Max Cure Foundation Overview
The Max Cure Foundation

In June 2007, following 4 year-old Max Plotkin’s diagnosis of cancer, the Plotkin family formed the Max Cure Fund at Memorial Sloan-Kettering Cancer Center (MSK) to underwrite an Immune Cell Therapy Laboratory that would treat children and young adults that did not respond to standard chemotherapy and radiation treatments.

In December 2008, the Plotkin family formed the Max Cure Foundation, Inc. a 501(c)(3) nonprofit (MCF). It is registered in all states requiring such registrations. Co-founders are David and Annemarie Plotkin, Max’s parents, and Richard Plotkin, Max’s grandfather.

The mission of The Max Cure Foundation, Inc., is to fund research for the development of pediatric cancer drug therapies, including the discovery of less toxic treatments for children with cancer; to financially assist low-income, military and first responder families battling cancer in their children; and pursue legislative and regulatory changes that seek to benefit children with cancer, and at the same time, raise awareness to the needs of those fighting pediatric cancers. As part of the family assistance program, MCF quietly created an initiative called the “Angels Fund” to help cover funeral related expenses of children who are included in the program. MCF is also actively involved in advocating for children with cancer and their families, including being an active participant in the Congressional Caucus On Pediatric Cancer.
Research

To date, MCF has funded over $1.5 million for childhood cancer research, including donating over $75,000 to the Children’s Joy Fund at MSK and in general over $32,000 to other research at MSK (the Max Cure Fund at MSK has received over $975,000 which included the seed monies that funded the development of T-Cells for therapeutic use laying the basis for the exciting advances tested in several clinical trials). In addition, over $110,000 in matching funds has been contributed to MSK from MCF’s donations. As part of MCF’s research funding outside of MSK, $150,000 was provided for Ewing Sarcoma research at Emory University, as part of two $100,000 collaborative grants from the Samuel Waxman Cancer Research Foundation, as well as a grant of $40,000 provided to a researcher at Duke University studying new treatment options for DIPG, an almost universally fatal pediatric brain tumor. Other funds were donated to various charities over the years to benefit childhood cancer research.

2017 Initiatives

2017 began MCF’s initiative to identify the most aggressive and transformational research efforts, thanks to funding from the Connor Fund (Connor Cures Foundation) and the Elisabeth Brain Cancer Fund along with the support of so many donors. MCF focused on four research pathways in 2017. To advance the treatment of the particularly difficult diagnosis of acute myeloid leukemia (AML), including relapse and refractory disease, MCF funded Kevin Curran, MD at MSK in the sum of $50,000, which sum is included in the $975,000 referenced above, for research into the use of CAR-T cells, specialized immune cell therapy treatment using modified cells that target and eliminate cancer cells, with the ultimate hope of being used against other forms of childhood and adult cancers. This research has its genesis at the same Immune Cell Therapy Lab at MSK that MCF initially provided critical funding as referenced above. Additionally, MCF through the Connor Fund and the RS Reynolds Foundation provided $33,500 to Maro Ohanian, DO, from MD Anderson Cancer Center with collaboration from Greg Aune, MD, himself a childhood cancer survivor from UT Health San Antonio, to conduct research hopefully leading to the launch of a clinical trial studying the harmful effects of heavy metals associated with chemotherapy treatment, environmental exposures and the related success rate of treatments and survivorship. An additional component of these efforts is to study the use of FDA approved chelation therapies to remove toxins from the blood stream in an effort to reduce acute life-long side effects exhibited by childhood cancer survivors.

MCF also made a grant of $1,000, made possible through MCF’s Run for the White House Program, to support the creation of a first of its kind osteosarcoma basket trial. Finally, MCF continued to support the fight against DIPG through the creation of the Elisabeth Brain Cancer Fund that allowed MCF to donate $47,500 to international clinical and research efforts, with another $42,500 granted in January 2018.
Roar Beyond Barriers®

Since its formation in 2009, Max Cure Foundation has directly contributed over $575,000 to families battling cancer in their children, including in excess of $450,000 through its Roar Beyond Barriers program.

The Roar Beyond Barriers program was started in November 2011 after Richard Plotkin, Vice Chairman of MCF, met with Harold Freeman, MD, Chair of the Ralph Lauren Cancer Center in Harlem. Dr. Freeman stated that of the 600,000 deaths in the United States each year from cancer, 200,000 were preventable. Richard speculated that an inordinate number of children with cancer from low-income families are included in the 200,000 preventable deaths.

The Plotkin family knew from its first hand experience with Max and from meeting other families that financial difficulties exist for many families whose children have cancer. Many of the financial struggles are independent of the costs that are generally covered through insurance or other reimbursement programs.

MCF created the Roar Beyond Barriers program to act upon Dr. Freeman’s plea that, “[p]overty should not be a death sentence” for cancer patients. In 2012, MCF expanded its family support mission with the inclusion specific support for military families with a child in active treatment and just recently in 2017 also included first-responder families.
Roar Beyond Barriers Continued...

Since November 2011, MCF has assisted over 150 low-income, military and first responder families at countless hospitals across the United States where children are in active treatment for cancers.

The families are given gift cards from Walmart and Sam’s Club each month for necessities such as food and clothing. Non-toxic cleaning supplies from Berkley-Green are also distributed to the families. In addition, the Foundation provides back to school supplies for school age children enrolled in our program and their siblings as well as an emergency fund budget used in the event the family experiences a pressing financial crisis.

MCF works with social workers from partner hospitals to identify families with a child in active treatment that is experiencing financial hardship. We are gratified to hear from families and social workers alike that MCF’s Roar Beyond Barriers program continues to improve the quality of life for those we assist.

Unfortunately, the child passed away in 2017.

MCF also expanded the Roar Beyond Barriers program to include Young Adults from ages 20 to 39. A young adult with a rare form of cancer in this program has received over $50,000 to date from MCF.

In September 2015, MCF added U.S. Special Forces families whose children are battling cancer to the Roar Beyond Barriers program. The first family was a U.S. active duty Navy SEAL whose 4-year-old daughter was diagnosed with cancer. As a result of its fundraising efforts, MCF raised over $20,000 to help alleviate the financial stresses confronting the family. MCF is privileged to assist a Navy SEAL who risks his life for America and who, with his wife was in their greatest battle to save their daughter’s life.
Psychosocial Support

Pediatric cancer is a disease that affects an entire family, not only the child that is diagnosed. The threat that cancer poses to a family, both nuclear and extended, is immense and burdensome, most especially for the child in treatment. Psychosocial care is a necessary, yet often overlooked part of any pediatric cancer treatment plan as families endure fiscal and emotional stresses during their experience, both during treatment and beyond. The introduction of psychosocial support during the course of treatment can increase management of symptoms, improve adherence to treatment, and provide better outcomes and quality of life.

Funds designated for psychosocial programs are used to provide families with access to counseling services, including psychiatric care and support-group activities as well as preparations for future visits and check-ins. Development of long-term psychosocial goals goal are meant to assist children and their families along the entire course of treatment and beyond, including unfortunately support for bereaved families.

In 2017 MCF was grateful to receive a substantial grant from socially-conscious apparel company Love Your Melon, whose famous beanie initiative to help pediatric cancer patients allowed RBB to support an additional ten low income, military and first responder families while also providing a grant to Maimonides Medical Center in New York to continue providing child life services that had been cut from its budget.
MCF’s Vice Chairman, Richard Plotkin, has translated the advocacy skills he developed over a 40-year career as a litigation lawyer to advocate for children with cancer. Over the last few years, Richard was credited with being a major factor in the passage of the Creating Hope Act, which incentivizes pharmaceutical companies to invest funds in drugs for rare children’s diseases, including cancer. In early 2014, Richard was solely responsible for obtaining from the FDA the first ever Compassionate Use Waiver for a combination drug therapy, which included an experimental drug, for a child with cancer. Richard is also on various national pediatric cancer advocacy committees relative to his involvement with the Coalition Against Childhood Cancer (CAC2). He has consulted with Congress (as to proposed legislation) and the White House on pediatric cancer issues. Richard has also been interviewed on the CBS Radio program People of Distinction, syndicated nationally, regarding his work with MCF. Richard has been a frequent panelist at conferences on health-related issues hosted by CBI, a division of UBM Life Sciences. In April 2016 Richard was appointed as an Advisory Council Member to the Patient Navigation System formed by Kids v Cancer to address requests by families of children with cancer for assistance in obtaining investigational drugs not yet approved by the FDA. See pages 8 and 9 as to MCF’s involvement with Josh Hardy.

Jonathan Agin, an attorney, joined the MCF Team in 2015 as Executive Director. Jonathan has been a leading advocate for pediatric cancer causes since the death in January, 2011, of his four year old daughter, Alexis, to a rare form of childhood cancer. Jonathan’s advocacy work has encompassed many facets of the fight against childhood cancer. His legislative advocacy has proven effective in the passage of several bills in a climate of congressional stagnation. Along the way, following Alexis’ death, Jonathan began to write and speak on issues impacting the childhood cancer community. Jonathan frequently interacts with members of Congress and their staff, the White House, as well as various regulatory agencies and other cancer foundations in an effort to improve the plight of children with cancer. A frequent contributor to the Huffington Post, Editor for the Canadian as well as oncology journal Cancer Knowledge Network and as a guest writer in other media outlets, Jonathan has quickly become one of the most trusted voices in the childhood cancer community. Jonathan was recently nominated to and elected to sit on the National Cancer Institute Brain Malignancy Steering Committee as one of two patient advocates assessing Phase II and Phase III pediatric and adult clinical trials.
The Josh Hardy Story

Richard was asked in March, 2014 to take a lead role in seeking a Compassionate Use Waiver from the FDA to obtain an experimental drug (Brincidofovir) for 7-year-old Josh Hardy who, without the Drug, was given by St. Jude less than two weeks to live. The manufacturer, a biotech firm from North Carolina, Chimerix, had turned down over the prior two-year period over 300 requests for the Drug. The Hardy family wrote to MCF stating that through its efforts the Drug was obtained 3 days or so prior to the time Josh was otherwise expected to die – they credited MCF with saving Josh’s life. Sadly, Josh passed away on September 22, 2016 at the age of 10. The Drug was successful in extending Josh’s life for 2 ½ years. Please see page 9 for a copy of the letter.

As a result of the national, indeed international, attention given to the Josh Hardy matter, Richard was appointed as the sole pediatric cancer representative on a committee (formed by NYU Department of Medical Ethics) looking into whether the manner in which the FDA grants Compassionate Use Waivers ought to be changed. Richard also participated in presentations to graduate business classes at Texas A&M (Mays Business School) of the story of Josh Hardy from the perspective of establishing a business plan and strategy, which, over a five-day period, was successful in saving Josh’s life.

In February, 2015, Richard appeared on a panel at Harvard Medical School (through the Harvard Center for Bioethics) to address the ethical and legal issues arising out of what has come to be known as the Josh Hardy matter.

In March 2015, as the first anniversary (March 12, 2015) was approaching (Josh was given the Drug on March 12, 2014), Richard was interviewed on National Public Radio (NPR) about his role in the Josh Hardy matter. The interview aired nationally in March 2015 on 500 radio stations, and appears online.

In July 2015, the Boston Globe ran an article about Josh Hardy, stating “The family was introduced to Richard Plotkin, [characterized in the article as an ‘aggressive patient advocate who masterfully choreographed a PR siege against the company’] a former litigation lawyer who heads the Max Cure Foundation, which he founded after his grandson was diagnosed with lymphoma. With the same relentless energy once deployed in the courtroom, Plotkin plunged headlong into the Hardy cause, directing its PR campaign.” See also an article asking the question in the June 2016 edition of Harpers Magazine “What Would You do to Keep Your Child Alive” which also discusses the impact of the #SaveJosh campaign.

All of the articles and interviews can be found here: https://maxcurefoundation.org/max-cure-in-the-media
March, 2014

Dear David,

On behalf of the entire Hardy family and particularly Josh, I wanted to take a moment to personally thank you and forever memorialize the good works and impact The Max Cure Foundation made in working to save my son’s life.

I believe your organization’s role was the lynchpin in a chain of events that finally prevailed on the drug manufacturer, Chimerix, and compelled them to make their life-saving drug available to my son. You and your organization were a Godsend – your staff, your donors. The Foundation’s management should be commended for getting involved and making things happen. It could not have happened without you and the Foundation’s good works and we will always be indebted and inspired by your efforts.

To recap, my son lay close to death in desperate need of an experimental, antiviral drug developed by Chimerix. Our direct pleas for compassion to the company went unheard. We mounted an aggressive public relations and social media campaign to bring this injustice to light and to give Josh a chance at survival. Thousands of people helped. The media joined in with some progress, but not enough, fast enough.

And then, you and the Foundation came to our rescue. You learned of our despair. You mobilized. You got involved. You applied your unique understanding of the healthcare industry, reached out to your network and used social media to apply pressure. Your father, Richard, called me on Saturday to introduce himself. He told me to leave things up to Max Cure. He only wanted to be assured Aimee and I would make ourselves available to the media. I of course agreed. Never did I imagine what Max Cure would make happen. He called Chimerix’s CEO directly. He uncovered his deception. He painted him into a corner when he outrageously suggested that his indifference was due to the high price of the drug. He called his bluff on national TV by offering to pay the $50,000 for treatment. His response was masterful. It created international outrage that led the FDA to rise up and right this wrong.

David, I had never heard of the Max Cure Foundation before you and your people decided to act. But I can assure you I will never forget. I want the world to know what your organization did to help this one little boy from a small town in Virginia. If there is anything we can do for you in the future, if you ever need a testimonial, a speaker, a subject to articulate the value of your organization and its impact on real people, call us. We will be there for you.

Josh has faced a lot of challenges since becoming sick. Watching my son suffer, well, it’s enough to sour anyone on the ways of the world. And then something like the Max Cure Foundation enters your world, and renews your belief that the world is a magical place filled with incredible, giving people who can do the impossible to make it even better for others.

Good show The Max Cure Foundation! David, from my wife, myself, my kids and from Josh, we extend our deepest and most heartfelt thank you for all Max Cure did for Josh.

- Todd Hardy
MCF established a program known as Dunk Your Kicks®. MCF in conjunction with an entity known as Rethink Nation collects used sneakers from various sources that are ultimately sold to a recycler for sale to exporters and distributors as part of the Affordable Clothing Market in emerging market countries. This results in, among other things, the creation of tens of thousands of jobs in the global marketplace.

Rethink Nation pays substantially all the costs of collecting the sneakers, donating to MCF $1.00 a pair for adult sneakers and 67 cents a pair for children’s sneakers. In addition to funding research, the funds received by MCF allow MCF to contribute to its Roar Beyond Barriers programs in the locales where the Dunk Your Kicks events are held. In addition the sneakers are kept out of landfills, the “resting place” annually for upwards of 200 million pair of sneakers.

The benefits to the environment are self-evident. Sneakers consist of about 80% petroleum products, including adhesives and other by-products of petroleum. After 50 years, sneakers typically break down into their component parts. Benzene and certain other of the chemical components have been identified as carcinogens. These chemicals inevitably find their way into the ground water, the soil and the atmosphere. Also, by selling sneakers in emerging markets, serious diseases are reduced. There is a high risk of incurring such diseases with horrific symptoms when one goes barefoot in these countries as bacteria infects the open wounds in the foot.
Contact Us

Thank you for your interest in The Max Cure Foundation. For more information on MCF, the Dunk Your Kicks program, or how you can help in the fight against pediatric cancer, please contact us or visit us online.

Max Cure Foundation, Inc.
560 Sylvan Avenue, Suite 1225
Englewood Cliffs, NJ 07632
(O) 201-569-5595
(F) 201-569-5597
Info@MaxCure.org

www.MaxCure.org
www.DunkYourKicks.org
Facebook.com/MaxCureFoundation
Twitter.com/Max_Cure

The Max Cure Foundation® ©2018.