



Children's Neuroblastoma  
Cancer Foundation



Pathways to a cure.





## Imagine Being Born With Cancer.

**Johnny started his first chemo treatment at 4 weeks old.**

Neuroblastoma invades early. It originates from immature nerve cells and manifests as a solid tumor most commonly in the adrenal glands above the kidney, and in nerve tissues in the neck, chest, abdomen or pelvis. Many of its young victims are diagnosed before they can even walk. Most of its victims are in advanced stages of disease at diagnosis.

Neuroblastoma is a cancer very few people know about, though it is very well known in the pediatric oncology medical community. Neuroblastoma accounts for 8 percent of all childhood cancers and is responsible for 15 percent of all childhood cancer deaths.

It is the most common solid tumor cancer in children second only to brain tumors.

Neuroblastoma has a high rate of relapse and the survival rate for high risk children is less than 40 percent.

Neuroblastoma is a predator. It's been called 'the great masquerader' because its symptoms mimic common childhood illnesses.

Neuroblastoma can strike twice in the same family, and a small percentage of patients have been diagnosed in their teens and as young adults.

There is no known cause of neuroblastoma.

The median age of neuroblastoma diagnosis is **2**

# Can Neuroblastoma Be Cured?

If research and awareness of neuroblastoma received the level of funding the government, corporations, sports teams, celebrities and individual donors gave to more publicized diseases such as breast cancer and leukemia, these babies would have better than a fighting chance.

Research is the answer. It is the key to unlocking the mysteries of the disease.

Within the past few years a single treatment was proven to increase survival of high risk children from 20 percent to nearly 40 percent. Sadly that research took 20 years to develop.

But progress is being made. And it is being made through the efforts of neuroblastoma families and their supporters.

Targeted therapy is now being researched and applied in clinical trials.

Genetics have played a role in understanding the disease and identifying links to hereditary neuroblastoma.

Proper funding is needed to accelerate the research process and support the tremendous resources we have in the medical community to open new trials especially for relapsed neuroblastoma.

Nearly 60 percent of children are enrolled in clinical trials compared to only 4 percent of adults.

The children are deserving of the best medical minds we have. And they must be supported with our dollars to continue on the pathway to a cure.



*“I had less than a 2 percent chance. The fact that I’m still here could give people hope.”*

**– Survivor Johnny Losurdo, 18, who continues to deal with medical problems related to neuroblastoma**



Neuroblastoma is responsible for **15** percent of all childhood cancer deaths.

The Odds



CNCF has earned the respect of the medical community in the United States. We created a medical advisory board of renowned researchers to guide us in funding the most innovative research projects.

We have collaborated with the Neuroblastoma Children's Cancer Alliance UK to present the first parent medical conference for neuroblastoma families in London.

Over \$2 million in research has been funded by CNCF. It is critical to improving survival rates and treatment of the thousands of children battling neuroblastoma and its late effects.

Federal spending has been cut over the years and private philanthropy is needed to fill the research gap of unfunded projects. Only a small percentage of federal grant applications are funded.

More clinical trials are needed. Funding for drug development is needed.

CNCF brings hope to hundreds of families across the world. It is what keeps us fighting and moving forward.

We will not lose sight of our mission but we can do so much more with your help.

A cure is within reach.



## Who is CNCF?

The Children's Neuroblastoma Cancer Foundation (CNCF) was founded in 2000 by parents who had lost a child to neuroblastoma.

Hundreds of families have joined us in our fight to make the journey of neuroblastoma a little easier. Our influence has extended to families in Canada and across Europe.

We are committed to finding a cure through research funding, education and awareness programs.

## What We've Given

Celebrity golf events and dodge ball tournaments, bake sales, dance marathons, wine tastings, adventure cyclists and marathon runners: All of these efforts by neuroblastoma family and friends have contributed to CNCF's ability to provide research grants that support advances in medicine. Funded research in recent years includes:

Dr. Ting Tao, Dana Farber Cancer Institute	<b>\$100,000</b>
Dr. Bilal Omer, Baylor College of Medicine	<b>\$100,000</b>
Dr. Eveline Barbieri, Baylor College of Medicine	<b>\$100,000</b>
Dr. Qiwei Yang, University of Illinois, Chicago	<b>\$100,000</b>
Dr. Yibing Xu, Children's Hospital Los Angeles	<b>\$100,000</b>
Dr. Susan Cohn, University of Chicago	<b>\$65,000</b>
NANT	<b>\$200,000</b>
Metin Gurcan PhD, Ohio State University	<b>\$100,000</b>
Dr. Kelly Goldsmith, Children's Hospital of Philadelphia	<b>\$100,000</b>
Dr. Hong Xu, Memorial Sloan Kettering	<b>\$100,000</b>
Sonia Hernandez, Columbia University	<b>\$50,000</b>
Dr. Jason Shohet, Baylor College of Medicine	<b>\$40,000</b>
Dr. Sam Volchenboum, University of Chicago	<b>\$50,000</b>





## Leadership: A Neuroblastoma Breakthrough

The INRG Neuroblastoma Patient Database. CNCF is one of the lead funders of the first-ever neuroblastoma patient database in the world. After nearly seven years of research study, the International Neuroblastoma Risk Group launched the INRG database in 2012. The database creates a single source for capturing poignant research data such as information attained from tissue and tumor analysis of patients worldwide. Led by research physicians Drs. Sue Cohn and Sam Volchenbom, neuroblastoma researchers at Comer Children's Hospital at the University of Chicago, and Dr. Andy Pearson, a neuroblastoma researcher in the UK, the INRG database enables access to larger sets of data and sample sizes, using common identifiers and metrics to define risk groups, so researchers can more accurately evaluate tumor tissue and genetic factors that contribute to disease.

Once a search engine for the database was built, Dr. Volchenbom teamed up with the COG Tissue Bank in Columbus, Ohio, to create a connection whereby a researcher can instantly search for tumor samples corresponding to patients in the database. Aided by COG's unique identifiers, researchers can now conduct high-density gene analysis and DNA sequencing of hundreds of tumors, and identify patients by age and other factors. A link to genomic data, both domestic and international, is now in development.

*“The big problem with studying any pediatric cancer is there aren't enough numbers to learn anything if you just try to do it locally. This was a big step to take; no other groups have been able to do this. Now one can link patient information to tissue availability and genomic data, connecting researchers to information in a way that was previously impossible. We will be able to do research more quickly. CNCF has been so generous. Without them, we wouldn't have been able to get this off the ground.”*

—Dr. Sam Volchenbom

There are an estimated **800** new cases of neuroblastoma diagnosed in the U.S. each year.

# Education

## Parent Symposium

Since 2002, CNCF has hosted and underwritten an annual two-day medical symposium in the Chicago area where families can hear directly from doctors and researchers specializing in neuroblastoma. Attendees leave with knowledge of advanced treatments and clinical trials, and emotional support from a network of friends and families who understand what they're going through.

"Attending the CNCF conference saved my child's life." As stated by Frank Kalman, parent of a neuroblastoma survivor.

Throughout the day, there are patient and sibling activities and support through interactive play. Friendships are made, lessening the impact of being alone in their world of bald heads, scars and tubes coming from their chests.

*“CNCF is unique in its support of both basic research and parent education. CNCF's Young Investigator grants have been vital to promoting the careers and research of the next generation of neuroblastoma investigators. This support is even more important in this era of reduced funding from the NIH. The family educational annual meeting is truly special.”*

*— Darrell J. Yamashiro, MD, PhD, CNCF Medical Board member*



## CNCF Parent Handbook

One of the most comprehensive resources on neuroblastoma is available on the Children's Neuroblastoma Cancer Foundation's Web site. Written by neuroblastoma parents, it's a handbook for families that decodes complicated medical terms, informs about advanced treatment therapies and potential side effects, and offers guidance in dealing with relapse. The handbook was created in 2007 and is 14 chapters and growing.



*"The CNCF Parent Handbook was my bible when we were going through treatment."*

*Stated by Judy Mendoza, mother of neuroblastoma survivor*

Less than **1** percent of research funded by the American Cancer Society goes to fight childhood cancers.

## Own This Cause

The world is full of need. If it were not for the generosity of corporate philanthropies and large individual donors, many advances in medicine and the sciences would never have transpired.

Corporations, nonprofits and government agencies that approve grant funding, and large individual donors support causes they feel are important. What's more important than saving a child's life?

Children with cancer shouldn't have to compete for research dollars against adult cancers or those that are better-known. Yet they do every day. With ongoing support from major corporate sponsors and large major donors, children with neuroblastoma won't have to fight. This is your opportunity to face a crisis head on and make change. It is an investment that pays off in securing the future of children with cancer.

*“If a baby killer were on the loose, we'd use every resource to end the scourge. Neuroblastoma is a baby killer. It robs us of our most precious gifts – our children. I lost my son, Nicholas, to neuroblastoma when he was 10 years old. To have the horror of neuroblastoma visited upon your family is difficult enough. To then be tasked with raising awareness and money to advance research is a burden many neuroblastoma families have accepted, because they're not willing to give up on their children. But they shouldn't have to do it alone. Our children are our future. We all should take an interest in their health and seeing them grow up.”*

**— Pat Tallungan, President and Founder of the Children's Neuroblastoma Cancer Foundation**



## Partner with Us

We've got the heart, the passion and the best reason of all to fight neuroblastoma – saving children's lives.

With your sustainable, ongoing support, CNCF can give hope to families facing a neuroblastoma diagnosis, increase public awareness and fund the next breakthroughs in neuroblastoma treatment and research.

- Raise public awareness
- Educate families
- Fund more research

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Parent of a child who passed away from neuroblastoma

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