



American Brain Tumor Association

## EDUCATING CHILDREN AND TEENAGERS

During childhood and adolescence, school is a part of daily life. School is a place for learning, enrichment, socialization and fun. Oftentimes, returning to school after a brain tumor diagnosis and treatment marks a return to routine and normalcy. As a result, children and teenagers with brain tumors often look forward to the moment when they are medically able to return to school.

On the other hand, some children or teens may be reluctant to return to school for fear of being perceived as different from the other students. The need to conform and be accepted by others is quite common in elementary school, middle school and high school. However, typical peer pressures may intensify due to the psychological, social and/or physical effects associated with a brain tumor diagnosis and treatment. Therefore, it is very important for parents, teachers and classmates to understand and accept the special needs of the child or teen.

Once the child or teen adjusts to the school setting, he/she may begin to exhibit difficulties with class work, tests and homework. These difficulties may be due to the short-term or long-term effects associated with medical treatments for a brain tumor. Some types of abilities that could become affected include: memory, concentration, problem-solving, comprehension and processing. Since each child is unique, it is not possible to predict accurately which abilities could become affected. However, physical, intellectual and neuro-psychological testing can be performed to assist in defining these effects.

Communication with the teacher, school staff and healthcare team is vital to the academic performance of the child or teen. It is also important to monitor and review the child/teen's progress during each academic year. By keeping open communication and a team approach to progress, the child or teen will thrive in an academic program specified to meet his/her individual needs.

*Educating Children and Teenagers* was developed for parents, teachers and school staff to bring some of these challenges to the forefront. More specifically, this resource highlights organizations which specialize in a variety of areas and are available to help. Topics addressed in this resource include: assistive technology, cognitive late effects, learning disabilities/special education, online support, school re-entry and transition resources/vocational rehabilitation. For further reading and information, a bibliography list for parents, teachers and school staff is also included.

## ASSISTIVE TECHNOLOGY

### ALLIANCE FOR TECHNOLOGY ACCESS (ATA)

707-778-3011

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

The Alliance for Technology Access (ATA) is a national network committed to providing information and support services to children and adults with disabilities. Click on the “ATA Community” link on the home page to access an ATA center in your state. ATA offers an “ATA Hub,” which is a free service to locate and receive information on assistive technology products and services. Information is also available for students with disabilities who are facing the transition from public school to the next stage in life.

### FAMILY CENTER ON TECHNOLOGY AND DISABILITY (FCTD)

202-884-8068

[www.fctd.info](http://www.fctd.info)

FCTD supports organizations and programs that assist children with disabilities and their families and provides a great deal of information on assistive technology. Information is available in English and Spanish. FCTD also offers online discussions and a monthly newsletter.

### TECHNICAL ASSISTANCE ALLIANCE FOR PARENT CENTERS

888-248-0822

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

Funded by the Department of Education and the Office of Special Education Programs, the Technical Assistance Alliance is a project which supports the purpose of developing, assisting and coordinating Parent Training and Information Projects and Community Parent Resource Centers under the Individuals with Disabilities Education Act (IDEA). To find your local parent center, click the map of the United States on the website homepage. Then click your region and state for more specific information.

## COGNITIVE LATE EFFECTS

CANDLELIGHTERS CHILDHOOD CANCER FOUNDATION  
800-366-CCCF (2223)

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

The mission of Candlelighters is to provide information and awareness, support research and advocate for children and adolescents with cancer and their families. The Candlelighters' website provides rich information on a variety of topics including cognitive late effects. Candlelighters also publishes a booklet entitled, "Educating the Child with Cancer." Two copies of this booklet are free to families of children with cancer (one to keep and one to provide to the school); the cost to others is \$19.95.

CHILDREN'S BRAIN TUMOR FOUNDATION (CBTF)  
888-228-HOPE (4673)

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

CBTF provides information, support and advocacy to families of young brain tumor survivors. CBTF provides information on medical late effects, educational late effects and Cancer Survivor Late Effect Clinics.

## LEARNING DISABILITIES/ SPECIAL EDUCATION

BEYOND THE CURE  
800-5-Family

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

Beyond the Cure is a program of The National Children's Cancer Society and is created for the survivors of childhood cancer. This website includes state specific special education information. There is also a section available on how cancer affects learning /learning challenges for both survivors and parents.

COUNCIL FOR EXCEPTIONAL CHILDREN (CEC)  
800-224-6830

[www.cec.sped.org](http://www.cec.sped.org)

CEC is an international, professional organization dedicated to improving educational outcomes for students with disabilities. CEC provides a number of services to include: professional development opportunities and resources, 17 divisions for specialized information, journals and newsletters with information on new research findings, classroom practices that work, federal legislation, and policies, conventions and conferences and special education publications. CEC targets teachers, administrators, students, parents, paraprofessionals and related support service providers.

## LD ONLINE

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

LD online is a website dedicated to learning disabilities for parents, teachers and other professionals. Basic information on learning disabilities, expert reviewed articles and an online yellow pages section to access information and tools on IDEA, IEP's, locate an LD professional or product and a school or learning center.

## NATIONAL CENTER FOR LEARNING DISABILITIES (NCLD)

888-575-7373

212-545-7510

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

NCLD is an organization committed to improving the lives of those affected by learning disabilities. NCLD provides the latest information on learning disabilities and local resources to parents, professionals, employers and others dealing with learning disabilities. To locate resources in a specific state, simply click "Resource Locator" and enter your state. Online publications can also be accessed at the NCLD website. NCLD also offers a Parent Resource Center and with an online community which includes message boards and chat rooms.

## NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES (NICHCY)

800-695-0285

202-884-8200

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

NICHCY is a central source of information on disabilities in youth and children, IDEA, No Child Left Behind and information on effective educational practices. State specific resources are available at the website. Information can also be accessed in Spanish by clicking the "En Espanol" tab. Resource pages for families, early intervention providers, schools and state agencies are available.

## OFFICE OF SPECIAL EDUCATION AND REHABILITATIVE SERVICES (OSERS)

U.S. DEPARTMENT OF EDUCATION

202-245-7468

[www.ed.gov/about/offices/list/osers/index.html](http://www.ed.gov/about/offices/list/osers/index.html)

OSERS is committed to improving results and outcomes for people with disabilities of all ages. OSERS provides a wide array of supports to parents, school districts and states. Information on IDEA as well as a "Tool Kit on Teaching and Assessing Students with Disabilities" is available through the website. To access a number of resources for children with disabilities, click the tab entitled "Parents" on the top of the page. Then click "My Child's Special Needs" and "Disabilities."

## TEACHING LD

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

Teaching LD is a service of the Division for Learning Disabilities of the Council for Exceptional Children. Teaching LD provides publications and resources about teaching students with learning disabilities. Located on the homepage under the section entitled, "Teaching how- to's," articles can be downloaded on reading, writing, math, and helpful teaching hints. The website also offers a question and answer section.

## ONLINE SUPPORT

### BRAVE KIDS

800-568-1008

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

Brave Kids is a non-profit organization that serves the needs of children with chronic life-threatening illness or disabilities. Brave Kids offers an online community, with message boards for parents and kids.

### EDUCATING BRAIN TUMOR KIDS

<http://groups.yahoo.com/group/EducatingBTKids>

Educating BT Kids is an online education resource center for parents, schools, teachers and social workers. This listserv promotes questions and answers and resource linkage.

### GROUP LOOP

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

Group Loop is an online community for teens and their parents. On the Group Loop home page, click "Cancer, School & You" to learn about problem-solving and helpful tips when returning to school. Group Loop also offers online support groups and discussion boards.

### IEP GUIDE

[http://groups.yahoo.com/group/IEP\\_guide](http://groups.yahoo.com/group/IEP_guide)

This online listserv is available for parents, teachers and education professionals to discuss special ed., NCLB, Section 504, disability rights, etc. This listserv promoted questions and answers and resource linkage.

### NATIONAL DISABLED STUDENTS UNION (NDSU)

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

NSDU is a national student organization which offers a listserv (an e-mail discussion list) for students with disabilities of all ages throughout the United States.

## PARTNERS FOR YOUTH WITH DISABILITIES (PYD)

617-566-4075- voice

617-314-2989- TTY

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

PYD is a national organization which offers one-to-one mentoring and group mentoring programs for youth with disabilities. PYD offers “Partner’s Online” an online community with forums and chat rooms. PYD also offers an online parent forum for parents to access support.

## STARBRIGHT WORLD

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

Starbright World (affiliated with the Starlight Starbright Foundation) is an online community for teens with chronic illnesses and their siblings. The online community includes a chat room, blogs, bulletin boards, contests and polls.

## YOUTHHOOD.ORG

NATIONAL CENTER ON SECONDARY EDUCATION AND  
TRANSITION (NCSET)

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

The Youthhood.org website is a curriculum based tool that is devised to help young adults plan for life after high school. The website provides a variety of activities to include a private journal, life map and class notebook. The website offers a section for young adults and a section for parents.

## SCHOOL RE-ENTRY

### AMERICAN BRAIN TUMOR ASSOCIATION (ABTA)

800-886-2282

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

ABTA offers a publication on school re-entry entitled, “When Your Child Returns to School.” This publication highlights questions to ask and steps to take to help prepare for your child’s return. Special education services are also discussed.

A DVD entitled, *Alex’s Journey* is also available through ABTA. This DVD is designed to provide school age children and classmates with basic information on brain tumors. This DVD can also be used as a tool for teachers to encourage discussion in the classroom.

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

ABTA offers a website for children to learn, share and participate in activities.

THE LEUKEMIA AND LYMPHOMA SOCIETY-SCHOOL AND  
YOUTH PROGRAMS- THE TRISH GREENE BACK TO SCHOOL  
PROGRAM

800-955-4572

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

The Trish Greene Back to School Program was developed to foster communication among health care professionals, parents, children and school staff. The Leukemia and Lymphoma Society's national and local chapters offer the informational booklet entitled, "*Learning & Living with Cancer: Advocating for your child's educational needs.*" Contact your local chapter to order this booklet.

LIVESTRONG AT SCHOOL  
LANCE ARMSTRONG FOUNDATION

866-467-7205

[www.livestrong.org/school](http://www.livestrong.org/school)

Livestrong at School is intended for teachers who would like to incorporate cancer education in the classroom. Livestrong at School offers a number of lesson plans, worksheets and videos for elementary, middle school and high school teachers.

PEDIATRIC BRAIN TUMOR FOUNDATION (PBTF)

800-253-6530

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

PBTF is a nonprofit organization committed to childhood brain tumor research and providing support to families. PBTF provides information and resources on education, which is located under the "Survivors" tab found on the PBTF website homepage.

STARLIGHT STARBRIGHT CHILDREN'S FOUNDATION

310-479-1212

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

A foundation which is dedicated to helping seriously ill children and their families cope with pain, fear and isolation through entertainment, education and family activities. Starlight Starbright offers a free Back to School DVD to help address issues teens face when returning to school. The DVD is geared towards teens with chronic illnesses and also addresses the importance of communicating with the physician and illustrates life in the hospital setting. Contact the foundation directly to order this free DVD.

## TRANSITION RESOURCES/VOCATIONAL REHABILITATION

### COLLEGE NAVIGATOR NATIONAL CENTER FOR EDUCATION STATISTICS

[www.nces.ed.gov/collegenavigator/](http://www.nces.ed.gov/collegenavigator/)

College Navigator offers a search tool to compare and contrast colleges for prospective students. This website also includes information on preparing and planning for college, financial aid and choosing a career. There is also a section for middle school and high school students called the NCES Kids' Zone. In this section, there are a number of educational games and trivia and tools to search for colleges.

### NATIONAL CENTER ON SECONDARY EDUCATION AND TRANSITION (NCSET)

612-624-2097

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

NCSET was established to create opportunities for youth with disabilities. NCSET coordinates national resources, provides technical assistance and disseminates information related to secondary education and transition. Click "State Contacts" on the NCSET homepage to access state resources and contact information.

### NATIONAL YOUTH LEADERSHIP NETWORK (NYLN)

866-480-6565

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

NYLN works to promote leadership, education and employment for youth with disabilities by providing resources on employment and youth development. NYLN also offers a "youth expert" program where youth experts can speak at conferences, provide mentoring and technical assistance to organizations and agencies. Youth Experts focus on a wide variety of issues which include: employment, college or vocational school and independent living.

### PACER CENTER

952-838-0190

888-248-0822

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

The PACER center is a parent training and information center for families of children and youth with all disabilities from birth through 21 years. The PACER center provides a number of educational materials for parents and professionals on education, vocational training and employment. Translated materials in Spanish, Hmong and Somali are also available.

## VOCATIONAL REHABILITATION AGENCIES

[www.jan.wvu.edu/cgi-win/TypeQuery.exe?902](http://www.jan.wvu.edu/cgi-win/TypeQuery.exe?902)

Click on the alphabetical list of states to locate vocational rehabilitation resources within the specific state of interest. This website is part of the Small Business and Self-Employment Services (SBSES) which is under the Office of Disability Employment Policy of the U.S. Department of Labor.

## BIBLIOGRAPHY LISTING FOR PARENTS, TEACHERS AND SCHOOL STAFF

### TO OBTAIN THESE BOOKS

- Books available at Barnes and Noble's web site are denoted with *BN.com*. If you choose not to order online, you can call Barnes and Noble at 800-843-2665 (201-559-3882) and still receive the BN discounted pricing.
- Some of the books were published by brain tumor patients and their families, or by organizations. Contact information is included in those listings.
- These books are *not* available from ABTA. We provide this list as a service; inclusion in this listing does not constitute an endorsement or recommendation of the book.
- If you are aware of a helpful resource not listed here, please write to us: [info@abta.org](mailto:info@abta.org) or ABTA, 2720 River Road, Des Plaines, IL 60018.

***An Angel's Kiss Embracing the Spirit of a Child Born with Cancer.*** Buffy Krajewski. A young mother depicts her personal story through pregnancy, delivery, diagnosis and treatment of her child born with an adrenocortical carcinoma. She openly and honestly shares her thoughts and emotions of guilt, fear and depression as well as love, devotion and persistence. She also shares the emotional and financial struggles of her family as well as the difficult experiences within the healthcare and education systems. Lulu.com, 2007. *BN.com*

***Childhood Brain and Spinal Cord Tumors: A Guide for Families, Friends and Caregivers.*** Tania Shiminski-Maher, Patsy McGuire Cullen, and Maria Sansalone. This book is a complete parent guide that offers both medical and practical advice on caring for a child with a brain tumor. Not only does this advice come from medical professionals but also from parents who have been there themselves. Includes a thorough resource listing to assist families in locating the help they need. O'Reilly and Associates Publishing, Sebastopol, CA. 2001. *BN.com*.

***Childhood Cancer: A Parent's Guide to Solid Tumor Cancers.*** Honna Janes-Hodder and Nancy Keene. The support provided in this book more than makes up for its exclusion of brain tumors information. Written by two parents whose children were diagnosed with cancer, the authors consulted numerous healthcare professionals to compile a "step-by-step guide" to childhood cancer. The text explains the "how and whys" of diagnostic procedures, medical treatments, and follow-up testing. Included are explanations of blood test results and various chemotherapy pumps along with help for maintaining family structure through this time of crisis. O'Reilly & Associates, Inc., Sebastopol, CA. 2002. *BN.com*.

***Childhood Cancer Survivors: A Practical Guide to Your Future.*** Nancy Keene, Wendy Hobbie and Kathy Ruccione. Provides information about late effects, the emotional aspects of surviving cancer, schedules for follow up care, and the choices and challenges that can face a childhood cancer survivor. Stories from over 100 survivors and parents are interspersed through the book. O'Reilly & Associates, Inc., Sebastopol, CA. 2000. *BN.com*.

***Educating the Child with Cancer, A Guide for Parents and Teachers.*** Nancy Keene, Editor. The Candlelighters Childhood Cancer Foundation. A guide for parents and educational professionals. Among other things this booklet addresses peer relationships, preparing a child for college, alternatives to college and caring for siblings during diagnosis and treatment. Candlelighters Childhood Cancer Foundation, Kensington, MD. 2003. For ordering information, contact: Candlelighters Childhood Cancer Foundation; 800-366-2223 or [www.candlelighters.org](http://www.candlelighters.org).

***Home Care for Seriously Ill Children: A Manual for Parents.*** Stacy Orloff, LCSW and Susan Huff, RN, MSN, Eds. Offers concrete advice on topics ranging from medications and pain control, controlling medical problems, attending to general care, such as nutrition, mouth, skin and eye care, daily activities, medical equipment and supplies, emotional concerns, finding support and end of life issues. Children's Hospice International, Alexandria, VA. 2006. Call 800-242-4453 or visit their website: [www.chionline.org](http://www.chionline.org) to order and for price information.

***Know Before You Go: The Childhood Cancer Journey.*** Sheryl Lozowski-Sullivan, MPH. Offers helpful basics for parents whose children have cancer. Covers the period from diagnosis through treatment. Candlelighters Childhood Cancer Foundation, Kensington, MD. 1998. For ordering information contact: Candlelighters Childhood Cancer Foundation, [www.candlelighters.org](http://www.candlelighters.org); 800-366-2223. (paper).

***Official Parent's Sourcebook on Pituitary Tumors.*** James Parker, Philip Parker, PhD, Editors. This sourcebook for parents provide guidelines on diagnosis, treatments and prognosis of pituitary tumors. Research information and online organizations are included. ICON Health Publications, San Diego, CA. 2005. *BN.com*.

***Your Child in the Hospital: A Practical Guide for Parents, 2<sup>nd</sup> Edition.*** Nancy Keene and Rachel Prentice. A practical guide for parents and children coping with a child's hospitalization. Discusses preparing a child for staying in the hospital, preparing for surgery, pain management, feelings and behavior, and keeping family life going. O'Reilly & Associates, Inc., Sebastopol, CA. 1999. (paper). *BN.com*.

This information is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician (s), utilizing your specific medical information. The American Brain Tumor Association does not endorse any of the organizations listed or guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines.

May 2009