

## CHAPTER 1

### INFORMATION ABOUT OUR ORGANIZATION

# About the Neuroblastoma Children's Cancer Society



Michael James Sexton's courageous effort in his fight against neuroblastoma cancer ended in September 1993 at the age of 3. During his nine months of intense treatment, he faced each day with determination, purpose and his smile! "We were shocked by the inability of the medical profession to combat the disease and that no major organization was funding significant research to

promote a front line treatment or cure to neuroblastoma cancer."

"Our family and friends decided to do something meaningful in Michael's memory and in memory of those children who lost their battle with neuroblastoma." Founded in 1994, the Neuroblastoma Children's Cancer Society is a 501(c) (3) nonprofit organization dedicated to promote research and to provide support to the children (and their families) diagnosed with neuroblastoma.

"Our organization is dedicated to raising funds for Neuroblastoma research, to change the outcome for all children diagnosed with this disease."

*James F. Sexton*      *Dori Sexton*  
Chairman                      President

## Help for Children & Families

The Neuroblastoma Children's Cancer Society is a group mainly of volunteers, many with children or relatives of victims or survivors of the disease. The organization is an advocate for the children and their families and is dedicated to provide support in the following ways:

- ☛ Promote research done by highly trained medical professionals;
- ☛ Provide research grant awards to medical specialists locally and nationwide;
- ☛ Educate health care professionals on early detection and the latest advances in treatment and diagnosis;
- ☛ Maintain updated information on current treatment;
- ☛ Provide moral, practical, and emotional support for patients and their families through newsletters, internet interaction, 800 telephone number support, etc.;
- ☛ Provide resource booklet listing nonprofit organizations and other resources offering support for patient's families.

### Missions & Goals

Significantly accelerate cures for neuroblastoma and its related children's cancers and improve the quality of life of patients and their families.

# Oncology Research

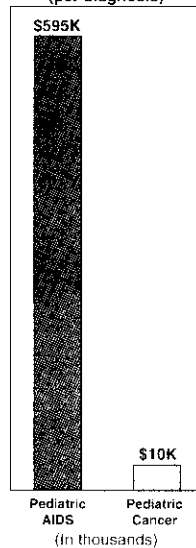
Children look at their parents and adults with expectant faith to take care of them, protect their innocence, keep them from harm and allow them a lifetime of opportunities and dreams. However, each year pediatric cancer "drafts" more children into a "war" than any other major condition or disease. For some, there are survivors. For others, they are sent to a war they cannot win.

As a society, we invest in our children and rightfully so. Children are our future! Shamefully, research dedicated to pediatric cancer lags far behind that of other less prolific diseases. Of the millions of dollars invested in cancer research, pediatric cancer research grants receive only a small fraction with neuroblastoma children's cancer receiving an even smaller portion of this.

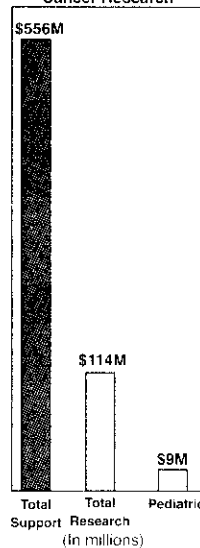
The major underwriters of cancer research, which the public has invested money and trust in, have given pediatric cancer a shockingly low priority. However, the minimal research money invested in pediatric cancer has resulted in amazing advancements and the saving of children's lives. The average age of a child diagnosed with cancer is 6 years old, while the average age for an adult is 67 years old. Through the efforts of pediatric cancer research, the number of patient-years of life saved each year among children cured of cancer now ranks second next to breast cancer, the only cancer of adults for which more lives have been saved.

These children are being sent to a "war" of intense chemotherapy, radiation and endless medical procedures. They deserve to be a high priority in funding research! It is this research where the "war" will be won!

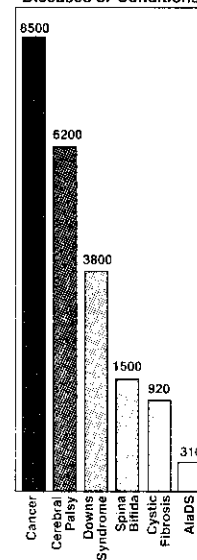
1998 Research Funding  
Public Health Service  
research funds  
(per diagnosis)



1998 American Cancer  
Society  
Cancer Research



Incidence of U.S.  
Children diagnosed  
each year with Major  
Diseases or Conditions



# **P**ublic Awareness

## **What is Neuroblastoma Children's Cancer?**

Neuroblastoma is a children's cancer diagnosed in approximately 500 to 1,000 children per year in the USA. Neuroblastoma is a complex tumor of the sympathetic nervous system, a condition that has been known for 35 years. Its frequency is second only to brain tumors and is seldom seen in children over 14 years old.

The median age for tumor discovery is 2 years and it occurs somewhat more in boys than girls. Like most cancers, its cause is unknown. It is extremely difficult to diagnose in small children and, once diagnosed, its progression is often rapid and very painful. Although Neuroblastoma accounts for only 8% of all cancers, it is responsible for over 15% of the deaths.

The disease is diagnosed from stage I ( a localized tumor confined to one organ or area of organ) to stage IV (solid tumors that have spread to several organs or parts of the body). Depending on the stage of the disease, treatment may be limited to tumor removal surgery to treatment which includes chemotherapy, radiation and bone marrow transplants.

Until recently, the majority of children are diagnosed at stage IV with long term stage IV survival rate a dismal 20% or less. However, encouraging developments have increased overall survival rates.

## **E**ducation

Of all the indicators, the two most important factors in the prognosis are the stage of the disease and age of the child at the time of detection. For all stages, infants of less than one year (six months is even better) have a much better remission (lessening of intensity) and survival rate than older children.

### **How is it diagnosed?**

It is often diagnosed by parents or physician feeling a mass or tumor somewhere in the body. Sometimes there are no symptoms at all. Often symptoms resemble those in many other more common childhood illnesses such as bruising, mild flu symptoms, diarrhea, and loss of appetite.

Sometimes the symptoms are more acute such as bone pain, hypertension, anemia, skin nodules and a pronounced limp or refusal to walk.

Pediatricians can order a simple, non-intrusive 24 hour urine test which is almost 100% accurate in detecting neuroblastoma cancer. Also, ultrasound, CT scans, and MRI scans are effective ways to detect "neuroblastoma" tumors.

## Board of Directors

Dori Sexton, President  
Jim Sexton, Chairman  
Kenna Anderson, Vice President  
Mayor Michael J. O'Malley \*  
(Mayor of Hoffman Estates, IL)  
Dr. Susan Cohn \*

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Cathy Crivellone  
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Connie Tracy

\* Designates Honorary Board Members

## We Need Your Help!

The organization is a 501(c)(3) nonprofit organization where your much needed contributions are 100% tax deductible. Donations of gifts are needed for fund-raising events and to make birthdays and holidays brighter with toys for our children. Volunteers are needed to provide public awareness, help find and provide resources to affected families and to assist in fund-raising.

## Help us Give **HOPE** for more Tomorrows for Children with Neuroblastoma!

 The Neuroblastoma Children's Cancer Society  
**Help us Complete our Rainbow!**

*Our mission and rainbow won't be  
complete until all children diagnosed with  
Neuroblastoma can be cured!*

## We want to help fight Neuroblastoma!

Together, we can *make a difference* with the following major leadership gifts from individuals, corporations, and foundations:

- Annual Membership — includes our newsletter  
(\$50 suggested donation)
- My tax deductible contribution is enclosed:
- |  |  |
|--|--|
| <input type="checkbox"/> \$1,000 Donor     | <input type="checkbox"/> \$10,000 Benefactor |
| <input type="checkbox"/> \$2,500 Patron    | <input type="checkbox"/> \$25,000 Sponsor    |
| <input type="checkbox"/> \$5,000 Supporter | <input type="checkbox"/> \$50,000 Founder    |
| <input type="checkbox"/> Other _____       |  |

MC/VISA \_\_\_\_\_ Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_

For All Donations:

My name is \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

For Memorial Donations:

(Please circle one) In memory of/In honor of \_\_\_\_\_

(Optional) Please inform \_\_\_\_\_

His/Her Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

That a gift has been made by \_\_\_\_\_

**Make checks payable to The Neuroblastoma Children's  
Cancer Society.**

Contact us or make a contribution to our cause:

**The Neuroblastoma Children's Cancer Society**

P.O. Box 957672

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Fax (847) 605-0705

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