

## Patient Advocate Corner

### Alliance for Childhood Cancer: Addressing the Needs of Children With Cancer



Craig Lustig

By *Craig Lustig and Mary Jo Kupst, PhD*

A diagnosis of childhood cancer can be the most frightening news a family ever hears. Annually, more than 12,500 children between birth and age 20 years are diagnosed with cancer. However, improvements in treatment for the types of childhood cancer have led to an overall 5-year survival rate of close to 80% for many pediatric malignancies.



Mary Jo Kupst

Children and their families receiving a cancer diagnosis face difficult issues and a need for services and treatment distinct from those for adults with cancer. The Alliance for Childhood Cancer is working to address the needs of children with cancer and childhood cancer survivors.

Formed in 2001, the Alliance for Childhood Cancer is a coalition of more than 20 national patient advocacy groups and professional medical and scientific organizations that collaborate to advance research

and policies to prevent cancer, as well as to improve public education and the diagnosis, treatment, supportive care, and survivorship of children and adolescents with cancer.

The Alliance for Childhood Cancer educates policy makers on policy issues that affect children with cancer and their families, including survivorship issues, pediatric drug development, clinical trials participation, and palliative care.

#### Survivorship

There is a significant population of childhood cancer survivors—about one in 640 adults ages 20 to 39 years has a history of cancer. Among the challenges that come with this success are the late effects of cancer treatment, which affect survivors' long-term health and quality of life. According to the Institute of Medicine (Washington, D.C.), up to two thirds of childhood cancer survivors may experience at least one late effect, including neurocognitive, psychological, cardiopulmonary, endocrine, and musculoskeletal problems, or second malignancies.

To address these issues, the Alliance for Childhood Cancer established "survivorship principles," which support programs

and policies that ensure access to and insurance coverage for long-term follow-up care, establishment of systems of care necessary for comprehensive follow-up care, and research to address the effects of childhood cancer.

#### Pediatric Cancer Drug Development

Most children with cancer are treated with therapies that the U.S. Food and Drug Administration (FDA) has approved only for adult cancers. The market for pediatric cancer drugs is relatively small, so some companies are unwilling to develop drugs specifically for children with cancer. In addition, there are concerns related to the risk of toxicities in children in early trials.

The Alliance for Childhood Cancer states that the FDA must reduce barriers to pediatric cancer drug development and make it clear to drug companies that pediatric cancer must be a primary target for new agents.

#### Clinical Trials Participation

The majority of children with cancer in the United States are treated through clinical research studies, typically at specialized, comprehensive pediatric hematology-oncology centers. The gradual but dramatic increase in survival rates of children with cancer can be associated with their participation in government-sponsored clinical trials.

The Alliance for Childhood Cancer advocates conducting more clinical trials on novel agents for childhood cancers, and studies already under way in adult populations need to begin earlier for children.

#### Palliative Care

The Alliance for Childhood Cancer supports the Compassionate Care for Children Act of 2005 to improve the quality of palliative and end-of-life care for children affected by life-threatening medical conditions and to assure their families can access appropriate resources.

For more information, visit the Alliance's Web site, <http://www.childhoodcanceralliance.org>.

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