
Michael's master plan

1 message

The Swifty Foundation <Info@swiftyfoundation.org>
Reply-To: The Swifty Foundation <Info@swiftyfoundation.org>
To: [REDACTED]

Wed, Nov 9, 2016 at 7:04 AM



Dear [REDACTED]—

It's been almost 4 years since we lost our son.

When we found out he was dying, all of us resolved to make the most of our time together. We planned some crazy adventures, and we did a lot of ordinary things that Mikey loved.

I shot [this video of Michael](#) on my phone in the parking lot of a steakhouse in Tampa, Florida. Having a meal there was one of the things on Michael's "bucket list."

It was homecoming night in Tampa. Local high school kids are coming in and out of the steakhouse as Michael talks, and at one point a limousine even drives by. It's a distracting environment for him, and it's hard to hear what he says in spots. But I thought it was important to preserve this moment, just like this. So after we had dinner, while Michael's dad went to get the car, I grabbed my phone and hit the record button.

You see, just hours earlier, **Michael had made a huge decision.**

In the video, he calls it his "master plan." Michael had just decided, when he died, to donate part of his body for cancer research.



Throughout the 5 years of his sickness, my son was passionate about helping others – and especially about helping other kids with cancer. So for him, this was a way to keep on helping even after he was gone. Even if Michael never met the ones he helped.

“I’m not really sure right now who I’m helping,” he says near the end of [the video](#). “But my goal is to help as many people as I can.”

That’s why we started the Swifty Foundation with Michael before he died. And that’s why we have continued working on his plan these last 4 years. So that someday, no child will have to do what Mikey did. So that we help as many as we can.

And for 4 years, **our biggest question has been: How?**

How do we help kids like Michael? Why have survival rates for children like him – children with brain cancer – stagnated? Why are brain tumors now the #1 cause of cancer deaths among children in the U.S.?

What can we do to turn that around?

In the years since Michael’s death, we’ve wrestled with that problem. We’ve met other families like ours, and we’ve talked with experts and researchers all over the country. Pediatric brain cancer is complicated, and there are a lot of reasons it’s so hard to beat.

But one reason is the biggest. And that's why from now on, the Swifty Foundation has decided to devote all our efforts to this single problem.

But that's another topic – so I'll save it for another message! Tomorrow, watch for another email from me titled **“We can't stop kids' brain cancer until we solve this problem.”**

Until then, may you help as many as you can –



Patti Gustafson

P.S. Do you know anyone whose life has been touched by cancer? Do you know another parent, or another child or friend or sibling, who would resonate with Michael's goal to “help as many as we can?”

Would you help us [share Michael's story](#)?

This month, we want to share Michael's video with anyone who'll find it meaningful. To help us, just use the share buttons on the page. Ask your friends to join the Swifty email list, and they'll get this story in their inboxes too.

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We can't stop kids' brain cancer until we solve this problem

The Swifty Foundation <Info@swiftyfoundation.org>
Reply-To: The Swifty Foundation <Info@swiftyfoundation.org>
To: [REDACTED]

Thu, Nov 10, 2016 at 7:05 AM



Dear [REDACTED] –

The tumor that took my son's life was not the tumor he was diagnosed with.

After Michael died, his brain tissue was donated for medical research just like he wanted. And one of the first things the researchers told me was this: **Many of the treatments Michael went through were a waste.**

These were uncomfortable, painful cancer treatments. But they were the wrong ones. The last months of Michael's life would have turned out the same if we had done nothing at all.

Can you imagine how that felt?

After that conversation, I was devastated. I laid on the floor of my bedroom for hours. I couldn't move.

Let's be clear: It's NOT that Michael's doctors made mistakes. Their information was limited. **We simply do not know enough about pediatric cancer.**

One problem: Cancer is a moving target. Michael spent 5 years with cancer in his body. And believe it or not, it's normal for brain tumors to completely change their properties over less time than that. Because our kids are growing. But also

because the **cancer actually changes in response to treatment**. My son's tumor was correctly diagnosed. But then, it changed... **and no one knew**.

How do you fight something you don't understand?

The answer seems obvious: You study. You learn as much as you can. And that's what makes brain cancer – especially in children – so insidious. The best brain research can only happen after death.

Right now, getting donated tissue from kids who die of cancer is a tall order. [We made this infographic](#) to explain the reasons it's so difficult. There are logistical challenges. And in many cases, children and their families simply never know donation is an option. But without that tissue, research stands still."



Our doctors do keep learning and improving. But real progress – major change – is limited by the number of tissue samples researchers have to work with. And that number is too small.

Over the last 4 years, as Swifty met with expert after expert, we heard different versions of the same thing: **Without more donated tissue, research is in the dark.**

Then we met some forward-thinking researchers willing to collaborate to solve this problem.

This solution is so smart, and so exciting, that **we've volunteered to fund it**. Every dollar raised by [Swifty's 2016 fundraising campaign](#) will go to this one effort. We believe it's a game-changer.

Tomorrow, I'll tell you all about it. Watch for another email with the subject, **"Here's how we fix research into kids' brain cancer."**

Until then, may you help as many as you can –



Patti Gustafson

SEE THE INFOGRAPHIC

**SWIFTY
ANNUAL
APPEAL**

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Here's how we fix research into kids' brain cancer.

The Swifty Foundation <Info@swiftyfoundation.org>
Reply-To: The Swifty Foundation <Info@swiftyfoundation.org>
To: [REDACTED]

Fri, Nov 11, 2016 at 7:05 AM



Dear [REDACTED]—

It turns out Michael was more right than any of us knew.

When my son decided to donate his brain tissue for cancer research after death, he called it “his master plan.” It was Mikey’s dream to be a scientist when he grew up. When he learned he couldn’t do that, he decided to aid research in the only way he could.

Today, after meeting with dozens of cancer experts in our work with the Swifty Foundation, we’re not sure there’s any better way Michael could have chosen to fight cancer.

A lack of tissue to study is the biggest reason we don’t understand children’s brain tumors better. There are **logistical problems** that make donated tissue hard to receive, and there are **communication problems** that keep many families from ever hearing about donation in the first place. Swifty is partnering with The Children’s Hospital of Philadelphia and The Children’s Brain Tissue Consortium (CBTTC) to solve both problems.

This won’t just help Philadelphia researchers; CBTTC partners with hospitals all over the United States and even overseas. That means in a few years, a donation solution could be available to hospitals and donor families in a multitude of places.

And *that* means **more tissue, more data and more knowledge** being shared

and studied by the many researchers who use the CBTTC.

But first, we need to fund the pilot program.

The Swifty Foundation is so excited about this joint effort from the hospital and CBTTC that we've made this pilot program the sole focus of our 2016 fundraising campaign. We've developed an **infographic** to explain the program in layperson's terms – you can [read that right here](#). The program will make it so simple for families to donate brain tissue that all anyone will have to do, after signing up to become donors, is make a single phone call at the time of death. Everything else will be taken care of.



We're making it easier for grieving families to donate their children's tissue for research.

Does that seem weird to you? Is it really ok to ask a grieving mom or dad to make a phone call like that?

If the question gives you pause, you're not alone. But I can tell you –for many grieving families, the experience of giving tissue is more than ok. And I should know. My family lived it.

I'll tell you what that felt like in tomorrow's email, when I finish Michael's story. Watch for another message in your inbox with the title "**Give yourself away.**"

Until then, may you help as many as you can –



Patti Gustafson

P.S. Our friends in Philadelphia are going to solve the problem of tissue donation, but they can't do so without our help. Will you be part of funding the solution?

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To: [REDACTED]

Mon, Nov 14, 2016 at 7:06 AM



Dear [REDACTED] –

We lost our son Michael to a brain tumor almost 4 years ago. But at a hospital in Toronto, a part of him literally lives on.

Before he died, Michael decided to donate his brain tissue for pediatric cancer research. It doesn't always happen, but we actually got to choose the researchers that would receive his tissue. Michael knew where it would go. And after his donation, his dad and I got a call to tell us they had established a cell line with our son's tissue.

What's that mean? It means tissue with the same genetic makeup of the cancer that was in Michael's body is in a hospital lab even now, years later, helping kids living with cancer today have better outcomes.

In addition to cell lines, researchers gather data from the genomes and the proteins; they study healthy parts and cancerous parts of the donated tissue and cross-reference it with other data from other cancers to look for similarities and differences. We're learning more about how pediatric cancer works, and how to beat it. And the more tissue we have, the faster we'll learn.

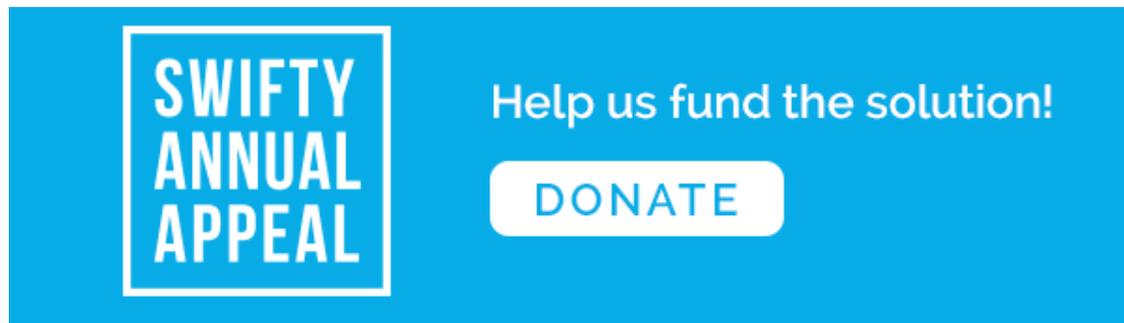
It's amazing. And I wish it wasn't needed. I wish research into children's cancer didn't need to go on for one single day more.

But it does.

Donated tissue is not the most important thing that Michael left us. But it does give me a certain comfort to know that his death was not the end. There are more good things still to come. My son continues to impact other kids with cancer. He continues to impact the future.

That's a comfort. That's something I want more families like mine to be able to choose.

That's why this year, for Michael's birthday, we're initiating a program that will improve tissue donation. Our goal is to **raise \$300,000 by December 30**. We're on our way. [But we need your help.](#)



Donated tissue is not the most important thing that Michael left us. When I watch him explain his [“master plan,”](#) I notice one thing he says early in the video: “I’m going to give my life up.” Michael knew he didn’t have much time. But he also knew that to truly let go of your life for others is a choice.

He knew the power in that choice. And now, in his death, we know his choice is working for good – and that there’s still more good to come.

I pray we can also learn what it means to give up our lives for one another. Whether we have a lot of time or just a little, there’s no greater power in the world.



Patti Gustafson

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