



# Pediatric Cancer

Insights, Challenges, Strategies and Resources



## Daniel Armstrong, PhD

*Professor and Associate Chair, Department of Pediatrics  
Director, Mailman Center for Child Development  
University of Miami Miller School of Medicine  
Associate Chief of Staff, Holtz Children's Hospital at  
the UM/Jackson Memorial Medical Center  
Miami, Florida*



## David S. Gordon, MS

*Executive Director  
Living Through Learning Foundation  
Woodbridge, New Jersey*

# Pediatric Cancer

Insights, Challenges, Strategies and Resources



## RESOURCES

### **American Childhood Cancer Organization (ACCO)**

*(Formerly known as Candlelighters Childhood Cancer Foundation)*

**Contact:** (800) 366-2223 **Web:** [www.acco.org](http://www.acco.org)

Provides information, awareness and support for children with cancer and their families.

### **The Association for the Education of Children with Medical Needs (AECMN)**

**Web:** [www.aecmn.org](http://www.aecmn.org)

Links communities of professional educators, parents, caregivers, healthcare professionals, and patients to support the delivery of quality education services to children with medical needs and those who care about them.

### **The Association of Pediatric Hematology and Oncology Educational Specialists (APHOES) (for healthcare professionals only)**

**Contact:** [info@aphoes.org](mailto:info@aphoes.org) **Web:** [www.aphoes.org](http://www.aphoes.org)

Addresses the educational needs of pediatric hematology and oncology patients.

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



### RESOURCES

#### **Children's Oncology Group (CureSearch)**

**Contact:** (800) 458-6223 or [info@curesearch.org](mailto:info@curesearch.org) **Web:** [www.curesearch.org](http://www.curesearch.org)

Supports lifesaving research and helps raise awareness of the importance of cancer clinical trials, and provides online information on types of childhood cancer and treatments.

#### **Grahamtastic Connection**

**Contact:** (207)324-0888 ext. 209 or [leslie@grahamtastic.org](mailto:leslie@grahamtastic.org) **Web:** [www.grahamtastic.org](http://www.grahamtastic.org)

Provides free laptops to critically ill children for educational purposes.

#### **Living Through Learning Foundation**

**Contact:** (732) 476-7242 **Web:** [www.livingthroughlearning.org](http://www.livingthroughlearning.org)

Provides virtual activities for homebound students to help keep them in touch with school.

Resources 2

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



### RESOURCES

#### **The National Children's Cancer Society (NCCS)**

**Contact:** (800) 532-6459 **Web:** [www.children-cancer.org](http://www.children-cancer.org)

Provides programs and services to improve the quality of life for children diagnosed with cancer and their families.

#### **SuperSibs!**

**Contact:** (866) 444-7427 **Web:** [www.supersibs.org](http://www.supersibs.org)

Dedicated to ensuring ongoing comfort, recognition and support to children with brothers and sisters with cancer.

#### **WrightsLaw**

**Contact:** [webmaster@wrightslaw.com](mailto:webmaster@wrightslaw.com) **Web:** [www.wrightslaw.com](http://www.wrightslaw.com)

Provides up-to-date information about special education law and advocacy for children with disabilities; includes information for college students.

Resources 3

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



### SCHOLARSHIP RESOURCES

#### **FastWeb**

**Web:** [www.fastweb.com](http://www.fastweb.com)

Offers Web-based information and search tools for scholarship assistance for all high school, college and graduate students as well as adults seeking to return to school.

#### **I'm Too Young for This**

**Contact:** (877) 735-4673 **Web:** [www.stupidcancer.com](http://www.stupidcancer.com)

Provides a listing of financial aid and scholarships for cancer patients, cancer survivors, children of a cancer patient or survivor, students who lost a parent to cancer and students pursuing careers in cancer treatment .

Resources 4

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



### SCHOLARSHIP RESOURCES

#### **Surviving and Moving Forward: The SAMFund for Young Adult Survivors of Cancer (the SAMFund)**

**Contact:** (866) 439-9365 **Web:** [www.thesamfund.org](http://www.thesamfund.org)

Provides grants and scholarships to young adult survivors to help supplement money that was lost during treatment.

#### **U.S. Department of Education (ED)**

**Contact:** (800) 872-5327 **Web:** [www.ed.gov](http://www.ed.gov)

Offers a wide variety of information and Web tools to assist students and families seeking financial assistance for education and career purposes.

Resources 5

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



### CAMP RESOURCES

#### **Camp Sunshine**

**Contact:** (207) 655-3800 **Web:** [www.campsunshine.org](http://www.campsunshine.org)

Provides respite, support, joy, and hope to children with life-threatening illnesses and to their immediate families through a free year-round camp program.

#### **Chai Lifeline**

**Contact:** (877) 242-4543 **Web:** [www.chailifeline.org](http://www.chailifeline.org)

Provides services to meet the non-medical needs of seriously ill children, their families and communities, including a peer-to-peer support program, sibling programs and case management.

#### **Children's Cancer Recovery Foundation**

**Contact:** (800) 238-6479 or (717) 545-7600 **Web:** [www.cancerrecovery.org](http://www.cancerrecovery.org)

Provides scholarship assistance to help children experience therapeutic riding, music, art, skiing and other types of camps and activities.

Resources 6

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



### CAMP RESOURCES

#### **Children's Wish Foundation International, Inc. (CWFI)**

**Contact:** (800) 323-9474 **Web:** [www.childrenswish.org](http://www.childrenswish.org)

CWFI fulfills wishes for children and does not have a minimum age.

#### **Hole in the Wall Gang Camps**

**Contact:** (203) 562-1203 **Web:** [www.holeinthewallcamps.org](http://www.holeinthewallcamps.org)

Provides a free week-long camp for children; many camps provide weekends and events for families and siblings.

Resources 7

# Pediatric Cancer

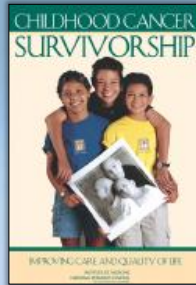
## Insights, Challenges, Strategies and Resources



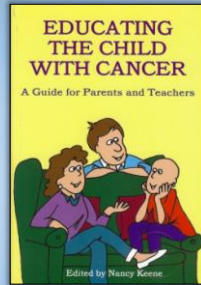
### EDUCATIONAL MATERIALS



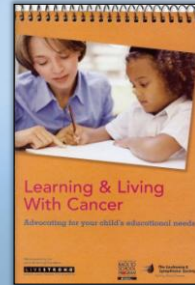
Article below



[www.nap.edu](http://www.nap.edu)



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



[www.LLS.org/resourcecenter](http://www.LLS.org/resourcecenter)

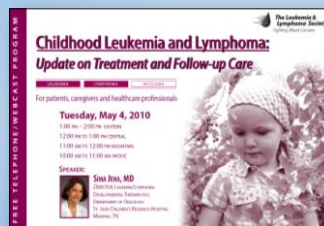
Resources 8

# Pediatric Cancer

## Insights, Challenges, Strategies and Resources



To view past programs, visit [www.LLS.org/pastprograms](http://www.LLS.org/pastprograms).



Resources 9



# *School and Learning Issues For Children with Cancer*

## *A Guide for Parents, Teachers, and Physicians*

*Developed by the Pediatric Psychology Program, Division of Pediatric Hematology/Oncology  
University of Miami School of Medicine and Holtz Center for Maternal and Child Health  
Jackson Health Systems, Miami, Florida*

### **Special Points of Interest**

**What is cancer in  
children, and how  
is it treated?**

---

**What are some  
concerns about  
school while  
children are  
undergoing  
treatment?**

---

**What are  
common learning  
problems the  
child might  
encounter?**

---

**What things can I  
(parent, teacher,  
pediatrician) do  
to make sure the  
child's school  
needs are met?**



Each year in the United States, about 8,500 children under age 15 are diagnosed with cancer. We now expect that about 70 percent of these children will be cured and go on to live healthy, productive lives. In fact, it is estimated that by the year 2010, one in every 900 adults will be a survivor of childhood cancer. This is really good news.

Because we are able to better treat childhood cancer, we now have to look more closely at what happens to children while they are receiving treatment, and what happens in the years after treatment is finished. Since the “work world” for a child is school, we need to pay special attention to school and learning.

In the past, school and learning were things that were lower on the priority list for parents and pediatricians. The main goal was to provide treatment and prevent death. This is still the major goal, but we are learning a great deal about the long-term effects of cancer treatment, particularly as it affects children’s development of learning skills, social skills, and overall quality of life. This is particularly true for children who have a kind of cancer that involves the brain and spinal cord (called the central nervous system or CNS). The CNS is involved or treated in about half (50%) of all children with cancer, and these children are of special concern.

## Q. What is cancer in children, and how is it treated?

**A.** Cancer happens when normal cells of the body suddenly start to divide and multiply very rapidly, losing the ability to do the job they were intended to do. Cancer can occur in many parts of the body, but the most common kinds of cancer in children are:

- **Leukemia** - cancer of the blood and bone marrow
- **Brain Tumors** - solid tumors in the brain and spinal cord
- **Lymphoma** - a tumor involving the lymph nodes
- **Other Solid Tumors**, including
  - Bone cancers (Osteogenic sarcoma, Ewing's Sarcoma)
  - Kidney cancer (Wilm's Tumor)
  - Muscle cancer (Rhabdomyosarcoma)
  - Peripheral Nervous System cancer (Neuroblastoma)
  - Eye cancer (Retinoblastoma)

There are other kinds of cancer that occur in children, but these are pretty rare. Some of the common cancers seen in adults (like lung cancer, skin cancer, ovarian cancer, and breast cancer) are extremely rare in children.

Treatment of cancer is very complicated, and depends on the type of cancer a child has, whether it can spread or not, and risk factors like age, blood count, location, and genetics. The common treatments for cancer include:

- **Surgery** - cut it out.
- **Radiation Therapy** - using X-rays to kill the tumor cells at the time they divide.
- **Chemotherapy** - using medications that destroy the tumor cells.
- **Bone Marrow Transplantation** - using radiation and chemotherapy to destroy cancer cells, and then replacing those cells with donated cells from another person.

Other new therapies are being tried in experimental trials. These include:

- **Biological Response Modifiers** - these try to help the immune system fight the cancer.
- **Gene Therapies** - these try to change the genetic structure of the cancer cells, making them stop multiplying.

Some types of cancer are treated just with surgery, some just with chemotherapy, and some with combinations of surgery, radiation therapy, and chemotherapy. It all depends on what kind of cancer the child has. Right now, there are more than 70 different treatments being used for all types of childhood cancer.

---

## Side Effects

Cancer treatment is tough. It requires regular visits to the clinic (sometimes several times a week), admissions to the hospital every 2-3 weeks for several days of treatment, and admission to the hospital to treat serious, life-threatening infections. For children who receive a bone marrow transplant, hospitalization lasting 100 days may be necessary, and some of these children may not be able to return to school for about a year after leaving the hospital after transplant.

Cancer treatment has both immediate effects and long-term effects, and these affect the child's health, family, school functioning, social functioning, ability to participate in activities, and overall sense of well-being. Some of the common side effects include:

- Scars or prosthetic limbs due to surgery
- Hair loss due to chemotherapy or radiation
- Nausea or vomiting due to chemotherapy
- Low blood counts and susceptibility to infection due to chemotherapy
- Irritability, mood swings, and changes in weight due to chemotherapy
- Pain and anxiety about procedures involving needles

These side effects may make it very difficult for a child to attend school regularly or engage in normal activities with friends.

## Q. What are some concerns about school while children are undergoing treatment?

**A.** First of all, children often have to miss a lot of school while being treated. Sometimes they can keep up with work by enrolling in a program called "Homebound," where a teacher visits them at their home or hospital room, gives them assignments, and works with them individually.

This is sometimes the best alternative when children are too sick to go to school, but we prefer for kids to go to school when they are well enough so they can better keep up with what their classmates are learning. By attending school they also have opportunities for social interaction with their peers, and this can be a very important contributor to the child's quality of life. If kids do attend school while on treatment they may look different from their peers and may also experience changes in the way they feel and in the way they act. Due to decreased immune functioning they may be at increased risk of developing infections and as a result should receive medical attention at the first sign of fever.





## Q. What are common learning problems the child might encounter?

**A.** About half of all children with cancer have a brain tumor or acute leukemia. These types of cancer and their treatments involve the CNS, often causing a number of problems that affect learning. These include:

- **Fatigue** – this may last for years after treatment is finished.
- **Hearing loss** – this happens when radiation therapy and certain types of chemotherapy are used to treat brain tumors.
- **Vision loss** – this is usually caused by a tumor on the optic nerve, but can also occur because of bleeding after surgery.
- **Partial paralysis or weakness** – this is usually a side effect of the tumor or surgery for a brain tumor.
- **Growth delays** – this occurs when radiation affects the endocrine system.
- **Damage to the heart** – a side effect of certain types of chemotherapy.

Other problems are seen over time, and are more subtle. However, these can cause major problems for the child for the rest of his/her life. These almost always occur for children treated with chemotherapy and radiation therapy for brain tumors, and for about 1/3 of children treated for acute leukemia. The problems may be seen at the time the child is treated, but more often they continue to emerge for years after treatment is completed. Additionally, since children's brains continue to develop into adulthood, new problems may be expected as new skills, which should be seen at different ages, fail to emerge. The severity of the problem seems to depend on the intensity of treatment and the age of the child at the time of treatment: *More intense treatment and younger age are associated with more severe problems.*

*The most common threat to a child's ability to learn is not having the opportunity!*

### Some of the common learning problems include:

- Fatigue.
- Declines in intellectual ability over time.
- Deficits in specific areas of ability. These include
  - The ability to sustain attention and avoid “spacing out.”
  - The ability to remember information that is seen as opposed to heard.
  - The ability to remember sequences of information.
  - The ability to comprehend material that is read visually (although reading the words is often not a problem).
  - The ability to handwrite quickly and accurately.
  - The ability to copy or write information that is seen.
  - The ability to complete tasks quickly.
  - The ability to keep pace with new material.
  - The ability to perform math calculations (e.g., multiplication, division).
  - The ability to learn and retrieve information that is novel and that does not have a meaningful context.
  - The ability to plan and organize.
- Problems keeping up in social conversations and in detecting social cues.

### Some abilities that seem to be unaffected include:

- The ability to learn and remember information that is heard.
- The ability to understand the application of math concepts.
- The ability to use spoken language to communicate understanding of concepts and new material.
- The ability to recall information accurately if provided enough time.
- The ability to be creative.



## Q. What things can I (parent, teacher, pediatrician) do to make sure the child's school needs are met?

### A. Interventions

#### During Treatment:

- Work out ways to make sure that schoolwork continues, even while in the hospital.
- Arrange for the child to visit with friends, and maybe even visit his/her classmates in school.
- Work with the school to develop a plan for school attendance whenever possible, with homebound or hospital teaching available when attending school is not possible.
- Adjust the workload for the child so it is manageable. There should be expectations, but they should be reasonable.
- Make sure the teachers know the specifics of what the child is going through... for example, what side effects to expect, how much school will be missed.
- Arrange for an educational "school re-entry" session with the classmates. Often, the child with cancer can be helped to teach his/her classmates about the disease and its treatment. This helps in two ways:
  - The children in the classroom learn about what is going on, and their anxiety is reduced. This usually reduces or eliminates teasing or social problems for the child with cancer.
  - The child with cancer establishes himself/herself as an expert, not the ill child. This goes a long way in supporting the child's sense of self-confidence and self-competence, and reduces social isolation that can occur.

#### After Treatment:

- Make sure your child has a neuropsychological evaluation during treatment, at the end of treatment, and approximately every 2 years after that. This evaluation should include the following components:
  - Cognitive (IQ) and Academic Achievement (Reading, Math, and Writing)
  - Memory (Verbal and Visual)
  - Reading and Listening Comprehension
  - Attention and Concentration
  - Visual-spatial and Visual-spatial-motor Integration
  - Processing Speed
  - Executive Functioning and Planning

*Don't Give Up!!!*

## After Treatment (continued):

- Schedule a meeting with the school to determine a plan for meeting his/her educational needs. This may involve a special education placement, or an inclusion under what is called the 504 regulation for children with chronic health or physical impairment. When indicated, the school should help develop an Individualized Educational Plan (IEP) for the child.
- If the results of neuropsychological testing suggest problems, the following may be very helpful in making sure the child continues to learn and do well in school:
  - Testing without time limits.
  - Minimization of written work through oral demonstration of knowledge, including dictation of written assignments on audiotape.
  - Use of books on tape (talking books) for children with reading comprehension and memory problems.
  - Avoidance of tests involving “scanning” or “bubbling.”
  - Assigning a peer to serve as a classroom aide, which may benefit both academic and social development.
  - Modification of physical education requirements to address mobility limitations, as well as limitations because of damage to the heart that some children experience. This will likely include creative strategies to provide opportunities for participation.
  - Use of “assistive technology” to provide educational supports. This may include:
    - s Using a calculator for math
    - s Using a tape recorder during class lectures
    - s Using a tape recorder to dictate assignments
    - s Learning to use a computer keyboard to type instead of handwrite
    - s Using voice recognition software on a computer to dictate into a word-processing program
    - s Using voice recognition with FM transmission from the teacher so that class lectures are transmitted directly into a computer program on the child’s laptop.
- Re-evaluate progress on a regular basis. Helping children treated for cancer requires careful monitoring and adjustment as success is achieved and new problems are encountered.





**Partial Support for this Project Provided by:**

**Health Foundation of South Florida  
The American Cancer Society, Florida Division  
The National Institutes of Health / National Institute of Child Health and  
Human Development**

**Contact Information:**

**Pediatric Psychology Program  
Division of Pediatric Hematology / Oncology  
University of Miami School of Medicine  
Mailman Center for Child Development (D-820)  
P.O. Box 016960  
Miami, Florida 33101**

**Tel: (305)243-6801**

**Fax: (305)243-5978**

**Email: darmstrong@miami.edu**