



NATIONAL
**PEDIATRIC
CANCER**
FOUNDATION

Pediatric Cancer Toolkit

YOUR GUIDE



Tyler Robinson Foundation



Share Your Story *of* Hope

We want to hear all about your journey. Share with us how you remained hopeful and what you learned that might be able to help other kids across the nation, including what worked or what didn't. This toolkit is always growing and evolving as research and data advances and changes.

We need your help to make sure that we always have the most up-to-date information because so much of what we are able to learn comes from hearing real stories, like yours. If you would like to be featured in our toolkit to inform and inspire others, please contact us at **nationalpcf.org/toolkit**.

On this page, you will be able to share you or your child's experience with pediatric cancer, upload photos, and offer additional advice to newly diagnosed pediatric cancer families.

TABLE OF Contents

INTRO AND PERSONAL INFORMATION

Key Personal Information	3
About The National Pediatric Cancer Foundation (NPCF)	4
About The Tyler Robinson Foundation (TRF)	6
Primary Contacts	7
Medical Disclaimer	8
Questions to Ask Your Child's Provider	9
NPC Foundation's Health Navigator Program	10

TAB 1: RECORD KEEPING

Medical Treatment Summary	11
Medicine Log	12
Diet Log	13
Home Tube Feeding Log	14
Exercise Log	16
Calendar	17
Dictionary	30
Stories of Hope	32

TAB 2: PEDIATRIC CANCER INFORMATION

Dear Parents and Caregivers	34
Types of Pediatric Cancer	35
Diagnosing and Stages	40
Stories of Hope	43

TAB 3: TREATMENTS

Cancer Treatment	45
Side Effects of Cancer Treatment	46
Managing Side Effects	47
Common Drugs Used to Treat Pediatric Cancer	50
Symptom Management Suggestions	56
Modern Medicine and Integrative Therapy	57
Research and Clinical Trials	59
Stories of Hope	62

TAB 4: WHAT NOW?

Notes From a Nurse	65
Things to Talk to Your Children About	68
Care for Childhood Cancer Survivors	69
Navigating School During Cancer and Beyond	72
Caregiver to Caregiver	74
Stories of Hope	75

TAB 5: RESOURCES

Diet	77
Managing Costs and Medical Information	78

TAB 6: EMOTIONAL SUPPORT

Exploring Emotions and Coping with Stress	79
Stories of Hope	84

TAB 7: SOURCES & CONTRIBUTORS

Sources & Contributors	86
Medical Imaging	88
Ben-Guard Products	92

KEY PERSONAL
Information

Patient Name:

Parent/Guardian Name 1:

Address:

Phone Number 1:

Patient Name:

Parent/Guardian Name 2:

Address:

Phone Number 2:

Notes:



THE Mission

In 1991, two mothers faced every parent's worst nightmare. Their children were diagnosed with cancer. Melissa Helms and Risa Tramel met at St. Joseph's Children's Hospital in Tampa, Florida while their infant daughters were undergoing cancer treatments. Through research advancements, both of their daughters survived and are now healthy young adults. However, through this experience, Melissa and Risa were inspired to continue fighting this disease.

Together, they founded the National Pediatric Cancer Foundation (NPCF), a non-profit organization whose mission is to fund research that will lead to the elimination of childhood cancer worldwide.

For the first 15 years, the NPCF funded seed grants at St. Joseph's Children's Hospital and Moffitt Cancer Center in Tampa, FL; All Children's Research Institute in St. Petersburg, FL; the University of Florida in Gainesville, FL; and the University of Miami School of Medicine in Miami, FL.

In 2005, the NPCF formed the Sunshine Project, an innovative collaboration with one goal: to bring together the nation's top doctors and researchers to fast-track new treatments and increase the survival rate for children battling cancer. Through the establishment of the Sunshine Project, the NPCF has developed a business model that capitalizes on the strengths of researchers from all different fields of science and streamlines the process to accelerate the development of new treatments.

Best of all, the NPCF has proven that this collaborative model works. Since 2005, through collaboration with leading hospitals across the nation, they have funded four Phase I clinical trials. New compounds have been, and continue to be, tested and hold great promise for children who have not experienced positive results under the standard treatment protocol. Despite the lack of advancement and funding towards research, the NPCF continues to raise funds and provide education through special events, corporate sponsorships, peer-to-peer/DIY programs, published research and literature pieces, and pediatric cancer ambassadors.

Since 1991, the NPCF has been a shining light for children who are battling cancer by yielding amazing discoveries that are saving their lives. The NPCF will continue to battle childhood cancer so that no child ever has to fight it alone. Together, we will rise up and fast-track a cure.



**NATIONAL
PEDIATRIC CANCER
FOUNDATION**

RISE UP FOR A FASTER CURE

ABOUT THE NPCF

88¢
OF EVERY
DOLLAR



FUNDS
RESEARCH



NATIONWIDE
COLLABORATION



\$30
MILLION+

We have donated
more than 30 million dollars
to pediatric cancer research.

14
INITIATIVES

Funding 11 clinical trials
yielding amazing results, and
saving children's lives.



30+
HOSPITALS

Collaborating with more
than 30 leading hospitals
nationwide for clinical trials.



Platinum
Transparency
2022

Candid.

TOP-RATED CHARITY

Recognized as the Top-Rated Cancer Charity by
Charity Navigator. Awarded a perfect 100% score
for financial health and transparency.

Our various programs and
signature events help fund
life-saving clinical trials that
yield amazing discoveries. Every
donation raised from these events
directly supports our mission to
eliminate childhood cancer and
helps families like yours.

Brewing
FUNDS THE CURE
FOR PEDIATRIC CANCER

Cooking
FUNDS THE CURE
FOR PEDIATRIC CANCER

Cut & Color
FUNDS THE CURE
FOR PEDIATRIC CANCER

Fashion
FUNDS THE CURE
FOR PEDIATRIC CANCER

Fishing
FUNDS THE CURE
FOR PEDIATRIC CANCER

Music
FUNDS THE CURE
FOR PEDIATRIC CANCER

Playing
FUNDS THE CURE
FOR PEDIATRIC CANCER

Walking
FUNDS THE CURE
FOR PEDIATRIC CANCER

ABOUT TRF

The Tyler Robinson Foundation (TRF) helps strengthen families financially and emotionally as they cope with the tragedy of a pediatric cancer diagnosis by providing grants specifically to offset out-of-pocket life expenses.

TRF is the nonprofit organization of the GRAMMY Award-winning band Imagine Dragons. TRF meets a critical need in communities across the U.S., Canada and Mexico. While many pediatric cancer organizations focus on growing awareness and support for families with the physical and emotional toll of a diagnosis, the huge financial hardship cancer treatment places on families is rarely discussed. More than 85-percent of every dollar TRF raises goes directly to families in need.

TRF is almost 7 years old, has raised almost 10 million dollars, and has supported over 500 pediatric cancer families.



**TRF PARTNERS WITH
HOSPITALS ACROSS
THE GLOBE.**

WHERE DOES THE MONEY GO?

We are thrilled that over 85 cents from every \$1 donated to TRF goes directly to our families!



Signature Grants - Grants made to families who have suffered financial hardship as a result of pediatric cancer diagnosis and treatment. These grants are issued to provide financial relief specifically for housing, utilities, and automobile expenses. Grant funds are paid directly to debtors in the amount of \$1,000 monthly for one year.



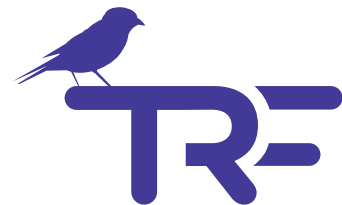
Fun Money - Grants given to celebrate special occasions such as birthday parties or gifts and fun nights out together as a family. These grants are issued in the form of a retail gift card in denominations of \$25 - 250 each. Families may apply for and receive unlimited fun vouchers each year with a maximum total value of \$2,500 annually.



Travel Grants - Financial assistance to cover hotel and travel expenses for family members to accompany their child during travel incurred for medical treatment or therapy. Each TRF family qualifies for up to \$5,000 per year.



Path to Heaven - For families faced with the exceptional burden and cost of laying their child to rest, TRF offers financial grants to pay funeral or burial expenses. Families receive up to \$5,000 to supplement these costs.



Tyler Robinson Foundation

www.TRF.org

PRIMARY

Contacts

Family Practitioner/Pediatrician:

Email Address:

Phone Number:

Address:

Hospital:

Email Address:

Phone Number:

Address:

Oncologist:

Email Address:

Phone Number:

Address:

Child Life Specialist:

Email Address:

Phone Number:

Address:

Primary Nurse:

Email Address:

Phone Number:

Address:

Social Worker:

Email Address:

Phone Number:

Address:

Other:

Email Address:

Phone Number:

Address:

Other:

Email Address:

Phone Number:

Address:

MEDICAL



Disclaimer:

All content in the educational toolkit is created and published for general informational purposes only. It is not intended to be a substitute for professional medical advice and should not be relied on as health or personal advice.

Always seek the guidance of your doctor or other qualified health professional with any questions you may have regarding your health or medical condition. Never disregard the advice of a medical professional, or delay in seeking it because of something you have read in this educational toolkit.

The information contained in this educational toolkit is not intended to recommend the self-management of health problems or wellness. It is not intended to endorse or recommend any particular type of medical treatment. Should any reader have any health care related questions, promptly call or consult your physician or healthcare provider. No information contained in this educational toolkit should be used by any reader to disregard medical and/or health related advice or provide a basis to delay consultation with a physician or a qualified healthcare provider.

In no event shall The National Pediatric Cancer Foundation be liable for any special, direct, indirect, consequential, incidental damages or any damages whatsoever, whether in an action of contract, negligence or other tort, arising out of or in connection with the use of the educational toolkit or the contents of the educational toolkit. The National Pediatric Cancer Foundation reserves the right to make additions, deletions, or modifications to the contents on the educational toolkit at any time without prior notice.

QUESTIONS TO ASK YOUR Child's Provider

- What is the Diagnosis/Stage?
- What are our treatment options?
Chemotherapy, Radiation, Immunotherapy, Targeted therapy.
- Are there available clinical trials for my child?
- What are the outcomes and side effects of proposed treatment options?
- Have you personally treated this type of cancer in a child of this age group?
- May I have a copy of all Imaging? (MRI/CT, etc)
- Where was the pathology sent?
Sometimes a sample of tumor is sent to multiple facilities; you can request that it is sent to another hospital for a 2nd opinion.
- Can you help me facilitate getting a 2nd opinion?
Do not be afraid to ask for another opinion. Other facilities may have other treatment options.
- Will additional testing (such as genetic testing) on the tumor be required before starting treatment?
- Is there a time frame or deadline to start a specific treatment protocol?
- Will my child be able to go to school during treatment?

National Pediatric Cancer Foundation's Health Navigator Program

The National Pediatric Cancer Foundation (NPCF) annually engages hundreds of families via our awareness and development programs. Many of these patients seek critical information related to their disease management. Although most hospitals provide a liaison for these patients, families stress the need for an external opinion and information. The NPCF is here to provide key information based on science. This program is a key bridge between the science and education that NPCF provides via its mission.



*We Are Here To Help
You Throughout Your
Pediatric Cancer Journey*

For additional information, please contact our Health Navigator by filling out the form at nationalpcf.org/health-navigator or calling (813) 269-0955, Ext 480.

Why Is This Important?

- More than 95% of childhood cancer survivors have significant health-related issues because of the current treatment options.
- Cancer is the number one cause of death by disease among children worldwide.
- Each day, 43 kids in the US are expected to be diagnosed with cancer. One in 285 children will be diagnosed with cancer before their 20th birthday.
- The NPCF created and governs a collaborative research model focusing on translational studies and phase 0, 1, and 2 clinical trials addressing all types of pediatric cancers.
- We leverage collaboration, both scientific and philanthropic, to identify promising, less toxic, novel therapies to treat and eliminate childhood cancer.
- Through our partnerships, top pediatric cancer specialists are able to collaborate, resulting in the fast-tracking of new treatment options into clinical trials.
- NPCF's research is affecting treatment protocols worldwide and giving hope to patients and families.

Tab 1

Record Keeping

A LOOK INSIDE

- Medical Treatment Summary
- Medicine Log
- Diet Log
- Home Tube Feeding Log
- Exercise Log
- Calendar
- Dictionary
- Stories of Hope

MEDICAL TREATMENT

Summary

Date _____

Make copies of this page for weekly logs

DATE	SURGERY	CHEMO OR RADIATION ROUND	BONE MARROW	TRANSFUSION	HOSPITALIZATION	SCANS	ADDITIONAL DETAILS

Notes: _____

WEEKLY MEDICINE

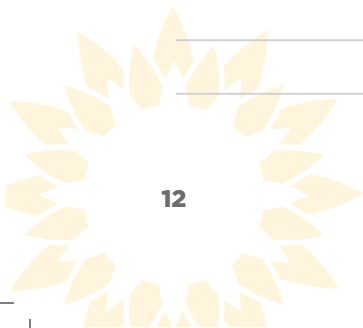
Log

Date _____

Make copies of this page for weekly logs

DAY	MEDICATION	WHAT FOR	TIME / FREQUENCY	SIDE EFFECTS?
MONDAY				
TUESDAY				
WEDNESDAY				
THURSDAY				
FRIDAY				
SATURDAY				
SUNDAY				

Notes: _____



WEEKLY DIET

Log

Date _____

Make copies of this page for weekly logs

DAY	BREAKFAST	LUNCH	DINNER	SNACKS
MONDAY				
TUESDAY				
WEDNESDAY				
THURSDAY				
FRIDAY				
SATURDAY				
SUNDAY				

Notes:

Daily Log

Type of Feeding Tube	PEG	NG Tube	J Tube
Feeding Method	Pump	Bolus	Gravity
If Pump Feeding	Goal Pump Rate _____ mL each hour		
If Bolus/Gravity Feeding	Goal of _____ cans each day		

[illegible]

HOME TUBE FEEDING

Daily Log

OUTPUT									OTHER
URINE COLOR			URINE AMOUNT			STOOL			COMMENTS/PROBLEMS
Dark	Light	clear	Lg	Md	Sm	Hard	Soft	Liquid	
	X			X			X		Nausea after tube feed

WEEKLY EXERCISE

Log

Date _____

Make copies of this page for weekly logs

DAY	EXCERCISE	DURATION	CALORIES BURNED	WEIGHT
MONDAY				
TUESDAY				
WEDNESDAY				
THURSDAY				
FRIDAY				
SATURDAY				
SUNDAY				

Notes: _____



JANUARY



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: NEW YEAR'S DAY AND MARTIN LUTHER KING JR DAY.

Notes:

FEBRUARY



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: GROUNDHOG DAY, VALENTINE'S DAY AND PRESIDENTS' DAY.

Notes:



MARCH



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAY: ST. PATRICK'S DAY.

Notes:

APRIL



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: APRIL FOOL'S DAY, EASTER SUNDAY AND EARTH DAY.

Notes:



MAY



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: CINCO DE MAYO, MOTHER'S DAY AND MEMORIAL DAY.

Notes:

JUNE



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: NATIONAL CANCER SURVIVORS DAY AND FATHER'S DAY.

Notes:



JULY



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAY: INDEPENDENCE DAY.

Notes:

AUGUST



SUN	MON	TUE	WED	THU	FRI	SAT

Notes:



SEPTEMBER



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAY: LABOR DAY.

Notes:

OCTOBER



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: INDIGENOUS PEOPLES' DAY AND HALLOWEEN.

Notes:



NOVEMBER



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: ELECTION DAY, VETERANS DAY AND THANKSGIVING DAY.

Notes:

DECEMBER



SUN	MON	TUE	WED	THU	FRI	SAT

THIS MONTH'S HOLIDAYS: CHRISTMAS DAY, KWANZAA AND HANUKKAH.

Notes:



Notes

COMMONLY USED TERMS BY



Caregivers

ANC (Absolute Neutrophil Count): the white blood cells that fight infections.

Anemia: a decrease in the amount of red blood cells (hemoglobin) in the body.

Anesthesia: a loss of feeling or awareness caused by drugs or other substances. Anesthesia keeps patients from feeling pain during surgery or other procedures.

- Local anesthesia is a loss of feeling in one small area of the body.
- Regional anesthesia is a loss of feeling in a part of the body, such as an arm or leg.
- General anesthesia is a loss of feeling and a complete loss of awareness that feels like a very deep sleep.

Antineoplastic: an agent that inhibits or ceases the growth of neoplasms.

Benign: non-harmful cell growth.

Bone Marrow: cavity within the bone where blood cells are produced.

Cancer: an abnormal growth of cells.

CBC (Complete Blood Count): blood test done to evaluate the cells in the body, such as hemoglobin, platelets, ANC, etc.

Central Line: a type of catheter that is placed in a large vein that allows multiple intravenous (IV) fluids to be given and blood to be drawn.

- Peripherally Inserted Catheter (PICC): a thin, soft, flexible tube placed in a vein in the arm. It is used for long-term intravenous (IV) antibiotics, nutrition, or medication and for blood draws.
- Broviac Line: a special intravenous IV line

inserted under the skin on the chest wall and into a large vein that leads to the heart. It's used for long term intravenous (IV) therapy.

- Port-A-Cath Line: A device used to draw blood and give treatments. The port is placed under the skin, usually in the right side of the chest. It is attached to a catheter.

Chemotherapy: cytotoxic agents used to treat cancer, that inhibits cell growth of rapidly dividing and growing cells.

Craniotomy: the surgical removal of part of the bone of the skull in order to see and evaluate the brain.

Cytotoxic: an agent that is toxic to living cells.

Dehydration: loss of water from an object, such as the body.

Fatigue: the sensation of being extremely tired as a result of illness, such as anemia.

Gastronomy tube: a tube inserted through the skin of the abdomen that brings nutrition directly to the stomach.

Hemoglobin: the red blood cell responsible for carrying oxygen throughout the body.

Immunocompromised: an immune system that has been impaired, most commonly from chemotherapy.

Intrathecal: space within the spinal theca in which medication can be administered and cerebral spinal fluid can be removed.

Lumbar Puncture: a procedure to remove cerebral spinal fluid for diagnostic purposes.

Malignant: invasive cells that are not growth limiting and can spread to other tissue.



Metastatic: abnormal spread of cancer cells to other parts of the body, including organs.

Mucositis: a side effect of certain chemotherapy agents and radiotherapy that results in painful sores and inflammation of the mucosal cells of the mouth, throat, stomach, and intestines.

Nadir: the point at which blood counts are at their lowest.

Nasogastric tube: a tube placed in the nose that carries food and medicine to the stomach.

Neoplasm: a characteristic of cancer in which a new or abnormal growth of tissue occurs in the body.

Neuropathy: a numbness or weakness of the limbs caused by dysfunction to one or more peripheral nerves.

Neutropenia: an abnormally low neutrophil count that increases the risk of infection.

Petechiae: reddish to purplish spots that appear on the skin resulting from localized hemorrhage, often accompanying low platelets.

Platelets (also known as Thrombocytes): cells in the body responsible for forming clots to stop bleeding.

Prophylaxis: an action or a specific means to prevent a disease process.

Radiotherapy (also known as Radiation Therapy): a form of treatment for cancer that involves high-energy ionizing rays that cause damage to cancer cells and inhibits their growth.

Resection: a surgical procedure to remove part, or all, of an organ or tumor.

Shunt: a hollow tube surgically placed in the brain (or occasionally the spine) to help drain cerebrospinal fluid (the liquid surrounding the brain) and redirect it to another location in the body where it can be reabsorbed.

Thrombocytopenia: a lower than normal platelet count that increases the risk of bleeding.

Transfusion (also known as Blood Transfusion): a procedure in which whole blood or parts of blood are put into a patient's bloodstream through a vein. The blood may be donated by another person, or it may have been taken from the patient and stored until needed.

Transplant: a procedure in which an organ, tissue, or bone marrow is removed from one person and placed into another person.

Tumor: abnormal growth of tissue that can be benign or malignant.

Tumor Lysis: a complication that may occur during chemotherapy as a result of tumor cells being killed off and emitting their contents into the bloodstream.

Tumor Resection: removal of a tumor through surgery.

- Gross Total Resection: the removal of an entire tumor, as determined by radiologic imaging or analysis in a pathology laboratory.
- Subtotal Resection: the removal of part, usually most but not all, of the tumor.

STORIES OF HOPE

In 2020 my family's lives changed forever when my 10-month-old daughter, Riley, was diagnosed with cancer. Riley was experiencing intermittent vomiting, which was originally misdiagnosed as a stomach virus. Less than a week later we were rushed to the nearest emergency room and a CT scan revealed a large mass in her brain that was causing a brain bleed. It was determined that she needed emergency brain surgery immediately. We were transported to another facility and for the next several hours my daughter endured a lifesaving brain surgery. A couple days later we heard those dreaded words "Your child has cancer." The mass in her brain was a Glioblastoma, Stage 4 brain cancer. Within days, Riley had to endure a 2nd surgery to remove the remaining portion of the tumor.

Though our wonderful neurosurgeon was able to remove the entire tumor, we were given a very poor prognosis. We were told that Riley would not survive longer than a year or two because of the aggressive nature of this cancer. As a mom and a nurse, I began doing research. I learned that Glioblastoma's are often misunderstood in infants. I gathered 2nd and 3rd opinions from lead Neuro-oncologists around the country. Ultimately, my family ended up temporarily relocating halfway across the country to seek out Riley's best treatment option. My daughter underwent a total of three brain surgeries and a very intensive chemotherapy regimen. I am happy to say my little warrior currently shows "No Evidence of Disease." She is happy, thriving and hitting all her milestones. In fact, we recently celebrated her 2nd birthday. My family could not be more grateful to have her here with us today.

While my daughter was in treatment, I made friends with several fellow cancer families near and far; some of which had similar stories to ours. I learned families are often so overwhelmed with the amount of information thrown at them and no one to help them navigate it. I found myself answering basic medical questions and translating some of the medical terminology for other parents. I determined that I wanted to help these families on a larger scale.

I now work as the Health Navigator for the National Pediatric Cancer Foundation and have the opportunity to help several childhood cancer families on a daily basis. I am not here to give medical advice, but rather consult fellow cancer families and guide them with this daunting journey. I will also be developing a national mentorship program to help cancer families connect with other families who have had a similar diagnosis. From my experience, I found the connection between cancer families to be very special by providing hope and emotional support for families.



RILEY

AGE
2

DIAGNOSIS
Stage 4
Glioblastoma

STORIES OF HOPE

King was only two years old when diagnosed with high-risk Acute Lymphoblastic Leukemia. His treatment plan included three and a half years of daily chemotherapy. He receives oral chemo daily – intravenous and spinal. King also has an enzyme deficiency called G6PD that complicates his treatment. It is a rare and deadly combination to have both G6PD and leukemia. G6PD is lifelong and there is no cure. Leukemia affects his white blood cells and G6PD affects his red blood cells. Avoidance of G6PD triggers is critical as the consequences require a blood transfusion and can be fatal.

King was taking over 70 pills monthly and that amount would continue to increase as his weight increased. King had many side effects, with the two severe ones being brain swelling and nerve damage. He actually lost the ability to walk for months, but thankfully we were able to rehabilitate him and if you saw him today, you would never know about his previous condition.

King is truly a walking miracle. He goes through things that many adults are not able to tolerate. He's had more spinal taps in two and a half years than an average adult will have in their lifetime. We are infinitely grateful for each and every day King wakes up to spend another day with us. He's a warrior with the heart of a lion. We know he will be the change we wish to see in the world.

I work full-time, but my husband (who has a bachelor's degree in Nursing) stays home with King and his siblings full-time. Although surviving on one income has caused a financial strain on the family and an increase in King's medical collection debt, King's health has significantly improved since my husband made the decision to be his primary caretaker.

When a child is diagnosed with cancer, it affects the entire family. Many survivors deal with chronic medical issues once the treatment is completed. Treatment should not be able to cause secondary cancer. Yet, pediatric cancer is heavily underfunded. We are childhood cancer advocates and believe research funding is important as it can lead to less-toxic treatment and cures. We are on a mission to spread global awareness about childhood cancer in hopes that one day that enough research is done to be able to declare cancer a thing of the past. All children deserve to grow up!

Despite all that King has been through and continues to go through, he is always smiling and inspires us and countless others daily. King does not let anything stop him and neither will we. Cancer does not define us. We define cancer.



KING

AGE
8

DIAGNOSIS
Cancer-Free
from Acute
Lymphoblastic
Leukemia

Tab 2

Pediatric Cancer Information

A LOOK INSIDE

- Dear Parents and Caregivers
- Types of Pediatric Cancer
- Diagnosing and Stages
- Stories of Hope



DEAR PARENTS AND Caregivers

TO A NEW PEDIATRIC ONCOLOGY CAREGIVER,

As you begin to digest and process the monumental news that has just taken over your life, realize first that there are many, many professionals who are able to help you. Of course, there are the oncologists, surgeons, specialists, doctors, and nurses, but also social workers, clergy (even if you don't consider yourself religious), child psychologists, child life specialists, and music and art therapists (for you as well as for your child).

Realize, too, that a palliative care team's goal is to minimize discomfort. It's a scary term and easy to think the worst, but by bringing them in right at the beginning, they can help minimize not only physical pain but psychological stress as well, both for you and for your child.

Everyone handles a new and serious diagnosis in a different way. Some caregivers spend hours into the night researching their child's condition, the latest clinical trials, current research, and even speculative therapies. Others become quiet and pensive, leaving treatment entirely to the specialists. There is no right or wrong way to react, no right or wrong way to behave.

Don't blame yourself. Yes, as parents, it is our responsibility and we do all we can to protect our children, especially from a serious, life-threatening peril. But nothing we could have done could have changed where we are now.

Know that you are not alone. Caregivers of pediatric cancer patients are a tight yet warmly welcoming community. You are family.

Richard Alpert
(FATHER OF MICAELA ALPERT)



TYPES OF PEDIATRIC Cancer

Facts about Pediatric Cancer

- 43 children per day are expected to be diagnosed with cancer.
- 95% of children who survive cancer will end up having health related issues around age 45 as a result of being treated with drugs designed for adults.
- Only 4% of the billions of dollars that are annually spent on cancer treatments and research are directed towards pediatric cancer.
- Since 1980, fewer than 10 drugs have been created for children battling cancer, as compared to the hundreds that have been created for adults.
- Cancer is the #1 cause of death by disease among children.

What is Cancer?

Cancer is an abnormal growth of cells. It is caused by changes to genes that control the way our cells function, especially how they grow and divide.

Brain Cancer

- The brain and spinal cord make up the central nervous system (CNS). Brain and spinal cord tumors are growths of abnormal cells in tissues of the brain or spinal cord.
 - Tumors that start in the brain are called primary brain tumors.
 - A tumor that starts in another part of the body and spreads to the brain is called a metastatic brain tumor.
- Brain and spinal cord tumors may be either benign (not cancer) or malignant (cancer). Both benign and malignant tumors cause signs and symptoms and need treatment.
 - Benign brain and spinal cord tumors grow and press on nearby areas of the brain but rarely spread into other parts of the brain.
 - Malignant brain and spinal cord tumors are likely to grow quickly and spread into other parts of the brain.
- There are many types of brain and spinal cord tumors. They form in different cell types and in different areas of the brain and spinal cord.
- The signs and symptoms of brain and spinal cord tumors depend on where the tumor forms, its size, how fast it is growing, and the age of the patient.
- Brain and spinal cord tumors can occur in children. The types of tumors that form and the way they are treated are different in children. The prognosis (chance of recovery) depends on many factors, including age, tumor size, tumor type, and where the tumor is in the CNS.

Germ Cell Tumors

A germ cell is a type of cell that forms as a fetus develops. These cells later become sperm in the testicles or eggs in the ovaries. Sometimes, germ cells may develop into a germ cell tumor in other parts of the body, either before or after birth, often beginning in the testicles or ovaries; although, they can form almost anywhere in the body. These types of tumors include:

- **Extracranial Germ Cell Tumors:** A germ cell tumor that forms in parts of the body other than the brain, such as the gonads (testicles and ovaries), chest, abdomen, or tailbone.
 - Extracranial germ cell tumors are most common in teenagers 15 to 19 years of age.
- There are three types of extracranial germ cell tumors:
 - The most common type is mature teratoma, a benign tumor that is not likely to become cancer. Other types are immature teratomas (which may become cancer) and malignant germ cell tumors (cancer).
 - Extracranial germ cell tumors in children, especially ovarian germ cell tumors or testicular cancer, can usually be cured.
- **Central Nervous System (CNS) Germ Cell Tumors:** A germ cell tumor that forms in the brain or spinal cord.
 - The most common places for one or more CNS germ cell tumors to form is near the pineal gland and the area of the brain that includes the pituitary gland and the tissue just above it. Sometimes germ cell tumors may form in other areas of the brain.
 - The cause of most childhood CNS germ cell tumors is not known.
 - There are different types of CNS germ cell tumors. The type of CNS germ cell tumor depends on what the cells look like under a microscope. The two main types of CNS germ cell tumors are Germinomas and Nongerminomas.
 - Germinomas are the most common type of CNS germ cell tumor and have a good prognosis.
 - Nongerminomas either make or do not make hormones. CNS teratomas are a type of nongerminoma that do not make hormones. They may have different kinds of tissue in them, such as hair, muscle, and bone. Signs and symptoms may depend on where the tumor has formed, the size of the tumor, and whether or not the tumor makes hormones. They include unusual thirst, frequent urination, early puberty, or vision changes.

Leukemia

Leukemia is a cancer of the blood cells wherein immature blood cells formed in bone marrow become cancer. These cells do not work the way they should and crowd out the healthy blood cells in the bone marrow. Different types of leukemia depend on the type of blood cell that becomes cancer. For example, lymphoblastic leukemia is a cancer of the white blood cells. White blood cells are the most common type of blood cell to become cancer. However, red blood cells and platelets may also become cancer. Leukemia is the most common cancer in children younger than 15 years old.

- Leukemia can be either acute or chronic.
 - Acute leukemia is a fast-growing cancer that usually gets worse quickly.
 - Chronic leukemia is a slower-growing cancer that gets worse slowly over time.
- The treatment and prognosis for leukemia depend on the type of blood cell affected and whether the leukemia is acute or chronic.

Types of leukemia include:

- **Acute Lymphoblastic Leukemia (ALL):** the most common cancer diagnosed in children and represents approximately 25% of cancer diagnoses among children younger than 15 years old.
- **Acute Myeloid Leukemia (AML):** a cancer of the blood and bone marrow. Cancers that are acute usually get worse quickly if they are not treated. Cancers that are chronic usually get worse slowly. Also called acute myelogenous leukemia, acute myeloblastic leukemia, acute granulocytic leukemia, and acute non-lymphocytic leukemia.
- **Chronic Myeloid Leukemia (CML):** an indolent (slow-growing) cancer in which too many myeloblasts are found in the blood and bone marrow. Myeloblasts are a type of immature blood cell that makes white blood cells called myeloid cells.
 - CML may get worse over time as the number of myeloblasts increases in the blood and bone marrow. This may cause fever, fatigue, easy bleeding, anemia, infection, a swollen spleen, bone pain, or other signs and symptoms.
 - CML is usually marked by a chromosome change called the Philadelphia chromosome, in which a piece of chromosome 9 and a piece of chromosome 22 break off and trade places with each other. It usually occurs in older adults and rarely occurs in children.
 - Also called chronic granulocytic leukemia, chronic myelogenous leukemia, and chronic myeloid leukemia.
- **T-cell leukemia:** a type of leukemia in which large T lymphocytes (a type of white blood cell) that contain granules (small particles) are found in the blood. It is a chronic disease that may last for a long time and get worse. Also called T-LGL leukemia.

Lymphoma

- Lymphoma is cancer that begins in cells of the lymph system. The lymph system is part of the immune system, which helps the body fight infection and disease. Because lymph tissue is found throughout the body, lymphoma can begin almost anywhere.
- The two main types of lymphoma are Hodgkin lymphoma and non-Hodgkin lymphoma (NHL). These can occur in both children and adults.
 - Most people with Hodgkin lymphoma have the classic type. With this type, there are large, abnormal lymphocytes (a type of white blood cell) in the lymph nodes called Reed-Sternberg cells. Hodgkin lymphoma can usually be cured.
- There are many different types of NHL that form from different types of white blood cells (B-cells, T-cells, NK cells). Most types of NHL form from B-cells.
- NHL may be indolent (slow-growing) or aggressive (fast-growing).
- The most common types of NHL in adults are diffuse large B-cell lymphoma, which is usually aggressive, and follicular lymphoma, which is usually indolent. Mycosis fungoid and the Sézary syndrome are types of NHL that start in white blood cells in the skin. Primary central nervous system lymphoma is a rare type of NHL that starts in white blood cells in the brain, spinal cord, or eye. The treatment and the chance of a cure depend on the stage and the type of lymphoma.

There are several types:

- **Hodgkin's Lymphoma:** a type of cancer that develops in the lymph system, which is part of the body's immune system. The immune system protects the body from foreign substances, infection, and diseases. If the Reed Sternberg cell is detected, the lymphoma will be classified as Hodgkin's Lymphoma.



- **Non-Hodgkin's Lymphoma:** a type of cancer that forms in the lymph system, which is part of the body's immune system. The immune system protects the body from foreign substances, infection, and diseases.
- **Large B cell lymphoma:** a type of B-cell non-Hodgkin lymphoma (cancer of the immune system) that is usually aggressive (fast-growing). It is the most common type of non-Hodgkin lymphoma, and is marked by rapidly growing tumors in the lymph nodes, spleen, liver, bone marrow, or other organs. Other symptoms include fever, night sweats, and weight loss. There are several subtypes of diffuse large B-cell lymphoma.
- **Anaplastic large cell lymphoma:** an aggressive (fast-growing) type of non-Hodgkin lymphoma that is usually of the T-cell type. The cancer cells express a marker called CD30 or Ki-1 on the surface and may appear in the lymph nodes, skin, bones, soft tissues, lungs, or liver. Also called ALCL.
- **T-cell lymphoma:** a type of cancer that forms in T cells (a type of immune system cell). T-cell lymphomas may be either indolent (slow-growing) or aggressive (fast-growing). Most T-cell lymphomas are non-Hodgkin lymphomas. There are many different types of T-cell non-Hodgkin lymphomas. These include mycosis fungoides, anaplastic large cell lymphoma, and precursor T-lymphoblastic lymphoma. Prognosis and treatment depend on the type and stage of the cancer.

Neuroblastoma (neural crest)

A disease in which malignant (cancer) cells form in certain types of nerve tissue. Neuroblastoma most often begins in the adrenal glands, which are on top of the kidneys. It can also form in nerve tissue in the neck, chest, abdomen, or spine. Neuroblastoma most often occurs in children younger than 5 years of age. Sometimes it forms before birth and is found during a routine pregnancy ultrasound. In children who are 6 months or younger, the disease sometimes goes away without treatment. Neuroblastoma is usually found when the tumor begins to grow and cause signs or symptoms. By the time it is diagnosed, the cancer has usually metastasized (spread to other parts of the body).

Melanoma

A form of cancer that begins in melanocytes (cells that make the pigment melanin). It may begin in a mole (skin melanoma) but can also begin in other pigmented tissues, such as the eye or intestines.

Sarcoma:

An uncommon group of cancers which arise in the bones and connective tissue, such as fat and muscle. In most cases, it is unclear what causes sarcoma. Family history and exposure to chemicals or radiation may increase risk. There are several types:

- **Ewing Sarcoma:** tumors that usually form in the hip bones, ribs, or middle of long bones. The disease occurs most often in teenagers. Ewing tumors are most common in bone but can also form in soft tissue.
- **Osteosarcoma:** the most common bone cancer. It starts in bone cells that make new bone tissue. It usually forms at the end of long bones, such as the leg bones, but can form in any bone. It is most common in teenagers.
- **Soft Tissue Sarcoma:** a cancer that starts in soft tissues of the body, including muscle, tendons, fat, lymph vessels, blood vessels, nerves, and tissue around joints. The tumors can be found



TYPES OF PEDIATRIC CANCER

anywhere in the body but often form in the arms, legs, chest, or abdomen. Signs of soft tissue sarcoma include a lump or swelling in soft tissue. Sometimes there are no signs or symptoms until the tumor is big and presses on nearby nerves or other parts of the body. Children can develop soft tissue sarcoma. Treatment often works best in children, and they may have the best chance of being cured.

- **Rhabdomyosarcoma:** the most common type of soft tissue sarcoma in children. It begins in muscles that are attached to bones and help the body move. Most rhabdomyosarcomas are diagnosed in children younger than 10 years. Rhabdomyosarcomas usually form lumps near the surface of the body and are found early.
- **Wilms tumor and other childhood kidney tumors:** there are two kidneys, one on each side of the spine, above the waist. The kidneys clean the blood to take out waste and make urine. Urine collects in the renal pelvis, the area at the center of the kidney, and then passes through the ureter, into the bladder, and out of the body. The kidneys also make hormones that help control blood pressure and signal the bone marrow to make red blood cells when needed.
 - There are three main types of kidney cancer. Wilms tumors are the most common in children. Wilms tumors form in the tissues of the kidney that make urine. Certain inherited disorders can increase the risk of kidney cancer in children including von Hippel-Lindau syndrome, hereditary leiomyomatosis and renal cell cancer, Birt-Hogg-Dubé syndrome, and hereditary papillary renal cancer.
 - Kidney tumors may be benign or malignant.

Hepatoblastoma

A type of liver tumor that occurs in infants and children.

Retinoblastoma

Cancer that forms in the tissues of the retina.

DIAGNOSING AND Staging



Cancer can cause many different symptoms. These are some of them:

- Skin changes, such as:
 - A new mole or change in existing mole.
 - A sore that does not heal.
 - A thickening or lump on or under the skin.
- Hoarseness or cough that does not go away.
- Changes in bowel habits.
- Difficult or painful urination.
- Problems with eating, such as:
 - Discomfort after eating.
 - A hard time swallowing.
 - Changes in appetite.
- Weight gain or loss with no known reason.
- Abdominal pain.
- Unexplained night sweats.
- Unusual bleeding or bruising and/or blood in urine.
- Feeling weak or very tired.
- Persistent Fever.
- Lumps (swollen lymph nodes) under the skin in the neck, armpit, and groin.
- Limping.
- Frequent headaches.
- Unexplained frequent vomiting.
- Sudden vision changes.
- Dizziness.
- Unexplained “glow” in eye.
- Bone pain and swelling.
- Seizures.
- Trouble walking or handling objects.

Diagnosis

If symptoms occur or a screening test result suggests cancer, the doctor must find out whether it is due to cancer or some other cause. The doctor may ask about personal and family medical history and do a physical exam. The doctor also may order lab tests, scans, or other tests or procedures.

Lab Tests

High or low levels of certain substances in the body can be a sign of cancer. So, lab tests of the blood, urine, or other body fluids that measure these substances can help doctors make a diagnosis. However, abnormal lab results are not a sure sign of cancer. Lab tests are an important tool, but doctors cannot rely on them alone to diagnose cancer.

Imaging Procedures

Imaging procedures create pictures of areas inside the body that help doctors see if a tumor is present. These pictures can be made in several ways:

CT scan

An x-ray machine linked to a computer that takes detailed pictures of the organs.

Nuclear scan

A small injection of radioactive material, sometimes called a tracer, is administered. It flows through the bloodstream and collects in certain bones or organs. A machine called a scanner detects and measures the radioactivity and then creates pictures of bones or organs.

PET scan

An injection of radioactive material, sometimes called a tracer, is administered. Then, a machine makes 3-D pictures that show what the tracer collects in the body. These scans show how organs and tissues are working.

MIBG scan

Commonly used for detection of neuroendocrine tumors, such as neuroblastoma and pheochromocytoma. It can also aid in the detection of carcinoid and medullary thyroid carcinoma.

Ultrasound

A device that sends sound waves, which people cannot hear, bounce from tissue to tissue inside the body. A computer uses these waves to create a picture of areas inside the body called a sonogram.

MRI

A strong magnet linked to a computer that makes detailed pictures of areas in the body.

X-Ray

Uses low doses of radiation to create pictures of the body's interior.

Lumbar Puncture

The insertion of needle into the spine in your lower back (lumbar region) to either remove a sample of cerebrospinal fluid (CSF) so that it can be tested in the laboratory or to inject medication.

Biopsy

In most cases, doctors need to do a biopsy to make a diagnosis of cancer. A biopsy is a procedure in which the doctor removes pieces of tissue to get a sample. A pathologist then examines the tissue to analyze if it is cancer. The sample may be removed in several ways:

- The doctor uses a needle to withdraw tissue, bone, marrow, or fluid.
- The doctor looks at areas inside the body using a thin, lighted tube called an endoscope. The scope is inserted through a natural opening, such as the mouth. Then, the doctor uses a special tool to remove tissue or cells through the tube.
- Surgery may be excisional or incisional.
 - In an excisional biopsy, the surgeon removes the entire tumor. Often some of the normal tissue around the tumor also is removed.
 - In an incisional biopsy, the surgeon removes just part of the tumor.

Staging

Stage refers to the extent of a cancer, such as how large the tumor is and if it has spread. Knowing the cancer stage helps the doctor:

- Understand how serious a cancer is and the chances of survival.
- Plan the best treatment.
- Identify clinical trials that may be treatment options.



A cancer is always referred to by the stage it was given at diagnosis, even if it gets worse or spreads. New information about how a cancer has changed over time gets added onto the original stage. So, the stage doesn't change, even though the cancer might.

How Stage Is Determined

To learn the cancer stage, the doctor may order x-rays, lab tests, and other tests or procedures. See the section on Diagnosis to learn more about these tests.

Systems That Describe Stage

- There are many staging systems. Most include information about:
 - Tumor location.
 - Tumor size.
 - Cell type (such as, adenocarcinoma or squamous cell carcinoma).
 - If the cancer has spread to nearby lymph nodes.
 - If the cancer has spread to a different part of the body.
 - Tumor grade, which refers to how abnormal the cancer cells look and how likely the tumor is to grow and spread.

The TNM Staging System

The TNM (Tumor Nodes Metastasis) system is the most widely used cancer staging system. Most hospitals and medical centers use the TNM system as their main method for cancer reporting. You are likely to see cancer described by this staging system in a pathology report, unless the type of cancer uses a different staging system. Examples of cancers with different staging systems include brain and spinal cord tumors and blood cancers.

Other Ways To Describe Stage

The TNM system helps describe cancer in great detail. For many cancers, the TNM combinations are grouped into one of five main categories. This staging system is more commonly used by cancer registries than doctors, but you may still hear the doctor or nurse describe the cancer in one of the following ways:

- In situ: abnormal cells are present but have not spread to nearby tissue.
- Localized: cancer is limited to the place where it started, without signs that it has spread.
- Regional: cancer has spread to nearby lymph nodes, tissues, or organs.
- Distant: cancer has spread to distant parts of the body.
- Unknown: there is not enough information to determine the stage.

Stage	What it means
Stage 0	Abnormal cells are present but have not spread to nearby tissue. Also called carcinoma in situ (CIS). CIS is not cancer, but it may become cancer.
Stage I, Stage II, and Stage III	Cancer is present. The higher the number, the larger the cancer tumor and the more it has spread to nearby tissues.
Stage IV	The cancer has spread to distant parts of the body.

STORIES OF HOPE

My name is Luna Belle! I am an 11-year-old athlete who was diagnosed with Ewing's Sarcoma (a rare aggressive bone cancer) when I was nine years old. At first, my bone cancer was misdiagnosed. The first doctor did an x-ray and said I had fractured my ASIS but missed the 5.5-inch tumor wrapped around my entire right pelvic bone. My pain increased over the next couple of months and my parents took me to another orthopedic specialist. After another X-ray the doctor saw shadowing in my pelvis and sent me right for an MRI. The MRI showed my tumor, and I was sent for a biopsy two days later.

I was admitted to the hospital straight from the biopsy. They told my parents I had either Osteosarcoma or Ewing's Sarcoma, bone cancer. I couldn't believe it. My parents were very upfront and honest with me from the beginning. They allowed me to be part of all decisions when it came to my cancer treatment. My medi-port was placed during my first ever hospital visit, which was the first hospital visit of MANY. I didn't understand how I could have cancer. I had never even been to the doctor for being sick, only ever had a common cold! Chemo started the next week. After a few months of chemotherapy, I started 36 rounds of proton therapy.

Proton therapy left me with 3rd degree burns on the front and back of my right pelvic region. It was very painful and hard to sleep. My burns are almost healed now after over six months. Scar tissue has left me with a limp but I still try my best at soccer. I just had scans and they showed no new growth. My chest CT was clear. I'm still dealing with inflammation in the pelvis, but I am hopeful that my upcoming scans will show more regarding reaching remission!

Throughout my entire journey, I played soccer. I practiced in the hospital and I got my nurses and parents to play with me. I juggled, passed against the wall and did drills! I brought weights and cables to keep strong. I knew keeping my body strong and mind positive was very important.



LUNA

AGE
11

DIAGNOSIS
Currently
Battling Ewing's
Sarcoma

STORIES OF HOPE

Remy was just two years old when my wife took him into an After-Hours Urgent Care. He was looking tired, pale and lethargic. All the color was gone from his face, and the nurse said he was bound for the ER one way or another that night.

Leukemia crowds out red blood cells with cancer cells. It deprives your organs of oxygen and they begin to shut down, causing the pale color and lethargy. The odds of his ailments being leukemia were about one in 1,000. One morning, they settled us into a little blue hospital room on the 2nd floor while Remy was out in another room for a procedure and told us Remy had cancer. I held my wife and we cried.

Those 10 days of that initial admission were the hardest days of my life. It was a lot of long days waiting at his bedside, and a lot of long sleepless nights, waking him every few hours for vitals. I remember feeling helpless; a feeling I hate. To me, it's the worst feeling in the world, when you submit to the notion that there is no action you can take to make your two-year-old feel better. Remy's older brother Charlie brought so much sunshine to that little blue room that had become our world. The outside world seemed too much to think about on top of everything. Too much internet scrolling and information and not enough answers as to what our life was going to be like. We had no idea.

As the word got out of Remy's diagnosis, I realized how incredibly kind and generous people are. Even as I say this now, I am overwhelmed with the outpouring of support and love from our friends, our family, from people we had never met, and some we will likely never meet. And all people who I will forever be indebted to in what was undoubtedly the hardest week and a half of my life. I am amazed and very grateful.

Today Remy is in remission and has completed all of his treatments! We don't know what the future will bring, but we do know that we wouldn't be where we are without everyone who has supported us and joined the fight for a cure. With the help of the NPCF, we are closer and closer to a world without cancer. A world where Remy grows up and tells his kids and his spouse that there was this thing called cancer, but with the help of many great people along the way, he beat it.



REMY

AGE
4

DIAGNOSIS
In Remission
from Pre-B Acute
Lymphoblastic
Leukemia

Tab 3

Treatments

3
Treatments

A LOOK INSIDE

- Cancer Treatment
- Side Effects of Cancer Treatment
- Managing Side Effects
- Common Drugs Used to Treat Pediatric Cancer
- Symptom Management Suggestions
- Modern Medicine and Integrative Therapy
- Research and Clinical Trials
- Stories of Hope

CANCER

Treatments



Surgery

The treatment of injuries or disorders of the body by incision or manipulation.

Radiation Therapy

A treatment where high doses of radiation are used to kill cancer cells or shrink tumors.

Proton Beam Radiation

A type of radiation therapy that uses high-powered energy (positively charged protons) to treat tumors.

Chemotherapy

A treatment that uses chemical substances, such as drugs, to kill off cancerous cells.

Immunotherapy

A treatment that helps your immune system to battle cancer. It can boost or change how the immune system works so it can find and attack cancer cells.

Targeted Therapy

A newer type of cancer treatment that uses drugs or other substances to more precisely identify and attack cancer cells.

Stem Cell Transplant

A procedure that restores blood-forming stem cells in cancer patients who have had theirs destroyed by very high doses of chemotherapy or radiation therapy.

Precision Medicine

An approach to cancer care that allows doctors to select treatments that are most likely to help patients based on a genetic understanding of their disease.

Chimeric Antigen Receptor (CAR) T-cell Therapy

A way to get immune cells called T-cells to fight cancer by changing them in the laboratory so they can find and destroy cancer cells.

Common Effects of Cancer Treatments:

- Anemia
- Appetite Loss
- Bleeding/Bruising
- Constipation
- Delirium
- Diarrhea
- Edema
- Fatigue
- Hair Loss
- Infection and Neutropenia
- Lymphedema
- Memory or Concentration Problems
- Mouth and Throat Problems
- Nausea and Vomiting
- Pain
- Sexual and Fertility Problems (Male/Female)
- Skin and Nail Problems
- Sleep Problems
- Urinary and Bladder Problems



SIDE EFFECTS OF CANCER

Treatments

Fertility

Some treatments used may affect your child's ability to have children in the future. Depending on your child's treatment, you and your child's doctor should discuss whether fertility preservation options should be pursued prior to starting treatment. The doctor may then refer you to a fertility preservation specialist. Often times fertility preservation is most easily addressed after puberty.

Effects of therapy will differ between males and females. Sperm production impairment is the easiest to predict for males and shortening of the fertility for females. These are the most common fertility effects with chemotherapy.

Many studies have found that learning about fertility prior to therapy, even if ultimately choosing not to go through any procedure, is helpful for patients and families.

Females: Egg cryopreservation can be used in females who have gone through puberty. It is relatively costly (thousands of dollars) and takes a few weeks. For younger females who have yet to go through puberty, the process of ovarian tissue cryopreservation is offered at some centers.

Males: For males who have reached puberty sperm banking is used (a few hundred dollars per year). For those males who have not reached puberty, testicular sperm extraction and testicular tissue cryopreservation are offered at some centers but are more complicated.

For additional resources providing more information regarding fertility preservation visit:

Alliance for Fertility Preservation
AllianceForFertilityPreservation.org

Critical Mass: The Young Adult Cancer Alliance
CriticalMass.org

National Cancer Institute
Cancer.gov

AYA Cancer Connect
AYACancerConnect.com/resources/fertility

ReproTech
ReproTech.com

MANAGING

Side Effects



Anemia

- Monitor for pale skin, shortness of breath, fast heart rate. Alert your child's oncologist if these signs are present, as a lab check may be warranted to check hemoglobin.

Appetite Loss

- Discuss appetite stimulants with child's oncologist.
- In severe cases, feeding tubes (NG tube, G-tube, GJ tube) may be recommended by child's provider. Feeding tubes can be very helpful with getting adequate nutrition and avoiding weight loss.

Bleeding/Bruising

- Alert child's provider for significant increase in bruising.
- Observe for nosebleeds, bleeding gums, excessive bruising or pinpoint-sized redish/purple spots (known as petechiae), or blood in urine/stools and discuss with provider, as lab check may be warranted to check platelets.

Constipation

- Discuss your child's diet with his/her Dietician.
- Establish a bowel regimen with your child's provider, which can include medications such as stool softeners, laxatives, and motility agents.

Delirium

- New onset delirium should be evaluated as soon as possible.
- Occasionally delirium may be a side effect of a medication or the cancer itself.

Diarrhea

- Many potential causes including infections, medication side effects, diet, etc.
- Discuss child's diet with his/her Dietician.
- Discuss antidiarrheal agents with your child's provider.
- Provide extra fluids to prevent dehydration.

Edema (swelling/fluid retention)

- There are many causes of edema and it is most common in the hands, arms, legs and feet.
- Your child's provider may need to do testing to determine cause of edema.
- Management could consist of sodium/fluid restriction, diuretics or "water pills" or albumin infusions, along with treatment of the underlying cause.

Fatigue

- Fatigue is extremely common with cancer treatments.
- Let your child get extra rest when they are able.
- Ensure your child is getting adequate sleep at night; sleep aides are sometimes recommended if insomnia becomes a chronic problem.
- If fatigue is severe or child is difficult to arouse, consider evaluation as soon as possible, as it could be a sign of something more serious.

Hair Loss

- Consider having your child speak with a Child Life Specialist, who can educate your child on hair loss using language your child will understand.
- Encourage your child to speak with a Mental Health Specialist about his/her feelings regarding hair loss.
- Consider use of hats or wigs, if your child is comfortable.
- Socializing with other children with hair loss can also make your child feel more comfortable.

Infection and Neutropenia (low white blood cell count)

- Neutropenia is a very common side effect of cancer treatments.
- Infection may occur in the setting of neutropenia, as the body's immune system cannot fight bacteria/viruses/fungi effectively.
- Fever may be the earliest or only sign of infection in immunocompromised children and urgent evaluation is necessary for any child with a fever who is undergoing treatment.
- Your child may require cultures and/or antibiotics if fever is present with low white count.

Lymphedema (swelling caused by lymphatic blockage)

- Symptoms include swelling, skin texture changes, pain and decreased movement of affected area.
- Management may include exercise, compression of affected limb and/or lymphatic massage.

Memory or Concentration Problems

- Discuss potential cause with provider; both the disease itself or treatment may contribute.
- Many times memory or concentration problems can improve with time, particularly after active treatment ends; in other cases, it may be a long term side effect from treatment (i.e-radiation).

Mouth and Throat Problems

- Mucositis (inflammation of the mucous membranes) is a common side effect of chemo medications and may cause ulcers in the mouth, throat or gastrointestinal tract.
- An alkaline saline mouth rinse may be prescribed by your child's provider to help prevent mucositis.
- Other agents such as Magic Mouthwash may also be recommended to alleviate pain.
- Some parents use homeopathic remedies and supplements for mucositis; always discuss anything new with your child's provider.

Nausea and Vomiting

- There are several anti nausea medications that may help combat nausea/vomiting (i.e. Zofran).
- There are also homeopathic remedies that may be helpful in some children such as Ginger lozenges/tea and peppermint oil.

Pain

- There are many pain medications that may be recommended by your child's provider.
- For younger children, distraction techniques (i.e-playing a game) can be very effective.
- Some treatment facilities may also have a Quality of Life team or a Pain Management team that specializes in pain control and making your child comfortable.

Sexual and Fertility Problems (Male/ Female)

- See pg. 53



Skin and Nail Problems

- Skin infections may manifest as redness, pain, purulent discharge, or fever. These signs should prompt evaluation, as antibiotics may be warranted.
- Skin rashes may also be a side effect of medications or may represent an allergic reaction to a medication so it is important to have your child's provider evaluate the rash.
- Abnormal appearance or discoloration of your child's nails can be a side effect of certain chemotherapy medications; often the nails will improve with time.

Sleep Problems

- Your's child's sleep schedule may be altered due to sedation, medications, or feeling unwell.
- Sleep aides, such as Melatonin, are sometimes recommended by your child's oncologist.
- Somnolence, or sleeping "too much" can be due to chemotherapy medications; however, if your child is difficult to arouse, consider having them evaluated for more serious causes.

Urinary and Bladder Problems

- Your child may be put on IV fluids for hydration during treatment, which can cause frequent urination and "accidents" particularly in young children. Discuss options with your child's provider, such as wearing pull-ups or scheduling regular bathroom breaks.
- Certain chemo medications may cause blood in the urine; any new-onset blood in your child's urine should prompt evaluation by your child's oncologist.



COMMON DRUGS USED TO TREAT

Pedriatic Cancer

NOTE: Most common side effects are bolded.

BLINATUMOMAB

Side Effects: **Flu-like symptoms (fever, chills), headache, central nervous system reaction (headache, confusion, seizures, loss of balance, and fainting), cytokine release syndrome (fever, chills, shortness of breath, confusion, rash seizures).** Weight gain, swelling of arms or legs, joint or muscle pain, nausea or vomiting, constipation, diarrhea, fatigue, rash, liver problems, pancreas problems, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue).

BUSULFAN

Side Effects: **Low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), seizures, change in skin color, liver problems.** Nausea, vomiting, loss of appetite, diarrhea, constipation, mouth sores, dry mouth, fatigue.

Administered/Taken: Take at same time every day, store tablets at room temperature, store liquid in the refrigerator, shake the medication bottle well before drawing busulfan liquid into syringe.

CARBOPLATIN

Side Effects: **Nausea, vomiting, bleeding/bruising, kidney problems.** Diarrhea, mouth sores, numbness or tingling in the hands or feet, hair loss, abdominal pain, fatigue, loss of taste, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), ringing in the ears, hearing loss, kidney problems, low levels of potassium, magnesium, calcium, sodium, or phosphorus in the blood, change in normal menstrual cycle, infertility.

CISPLATIN

Side Effects: **Nausea, vomiting, kidney problems, hearing loss.** Diarrhea, numbness or tingling in the hands or feet, hair loss, abdominal pain, fatigue, loss of taste, dehydration, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), ringing in the ears, change in normal menstrual cycle, infertility.

CYCLOPHOSPHAMIDE

Side Effects: **Kidney or bladder problems, blood in the urine or burning while urinating, hair loss.** Nausea, vomiting, bad taste in mouth during IV infusion, loss of appetite, weight loss, abdominal pain, diarrhea, mouth sores, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), change in normal menstrual cycle, heart problems (at very high doses), changes in color of fingernails or toenails, infertility (especially at high doses)

Administered/Taken: Take cyclophosphamide capsules on an empty stomach with a full glass of water. The oral liquid cyclophosphamide can be added to juice right before it is taken.

CYTARABINE

Side Effects: **Mouth sores, sore or red eyes, skin rash, fever.** Nausea, vomiting, diarrhea, loss of appetite, abdominal pain, hair loss, muscle or joint pain, fatigue, headaches, yellowing of skin or eyes, seizures, confusion, numbness/burning/tingling in arms and legs.

DACARBAZINE

Side Effects: **Nausea, vomiting, loss of appetite, hair loss, headache, flu-like symptoms (fever, chills).** Increased sensitivity to sunlight, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue).

DACTINOMYCIN

Side Effects: **Nausea, vomiting, yellowing of the eyes, liver problems.** Abdominal pain, loss of appetite, diarrhea, hair loss, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), rash, difficulty breathing or swallowing, mouth sores, black and tarry stools, blood in stools.

DAUNORUBICIN HYDROCHLORIDE

Side Effects: **Red or orange colored urine, mouth sores, change in skin color at site of radiation, heart problems, hair loss.** Nausea, vomiting, loss of appetite, diarrhea, abdominal pain, fatigue, change in nails, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), liver problems, infertility.

DEXAMETHASONE

Side Effects: **Heart burn, increased appetite, weight gain, water retention (can lead to increased blood pressure and/or swelling of legs or feet), increased blood sugar levels, changes in mood, problems sleeping.** Stomach irritation, headache, dizziness, increased hair growth, eye problems, change in normal menstrual cycle, increased white blood cell count, decreased potassium levels, low bone density (osteoporosis), bone breakdown (osteonecrosis), tumor lysis.

Administered/Taken: Take with food or milk to decrease stomach irritation.

DINUTUXIMAB

Side Effects: **Pain (can be severe) or burning, tingling and numbness, fever, low blood pressure.** Rash, diarrhea, loss of appetite, nausea, vomiting, swelling (face, lips, hands, ankles, or feet), trouble breathing, cough, chest pain, confusion.

DOXORUBICIN HYDROCHLORIDE

Side Effects: **Red or orange colored urine, mouth sores, change in skin color at site of radiation, heart problems, hair loss.** Nausea, vomiting, loss of appetite, diarrhea, fatigue, dehydration, abdominal pain, eye pain or irritation, change in nails, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), liver problems, change in normal menstrual cycle, infertility (may be temporary).

ETOPOSIDE

Side Effects: **Low blood pressure (IV form), liver problems, hair loss.** Nausea, vomiting, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), mouth sores, diarrhea, rash, stomach pain, fatigue, numbness or tingling in the hands or feet, secondary cancers.

Administered/Taken: Store capsules in the refrigerator. Capsules should be swallowed whole, do

not crush or chew. Liquid etoposide can be stored at room temperature and mixed with orange juice or flavored syrup immediately before taking. Dispose of oral syringe after each use. Do not reuse.

FILGRASTIM

Side Effects: **Mild bone pain, pain or bruising at the injection site.**

Administered/Taken: Store in the refrigerator. Can be stored at room temperature for up to 24 hours if needed. Take vial out refrigerator an hour before dose is due to let filgrastim warm to room temperature. Do not shake vial.

FLUDARABINE

Side Effects: **Nausea, vomiting, fever, chills, infections, fatigue.** Loss of appetite, mouth sores, sweating, muscle pain, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), cough, trouble breathing, weakness, headache, vision changes, confusion, rash, diarrhea, bleeding (in urine or stool), tingling in the hands or feet, swelling of feet or legs.

GEMCITABINE

Side Effects: **Flu-like symptoms (fever, chills, aches), low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), nausea, vomiting, rash, shortness of breath, kidney problems, liver problems.** Headache, fatigue, loss of appetite, diarrhea, constipation, mouth sores, hair loss, lung problems, capillary leak syndrome.

HYDROXYUREA

Side Effects: **Low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue).** Hair loss, nausea, vomiting, diarrhea, constipation, mouth sores, rash, fatigue, darkening of the skin or nails.

Administered/Taken: Taking hydroxyurea at bedtime may decrease nausea and drowsy feeling that can be caused by this medication. Call the doctor right away if you have a fever while taking hydroxyurea. If the liquid suspension is made by the pharmacy, keep it in the refrigerator. If the hydroxyurea capsules are too hard to swallow, you can open them and empty the contents into a glass of water. The full glass of water must be consumed right away.

IFOSFAMIDE

Side Effects: **Nausea, vomiting, decrease in blood levels of potassium, magnesium, phosphorus, or sodium, kidney or bladder problems, blood in the urine or burning while urinating, feeling drowsy, sleepy or confused, hallucinations or seizures, hair loss.** Loss of appetite, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), slowed wound healing, bad taste in the mouth, diarrhea, mouth sores, infertility, heart problems.

IRINOTECAN

Side Effects: **Diarrhea, dehydration (especially with diarrhea), hair loss.** Nausea, vomiting, loss of appetite, fatigue, flu-like symptoms (fever, chills, aches), runny nose and/or increase in tears or saliva, rash, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), stomach or back pain, constipation, mouth sores, heartburn, weight loss, liver problems.

Administered/Taken: Take medication on an empty stomach. If vomiting occurs within 30 minutes of taking irinotecan, another dose should be given. Liquid irinotecan should be stored in the refrigerator and mixed with cranberry-juice or a flavored syrup immediately before a dose is given. Dispose of oral syringe after each use. Do not reuse.



ISOTRETINOIN

Side Effects: Dry skin and mucus membranes, change in eyesight, problems wearing contacts, sun sensitivity, muscle or joint pain, change in behavior, liver problems, increased blood lipid levels, nose bleeds, birth defects. Rash, mouth sores, nausea, vomiting, fatigue, fever, sweating, abdominal pain, diarrhea, headache, hair loss, depression, anxiety, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), increased blood sugar levels.

Administered/Taken: Avoid multivitamins or other medications containing vitamin A unless recommended by a pharmacist or doctor. Do not take any medications containing tetracycline. Avoid drinking alcohol while on this medication. Take extra caution to protect your skin from the sun while on this medication.

MELPHALAN

Side Effects: Low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), nausea, vomiting, loss of appetite, changes in taste, dizziness, mouth sores, fatigue. Hair loss, diarrhea, constipation, rash, change in normal menstrual cycle, loss of fertility (may be temporary or permanent), kidney problems, liver problems, lung problems, heart problems (at very high doses).

Administered/Taken: Take medication at same time every day. Take tablets on an empty stomach, 1 hour before or 2 hours after a meal. Swallow tablets whole. Do not crush or chew. Store tablets in the refrigerator and protect from light.

MERCAPTOPURINE

Side Effects: Low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), liver problems. Nausea, vomiting, hypoglycemia (low blood sugar), loss of appetite, fatigue, rash, darkening of the skin, increased sun sensitivity, mouth sores, diarrhea.

Administered/Taken: Take mercaptopurine at about the same time every day. Store mercaptopurine at room temperature. When giving liquid mercaptopurine, shake the bottle well before filling the oral syringe.

METHOTREXATE

Side Effects: Nausea, vomiting, sores around the mouth, lips, or anus, sun sensitivity, kidney problems. Low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), loss of appetite, headache, diarrhea, hair loss, rash, liver problems.

Administered/Taken: Take methotrexate on an empty stomach. Follow instructions for administration carefully. Avoid taking multivitamins or other supplements containing folic acid, non-steroidal anti-inflammatory drugs (NSAIDs), or proton pump inhibitors unless recommended by a doctor.

METHYLPREDNISOLONE

Side Effects: Problems sleeping, increased appetite, changes in personality or mood, restlessness, stomach irritation, heartburn, nausea, water retention (can lead to increased blood pressure and/or swelling of legs or feet), increased risk of infection, slow wound healing, increased blood sugar levels. Headache, dizziness, acne, dry skin, increased sweating, eye problems, change in the normal menstrual cycle, low bone density (osteoporosis), bone breakdown (osteonecrosis), tumor lysis.

Administered/Taken: Take methylprednisolone with food or milk to decrease stomach problems. Store methylprednisolone at room temperature.

PEGASPARGASE

Side Effects: Increased blood sugar levels, increased risk of bleeding or clots, liver problems, increased triglyceride levels in the blood, allergic reaction, inflammation of the pancreas (pancreatitis). Nausea, vomiting, fever, ongoing abdominal pain that may spread to the back, increased risk of stroke, pain at the injection site.

PREDNISON

Side Effects: Heartburn, increased appetite, weight gain (especially in the face and abdomen), water retention (can lead to increased blood pressure and/or swelling of legs or feet), acne, increased blood sugar levels, changes in mood or personality, problems sleeping.

Stomach irritation, headache, dizziness, increased sweating, eye problems, change in the normal menstrual cycle, increased white blood cell count, increased risk of infection, increased hair growth, decreased potassium levels, low bone density (osteoporosis), bone breakdown (osteonecrosis), tumor lysis.

Administered/Taken: Take prednisone with food or milk to decrease stomach problems. Store prednisone at room temperature.

RITUXIMAB

Side Effects: Flu-like symptoms (fever, chills, aches), injection site reaction. Headache, low blood pressure, nausea, vomiting, joint or muscle pain, diarrhea, rash, flushing, night sweats, runny nose, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), liver problems, kidney problems, tumor lysis syndrome.

THIOTEPA

Side Effects: Nausea and vomiting (especially with high doses), eye pain or irritation, change in skin color (temporary darkening with high doses), contact dermatitis and/or skin rash.

Low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), loss of appetite and weight loss, dizziness, fatigue, headache, abdominal pain, mouth sores, hair loss, change in the normal menstrual cycle, infertility, liver problems.

TOPOTECAN

Side Effects: Diarrhea (can occur within 24 hours or develop later), low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), liver problems. Nausea, vomiting, loss of appetite and weight loss, fatigue, flu-like symptoms (chills, aches, fever), dehydration (especially with diarrhea), hair loss, constipation, mouth sores, lung problems.

Administered/Taken: Topotecan by mouth is usually taken once a day. Store topotecan (liquid or capsules) in the refrigerator and protect the medication from light. If vomiting occurs after taking topotecan by mouth, do not give another dose. Liquid topotecan can be mixed with juice or flavored syrup immediately before use. Capsules should be swallowed whole.

TRETINOIN

Side Effects: Dry skin and mucus membranes, rash, nausea, vomiting, abdominal pain, diarrhea, headache, low blood counts (may increase risk of infection, bleeding, anemia, and/or fatigue), APL differentiation syndrome (may cause fever, weight gain, trouble breathing, and/or lung and heart problems). Mouth sores, eye problems, sun sensitivity, loss of appetite, weight loss or gain, fatigue, muscle or joint pain, fever, sweating, flushing, chills, constipation, earache, hair loss, depression, anxiety, change in behavior, liver problems, increased blood lipid levels.



Administered/Taken: Avoid multivitamins or other medications containing vitamin A unless recommended by a pharmacist or doctor. Do not take any medications containing tetracycline. Avoid drinking alcohol while on this medication. Take extra caution to protect your skin from the sun while on this medication. Take the medicine with meals and a full glass of water. Capsules should be swallowed whole. Store capsules at room temperature and protect from light.

VINCRISTINE SULFATE

Side Effects: Constipation, abdominal pain, jaw pain, difficulty walking, numbness, tingling, or burning in the hands or feet, muscle pain or weakness, bone or joint pain. Nausea, vomiting, loss of appetite, pain when urinating, blurry vision, dizziness, seizures, low sodium levels in the blood, hair loss.

SYMPTOM MANAGEMENT

Suggestions

Every person's experience with cancer and the various forms of treatment are unique to that individual. While one patient may experience one side effect, it does not guarantee that another patient will have the exact same experience. The same is true for pain management. One patient may have great results in using liquid aloe to help curb or eliminate mouth sores while another patient could use liquid aloe multiple times a day and not experience any relief. This is why it is so important to be open to trying multiple methods of symptom management in order to find just the right fit for you.

Below are some alternative suggestions, from various nurses, doctors, and families. Please remember to always consult your doctor and share any new treatment methods or routines you are implementing with them.

**Consult your
health care
provider
about these
methods:**

- Massage
- Acupuncture
- Tai Chi, Yoga, etc.
- Integrative approach
- Mind-body therapies
- Nutraceuticals and medicinal food
- The biochemistry of botanical medicine
- Practical approaches to creating and expanding a holistic practice

BRIDGING THE GAP BETWEEN

Modern Medicine and Integrative Therapy

In December of 2019, our son, Micah, then 4 years old, was diagnosed with a rare form of stage 4 genetic cancer - adrenocortical carcinoma (ACC). His k167 markers were high, his tumor spilled during the emergency tumor resection, and he had metastatic disease. He was given a less than 10% prognosis at its best. We were told later by St. Jude that his protocol was one of the hardest on his floor. We looked to the medical world for hope. They unfortunately could not give us any, instead they prepared us for loss. It was a very rare disease with no funding and the protocol set in front of us was similar to a game of Russian roulette. It was toxic and extremely dangerous with a small chance of success.

In my heart I knew there was another way. Prior to his diagnosis, I had always leaned toward natural remedies for healing. I had a knowingness that our bodies were designed to heal when we gave them what they needed. Many of my friends were educated in integrative, nutritional, and functional medicine. They connected me quickly with others who offered us hope. We learned that there were ways that we could support our son through this toxic protocol. We learned that healing from cancer meant healing Micah's full terrain and that's what we set out to do.

We realized that it was our responsibility to create our son's team. We transferred care to St. Jude Children's Hospital because they had treated children with ACC. We had a private nutritionist who completely understood that proper nutrition IS medicine. There's a myth that these kids can eat whatever they want. This is simply not true. Our bodies need real food, real nutrients, real vitamins, real proteins, real healthy fats, and very minimal sugar to heal. When Micah had his g-tube placed and I looked at the ingredients on the formula that the hospital recommended I cringed but it validated our need for a private nutritionist. We hired an integrative doctor who ran toxicity tests, helped us detox Micah, provided DNA nutrition tests, and prescribed the many integrative therapies tailored to Micah's needs. At times it wasn't easy for all of them to work together and we had to advocate hard; my husband and I became the General Contractors of his health. We consulted very intelligent individuals on our team and with a mixture of honor, advocacy, and bravery set out to heal Micah.

Micah thrived through treatment. The results we achieved were miraculous. We were told in the beginning to expect to be sent home to focus on quality of life but here we are with NO EVIDENCE OF DISEASE. When treatment ended there wasn't anything our oncology team could do for prevention and we were sent home to wait and see if he would relapse. I refused to wait and see and we've continued to pursue safe detox, integrative therapies, healing nutrition, and spiritual wholeness. We were told his hearing loss from chemotherapy wouldn't improve. It has. Surprising everyone, he was off of all steroids 7 months after treatment ended. His counts never delayed treatment. After the 2nd round of chemotherapy he maintained his weight. He didn't have neutropenic fevers, and the end of treatment when it was expected to be the hardest it became easier.

Micah

4 years old / Stage 4 genetic cancer -
adrenocortical carcinoma (ACC).



Our heart's desire is to see these two worlds collide – modern medicine and nutrition/integrative care. We are seeing more and more parents that are making that happen by learning to advocate for their children. Some hospitals are now even agreeing to offer high dose vitamin C in conjunction with chemotherapy. However, a lot of parents are discouraged from seeking out proper nutrition and integrative therapies. Until childhood cancer isn't the number one cause of death in children I think it's safe to say we don't have it all figured out (yet). Sometimes our deep knowledge is our strongest navigator to achieve success. My knowingness, or some would call it God's wisdom, weighed much more heavily than a protocol with old chemotherapies that were toxic and provided little hope.

There are a lot of incredible resources and many passionate and well-educated foundations that have set the stage for bridging the gap between mainstream medicine, nutrition, and integrative medicine. Our children deserve to have these worlds combined if parents desire a full approach healing. My advice is to hire an integrative doctor that works with pediatric oncology, find other parents, foundations, and groups with the same mindset. Read all of the studies. Most importantly push fear aside and find your peace. Your knowingness that you're doing what's best for your child is key. Don't be afraid to honorably disagree and bravely advocate for your child. There are big changes happening to promote a better way to heal, but it takes brave parents like us to advocate that change.

Deep breaths, you can do this.

Heather Ternahan

MICAH'S MOM

CO-FOUNDER OF MADE4MIRACLES

WRITER | FULL TERRAIN HEALING ADVOCATE

RESEARCH & CLINICAL TRIAL Information



“To accomplish great things, we must not only act,
but also dream, not only plan, but also believe.”

– Anatole France

When facing a cancer diagnosis, your child’s doctor may provide several treatment options, including clinical trials.

What is Clinical Research?

According to the National Cancer Institute (NCI), clinical research is the study of people, data, or biological samples to better understand health and disease. Clinical trials are essential for the discovery, prevention, diagnosis and treatment of cancer. Clinical trials not only test new treatments for cancer, they also help determine the best use of existing treatments.

Two Types

1. **Observational Studies:** Used to gather information through observing people to see how specific characteristics change overtime.
2. **Clinical Trial:** Tests new treatments for a specific disease and allows researchers to better understand how a disease develops over time.

Different Types of Clinical Trials

- **Treatment:** This is the most common type of clinical trial. Treatment trials test all new treatments, including vaccines, drugs, new approaches to surgery, or combinations of different treatments.
- **Prevention:** These trials are for individuals who do not have cancer, but have a high risk of a cancer diagnosis.
- **Screening:** Looks for new ways of detecting cancerous cells in earlier stages so treatment can begin sooner. This could be done using a blood sample or a piece of tissue from your child’s tumor.
- **Supportive and Palliative:** These trials are done in order to improve your child’s quality of life by helping with pain management or other sicknesses that may arise from their cancer.

Different Phases of Clinical Trials

- **Early Phase (Phase I) Trials: From Laboratory to Clinic**
 - o Test promising new agents in a small number of patients (usually around 20 to 80).
 - o Used to determine if the treatment is safe and what the most effective dose of that drug is.
 - o Often incorporate the standard of care therapy with the addition of another form of treatment.

- **Phase II and Phase III Trials: Does the Treatment Work?**

- These trials are often the standard treatment when treating pediatric cancers.
- While safety is still a concern during these phases, determining how effective the drug is, is the main focus.
- Phase III trials are often randomized. A randomized trial randomly assigns a participant to either the standard treatment for their cancer or to the new treatment being studied to determine if one is better than the other.

Reasons for Participating in a Clinical Trial

- Obtain access to new drugs.
- Previous cancer treatments did not work or are no longer working.
- No other treatment options available.
- Help researchers learn more about your child's cancer.
- Help future generations of children diagnosed with cancer.

What to Expect

- Taking part in a clinical trial is 100% voluntary, participation in a trial is not required for treatment of your child's cancer.
- Before joining a clinical trial, the trial will be explained to you by a medical team. This explanation will include any risks or side effects that may be associated with the treatment, how long the trial will last, and what to expect at study visits. You will be given the opportunity to ask questions at any time during the study explanation and/or during the treatment period. Possible questions to ask before participating in a clinical trial:
 - How will this affect everyday life for my child and family?
 - How will I know if the treatment is helping my child's cancer?
 - What happens if the treatment doesn't help my child's cancer?
 - Where will trial visits take place and with who?

Costs Associated with Participating in a Clinical Trial

- Trial participants and their insurance company are financially responsible for charges that are considered part of their routine care since they would be receiving these services even if they weren't participating in a trial.
- Any service provided that is specifically required for research purposes and is not considered part of routine care, will not be your responsibility.

How the National Pediatric Cancer Foundation is Supporting Cutting-Edge Clinical Research

The NPCF funds the Sunshine Project, which is an innovative collaboration with one goal: to bring together the nation's top doctors and researchers to fast-track less toxic, more targeted treatments and increase the survival rate for children battling cancer. By capitalizing on the strengths of researchers from a variety of scientific fields, the NPCF has been able to streamline the process of protocol development in the hopes of delivering more personalized medicine to children with cancer.

Through the Sunshine Project, the NPCF has launched five Phase I clinical trials in just eight years, an incredibly short time in the medical world. New drugs and drug combinations have been, and continue to be, tested in these clinical trials and hold great promise for children who have not experienced positive results under the standard protocol treatment.

**Sunshine Project Affiliate Hospitals:**

1. Atrium Health / Levine Children's Hospital, Charlotte, NC
2. Children's Healthcare of Atlanta, Atlanta, GA
3. Children's Hospital Colorado, Aurora, CO
4. Children's Hospital Los Angeles, Los Angeles, CA
5. Children's Hospital of Philadelphia, Philadelphia, PA
6. Children's Medical Center, Dallas, TX
7. Children's National Medical Center, Washington, DC
8. Children's of Alabama, Birmingham, AL
9. Cleveland Children's Clinic, Cleveland, OH
10. Connecticut Children's Medical Center, Hartford, CT
11. Dana-Farber Cancer Institute, Boston, MA
12. Duke Cancer Institute, Durham, NC
13. Johns Hopkins All Children's Hospital, St. Petersburg, FL
14. Johns Hopkins Sidney Kimmel Comprehensive Cancer Center, Baltimore, MD
15. Kentucky Children's Hospital, Lexington, KY
16. Moffitt Cancer Center, Tampa, FL
17. Montefiore Medical Center, Bronx, NY
18. Nationwide Children's Hospital, Columbus, OH
19. Nemours/Alfred I. duPont Hospital for Children, Wilmington, DE
20. Nemours Children's Clinic,
21. Nemours Children's Hospital, Orlando, FL
22. Primary Children's Medical Center, Salt Lake City, UT
23. Roswell Park Comprehensive Cancer Center, Buffalo, NY
24. St. Louis Children's Hospital, St. Louis, MI
25. Sylvester Comprehensive Cancer Center, Miami, FL
26. UF Health Shands Children's Hospital, Gainesville, FL
27. University of Chicago, Chicago, IL
28. UNC Lineberger Comprehensive Cancer Center, Chapel Hill, NC
29. University of Texas MD Anderson Cancer Center, Houston, TX
30. Vanderbilt-Ingram Cancer Center, Nashville, TN
31. Weill-Cornell Medicine, New York, NY

Additional Resources:

- **National Cancer Institute**
[Cancer.gov/about-cancer](https://www.cancer.gov/about-cancer)
- **ClinicalTrials.gov**
[Clinicaltrials.gov](https://www.clinicaltrials.gov)
- **Children's Oncology Group**
[Childrensoncologygroup.org](https://www.childrensoncologygroup.org)

STORIES OF HOPE

In early December 2018, we took Kinsley to the doctor because she had redness in her right eye. When the redness persisted, we sought a second opinion from an eye doctor. A family ophthalmologist determined that she had a detached retina and stated that it could be the result of trauma to the eye or something much worse such as a tumor.

Two rounds of doctors, tests, and ultrasounds later we were told that Kinsley did not have a tumor. However, an evaluation under anesthesia was scheduled with the pediatric retina specialist the following day to determine if Kinsley's detached retina could be repaired.

On December 19, 2018, the relief that we had just 24 hours prior came crashing down when the pediatric retina specialist found an advanced stage tumor in Kinsley's right eye. We went from hearing the words "I'm 99% sure that there is no tumor" to our sweet four-year-old daughter being diagnosed with Retinoblastoma - an extremely rare and aggressive eye cancer that could take her life.

"It was every parent's worst nightmare. To hear your child has cancer is earth-shattering, soul-wrenching, and a true test of strength"
- Kim.

Just days before Christmas on December 21, 2018, Kinsley received her first round of systemic chemotherapy. Just two days after being discharged and returning home to Sarasota, Kinsley developed some serious side effects to the chemotherapy and was admitted to the local hospital for 10 days.

Kinsley's ocular oncologist confirmed that the tumor was very advanced and complex. Due to this advanced stage presentation, hemorrhaging in her eye, and the life-threatening risk of the cancer spreading to her optic nerve, orbits and/or brain, the decision was made to have her right eye enucleated (removed).



KINSLEY

AGE
8

DIAGNOSIS
Cancer-Free from
Retinoblastoma

From January through March, Kinsley underwent three more rounds of systemic chemotherapy. One month after Kinsley's 5th birthday, she had her right eye enucleated, and an orbital implant placed.

On March 1, 2019, we received the best news ever. Pathology results of the globe and optic nerve found that the cancer was completely contained to her right eye that was removed and Kinsley was considered to be cancer free. A few months later she received her permanent prosthetic eye, custom painted to match her eye color.

In an attempt to avoid cabin-fever while receiving chemotherapy and being quarantined to our home, Kinsley took up a love of baking. She baked almost every day and her signature cookies were placed in neighbor's mailboxes, dropped off at her school, and passed out to family and friends. Kinsley absolutely loved the joy that her cookies brought to others. Her cookies became very well-known amongst the community.

One day, she asked her dad if he would build her a cookie cart so she could sell her cookies and give the money to other kids that were fighting cancer like her. You see, Kinsley was in the fight for her life, yet still thinking of how she could help others. Her dad, Adam, spent countless nights in their garage building her the perfect cookie cart.

“Hearing the words that our sweet girl had cancer was a time that I will never forget but I put my trust in God and the big plans He had for her. Building her cookie cart helped give me strength at a time when our family needed it the most because I knew that it would be a vehicle for her to inspire and impact the lives of so many other little warriors and their families.”

- Adam



It was from there, that Kinsley's Cookie Cart was born. Today Kinsley's Cookies can be purchased and shipped all across the country and 43% of the proceeds go to supporting pediatric cancer research. Kinsley and her cookies have raised over \$200,000 for pediatric cancer research!

STORIES OF HOPE

It was a normal day in October, my daughter Avery had been experiencing weakness and pain in her right ankle for about two months and something nudged me to take her to the doctor. The first visit was relieving, maybe a sprain? Our doctor recommended ice, rest and Tylenol. After three weeks, I picked Avery up from school and she was in severe pain. We visited the doctor again where she had an X-ray that led to an MRI. Little did we know that would be the beginning of a long battle of Avery's Acute Myeloid Leukemia.

If you've ever experienced cancer, you know chemotherapy is the beginning of the battle. The real war is with the aftermath of the chemotherapy. As contained as Avery was and regardless of following all the hygiene rules, we kept running into infections that would set us back. The endless blood tests, cultures, EKGs, meeting with the doctors, and pill after pill after pill. This experience has been hard on Avery and an overwhelming struggle for her sister, Ella. I am a single mom and our somewhat chaotic, but normal life has been turned upside down. Avery's illness is hard enough but taking unpaid leave from work to care for a consistently inpatient Avery, and the endless need to find places for her 7-year-old sister to sleep while we're commuting for Avery's treatment was devastating.

Thankfully Avery is always looking on the bright side and was able to keep her spirits high despite all the pain and hardships of her diagnosis.

"Cancer has taught me inner strength and resilience. I uncovered my ability to cope with difficult situations, deal with stress, and overcome the odds. Not only am I strong but also sensitive. I've faced cancer by being completely myself; sensitive to mine and other's needs. I want society to know that being strong AND sensitive is possible."

- Avery



AVERY

AGE
14

DIAGNOSIS
Acute Myeloid
Leukemia

Tab 4

What now?

A LOOK INSIDE

- Notes From a Nurse
- Things to Talk to Your Children About
- Care for Childhood Cancer Survivors
- Navigating School During Cancer and Beyond
- Caregiver to Caregiver
- Stories of Hope

4

What Now?



NOTES FROM A Nurse



As a Pediatric Oncology Nurse, I work very closely with the families of patients. When patients are not in the hospital or clinic getting their chemo or radiation, I encourage families to make memories and have some fun. Here are the most common questions I come across with the families I have worked with. If you are curious or concerned about an activity, don't hesitate to ask your child's nurse or health care provider.

Nurse Sarah

Q: Can my child go to school?

A: School is a valuable part of your child's life that offers not just education but also an opportunity to socialize with, and learn from, their peers and school staff. Chemotherapy protocols vary greatly; some require intensive medications and appointment schedules that make in-person attendance unlikely, and some allot for more time in between cycles that make it easier for a child to attend school. Ask the assigned oncologist if your child will be able to attend school in person. If a referral for "home bound instruction" will be needed, talk with your child's school and/or the hospital social worker (or school liaison) to see if there are creative ways your child can remain connected with his/her peers. Even when your child is allowed to attend "in person" there may be moments when your child's blood counts are really low or when there is an illness going through the school; during these times, it is best not to send him/her to school (in person).

Q: Can my child play with other children?

A: Yes, keeping a couple general rules in mind. Be sure to ask if the other child/children have been, or currently are, sick or with fever within the past 72 hours. Have they recently been around someone else who was sick in the past 72 hours? Make sure hand hygiene is strictly followed with everyone. Don't be afraid to ask everyone who comes over to wash their hands, or use hand sanitizer, upon arrival.

Q: Can my child go out in public without wearing a mask?

A: Yes, with the exception of a bone marrow transplant patient. Good hand hygiene is your strongest defense against viruses and illness. It is strongly suggested to stay away from crowded indoor facilities, such as movie theaters, especially when blood counts are low. If you are out and notice someone who appears to be sick, do your best to avoid that person and the area they are in.

Q: Can my child swim in freshwater such as lakes, ponds and rivers?

A: If your child has a central line that lies outside the skin (e.g. PICC line or Hickman-Broviac), then **NO they may not allow that area to be submerged under water.** In addition, it is highly recommended to limit exposure to these bodies of water because there can be parasites and bacteria that live in these types of water. Many of which may have no harm to a healthy individual, but to someone who is immunocompromised, it can be harmful. The general rule of thumb is if the body of water is "nonmoving" you should avoid it at all costs. Moving bodies of water tend to be safer but can still present the risk of bacteria.

Q: Can my child go to public pools?

A: If your child has a central line that lies outside the skin (e.g. PICC line or Hickman-Broviac), then **NO they may not allow that area to be submerged under water.** In addition, there is no way to know how well the pools are kept clean, and when you have multiple people in and out of a pool at any given time, the risk of contaminated water is very high. You never know how many people urinate in a pool, and there is no way to know if there is enough chlorine in the pool to kill off any bacteria. It is best to only swim in a private pool of a your own or a close friend that you know keeps their pool clean.

Q: Can my child go to the beach?

A: If your child has a central line that lies outside the skin (e.g. PICC line or Hickman-Broviac), then **NO they may not allow that area to get sand on it or be submerged under water.** In addition, keep in mind that at various times there can be viruses in the water that should be avoided. It is recommended that time spent in the ocean is limited as well. Also, it is imperative that your child wear sunscreen and that it is reapplied multiple times while being exposed to the sun. Children going through chemotherapy are extremely sensitive to the sun and can develop a sunburn much quicker, and more severe, than others.

**Q: Can we have pets in our home, and if so, what kind?**

A: If you already have pets, please talk with your child's treatment team to learn more about whether there are special recommendations about how to keep your child safe from potential infections. There may be a safe way for your family to keep an already established pet. If you want to get a new pet, still ask the treatment team for guidance. Typically, yes pets are allowed in the home. The recommended types of pets are often restricted to cats, dogs and fish. Rodents (Hamsters, guinea pigs, etc), birds and reptiles (lizards, snakes, etc) should not be in the home as they can carry many parasites and bacteria in their feces. With cats, the litter box should be kept clean and in an area of the home that is away from a return air duct or where a child may come into contact with it.

Q: Can my child ride roller coasters with a medi-port?

A: Yes, but keeping in mind that certain roller coasters may cause damage to the port. Roller coasters that have an over the head safety bar should be avoided if they will be on or near the port as the jolting around can cause harm to the port. It is also a strict rule that if the child's platelet count is below 50, they are not to go on a roller coaster as they are at an increased risk for bleeding.

Q: Can my child fly on a plane while on chemotherapy?

A: Essentially, yes, however, any travel should be coordinated with the treatment team. It's important to note, if your child's ANC is low (below 500), it would be strongly advised not to fly during that time as the risk for infection is high. The air on a plane circulates, and you cannot be sure what your child will be exposed to on the plane. If you wish, you may have your child wear a mask, but to be truly effective, you would have to change it frequently during the flight.

Q: Can my child be around someone who just had vaccines, e.g. a sibling?

A: Yes, with the exception of the live flu-mist vaccine that is given nasally. You cannot contract anything from a vaccine that another person received.

Q: Are there certain diseases my child should not be around?

A: Yes, all of them. You should avoid exposing your child to any communicable disease at all costs as they will be much more susceptible to having complications from them and being hospitalized. Should you learn that a child whom your child was recently interacting with develops a communicable disease, contact your oncologist immediately.

Q: Are there certain foods that my child should or shouldn't eat during chemotherapy?

A: In general, no. There are certain times that some patients may be receiving an oral chemotherapy agent that should not be administered with milk products as it may decrease the absorption of the chemotherapy. It is recommended that children eat a well-balanced diet. They may also take a multivitamin as long as it is discussed with your oncologist first.

Q: I know of special herbs, teas and other supplements that can be helpful. Can I give them to my child?

A: No supplement or vitamin should be given to your child without first consulting the child's oncologist. There may be some ingredients in the supplement that can interfere with, or decrease the effectiveness of, chemotherapy agents.



THINGS TO TALK TO YOUR

Children About (WITH AND/OR WITHOUT CANCER)

- Talk to your child about cancer and explain how together you will overcome this big obstacle in their life.
- Inform your child and your friends and family about what they're going through.
- Do not lie to your child. Lying only makes things worse. No matter your child's age, they need to know.
- Tell your child about the treatment they will be undergoing.
- Explain where your child will be staying.
- Talk to your child's friends' parents about what is happening. This lets them explain to their child(ren), in their own way, why their friend has not been at school, practice, etc.
- Talk to their siblings and explain what their sibling is going through so they are informed as opposed to being stuck in the dark.
- Be there for your child. This is one of the hardest battles your child will face in their life, and they need your support.
- Inform your child that cancer is not contagious, so no one gave it to them, and they cannot give it to anyone else.
- Have your neighbors and friends talk to their children about what your child is going through and how they need their support.
- Inform your family members, and encourage them to inform the rest of the family so everyone is aware of what is happening.
- Consult your kids on how their diet is going to change and of the foods they should and should not eat based on their condition.
- Talk to your child about the treatment side effects they might be experiencing or will experience in the near future.
- Stay strong. Everyone knows this is a tough time, but if you stay strong chances are that your child will too.
- Don't jump to conclusions. Stay in the know and take things one step at a time.
- Be the best parent you can be, and treat your child as if they are no different. Although they are going through a tough time, they still want to be a kid.
- Let your kid be a kid. Kids may not understand what is happening so don't throw it all on them. Instead, let them continue to smile and be joyful. Still, do not lie, but only bring up important topics if asked by your child or told they need to know.
- Allow parents to talk to their child(ren) about what is happening. No matter your opinions as a friend/neighbor/teammate, it's a parent's job to inform their child, and they can do so as they please.
- If money is a problem, and you are unable to pay for treatments, don't be afraid to ask for help. Not only does your child need support, but you may too - so please don't be afraid to ask for support.
- Finally, make sure to tell your child every day that you love them. Through this part of a child's life, they are under a lot of pressure and need love and support from all the people in their life.
- If you need assistance like financial, housing, food and/or other needs, it is best to consult with your assigned social worker.

CARE FOR CHILDHOOD

Cancer Survivors



While the completion of your child's cancer treatment is something to celebrate, it may also bring new challenges. You may worry that the cancer will return. Your child may struggle getting used to new routines. Some families enter this new phase feeling stronger, whereas others are more fragile. Many families are surprised by anxious feelings that arise during this long-awaited time when they expected to feel only relief. Instead of this being a time to go back to life as it used to be, it may be a time of continued adjustment as you leave the security of the people on your child's health care team. Some said the transition to life after treatment took longer and was more challenging than they thought it would be.

Follow-Up Care After Cancer Treatment

It is both reassuring and essential that your child receives follow-up care from specialists after completing cancer treatment. Get a written copy of your child's treatment summary and survivorship care plan. Ask for recommendations to hospitals that offer the type of follow-up or survivorship care that your child needs.

Treatment Summary

The treatment summary includes both diagnostic and treatment information, such as:

- Type of cancer, severity (stage, grade, or risk group), date of diagnosis, and pathology report.
- Type(s) of treatment received, including the names and doses of all medications, as well as the total amounts and sites of any radiation therapy received.
- Treatment dates.
- Key reports and scans, such as CT scans and MRIs.
- Side effects and/or complications experienced during treatment.
- Supportive care received (also called palliative care)—such as counseling or physical therapy.
- If your child was in a clinical trial, the identifying number and title of the clinical trial.
- Names and contact information of key people on your child's health care team.

Survivorship Care Plan

A survivorship care plan (also called a follow-up care plan) is developed for each child. Survivorship care plans are based on the type of cancer and treatment your child received. For example, some children may need to return for visits each month for the first year after they have completed treatment. Others may not need to return as often. Here is the type of information that's included in follow-up care plans for children who have been treated for cancer, as outlined in the Institute of Medicine's fact sheet:

- Exams and tests/procedures to check for the recurrence or metastasis of cancer and a schedule of when they are needed.
- Care and support to manage any long-term side effects and check for late effects.
- Psychosocial support or counseling and referrals, as needed.
- Referrals for legal aid or financial support, as needed.
- Referrals to and coordination with specialists such as cardiologists, education specialists, endocrinologists, physical therapists, and psychologists and to appropriate treatments, clinical studies, and rehabilitation specialists.

Recommendations for healthy behaviors, such as advice regarding nutrition and physical exercise. Family-based care, education, and outreach to your child and family.

Follow-Up Care Clinics/Survivorship Clinics

Places that specialize in follow-up care for children who have been treated for cancer are called follow-up care clinics or survivorship clinics. At these clinics, your child will see specialists (for example, in cardiology, endocrinology, fertility, nutrition, psychology, and/or pulmonology) who will monitor your child's health. These clinics are usually found within hospitals.

If the hospital where your child was treated does not have such a clinic, ask your child's doctor to recommend one. You can also refer to the Children's Oncology Group which has Late Effects Directory of Services that can help you find a hospital that offers services for late effects of treatment for children's cancer.

Long-Term and Late Effects

While it may take a while for your child to get used to their new schedule, it's important to check with your child's doctor for new problems or side effects that don't seem to get better after treatment. Although many side effects go away once treatment has ended, long-term side effects, such as fatigue, may take some time to go away. Other side effects, called late effects, may not occur until months or even years after treatment.

Whether or not your child may have late effects of treatment depends on the type of cancer your child had and how it was treated, as well as personal factors, such as:

- Cancer-related factors like the type of cancer, where it was in the body, and how it affected tissues and organs.
- Treatment-related factors such as the type and dose of treatment(s) or the type of surgery.
- Patient-related factors such as your child's gender, age at diagnosis, length of time since diagnosis/treatment, personal and family health history, and health habits.

Types of Late Effects

Late effects may be physical, emotional, or cognitive. Knowing what symptoms to be aware of and when they may occur can help you plan for the needs of your child. Not knowing what to expect can cause anxiety for some parents. However, for other parents, knowing about late effects that may or may not happen to their child in the future can be overwhelming. Many parents find it helpful to ask their child's doctor what to focus on at each step of their child's recovery.

Physical Late Effects

Physical late effects involve changes to organs, tissues, and/or body functions. They may affect your child's growth and development. Some children who have been treated for cancer have many physical late effects, whereas others have relatively few. As you talk with your child's doctor to learn what to expect, you can also learn more about treatments that may increase the risk of physical late effects in Late Effects of Treatment for Childhood Cancer.

Emotional Late Effects

Emotional late effects include changes to your child's mood, feelings, and actions. Many children are very resilient after cancer treatment. Others experience social and/or emotional problems. If your child is not sleeping well and no longer enjoys activities that they once did, it is important to talk with your child's doctor about having your child evaluated for depression.

Some children develop post-traumatic stress disorder (PTSD). This anxiety disorder arises in reaction to physical injury or severe mental or emotional distress. Symptoms of PTSD may include having flashbacks about diagnosis or treatment, avoiding places that are reminders of the experience, and being fearful, irritable, unable to sleep, or having difficulty concentrating. Ask your child's health care team to suggest resources for mental health support in your area.



Cognitive Late Effects

Cognitive late effects include changes in your child's ability to memorize, learn, and think. These types of late effects are more likely to occur in children who've had certain cancers such as brain and spinal cord tumors, head and neck cancers, and some types of leukemia, such as ALL. Treatments such as radiation therapy to the head and certain types of chemotherapy also increase the risk of cognitive late effects. These late effects are more likely in children who were very young during treatment, who received very high doses of treatment, and whose treatment lasted a long time.

Children with cognitive late effects may have a more difficult time:

- Memorizing or remembering.
- Learning - handwriting, spelling, reading, vocabulary, and/or math may be particularly challenging.
- Thinking including concentrating, completing work on time, doing work that involves multiple steps, problem solving, and planning.

As you talk with your child's doctor, here are some questions to consider:

About treatment

- Who should we talk with to get a comprehensive record of treatment(s) and medications that our child received during treatment?

About practical steps to take at home

- What health problems in our child should we be aware of?
- Who should I contact if health problems occur?
- Does my child need to continue taking any medicine(s)? If so, for how long?
- What types of activities may help my child? Are any activities not recommended?
- What vaccines should my child receive? When should they be given?

About follow-up care (plan and schedule)

- Who should I talk with to get a follow-up care plan and schedule for my child?
- Which medical experts should my child see for follow-up care?
- What tests will be done during follow-up care visits? How often and for what reason?
- Where should my child go for follow-up care visits?
- What is the schedule for these visits?

About possible long-term and/or late side effects

- Is my child at increased risk of having long-term side effects? If so, which ones, and how can they be managed?
- Is my child at increased risk of developing late effects later in life? If so, which ones and how likely are these to occur? How long after treatment might they occur?
- What types of specialists should my child see to manage these effects?

About support and coping

- What survivor support groups are available for my child? For our family?
- What are the benefits to my child of receiving professional counseling? Is this something you recommend for my child? Why or why not?

Learn more about care for pediatric cancer survivors at cancer.gov/about-cancer/coping/survivorship/child-care



NAVIGATING SCHOOL DURING

Cancer & Beyond

Importance of Education During Diagnosis

Keeping your child academically engaged during this difficult time is not only a good idea, it is necessary and valuable. Staying academically involved and motivated can help your child feel a sense of normalcy, can be a break from the new routine of treatment and can help your child stay on track with their current grade level.

School is an important aspect in any child's life but it may be challenging to maintain consistent attendance during diagnosis and treatment. While the medical team encourages parents to keep their children physically in school for as long as they can, frequent appointments, procedures and chemotherapy side effects can derail the plan of attending school on a regular basis.


There are still ways for children to continue to be involved in their education and school environment even if they are not physically present:

- Attend school when they can and/or feel good enough to be there. Some kids decide to go to school for the morning hours when they are feeling the best. Any amount of time is helpful for the child academically and socially and, in return, helps the other children around them become more empathetic to what your child is going through. Consider asking for a special presentation during which your hospital school liaison (if there is one) and your child can present to your child's class and/or grade, so the peers and school staff are aware of the circumstances.
- Use technology to keep up with classes and classmates while in the hospital or at home. As long as the teacher(s) approves of participating in a live lesson, then your child is not only learning but also feels a sense of connection to their classmates and school, which can be a moral boost for your child. There are organizations that may be available to assist with the technology to connect your child and his/her class.
- Attend after school or extracurricular events. Even if this requires your child to wear a mask to be around a large group of people (during times of a weakened immune system), it is important for them to be involved and a part of what is happening in their school community. Let your medical team know if there is a special event coming up; they can provide guidance on whether your child can/should attend, and they might be able to coordinate the treatment cycle to give your child the best chances of feeling well enough to attend.

Hospital/Homebound Schooling

Hospital/Homebound schooling, also known as Home Instruction (H/I) allows a child to engage in school around their schedule of hospital visits. It is important for children going through cancer treatment to remain engaged in their education as much as possible. Once it has been determined that hospital or homebound instruction is right for your child, an official referral will need to be completed by the medical team and submitted to your child's community school or the school district. Talk with your child's school's main office staff to find out who your primary contact person should be. Also talk with your child's oncologist to find out whether their office has someone who can assist you in ensuring the application is completed/submitted.

Keep track of all paperwork submitted and conversations with the school staff; including keeping track of day/time of call/submission and name of who you spoke with.

- 
- Each state and school district's policies regarding the H/I program differ. In some districts, your child will receive a temporary Individual Education Plan (I.E.P.) or a 504 Plan. Either of these will give you and your child legal coverage to protect them while in the program. These plans can be modified based on how your child's medical needs. The plans will specify some "Special Accommodations" your child needs in order to maximize his/her educational experience.
 - Some districts will allow your child to have both in class and a tutor in home on days when s/he cannot get to the school building. The hospital social worker and/or school staff can explain what your child is eligible for and entitled to. Even if the school district won't allow a H/I student to attend school or school activities, sometimes the individual school is willing to arrange for your child to make a special visit or participate in an event/outing (if the oncologist provides medical clearance).
 - When on H/I, your child will receive between 3-10 hours of in-home instruction weekly; the number of hours is dependent on your child's grade and the local district's guidelines. A tutor (or multiple tutors if your child is in high school) will instruct your child on the core classes (i.e. math, reading, science, history). In unique circumstances, the tutor may have special skills (i.e. knowledge of another language) that may enable him/her to provide instruction in that topic area as well.
 - The tutor may leave work with your child to complete while they're in the hospital or at home recovering.
 - When your child is in clinic or on the inpatient unit, there may be a "Hospital Teacher" available to provide educational instruction to your child. The H/I and Hospital teachers may be willing to coordinate their efforts to help your child.
 - Don't push your child on days they aren't up to learning. They will eventually feel better and catch up with missed work. However, even on days when s/he isn't feeling well, there may be something educational that can be accomplished (even if it is just listening to a book).
 - The teacher will typically only focus on larger aspects of learning in each of the core subjects. Your child will not be responsible for every single assignment that is assigned while in school. Also, this should not count against their grade.
 - Once your child is off treatment, his/her learning needs will change. The IEP or 504 plan will need to be reviewed with intent to amend or eliminate it altogether. Keep in mind that late effects can impact learning. Additional educational assessments may be indicated especially if your child received high doses of chemotherapy, had a brain tumor, radiation to the head, underwent a Bone Marrow Transplant, etc. Educational assessments can be conducted through the school district, by a psychologist and/or by a neuropsychologist. The specific evaluations needed should be personalized dependent on your child's disease/treatment history, symptoms and current learning needs. If your child is evaluated by a neuropsychologist, make sure you share the written assessment/ recommendations with the school evaluators.
 - Most importantly, always be the advocate for your child. If your "something-is-not-right o-meter" is going off, listen to it, and advocate for your child. Most schools go out of their way to help children and families through this process, but always listen to your gut and speak up when necessary.



CAREGIVER *to* CAREGIVER

BY **MONICA SANTIAGO**

When my child was first diagnosed with cancer, it was the worst day of our lives. We couldn't believe what was happening. We didn't understand why it was happening to our daughter and to us. I felt all kinds of different emotions. I felt guilty, mad, angry, and I started questioning myself. Maybe I missed something. I felt helpless. It was really, really hard.

A time during my child's treatment when I used my intuition was when our daughter had an allergic reaction to one of the chemo medicines, and they had to stop it. But it was a medicine that was very important as part of her treatment. Dad did his research and found another medicine that could work so we discussed with her doctors. They were all on board to help us get the medicine, and she was able to have the complete the protocol.

If there is one thing I could tell parents, whose children are newly diagnosed I would say to trust God and know that He'll bring you through it.

We found a lot of laughter or happiness during our time in the hospital when we played board games with the whole family. Told stories about our childhood; we got to know each other more.

Something I learned about myself during my child's treatment was how to trust God. My faith grew stronger. I learned that God is always in control, and you have to rest knowing that He's got you!

Advice I would give to another parent going through a similar experience would be that you have to stop asking yourself WHY and start asking "What for?" There is always something to learn from each experience.

Communicating with others about my child's diagnosis has been difficult. One thing that I learned the hard way is who your real friends are and who the people you can always count on are. People don't know how to react, and sometimes the questions that they ask are very weird and annoying.

To help with overall treatment and feeling better, for nausea we got our daughter some acupressure bracelets that helped her a lot. We also used essential oils for the smells. As far as food, to help with her counts, she tried to eat beans, spinach and red meat. She also had and still has a sound machine in her room that helped her relax and sleep better.

Now that our child has completed treatment, we continue to help other families.

My daughter came up with an idea for a fundraiser at her school for Pediatric Cancer, and we collected money to donate to the National Pediatric Cancer Foundation. She also wanted to make Care Packages for the kids in the hospital that included the things that helped her during treatment. She has done this for 2 years, and she is planning to continue doing it.

STORIES OF HOPE

After months of dismissed concerns from doctors, Ellie was sent to the ER. She was only five years old at the time. We were told that her spleen was dangerously large and that her blood counts indicated she was anemic. Originally, she was diagnosed with what they believed to be some sort of leukemia, that is until her bone marrow biopsy came back. The oncologist told us that he had never seen anything like it and that it wasn't leukemia, but he had no idea what kind of cancer we were dealing with.

After an open liver and spleen biopsy, she was ultimately diagnosed with Hepatosplenic Gamma Delta T-cell Lymphoma, a cancer that is so rare Ellie is the first female under the age of 21 to ever be diagnosed with it. At the time she was 1 of 3 under 21 and 1 of 53 worldwide with this specific subtype of non-Hodgkins Lymphoma.

Once we started the chemo, she got sicker every day and the only option was to remove her spleen. After surviving the surgery, she started to adjust to all of the medicine. By her 3rd round of chemo she was in remission and being prepared for a bone marrow transplant, to which her sister was the perfect match!

Ellie received her sister's life-saving gift on Thanksgiving Day, and after 23 long and complicated recovery days, we were released from the hospital. We spent the next 9 months in and out of the hospital, but mainly in complete public isolation due to the potential germ exposure. We are now almost 4 years post-transplant and Ellie remains cancer-free!



ELLIE

AGE
12

DIAGNOSIS
In Remission
from Lymphoma

STORIES OF HOPE

In May of 2018, we noticed that Xander had an abnormally large (what we thought) testicle. When we saw his pediatrician, we told him he didn't have any fever or pain, so his first thought was that it could be a torsion. However, after a few tests, he realized it was a mass and immediately scheduled an ultrasound and sent us to a urologist. The urologist confirmed it was a mass and strongly suspected Rhabdomyosarcoma. Xander had surgery to remove the mass and his left testicle that Friday. The following Friday we met with one of Xander's two oncologists, Dr. Rico, who confirmed the diagnosis and we discussed chemo options because there appeared to be a slight spread of his cancer. Xander was classified as Stage 2A and we scheduled for his port to be placed and chemo to start the next Friday.

It was a whirlwind of a month to be sure, but I've never been more thankful to have doctors that actively sought answers and treatments as quickly as they did. We opted to do 26 weeks of chemo, rather than 43 weeks. It meant more overnight visits at the hospital, but also a lot shorter time doing the chemo itself. We started weekly visits to the hospital at the beginning of July, and overnight visits every three weeks. He lost all of his hair around his fourth week of chemo. Any slight cold required a trip to the ER, if he got a fever of 100.4 or higher, so hand sanitizer and extra cleaning became a regular occurrence. He had to see a pulmonologist and begin taking Flovent daily because he would start wheezing and once had an oxygen scare during an ER visit. He became neutropenic, thankfully only once, and required medicine to help boost his white blood cell count.

During the month of August, we spent 24 out of 31 days in the hospital. There were times when it was hard and times when Xander was scared, but mostly he was one of the happiest kids you've ever seen. He's incredibly brave and smart and we are so thankful to be his parents. Xander has been through so much in his short life, including many things unrelated to cancer. He was born at 30 weeks because I got Preeclampsia and HELLP Syndrome and he spent six weeks in the NICU. Xander had to have double hernia surgery when he was 6-months-old and then Hypospadias surgery at 9-months-old. He also had to wear a helmet for about six months around his first birthday due to Torticollis. But despite all, Xander has been resilient and brave and we're so thankful for everything the NPCF has done for us!



XANDER

AGE
9

DIAGNOSIS
In Remission from
Rhabdomyosarcoma

Tab 5

Resources

A LOOK INSIDE

- Diet

- Managing Costs and Medical Information

Diet



Helping your children find the right balance of what they are willing to eat and what is good for them can be a challenge. Now, when you factor in chemotherapy, which can change the way things taste, it can feel like a monumental task. Keep in mind that while we want our children to eat a healthy variety of nutrient dense foods, sometimes just getting them to eat anything is what is needed. Solid foods and fluids are an important factor in helping clear the body of these treatments. So, if your child is a picky eater and only wants to eat one thing during the entire treatment, don't stress about it. However, if they are willing to try some different foods, jump on the opportunity to incorporate some healthy variety.

Remember to always consult your child's nutritionist so that you are aware of any foods to avoid during treatment.

Things to know when changing your child's diet

- See a dietitian who knows your child's exact condition and what they need to be eating throughout the day.
- Most diets for a child battling cancer have a base of fruits and vegetables used to help the patient stay healthy while battling this disease.
- Most diets also recommend lower fat intake, leaner choices, and refraining from animal meats. For example, instead of a steak choose a salad with a tiny bit of dressing. Dressing happens to be one of the fattiest things in the world, and although it is healthy to have a salad, it isn't healthy to have a salad loaded with dressing.
- No raw fish or shellfish.
- Avoid foods and drinks like candy, soda, fried foods, mayonnaise, salad dressing, and butter.

Examples of foods that may be integrated into your child's diet:

Whole Grain Foods

Clif and Luna Bars
Whole Grain Crackers
Whole Grain Cereals
Wheat Breads
Wild Rice
Wheat Pasta
Corn
Popcorn
Kasha
Tabouleh
Potatoes
Beans

Vegetables

Baby Carrots
Brussel Sprouts
Asparagus

Cauliflower
Cabbage
Tomatoes
Broccoli
Green, Leafy Vegetables
Celery
Kale

Fruits

Dried Fruits
Whole Fruits
Frozen Grapes
Bananas
Oranges
Kiwi
Peaches
Mangoes
Pears

Strawberries
Avocado
Apricots
Guava
Figs
Prunes
Raisins

Proteins

Lean Meats
Poultry
Cooked Fish (limited quantities)
Eggs
Dairy Products
Nuts
Dry Beans
Soy Foods

MANAGING MEDICAL



Costs & Information

Understand The Cost

Before treatments start, make sure you are aware of all the costs and whether or not your insurance covers it.

Understanding Your Health Insurance

It is totally normal not to have a great understanding of your health insurance, but it is important, especially when dealing with this situation. The first step is calling your health insurance to explain to them what is happening; include key details. For example, mention the type of treatments, drugs, and tests that are administered to your child to find out whether your insurance covers the treatment plan or not.

Be sure to ask about co-pays, deductibles, and other costs to ensure you know when money is due and when it is not. Be sure to ask how and when to make payments. By asking this you will know whether the insurance directly pays for your child's treatments or if you pay and are reimbursed after. Explain the Explanation of Benefit papers so your insurance knows what you paid for. If you would prefer to speak to the same person every time you call, you can request a case manager.

Save Money On Pain Medicine

Thus far, several dollars have been spent on treatment plans and more but now you have to pay for pain medication. So what are the most affordable options?

- Ask your doctor about the generic options of medicine. Generic brand medicine usually costs less, but be sure to ask about the form of drug. Pills may cost less than other forms of medicine.
- Find out about discount drug programs.
- Some organizations have special programs to help pay for prescribed drugs. Speak with your social worker for more details.

Track Key Medical Information

Staying organized is really important when it comes to keeping track of medical documents, prescriptions, etc. When keeping track of medical information, here are a few key documents that must be recorded:

- Dates of medical visits.
- Tests and procedures received.
- Results of all procedures.
- Treatment dates.
- Side effects and symptoms with dates experienced.
- Medicine prescribed.
- Other complementary care received.



Tab 6

Emotional Support

A LOOK INSIDE

- Exploring Emotions and Coping with Stress
- Stories of Hope

EXPLORING EMOTIONS AND

Coping with Stress



Key Terms

Core Emotion

There are 4 basic emotions: happiness, sadness, fear and anger. Identifying them provides us with helpful information to cope through difficult situations.

Core Emotion Check in

Teaches emotional regulation versus emotional repression, fosters open communication through the identification of feelings.

Sustained Emotional Wellness

Practices needed to remain healthy and well over a period of time.

Consistency

Showing up physically and emotionally for yourself and others through the practice of daily routine.

Safe Space

A place to discuss your core emotion openly without feelings of judgement.

Identifying and Coping with Difficult Emotions

It is important to teach your child how to identify emotions before expecting them to cope.

When your child is diagnosed with cancer, you as the parent or caregiver, experience a whirlwind of emotions. It often feels overwhelming and can be challenging to identify everything all at once while also navigating the emotions of your child and their siblings. Taking care of yourself both emotionally and physically is equally important as the treatment your child is receiving. We are here to help identify, navigate and process the emotions as you and your family adapt to this new reality.

Although at times, you may feel alone, it is important to remember there is an experienced team - your doctor, social worker and child life specialist available to listen and provide additional resources to help sustain your emotional wellness.

How to Help Your Child Identify and Cope with their Emotions

Changes in Feelings

Throughout the treatment plan, your child, just like you, will experience a variety of emotions. They may feel anxious, sad, stressed, scared, isolated and become withdrawn. Open communication is essential - ask your child to identify their Core Emotion. Identifying the root of the feeling, calling the emotion by name creates an acceptance of the feeling as opposed to shame.

Core Emotion Check In as Part of Your Daily Routine

When to practice the Core Emotion Check In.

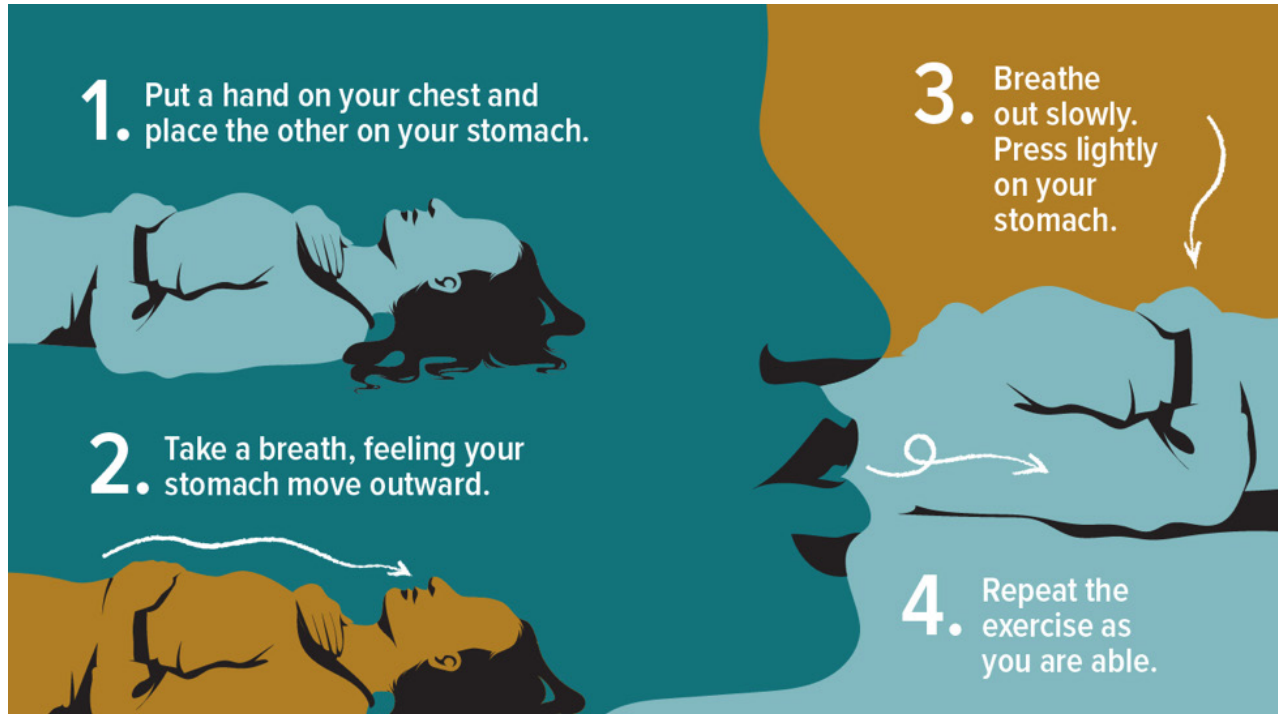
- At the start and end of each day (this helps to build consistency and maintain a safe space).
- Before and after treatments.
- When your child appears upset but is not openly vocalizing their emotions.

Distraction Techniques

Distraction techniques are simply any activity that redirects the mind from current emotions.

- Play.
- Creative play through art - color, painting, drawing, crafting.
- Watch a movie.

Talk to your medical team about integrative medicine practices such as muscle relaxation, guided imagery, and breathing techniques.



4-7-8 Breathing Method

1. To start, put one hand on your belly and the other on your chest.
2. Exhale deeply, letting out all the air in your lungs. Allow yourself to make a “woosh” sound as you exhale.
3. Take a deep, slow breath from your belly, and silently count to 4 as you breathe in.
4. Hold your breath and count from 1 to 7.
5. Breathe out completely as you count from 1 to 8, letting all the air out. Allow yourself to make noise or a “woosh” sound as you exhale.
6. Repeat 3-6 times or until you feel calm.



Stay Calm

Your child can feel your emotions and take them on as their own. It is important for you to be honest with yourself and your children regarding your emotions. A lengthy description is not necessary but identifying your own emotions will help role models open communication to your child.

Example - It is normal to feel scared, we are in this together - we always have each other.

Be aware of signs of Depression in your child

Sadness is a normal part of this experience, however if there are more sad days than good days, this may be a sign of Depression. Practicing the Core Emotion Check In is a good way to evaluate your child's feelings over an extended period of time. It is important to talk to your doctor if you notice emotional changes in your child.

Create a Safe Space

In this space, no medications are given, no treatments take place.

How to Help Siblings Cope with their Emotions

As a parent you want to be there for all of your children. However this can be challenging when caring for a child with cancer. You may be away from the home more than normal while your child is undergoing procedures and receiving treatments.

- **Create consistency through a routine** that anyone (grandparent, babysitter, neighbor, etc) can carry out.
- **Keep communication open** by asking them their Core Emotion.
- **Keep them informed and involved** by providing age appropriate and honest updates about what is going on with their sibling who was diagnosed with cancer, which takes away some of the "fear of the unknown." While providing updates, it is important to acknowledge that the doctors and medical staff are doing everything possible to help your child with cancer.
- **Find ways to include them in visits to the hospital.** This may be scheduled visits or a Zoom Chat, allowing them to help their sibling pack their bag or pick which toys to bring, etc.
- **Have a weekly meeting (even if by videochat) and review the family schedule with them.**
- **Limit surprises** to ensure they know when you will and won't be home.
- **Keep things as normal as possible** by arranging to keep your other children involved in school related and extracurricular activities that are important to them. This is a good outlet and helps facilitate consistency, which helps them.
- **Spend time with them.** One on one time with siblings, even as simple as taking a walk or prepping a meal together, will allow them to see they are still loved and appreciated. This time will also allow them to openly talk about their emotions if/when they are ready. Do not push them to discuss the situation but allow them to talk about it if they choose.

INTERVIEW WITH WARRIOR CANCER SIBLING HAYLEY



Hayley and her sister

What were some of the most difficult parts of watching your sibling go through treatment?

H: Seeing my sister cry, not being able to play with her and watching her be sad, grumpy, or in pain.

What helped you get through these challenging times?

H: I enjoyed watching movies with my sister, painting our nails together, playing games and seeing my sister smile.

What are some things that siblings can do to help support their brother or sister during treatment?

H: Well the most memorable thing I did was shave my head for my sister so she didn't feel alone. I also drew pictures for her. I held her hand during treatment, and I gave her lots of hugs.

What are some things that people (like your friends/family) can do to help support siblings like you during these difficult times?

H: I'd really like it if someone that I enjoy spending time with would take me out to a special meal...like the Cheese Cake Factory.

Tell us something funny that you remember when your sister was in treatment?

H: Her doctor sent her a cape and she would run all around the house in her cape with her diaper hanging out. She tried to dress herself so her diaper was always hanging out.

What words of encouragement can you provide to siblings that are going through this?

H: Someone once told me that watching my sister go through cancer treatment would be hard but my only job was to do my best to make my sister laugh, and I knew I could do that! Also, don't give up...you'll make it through this.

How to Help the Parent Cope with Emotions

Questions for Self Reflection

- Check in with yourself - what is your Core Emotion?
- What helps soothe and keep me well?
- What do I need to remain healthy and well to care for my child?
- How can I nurture these needs consistently?
- What can I release to lighten my load?
- Who can I ask for help?

Come back to these questions monthly as your needs will change throughout this experience. Learn what works best and modify your sustained emotional wellness plan as needs change and evolve.

Make time to renew your whole self - Mind, Body and Spirit by identifying ways to Self Soothe

Soothing the Self allows us to heal what we feel. The ability to Self Soothe enables the body to relax - heart rate slows down and breathing is deeper, more expansive. The body is no longer living in a constant state of emergency. Finding ways to soothe, even in what may feel like chaos, allows us to stay grounded when navigating even the toughest of challenges.

Practice the 3 Components of Self Compassion

1. Loving Kindness

- When emotions are heavy and times are challenging, speak to yourself with loving kindness, the way you would a dear friend or loved one.
- Practicing Loving Kindness helps to avoid self judgment by practicing the mantra Compassion over Criticism.

2. Common Humanity (The Human Experience)

- Common Humanity is the understanding that unpleasant emotions and feelings are a part of the collective human experience. That, we as humans are not only connected by the joy in our life but in the struggles as well.
- Adopting this mindset enables us to feel connected to others and makes us more likely to ask for help.

3. Mindfulness

- Allows you to be present in the moment as you turn inward with loving awareness. Here are some things you can do to overcome difficult or heavy emotions:
 - Meditation.
 - Avoid isolation by making time for friends, family and loved ones.
 - Ask for help when needed.
 - Stay physically active.

STORIES OF HOPE

Imani was a very happy talkative little girl but just after her fourth birthday she became sick. It took over four months to find out the reason why. Her pediatrician and hospital thought she had a virus or a gastrointestinal problem. She became so sick that she stopped talking. She couldn't eat or drink without throwing up, and she was sleepy all the time. Then on the morning of April 16, 2013, she woke up with one side of her face droopy. I rushed her to the hospital, and they did an MRI that found a tumor the size of a peach. It was so big that they could not see exactly where it was. She was rushed into surgery because there was so much fluid built up and they needed to relieve the pressure. As they were shaving away the tumor, they realized it was on her brainstem and had to stop immediately.

After the surgery, everything was different. Imani could not eat, talk or walk. There were plenty of times she wanted to give up trying to walk again because it was so painful and too hard. It was the love and support from her mother, father, stepfather, stepmother, grandmas, aunts, uncles and her wonderful siblings (nine to be exact spread throughout the joined family) that made her more determined than ever! Within 10 months my baby was walking with the assistance of a walker and braces. She did have a wheelchair but just refused to use it. Imani never looked back. She also started eating and talking again during that time. Since then, Imani has completed chemotherapy twice, but in 2017 they found four new growths on her brainstem. It was heartbreaking.

She was 25 days short of being done (with chemotherapy) again when one of the tumors started growing in June 2019. Back in 2017 and 2019 with these new discoveries she said, "Mommy don't worry about me, I will be all right." Her determination and never-give-up-attitude keeps her going strong. She has had plenty of surgeries and lots of different medications. It has been a rollercoaster of emotions with many ups and downs, but she shines through them all!



IMANI

AGE
14

DIAGNOSIS
Battling 5 Pilocytic
Astrocytoma Brain
Tumors

STORIES OF HOPE

Emily was diagnosed in October of 2017 with Neuroblastoma at 11 months old. That day started out like any other day. We were playing in the living room, watching TV, and I turned around to find a large marble in her mouth. Knowing that her older brother had been playing with two marbles, I searched everywhere for the second marble and could not locate it. For fear that she had swallowed it, I took her to our local ER for an X-ray to make sure she would be able to pass it.

The next week was a whirlwind of testing and hearing the words “your child has cancer.” The X-ray to find the marble found a mass in her chest the size of a baseball. We quickly started chemo with no success. The mass was so large and intertwined that no local doctor would operate but the chemo wasn’t working. So, we traveled to Memorial Sloan Kettering in NYC for a grueling 11-hour surgery. They removed 95% of her tumor. Since her surgery, the remaining tumor has remained stable for two years. She will never actually be cancer-free, but she does remain stable.

Emily loves to dance and sing. She is one of a kind! One particularly entertaining habit she has is changing her clothes to suit the occasion, or just popping out of her room totally decked out in a Disney Princess costume complete with accessories, just as happy as can be, which always puts a smile on our face. Other times she has to make sure she changes for dinner, even though it’s a regular weeknight boring dinner.



EMILY

AGE
5

DIAGNOSIS
Battling
Neuroblastoma

Tab 7

Sources & Contributors

A LOOK INSIDE

- Sources & Contributors
- Medical Imaging
- Ben-Guard Products

SOURCES

National Cancer Institute
Cancer.gov

APHON
APHON.org

CONTRIBUTORS

William (Trey) Carlson is headed into his senior year at H. B. Plant High School and has been involved with NPCF since he was going into his freshman year of high school. Along with the help of Preslie Price, he was able to write this toolkit and do something that he loves, helping people be better and realize new paths.

Caroline Brasfield is a Parenting Coach, Curriculum Specialist, and Educator in Pinellas County, FL. Her son Jackson was diagnosed with Osteosarcoma, a solid bone tumor, in 2014 at age 9. Caroline, Jackson and their family are passionate about raising funds and awareness for pediatric cancer, connecting with other pediatric cancer families around the country and volunteering with NPCF.

Shari Feinberg is a pediatric hematology-oncology nurse practitioner in NYC. She has been in the field for almost 30 years, working in both inpatient and outpatient settings. Her primary area of expertise is pediatric solid tumors.

Sarah Haines, RN, BSN, CPN, has been a nurse for 6 years, all of which has been working as a pediatric oncology nurse. Since beginning her career in pediatric oncology she has developed a passion for advocacy and awareness. For several years she has been working closely with the NPCF as a liaison to help connect families for events.

Dana Levin is a 15-year survivor of Hodgkin's Lymphoma. After having cancer, she discovered her passion for a career in nursing. She is a Nurse Practitioner with experience in adult oncology. Because of research that was done many years ago to improve the cure rate of her disease, she is living a full life with her husband and one-year-old daughter.

Amanda McNary is the loving mom of two amazing children. Ethan was diagnosed with Osteosarcoma in

October of 2016. Treatment for him was successful and he has been in remission for two years. Ethan is now going into his junior year of high school and his sister, Josie, is a freshman this year. Amanda is a teacher and now has even more empathy and insight into the varying difficulties that children go through. Ethan's cancer journey taught her the patience, kindness, and understanding that she now utilizes every day.

Preslie Price is headed into her senior year at H. B. Plant High School and joined the NPCF team while headed into her sophomore year of high school. She was inspired to write this toolkit with Trey Carlson after her mother's breast cancer diagnosis. She has found her passion for volunteering and making a difference through the NPCF.

Tiffany Smith, MS, is the Project Manager of the NPCF's Sunshine Project at Moffitt Cancer Center in Tampa, FL. Tiffany has over 15 years of professional experience working in an oncology setting, with the last five of those years being in pediatrics. In 2019, Tiffany was awarded NPCF's Heart of Gold Award for her dedication to NPCF's cause of finding more targeted and less toxic treatments for children with cancer. Tiffany lives in St. Petersburg, FL with her two dogs, Ollie and Bitsy, and her cat, Moe.

Daniel Wilentz is a junior at Pine Crest Preparatory School in Ft. Lauderdale, FL. As a member of his school's Science Research Program, Daniel has had the opportunity to study and interpret research in the field of pediatric cancer. Currently, Daniel is investigating laboratory models of cancer invasion with a professor at The Johns Hopkins School of Medicine, and he hopes one day to apply his findings to help cure pediatric cancer. Daniel is excited to contribute to this Toolkit and to support all of the wonderful programs of the National Pediatric Cancer Foundation.

Sawyer Duffey is a current fourth-year student pharmacist at the University of Tennessee College of Pharmacy. During his four years of pharmacy school, he has had the pleasure of working as a pharmacy intern alongside many talented pharmacists and healthcare team members at St. Jude Children's Research Hospital. After graduation, he plans on pursuing a PGY1 residency with the goal of eventually practicing as a clinical pharmacy specialist in one of his areas of interest which include oncology, emergency medicine, and critical care.

Gena Midyette is a Physician Assistant with 12 years of experience in the fields of Urologic Oncology/Female Urology, Interventional Radiology and Dermatology. Her six year-old daughter recently completed treatment for Medulloblastoma, a type of brain tumor. Gena is passionate about pediatric cancer research and helping other patients and families navigate the difficult pediatric cancer journey.

Denise Velazquez, LCSW, received her MSW from New York University. She has a history of working in non-profit organizations, supporting families in foster care, advocating for people charged with crimes in the Bronx and supervising case management teams. She is a senior social worker in a children's hospital in the Bronx, where she provides support to the children (and their families) who are living with hematologic malignancies, bone or soft tissue cancers and patients undergoing Bone Marrow Transplants. She engages with patients/families from diagnosis through to post treatment survival and/or end of life and bereavement.

Amanda Reed Williams resides in Germantown, Tennessee with her husband and three children. She holds a Doctorate of Pharmacy Degree from the University of Mississippi. After a satisfying career in retail pharmacy, she is a stay-at-home caregiver to her own child with Acute Lymphoblastic Leukemia. She loves empowering other cancer-parents/caregivers with knowledge and support to help them navigate their cancer journey.

Kelly Goddard is a Registered Nurse with a background in critical care settings. After her own child was diagnosed with stage 4 brain cancer at only 10 months old, Kelly developed a passion for advocacy and promoting awareness for the pediatric cancer community. Kelly is currently the Health Navigator for the National Pediatric Cancer Foundation, where she supports families as they process the information they receive, helps them find the best treatment options, provides available resources, and connects cancer families with those of same/similar diagnosis.

Tara Ryan Kosmas, MSN, RN, CHSE, SOAR, has a Masters degree in Nursing Education and holds both a debriefing (CHSE) and peer support (SOAR) certification. While working as a Nursing Professor and Simulation Lab Coordinator at Towson University in Baltimore Maryland, she and her husband, Nik, an air force veteran, founded 501(c)(3) Debriefing the Front Lines, Inc. and created the Heal the Healers Programs. Through professional education and lived experience as a pediatric burn survivor, Tara created a psychologically safe space for nurses to come both alone and in commUNITY for support.

If you have comments, questions or suggestions, email us at education@NationalPCF.org



Get started uploading your medical images to the cloud from CDs using our simple upload process.



Want us to upload them for you? Order our **StarterKit** online.

What is mymedicalimages.com?

mymedicalimages.com is an easy to use, safe and secure platform for viewing, sharing and managing medical images. CDs are hard to keep up with and difficult to share when time is critical. Use the **Referral Code NPCFKids to join today for FREE** and start managing your family's medical images.





Order our

StarterKit

Now you can view, share and manage your medical images on any device.

Step 1

Start your **free** subscription at mymedicalimages.com and begin uploading your images in the cloud with our easy to use uploader. If you don't have access to a CD drive we can upload them for you with our starter kit.

Use referral code **NPCFKIDS**



Step 2

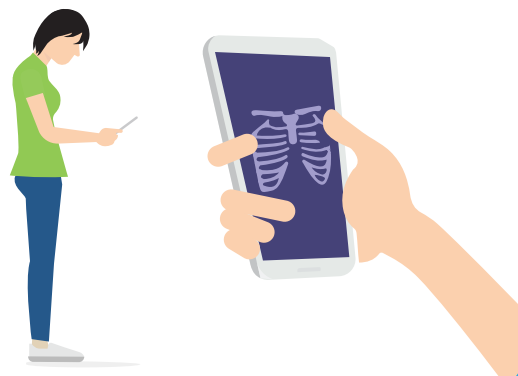
Just place CDs with your medical images in the starter kit and return the kit to us. Shipping is included.



Referral Code **NPCFKids**

Step 3

Once we've processed your CDs, you will receive an email or text. All your medical images will be available for you to view, share and manage in the cloud.



Referral Code **NPCFKids**

by Caroline Brasfield-Carter
Advocate

When our son was diagnosed with cancer in his femur at age 9, we were immediately scheduled for X-Rays, MRI's with and without contrast, Nuclear Medicine Bone Scans and CT scans. In the first 3 months of his diagnosis we had already had over 20 different imaging CDs we were storing and keeping track of.

We are amazed at the ease and efficiency of storing all of these images on mymedicalimages.com. This is an amazing place to store these high tech DICOM images in their exact form so that they are at our fingertips for reviewing or sharing with other medical professionals.

We are excited to share mymedicalimages.com with other families whose children are being treated with cancer because we know this technology is a game changer in the way that each child can be treated. We understand that just like each person is different so is each diagnosis, treatment and reaction. mymedicalimages.com allows a family to share with a doctor an image that needs an extra look or may need to be discussed among colleagues with all of the qualities of a high tech DICOM image. This record keeping is amazing and we are so grateful to have it for our son.



Referral Code **NPCFKids**

Go to **mymedicalimages.com**
to get your **FREE** subscription!

Don't Compromise Pediatric Patient Safety



Creating a New Category
in Catheter and
Device Securement
for Children



Put on Love

www.ben-guard.com

A New Standard of Care for Pediatric Line Management

- ✓ Load bearing restraint inside water resistant pocket to reduce contamination
- ✓ Conceals and secures tubing during treatments and daily activities
- ✓ Easy access to insertion site
- ✓ Removable without disconnecting tubing
- ✓ A soft and durable bamboo and cotton blend
- ✓ Shoulder and side straps provide additional safety and flexibility
- ✓ Accommodates CVC, G/J, Cardiac and other tubing devices
- ✓ Diagnostically imageable material
- ✓ Tank tops and bodysuits in 0-3 mos. to small adult sizes
- ✓ FDA Registered Class 1 Medical Device



To order Ben-Guard Products:

www.ben-guard.com
info@ben-guard.com
833-BEN-LOVE



Facebook: @benguardhealth

Twitter: @putonluv

