

**This article was written for the Childhood Brain Tumor Foundation, Germantown, MD.**

## **CureSearch.org: A Valuable Resource for the Childhood Cancer Journey**

This is the first of two planned articles by members of the CureSearch web team to introduce families and friends of children with brain tumors to an internet site that is designed specifically for patients, parents and families of children with cancer. The CureSearch.org team is interested in your feedback about the brain tumor content of the site. There is a site suggestion area dedicated to the readers of this newsletter at <http://www.CureSearch.org/BrainTumor/>. Please take advantage of the opportunity by making your suggestions for features and content that would enhance the utility of the site. The follow-up article will reveal and discuss what families have told us about their needs and highlight changes made to the CureSearch.org site as a result of your comments.

CureSearch is the umbrella name for the combined efforts of the Children's Oncology Group (COG) and the National Childhood Cancer Foundation (NCCF), two organizations united by a common goal: finding a cure for childhood cancer. The vision for this site was defined by a team that included parents of children with cancer, adolescent survivors, health professionals, social workers, and educators. The site launched in the Fall of 2004.

The primary focus of the site is to empower and educate patients and families. The goal is a site that will provide informational tools to parents, families and patients that facilitate communication with clinicians and researchers. Printer friendly downloadable files and the ability to email articles to a friend are hallmarks of the site.

The core site content elements include separate areas for patients, parents and families, health professionals, cancer overviews, how you can help, about us, resource directory, and a discussion board. The site also contains a powerful search engine and a feedback mechanism for site suggestions so visitors can help inform the next generation of the site.

The focus of this article is the parents and families section of the site which is divided into 4 key "stages: newly diagnosed, in-treatment, end-of-treatment, and after treatment. A visitor customizes their experience by cancer type and age group thus allowing them to review the most appropriate information to their situation.

In the *Newly Diagnosed* stage, visitors are able to learn about a specific type of cancer and the available treatment options. This section includes important information about diagnostic tests, the impact of childhood cancer on the patient and family, school issues and navigating the healthcare system. The recently developed Children's Oncology Group (COG) Family Handbook is located in this section. It contains information and concrete suggestions to deal with childhood cancer and it can be custom-tailored with information specific to a child's care.

The *In Treatment* stage helps the visitor understand the relative risks and benefits of specific treatment methods through discussions of living with treatment and medical information. Illustrations and special "know your body" features were specifically specifically designed to enhance the visitor's understanding of diagnostic tests, procedures, and devices.

The *End of Treatment* stage includes articles that address the unique issues that relate to the transition between in-treatment and after treatment. Of particular interest in this section is information about "getting back to normal" and how to interact with the school.

The *After Treatment* stage includes information about follow-up, survivorship, relapse/secondary cancer, end of life, and bereaved issues. Families have cited this section's frank discussion about providing both physical and emotional comfort to a child and their family at the end of life as information long needed. The long term follow-up guidelines for survivors of childhood cancer which provide recommendations for screening and management of late effects that may potentially arise as a result of the treatment for childhood cancer are located in the survivorship section.

Two popular features have prominence on the site: a resource directory and discussion board. The resource directory contains a listing of local, national and international organizations that offer a wide variety of

resources and is searchable by zip code. The discussion board provides a way for anyone affected by childhood cancer to connect with each other and share information, experiences, and advice, providing a virtual community of individuals affected by childhood cancer.

The depth of the information on the site prohibits a full description in this article. We encourage you to visit [www.curesearch.org](http://www.curesearch.org) and take advantage of the site's resources. The authors of this article look forward to receiving your comments at <http://www.CureSearch.org/BrainTumor/>.

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