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'A wonderful feeling': Hudson man with aggressive brain tumor defies odds

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Katie and Peter Mang of Hudson have started a nonprofit to help other patients with glioblastoma and other advanced brain cancers. Peter was diagnosed five years ago with a glioblastoma, an aggressive brain tumor with a 6.9% five-year survival rate. PHIL MASTURZO, AKRON BEACON JOURNAL

For five years, Hudson resident Peter Mang has been bucking the odds.

In 2018, he was diagnosed with the most aggressive type of <u>brain tumor</u>, a <u>glioblastoma</u>. According to the National Brain Tumor Society, the five-year survival rate is 6.9%.

The average life expectancy after a glioblastoma diagnosis is eight months.

Following surgery to remove the tumor, Peter was left with serious cognitive impairment.

"When I came out of surgery, I could barely talk," he said. "Nouns were extremely difficult. If I looked at a tree, I couldn't even find the word 'tree.'"

Therapy helped him regain those skills — reading, writing and speaking well — but another hit was coming.

Two years later, his cancer returned in an inoperable spot in his brain. At the recommendation of his doctors, Peter entered a clinical trial at the Cleveland Clinic.

Three years after beginning the trial, Peter's cancer is undetectable.

However, amid all this, the family — Peter, 39, his wife, Katie, and their two children — were the victims of a total-loss house fire.

In a testament to their resilience, they're rebuilding the home at the same property. They're also running a foundation called <u>Go With the Good</u> meant to support others battling brain cancer.

'The next thing I remember, I was at the Cleveland Clinic'

For Peter, the onset of his symptoms was sudden.

An architect, Peter was working at a firm in downtown Kent when he experienced a medical crisis.

"I was in a stressful situation with work. I was trying to get a job done quickly and at one point, from what I hear, I just started saying weird things," Peter said.

That's when he experienced a seizure, and his coworkers called an ambulance.

"The next thing I remember, I was up at the Cleveland Clinic," he said.

Katie, his wife of 14 years, said the ambulance took him to a hospital, where doctors performed a CT scan that revealed a mass in Peter's brain.

He was transferred to the Cleveland Clinic, where he stayed for nearly a month.



During that time, doctors brought his seizures under control, performed a craniotomy and determined he had glioblastoma.

Upon hearing the diagnosis, Peter said that he was shocked, his mind filling up with "everything and nothing all at the same time."

Katie's first questions of the doctors were: "What's the prognosis, and is it genetic?"

"Prognosis was at best three years, and it is not genetic," Katie said.

After hearing the initial diagnosis, Peter said he wasn't in a good place, but his focus quickly shifted to his young children.

Meanwhile, Katie took over planning for the radiation and chemotherapy sessions, working out child care, notifying family and more.

"In hindsight, it felt overwhelming, but I think it gave me purpose," Katie said.

Road to recovery

The tumor removal surgery was successful, but it left Peter with a new set of challenges to tackle.

"I knew what everything was - I just couldn't find the words for things," Peter said.

He engaged in physical, occupational and speech therapy on his journey back to a semblance of normal -a journey that could be frustrating at times, especially with the side effects of treatment compounding the effects of the surgery.

"I'm a freaking architect and I can't even find the word 'ceiling' or 'floor' or 'window,' " he said.

Learning to read again was something he was able to do with his children, both of whom were grade school age at the time.

Hobbies have helped as well. Peter does a bit of woodworking and has been working his way through some classic literature after years of not having been an avid reader. Katie got him an Audible account so that he can listen if he doesn't feel up to reading. During the days, he takes care of the house or spends time with the kids.

Clinical trial offers new hope

For two years, Peter's cancer was undetectable. Then, an MRI revealed that his cancer had returned in an inoperable place in his brain. At the time, a clinical trial was underway at Cleveland Clinic.

Dr. David Peereboom, medical oncologist and director of clinical research at Cleveland Clinic's Brain Tumor Center, said the trial was a good fit for Peter.

"Clinical trials do best for patients when they're used earlier in a patient's disease course," Peereboom said. "For him — being a young person, very functional, very willing and engaged with his treatment — he was a perfect candidate for this clinical trial. It was our first recommendation."

It's no small thing to decide to test a new treatment. Peereboom said it requires courage and trust from the patient.

The trial involves an intravenous drug administered twice a week designed to disrupt a protein that's responsible for the development and growth of a few different cancers. Glioblastoma patients respond particularly well to the drug, Peereboom said.

"If things go well, it might become part of the treatment options that are normally available to any patient with glioblastoma. That's the hope," Peereboom said.

Over the course of treatment, Peter's tumor has slowly been shrinking. Currently, all that can be seen on an MRI is scar tissue.

"His tumor has essentially shriveled up and is completely inactive," Peereboom said. "I wish I could say he's cured. I think it's a little bit premature to say that, but he is doing as well as could be hoped for having this type of cancer.

"It's a blessing to be alongside a patient and their loved ones to enjoy how well things are going — most importantly, to enjoy seeing him live basically a normal life right now, watch his kids grow up. It's a wonderful feeling. It's a happy feeling. It's a motivating feeling. It's what makes us tick as we do this work."

One day at a time



Katie and Peter Mang take a portrait with their children Elliott, 7, and Owen, 11, this year on the beach at Marblehead. The Mang Family

Peter's diagnosis taught him to slow down and take things as they come.

"If I were to look and start thinking about everything, I'd be a wreck. I'd be a huge wreck," he said. "Going step by step, and do little steps and do smaller things, I was able to - I could handle it better."

Little moments with his family have become more important to him — playing board games with the children, going to a movie together, cooking dinner.

"I've told Katie, if I didn't have her to help me with this, I wouldn't be here right now. I wouldn't," Peter said, running down a list of things she's taken on from getting him to appointments to motivating him to take care of himself.

Katie said that she draws strength from Peter's optimism and asking for help from friends and family.

Although their children — now 7 and 11 — have grown up watching their father deal with cancer, Peter and Katie have kept them reasonably sheltered from the realities of the situation, dishing out information as necessary so as not to overwhelm them.

Peter's goal has always been to keep going. He knows there's only so much he can control, and he tries not to focus on the uncontrollable.

"What can I do for myself?" he asks. "That's where I'm like, 'Go jogging, I can do that. That's something I can be in control of it.'

"There's always, in the back of my head, that by tomorrow, something could happen," he said. "It's always there, and I can turn it off and go jogging with the kids, and it's not in my mind."

Katie is a planner. Having support networks and plans in place gives her peace of mind.

"I think without facing the truth of what we're going through, and what we could go through, it would bring more anxiety," she said. "But as we learned with the fire, everything is unpredictable. So I'm learning to accept unpredictability at a whole new level."

Fire adds to family's struggles

In the midst of everything, the Mangs' Hudson home burned down in March; it was deemed a total loss. They're living in a rental in town while they rebuild the home.

Peter said that because of the extensive damage, a cause was never determined. When the blaze began around 10:30 p.m., the whole family was at home. Peter and Katie were upstairs in bed watching television and the kids were asleep in their rooms. First, they heard a window shatter in the sunroom. Peter, thinking at first that someone was breaking in, went to investigate but quickly realized the sunroom was on fire.

The smoke alarms went off almost as soon as he called to his wife.

"It was pretty scary. Katie was upstairs and said we're getting out, and we got out pretty quickly. At that point when we were getting outside, we called 911," he said.

Everyone got out safely, but they regrettably lost a pet rabbit to the blaze.

By the time the fire department arrived, it was too late. The house was gone.

"We're safe," Peter said, "and that's all that mattered."

Helping others with Go With the Good nonprofit

Through it all, Peter and his wife have managed to find time to start a nonprofit called <u>Go With the Good</u>, named after the couple's dedication to finding something enjoyable in every situation.

Incorporated in 2022, Go With the Good's mission is to help support young adults diagnosed with glioblastoma and other advanced brain cancers through financial aid and other resources.

Depending on the study, Katie said, a glioblastoma is the most expensive or second most expensive cancer to treat.

Peter said that they had financial issues due to the cost of treatment, but friends and family helped defray the cost by holding a spaghetti dinner fundraiser for him.

The clinical trial now takes care of the cost of the medicine, while insurance picks up a portion of the remaining medical expenses.

Once he was accepted into the trial and things were more stable, Peter and Katie decided to pay it forward by helping ease other patients financial burden, sharing with them what they learned through navigating the health care system.

"We were like, we've had so much help, we're in a good spot. There's other families or patients who have gone through what we've been through, or they're going through it now," Peter said. "We want to show a big thank you to everyone who helped us and pass that along to other people."

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