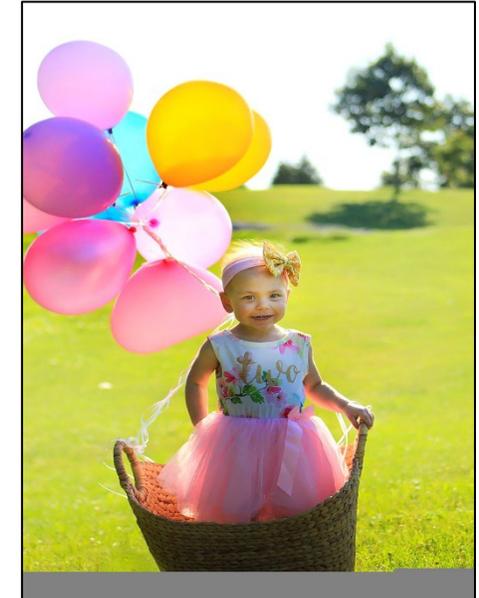




The
National
Children's
Cancer
Society

The National Children's Cancer Society (NCCCS)



History and Mission of the NCCS

- The NCCS was founded in 1987 by our current President and CEO, Mark Stolze to ensure that children with cancer were given every chance for survival by assisting those in need of a bone marrow transplant (BMT). At the time, BMTs were gaining recognition as a viable treatment and represented the last hope for survival for many patients who did not respond to conventional treatment. Unfortunately, most insurance companies considered bone marrow transplants experimental and denied coverage. Over time, these transplants became a standard form of treatment and covered by insurance. This allowed the NCCS to expand its programs and services, while remaining committed to ensuring every child with cancer is given every opportunity for survival. Our programs ease the financial burdens that accompany a diagnosis, give crucial support and comfort, and address the challenges of survivorship.

A little about the families we serve

- The parents of nearly 16,000 children in the United States will hear “your child has cancer” this year. Across all ethnic groups, ages, and socioeconomics, this disease remains the leading cause of death by disease in children.
- Out of pocket costs coupled with loss of income makes childhood cancer financially crippling.
- In a recent needs assessment conducted by the NCCS, we found that over 47% of our families were living below the poverty line after their child was diagnosed with cancer.
- 90% of families served, express difficulty in financially managing their household.



NCCS National and International Programs

- *Family Support Program* provides practical and emotional assistance to parents, caregivers and survivors.
- *Beyond the Cure* survivorship program prepares survivors and their families for life after cancer.
- The *Transportation Assistance Fund* alleviates the financial burden of travel and lodging for families who have a child with cancer.
- The *Emergency Assistance Fund* provides a stipend to families to address basic needs who have a child that has been inpatient or away from home for an extended period of time.
- *Michele Hertlein Global Outreach Program* coordinates worldwide distribution of donated pharmaceuticals and medical supplies to healthcare facilities in less-developed countries throughout the world. The program is dedicated to addressing the critical effects of inadequate and nonexistent medical care for thousands of children with cancer worldwide.



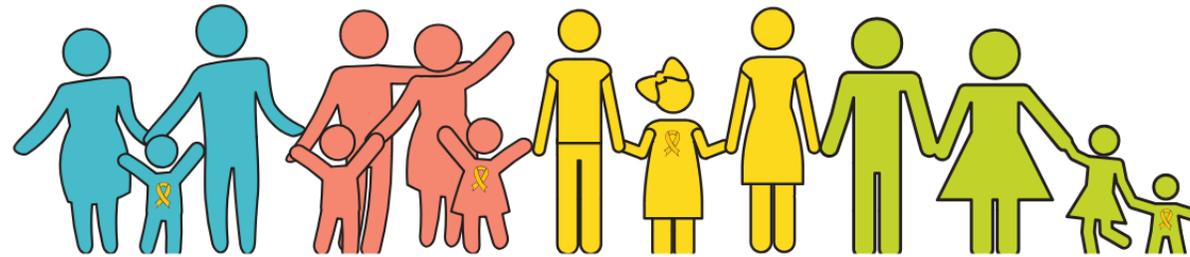
NCCS National Programs



- The NCCS **Family Support Program** provides practical and emotional assistance to parents, caregivers and survivors. Our staff are dedicated individuals who offer support, educate parents and caregivers on how to best advocate for their child, and provide referrals when needed.

Facebook Support Group

Childhood Cancer Support Group



Because no family should go through childhood cancer alone.™

Childhood Cancer Support Group (NCCS)

- The purpose of this group is to provide a compassionate and supportive environment for parents, guardians, and survivors of childhood cancer. It is a place to connect, offer and receive support and encouragement and to share tips and resources.
- This is a closed Facebook group, members must be a parent, guardian or survivor of childhood cancer and members of this group must be at least 18 years old. To ensure that it is a safe environment for the members we require an approval process and staff monitors the posts.
- We have over 1,000 active members on the site.



Mentorship Program

- **Mentorship program** pairs a younger child in treatment between the ages of 10-17 with one of our scholarship recipients. The mentors are an experienced guide, trusted ally, and caring role model. The program goes throughout the academic year. Mentees are able to participate in sessions year after year until their 18th birthday.



Financial Assistance Programs



Since inception, we have provided more than **\$68 million** to over **47,000** children with cancer.

Transportation Assistance Fund

- **Transportation Assistance Fund** alleviates the financial burden of travel and lodging for families who have a child with cancer. The NCCS takes a “no matter what” approach to ensuring that children get to the treatment they need. The fund also provides assistance for lodging when non-profit lodging is not available.





- The Transportation Assistance Fund ensures children with cancer, like Mackinsley (pictured at the left), have access to treatment. Mackinsley was diagnosed with Embryonal Rhabdomyosarcoma. In addition to chemotherapy, Mackinsley needed 6 weeks of daily radiation. Living over 2 hours from their treatment facility, this posed a huge financial hardship for the family. The NCCS was there for them every step of the way.

Eligibility Guidelines

- Child must be diagnosed with cancer. If child has a brain tumor, the tumor must be high grade (III or IV) or anaplastic to be eligible.
- Child must have been diagnosed on or before his/her 18th birthday and treated before their 21st birthday. Adults who relapse after their 18th birthday and who were not previously assisted are not eligible for services.
- Child must be a citizen of the United States or reside in the United States with an I-551 card (green card) for 12 months without prior history of the current illness.
- Guardian applying for assistance must have less than \$5,000 in easily accessible bank accounts (such as checking and savings).

We are grateful for the support from the American Legion Child Welfare Foundation which provided funds towards the Transportation Assistance Fund and enabled the NCCS to produce a program brochure dedicated to families.



The National Children's Cancer Society (NCCS) is here to support your family as you make your way through the world of childhood cancer.

Unwavering commitment to families. No matter what.

With over thirty years of experience, the NCCS has become a master navigator of this world, helping get you where your family needs to be – physically, financially and emotionally. Whether that is helping to ensure you can get to the treatment center where the best care is available, providing guidance on the many issues that accompany treatment and survivorship or simply serving as a source of hope and compassion – our unwavering commitment to families enables you to give your child the best possible shot at survival.

We take a "no matter what" approach when it comes to supporting you, creating a clear path through the maze of childhood cancer and survivorship that helps your family stay strong, stay positive and stay together. Because no family should go through childhood cancer alone™.



This brochure was made possible through a grant from the American Legion Child Welfare Foundation, Inc.



Because no family should go through childhood cancer alone.™



Strength and support start here.

The NCCS ensures access to health care and eases emotional distress so you can focus on what matters most—your child.



The NCCS Family Support Program provides someone to lean on in tough times. An NCCS case manager provides practical and emotional support to help you be your child's best advocate.



Our private Facebook support group, www.facebook.com/nccs, provides a compassionate place for parents, guardians and adult survivors of childhood cancer to connect, offer and receive encouragement and share tips



and resources. Our Transportation Assistance Fund alleviates the financial burden of travel and lodging costs associated with appointments. And when your child is hospitalized for an extended period of time, our Emergency Assistance Fund provides financial support that can be used toward basic living expenses like mortgage/rent, meals, utility bills, and vehicle expenses.



For current eligibility guidelines and to apply for financial assistance, visit our website at: www.thenccs.org/financial-assistance.



Resources for every step of the way.

The NCCS offers a number of free resources to help you navigate the social, practical and emotional aspects of childhood cancer and survivorship. Publications can be requested through our online store at: thenccs.org/publications.



The Other Side of the Mountain: A Parent's Guide to Surviving Childhood Cancer, helps parents along each phase of their child's treatment, from navigating emotions and spirituality to offering practical health insurance, school and family support.



The View From Up Here: Your Guide to Surviving Childhood Cancer, is exclusively for teens and young adult cancer survivors and addresses emotional and spiritual growth and offers support on health insurance, school and relationships.



I Can Move Mountains, provides a creative outlet for patients to learn about themselves and their cancer journey while also having some fun.



Sammie's New Mask, designed for children kindergarten through third grade, addresses concerns and common misconceptions about cancer (also available in Spanish).



Making the Right Transition into College is a pamphlet designed to help prepare college-age survivors for the practical issues and challenges they may face as they transition to college.

Believe in new beginnings.



Rest assured, there is life beyond cancer. The Beyond the Cure survivorship program prepares survivors and their families for life after cancer.

Our Late Effects After Treatment Tool (LEATT), provides survivors with a private, customized online assessment of potential late effects based on their diagnosis and treatment. For more information and to create an assessment visit <https://leatt.thenccs.org>.

Young childhood cancer survivors face the future with an amazing outlook and perspective on life.

We established the Beyond the Cure Ambassador Scholarship Program to celebrate our young warriors as they move into the next chapter of their lives and provide assistance for survivors attending college in pursuit of their future goals.



In addition, the program sponsors survivorship conferences and distributes free educational materials for survivors and their families.

Emergency Assistance Fund

- The **Emergency Assistance Fund** provides a \$300 stipend to families who have a child that has been inpatient or away from home for 15 consecutive days. Assistance is unrestricted and may be used for living expenses, meals, childcare, health insurance premiums, and other healthcare costs.



Beyond the Cure

- The **Beyond the Cure** survivorship program prepares survivors and their families for life after cancer through educational publications, conferences, scholarships and a personalized late-effects online assessment tool.



Late Effects After Treatment Tool

<https://leatt.thenccs.org/>

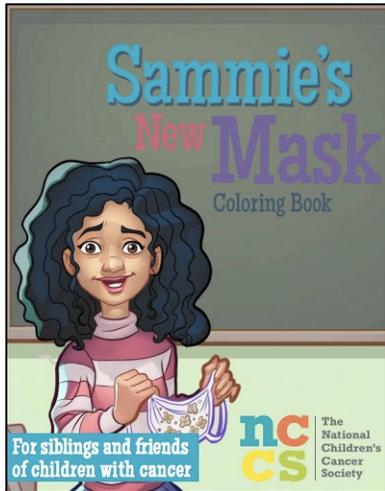
- Due to the toxicity of the treatment they received, **90%** of childhood cancer survivors will experience some late effects of treatment such as complications with fertility, focus or comprehension issues, and heart damage. Around **1/3** will have severe, disabling or life-threatening chronic conditions.
- **Late Effects After Treatment Tool (LEATT)**, was created in collaboration with Dr. Robert Hayashi, who is the Director of the Late Effects Clinic at St. Louis Children's Hospital/Washington University School of Medicine. This tool provides survivors with a private, customized online assessment of potential late effects based on their diagnosis and treatment.

Beyond the Cure Ambassador Scholarship Program

- **The Beyond the Cure Ambassador Scholarship program** offers college scholarships to help survivors move forward with their lives in meaningful ways by providing **\$3,500** scholarships to **58 recipients** each year.
- The window for accepting applications begins **January 1** through **March 31** each year.
- To date, we have awarded over **\$2 million** to **227** recipients.



Publications

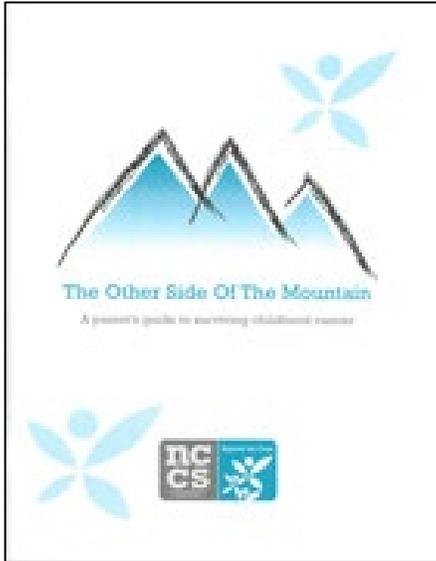


A coloring book for elementary school aged children that addresses common misconceptions about childhood cancer.

An activity book designed for children ages 8-12 that provides a creative outlet for patients to learn about themselves and their cancer journey.

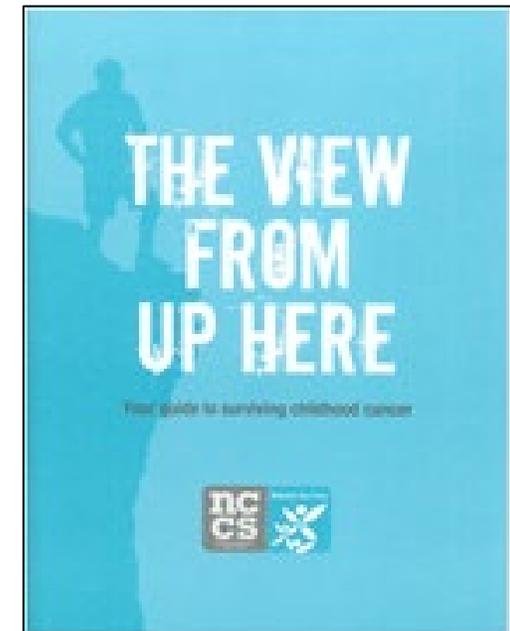


Publications



The Other Side of the Mountain is a parent guide that is designed to help parents and families through every phase of the cancer journey.

The View From Up Here is a guide exclusively for teens young adults that address many aspects of their cancer experience.



Questions???

