

ABOUT

CHILDREN



CHILDREN'S HOSPITAL
OF MICHIGAN
FOUNDATION

SUMMER 2016



Special edition
pediatric cancer

Through our efforts to improve children's health and wellness, children have more days to play, nights to dream, and time - to just be kids.

PEDIATRIC CANCER

Know the facts

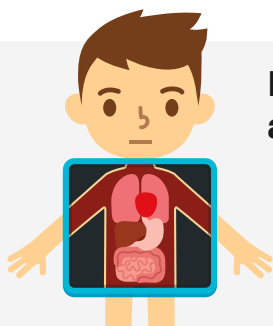
Cancer is the **leading cause of death** by disease past infancy among children in the U.S.

28 KIDS EVERY DAY will be diagnosed with cancer

1,250 KIDS EVERY YEAR will die from cancer



The average child diagnosed with cancer is only 10 years old



Pediatric cancers are often found in different areas of the body than adult cancers.

Childhood cancers are often the result of changes in the cells' DNA which happen very early in life or before the child is even born.

More research is needed to continue to improve survival and decrease the toxicity of treatment.

It costs **more than \$2.5 billion** to bring one drug to market



Five-year survival rate for those with childhood cancers:

The 5-year survival rate refers to the percentage of patients who live at least 5 years after their cancer is diagnosed.



Support from donors like you will help to improve treatment and provide a better outlook for patients.

Please use the remittance envelope found in this issue or visit chmfoundation.org/GiveHope to make a donation today.

SOURCES:

Dana-Farber Boston Children's Cancer and Blood Disorders Center. Four Things to Know About Childhood Cancer. www.danafarberbostonchildrens.org
The Children's Hospital of Philadelphia. Facts About Childhood Cancer Infographic. www.chop.edu

An Update on Pediatric Cancer Research from Jeffrey Taub, M.D., division chief of oncology at Children's Hospital of Michigan

Q. What are some of the promising areas of research?

A. There are new and potentially more effective drugs and we can apply to test them for children. Some new drugs don't have the profit potential for drug companies so this special research is important. Immune-based therapy or immunotherapy is a new area that is being investigated. Cancers block the immune system but a new drug may turn that blockage off. Genomic medicine is making a difference.

Q. What is the prognosis for children with cancer today?

A. Approximately 75 to 80 percent of children with cancer can be cured today. However, some forms of pediatric cancer are still very challenging.

Q. How does the Children's Hospital of Michigan Foundation (CHMF) help with cancer research?

A. It's critical. You need to get data for national grants and the Foundation supports pilot studies. The amount of federal funds devoted to childhood cancer research is very small. We need to support local patients.

Q. What keeps you going in your work with pediatric cancer patients?

A. The photos of the healthy children I have treated that are posted in my office. Also, the teamwork of the hospital and Wayne State University staff is motivating.

Did you know?



Since 2011 CHMF has awarded **34 grants** focused on pediatric cancer research



totaling more than **\$1.4 million.**

How the Foundation Advances Pediatric Health

Children's Hospital of Michigan Foundation improves pediatric

health by funding a broad range of medical research, medical education and community benefit projects. This philanthropic support helps in the discovery of the causes and potential treatments for pediatric illness, education to enhance clinicians' capabilities, as well as preventive and supportive services for children.

This issue of *About Children* focuses on pediatric cancer, providing updates on promising research, treatment innovations and special services for sick children. In the profile of donor Barbara Cushing, M.D., a retired Children's Hospital of Michigan (CHM) hematologist-oncologist, we learn first-hand that some pediatric cancer treatments now offer hope when these diagnoses were once considered hopeless. Progress cannot come too quickly for the 115 children who are diagnosed annually with cancer at CHM. ♦

On the cover:

Last year, at age five, Aidyn was diagnosed with Acute Lymphoblastic Leukemia (ALL) and treated at Children's Hospital of Michigan. Today he is healthy and his parents are thankful not only for the care he received, but also for the philanthropy that has helped fund research. "I know that when it comes to cancer research, only a fraction of the funding goes to pediatric research versus research for adults," says his father.



Dr. Taub with Aidyn, a leukemia patient, show how they are standing up to fight cancer.

Children's Hospital of Michigan Foundation Helps Cancer Patients Cope and Thrive



cancer diagnosis is the start of a challenging journey with rigorous treatments and an uncertain future. Support provided by donors allows Children's Hospital of Michigan Foundation to help families cope, recover and even celebrate progress along the way.

Foundation-Funded Project Helps Young Cancer Patients Stay Healthy at Home

When a young patient is first diagnosed with cancer, there is a lot of information for the entire family to absorb. Shannon Konieczki, MSN, RN, CPAP-AC works with patients who are discharged soon after diagnosis and return for outpatient chemotherapy. Whether the child has a blood cancer such as leukemia or a solid tumor such as neuroblastoma, there is a higher risk of infection due to the use of a port—a central line used for chemotherapy. This means signs of illness need to be monitored carefully at home.

"Many parents don't really know why it's important to take temperatures or know the signs of fever such as chills, headache or fatigue," Konieczki explains. She decided that some special supplies and educational information would help cancer patients stay healthy and put together a package with a small green cooler, pill cutter, thermometer and a fever tracking form. Children's Hospital of Michigan Foundation funded these kits.

The coolers are important because many children have multiple medications needing to be refrigerated such as antibiotics and neupogen, a medication used to counteract depleted white blood cells. The coolers

help them keep track of the different medicines. And, for those who spend time at different family homes, the coolers enable their medications to safely move with them. Also, patients bring their kits when they return to the oncology clinic at Children's Hospital of Michigan, so that medication supplies can be checked and replenished. "The coolers make sure that they have all of their medications in one place," Konieczki explains, providing a sense of control.

The fever form has what to look for and who to call if there are signs of fever. Usually, when children are sick it's a cold or other viral infection, but if there is a high fever it's important to check for bacterial infection.

With support from the Children's Hospital of Michigan Foundation, Konieczki has been able to provide the "Staying Healthy at Home" kits to approximately 80 new oncology inpatients since 2014. "We want to make sure patients feel safe and comfortable at home and the supplies have been really appreciated by families," she says. ♦

Shannon Konieczki, MSN, RN, CPAP-AC poses for a photo after providing cancer patient Trista, a cooler and some education about the importance of staying healthy at home.



Child Life Specialists Ease the Distress of Hospitalization

In many ways, to be hospitalized is to completely relinquish control. Children are particularly vulnerable to this phenomenon with little autonomy and few choices in the hospital environment. Child life specialists at the Children's Hospital of Michigan work as part of a comprehensive health care team to alleviate the physical and emotional distress of hospitalization for children and families. Holding specialized degrees in child development, psychology and early childhood education, child life specialists have the sensitivity and knowledge to connect with children across varied stages of their development. Beyond this, they incorporate non-pharmacological pain management approaches to help mitigate the trauma of procedures and treatments, provide distraction through interactive play, and finally, advocate for empathetic, culturally-sensitive care for all children and families.

Channel Pack is one such child life specialist, now beginning her ninth year on the Hematology/Oncology unit of the Children's Hospital of Michigan. While no two days are the same for Channel, education for newly diagnosed patients and families, preparing children for procedures and facilitating opportunities for joy are consistent themes throughout her work. "I think most people think I am teaching children about the hospital but (it) is so much more. I am teaching children how to have compassion for others, how to advocate and ask questions, and most importantly, how to cope with life when it is difficult and scary," Channel explains. One physician recently named Channel a

Child life specialist Channel Pack utilizes medical play to prepare young cancer patient Brandon for his upcoming treatment.

"pillar" of the Hematology/Oncology unit, crediting her services as of equal importance to the medical team.

Grateful mother Jonelle Tolhurst knows first-hand the impact child life assistance can have. When her son Brandon was diagnosed with cancer in 2014 at the age of two, the Tolhursts met Channel. "From the beginning of Brandon's diagnosis, child life has been a big part of our lives. We met Channel on his date of diagnosis and she was a very understanding and comforting individual. In the early days of Brandon's treatment, child life was his distraction to the not so great things that come along with his disease," shared Tolhurst.

The Children's Hospital of Michigan Foundation funds several child life initiatives in oncology, including a child life fellow in the Bone Marrow Transplant (BMT) unit and a child life fellowship in collaboration with CHM, Wayne State University and Karmanos Cancer Institute. Children's Hospital of Michigan has one of approximately

Did you know?



CHM has the **oldest** pediatric cancer treatment program **IN MICHIGAN**

20 child life fellowship programs in the United States. These fellowships provide an additional year of education, clinical and research experience for child life specialists.

The child life fellow's effectiveness is based on the ability to listen, assess and meet the individual needs of each patient and family that they encounter. In Channel's words, "Every patient and family is different. As a clinician, it is so important to recognize this truth and provide individualized support that is effective for that particular family unit." ♦

Special thanks to contributing author Divna M. Wheelwright, MA CCLS.



Retired Physician Continues to Make a Difference in Children's Health



Barbara Cushing, M.D., retired hematologist-oncologist at Children's Hospital of Michigan

Barbara Cushing, M.D., served as a hematologist-oncologist at Children's Hospital of Michigan for more than 40 years. Medical advances during that time have dramatically changed the outlook for pediatric cancer patients. When she joined the medical staff in 1972, "Leukemia was almost certainly a fatal diagnosis and now some forms are treatable," Dr. Cushing says.

Today there are many more effective medications for childhood cancers than when she began her medical training and practice. Dr. Cushing notes particular progress with germ cell tumors, many of which can now be cured.

Since retiring in 2013, she has been planning charitable donations "to make a lasting contribution." Dr. Cushing chose to donate to three Children's Hospital of Michigan Foundation funded programs that are particularly significant to her: the Hamtramck School-Based Health Center, Project Enrich and Celebration of Life. ♦



Hamtramck School-Based Health Center

The Hamtramck School-based Health Center administered by Children's Hospital of Michigan staff, is an important program to Dr. Cushing and many Michigan children. Dr. Cushing's late husband, Ralph Cushing, M.D., was an infectious disease specialist, so the need for immunizations is personally meaningful. Despite being a small, part-time clinic, the staff provided more than 2,400 vaccinations and conducted 1,500 patient visits to students from kindergarten through high school during a recent school year.

Project Enrich

Project Enrich provides educational and social support for local children with sickle cell disease, a chronic, painful disorder that can hinder academic success and confidence. As a board member of the Sickle Cell Association of Michigan, Dr. Cushing understands the importance of supportive services for children battling sickle cell disease.



Dr. Cushing's gift will touch many children now and in the future—continuing her tremendous impact on children's health beyond her clinical career.



Did you know?

Children's Hospital of Michigan has

13 board-certified
pediatric cancer
specialists

and more than

75 support staff
members



Celebration of Life

Celebration of Life is an annual fun event for cancer patients and former patients, as well as their families. They celebrate survivorship with a day of games, prizes and refreshments, funded in part by Children's Hospital of Michigan Foundation. Dr. Cushing was involved with Celebration of Life since its inception 21 years ago. Many of her former patients participate and she has often attended this happy event.

Children and Families Enjoy the Annual Celebration of Life

Held in conjunction with National Childhood Cancer Survivor Day, the 2016 Celebration of Life was the largest ever, drawing 1600 participants. Here's what one attendee thought about this very special day.

"I was diagnosed with cancer when I was five years old in 2004. I'm here to have fun and to celebrate everything I've been through and being alive today. I've been on the go karts, the water balloon fight and my favorite is the bungee jumping," said Charnese Jane Jackson. When asked what advice she would give other children fighting cancer, Charnese shared, "You have to be strong and never worry about things unless you have to."

According to oncology social worker Wendi Henning, the first Celebration of Life was organized because hospital social workers thought that patients needed camaraderie with other survivors as well as information about long-term side effects and other issues. The first event was relatively small and was held in the Children's Hospital of Michigan Auditorium. Until the Children's Hospital of Michigan Foundation stepped in, funding was a challenge, especially as the number of attendees grew. Today the CHM Celebration of Life event is believed to be the biggest such event in the country.



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Step up to the plate.

Let's fight childhood cancer together...
at the Tigers game.

Friday, September 9 @ 7:00 PM

Join us at Comerica Park for Children's Health Day. While the Detroit Tigers are taking on the Baltimore Orioles, we'll be taking on children's cancer. Your ticket purchase includes a T-shirt to raise awareness of pediatric cancer at the game... plus, the Tigers will provide a donation to the Children's Hospital of Michigan Foundation.

Stay tuned after the game for the fireworks show.



Get your tickets now at
tigers.com/children

Can't make it to the game?
Support the fight with a donation at
chmfoundation.org/GiveHope



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