

Brain and Spinal Cord Tumor Family Resource Guide

INTRODUCTION

When a child is diagnosed with a brain or spinal cord tumor it impacts the entire family. At Children's Minnesota we not only treat the child, we are here for the whole family. It is this unique treatment philosophy, combined with world-class facilities, clinical expertise, leading technologies, and remarkable outcomes, that makes Children's the best place for pediatric oncology treatment.

In addition to expert medical care you also need the support of family, friends, and a compassionate health care team. The Cancer and Blood Disorders Program at Children's Minnesota works with you and your primary doctor to provide the best care available with as much care as possible close to home.

The following sections contain additional information about the brain and spinal tumor program at Children's Minnesota. Please contact your child's health care team with suggestions, questions, and concerns throughout treatment, recovery, and after treatment.

Children's Minnesota
Cancer and Blood Disorders Clinic
2530 Chicago Avenue South, Suite 175
Minneapolis, MN 55404
P: 612-813-5940
F: 612-813-7258
www.childrensmn.org/services/cancer-and-blood-disorders

IMPORTANT PHONE NUMBERS

Cancer and Blood Disorders Clinic	612 - 813 - 5940
Inpatient Minneapolis Unit	612 - 813 - 6144
Children's Neurosurgery - St. Paul	651 - 220 - 6420
Neurosurgical Associates - Abbott	612 - 871 - 7278

YOUR TEAM MEMBERS

	NAME	
Neurooncologist	Dr. Bendel or Dr. Skrypek	Call Outpatient Clinic
Nurse Practitioner	Heather Johnson	Call Outpatient Clinic
Clinic Nurses	Sarah and Ana	Call Outpatient Clinic
Social Worker	Lisanne Racine	Call Outpatient Clinic
Child Life Specialist	_____	Call Outpatient Clinic
Physical/Occupational Therapy	_____	Call Rehabilitation Therapy
Speech Therapist	_____	Call Rehabilitation Therapy
Psychologist	_____	Call Psychology Services
Chaplain	_____	Call Chaplaincy

CALL 911 right away if your child stops breathing, isn't responding or has a seizure.

CALL THE CLINIC NUMBER 24 HRS/DAY to reach the answering service and on-call provider when:

- Thermometer reading greater than or equal to 101.5° F or 38.5° C
- Shaking chills with or without fever
- Excessive vomiting/severe nausea without relief after giving medicine
- Not urinating for greater than 8 hours or unable to drink
- Uncontrolled bleeding
- Uncontrolled pain
- Head injury
- Dramatic change in your child's behavior and/or energy level
- Any major concern

After hours, expect calls to be returned within 20 minutes, otherwise call the answering service again (remove call blocking from your phone).

For prescription refills, please call your pharmacy. Other questions about prescriptions should happen during your appointment or regular clinic hours.

LOCATIONS AND PARKING

Minneapolis

Children's Specialty Center
2530 Chicago Avenue South
Minneapolis, MN 55404

Children's Minnesota Hospital
2525 Chicago Avenue South
Minneapolis, MN 55404

Minneapolis Parking Information

The entrance to the Children's Specialty Center parking ramp (Green Parking Ramp) is off East 26th Street, west of Chicago Avenue. To access the hospital, take the ramp elevator or stairs to floor 2 and proceed through the skyway across Chicago Avenue.

Children's Minnesota Emergency Department drop-off and pick-up is off East 25th Street.

Parking fees are posted at the ramp entrance. If you will be visiting for several days, you may purchase discounted parking coupons from the hospital cashier, located on the second floor of the hospital (weekdays 8 to 11 a.m. and noon to 4 p.m.).

Saint Paul

Gardenview Tower
347 North Smith Avenue
Saint Paul, MN 55102

Children's Minnesota Hospital
345 North Smith Avenue
St. Paul, MN 55102

Saint Paul Parking Information

Three parking ramps are located on campus.

- The **Red Ramp** is the main parking ramp at the Children's Minnesota St. Paul campus, located near the corner of Smith Avenue and Grand Avenue.
- The **Green Ramp** is closest to the Ritchie Medical Plaza. When going south on Smith Avenue, the entrance to the Green Ramp is on the left, across the street from Children's Minnesota St. Paul hospital.
- The **Blue Ramp** is closest to the Fort Road Medical Building. When going South on Smith Avenue, the entrance to the Blue Ramp is on the left on Sherman Street.

The first 30 minutes of public parking in all St. Paul campus ramps is free. Special parking rates are available to parents who are at the hospital for long periods of time or for those who make frequent daily trips to the hospital. Ask your child's nurse about special parking rates for parents.

Call campus services at [651-241-7275](tel:651-241-7275) or the family relations liaison at [651-220-6888](tel:651-220-6888) for more details.

The Neurooncology Team

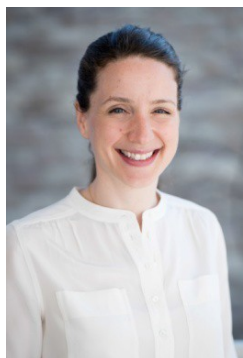
Children's Minnesota

The neurooncology (brain and spinal tumor) group at Children's Minnesota is a multidisciplinary team that cares for children with brain and spinal cord tumors. We treat more children with brain and spinal cord tumors than any other institution in the five state area.

At Children's we pride ourselves in providing comprehensive care to our patients. To do this, we include numerous specialists in the care of our patients. These specialties include oncology, physical therapy, occupational therapy, speech therapy, child life therapy (teaching children through play), endocrinology, neurology, sleep medicine, neurosurgery, radiation oncology, integrative medicine, audiology, neuropsychology, nutrition, research, and social work. Here are introductions to many of the members of our neurooncology team.



Anne Bendel, MD is a Pediatric Neurooncologist who specializes in the treatment of central nervous system (CNS) tumors of children and young adults. She completed medical school, pediatric residency, and pediatric hematology/oncology fellowship training at the University of Minnesota. She joined Children's Minnesota in 1994. Anne is the director of the Brain and Spinal Tumor Program at Children's Minnesota, where she manages the diagnosis, treatment, and follow-up of patients with brain or spinal cord tumors. When she is not working she enjoys traveling, watching sports, hiking, and spending time with her husband and four children.



Maggie Skrypek, MD is a Pediatric Neurooncologist who specializes in the treatment of central nervous system (CNS) tumors of children and young adults. She completed medical school at Creighton University in Omaha and her pediatric residency and pediatric hematology-oncology fellowship at the University of Minnesota. Dr Skrypek went on to complete an additional year of fellowship training in pediatric neurooncology at Northwestern University in Chicago. She joined Children's Minnesota in 2015. Maggie manages the diagnosis, treatment, and follow-up of patients with brain or spinal cord tumors. When she is not working she enjoys camping, hiking, running, and spending time with her husband and two children.



Heather Johnson, PNP completed her nursing degree at Winona State University and received her master's degree from Saint Catherine University. Heather joined Children's in 2008 and worked in the Cancer and Blood Disorders Clinic for 11 years before completing her training as a nurse practitioner. Her focus has always been neurooncology. Heather sees patients while in the hospital and in the clinic. Outside of work Heather enjoys spending time with her husband and their three children, working on their hobby farm, and spending time with friends and family.



Lisanne Racine, LICSW, is a clinical social worker in the neurooncology program. She received her Masters of Social Work degree from the University of Wisconsin-Milwaukee and attended Saint Olaf College as an undergraduate, receiving a B.A. in Sociology. Lisanne has been helping children and families for almost 30 years. In her role she provides support, counseling, education, and referrals to community resources, along with helping families manage the daily challenges associated with having a child diagnosed with a brain tumor. When not working she enjoys spending time at her cabin, teaching fitness classes, playing with her puppies, and spending time with her husband and four children.



Sarah Wimmer, RN, BSN completed her nursing degree at St. Catherine University. Sarah joined Children's Minnesota in 1987. Her focus area is neurooncology, where she case manages and sees patients in the clinic. When you call the clinic, Sarah will be one of the nurses returning your call. Outside of work she likes to spend time at her cabin, gardening, reading, hiking, and spending time with her husband and four children.



Ana Brown, RN, BSN completed her nursing degree at St. Catherine University. Ana joined Children's Minnesota in 2012. Her focus area is in neurooncology, and she has a special interest in research. She case manages and sees patients in the clinic. When you call the clinic, Ana will be one of the nurses returning your call. When not working Ana enjoys camping, hiking, and spending time with her husband and two children.



Kristy, Jodi, and Sam are the oncology child life specialists. They are developmental experts who help children cope with their health care journey. They provide age-appropriate information and support for patients, siblings, and their families. They are specially trained to establish a non-threatening, supportive environment in which patients and families can be met creatively. They are excellent teachers.



Claire, Audrey, and Katherine are the neurooncology research team at Children's Minnesota. Audrey is a nurse who specializes in research. Claire and Katherine are research associates who help to ensure we are following protocols accurately. We participate in research protocols to provide our patients with the opportunity to access cutting edge treatments in the field of neurooncology and to push the envelope of current medical knowledge to provide future patients with the best care possible.



These are a few of the rehabilitation specialists you may meet. Physical therapy (PT) and Occupational therapy (OT) are available both in the hospital and in our outpatient clinic. PT and OT are used to help restore function in patients after surgery. They promote the ability to move, reduce pain, restore function, and prevent disability. By receiving PT and OT loss of mobility can often be prevented before it occurs. Speech therapy (ST) is used to treat speech, language, social communication, cognitive-communication, and swallowing disorders. ST can be done both in the hospital and in the outpatient rehabilitation office.



Alycia and Rachel are the two dietitians you may meet. Compromised nutrition can lead to slow healing and recovery, and may extend hospital stays. Our dietitians can help design a nutrition program to improve or maintain the health of your child, both during hospital stays and throughout any treatment that may be needed.



Emma and Kim are the oncology pharmacists in clinic. There are other oncology pharmacists who work in the hospital as well. In clinic, Kim and Emma help the team to make sure your child receives the appropriate medications, and other oncology treatments. They watch for interactions between medications, and recommend ways to minimize side effects. While they don't get to meet with families often, our pharmacists are working hard behind the scenes to support your child along this journey.

Additional providers that may see your child:

Neurosurgery: A neurosurgeon is a physician who is an expert in children's brains and spinal cords. Neurosurgeons perform surgeries to remove tumors and manage side effects related to them. <https://www.childrensmn.org/services/care-specialties-departments/neurosurgery/>

Endocrinology: An endocrinologist is an expert in everything involving the endocrine glands and the hormones they release. They treat everything from diabetes to growth disorders to thyroid disorders. <https://www.childrensmn.org/services/care-specialties-departments/diabetes-endocrinology/conditions-and-services/>

Neurology: A neurologist provides first-line care for seizures, head trauma, and other nervous system issues. They will work closely with the oncology team to manage the common side effects of brain tumors, including severe headaches or seizures. <https://www.childrensmn.org/services/care-specialties-departments/neurology/>

Integrative Medicine: Our integrative medicine program combines the best of complementary and conventional medical therapies to develop holistic solutions for children. Our approach is not meant to replace traditional treatments, but rather to enhance them. <https://www.childrensmn.org/services/care-specialties-departments/integrative-medicine/>

Music Therapy: It's no secret that music can be uplifting and relaxing in any situation and a growing amount of evidence suggests that the power of music can have significant benefits to kids in hospital settings. <https://www.childrensmn.org/services/family-services/child-life-specialists/music-therapy/>

Massage Therapy: For many, thinking of a massage brings images of a relaxing environment with low lights and soft music, however massage has also been proven to help with children's stress and anxiety levels, decrease muscle tension, and improve quality of sleep. At Children's Minnesota we have highly trained massage therapists who use different techniques to reduce pain and improve physical, emotional, mental, and spiritual health and healing. For more information on massage visit the Integrative Medicine page.

Psychology: Child psychologists work with children and adolescents to diagnose and help resolve issues causing emotional or behavioral problems, such as anxiety or depression. At Children's Minnesota we have psychologists who work specifically with our oncology patients to help children navigate their emotional health throughout this process.

Audiology: Our audiologists have expertise in providing diagnostic and rehabilitative services related to hearing. <https://www.childrensmn.org/services/care-specialties-departments/ear-nose-throat-ent-facial-plastic-surgery/conditions-and-services/audiology/>

HELPFUL RESOURCES

MyChildren's Portal

This portal offers online access to your Children's Minnesota medical records. Ask the front desk staff in the outpatient clinic or the patient registration staff on the inpatient unit for more information. You can also enroll by calling Children's Health Information Management at 612-813-6216. Patients under 18 must have their parent/legal guardian request a MyChildren's account.

Parent and Survivor Support Groups

<http://cbtf.org/>

Groups bring parents and survivors together to talk about and support each other through challenges that only other brain and spinal tumor families understand. It is run by the Children's Brain Tumor Foundation and is held at Gilda's Club in Minneapolis. For more information please email info@cbtf.org or call 212-448-9494.

Kids Can MN

www.kidscanmn.org/tote-bag/

It is difficult to keep kids entertained during numerous clinic and hospital visits. Kids Can MN aims to help by providing patient tote bags which contain age and gender appropriate gifts and a gift card. The bags also contain resources, supplies, and items to help make hospital stays easier.

Lisa's Army

www.lisasarmy.org

To help wind down and relax, Lisa's Army provides comfort to those battling cancer. If desired they may provide an iPad or Beats headphone, along with a comfort care package.

Warrior Wagons, Inc.

www.warriorwagonsinc.com

This foundation was created to give newly diagnosed pediatric cancer families a wagon filled with comfort and helpful items. You must request the wagon within the first 60 days of diagnosis and wagons are aimed at children less than 7 years of age. Ask Lianne for an application.

LODGING RESOURCES

Ronald McDonald House

- **Minneapolis:** We have an on-site Ronald McDonald House on the 3rd floor of the hospital. The Ronald McDonald House provides accommodations and services to families and caregivers of patients receiving care in the PICU or other intensive care units in Minneapolis.
- **St. Paul:** There is a Ronald McDonald Family Room on the third floor of the River Tower, near the Child Life Zone and Family Resource Center, which can be accessed from 8am to 10pm seven days a week in St. Paul. Family members and friends of patients who are admitted to the PICU are automatically eligible for services provided by the Family Room. Other families may be considered, please talk to social work for more information.
- **Oak Street:** There is also an offsite Ronald McDonald House at 621 Oak Street SE, Minneapolis which families have access to. Please talk to social work for more information to see if this is a good fit for your family.

Hope Lodge (American Cancer Society)

Free lodging is provided for cancer patients and caregivers traveling far from home for outpatient medical care related to the patient's cancer diagnosis. Patients staying at Hope Lodge must be 18 years of age or older, in active cancer treatment, and permanently reside more than 40 miles or 1 hour away from the Cancer Treatment Center. Each patient must be accompanied by a caregiver. Children under the age of 18 are not allowed to stay in the facility. The address of Hope Lodge is 2500 University Avenue SE, Minneapolis 55414, phone 612-379-6352.

Local Hotels

A listing of local hotels with a medical rate is available. The most up-to-date list is printable from the Children's web site at <https://www.childrensmn.org/your-visit/while-you-are-here/local-lodging-options/>

FINANCIAL COUNSELING

Children's Minnesota

www.childrensmn.org/your-visit/after-your-visit/billing-and-financial-matters/billing-policies

Financial counseling at Children's in Minneapolis is located in the Family Resource Center on the 2nd floor of the hospital, across from the hospital "welcome desk." The phone number in Minneapolis is 612-813-6432. In St. Paul it is located in the Family Resource Center in the River Tower on the 3rd Floor, Suite 3107. The phone number in St. Paul is 651-220-6367.

Consumer Credit Counseling Foundation

www.cccfusa.org

A national, nonprofit consumer credit counseling agency that provides 24 hour toll-free telephone credit counseling. They provide help with budgeting, payments, and debt collection.

American Financial Solutions

www.myfinancialgoals.org

A nonprofit credit counseling agency that offers free debt management and educational programs to help financially distressed families.

Lutheran Social Services Financial Counseling

www.lssmn.org/financialcounseling/financial-wellness-services/budget-debt-counseling

This agency offers a variety of services including budget and debt counseling, credit improvement, foreclosure prevention, home buying, home ownership services, reverse mortgage counseling, and student loan debt analysis. Their phone number is 888-577-2227.

EVENTS SUPPORTING BRAIN AND SPINAL TUMOR RESEARCH

Walk for Amazing

This walk is typically in June and it raises money for Children's Minnesota. If you choose to walk, you can raise money for the Cancer Kids Fund, which is a fund that helps children who are going through a journey with cancer. Another option is to donate directly to Heroes for Hope which is a fund that specifically helps our pediatric brain tumor program at Children's Minnesota. More information can be found at:

<https://www.childrensmn.org/childrens-events/walkforamazing>

Heroes For Hope

This event is typically held in October and raises money for pediatric brain tumor research at Children's Minnesota. Money raised goes to an endowment at Children's Minnesota, which was founded when three families came together to honor their little heroes. The event is a day of fun at the farm featuring hay rides, a corn maze, a silent auction, and fun. More information can be found by visiting the Heroes for Hope Facebook event page.

Ride 4 Kids

This event is typically held in July and raises money for the Pediatric Brain Tumor Foundation. The event starts with a police-escorted motorcycle ride in Vadnais Heights and ends with a lunch and a program to honor survivors of pediatric brain tumors. If your child would like to be honored at the event, they are welcome to register! More information can be found at: <http://www.curethekids.org/events/ride-for-kids/>

Curesearch Walk

This walk is typically held in September and money raised goes to fund children's cancer research. The walk is around Lake Phalen and there is also a celebration for the superhero children who survived and a tribute to those who lost their battle. The event includes the walk, ceremony, face painting, games, music, and food. More information can be found at: <http://www.curesearchevents.org>

Humor to Fight the Tumor

This event is typically held in September and raises money for the American Brain Tumor Association and awards research grants to many different hospitals. Their goal is to move people through the power of hope and laughter. The gala features silent and live auctions, live comedy, dinner, and stories of determination and courage by brain tumor survivors and honorees. More information can be found at: <https://www.humortofightthetumor.org>

Brain Tumor 5k (BT5K)

This event is typically held in October and raises money for the American Brain Tumor Association, which helps support brain tumor patients by advocacy, education and research. Information about the BT5K can be found at: <https://hope.abta.org>

CAMPS AND RETREATS

Camp Victory (Zumbro Falls, MN)

www.campqualityusa.org/mn

A five day overnight camp for kids ages 7-17 with Cancer or sickle cell disease and their siblings. Campers have the opportunity to partake in a variety of activities including dancing, crafts, archery, a high ropes course, river tubing, zip lining, mini golf, and laser tag. Check the website for dates and registration information.

Camp Mak-a-Dream (Gold Creek, MD)

www.campdream.org

There are a variety of camp programs for kids, siblings, teens, parents and families. Please see the website for further information and registration. Camp activities include swimming, field sports, art, zip lining, a climbing wall, hiking, and archery.

Teen Heads Up Conference/Young Adult Heads Up Conference

The heads-up conference was created by the Children's Brain Tumor Foundation (CBTF) and Camp Mak-a-Dream to answer questions and build peer support. They designed retreats for teens ages 13-18 as well as conferences for young adults ages 18-30. In addition to camp experiences like a ropes course, zip lining, and pool parties, survivors also have an opportunity to talk with peers who have shared similar experiences. There are information sessions on college, career, nutrition, and exercise. Flights are paid for by CBTF for anyone who needs assistance and the conference is free of charge.

Camp Sunshine (Sebago Lake, ME)

www.campsunshine.org

Camp Sunshine offers sessions full of activities and programs for the whole family. Sessions are held throughout the year. See the web site for specific programming.

Kamp Kace (Fargo, ND)

www.kampkace.org

Kamp KACE (Kids Against Cancer Everywhere) provides a safe, rewarding, and memorable camp experience for school age kids with cancer and their siblings. See their web site for more details and registration.

Camp Hozhoni and Camp Angel (Wisconsin Lions Camp, Rosholt, WI)

www.angelonmyshoulder.org/camps/

Camps are designed for kids ages 7-14 who are experiencing the cancer of a parent, sibling, or grandparent or who have lost that person to cancer. Please see the website for a description of all the camps.

REPUTABLE WEBSITES FOR MORE INFORMATION

CHILDREN'S ONCOLOGY GROUP

The **Children's Oncology Group** provides important information for children and their families from the time of diagnosis, through treatment, and following cure.

www.childrensoncologygroup.org



The **Children's Brain Tumor Foundation** is an organization that aims to improve the treatment, quality of life, and long-term outlook for children and families affected by a brain or spinal cord tumor. They are also the group which hosts monthly support groups right here in the Twin Cities. www.cbtf.org



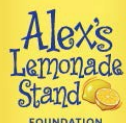
Pediatric Brain Tumor Foundation

The **Pediatric Brain Tumor Foundation** is the world's leading nonprofit dedicated to the childhood brain tumor community. They serve more than 28,000 U.S. children and teens battling brain tumors by investing in the most promising research and providing practical, informational, and emotional support to families.

www.curethekids.org



The **Mattie Miracle Cancer Foundation** is dedicated to increasing childhood cancer awareness, education, advocacy, research, and psychosocial support services to children, their families, and medical personnel. <https://www.mattiemiracle.com/>



Alex's Lemonade Stand Foundation is changing the lives of children with cancer by funding impactful research, raising awareness, supporting families, and empowering everyone to help cure childhood cancer. www.alexslimonade.org



The **American Childhood Cancer Organization** is dedicated to fighting. They engage in the ongoing struggle because they understand the emotional and physical toll childhood cancer takes on its victims and their families. The American Childhood Cancer Organization was founded by a talented and committed group of parents whose children were diagnosed with cancer at a time when surviving childhood cancer was nearly impossible. www.acco.org

SCHOLARSHIPS

Association of Cancer Online Resources (ACOR)

<http://www.ped-onc.org/scholarships/index.html>

This is a great list of cancer scholarships. Some are region-specific or cancer type-specific, but there are some general ones as well.

Brain Injury Survivors Grant Program: Educational Award

<http://www.biadc.org/grants.html>

Awarded to high school seniors with an acquired brain injury. Includes 2-year, 4-year colleges or professional trade schools. Contact 202-659-0122 or info@biadc.org.

Cancer for College

<http://www.cancerforcollege.org/application.html>

This is a great list of cancer scholarships. Some are region-specific or cancer type-specific, but there are some general ones as well.

Cancer Survivors Fund

<http://www.cancersurvivorsfund.org/ScholarshipEligibilityRequirements.htm>

Scholarships for young cancer survivors. A selection committee chooses scholarship recipients based on the applicants' personal hardships, assessing their financial and emotional needs as well as their qualifications.

Christine B. Dexter Scholarship

<http://www.chrisbfund.org/christine-b-dexter-scholarship/>

For undergraduate students, \$2,000 towards Fall tuition. All recipients demonstrate a history of community service and resilience through their cancer journey. Must be attending college in Maine, New Hampshire, Massachusetts, Vermont, Rhode Island, Connecticut, or New York.

Fastweb

<https://www.fastweb.com/college-scholarships/articles/cancer-scholarships>

Students searching this free site will have access to more than 1.3 million scholarships. Updates on scholarship matches are sent via e-mail.

FinAid

<http://www.finaid.org/scholarships/cancer.phtml>

Scholarships for cancer patients, cancer survivors, children of a cancer patient or survivor, students who lost a parent to cancer, and students pursuing careers in cancer treatment.

Jackie Spellman Scholarship Foundation

<https://jackiespellmanbenefit.org/wp-content/uploads/2018/12/2019-JSSF-Scholarship-Application.pdf>

Awarded to graduation high school seniors, community college and four year university and graduate students who are leukemia or lymphoma patients and/or children, siblings, or parents of LL patients. Must have a minimum un-weighted 3.0 GPA who plan to enroll full time at college or university.

Keaton Raphael Memorial

<https://childcancer.org/healing/resources/scholarships>

The Keaton Raphael Memorial aims to assist all ages of young adults going through their childhood cancer battle and provide different resource opportunities specifically aimed towards teens and their siblings.

Kids 4 Kids Scholarships

<http://www.kids4kidswithcancer.org/scholarships>

This scholarship is awarded to patients diagnosed with cancer before age 18. Spring deadline is February 1st and fall deadline is October 1st. Awards range from \$500-\$2500.

Matthew Debono Scholarship Fund

<https://www.aamds.org/patients/resources-to-help>

List of scholarships and other resources available for financial support for aplastic anemia/bone marrow transplant survivors.

Michael A. Hunter Memorial Scholarship

<https://oc-cf.academicworks.com/opportunities/1845>

Scholarships to help improve the quality of life for those affected by Leukemia/Lymphoma. Focus is on supporting secondary education for Leukemia/Lymphoma patients and/ or children of non-surviving Leukemia/Lymphoma patients. This scholarship is offered nationwide.

The National Children's Cancer Society

<https://www.thencecs.org/scholarship>

Scholarship for childhood cancer survivor under the age of 25 and diagnosed before the age of 18 with cancer or a high grade or anaplastic brain tumor

National Collegiate Cancer Foundation

<http://collegiatecancer.org/scholarships/>

Provides services and support to young adults whose lives have been impacted by cancer and who have continued with their education throughout treatment or after their treatment.

The National Grace Foundation

<http://graceamerica.org/GraceFoundation/>

Provides counseling services on college admissions and financial aid applications. They themselves are not giving the money but help people who have been affected by pediatric cancer through these application processes since they can be a bit overwhelming, particularly if you are still in the midst of treatment.

Pacific West Cancer Fund

<https://www.eduinreview.com/scholarships>

Scholarships for collegiate cancer survivors throughout the United States.

Patient Advocate Foundation Scholarship for Survivors

<http://www.patientadvocate.org/help.php?p=69>

Provide supports to individuals that are legal residents of the USA, **under the age of 25**, diagnosed with or treated for cancer, a chronic, or life threatening debilitating disease **within the past five years**. Scholarships are intended to "provide support to a person seeking to initiate or complete a course of study that has been interrupted or delayed by a diagnosis of cancer or other critical or life threatening disease." Ten scholarships of \$2000 each are awarded each year.

Pediatric Brain Tumor Foundation of the United States (PBTBUS)

<http://www.curethekids.org/family-resources/scholarships/>

PBTBUS offers college scholarships for brain tumor survivors. The deadlines for the application are June 1st and Dec. 1st; an essay is required, as well as proof of brain tumor diagnosis, GPA, intent to register for college, high school transcripts, and recommendations.

The SAMFund (21+)

<http://www.thesamfund.org/>

Helping young adult cancer survivors with a successful transition into their post-treatment life by providing financial support through grants and scholarships.

The Simon Cancer Foundation: Harvey Simon Memorial Scholarship

<http://www.thescf.org/Scholarships.html>

Scholarships for students who have had cancer during their lifetime. Applicants must be enrolled in a four-year university or college in the United States. Applicants are evaluated according to their unweighted GPA (30%), display of leadership (30%), engagement in extracurricular activities (20%), and their response to an essay question (20%).

Transplant Recipients International Organization (TRIO)

<https://www.trioweb.org/resources/trio-scholarships.html>

Must be a solid organ or bone marrow candidate, recipient, donor, or an immediate family member (defined as parent, child, spouse or sibling). Must be a TRIO member, to join you can go to www.trioweb.org.

Ulman Cancer Fund

<http://ulmanfund.org/scholarships/>

Scholarship for those affected by cancer or their siblings. Applicants must have been between the ages of 15 and 39 during their own diagnosis/treatment or during the diagnosis/treatment of their parent or sibling. Scholarship winners will be awarded a total of \$2500 over two academic semesters. Each scholarship winner is obligated to organize and run a bone marrow registry drive with the support of Delete Blood Cancer and There Goes My Hero.

Wishes and More

<http://wishesandmore.org/what-we-do/>

Wishes & More® enhances the life of a child fighting a terminal or life-threatening condition by providing extraordinary experiences including wishes, scholarships, memorials and more. Each wish child is presented a Scholarship of Hope certificate redeemable as a \$1,000 grant, applicable to any higher education institution of learning.

TIPS FOR WELL-BEING

While your child is in the hospital

For families,
from families

Having a child in the hospital is stressful. It is easy to put your own well-being as a last priority, but keeping yourself healthy helps you be your best for your child. Families and caregivers of children who have been hospitalized at Children's Minnesota put together these tips to help you maintain your well-being.

Be your child's advocate.

You are your child's champion. You know better than anyone what your child needs. Trust your inner voice and ask questions. Use the communication board in your child's hospital room to write down all of your questions.

Eat, sleep, breathe and be active.

Go for a walk every day to get fresh air and sunshine. Slow your breathing to keep calm. Take 10 slow, deep breaths to slow your heart rate, relax your body, and your mind. Feed your body healthy foods to keep it energized. Connect with the Family Resource Center or speak with a social worker for resources to help you maintain basic needs for your well-being.

Be comfortable.

The hospital environment can be cold and dry. Drink plenty of water to stay hydrated and healthy. Ask your child's nurse for a warm blanket, or bring one from home, to stay cozy in the cooler environment. You can get personal care items, such as toothpaste, shampoo, body wash and shaving cream at the Family Resource Center. Ask your nurse or the Welcome Center for these items if you are unable to go to the Family Resource Center.

Ask for help. Allow help. Prioritize.

It can be difficult to ask for help. Be willing to ask for help and to accept help. Make a list of things you need help with, such as delivering meals, laundry or cleaning, or taking care of other children while you are at the hospital. Deal with only the things that must be taken care of right now and let the rest go for now.

Ask for credible resources regarding your child's condition.

Your child's care team and staff at the Family Resource Center can provide credible resources if you would like to do further research. It is always okay to ask questions or request more information about your child's condition.

Connect with people who can be supportive.

Call a family member, a friend, or ask your child's care team to speak with spiritual care resources or a social worker. There is always someone to help you.

Communicate efficiently.

CaringBridge and social media can reach a large audience with one post. You can reduce the amount of communication you send out and still keep people informed and connected to what is going on with your child. Contact the Family Resource Center for help using these tools.

Whatever you are feeling, it's OK.

Remember the chaos, the grief, and the roller coaster of emotions are normal. Having a child hospitalized can be a very challenging and emotional time.

Counseling can help you process your emotions.

Your emotional well-being is important. Talking with a therapist can help you work through your concerns, sort out your emotions, and minimize your stress. If you need help connecting to these resources, ask your child's care team to connect you with a social worker.

Utilize the Family Resource Center and the Family Resource Guide.

Staff at the Family Resource Center can help you navigate the many resources and amenities available to you and your family. They can also give you a For Families, From Families Resource Guide, created by Children's Minnesota Family Advisory Council to help other patient families through their health care journey — including tips for organizing your child's health information.

The logo for Children's Minnesota, featuring a blue star above the word "Children's" in a serif font, with "MINNESOTA" in a smaller, blue, sans-serif font below it.

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