Making a Difference

Annual Report of Donors

UMass Medical School and UMass Memorial Health Care



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this annual report and a complete list of FY15 donors are available online at

www.umassmed.edu/donor-recognition



thank you from the leadership

It is with great appreciation that we present this annual report of donors for the 2015 fiscal year.

ithin these pages, you will find stories that highlight and celebrate some of the many charitable efforts made this year by friends, corporations, foundations and community groups in support of the life-saving work being conducted by our two institutions—UMass Medical School and UMass Memorial Health Care.

Your remarkable generosity has helped us advance our critical mission areas in education, research and patient care. Through philanthropy, we have been able to upgrade facilities and purchase stateof-the-art equipment; fill key clinical, faculty and research positions; endow scholarships; fund clinics; provide quality, patient-centered health care services here at home and across the world; and delve deeper into research that may, one day, lead to better treatments, and ideally cures, for a variety of diseases such as ALS, Huntington's disease, cystic fibrosis, cancer and diabetes, among many others.

As you well know, our academic health sciences center is a special place. It is a place where the well-being of others is put above all else. It is a place where people work collaboratively each and every day to improve the health of our local and global communities. It is a place where making a difference is an institutional value and a personal responsibility.

By supporting our efforts to educate tomorrow's health care workforce, conduct groundbreaking research and deliver quality health care services, you are also making a difference. You are empowering us to achieve and exceed our goals in support of our shared mission and inspiring us to reach even higher in our aspirations to improve the health and well-being of all. You are also sending a powerful message about the importance of the work we undertake to positively impact the health and well-being of people here at home and across the globe.

Thank you for your generous support and for your belief in our work.

Michael F. Collins, MD

Chancellor

University of Massachusetts Medical School

Senior Vice President for the Health Sciences University of Massachusetts

Eric W. Dickson, MD, MHCM, FACEP President and CEO UMass Memorial Health Care

healing in time

Donors support music therapy for pediatric patients

toddler bangs on a drum. A teenager sings a Top 40 tune with new lyrics she's written to express something personal. A shy young boy is drawn out and dances while his new friend plays the guitar. In a place where tears and fears are all too common, the music therapy program at the UMass Memorial Children's Medical Center (CMC) brings smiles and harmony to many patients.

It is a program made possible only by philanthropy. This year, music therapy will continue to be a part of the care delivered at the medical center because of leadership gifts made by Carol and Michael Sleeper of Worcester and another local couple who wish to remain anonymous.

Above: Trish Jonason conducts a music therapy session with Audri, a pediatric patient.



"We have a special spot in our hearts for pediatrics," Michael said. "Carol and I both feel blessed that we have three healthy children, but we know people who have not been as fortunate. Seeing what those families have gone through inspired us to do what we could to help children heal. That's been our focus with this annual donation." "These children have no control over what's happening to them, and that makes them feel scared and powerless... I become an instrument for them. They are in control, and that makes all the difference."

Through their family-owned business, Imperial Distributors, the Sleepers have partnered with the CMC for 13 years, making annual donations to support a range of services and programs. In early 2015, the Sleepers and an anonymous donor couple responded to a need for the music therapy program, which was first launched in 2013 because of the generosity of another anonymous donor couple.

"We are so thankful for the Sleepers and the other families who have made it possible for us to have this therapy program," said Melissa Luman, manager of the CMC's Child Life Program. "Music is an important part of what we can offer children who find themselves hospitalized."

The program is delivered by Trish Jonason, a board certified music therapist. Currently, she's in the CMC twice a week and can see four to five patients each day, one-on-one, based on a referral from the patient's nurse or physician.

"These children have no control over what's happening to them, and that makes them feel scared and powerless," Jonason said. "So my first step, always, is to ask each child what music they like and how they want to work together. I become an instrument for them. They are in control, and that makes all the difference."

Jonason may play songs requested, or together she and the patient may listen to recorded music. Patients may sing along, or keep time with rhythm instruments like drums, maracas or tambourines. If she sees a patient for multiple sessions, they may write music or lyrics together. Often, Jonason will give willing patients guitar lessons.

"I get to spend 45 minutes with each child—a monumental amount of time in the clinical setting," she said.

According to Luman, the positive effects of music therapy are multifaceted. It can help relieve stress and can foster cathartic emotional expression. The muscular control needed to play simple instruments is a form of physical therapy for some children. Furthermore, said Jonason, when music brings out otherwise withdrawn patients, they often communicate better with the entire care team and that can lead to better outcomes.

For the Sleepers, supporting the music therapy program was an easy choice. "It's another example of the extraordinary range of care provided to the community by the Children's Medical Center.

"When I was a kid growing up in Worcester, this was still an industrial city," Michael said. "Worcester is now an international leader in biomedical research, medical education and clinical care. The impact that this medical school and hospital system have had on our community has been tremendous. Carol and I feel privileged to be able to support the UMass Memorial Children's Medical Center." ◆

For more information about the Child Life Program at the UMass Memorial Children's Medical Center, visit http://bit.ly/umassmemorial_child_life.



five new endowed funds established at UMass Medical School



Generous benefactors support faculty research and community service programs

ndowed funds are widely considered to be essential for any institution of higher education as they serve to sustain valuable programs and initiatives that make a notable and lasting impact. They provide exceptional faculty and programs with the financial flexibility to pursue novel research ideas that might otherwise take years to get funding through traditional avenues. Extraordinary investments like these demonstrate the value generous benefactors place on the work being conducted.

In FY2015, substantial gifts from local and international benefactors established a fund for community service programs and created four new endowed chairs, bringing the number of endowed positions at the University of Massachusetts Medical School to 41.

Pillar Chair in Biomedical Research

Established in the spring of 2015 by the Pillar Group, a global investment firm committed to partnering with world-class researchers and clinicians to support pioneering biomedical research in the fields of innate immunity and gene therapy. According to Chancellor Michael F. Collins, the Pillar Group's approach to partnering is deliberate, rigorous and strategic, and is underpinned by one standard: excellence.

"With a keen intuition, discerning eye and clear vision, the Pillar Group invests in the best," he said. "Through the creation of this endowment, it made an unequivocal statement that UMass Medical School is among the best."



Douglas T. Golenbock, MD

Douglas T. Golenbock, MD, professor of medicine and microbiology & physiological systems and chief of the Division of Infectious Diseases in the Department of Medicine, was named the inaugural recipient of the Pillar Chair in June 2015.

"An internationally recognized authority in the field of innate immunity, Dr. Golenbock studies microbial products in innate immune activation, and his laboratory was one of the first in the world to study Toll-like receptors," said Chancellor Collins. "He has authored or coauthored nearly 250 peer-reviewed articles, holds one patent and has five additional pending. Since joining the Medical School faculty in 2001, Dr. Golenbock has transformed the division into one of the strongest in the nation, which includes nearly 50 clinicians and researchers."

Remillard Community Service Fund

Established by the Remillard Family Foundation, which has been a staunch supporter of UMass Medical School and UMass Memorial Medical Center—most notably for a \$10 million donation in 2005 to the UMass Memorial Emergency Care Campaign. This new gift, made in March 2015, aligns with the Medical School's public service mission and will support a range of community initiatives, exemplifying the Remillard family's forward-thinking philanthropic vision and steadfast commitment to the academic health sciences center and the region.

"Our faculty, employees and learners are extremely dedicated in their daily efforts to improve the health and well-being of our local communities, and that commitment often extends beyond their regular dayto-day responsibilities," said Collins. "Whether they are providing safety education, implementing children's wellness and protection initiatives, delivering health care services in low-income neighborhoods, exposing young students to STEM education and career opportunities, or providing services for area seniors, our people understand that we have a special responsibility to undertake efforts that serve the public good. This innovative Community Service Fund will provide critical resources to help support and advance such efforts."

Stoddard Chair in Pediatrics

Established in the spring of 2015 by the Stoddard Charitable Trust, a philanthropic foundation created



Mary M. Lee, MD

in 1939 by Worcester businessman and entrepreneur Harry Stoddard. Its interest in supporting an endowed position for the chair of pediatrics at UMass Medical School stemmed from the strong desire of its trustees to ensure the long-term health and well-being of children in Central Massachusetts.

"The Stoddard Charitable Trust's most recent investment in our institution not only connects two prominent Worcester organizations that share a common goal of improving the well-being of our communities, but also links Worcester's storied past with its shining future," said Collins. "While the Trust is rooted in this city's famed manufacturing base, through this endowed chair it is rooting for Worcester's new innovation economy, marked by a growing cluster of higher education, life sciences and health care institutions."

Mary M. Lee, MD, professor and chair of pediatrics, professor of cell & developmental biology and physicianin-chief of the UMass Memorial Children's Medical Center, was named as the inaugural recipient of the Stoddard Chair in June 2015.

"Dr. Lee is among the most accomplished physician-scientists in the nation," said Collins. "In addition to overseeing the Department of Pediatrics and maintaining a pediatric endocrine practice, Dr. Lee researches environmental health and the mechanisms contributing to juvenile diabetes and other pediatric endocrine disorders. Her tireless work and scholarly contributions include authoring or co-authoring more than 80 peer-reviewed articles and 45 editorials, reviews and book chapters, and have earned her key roles in leading professional organizations."



Katherine F. Ruiz de Luzuriaga, MD

UMass Memorial Health Care Chair in Biomedical Research

Established in November 2014 by UMass Memorial Health Care, the largest health care system in Central and Western Massachusetts and the clinical partner of UMass Medical School.

"The establishment of the UMass Memorial Health Care Chair in Biomedical Research recognizes and celebrates the interrelated and interconnected nature of our education, research and patient care missions," said Collins. "UMass Memorial Health Care's generous donation is not merely an investment in one faculty member, mission area or even one institution. Rather, it is an investment in our joint enterprise and the future of our academic health sciences center."

Katherine F. Ruiz de Luzuriaga, MD, professor of molecular medicine, pediatrics and medicine; vice provost for clinical and translational science and global health; and director of the UMass Center for Clinical and Translational Science is the inaugural recipient of the UMass Memorial Chair.

One of the nation's leading physician investigators in academic medicine, Dr. Luzuriaga has conducted research that has provided key insights into viral and host factors that result in persistent viral (HIV, EBV, CMV) infections in children. She has been active in translational research that led to new ways to diagnose and treat pediatric HIV-1 infection and she led the first trials that demonstrated that early infant therapy markedly limits the establishment of HIV reservoirs. Luzuriaga has held several leadership positions within the U.S. National Institutes of Healthsponsored Pediatric AIDS Clinical Trials networks and currently serves on the NIH NCATS-CTSA Steering Committee. As the founding director of the UMMS Office of Global Health, Luzuriaga has taken a leadership role in several global health initiatives, including the Medical School's Liberian Ebola relief project funded by the Paul G. Allen Family Foundation (see story on p. 22).

Worcester Foundation Chair for Biomedical Research

Made possible by prudent investment of the Worcester Foundation for Biomedical Research (WFBR) endowment, which has been used to support research by UMMS faculty since the WFBR merged with UMMS in 1997. The second endowed chair supported by the WFBR, it was established in November 2014.

"The Worcester Foundation for Biomedical Research Chair celebrates the scientific legacy of its founders, Hudson Hoagland and Gregory Pincus, as well as the legacy of hundreds of influential and forward-thinking leaders in this region, who endowed and supported the WFBR and who encouraged imagination, vision and above all, that fire of discovery," said Collins. "We are deeply grateful for the WFBR and its legacy of supporting impactful research."

Gyongyi Szabo, MD, PhD, professor of medicine, vice chair for research in the Department of Medicine, associate dean for clinical and translational science and director of the MD/PhD Program is the recipient. An internationally recognized leader in the field of liver disease, Dr. Szabo conducts research that focuses on mechanisms for regulation of immunity and inflammation in liver diseases, including alcoholic and non-alcoholic fatty liver disease and viral hepatitis. Her work has led to a more thorough understanding of viral hepatitis, alcoholic liver disease and non-alcoholic steatohepatitis. Further, she has made seminal advances in the role of miRNA and innate immunity as they apply to various liver diseases, and she has worked to bring new therapies for liver diseases to the clinic. Szabo's leadership among esteemed peers around the world is evidenced by her induction into the Hungarian Academy of Sciences in October 2014. She also serves as the president of the American Association for the Study of Liver Diseases. \blacklozenge



Gyongyi Szabo, MD, PhD

Community-driven fundraising events *raise nearly \$500,000 for academic health sciences center*



G olf-a-thons and golf tournaments. 5Ks and fun-walks. Karaoke, car races and a tribute road race. Even a facial hair competition. These are just a few of the 63 fundraising events that were organized by members of the Worcester and Central Massachusetts communities in FY2015 to support various programs at UMass Medical School and UMass Memorial Health Care. The funds raised by these events, which were held between July 1, 2014, and June 30, 2015, totaled nearly \$500,000 and play a critical role in propelling innovative education, research and patient care, and enhancing community awareness of the need for clinical and scientific medical advances.

Above left: Sapna Krishnan, owner of the Lasya School of Dance, raised \$10,000 in memory of her mother who died of pancreatic cancer in India. To celebrate the school's 10th anniversary, she held a show at Ashland High School in October 2014 where dancers performed bharatanatyam, an Indian classical dance.

Above right: Whiskered Wonderland held its third annual event in March 2015 to support the Child Life Program at UMass Memorial Chidren's Medical Center. Photo by Studio Lovina.



Chancellor Michael Collins and Chair and Professor of Neurology Robert H. Brown Jr., DPhil, MD, took the "Ice Bucket Challenge" on Aug. 6, 2014, with first-year medical students and members of Dr. Brown's lab dousing them to raise awareness of ALS.

Areas that benefited substantially from these community-based efforts include:

Breast cancer research and patient care 15 events raised nearly \$43,000

Pancreatic cancer research and care 12 events raised nearly \$129,000

UMass ALS Cellucci Fund, benefiting ALS research

Five events, including the 2015 Boston Marathon, the inaugural Gov. Cellucci Tribute Road Race (see story on p. 15) and efforts fueled by the 2014 ice bucket challenge phenomenon raised more than \$185,000

UMass Memorial Children's Medical Center

20 events raised nearly \$74,000 for:

- > Child Life Program
- > Neonatal Intensive Care Unit
- > Pediatric cancer research and care

In addition, 10 events raised more than \$61,000 to support:

- > research and care for cancer, colorectal cancer and diabetes,
- > chronic obstructive pulmonary disease research,
- > the intensive care unit, and
- > the Transplant Patient Assistance Fund

A complete list of FY2015 community events is available online at www.umassmed.edu/donor-recognition. If you would like to create a fundraiser to support UMass Medical School and/ or UMass Memorial, please contact the Office of Advancement: 508-856-5520, giving@umassmed.edu.

In a quest to save their daughter,

one couple finds hope at UMMS

Dynamic fundraising efforts support promising research to cure rare disease

n August 2013, Christine Waggoner and her husband Douglas Dooley faced every parent's worst nightmare. Their 5-year-old daughter Iris was diagnosed with GM1 gangliosidosis, a rare, fatal condition that destroys nerve cells in the brain and spinal cord. It's part of a group of neurodegenerative disorders known as lysosomal storage diseases. GM1 leaves children unable to speak, swallow, see, hear or move their limbs. They all eventually die. There is no cure.

Yet.

Gene therapy research underway at UMass Medical School holds tremendous promise for treating this devastating disease. And thanks to Waggoner's and Dooley's fundraising efforts to support this work, achieving that promise may be closer than ever.

Seeking answers after Iris' diagnosis, Waggoner began utilizing the internet and social media to find other families with children who have GM1. The condition is known to affect only a couple of dozen children a year in the U.S., underscoring how challenging her search was.

"I came across an appeal for funding to complete the IND (investigational new drug application to the FDA) for a clinical trial to study a gene-based therapy for GM1 in humans," said Waggoner. Soon after, she learned of UMass Medical School's Miguel Sena-Esteves, PhD, associate professor of neurology, the lead collaborator on groundbreaking gene therapy research for GM1. It gave her family hope that they might be able to save Iris.

In the meantime, Waggoner saw a viral video produced by another family whose child had Sanfilippo syndrome (another lysosomal storage disease); it had raised nearly \$2 million in donations.

"I realized we could be doing more for GM1 research," she said. "Fortunately, my husband and I have a background in media, so we produced a video, too."

But that wasn't all. Because Iris loves art, Waggoner organized an art auction that raised \$100,000 in a single evening in April 2015, with the funds going directly to Dr. Sena-Esteves' GM1 gene therapy research. She and Dooley also established a nonprofit foundation and set up a GoFundMe page to accept donations. They built two websites (www. curegm1.org and www.sweetiris.org). They started a Facebook page and a Twitter account. And they continually remind donors to seek matching funds from their employers whenever possible.

By the end of July 2015, they raised upwards of \$500,000—most of it within their first four months of fundraising. All monies from those efforts went directly to the Sena-Esteves lab and to the lab of longtime GM1 research collaborator, Douglas T. Martin, PhD, at Auburn University. In GM1 gangliodosis, due to a gene mutation, the body produces an insufficient amount of an enzyme called beta-galactosidase. This dysfunction results in cell death, particularly in extremely fragile neurons and spinal cells. As a result, the disease robs children of nearly every skill and bodily function required to live. GM1 is estimated to occur in one in 360,000 newborns.

Sena-Esteves' lab is investigating new gene-therapy approaches for treating lysosomal storage diseases, including GM1. He and his collaborators have devised new ways to deliver therapeutic levels of the missing enzymes to the entire brain by injecting adeno-associated virus (AAV) vectors into the central nervous system.

"This means we introduce a good version of the mutated gene using a virus as the delivery vehicle," Sena-Esteves explained. "The virus 'infects' the neuron and delivers genetic material that tells the neuron to start making normal proteins. This turns cells inside the patient's brain into micro-factories that pump out normal enzymes to the other cells that need them."

Sena-Esteves reports that, in animal studies, this gene therapy has demonstrated a remarkable increase in lifespan from 8 months to more than 4.5 years, with dramatic improvements in quality of life.

"These experiments have been spectacular," he said. "It's so very exciting, and there's not much else to do now but to test this in patients."

In fact, in February 2015 UMass Medical School entered into a groundbreaking agreement to collaborate with Lysogene, a French biotechnology

> "This is an amazing time in medical history with gene therapies being developed. That there may be a chance of dealing with these diseases is amazing."



Miguel Sena-Esteves, PhD

company, and Auburn University to develop pre-clinical studies of GM1. The collaboration combines Lysogene's clinical expertise in gene therapy with the pre-clinical expertise and infrastructure of UMMS and Auburn University.

"We will take one of the gene therapy approaches for GM1 into a first-generation clinical trial in humans," Sena-Esteves said. "We're doing the work now to go to the FDA about this.

"Christine's funding also allows us to expand on other ideas to develop next-generation gene-delivery vehicles, which brings us ever closer to a cure," he continued. "It shows how one person can have a tremendous impact—and not just on this rare disease; it's likely that our findings may be translatable to other neurological diseases as well."

For Waggoner and her family, these advances can't come too soon.

"I feel a tremendous sense of urgency," she said. "Iris is 7 years old; it's around the age of 10 that symptoms become extreme if untreated. If a human clinical trial emerges by 2017, we'll be right on the cusp.

"The reality is that this research is extremely promising," Waggoner continued. "This is an amazing time in medical history with gene therapies being developed. That there may be a chance of dealing with these diseases is amazing." \blacklozenge

For more information, please visit www.curegm1.org or www.sweetiris.org.

from heartbreaking loss, opportunities for others

From right: Kristen Ettensohn, with fellow Class of 2010 classmates Lydia Helliwell, Jhilam Biswas and Emily Marsters during a 2007 medical mission trip to Peru.

Parents establish an endowed scholarship at UMass Medical School in memory of their daughter to help students "pick up where she left off"

risten M. Ettensohn, UMMS School of Medicine Class of 2010, wasn't able to graduate with her class. Ill with cancer at the time, she passed away that summer. She was, however, the type of person who left a lasting impression on nearly everyone who met her. Active, engaging, thoughtful, studious and compassionate, this kind and industrious young woman had a passion for learning and for helping others.

At UMass Medical School, her memory will be constantly refreshed thanks to a new endowed scholarship established by her parents. When asked what motivated them to create a scholarship in memory of their daughter, Linda Hassan Ettensohn, MD, and David Ettensohn, MD, said that Kristen left unfinished business.

"We like to think that this scholarship will enable future students to pick up where she left off," they said. Kristen was diagnosed with cancer in 2008, when she was a third-year medical student. After a brief period of remission in 2009, she had a relapse and died on July 11, 2010. That period of remission provides an important insight into Kristen's outlook on life and some of her unfinished business. According to Dr. Ettensohn, she used that time to sign up for a medical mission in the Dominican Republic.

"She was tired of sitting around 'doing nothing,'" he said. "Kristen always wanted to be making things happen."

An honor student throughout high school, Kristen constantly sought out ways to fill her time with academic, athletic or artistic endeavors. As an undergraduate studying biogenetics at Dartmouth College, for example, she conducted research at the National Institutes of Health and at the Woods Hole Oceanographic Institution. She was also an awardwinning artist and a Division 1 college athlete. "Kristen just loved to run," said Dr. Hassan Ettensohn. "She ran track and cross-country all four years in high school and continued with the Dartmouth track team for the next four years. She was a team captain in her senior year."

That experience as team captain revealed the kind of doctor Kristen might have become.

"She was very tuned in to all of her teammates and she knew that many female runners struggled with anorexia," her mother said. "She talked with women who she thought were at risk and convinced them to sign a contract with her—a commitment to maintain a healthy daily caloric intake and to conduct weekly weigh-ins."

In addition to her many skills and talents, Kristen is best remembered by her UMMS classmates for her intense curiosity, which they say was for everything that caught her attention. According to Jhilam Biswas, MD'10, Kristen just couldn't slow down.

"When we were on a medical mission to Peru in 2007, she told me that she wanted to walk but she had the urge to run," said Dr. Biswas. "She said she got to see so much more of the world when she ran."

The former team captain was still looking out for other runners well into her medical school career. Emily Marsters, MD'10, who was also on the 2007 Peru mission, was Kristen's frequent running partner.

"She was a much better runner," said Dr. Marsters. "Still, she would always stay one pace behind me in order to help keep me going."



Linda and David Ettensohn (far right and left) with their children Kristen and Derek in 2006.

"So use your time on this earth and your time as a doctor to live and work like Kristen would have. Bring that same care, joy and enthusiasm that she would have brought to her endeavors to your own life and to your medical practice."

When asked what she would say to a future recipient of this memorial scholarship, friend and classmate Lydia Helliwell, MD'10, said she would talk about Kristen's love of life and impart that Kristen was someone who took advantage of every opportunity she could, and did so with great excitement.

"Everything and everyone were interesting to her," said Dr. Helliwell. "Anyone who talked with her felt as though there was no one else in the room she'd rather be talking with.

"So use your time on this earth and your time as a doctor to live and work like Kristen would have. Bring that same care, joy and enthusiasm that she would have brought to her endeavors to your own life and to your medical practice."

The first Kristen Ettensohn Memorial Scholarship was awarded in fall 2015 to a first-year student.

"Being kind, helping others... that is what it was all about for Kristen," said her parents. "We wanted to honor that and are so pleased to be able to do so." ◆

Family, friends, classmates and other alumni can contribute to this fund. Please contact the UMass Medical School Office of Advancement (508-856-5520, giving@umassmed.edu) for details.

Term chairs established to support young investigators at UMMS

Gifts from George F. and Sybil H. Fuller Foundation, Glass Charitable Foundation provide five-year funding to three diabetes researchers

creative new approach to support promising scientists early in their careers took shape at UMass Medical School in June 2015 when gifts from The George F. and Sybil H. Fuller Foundation and The Glass Charitable Foundation were made to establish three, five-year, term chairs for junior faculty in diabetes research. The researchers will each receive \$300,000 over five years to support their scientific work.

"Resources for research are becoming increasingly competitive, even for established scientists with track records of innovation and discovery," Chancellor Michael F. Collins said. "We are determined to address these challenges. With the support of The George F. and Sybil H. Fuller Foundation and The Glass Charitable Foundation, we are creating innovative tools to retain our top young talent. The prestige and recognition associated with being appointed to these term chairs also positions the recipients well for future external funding opportunities."

Terence R. Flotte, MD, the *Celia* and Isaac Haidak Professor of Medical Education, executive deputy chan-



Photo by Peter Vanderwarker

cellor, provost and dean of the School of Medicine, said the new term chairs align with the goal of UMMS to create funding mechanisms to invest in the promise of junior faculty members.

"One of the major strategic objectives in both the Medical School's new joint strategic plan with clinical partner UMass Memorial Health Care and the UMass System's Life Sciences Strategic Plan is recruiting and retaining talent, particularly outstanding junior and mid-career faculty," Dr. Flotte said. "Our assistant and associate professors are essential to the Medical School's research enterprise. The competition for such talent is intense and decreasing federal support for research is exacerbating this issue. We are proud to support Drs. Laura Alonso, Michael Brehm and Rene Maehr and know they will continue making meaningful discoveries with this support that further the research into diabetes."

The George F. and Sybil H. Fuller Foundation, a longtime benefactor of UMass Medical School and UMass Memorial Health Care, proposed the idea of term chairs as a way for its board to support important research without an endowment, said Mark W. Fuller, chairman and treasurer of the Fuller trustees. The foundation primarily supports capital projects; it does not support endowments.

"Funding research is critical because we all understand that the numbers coming from the federal government are going down, so it's harder and harder for scientists to get those dollars," Fuller said. "We have supported UMass Medical School and UMass Memorial Health Care for many years; we want to support research, especially young researchers; and type I diabetes is prevalent in several of our trustees' families. So, supporting a term chair for diabetes research made a lot of sense for us. I also hope this is an option for other donors, particularly those who can't fund an endowment but could make an annual contribution such as this."

The commitment to support young scientists is essential with the continuing decline in federal research funding, said David M. Harlan, MD, the *William and Doris Krupp Professor in Medicine,* and co-director of the Diabetes Center of Excellence.

"The impact of that decreased funding is particularly acute for the young investigator who has not yet had time to establish the productivity record so critical to successfully compete for limited research dollars," Dr. Harlan said. "Senior researchers around the world recognize that we risk losing an entire generation of younger investigators who may conclude the research path is closed to them. And yet, history has shown that it is very often the young investigator driving major innovation. Sir Frederick Banting was only 31 years old when he and Charles Best first isolated insulin.

"The term chairs for our diabetes research young investigators will give these best and brightest young minds a career foothold from which they might establish their careers and, more importantly, pursue new ideas that may be the missing puzzle piece required to better treat or cure diabetes." \blacklozenge

Meet UMass Medical School's first term chair recipients

Laura Alonso, MD Associate Professor of Medicine

The George F. and Sybil H. Fuller Foundation Term Chair in Diabetes

Dr. Alonso is the director of Beta Cell Biological Studies in the Department of Medicine,



where her lab is focused on finding ways to increase the number of insulin-secreting pancreatic beta cells, so as to prevent or treat diabetes. She uses mouse models to determine how nutrients influence beta cell proliferation, with the goal of identifying therapeutic pathways that can potentially expand the number of human beta cells.

Michael Brehm, PhD Associate Professor of Molecular Medicine

The Robert and Sandra Glass Term Chair in Diabetes

Dr. Brehm was recruited to the Diabetes Center of Excellence following a successful postdoctoral and junior

faculty research career at UMass Medical School. He is using humanized mice to focus on autoimmune type 1 diabetes and the cells that regulate immune responses in humans.

Rene Maehr, PhD Assistant Professor of Molecular Medicine

The Glass Charitable Foundation Term Chair in Diabetes

Dr. Maehr was recruited to the Diabetes Center of Excellence





reunion class gift campaign 2015

n honor of their respective reunions, the UMMS School of Medicine Classes of 1975, 1980, 1985, 1990, 1995, 2000, 2005 and 2010 collectively donated more than \$250,000 for financial aid and to support other needs throughout the academic health sciences center. In doing so, they established seven endowed scholarships and one current-use scholarship in honor of their graduating classes. These scholarships will be awarded annually to promising medical students based on financial need. \blacklozenge



Total Giving: \$42,500, Participation: 85.7% Gift Chair: Erica E. Johnson, MD



Total Giving: \$39,216, Participation: 44.9% Gift Chair: John T. Szymanski, MD



Total Giving: \$28,715, Participation: 49.5% Gift Chair: Diane M. Savarese, MD



Total Giving: \$48,300, Participation: 42.7% Gift Chair: Craig N. van Roekens, MD, MBA, MPH



Total Giving: \$35,306, Participation: 40.2% Gift Chairs: Eric W. Dickson, MD, MHCM, FACEP, and Deborah A. Sullivan, MD, FAAFP



Total Giving: \$29,425, Participation: 55.4% Gift Chairs: Jeremi M. Carswell, MD, and Lucy Y. Chie, MD



Total Giving: \$25,925, Participation: 41.4% Gift Chair: Jean A. Marcelin Jr., MD



Total Giving: \$3,865, Participation: 40.4% Gift Chairs: Aimee B. Falardeau English, MD, and Timothy J. Lin, MD

Inaugural Cellucci tribute race draws huge crowd, supports ALS research at UMMS



Left: Amy Wiswell, of Townsend, was among the hundreds of runners off at the starting line. Right: From left are, Anne Cellucci Adams holding daughter Lucia; former Massachusetts Gov. William Weld; Gabriel Westberg, Francesca and Rhys Adams with grandmother Jan Cellucci; and former Massachusetts Gov. Deval Patrick. Adams is the daughter of Jan Cellucci and the late Gov. Paul Cellucci.

few showers on the morning of Saturday, Aug. 2, 2014, could not dampen the spirits or the enthusiasm of the more than 1,000 runners and walkers who participated in the inaugural Governor Cellucci Tribute Road Race in Hudson, Mass. Held in honor of the late Paul Cellucci's commitment to fund ALS research at UMass Medical School and his lifelong dedication to public service, the race, which ran through his historic hometown, benefited the UMass ALS Cellucci Fund, launched in 2011 by the former governor to fund research into a cure after he was diagnosed with the disease.

"What's important is that 20 minutes from our home is one of the world's foremost ALS researchers with an extraordinary team," said Jan Cellucci, race organizer and the governor's widow, referring to UMass Medical School's Robert H. Brown Jr., DPhil, MD, who was the late Gov. Cellucci's physician. "That team has the ability to take breakthrough opportunities and go in so many different directions. There is an extraordinary amount of excellence at UMass Medical School and we need to support their work."

Jan Cellucci said she, her daughters, Kate Cellucci and Anne Cellucci Adams, and the entire race committee were thrilled by the large turnout. She noted the event served as a "rallying point" for the many

Robert H. Brown Jr., DPhil, MD is interviewed by New England Cable News prior to the start of the race.



participants who were supporting a loved one with ALS or remembering someone lost to the disease.

The goal of the UMass ALS Cellucci Fund is to establish an endowment to seed the boldest research ideas in the interdisciplinary laboratories at UMMS under the direction of Dr. Brown, the Leo P. and Theresa M. LaChance Chair in Medical Research and chair and professor of neurology, who is one of the world's foremost authorities on ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's disease). Approximately \$3.5 million in gifts and pledges have been raised as of July 2015. Cellucci died in June 2013 from complications of ALS. He was 65. 🔶

View a video recap of the inaugural Cellucci Road Race online: http://bit.ly/cellucci_road_ race_2014_video

2014 Winter Ball *hits record highs for fundraising*

Nearly \$200,000 earmarked for 'miracles' at Craniofacial Clinic

riday, Dec. 5, 2014, was an evening of record for the Winter Ball, the gala fundraising event that supports the academic medical center consisting of UMass Medical School and UMass Memorial Medical Center. The sixth annual event, co-chaired by Paula and Eric Dunphy, Elizabeth and David Klein, and Kimberly Malloy-Salmon and Matthew Salmon, raised more than \$750,000 overall through sponsorships, live and silent auctions, and ticket sales.

The featured Fund-a-Need recipient for the 2014 event was the Craniofacial Anomalies Clinic at UMass Memorial Medical Center, which treats children and adults with skull and facial deformities, such as cleft lip and palate. Nearly \$200,000—at that date the highest amount for a Fund-a-Need recipient in the history of the event—was raised to help families with expenses not covered by insurance during their children's treatment for cleft palate and other birth defects of the head and face (see sidebar).

Nearly 40 local organizations and individuals signed on as sponsors of the event, including Duddie Massad as the first-ever Winter Ball





Platinum Sponsor, Blue Cross Blue Shield of Massachusetts, Crothall Healthcare, and Vital Emergency Medical Services in collaboration with MedStar Ambulance.

"Incredible support for the Winter Ball each year comes through the sponsorships. In fact, more than half the monies raised by this event come from those sponsorships," said Eric Dunphy and Matt Salmon, sponsorship co-chairs for the 2014 Winter Ball Steering Committee. "For the sixth annual event, our sponsors collectively donated nearly \$390,000, which was an all-time high for this event. We couldn't be more grateful for their support."

More than 360 people attended the event, which was held at Mechanics Hall in Worcester, with many guests participating in both live and silent auctions.

"Attendees demonstrated wonderful enthusiasm for and participation in the auctions, which featured many new and exciting items as well as some perennial favorites, thanks to a dedicated planning committee," said Elizabeth Wetherbee Klein, auction chair for the 2014 Winter Ball Steering Committee. ◆

For more information, please visit www.umassmed.edu/winterball

2014 Winter Ball Steering Committee

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Funding a need

Brooke Putelis' son was born with a cleft palate and was treated at the Craniofacial Anomalies Clinic at UMass Memorial Medical Center. His now picture-perfect smile which Putelis calls "a miracle"—is the result of the skilled care he received from the clinic's comprehensive team.

"When I start to cry is when I see the power of the child's personality scorch through the defect and take over," said Janice Lalikos, MD, professor of surgery and director of the Craniofacial Clinic.

Through the efforts of Dr. Lalikos and other members of an interdisciplinary team, the clinic was awarded a sixyear accreditation in 2014 as a Cleft Palate Team by the American Cleft Palate-Craniofacial Association and Cleft Palate Foundation. The team addresses all aspects of a patient's care beyond surgery, including orthodontics, speech therapy and psychosocial support.

"My plastic surgeon [Dr. Lalikos] is my hero," said 19-yearold Emily Keefner, who was named a Plastic Surgery Patient of Courage by the American Society of Plastic Surgeons in 2013. Keefner has undergone 34 procedures at the UMass Memorial Children's Medical Center and has been under Lalikos' care as Craniofacial Clinic director and reconstructive plastic surgeon since 2002.

"The goal is to allow these children to live a fundamentally completely normal life by simply restoring their facial appearance," said Raymond Dunn, MD, professor of surgery and chief of the division of plastic surgery.

For more information, please visit the Craniofacial Anomalies Clinic at UMass Memorial Medical Center at http://bit.ly/craniofacial_clinic



Gene Therapy Center endowed with \$2M gift

Horae Gene Therapy Center at UMMS named for Chinese benefactor

n the 1990s, gene therapy was first hailed as a potential cure for a myriad of diseases from sickle cell anemia to cystic fibrosis. It mesmerized the scientific community at the time—patients who participated in early clinical trials showed marked improvement, illustrating the treatment's great promise. Sadly, that promise was hindered by the unfortunate and high-profile death of a patient during a trial in 1999. As a result, gene therapy was largely forgotten by the public and most of the scientific community.

Nearly two decades later, UMass Medical School is leading a resurgence in gene therapy treatment strategies that have had some notable successes-and are beginning to re-engage the public and attract the attention of prominent investors. In April 2015, the Medical School's Gene Therapy Center, a global leader in adeno-associated virus (AAV) gene therapy, received a \$2 million endowment from the Horae Oriental Shenzhen Investment Company of Guangdong, China, a private company focused on developing the life sciences, medical research, medical education and medical care in Shenzhen, China. In recognition of the gift, the Gene Therapy Center was named the Horae (红瑞) Gene Therapy Center.



Front row, from left: Guangping Gao, PhD, P.J. "Chuck" Chen, Chancellor Michael Collins, Dean Terence Flotte and Yuet Chai appear with the staff of the Horae (红珊) Gene Therapy Center in August 2015 to celebrate the endowment.

"The field of AAV gene therapy is attracting significant attention around the world and our scientists at the Gene Therapy Center are at the forefront of its discovery and development," said Chancellor Michael F. Collins. "This gift supports our translational research into therapies for diseases that include cystic fibrosis, alpha-1 antitrypsin deficiency, lysosomal storage diseases, retinal and macular degeneration, and other genetic diseases."

Guangping Gao, PhD, a top AAV researcher who has played a key role in the discovery and characterization of new AAV serotypes, is the director of the Horae (红瑞) Gene Therapy Center & Vector Core. Dr. Gao, the *Penelope Booth Rockwell Professor in Biomedical Research*, professor of microbiology & physiological systems and scientific director of the UMMS-China Program Office, said researchers at UMMS have a long history as pioneers in the field of AAV gene therapy.

"We are well known for the development of high quality AAV vectors for both academic researchers and

> "The field of AAV gene therapy is attracting significant attention around the world and our scientists at the Gene Therapy Center are at the forefront of its discovery and development."



industrial pharmaceutical companies around the world," Gao said. "This gift will fuel our continuing discoveries and allow us to further expand our research. It will help us to translate many exciting preclinical discoveries and basic research into human clinical trials."

"As a leading capital management group in China, we are not only seeking business opportunities in the area of life sciences, but we are also committed to scientific research," said Yuet Chai, chairman of China Horae Capital Management Group, the holding company of Horae Oriental. "We greatly admire the world-class scientific achievements of UMass Medical School and are most honored to present this donation."

Terence R. Flotte, MD, the *Celia and Isaac Haidak Professor of Medical Education,* executive deputy chancellor, provost and dean of the School of Medicine, was the principal investigator for the first use of recombinant AAV in humans, using the vector in cystic fibrosis trials beginning in 1995 before shifting his emphasis to alpha-1 antitrypsin deficiency, a genetic cause of emphysema. Dr. Flotte's studies established important safety data and contributed seminal observations regarding the molecular mechanisms of rAAV persistence and immune response in humans.

"Our Gene Therapy Center has also provided a platform technology to allow disease-focused researchers to directly translate knowledge about the genetic basis of diseases like ALS and Huntington's disease into potential therapies for those diseases," Flotte said. "The impact of this gift is multiplied by how thoroughly the center is interconnected with the RNA Therapeutics Institute and clinical departments like neurology and pediatrics."

P.J. "Chuck" Chen, the CEO of the China Horae Group, said, "Our partnership with UMMS will be a perfect model of international collaboration between universities and companies, especially for the United States and China.

"A collaborative relationship between an academic research institution and a financial organization will generate great results beneficial to people, industry and science. We are looking forward to working with UMMS on developing biomedical markets in China for the long run." \blacklozenge

targeting Huntington's disease



Family affected by fatal illness supports UMMS study testing efficacy and safety of a "Trojan Horse" therapeutic

> he deadly odds are 50-50: If a parent has Huntington's disease (HD), then each of his or her children has a 50-50 chance of developing this fatal disease. For many years, Michael Berman's family thought they had beaten the odds.

Jocelyn Topper, Michael's life-partner, lost her father to Huntington's. She had been tested after he was diagnosed and was told she did not carry the gene that causes the disease. Then in 2014, after a battery of more sophisticated tests following an automobile accident, she learned otherwise.

Above: From right, Michael Berman with Jocelyn Topper and her children.

"It was as if a bomb went off in our family," Michael Berman said. "We thought the chain had been broken. Now, there is a grandchild—all are at risk."

Huntington's disease is a fatal neurodegenerative disorder. A mutant copy of the Huntington gene causes a cascade of damaging effects that ultimately destroys nerve cells in the brain. As HD progresses, people lose muscle control and cognitive abilities. Today, some 30,000 people in the United States suffer from the disease—and an estimated 200,000 more carry the mutant gene and will eventually develop symptoms. There is no cure.

A retired CEO of a major investment bank, Berman understood how to approach complex issues and focus on reasonable solutions—and knew he would be drawing on these skills to address this sudden and vital new priority.

"Huntington's became the focus of my life," he said. "I wanted to learn everything I could about the disease, get the lay of the land for ongoing research, and see how we could make a contribution to finding a cure."

Beginning with Jocelyn's medical team in the couple's home state of California, Berman reached

out to HD experts across the country seeking information and guidance. That led him to Neil Aronin, MD, co-director of the Neurotherapeutics Institute at UMass Medical School.

"Michael called me, and I could hear the pain in his voice," Dr. Aronin said. "I knew just 40 minutes on the phone wasn't going to be enough to help him, so I agreed to meet with him and his family."

Over the course of three days, Aronin, who is also a professor of medicine, cell & developmental biology, and microbiology and physiological systems at UMMS, delivered an intensive tutorial on human genetics and the disease. He explained how genes coded in DNA send messenger-RNAs to direct protein production in cells. People inherit two copies of most genes—one from each parent and if one copy of the Huntington gene is mutated, it sends errant messenger-RNAs that cause the mutant Huntington protein, which is the hallmark of the disease.

Aronin also explained that much remains unknown about how the mutant Huntington protein actually damages nerve cells. So the focus of the Aronin lab is to go "upstream" and target the defective gene itself to try to "knock down" production of the errant messenger-RNAs and toxic proteins, thereby preventing nerve cell damage.



Neil Aronin, MD

"Private support like this is critical for the implementation of essential early-stage studies such as the 'Trojan Horse' project. If it's successful, then we can take the idea to the next level..."

Berman subsequently traveled to Worcester to meet with Aronin and colleagues from the UMMS Neurotherapeutics Institute. Impressed with their work, Berman decided to support a significant new study at UMMS to test the efficacy and safety of a "Trojan Horse" therapeutic designed to infiltrate nerve cells in the brain and release an RNA-based construct that will reduce production of the Huntington protein.

"I spent a career making decisions based on a bunch of facts and on the quality of people involved. I believe I know a good thing when I see one. What's happening with Neil and the team at UMass Medical School is extraordinarily exciting," Berman said.

Back home, Berman said his family is adjusting to their new reality. Jocelyn is doing well and has no HD symptoms. Her children are getting counseling to grapple with the possibility of HD arising in the years to come. They all remain hopeful that supporting the HD research at UMMS will accelerate development of a cure, not just for their family, but for everyone affected by the disease.

"We are so grateful for Michael's generous philanthropic contribution and the backing of his family," Aronin said. "Private support like this is critical for the implementation of essential early-stage studies such as the 'Trojan Horse' project. If it's successful, then we can take the idea to the next level and present it to other private donors, foundations or the NIH (National Institutes of Health) for additional funding to support its development."

\$7.5M Paul G. Allen Family Foundation grant accelerated UMMS Ebola Relief effort



Academic medical centers partnered to provide health care, training and infrastructure in Liberia during 2014 Ebola crisis

> ith a \$7.5 million grant awarded from the Paul G. Allen Family Foundation in October 2014, UMass Medical School led a team of academic partners in providing comprehensive relief efforts in Liberia, bringing doctors, nurses, and training and medical supplies to the then Ebola-stricken country.

"We at the University of Massachusetts Medical School were grateful for the support of the Paul G. Allen Family Foundation, which allowed us to specifically work with our strategic partners on this grant and our Liberian colleagues to help stem the Ebola epidemic and strengthen Liberia's fragile health care system," said Chancellor Michael F. Collins. "Our academic collaborative had worked



Ellen Johnson Sirleaf, president of Liberia and a 2011 Nobel Peace Prize winner, with Chancellor Michael Collins at a community event organized by members of the local Liberian community on the occasion of her visit to Worcester in June 2012. President Johnson Sirleaf delivered the keynote address at the Medical School's 39th Commencement exercises that year.

productively in the past with the Liberian leadership and health care workforce, and we were eager to continue that partnership by engaging directly with our Liberian collaborators and providing on-the-ground relief, training and supplies." Shortly after the UMMS Ebola Relief effort was launched, UMMS and its collaborators on the grant partnered to reopen 16 hospitals that were overwhelmed by Ebola outbreaks.

"Everyone had heard about the deaths from Ebola, but many people didn't realize how many women who needed C-sections were still dying. Children with malaria had nowhere to go," said Patricia McQuilkin, MD, clinical associate professor of pediatrics at UMMS and a project leader on the Ebola relief grant. "Most hospitals were still closed and health care workers had no personal protective equipment and were too afraid to come back."

The UMMS-led team hired and trained teams of Liberian health care workers to become experts in safely managing Ebola cases. Teams of master trainers, which each included a Liberian doctor, nurse, midwife, psychologist and sanitation expert, were dispatched to spend one week at each hospital to train staff on U.S. Centers for Disease Control and Prevention standards for Ebola safety, triage, patient care, sanitation and getting in and out of personal protective equipment (PPE). The goal was to train everyone in the hospital, including janitors and cafeteria staff. One employee at each site was trained extensively on infection control and would monitor compliance closely. Bolstering the training effort, a critically needed shipment of \$1.7 million in personal protective equipment for health care workers was flown to Monrovia, Liberia, in January 2015.

"The PPE was critical because, despite the fact that the Ebola epidemic had been going on for several months, many rural hospitals still did not have it," said Dr. McQuilkin. "Also, it was critical that when the training teams were deployed to the hospitals that they had PPE to train with, to teach staff to 'don and doff.'"

Built on a years-long relationship between UMMS and Liberia, the UMass Medical School Ebola Relief efforts funded by this grant were a new component of philanthropist Paul G. Allen's increased commitment of at least \$100 million in 2014 to the Tackle Ebola campaign he launched.

"This collaboration capitalized on the strong partnerships and relationships that UMMS and its academic partners have developed in Liberia to provide a multifaceted, cohesive response to the Ebola virus outbreak, and to provide critically needed routine health care to the people of





Top: From right, Patricia McQuilkin, MD, with local pediatric medical staff and Tammy Chang (then a pediatric resident) in Liberia in 2011. Above: Training team in Liberia in 2015.

Liberia," said Katherine Luzuriaga, MD, professor of molecular medicine, pediatrics and medicine, director of the UMass Center for Clinical and Translational Science, and vice provost for clinical and translational research.

Dr. Luzuriaga had led past UMMS efforts in Liberia, and worked with faculty to submit the grant proposal on behalf of the Academic Consortium Combating Ebola in Liberia (ACCEL). The ACCEL consortium members include UMass Medical School, Boston Children's Hospital, Mt. Sinai School of Medicine, University of Maryland, University of Florida, Addis Ababa University in Ethiopia and Vanderbilt University, and Massachusetts Institute of Technology.

The Ebola epidemic in West Africa was the largest in history, with nearly 17,600 suspected cases reported and 6,500 deaths since December 2013. ◆

For more information about the UMMS Ebola Relief effort, visit www.umassmed.edu/ebola.

Hudson Hoagland Society celebrates 30 years

Annual Meeting features talks by Munson, Freeman

he Hudson Hoagland Society celebrated a milestone anniversary at its 30th Annual Meeting on May 12, 2015: three decades of philanthropic support for scientific research. Thoru Pederson, PhD, the Vitold Arnett Professor of Cell Biology, professor of biochemistry & molecular pharmacology and scientific director of the Worcester Foundation for Biomedical Research (WFBR) when it merged with UMass Medical School in 1997, reminded the audience of HHS members, faculty, students and WFBR research grant recipients that the giving society's origins were based on the understanding that biomedical research would lead scientists-and society—in unexpected directions, and that support for pioneering research was a necessity.

Dr. Pederson highlighted several early members of the HHS and the WFBR in photographs from previous



Researchers from the lab of Marc Freeman with Michael Gaffin (far right).



From left, Thoru Pederson, PhD; Dean Terence Flotte; Marc Freeman, PhD; Mary Munson, PhD; and Chancellor Michael Collins.

annual meetings, including Warner Fletcher (recipient of the WFBR's Hudson Hoagland Award in 2014), WFBR scientist M.C. Chang and Bob Cushman, who originally proposed the idea of an annual giving society to support the scientific work of minds like Chang, whose discoveries were precursors to the development of in vitro fertilization and oral contraceptives.

The annual meeting also featured talks by Chancellor Michael F. Collins; Mary Munson, PhD, associate professor of biochemistry & molecular pharmacology, recipient of the inaugural WFBR Bassick Family Foundation Award; and Marc R. Freeman, PhD, Howard Hughes Medical Institute Investigator and vice chair and professor of neurobiology, a 2005 Worcester Foundation Grant recipient.

The Hudson Hoagland Society was founded in 1985 and continues to build upon now three decades of discovery and extraordinary advancements. Named in honor of the co-founder of the WFBR, the Hudson Hoagland Society supports basic scientific research that enables UMass Medical School scientists to make advances that have the potential to improve treatments and to speed the discovery of new medicines for countless diseases and afflictions. ◆

For more information about the Hudson Hoagland Society, visit www.umassmed.edu/hhs.



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