Thursday, May 16 Dine to Donate Dine at Twisted Rooster & 10% of sales benefits pediatric cancer research. 5pm to Close

Thank you special donors:

The Mervenne Family

John Dykema & Michele Maly-Dykema Family Foundation

Black Cat Golf





milansmiraclefund.org Facebook.com/MilansMiracleFund

> "YOU " have made my dream of DIPG Research and Clinical Trials come true!

Now families that receive this devastating diagnosis have treatment options along with a tremendous amount of hope for a cure!

Some of Milan's Miracle Fund board members and I recently had the privilege of touring the research laboratory where Dr. Giselle Sholler and her team shared with us their latest discoveries and new drug therapies for treating DIPG and other pediatric brain tumors. It was so encouraging to see our donated dollars at work and to see the enthusiasm of the entire research team!

We've come a long way since Milan was diagnosed and we had nowhere to turn with absolutley no treatment options locally or nationwide. I cannot thank our supporters and donors enough for helping provide hope for children and families dealing with this vicious cancer. Though the prognosis for those with DIPG has remained the same for the last 40 years, we intend to change that dismal statistic!

I've never been more hopeful than I am now that a cure can be found. I believe that along with your continued support we will undoubtably make that happen!!

"Help us in our fight for kids, winning the battle against pediatric cancer . . . help us remember the ones we lost." - - Philip Capobianco

I'm committed to Never Give Up! Let's find a cure together!

BIG HUGS!

Sharyn Capobianco Milan's Mom sharyncapobianco@gmail.com

Friday, June 7 **Black Cat Golf** Annual Golf Classic 4-Cat Scramble 9:00 am Shotgun Start Deer Run Golf Club



Saturday, May 11 Strike Out Cancer **Baseball Tourney** 9:30 a.m. 3835 Baldwin St. Hudsonville

Sunday, June 2 Milan's Miracle Run 5K Run/3K Walk/Kids' Fun Run Superhero/Princess Themed Run Mutt Strut, Silent Auction, Police Academy Heroes 10 am Millennium Park Walker, MI

> Aren't able to attend the event? There are other ways to support Milan's Miracle Fund (MMF):

Register as a virtual runner/walker and participate from any location. Visit: Runsignup.com/milans

Shop on smile.amazon.com for MMF and 0.05% of qualifying items will be donated.

> In lieu of wedding favors or birthday gifts, make a donation.

> > Shop Forest Hills Foods pick MMF as your charity.

Thanks to Our Sponsors & Supporter

Express Employment Professionals The Lardieri Family Papa & Grams Jarratt The Chamberlain Family

Bissell MK & Associates Weller Truck Parts Meijer

Bill & Tricia Dodds Jandernoa Foundation Matt Missad Foundation **Global Financial Trust**



1646 Thornapple River Dr. Grand Rapids, MI 49546



DIPG Scope & Screen



New DIPG Trial set for 2019

Milan's Miracle Fund, with your support, is funding preclinical work in Diffuse Intrinsic Pontine Glioma (DIPG) within the Pediatric Oncology Translational Research Laboratory located at Helen DeVos Children's Hospital (HDVCH). The laboratory is part of the Beat Childhood Cancer Research Consortium which has over 40 children's hospitals as clinical partners offering treatment to kids with cancer across North America.

Our funding has helped our team of researchers at HDVCH to use high throughput drug screening, RNA sequencing and flow cytometry to study DIPG. Preliminary data collected has shown drug therapies that reduce the ability of DIPG to proliferate. More importantly, these therapies have been shown to decrease the viability of DIPG cells including a specific cell population that has been linked to brain tumor initiation. A new clinical trial for DIPG patients is set to open in 2019, a direct result of the preclinical work we have helped fund.

The 2019 DIPG clinical trial will be personalized for each patient as part of the Signatures Program which delivers the right drug to the right patient at the right time. Full genomic analysis will be performed to select the best targeted agent to add to each child's regimen. This type of work has been done for nearly a decade by this team in treating other childhood cancers.

DIPG is an extraordinarily deadly brain tumor of childhood. There are no survivors. The majority of the 300 children diagnosed annually with this cancer are between 4 and 11 years old. DIPG grows quickly in the pons, the part of the brainstem which controls crucial functions such as breathing, heartbeat, balance, swallowing and blood pressure. Early symptoms are seen in facial muscles and eve movement because DIPG also usually impacts the cranial nerves.

Treatment of DIPG brain tumors is incredibly complex. Surgical access to the tumor is difficult due to its location in the brainstem deep within the skull. Furthermore, the tumor cells infiltrate normal brain tissue with fingerlike projections making them impossible to fully resect surgically. Chemotherapy can attack the tumor cells but their response can lead to swelling and bleeding, which itself, can be fatal. An elegant treatment solution is needed and we are optimistic our new 2019 DIPG Trial will provide treatment options and hope to families dealing with this horrible disease.

We have come so far from when Milan was diagnosed with DIPG in 2007 and we were faced with absolutely no treatment options either locally or nationwide. We cannot thank our supporters and donors enough for helping us provide hope for children and families dealing with DIPG. Though the prognosis for those with DIPG has remained the same for the last 40 years, we intend to change that dismal statistic!

Fund Stats

\$63,812 raised by Milan's Miracle Fund in 2018

Close to **5,000** runners/walkers in our 8 years

\$523,940! Over a Half a MILLION dollars raised to fight pediatric cancer over the life of the fund!







We are exceedingly thankful for the generosity of Milan's Miracle Fund and its passionate supporters. We have made great strides toward finding better therapeutic options for children with DIPG, and I am eager to share with you what is next...

Precision medicine is an approach to patient care that allows us to select treatments that are most likely to help patients based on a genetic understanding of their tumor. Using this method, we have experienced many victories in the fight against children's cancers, and, with your support, we hope to see the same results with DIPG. Milan Miracle Fund's dedication to our research will lead to vital new insights, as well as the development and testing of new therapies, which will improve the outcomes for children with rare childhood cancers.

We are actively working with insurance companies to make genomic testing a standard procedure, but until then, donor support is essential to giving children with brain tumors access to innovative treatments.

We will always be strengthened by the life and spirit of Milan and are incredibly grateful for your support.

Gratefully, Giselle Sholler, MD

