volunteers, but occasionally patients, participate in these studies.
- *Phase 2 clinical trial*—The stage in which drug effectiveness is determined preliminarily in patients with the targeted medical condition. These studies are aimed at assessing short-term safety and therapeutic dose-range (minimum and maximum doses), and determining short-term side effects and risks associated with the investigational product. Usually a moderate number of patients (100-250) participate in these studies.
- *Phase 3 clinical trial*—The stage in which large-scale safety and effectiveness are ascertained in a larger number of patients who ultimately will receive the investigational product. These studies are aimed at demonstrating short- and long-term safety and efficacy, and assessing overall therapeutic value as well as determining the benefit/risk relationship of the investigational product.
- *Phase 4 clinical trial*—These studies are performed after the investigational product is approved for a medical condition by the Food and Drug Administration (FDA) to gather additional data about the product.
- *Protocol*—A set of strict rules or guidelines to follow during a clinical trial. These rules include the clinical trial start and finish dates, blood tests and x-rays required, and interviews and questionnaires to complete. A protocol has been called a "recipe" for how to conduct a clinical trial.

- *Study arm*—Study arms are the options for treatment in a clinical trial. For example, one arm of a study may be those patients who take the research drug, while another arm of the study may be those who take the standard-of-care drug. A study may have multiple arms.
- *Blind studies*—In a *single-blind* study, patients are assigned to a study group (either research drug, "standard-of-care" drug, or standard-of-care drug plus placebo) but do not know which group they are in. In a *double-blind* study, neither the patient nor the doctor knows which study group the patient is in. This reduces the effects of prejudgment by patients and doctors.

***Colony-stimulating factors***—Also called CSFs, colony-stimulating factors are drugs that promote the production of various blood cells. Examples of CSFs are [Neulasta® \(pegfilgrastim\)](#) and Aranesp® (darbepoetin alfa).

***Combination chemotherapy***—Using more than one anticancer medication together, with the goal of destroying more cancer cells.

***Complete blood count (CBC)***—The CBC is a test that determines the number of red blood cells, white blood cells, and platelets in the blood.

***Complete remission***—Complete remission, also known as a clinical complete remission, is when physician can no longer observe the tumor cells by simple examination, chest X-rays, and/or blood tests. This is opposed to a partial remission where some tumor cells are still detected by the tests.

***Computed axial tomography (CT/CAT)***—CT/CAT scans use x-rays to see the body in a three-dimensional way. Doctors use CT scanning to diagnose and stage cancer. Sometimes it is necessary to use a *contrast medium* for the images to show up on the computer. One type of

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contrast medium is injected into a vein and contains iodine. If you are allergic to iodine or shellfish (shellfish contain iodine), please let your technician know. Another type of contrast medium is used when the CT scan involves the gastrointestinal tract. Following the CT scan, you are encouraged to drink fluids to promote elimination of the dye.

***Constipation***—Constipation is difficulty passing stool. It can also refer to a decrease in the normal frequency of bowel movements. It may be accompanied by gas, pain, or pressure in the abdomen.

***Creatinine***—A compound excreted in the urine that is used to monitor kidney function. Creatinine levels are measured to determine if a patient has kidney problems or if a treatment is producing side effects related to the kidney.

***Cultures***—Laboratory tests that encourage the growth of microorganisms for the purpose of identifying and diagnosing an infection.

***Cycle***—Chemotherapy can be given in a variety of time arrangements, such as daily, weekly, or monthly. Chemotherapy is generally given in cycles. A cycle can last 1 or more days but usually lasts 3 or 4 weeks.

***Diagnosis***—Identification of a condition or disease based on the signs and symptoms, laboratory tests, procedures, history, and physical examination of the patient.

***Diarrhea***—Bowel movements that occur more frequently and are more liquid in consistency than normal. Chemotherapy, medication, radiation, and infection may cause diarrhea. Diarrhea can also be caused by medications given to prevent nausea or by antibiotics given to treat or prevent infection.

***Echocardiogram***—A graphic record of the heart that provides information about its position,

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internal parts such as valves, and the motion of the heart walls. The procedure ( *echocardiography* ) involves ultrasonic waves directed over the chest.

***Edema***—An abnormal buildup of fluid in body tissue.

***Electrocardiography (EKG)***—An EKG records the electrical activity of the heart. "Leads" (wires) are placed on the chest and the extremities.

***Endoscopy***—Endoscopy uses either a bendable or a rigid tube with a camera and a fiber-optic light on the end to view areas inside the body. Doctors use endoscopy to perform biopsies and staging. Many different organs can be viewed by endoscopy. Each procedure has its own name:

- Esophagus: esophagoscopy
- Stomach: gastroscopy
- Colon : colonoscopy or sigmoidoscopy
- Bladder: cystoscopy
- Trachea (windpipe), bronchi, and lungs: bronchoscopy
- Cervix and vagina: colposcopy
- Abdomen: laparoscopy
- Lung: thoracoscopy or mediastinoscopy

***Endoscopic ultrasound (EUS)***—EUS combines ultrasound and endoscopy so that doctors can see the amount of cancer in nearby tissues.

***Erythropoietin***—A naturally occurring substance that stimulates the bone marrow to make more red blood cells. Red blood cells carry oxygen and carbon dioxide through the bloodstream to and from all cells in the body.

***Fatigue***—Fatigue means feeling tired, weak, sleepy, forgetful, or worn out, and having no

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energy to go about your daily routine. Fatigue is commonly caused by cancer treatments, but can also result from the disease itself. Fatigue is also often present in patients with anemia.

**Food and Drug Administration (FDA)**—The FDA is the federal agency responsible for ensuring that all prescription drugs and medical equipment are safe and effective. The FDA checks on all clinical trials while they are in progress.

**Gene**—Cells contain genes, which are pieces of DNA that contain information for making proteins. Genes contain information on hereditary characteristics such as hair color, eye color, and height, as well as whether one is at higher risk for developing certain diseases.

**Grade**—Grade is the measurement of a cancer, reflecting how abnormal the cells look under a microscope. There are several grading systems for cancer, but all divide cancers into those with:

- Least abnormality (grade 1 or well differentiated)
- Intermediate features (grade 2 or moderately differentiated)
- Greatest abnormality (grade 3 or poorly differentiated)

A specialist called a *pathologist* performs the grading by examining the biopsy specimen.

Knowing the grade is important because higher-grade cancers tend to grow and spread more quickly and have a worse prognosis. A cancer's nuclear grade is based on features of the central part of its cells, the nucleus. The histologic grade is based on features of individual cells as well as how the cells are arranged together.

**Growth factors**—A substance that is normally produced in the body that is involved in cell division, maturation, or survival. Growth factors may also be produced in a laboratory to mimic the growth factors naturally produced by the body. These synthetic growth factors may be used as biologic therapy to stimulate the immune system to fight cancer or lessen side effects of

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treatment.

***Hematocrit (Hct)***—A blood test that measures the number of red blood cells in the bloodstream.

The lower the hematocrit, the lower the number of red blood cells in the blood. A person with a low hematocrit may have anemia.

***Hematology***—The study of the blood and disorders of the blood.

***Hemoglobin (Hb or Hgb)***—The part of the red blood cell that carries oxygen from the lungs to other organs in the body, such as the brain and the heart. A person with a low hemoglobin level may have anemia.

***HER-2/neu (human epidermal growth factor receptor 2)***—A protein that is involved in growth and replication of a cell. Some cancers have abnormal HER-2/neu proteins, which are believed to be involved in the unregulated multiplication of cancer cells.

***Histology***—The study or examination of tissues or cells under a microscope.

***Hormones***—Chemicals secreted by glands. Hormones circulate in the bloodstream and control certain cellular actions.

***Hospice***—An organization or agency that provides care for people with end-stage diseases, when no therapy can cure the cancer or put it into remission. Hospice services aim to provide comfort and support.

***Immune system***—The body's defense system against bacterial, viral, and fungal infections. The immune system includes white blood cells and protective barriers such as the skin and mucous membranes. The principal organs of the immune system are the bone marrow, spleen, and lymph system.

***Immunotherapy***—A type of therapy that stimulates the immune system to help fight cancer.

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Immunotherapy may also be used to lessen side effects of treatment. Immunotherapy is sometimes referred to as *biological therapy*.

***Infection***—An invasion of microorganisms that have the ability to multiply and produce disease.

***Inflammation***—The body's response to an infection, irritation, or injury.

***Informed consent***—A document that outlines an entire procedure or research study. It describes the procedure or study, including possible risks and benefits. Signing the informed consent means you understand and agree to the procedure or participation in the study.

***Infusion***—A process of delivering medications, fluids, or blood products into the body through the bloodstream. A needle is used to gain access through a vein, and a catheter with tubing is used to deliver the fluid.

***Institutional review board (IRB)***—An IRB is an outside panel of experts that checks and monitors any clinical trial research involving people. This committee represents the interests of the patients who participate in the clinical trial. The committee always includes people who are qualified to evaluate new and ongoing clinical trials on the basis of scientific, legal, and ethical merit. The federal regulations mandated by the Office of Human Research Protection require that an IRB includes at least five people from different backgrounds. Some committee members are doctors and scientists; others are nonmedical people like clergy and teachers. The most important functions of an IRB are to make sure that a clinical trial has scientific merit, minimizes patient risk, and ensures that the privacy of all participants is protected.

***Intravenous (IV)***—Inside the veins. An intravenous medication is delivered into the body through a vein.

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**Jaundice**—A yellowing of the skin caused by abnormal liver function.

**Lesion**—A wound, injury, or abnormal change in the body tissue such as a sore, rash, boil, or tumor.

**Liver function tests**—Tests that are performed to monitor the functioning of the liver. Levels of specific compounds that can be measured in the blood can help determine if a patient has a liver disorder and monitor side effects from treatment to the liver. Combinations of specific compounds (AST, ALT, albumin, etc.) are typically measured together to help provide a clearer indication of the disorder.

**Living will**—A living will is a legal document that describes a person's wishes or intentions regarding his or her medical care under certain conditions.

**Lumbar puncture**—Removal of a sample of the fluid that surrounds the spinal cord. Doctors numb the lower back area so patients do not feel pain. A thin needle attached to a syringe is inserted into the lower back. The fluid is removed and examined for cancer cells or for infection. Generally you will experience some pressure at the needle insertion site. It is best if you relax and lie still throughout the procedure and for a while afterward. To avoid a severe headache, you may be asked to lie flat on the exam table for a period of time following this procedure.

**Lymph nodes**—Lymph nodes are small, oval glands found throughout the body. They act as filters and fight infection. Cancer cells often spread to other parts of the body through the lymphatic system.

**Lymphedema**—A condition in which excess lymphatic fluid collects in tissues, causing swelling, numbing, pain, or a limited range of motion in extremities. This often occurs when many lymph nodes are removed for the treatment or staging of cancer, or lymph nodes are treated with

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radiation therapy. Lymphedema most often occurs in the arms if lymph nodes under the arm are removed or radiated, or in the legs if lymph nodes in the groin are removed or radiated.

***Malignant***—Malignant means that a tissue has cancer cells present; it also refers to a cancerous disease.

***Mastectomy***—Surgical removal of breast tissue. There are several different types of mastectomies: modified radical mastectomy, partial mastectomy, simple mastectomy, and prophylactic mastectomy.

***Melanoma***—A cancer that starts in the skin cells. Melanoma is more serious than other cancers of the skin because it spreads easily to other cells in the body. Symptoms include changes in size, shape, or color of a mole; bleeding from a mole; or a mole that feels itchy, hard, lumpy, swollen, or tender to the touch. Melanoma can also appear on the body as a new mole.

***Metastasis***—The spread of cancer from one part of the body to another.

***MRI***—Magnetic resonance imaging, or MRI, creates three-dimensional sectional images similar to CT scanning. An MRI differs from a CT scan in that it does not use ionizing radiation, but instead uses a powerful magnet to transmit radio waves through the body. Images then appear on a computer screen. Doctors use MRI to diagnose and stage cancer. A contrast medium may be used in MRI imaging to enhance the picture.

***Mucositis***—Inflammation of the lining of the gastrointestinal tract. *Oral mucositis* refers to inflammation of the lining of the mouth. Mucositis may involve sores, swelling, pain, and redness.

***MUGA scan***—A multigated acquisition scan, MUGA scan, is a procedure that allows a physician to examine the heart. Special pictures are taken of the heart following the introduction

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of a radioactive substance into a vein. Your doctor can then visualize the contraction and relaxation of the heart and blood supply to the heart.

***Myelosuppression***—Myelosuppression occurs when the bone marrow slows production of blood cells. This results in fewer red blood cells, white blood cells, or platelets available to perform their normal functions in the body. Chemotherapy can cause decreased bone marrow function. Most often, myelosuppression refers to the loss of white blood cells.

***Nadir***—Nadir is the lowest point to which blood counts drop after chemotherapy. When referring to the nadir, doctors are usually referring to the nadir of a patient's white blood cell count, which usually occurs about 7 to 10 days after receiving chemotherapy.

***Neoplasm***—An abnormal growth of tissues from a single cell. A neoplasm can be cancerous or noncancerous. Cancer is sometimes called a *malignant neoplasm*.

***Neutropenia***—Neutropenia occurs if there is a lower-than-normal number of neutrophils (infection-fighting white blood cells) in the blood. It is a common side effect of chemotherapy treatment. Neutrophils fight infection, so a person with a low neutrophil count will be more at risk for developing infection. Doctors check the number of neutrophils when they measure the white blood cell count; the result is often referred to as the ANC, or absolute neutrophil count.

***Neutrophil***—The most common type of white blood cell. Neutrophils help the body fight infection. Since the most common type of white blood cell is the neutrophil, a low white blood cell count usually indicates that the neutrophil count is low. It is easier to get an infection and harder to recover from an infection when the number of neutrophils in the bloodstream is low.

***Oncogene***—Oncogenes play a role in cell growth and are normally found in cells. When an oncogene is damaged, it causes cells to grow too quickly and form tumors.

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***Oncologist***—A doctor who specializes in the treatment of cancer.

***Oncology***—The branch of medicine that focuses on the study and treatment of cancer.

***Osteoporosis***—A disease that causes bones to become weak and fragile.

***Palliative care***—Palliative care focuses on controlling symptoms and improving quality of life for patients who have incurable diseases.

***Palmar-plantar erythrodysesthesia (PPE)***—PPE is commonly called "hand and foot syndrome."

A side effect of some chemotherapy, PPE is characterized by peeling, itching, burning, and reddened skin on the palms of the hands and soles of the feet.

***Partial remission***—Partial remission is a significant decrease in the number of cancer cells, but not their complete disappearance, in response to the cancer therapy. This is in contrast to a clinical complete remission where the tumor cells are no longer observable by, for example simple examination, chest X-ray and/or blood tests.

***Pathology***—The study of the causes and characteristics of disease.

***Peripheral neuropathy***—A possible side effect of some chemotherapy, characterized by numbness, tingling, or burning in the hands and feet.

***Peripheral stem cell transplant***—During a peripheral stem cell transplant, peripheral stem cells are removed from a patient or donor and are processed and stored. The patient then receives high-dose chemotherapy to kill cancer cells. Afterward, the stem cells are given back to the patient to "rescue" the patient from the harmful effects of the chemotherapy. The stem cells find their way back to the patient's bone marrow and begin making healthy blood cells. This procedure makes it possible to treat cancer with higher doses of chemotherapy because it replaces the cells damaged during chemotherapy.

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**Placebo**—A pill or infusion that has no active ingredients but looks just like a regular pill or infusion.

**Platelets**—One of the three types of cells made in the bone marrow. The main function of platelets is to aid in clotting the blood following an injury.

**Positron emission tomography (PET)**—PET scans use whole-body imaging to allow doctors to view cellular activity of tissues inside the body. A sugar labeled with a radioactive isotope is injected into the patient's vein. The scanner takes measurements of the cells as they use the sugar. The measurements produce a picture.

**Prognosis**—A prediction of the likely outcome of a disease based on the current health of the patient and the usual course of the disease.

**Prosthesis**—An artificial replacement for something that is missing on the body, such as a breast or limb.

**Radiation**—The use of radioactive substances for the diagnosis or treatment of diseases.

**Radiographs**—Also known as x-ray studies, radiographs are used to examine bones and soft tissues of the body. A radiograph image shows all structures superimposed on one another. A doctor may request x-rays of many parts of the body.

**Radiologist**—A doctor who specializes in the practice of radiology.

**Radiology**—A branch of medicine that focuses on the use and study of radioactive substances to treat and diagnose disease.

**Randomization**—Randomized clinical trials assign patients, in no particular order, to different groups in a study (for example, one group receives the research drug and the other group receives the usual treatment). Randomization reduces the risk of favoritism in the patient

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selection process. To make it fair, a computer performs the randomization process; your doctor is not involved.

**Randomized trial**—A research study design in which patients are randomly assigned (in no particular order) to receive different treatment regimens.

**Recurrence**—The return of a primary cancer that previously showed no signs of activity.

**Red blood cell**—Red blood cells are made in the bone marrow and released into the blood. They circulate in the blood and carry oxygen and carbon dioxide to and from every cell in the body.

**Refractory**—When a disease is said to be refractory, it means that it is unaffected by treatment.

**Regimen**—A plan of treatment, including doses, scheduling, and duration of treatment.

**Regression**—The shrinkage of a cancer or a decrease in the signs and symptoms of the cancer in response to treatment.

**Relapse**—The recurrence of disease after an apparent recovery.

**Remission**—The disappearance of a cancer, as determined by clinical evaluation, resolution of symptoms, or both. Complete remission is the disappearance of all signs of cancer after treatment. Partial remission is a notable decrease in cancer cells, but not their complete disappearance, in response to therapy.

**Research nurse**—A nurse that specializes in clinical trial studies. He or she is generally responsible for talking to patients about the study, helping monitor patients in the study, and collecting and reporting study data.

**Risk factor**—Anything that increases the chance of getting a certain disease, such as cancer. Some risk factors can be controlled, such as smoking. Other risk factors, such as age and race, cannot be controlled.

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**Shingles**—When a dormant (inactive) chicken pox virus is reactivated, the resulting illness is called shingles. This virus can lay dormant in the body for many years and can be reactivated at a later time for unknown reasons. Symptoms include blisters, rash, and pain.

**Side effect**—A change in a person's condition caused by taking a drug. For example, common side effects of chemotherapy include fatigue, nausea, vomiting, and loss of appetite.

**Single agent**—*Single-agent therapy* refers to the use of one chemotherapeutic medication for the treatment of cancer.

**Spiral CT**—Modified conventional computed tomography (CT) technique utilizing continuous scanning. For a spiral CT, the x-ray tube continuously revolves around the patient. This produces a three-dimensional reconstruction and helps doctors detect nodules that are too small to be seen on a conventional x-ray.

**Squamous cell carcinoma**—Cancer that arises from the epithelium of the body's tissue and is frequently found in the lungs and skin.

**Stage**—Staging is a method of determining the extent of the cancer, or how far the disease has spread. The stage is determined after performing a series of diagnostic tests, which may include x-rays, scans, and sometimes surgery. Knowing the stage of the cancer will help your doctor decide the best treatment course.

**Stem cell**—A special type of cell that is immature (not fully formed). A stem cell can become any of the three types of blood cells—a red blood cell, white blood cell, or platelet depending upon what the body needs. Most stem cells are found in the bone marrow, but a small number are found circulating throughout the body in the bloodstream. These are called *peripheral stem cells*.

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***Stem cell transplantation***—The use of stem cells to restore blood cell levels following treatment. Stem cells can be collected from the bone marrow or peripheral blood of a patient prior to treatment, frozen, and then reinfused following treatment, which is referred to as an *autologous stem cell transplant*. Stem cells may also be collected from a donor and infused into the patient following treatment, which is referred to as an *allogeneic stem cell transplant*. Donor stem cells also may be used to help fight cancer, since they can mount an immune response against the patient's cancer cells.

***Subcutaneous injection***—An injection that is made just beneath the skin with a very small needle.

***Symptom***—A sign or indicator of a disease or illness.

***Thoracentesis***—A thoracentesis, or *pleural tap*, involves putting a needle into the space between the lining of the lung and the lung itself to remove fluid or air. The procedure is relatively painless, but you must remain still. A chest x-ray may be done following the procedure.

***Thrombocytopenia***—A condition resulting from an abnormally low number of platelets (thrombocytes) circulating in the blood. Bleeding and/or bruising may occur if the platelet count is especially low (less than 20,000/mm<sup>3</sup>).

***Toxicity***—Toxicity refers to side effects that are related to the dose of a drug.

***Transfusion***—An intravenous (IV) infusion of blood or blood components.

***Tumor***—A collection of cells that appears as a lump, mass, or swelling.

***Tumor markers***—Chemicals in the blood that are associated with particular kinds of cancer. These chemicals can be measured to help doctors diagnose cancer and evaluate the effectiveness of a cancer treatment. A rise in the level of a marker could mean the cancer is growing; a drop in

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the level could indicate the treatment regimen is effective.

**Ultrasound**—A test used for diagnosis and assessment. Ultrasound uses high-frequency sound waves to create a picture of the structures inside the body.

**Vascular access device (VAD)**—VADs are catheters, or "ports", that are surgically placed in a large vein near the heart and stay in place for long periods of time. When a VAD is used, smaller, more easily irritated veins in the arms do not have to be accessed for chemotherapy.

**White blood cell**—A white blood cell is one of the three main types of blood cells. White blood cells are responsible for fighting infection. There are several kinds of white blood cells, including monocytes, lymphocytes, neutrophils, eosinophils, and basophils.

**X-ray**—A test used for diagnosis and assessment. During an x-ray, a small amount of radiation passes through the body and leaves an image of the shape of the internal organs on film.