

Resources Abound for Brain Tumor Patients. Where to Begin?

By Mike Tancredi for UnlockingBrainTumors.org

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There are a great many resources for individuals who have been diagnosed with a brain tumor, and for their loved ones. When I was first invited to participate in UnlockingBrainTumors.org, my understanding of the topic, which I still consider to be in its infancy, was immediately expedited by the extensive online literature. The goal of this article is to provide the layperson or newly-diagnosed patient with a quick guide to some of these resources. It goes without saying that this guide will be incomplete, so we'll update this at a later date. Because of the ambitious mission, and indeed their success, of so many organizations to provide comprehensive support services to the brain tumor community, it is difficult to really categorize groups in a simple manner. But we'll try to help you navigate these excellent resources. Links to these sites can be found at UnlockingBrainTumors.org's *Beneficiaries* section.

SUPPORT, COMMUNITY AND RESOURCE LINKAGE

The International Brain Tumor Association, **The American Brain Tumor Foundation**, and the **National Brain Tumor Foundation** are but a few of the comprehensive community organizations that are offering a wealth of information, advocacy and support. Expansive in their goals, these organizations are a meeting point for patients, doctors and others, sharing important information on brain tumors, the latest research, conferences and events that are taking place, and much more. Visit IBTA's site and you'll find dozens of links to other community resources and sites, from large international groups to smaller foundations started in a loved one's memory. It would be impossible to fully describe the array of support and information that you can access here.

RESEARCH AND RESEARCH FUNDING

The **National Cancer Institute** is the primary site for the U.S. National Institutes of Health's principal cancer research agency. It provides a wealth of information on all cancers, and its area on brain tumors has in-depth technical discussions, statistics, and literature on clinical trials and therapies. Sites such as **VirtualTrials.com** monitors the progress and outcomes of clinical trials, with a staggering database of outcomes. As if this weren't enough, VirtualTrials.com, operated by The Musella Foundation, provides an extensive library of literature and video materials for patients and their families, as well as administering online support groups and bulletin boards where you can interact with others and find like-situated patients or families. **The Tug McGraw Foundation** is dedicated to raising funds for brain tumor research and awareness; it also links to a nice section for caregivers, recognizing the special challenge that families, friends and other caregivers will face, and its resource linkage area identifies yet more resources that you will find helpful. We also recommend you read *Surviving Terminal Cancer: Clinical Trials, Drug Cocktails, and Other Treatments Your Oncologist Won't Tell You About* by Ben A Williams.

We are privileged to have some of the world's leading university-based research and treatment centers in the U.S., and these institutions are on the leading edge of cancer research; they are also among the most sought-after in terms of diagnosis and treatment options. Our list of recommended resources includes, but is not limited to, **Duke University Comprehensive Cancer Center**, **the Jonsson Comprehensive Cancer Center (UCLA)**, **the Robert H. Lurie Comprehensive Cancer Center of Northwestern University**, **the M. D. Anderson Cancer Center at the University of Texas**, **the University of Pittsburgh Cancer Institute** and **Memorial Sloan-Kettering Cancer Center**.

PEDIATRIC SUPPORT

Special support to our youngest survivors is available through several notable organizations, including **I'm Too Young For This**, **the Pediatric Brain Tumor Foundation** and **the Brain Tumor Foundation for Children**. Like anyone trying to interact with younger patients and adults, these sites get it – their sites are friendly, informative, easy to use and speak to their audience. I'm Too Young For This is especially noteworthy for its message of optimism and efforts to end the isolation of patients; it also offers sign-up for a blog and newsletter, but its links to Get Help Now! and Get Involved Now! are truly impressive. We also recommend the inspirational *Force a Miracle* by Darryl C. Didier, with a Foreword by Mike Ditka.

To share a brain tumor resource you have found valuable, please contact mike@unlockingbraintumors.org