

Faith, fortitude, love... and a medical miracle

*Dr. Tirone David, a legend of cardiac surgery,
and a multidisciplinary team tested their skills
and gifts in the case of patient Rebekah Hughes*

By Judy Gerstel



Medical miracles are becoming commonplace at the Peter Munk Cardiac Centre (PMCC), but the life of Rebekah Hughes will always be incredible.

Ms. Hughes lives with her husband, Jon, and their three children in Everett, Ont., near Alliston, where Mr. Hughes works at the Honda plant.

Perennials grow at the front porch, and there's a trampoline in the big fenced backyard.

A framed poster made by teenager Larissa Hughes hangs on a wall near the front door: "Every family has a story. Welcome to ours."

The story of Rebekah Hughes and her family is a remarkable story of faith, fortitude and love.

And the miracle?

"That I'm here to tell it," says Ms. Hughes.

This is also a story of two people brought together by fate or providence in a cold operating room at the PMCC: one with a severely damaged heart and scorched lungs caused by childhood cancer treatment, and one with a compassionate heart, a creative mind and an intuitive surgical skill that astonishes colleagues.

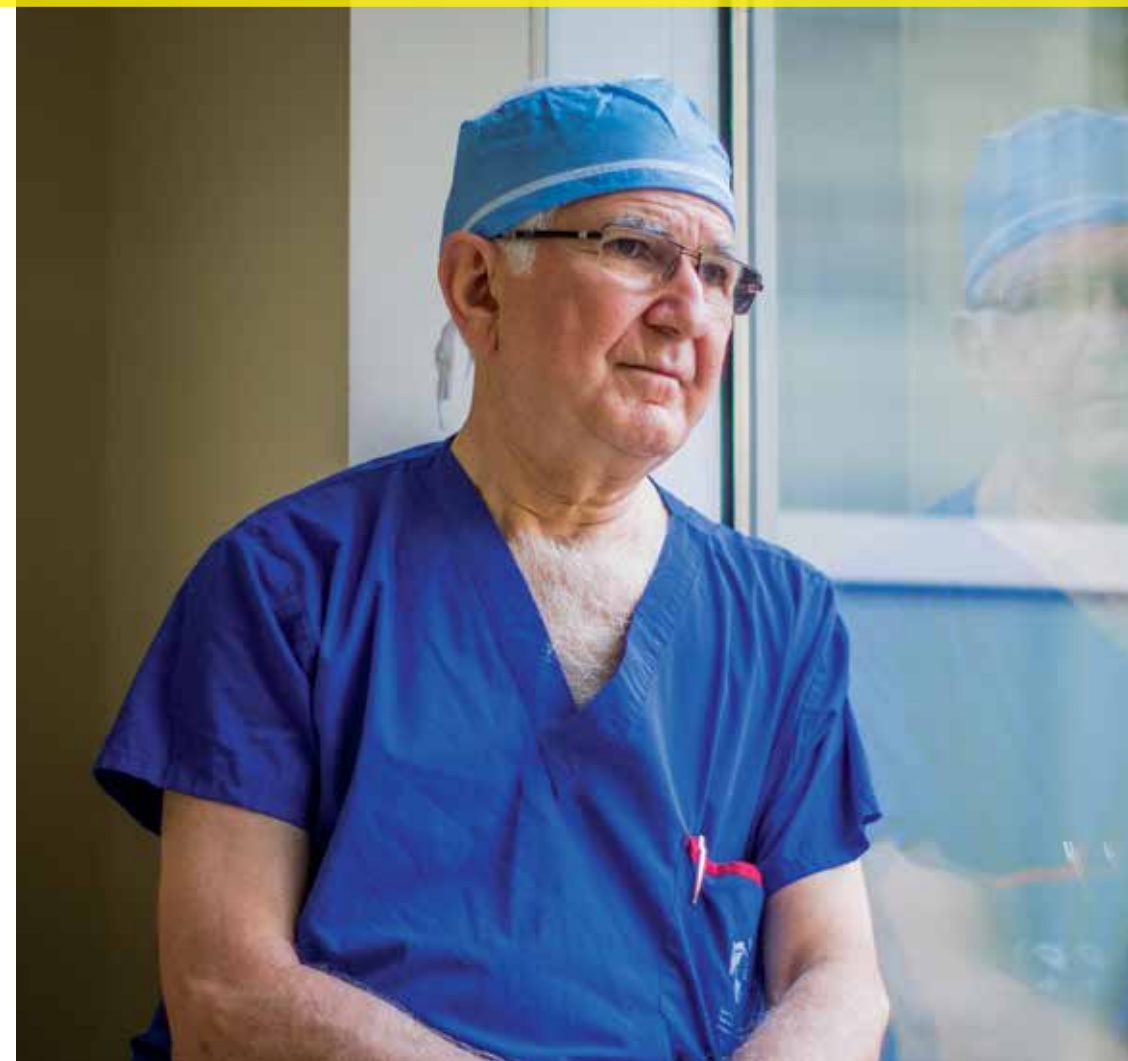
"Dr. David is the legend of cardiac surgery. He's the best heart-valve-repair surgeon in the world," says PMCC cardiologist Dr. Paaladinesh (Dinesh) Thavendiranathan. "He does things that are not routinely done in surgery. It's just innate for him, a gift."

With all his skill, Dr. David didn't minimize the risk of Ms. Hughes' surgery.

She recalls his warning after she checked into the PMCC in August 2014 for presurgery tests.

"He said, 'It's going to be extremely high-risk. But if we don't do it, you won't live.'"

Whether or not there was divine intervention in the life of Ms. Hughes, as she believes, depends on your faith.



Physiotherapist Moissei Zinguer, left, CVICU Nurse Manager, Helen Storey, centre, and nurse, Lorna Baptiste, right, played important roles in Rebekah Hughes' months-long recovery.



What can be known for certain is that the intervention and care of Dr. Tirone David and a multidisciplinary team at the PMCC – nurses, pulmonologists, respiratory therapists, pharmacists – made it possible for Ms. Hughes to come home to her husband and their children after spending 80 days in the Cardiovascular Intensive Care Unit (CVICU).

Those days included her 38th birthday and her 15th wedding anniversary, a Thanksgiving dinner and her son's ninth birthday.

The CVICU team arranged celebrations in a conference room adjacent to the unit for some of those occasions. "We brought in some pizza, and one of the physicians had an ice cream cake picked up for her son's birthday," says Helen Storey, Nurse Manager of the CVICU at the time.

"That's part of caring for patients," she explains. "It's not just the task or the problem that needs looking after. It is the total

patient, it is the person, it is the family."

Ms. Hughes' critical months in cardiac intensive care followed a heart operation that other surgeons declined to attempt.

"Every other cardiologist I talked to said it's near impossible to fix," she recalls, "and the risks too high."

Then she spoke with Dr. David. "She was going to die otherwise, so I had no choice," says Dr. David.

"She's so young, a wonderful human being, with three kids at home."

The bond between patient and surgeon goes beyond what happened in that operating room. "Every day he was in the hospital, he came to see me," she says.

When she went home, he asked her to stay in touch and told her, "I'm going to miss you, Rebekah."

Ms. Hughes adds: "He intrigues me because he has this emotional side. We shed tears together."

The story of Rebekah Hughes really begins with a three-year-old girl who swallowed a penny.

After Rebekah Hughes had her successful surgery, Dr. Tirone David, above, told her that had he known the amount of damage he would find when he opened her up, he would not have attempted the surgery. To the right are examples of the heartfelt correspondence, post-surgery, between Ms. Hughes and Dr. David.

TO: Dr. Tirone David
FROM: Rebekah Hughes

Dr. David, you have had made an extraordinary difference in my life. You and I have shed tears together over the good things God has done in my life, despite how difficult my life has been from a medical perspective, and how God has blessed me with a husband who has loved me so well in sickness and in health, and three miraculous children. I thank God for you and will never forget you.

TO: Rebekah Hughes
FROM: Dr. Tirone David

You are an exceptional woman with a rare strength, magnificent character, and an inspiration to all of us.

Ms. Hughes travelled to Britain with her parents in 1979 to visit relatives there and somehow managed to swallow an English penny.

An X-ray found more than the penny, which was easily removed.

The scan revealed a sarcoma, a rare soft-tissue malignant tumour with a terrible prognosis, growing large in the child's chest, but as yet causing no symptoms.

"So much was unseen until the penny revealed the tumour," says Ms. Hughes.

The family flew home, and within four days she was undergoing surgery at SickKids, followed by intense radiation and two years of chemotherapy.

"They did kill the cancer," she says, "and it never returned. But I was left with significant scars from the radiation, one functioning lung and ongoing health issues."

What was not known 35 years ago was the damage that cancer treatment could cause to the heart.

In recent years, because of the prolonged survival of cancer patients, an important new medical field of onco-cardiology has evolved to screen cancer patients at risk of heart damage from treatment, to prevent cardiac complications and to treat damage that might occur.

Decades ago, no one knew that irradiating the chest of a young person can cause severe injury to the heart and lungs that becomes evident only many years later.

"The consequence of the radiation was that everything turned and twisted in her heart, and arteries closed with scarring from being burned and one lung was destroyed," explains Dr. David. "The main artery that feeds the heart muscle was 99 per cent narrowed. Radiation damaged both nerves that make the lungs move."

Ms. Hughes was left with a 30-per-cent lung capacity.

Only after her youngest child was born in 2010 did her body begin to fail.

Simple household tasks made her short of breath. So did reading out loud to her children.

She began to wonder if the exhaustion and breathing difficulties could be connected to her past.

"There was a whole world in my past that I hadn't explored,"

says Ms. Hughes. "It was not a discussion that was open in my family. But around that time, people started understanding the long-term effects that cancer survivors were having. I realized I needed to know what the long-term effects were from what I had gone through – and what, exactly, I had gone through."

A program she found for adult survivors of childhood cancers at Princess Margaret Cancer Centre led Ms. Hughes to request a copy of her 35-year-old file from SickKids.

"I pored over that," she says. "It was strange reading about that child, and I was that child. I began to understand what I had gone through, medically and emotionally."

And what had brought her to Dr. David, and the necessary but risky surgery.

The night before the operation, on the Labour Day weekend, her husband, Jon, and the three children came to her bedside.

She knew she might be saying goodbye to them, "bearing this weight of not knowing what would happen," she recalls.

"My daughter was 14, my son was eight and the youngest was four. They understood that my heart was sick, and that Dr. David was going to do his best to help make it better. The 14-year old knew there was a risk."

The children went to stay with Ms. Hughes' sister's family. Her husband packed a suitcase to stay in downtown Toronto to be with her. He packed enough for the seven to 10 days she was expected to be in hospital.

He ended up staying until she was discharged, 80 days later.

It would be almost three months before the Hughes family returned home.

The surgery itself was supposed to be an aortic valve replacement that normally takes about two hours.

Instead, it was an unexpected and complex operation that lasted seven hours.

Parts of her heart were so scarred and calcified that they shattered like eggshells.

Weeks later, Dr. David told Ms. Hughes that had he known what he would find when he opened me up, he would not have attempted the surgery. It was even riskier than what he'd anticipated.

"At one point he looked up

around the operating table and said he wasn't sure he should continue. Then he said, "This woman has three children to go home to." So he carried on and did his job."

This was the job Dr. David did: "I cut her leg, took the vein, cut the main artery, replaced the aortic valve, the main pipe, as well. It was not conventional surgery. It was something creative that I do sporadically and only out of desperation."

He adds: "It was in my head that I was doing a salvage operation, where the patient has no alternative but what I can do."

Around nine in the evening, Dr. David came out of the operating room to speak to her family.

He told them that Ms. Hughes had come through the surgery. But he was sombre. When her sister cheered, he admonished her, "Don't cheer yet. I'm not sure she'll make it through the night or the week."

It was close.

"All those risks they feared actually happened," she says. "After surgery, I went into respiratory failure."

Dr. David explains: "I knew I can fix the heart, but the lungs were marginal. Her chest wall doesn't move enough."

Under anesthesia or with a high dose of narcotics, the movement is further impaired.

"If you cannot move your chest wall," he adds, "you cannot breathe."

When Ms. Hughes entered the CVICU postsurgery, "she was very critical and very sick, unconscious and unaware," recalls Ms. Storey. "In CVICU, we see miracles and we see people close to death, but we're a very large team and we work really hard and do what we can, working together."

Ms. Hughes recalls those first days and weeks: "I struggled to breathe and I struggled with hallucinations and delusions because the carbon dioxide was elevating in my blood. Then things would improve and my mind would clear before the CO2 elevated again. It was days of up and down."

After a week, Ms. Hughes was discharged from CVICU, but was brought back 24 hours later when her CO2 level spiked so high she went into a coma.



Shortly after, her only functioning lung collapsed with pneumonia.

"I was fighting to live," she says, "and it was such a hard fight physically and emotionally. I had no fear of death. I am fully confident that this world is not the end. I had the hope of being with Jesus. And I wasn't sure that I could keep that fight going. But I realized, No, it's not just about me. I was determined to keep fighting. I did it for my family, to experience with them the joys we have in this world, as well as the hardships."

She was not fighting alone. "My husband would tell me that God wasn't giving up on me," she recalls. Mr. Hughes remained at her bedside constantly. "He was my rock," Ms. Hughes recalls.

"I was aware that everyone was doing so much to keep me alive. The nursing staff was fantastic. The doctors doing rounds would include us in their conversations."

Ms. Hughes' physical condition began to improve after she underwent a tracheotomy. A tube inserted in her windpipe allowed a ventilator to push oxygen into her one working lung.

"Those were hard days of having to surrender everything," she says. "I couldn't eat, couldn't talk."

Weaning herself off the machine was a challenge. "Every day I'd have to breathe more on my own,

starting with an hour a day. It was a wearing process. There were weeks and weeks of doing that. I really got stuck. I could manage through the day but wasn't sure I could get through the night."

As long as she needed the ventilator, Ms. Hughes remained in the CVICU.

"She knew there was work to be done and she owned it," says Ms. Storey.

"I realized I had to push through the night because that was the only way I could go home," says Ms. Hughes.

Although the breathing tube was removed after a month – "to be eating and talking again, things we take for granted!" – she still required breathing support.

She was discharged from the CVICU and sent to a rehab hospital to learn to use a BiPAP machine, similar to the CPAP machine used by people with sleep apnea.

And then at last, Ms. Hughes went home. Her husband was her primary caregiver, she says.

"I was still on oxygen, very weak, able to walk about four steps at a time. The thing we kept in mind was head nurse Helen reminding us to keep moving forward. I focused on the joy in my children's faces, and I managed to get outside with all my equipment, even though the oxygen line would freeze in winter."

In the fall of 2015, Rebekah Hughes was given the okay to start exercising – another milestone in her remarkable journey.

In early fall 2015, an echocardiogram showed that Ms. Hughes' heart was healing. She was given the go-ahead to begin exercising.

"We went on a hike on the Niagara Escarpment. The leaves hadn't changed yet," she says. "We came home and planted tulip bulbs."

It doesn't much matter whether you attribute Ms. Hughes' survival to Dr. David and the PMCC, to her faith, to the steadfastness and love of her husband or to a higher power.

Ms. Hughes is, against all reason, in defiance of every prognosis but one, alive.

How is it possible to explain that?

Was it a surgeon's skill, a dedicated and expert team of intensive care practitioners, a patient's determination, a community of love and support? Was it all of that?

Or was it a miracle?

Sometimes, a miracle is all it takes. ♥



Heartfelt thanks to the Peter Munk Cardiac Centre.

For more than 75 years you've helped countless people receive world renowned cardiac care.

You stand out as much for your commitment to cardiac innovation as for your compassion and respect for patients.

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