Advocating for Children with Sarcoma

An ESUN Op Ed
This article appears in the April 2010 Issue of the Electronic Sarcoma Update Newsletter V7N2 ESUN Copyright © 2010 Liddy Shriver Sarcoma Initiative

Mary Sorens
Associate Editor, ESUN

About 12,400 children under 20 years old in the United States are diagnosed with cancer each year (1). The SEER Pediatric Monograph explains that "Childhood cancer is not one disease entity, but rather is a spectrum of different malignancies (1)." While the 5-year relative survival rate for pediatric cancers was about 78.2% from 1996-2003, survival statistics for various childhood sarcomas ranged from 59.2% to 68.5% (2). Sarcomas are among the most life-threatening cancers that children face.

The Cancers that Affect Children

In order to best advocate for families dealing with pediatric sarcomas, it is important to understand the types of childhood cancers and the sources of funding for those cancers.

![Figure 1: Percent Distribution of Childhood Cancers by Category](image)

Each year, about 5047 cases of childhood cancer are leukemias and lymphomas, 2071 cases are brain and central nervous system (CNS) tumors, and 1612 cases are sarcomas (1). The remaining cases include tumors of the sympathetic nervous system, retinoblastomas, renal cancers, hepatatic cancers, germ cell cancers, carcinomas, and other tumors (Note 1).

NCI Research Funding for Cancers that Affect Children

When we look at the National Cancer Institute’s research expenditures (3), we find that funding for sarcoma research is disproportionately low compared to research into the other common childhood cancers (4).
Based on the prevalence of the cancers in Figure 1, one would expect to see NCI investing about 1/3 of the amount of money into sarcomas as they do leukemias and lymphomas. The fact is, sarcomas receive only 1/9 of the amount of research funding as leukemias and lymphomas do. There is a similar issue when comparing funding for brain and central nervous system tumors and sarcomas. Though a similar number of children are affected by these cancers, brain and CNS tumors receive four times the funding as sarcomas do.

We can look at this data another way by calculating the amount of NCI annual spending on a particular type of cancer research per child diagnosed with that cancer.

Not only do leukemias, lymphomas and brain tumors affect a significant portion of children who are diagnosed with malignancies, but they also affect more adults than sarcomas do. This creates more support for medical research into these cancers at the public and private level.
Private Funding for Support and Research into Cancers that Affect Children

A look at private charitable funding indicates the support services available to pediatric cancer patients and their families, as well as the private research funds invested in cancers that affect children. The major childhood cancer organizations like St. Baldrick's Foundation and St. Jude Children's Research Hospital do not provide a breakdown of their budget according to cancer type. Thus, the graph below uses a sample of charities dedicated to specific types of cancer (Note 2). The graph can be used to understand the difference between private funding of specific childhood cancers. One would expect that each total figure is increased by several million dollars when general "childhood cancer" charitable funds are included and distributed.

![Graph](image1)

Organizations like the Leukemia & Lymphoma Society illustrate the power of private collaborative effort. Their expenditures on patient services, advocacy and research topped $193 million in 2007. This one organization has an annual budget that is nearly 60% of the NCI budget for leukemia and lymphoma. In order to accomplish so much, the Leukemia & Lymphoma Society must have found a way to unite families of pediatric and adult patients, as well as those who are affected by several types of leukemia and lymphoma.

We can look at private funding another way by calculating the estimated funds that are spent on each type of cancer per newly-diagnosed child with that cancer.

![Graph](image2)
Discussion

The statistics presented in this piece provide good reason for parents of children with sarcoma to unite in order to fill the gap in funding for sarcomas. The numbers clearly show that there is much less public research funding per child for sarcomas than the more common cancers. There is also significantly less private funding per child that is used for sarcoma patient services, support, advocacy and research. In addition, children with sarcomas have a lower chance of survival than most children with cancer (2). These facts are a clear call for parents and families to:

1. Advocate for more government funding of sarcoma research or for a fairer distribution of funds.
2. Work in partnership to support and create fiscally responsible organizations that fund sarcoma patient services and sarcoma research.

Consider what we can do to improve the lives of children with sarcoma. Notice the parents and families who are joining the Team Sarcoma Initiative, hosting events and raising money for support and research into the sarcomas that affect thousands of children around the world.

As families of children with sarcoma work together, they realize that some of their greatest allies are people of all ages with sarcoma. People with sarcomas face a difficult situation with an often aggressive cancer. The distance from one patient to another, regardless of age or type of sarcoma, is not as far as it appears. And even though the statistics in this article come from the United States, people around the world share these same challenges. What we do for children with sarcomas can improve the lives of hundreds of thousands of people worldwide.

Read more about the sarcomas that often affect children:

Notes and References
Note 1: An unknown number of sarcomas were placed into these specific categories instead of the more general “bone and soft tissue” categories, which may explain why this figure is lower than 15-20%, which is a widely published statistic about childhood sarcomas.

Note 2: Guidestar.org was used to find data on private charities dedicated to specific cancers. Twenty organizations that provided financial data were included for each category of cancer in the graph. The organizations were chosen based on relevancy within the Guidestar search engine and only included those with program expenditures above $15,000 a year. A couple of well-known organizations that did not appear in Guidestar were included in the calculations. Funds included are only those that were spent on programs and services, not those that were spent on overhead/administrative expenses.


V7N2 ESUN Copyright © 2010 Liddy Shriver Sarcoma Initiative