

THE PITTSBURGH
FOUNDATION
QUARTERLY
Spring 2019

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is producing new tools
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mind in a Pittsburgh Foundation
grant to speed development of
breakthrough therapies.*

FORUM



FEATURE STORY

PAYING IT FORWARD

How one family's medical crisis led to endowment of a trailblazing supportive care program and palliative-care research.

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Maggie Elder celebrates with mom, Cyndi McGinnis, at a 2011 5K race fundraiser held in her honor four months after she was diagnosed with Ewing's sarcoma. Read their story on p. 10.

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JUST AFTER THE CHRISTMAS-NEW YEAR'S HOLIDAYS IN 2002, a packet from the vice president of the Wills and Trusts section of PNC Bank was delivered to our offices. Inside was a letter announcing the death of Robert Nicholls Kohman, along with a copy of the trust agreement that was part of his will.

No one connected to The Pittsburgh Foundation knew him. His only contacts with us had been through advisors.

He had never been to our public events. He wasn't on the mailing list for our publications. And while he had a professional career in his family's commercial baking company and as a researcher at the Mellon Institute, no one in business or academia had referred him to the Foundation.

But somehow he had enough confidence in the Foundation to direct \$14.5 million from his substantial estate to establish the Robert N. Kohman Fund for Medical Assistance and Research.

A note from a staff member who followed up after this extraordinary delivery quotes the bank official saying that Mr. Kohman had studied "the community foundation structure and was excited about The Pittsburgh Foundation awarding grants to do good continuously—far into the future."

Mr. Kohman never married and had no direct heirs. He was, according to the few accounts available of his life's activities, the scion of a prominent Pittsburgh family. He was a graduate of Yale and served as a Naval officer during World War II. He loved the opera, gardening and his golden retriever, Tyler, who was his main companion. While his parents relished the society scene, he avoided the limelight and lived quietly.

The few personal details gleaned from his will and trust fill him out as a man deeply committed to the value of scientific research and medical interventions that save lives. Also, it's clear that he was so devoted to Pittsburgh that he wanted to improve life prospects for future generations.

In the 17 years since it was established, the Kohman Fund has grown to \$20.9 million and awarded \$7.2 million to support groundbreaking research including drug development for immunotherapy, Alzheimer's disease and dementia, and HIV/AIDS. I believe he would be pleased by the evidence of our ongoing efforts to realize his dream of continuous philanthropy.

In my 20 years of leading two Pittsburgh philanthropies and a university center, nothing has impressed me more than the power of our Foundation to make gifts in perpetuity. The community foundation model allows for all sorts of philanthropic immortality, and it is truly wonderful to see it used by hundreds of donors who continue to choose, as Mr. Kohman did, to further medical research as a promissory note on the region's future.

Many of our donors fund medical research in response to the loss of a loved one to disease or other tragedy, and the sentiment behind that is endearing: that a life cut

\$4,780,616

in total
grants for
medical
research
in 2018

DISCRETIONARY

■ Medical Research	\$3,840,890
■ Unrestricted	\$275,000

DONOR DIRECTED

■ Advised	\$460,470
■ Designated	\$204,256



short should inspire a gift to cure a disease or develop treatments that save or prolong lives in the future.

Last year, The Pittsburgh Foundation made nearly \$5 million in grants for medical research, based on an asset base for that giving area of nearly \$24 million. That places us in the top tier of the country's community foundations for medical research grantmaking.

Our donors recognize that medical research grantmaking is the essence of patient investing. It's hardly ever one grand donation that quickly produces a miraculous cure for a dreaded disease. It's about enabling the daily slog through trial and error that increases knowledge and leads to the next step and then the next 10 steps after that before finally arriving at life-saving drugs or treatments.

This issue of Forum reports on the Foundation's expansive medical research agenda and highlights some of our donors' thoughtful efforts. It is amazing to know that they are the latest wave in a series that goes back to donors who made bequests many decades ago. Their funds continue to spur medical advances today under the stewardship of our Foundation.

I can't think of a better issue in which to have my final message. In June, I will be passing on the leadership baton to an immensely talented and devoted nonprofit leader, Lisa Schroeder, who knows the region well from her many years of running Pittsburgh's Riverlife, the organization that has transformed our riverfronts and — by extension — transformed Pittsburgh's expectations of its future.

I know she understands as I do, that while leaders of community foundations come and go, the leadership responsibility of assuring our donors of the value of patient investing is ongoing. We are the caretakers of the promise of perpetuity.

97%

of medical research
dollars were granted to
institutions in Pittsburgh
and the surrounding area.

Maxwell King
president & CEO

In the Know

In March, The Pittsburgh Foundation launched a quarterly conference call for donors invested in the Legacy Fund. In what will be an ongoing service offered by the Foundation, listeners were introduced to Pavilion Advisory Group Inc., the consulting and advisory firm hired in 2017 to work with the Foundation on overseeing the Legacy Fund.

Foundation Executive Vice President Yvonne Maher moderated the call, which aims to give donors the same level of confidence, oversight and due diligence for their philanthropic investments as they would receive from advisors for their personal investments.

Also participating in the call were Foundation Senior Vice President of Finance and Investments Jonathan Brelsford along with Pavilion's Cori Trautvetter and David Thompson. They outlined Pavilion's relationship with the Foundation and discussed fourth-quarter 2018 investment returns, in which losses had some people concerned about this year's prospects.

"We believe that the chances of that dreaded 'r' word, 'recession,' are elevated relative to what we've seen in the last couple of years," Thompson says. Still, he believes the risk of recession is low.

Indeed, the first quarter of 2019 is looking up, according to Brelsford, who says it was almost the exact opposite of the fourth quarter, adding that all dollars lost have been recouped.

The Foundation and Pavilion connect weekly to discuss the fund, and they meet in person each quarter with the Foundation's Investment Committee. The investment performance calls will coincide with those quarterly meetings.

A recording of the first call can be found at www.PittsburghFoundation.org/legacy-update.

The next call—May 30 at noon—will involve detailed discussion of investment performance for the first quarter of this year, and time will be reserved for questions. Donors wishing to participate can register and receive dialing instructions at the website cited above.



Foundation Executive Vice President Yvonne Maher receives a \$10,000 gift from Rob Cochran at #1 Cochran's holiday luncheon for the #LovelsStronger campaign.



Driven to Give

After the devastating shooting at Tree of Life Synagogue on Oct. 27, The Pittsburgh Foundation's #LovelsStronger Critical Needs Alert received more than 1,000 donations, including a \$10,000 check from #1 Cochran Automotive. Yvonne Maher, the Foundation's executive vice president, attended the company's Dec. 20 luncheon to accept the gift, which aligns directly with the Foundation's effort to expand its corporate philanthropy program.

The holiday lunch tradition at the dealership involves team members selecting a charity to present to the organization at the event. The tragedy at Tree of Life had happened just weeks before, and the team was searching for an organization with a mission of bringing the community together.

"Our team came back and said that we should be giving to The Pittsburgh Foundation's #LovelsStronger campaign," says the dealership's president and CEO, Rob Cochran. The gift is in addition to the company's eight-year tradition of funding a Make-A-Wish® trip for a child with life-threatening medical issues.

The company, which began in 1965 as a small North Braddock-based Pontiac dealership, now has more than 1,200 employees at 30 locations. It's also one of the last family-owned auto dealerships left in the region, which is now dominated by large-volume corporations, Cochran says. That local connection is a factor in the company's giving.

For Cochran and his team, the gift is directly related to their shared values about corporate citizenship, where "you take care of others and they take care of you."

"The culture of community service starts at the very top of our company," Cochran says. "We feel a responsibility to work with our team members to give back to the local communities that support our business. Plainly and simply, it's the right thing to do."

The team has also supported various disaster relief efforts over the years and sends team members to volunteer for nonprofits across the region, including Family House, Junior Achievement, Central Blood Bank (now known as Vitalant), U.S. Marine Corps Toys for Tots, the American Cancer Society, Animal Friends, Butler County Humane Society, Pittsburgh Cares and Toys for Pittsburgh Tykes.



Shari Kienzle owes her life to immunotherapy. She received genetically engineered white blood cells and fought through significant side effects for a month to earn eradication of her lymphatic cancer.

THE FOURTH PATHWAY

**PITTSBURGH FOUNDATION
DONORS ARE THE EARLY INVESTORS
AT HILLMAN CANCER CENTER
WHERE IMMUNOLOGY RESEARCH
IS PRODUCING NEW TOOLS
TO FIGHT CANCER**

Shari Kienzle was running out of chances.

In 2017, after a diagnosis of diffuse large B-cell lymphoma, the most common form of non-Hodgkin's lymphoma in adults, the Canonsburg woman had failed to respond to three rounds of chemotherapy. When her doctors at UPMC Hillman Cancer Center offered an audacious new treatment that would transform her own blood cells to fight back, the 52-year-old liked her odds. "I was scared," admits the mother of three. "But I agreed with my doctors. It gave me a chance."

Hillman is among a select group of U.S. institutions to test new immunotherapy treatments in clinical trials. The breakthrough treatment presented to Kienzle had just become available in Pittsburgh: Chimeric antigen receptor (CAR T-cell therapy) treatment programs the individual's immune system to attack cancer, with astounding results. Early results showed 51% of treated patients experienced complete remission. Kienzle was willing to try to be one of them.



↓ Drs. Patrick S. Moore, the Foundation's endowed chair in innovative cancer research, and Yuan Chang received the 2017 Paul Ehrlich and Ludwig Darmstaedter Prize for discovering two of the seven known human viruses that cause cancer. Both are University of Pittsburgh School of Medicine faculty members.



On April 2, 2018, Kienzle received her genetically engineered white blood cells. Over the next 30 days, her body fought hard, through severe side effects and four days in a coma. On May 2, a scan announced the result: Her tumors had vanished. “It’s a miracle,” she says.

Pittsburgh’s groundbreaking work in immunology — the study of how the body’s immune system can be activated to fight invaders from within — has bettered the odds for patients like Kienzle.

Dr. Robert Ferris, director of Hillman Cancer Center, says the field is in a state of transformative discoveries. Moreover, in addition to surgery, radiation and chemo, immunotherapy is now “a fourth modality” for successfully treating tumors and blood cancers.

“Many diseases are joining the immunology club — including, recently, triple negative breast cancer,” he says. “We’re getting to [therapy] results that double positive response. Now the question is how to combine immunology with other therapies. We almost have to relearn oncology.” Hillman researchers have led the way. Among other breakthroughs, its labs have identified two of the world’s major cancer-causing viruses. Its clinicians are deploying CAR T-cell therapy. Integrating discoveries in genomics and drug development with immunology, researchers are taking giant steps toward realizing the dream of personalized medicine, the type of medical intervention in which treatment is customized for an individual patient.

The weapons are huge. But the local donations that make them possible are large and small. Take the fund created at The Pittsburgh Foundation in 1964 by Portia Hosler, an Alcoa secretary from Avalon who endowed a fund with \$36,000 in 1995 to study pancreatic cancer, among other causes. Or physician Rose Neumann, who honored her parents with the creation of the \$18,000 Marchand Fund in 1964. Or Robert Kohman, whose gift of \$14.5 million in 2003 funds cancer research as well as assistance for patients. A decade ago, the Foundation decided to combine six such funds for early sustained support of experimental research at Hillman.

“Immunology and personalized medicine were the direction that our Board’s subcommittee, which includes physicians, recommended,”

THE FOUR PITTSBURGH FOUNDATION ENDOWED CHAIRS AT HILLMAN CANCER CENTER: (THE FIFTH TO BE NAMED)

Patrick S. Moore, MD, MPH

Distinguished and American Cancer Society Professor

UPMC Hillman Cancer Center & University of Pittsburgh School of Medicine

Pittsburgh Foundation Endowed Chair in Innovative Cancer Research

Adrian Lee, PhD

Director, UPMC/University of Pittsburgh Institute for Precision Medicine

Professor, Pharmacology & Chemical Biology, Women’s Cancer Research Center at UPMC Hillman Cancer Center & Magee-Womens Research Institute

Pittsburgh Foundation Endowed Chair in Precision Medicine

Shou-Jiang Gao, PhD

Director, UPMC Hillman Cancer Center Cancer Virology Program

Professor, Microbiology and Molecular Genetics, University of Pittsburgh School of Medicine

Pittsburgh Foundation Endowed Chair in Drug Development for Immunotherapy

Warren Shlomchik, MD

Director, Hematopoietic Stem Cell Transplant and Cell Therapy, UPMC Hillman Cancer Center

Professor, Medicine and Immunology, University of Pittsburgh School of Medicine

Pittsburgh Foundation Endowed Chair in Cancer Immunotherapy Designate*

*awarding process is currently underway



says Jeanne Pearlman, senior vice president for Program and Policy. “As a foundation, we’re interested in being the early money in a project.” The Foundation’s decision to endow research chairs for new fields’ luminaries has backed researcher’s drive to achieve life-saving breakthroughs, like Kienzle’s.

The local support also buoys Hillman’s international reputation. The group headed by Dr. Patrick Moore, a Hillman virologist who holds one of the endowed chairs, has discovered two of the seven viruses that cause 20% of all cancers. “Together with our other faculty, we have the most expertise in cancer virology,” he says. “We’re definitely a leading center in the world.”

Dr. Ferris agrees. “Pittsburgh has punched above its weight,” he says. “We have vision and tremendous community support.”

Even though Pitt is among the top five U.S. institutions receiving NIH funding, “there’s tremendous competition,” Dr. Ferris says. Focused on immediate applications, the National Institutes of Health can’t fund highly experimental work. “We’ve made an intentional effort to provide discretionary funding that scientists can use to follow their instincts. That realization came eight or 10 years ago. Then we found The Pittsburgh Foundation — a great partner that gives us more bang for the buck. It’s a great marriage.”

Since 2012, The Pittsburgh Foundation has endowed four research chairs at Hillman,

including Moore’s. Dr. Adrian Lee, director of the Pitt/UPMC Institute for Precision Medicine, holds the chair in personalized medicine.


Dr. Warren Shlomchik examines the events that lead to graft-versus-host disease following stem cell transplant in patients with leukemia and related blood cancers. He is the designate for the chair in cancer immunotherapy. In 2018, Hillman welcomed famed cancer virologist Dr. Shou-Jiang Gao, who holds the Foundation’s endowed chair in drug development for immunotherapy.

Hillman is currently recruiting a scientist for a fifth Foundation-endowed chair: Personalized Cancer Therapy Investigator for Innovation and Approach, and Environment.

“Personalized medicine is where the action is,” says Dr. Stanley Marks, chairman of UPMC Hillman Cancer Center. But he acknowledges the challenges ahead. “It’s one thing to identify a genetic mutation. It’s another to identify a drug that will work on it. There are certainly thousands of targets, but we’ve narrowed them down. Our goal is to make cancer a manageable disease people can live with.”

Shari Kienzle has returned to her job as human relations director of a tech recruiting firm headquartered at North Side’s Nova Place. She is living joyfully in remission from her disease and sharing her story with other lymphoma patients. “My motto is: ‘Thank God for today.’ I live every day to the fullest that I can.”

by **Christine H. O’Toole**

 Dr. Warren Shlomchik investigates the biology of transplanting blood stem cells from one person to another. These transplants are usually performed to treat blood cancers. Through his studies Dr. Shlomchik works to improve the safety and effectiveness of these therapies.

ADVISOR
PROFILE

FINANCING A CURE

Moved to act by a brother lost in childhood, financial advisor James “Jim” Beck embraces medical research philanthropy

JIM BECK and his twin sister were born into a family that had been marked by terrible loss, and what he learned would profoundly affect the direction of his life, even to the point of embracing medical research in his personal philanthropy.

On Christmas Day 1951, six years before Jim was born, the family’s second child, Bobby, died of leukemia at age 4. Though the disease had been named by a physician in 1899, treatment was still not widely available in the 1950s, and few people survived leukemia in those days.

When Jim and his twin arrived in 1957 to join two older brothers, the family had begun to work around the loss of Bobby and carve out a home life in Butler County. Jim’s parents went on to have another daughter. Each of the Beck children noted the effect Bobby’s death had on their parents, even years later, and their experience with that explains in part why Beck and each of his four siblings are involved in philanthropy.

As a senior vice president at Hefren-Tillotson, and an approved third-party manager with The Pittsburgh Foundation, Beck, CFP®, CAP®, identifies himself as

◀ Advisor James “Jim” Beck practices what he preaches by sending clients to The Pittsburgh Foundation where he and his siblings have had a fund since 2013.

committed to philanthropy and takes pleasure in helping clients shape their charitable gift-giving and philanthropic efforts.

Offering his expertise as a financial advisor, Beck has served as a national board member of the Leukemia & Lymphoma Society and has devoted much of his adult life to fundraising for the organization. His philanthropy also helps him guide his clients with their giving.

“I help them prioritize and decide how to fit charitable gifts into their plans, because so many people want to give,” Beck says. “We all work hard, but not everybody goes from rags to riches and can give millions. Still, even those who don’t think they have the means to give might be surprised to learn that they can. When you’re successful, it’s incumbent upon you to give back to society in some way.”

For Beck and his four siblings, philanthropy began with their parents, who encouraged generosity. The John and Frances Beck Family Foundation was founded as a private foundation after Frances’s death in 2001. It was made part of The Pittsburgh Foundation in 2013.

In the nearly two decades that the Beck Fund has been operating, more than \$972,000 in grants have been made to numerous organizations, including medical research grants to the Leukemia & Lymphoma Society, Children’s Hospital of Pittsburgh Foundation for depression research and Juvenile Diabetes Research Foundation International. The fund has also supported food banks, veterans’ services and churches. In 2015, members of the Beck family were part of the Foundation’s Alzheimer’s and Dementia Impact Giving Circle, which raised \$80,000.

Mary Jane Ritter, the youngest of the siblings, says the way the fund is set up allows the five of them to maintain contact and work together. Each quarter, they have a conference call to decide, as a group, where money goes. They also each have a set amount for their individual interests. She says the collaborative way in which she and her brothers and sister manage the fund would make her father proud.

“Dad was president of a subsidiary of Pennzoil and was very involved with the community and very generous,” Ritter says. “It’s a privilege for us to be able to put the money our parents left us to good use.”

For Jim Beck, philanthropy comes down to dreaming about what is possible and trying to make it reality, particularly when he’s recommending The Pittsburgh Foundation to his clients.

He recalls that in one of his first meetings with a client and the Foundation’s executive vice president, Yvonne Maher, the client was interested in funding a golden retriever guide dog program. “Yvonne asked my client, ‘What do you want to fund when we cure blindness?’ And that was so striking. It showed me how forward-thinking philanthropy is.”

What about when cures are found for leukemia and lymphoma? Beck says he would focus on funding research to develop vaccines for blood cancers and other solid tumor cancers.

“I’d watch my mom cry at Christmas, and if there is any way I can keep that from happening to some other young mother, I’m willing to give a lot.”

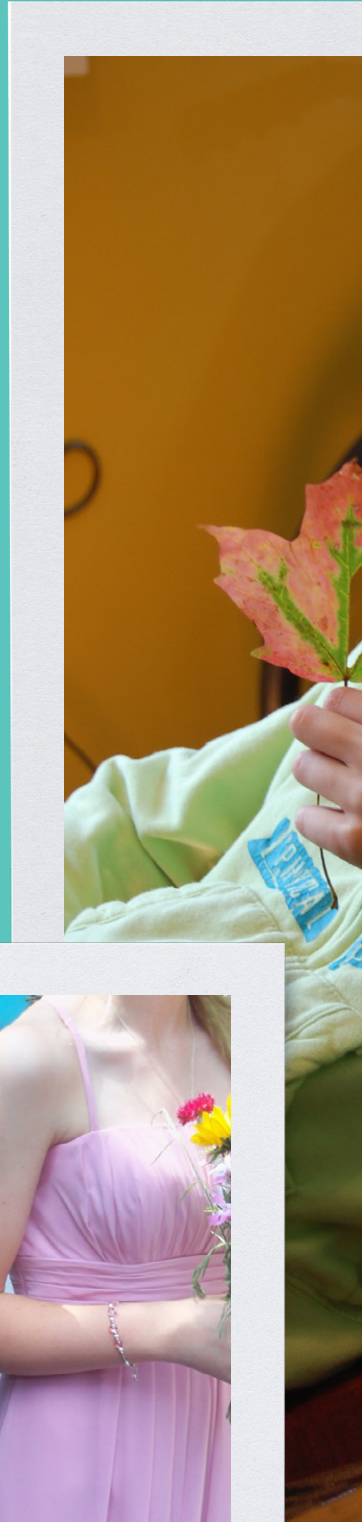


**We all work hard,
but not everybody
goes from rags
to riches and can
give millions. Still,
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that they can.**

JIM BECK

by **Deanna Garcia** | communications officer

PAYING IT FORWARD





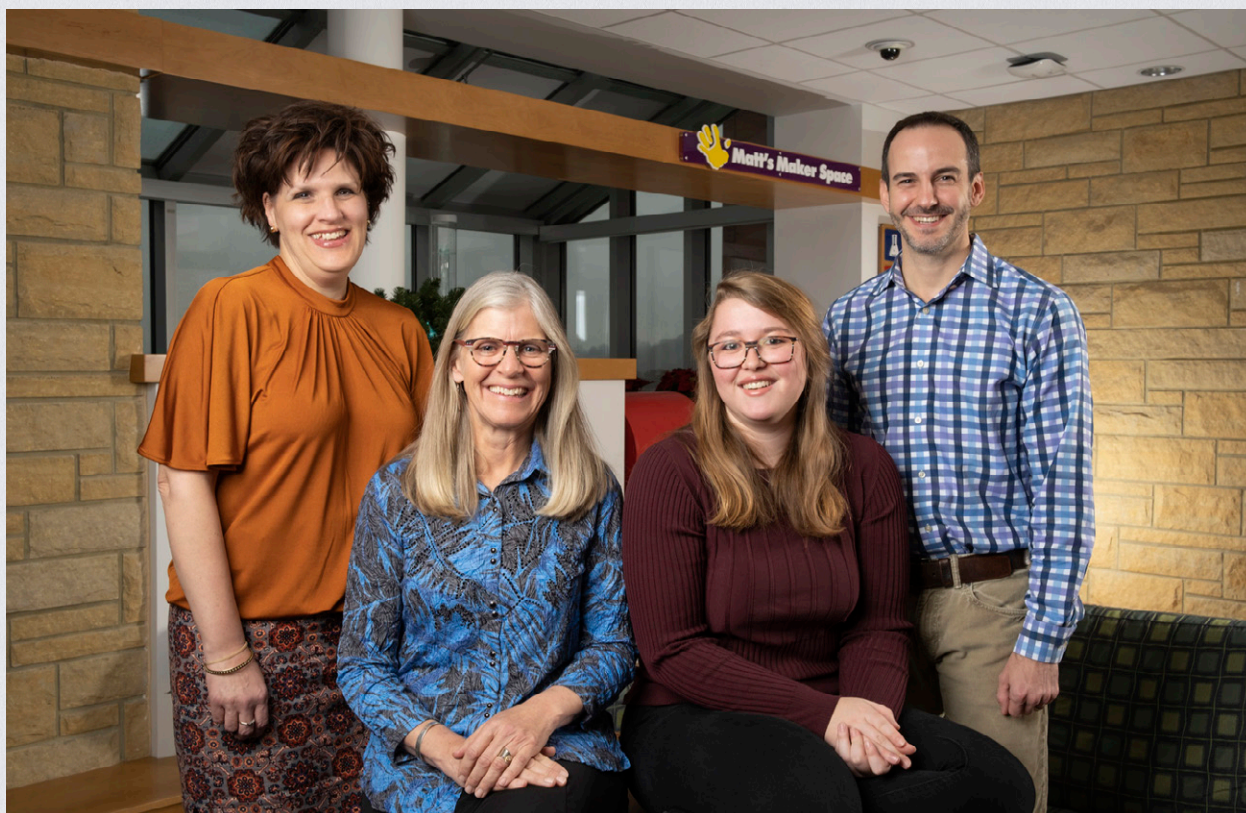
◀ LEFT: Maggie Elder, 10, holds a bouquet at the 2010 wedding of her mother, Cyndi, to Jim McGinnis. Exactly one year later, Maggie would be battling cancer. ABOVE: This leaf with a heart inside, which Maggie found in the fall of 2011, became an emblem of faith and love for her entire family.

ON SEPT. 7, 2011, Maggie Elder wrote in her journal, “Today has been a day of 1,000 tears. Today has been a crying day for me, although I’m not sure why... Mom also says those are healing tears and to just let it flow out of me... Tomorrow will be better.”

Maggie, 11, had been diagnosed in July with stage four Ewing’s Sarcoma, a rare bone cancer, and had spent three months shuttling from Ligonier to UPMC Children’s Hospital of Pittsburgh with her mother and stepfather, Cyndi and Jim McGinnis. Maggie would spend a week at a time in the hospital for treatments and then head home to recover. It was grueling and terrifying. The family turned to Carol May, founder and manager of the Supportive Care Program at Children’s, for guidance through an unthinkable situation.

The Supportive Care Program—which oversees treatment, provides pain management, guides family members, and helps them manage their hopes and fears—became the family’s anchor. May and the team were especially helpful in providing emotional support to Maggie’s 13-year-old sister, Mackenzie, and helped the entire family manage their anguish as Maggie’s illness progressed.

May, who became familiar with hospice at age 17 when her grandfather died at home, has dedicated her career to helping people die with grace and dignity. She earned three advanced degrees in nursing and management, working in adolescent oncology and running a hospice program in Michigan before returning to



Pittsburgh 15 years ago to establish Supportive Care, one of only five such programs based at children's hospitals in the country.

The young patients and their families are wrapped in a cocoon of care that begins with medical treatment and extends to emotional support for the loved ones of children who do not survive. Program staff are currently following about 1,200 families who have lost children over the past 10 years. The goal is to improve pediatric palliative care.

"The program provides a space to deal with the most horrible thing imaginable," May says. "We work with families on how to honor and meet their cultural and religious needs, so that their child is comfortable and understands what's happening."

For Cyndi McGinnis, the program's groundbreaking work eased what would have otherwise been unbearable.

"They made it a point to understand what we value most," she says. "They knew we are a faith-driven family and they honored that. They

They made it a point to understand what we value most. They knew we were a faith-driven family and they honored that. They knew we wanted to get Maggie home and they made it happen.

CYNDI MCGINNIS

← Carol May (far left), who has three advanced degrees, including nursing, founded the Supportive Care Program at UPMC Children's Hospital of Pittsburgh. She manages it with Scott Maurer, MD, who oversees palliative care at the hospital and also sees oncology patients. May and Maurer are pictured here with Maggie Elder's mother, Cyndi McGinnis, and sister, Mackenzie Elder.

knew we wanted to get Maggie home and they made it happen. Maggie got to spend five weeks at home on hospice care before she died.”

Their care for Maggie continued as she transitioned to home hospice.

“Once we got her home, pain management was a big piece,” McGinnis says. “Carol was on the phone with us every day helping to adjust medications because managing pain in children is completely different than for adults. She drove 70 miles each way to visit with Maggie. They even managed to get us out on a Make-a-Wish® family ski trip a month before Maggie died.”

While families say the value of supportive care services is immeasurable, only a fraction of the costs — May estimates 15% — are reimbursable under health insurance. The program relies on funding from hospital administrators who believe in its mission, philanthropies that see the benefit, and communities like Maggie's, who organize fundraising events.

After Maggie's death in February 2012, the family used money raised from a series of road races and wristband sales to establish the Miracles from Maggie Fund at The Community Foundation of Westmoreland County. To date, \$130,500 has been donated, including \$100,000 from the CFWC fund, to establish an endowment that now provides a permanent funding source at the hospital for the program that meant so much to Maggie and her family.

That endowment helps to fund research into new palliative- and bereavement-care methods to improve quality of life for children facing life-threatening medical conditions. The research is meant to guide other hospitals in establishing their own supportive care initiatives. Under the direction of Dr. Scott Maurer, an oncologist who oversees palliative care, the program publishes its research findings in medical journals and presents at national and international meetings. The researchers' biggest initiative to date is the Pediatric Patient-Reported Outcomes study, a project involving care teams and families at hospitals and universities in five cities.

“To study symptom control and quality of life in children who are undergoing cancer-related therapy, we've developed a tool to allow children as young as age 7 to report their own symptoms, including those as complex as depression,” Maurer says. “The goal is to give children a voice by asking them directly instead of going through parents or caregivers.”

The team is also studying the intersection of spirituality and medicine and how spiritual distress — a common occurrence in life-threatening medical crises — affects overall quality of life. They also teach pediatric residents and medical students how to communicate with families and listen compassionately when sharing bad news. Cyndi McGinnis and other parents who have benefited from Supportive Care share their experiences with second-year residents. Mackenzie Elder, now 21 and pursuing her bachelor's degree and soon her master's in social work at the University of Pittsburgh, speaks at the program's annual memorial service for families. She also serves as a counselor at the program's overnight camp for bereaved siblings.

The pay-it-forward volunteerism gives comfort to their family, McGinnis says.

She remembers the motto that Maggie created to help her through the journey: “Faith can crush fear.’ She really left a blueprint for how to live. It would just make her heart so happy that we're able to continue helping other people in her memory.”

by **Kitty Julian** | director of communications

To make a gift to the Miracles from Maggie Fund for the Supportive Care Fund, visit miraclesfrommaggie.org or pittsburghfoundation.org/Miracles-from-Maggie. More information about the Supportive Care Program is available at chp.edu/our-services/supportive-care.

CAROL MASSARO ALWAYS EXPECTED THAT HER FAMILY'S PHILANTHROPY WOULD SPEED RESEARCH TO CURE ALZHEIMER'S DISEASE

A LASTING LEGACY

CAROL MASSARO WAS SICK, her lungs weakening. But even in the months before she died, on Dec. 27, 2018, she was out raising money for the Joseph A. Massaro Jr. Alzheimer's Research Fund at The Pittsburgh Foundation — the charity she started in memory of the love of her life. “She worked on it to the end,” says the couple's daughter, Linda Massaro.

Linda marvels at her mother's determination to fight the disease that took her husband, even as she was dealing with the effects of interstitial pulmonary fibrosis at 79.

Carol established the fund in 2014, four years after her husband received his diagnosis of Alzheimer's disease. When the memory lapses started, Joe used a notebook to supplement his failing memory on details of daily life. For a while, that simple strategy was enough, but as the months went by, his memory declined more rapidly, and he started to mix up words. He became lost while driving, and he struggled to remember the names of several longtime employees at his construction company.

Each piece of evidence of her husband's diminishment hit Carol like a physical blow. She had him try every possible

treatment—hyperbaric oxygen therapy, which is thought to heal the brain through the inhalation of 100% oxygen in a total body chamber; nicotine patches, which had shown some benefit in patients with mild dementia in small studies; and even coconut oil, which some people believe can either help reverse or even stop the progress of the disease, though this is not backed by any scientific evidence.

Joe, who had been widely known for his dynamic personality and quick-witted engagement with his four children, failed to respond to any of the treatments. Carol's sadness turned to outrage—and then action. “She was so angry that there was nothing we could do about it,” Linda says, “and moreover, she was shocked at the lack of resources and information available for the hundreds of thousands of families caring for patients with this disease.”

Some 5.7 million Americans have Alzheimer's, and by 2050, as people live longer, the number is projected to be 14 million, according to the Alzheimer's Association.

People with Alzheimer's have two types of critical pathological lesions in their brains. Amyloid plaques, which are clumps of proteins normally deposited outside the



Drs. William E. Klunk, left, and Oscar L. Lopez, who is also a professor of neurology, direct the Alzheimer Disease Research Center at UPMC.

neurons, and neurofibrillary tangles, which are deposits of tau proteins localized inside the neurons. Scientists have identified an excess of these plaques and tangles in the brains of Alzheimer's patients, but they have not yet determined why they develop in the first place.

This is why further research is so important, and why Carol wanted to help fund it. From 2015 to 2018, the fund contributed \$893,000 to innovative Alzheimer's research in Pittsburgh.

When Japanese researchers published a paper in February 2018 announcing development of a simple blood test to detect Alzheimer's, Dr. Nathan Yates, a chemist at the University of Pittsburgh Alzheimer's Disease Research Center, wanted to replicate it. He met with Carol and her children about the study, and in May received \$100,000 to jump-start the project.

Yates says the money from the Massaro Fund enabled his lab to start testing patient samples six months after he proposed the study. "This could revolutionize the treatment and screening of Alzheimer's disease," Yates says. "Developing an inexpensive and accurate test for Alzheimer's disease has been the Holy Grail of research." He shared the early promising results with Carol.

"She was always excited to know how things were going," he says. "She was passionate about making a difference and generous enough to use her resources."

Fueled by a passion for the cause and blessed with an ebullient personality, Carol became a superstar fundraiser for Alzheimer's research. "Carol could chat with anyone, and her story would encourage others to share their stories," says Kelly Uranker, director of the Center for Philanthropy at The Pittsburgh Foundation.

The Longest Table, a dinner party fundraiser, drew 450 people its first year. "Carol was magnetic. She had this charismatic smile and this twinkle in her eye," says Carol Kinkela, who owns Carabella, a women's clothing store in Oakmont, and worked with Carol to organize the event three times. The Massaro family held other fundraisers as well.



While Carol always ensured that the events were entertaining and engaging, friends and family say it was always front-of-mind with her that many of the attendees were escaping the havoc Alzheimer's causes for their loved ones and for themselves as caregivers. In her own life dealing with the disease, Carol was fortunate to be able to have home health aides help her in tending to Joe at the couples' residence in Oakland. "She had a tremendous amount of empathy for those who were the sole caregivers for their loved ones," Uranker says. Last year, the fund awarded a \$10,000 grant to the Alzheimer's Caregiver Conference in the Pittsburgh region.

Other Joseph A. Massaro Jr. Alzheimer's Research Fund grants include \$75,000 to support Dr. Edward Allen Burton's research at the Pittsburgh Institute of Neurodegenerative Diseases in the Department of Neurology at the University of Pittsburgh; \$50,000 to fund research by Dr. Alberto Vasquez at the University of Pittsburgh Medical Center; \$25,000 for Allegheny Health Network's Neuroscience Institute's memory disorder clinic; and \$35,000 to Pittsburgh Lifesciences Greenhouse for a new piece of equipment aiding in cognition therapeutics research.

For all her philanthropy, Carol was most passionate about helping to find a cause for Alzheimer's. As her daughter Linda says, "We learned that every family has a story to tell about the devastation it leaves behind. We need to find the cause and cure."

by **Cristina Rouvalis**



Joe and Carol Massaro at home in 2010

RESEARCHING A RARITY

PASSED OVER BY LARGE RESEARCH FUNDERS DUE TO THEIR SMALL NUMBERS, SICKLE CELL ANEMIA PATIENTS ARE FRONT-OF-MIND IN A PITTSBURGH FOUNDATION GRANT TO SPEED DEVELOPMENT OF BREAKTHROUGH THERAPIES



Sickle cell disease results when genetic mutations cause red blood cells to become misshapen and clog blood vessels, leading to searing pain.

HOW CAN WE TELL THAT SOMEONE HAS SICKLE CELL ANEMIA?

That's a mystery without an easy answer. The dysfunction and malformation happen deep below the body's surface. Those who have the disease, a genetically passed-on condition that causes red blood cells to become misshapen, clogging blood vessels and depriving organs of oxygen, bear no outward markers. And the disease itself can't be detected by the standard diagnostic tools.

The pain mimics other chronic conditions. It is searing; it comes in waves and it is often centered in joints and bones. Known as a sickle cell crisis, the pain can be so severe that a person having an episode often must be hospitalized.

And there are many false assumptions about the disease. Because of the severity of the pain, opiate analgesics often must be prescribed for relief. Health care professionals unaware of the disease often mislabel sickle cell patients as addicts in search of drugs for themselves or to sell on the streets.

Another is that, despite statistics showing that people with sickle cell come from every socio-economic level, people who have it are often presumed to be at the bottom.

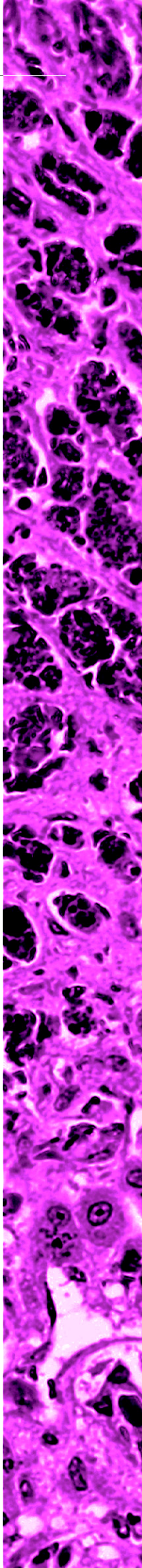
Because sickle cell is on the list of medical conditions known as "orphan diseases," meaning those that have not been adopted by institutional researchers or the pharmaceutical industry due to the small numbers of people who would benefit, the disease has remained a scourge since it was discovered in 1910.

Ignoring those numbers and stepping into that breach is The Pittsburgh Foundation, which has awarded a \$500,000 grant to boost potentially ground-breaking investigations at the Vascular Medicine Institute of the University of Pittsburgh's School of Medicine, one of the centers working against the backdrop of the National Institutes of Health to develop a pathway to a cure.

Created a decade ago, the Institute is now directed by Dr. Mark Gladwin, who also leads the university's Division of Pulmonary, Allergy and Critical Care Medicine and serves as the chair of the Department of Medicine. He has recruited a team of experts from various medical disciplines to spearhead hemolytic research into sickle cell. The immediate goal, he says, is to develop a noninvasive technique for detecting the source of disease flare-ups at the molecular level.

"One fundamental problem related to [sickle cell] pain crisis is that it is not visible," says Dr. Enrico Novelli, a medical oncologist and hematologist who leads the sickle cell team at VMI. "People may be in pain, but there's no outward, physical sign that can be seen by medical providers."

In the United States, the overwhelming number of the estimated 100,000 residents with the disease are African American. One in every 13 Black children is born with the genetic trait, a mutation traced thousands of years back to sub-Saharan Africans' adaptation to malaria outbreaks.





“One fundamental problem related to sickle cell pain crisis is that it is not visible. People may be in pain, but there's no outward, physical sign that can be seen by medical providers.

DR. ENRICO NOVELLI

Key drivers of the team's research are the recent breakthroughs in nuclear medical tracers and advanced studies utilizing laboratory mice. Dr. Carolyn Anderson, a professor in the Department of Radiology whose expertise includes translating mouse studies into medical protocols appropriate for people, believes that the researchers are very close to being able to accurately and rapidly image the actions that cause sickle cell pain at the molecular level.

“The important thing about this grant is that it is bringing together people like myself and Enrico, who is a clinical medical doctor,” Anderson says. “In nuclear medicine, we image the biochemistry and physiology, so it's a very active process. Changes that happen at a molecular level happen long before you can see changes on an anatomical level.”

Novelli says that a complex network of players is essential to continued progress. “We now have therapies—drugs that target these molecules and these events.”

Because of the research with mouse studies, he says, “there has finally been a revolution in sickle cell disease research. We are on the cusp of a cure by way of treatment that would become widely available.”

The researchers say that The Pittsburgh Foundation grant will move the work more quickly from mouse models to humans. Upcoming multi-center clinical trials will enlist African American adults in western Pennsylvania, Ohio and West Virginia to test the accuracy of the methodology developed at the institute. While about 500 people are currently referred to UPMC for treatment, not all of them will be part of the study.

“If this project is successful,” Novelli says, “it will lead to a better understanding of the disease in humans and restore credibility to the patients who present with pain, and it will improve the relationship between health care providers and patients. It has far-reaching consequences.”

by **Tony Norman** | columnist at the Pittsburgh Post-Gazette

STAFF
PROFILELIFELONG
LEARNING

Mallory Reese

Mallory Reese joined The Community Foundation of Westmoreland County in July 2018.



WESTMORELAND COUNTY NATIVE MALLORY REESE has built a career that merges her appetite for lifelong learning, business and fundraising to help others fulfill their philanthropic passions. Her own passion for the work serves her well in her position as the development and donor services officer at The Community Foundation of Westmoreland County.

Even as a student at St. Vincent College, Reese was determined to shape her education according to the inter-relationships she saw emerging in the sectors of business, information technology and education. After changing her major three times, Reese's professors introduced her to a new curriculum that combined those fields. At the time, only she and another student enrolled in the program. She graduated in 2010 with a degree in business education information technology, a K-12 teaching certificate, and enough business credits to enter the field of corporate training.

After graduation, Reese landed a position as the sole fundraiser at Valley School of Ligonier, where she supported its mission of educational excellence and soon became director of development. She earned her master's degree from St. Vincent in educational media and technology. In 2016, Reese left Valley School to join the staff of the Diocese of Greensburg to raise funds for its Catholic schools. The Diocese soon tapped her to reinvigorate the advancement program at Greensburg Central Catholic High School.

When a position opened at the Foundation last year, Reese understood that it was an opportunity to improve lives on a much greater scale.

At CFWC, Reese combines her love of teaching, her business background and her fundraising savvy to help donors discover their philanthropic interests and goals. She uses her knowledge of different learning styles to guide donors and build relationships in the larger community. The most important part of her job, says Reese, "is to listen carefully to people's stories and understand what is most important to them in terms of how they want to contribute to the community around them." One area that is especially rewarding, she says, is helping families establish funds that inspire the younger generation to give back, particularly when they memorialize loved ones.

"Every day, I am able to help our donors make meaning out of circumstances that are often extremely difficult," says Reese. "It's my responsibility to create a structure for them to give back. Our donors give me the opportunity to be a part of something that has so much impact on a larger population and an infinite amount of potential. I feel so lucky to have found the Foundation, and I'm grateful for all of the experiences that have led me to it."

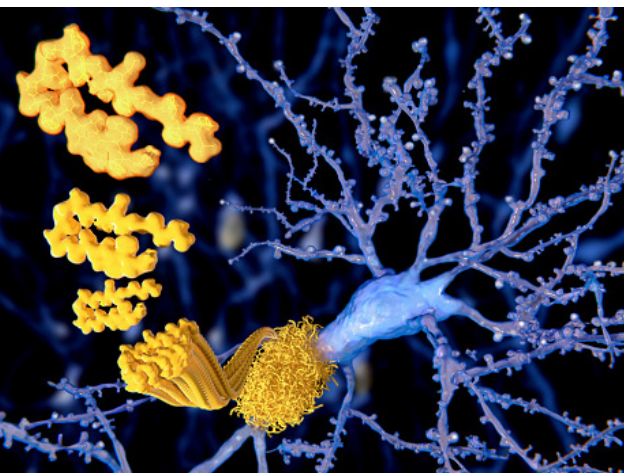
by **Aubrey Marquis** | Youth Philanthropy Program Manager,
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Scientists do not yet know why excess amyloid plaques, depicted here in yellow, develop in the brains of people with Alzheimer's disease. Story on p. 14.

NEW FUNDS January 1, 2019 – March 30, 2019

Aros Sokol Family Fund
Pat Chew and Robert Kelley Family Fund
Sherle and Michael Berger Charitable Fund
Kramer Family Fund
Wysor Wassmann Fund
Lambert Family Charitable Fund
Sieminski Family Fund
James G. Meredith Fund
Eugenio R. Ricci and Rose DeNapoli Scholarship Fund
Kenneth and Kay C. Neuhausen Fund
Lori Trautwine Dollard Charitable Fund
Rebecca Nicole Sefscik Memorial Fund
End Food Insecurity Fund
Starck Family Foundation Fund
Scherrbaum Family Charitable Fund
Joseph L. and Elsie Meyer Fund
Frembgen Petersen Fund
James Myers Designated Fund
Livingston Family Fund of South Carolina
R.P. Simmons Family Fund

Klinvex Family Fund
Salvatore and Diana Tresco American Dream Scholarship Fund
Greg and Audrey Bisignani Family Charitable Fund
Horne Family Fund
Stalder Family Trust Fund
Shady Lane Budding Scholar Fund
Sherwood & Shawna Johnson Charitable Fund
Bovard Family Fund
Mike Yuhar Memorial Fund
Wallace Scholarship Fund
Spiardi Fund
Excelsior Fund
LVE/ J. David and Pat J. Piper Family Fund
Diana Greco Manley Fund

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