

This year's cover is an original photo realistic watercolor painting, titled <i>Checked Wood Door</i> , by Laura Barnhardt Corle, a friend of Thomas Overley. Laura donated her artwork in dedication to Tom, a 9-year GIST survivor and an inspiration to the GIST community.



Dear Friends.

As the Life Raft Group (LRG) looks back over our sixth year, we have much to celebrate as we have continued to strengthen our efforts to find a cure for Gastrointestinal Stromal Tumor (GIST) and helped keep patients alive through information, education and better disease management until we achieve our research goal.

In 2008, we expanded the LRG Research Project by welcoming additional expert investigators to the effort. Our team continues to investigate the reasons for GIST treatment resistance and to identify molecular targets that will open the door to the development of new therapies with the potential for a cure.

We forged new partnerships with other cutting edge patient organizations, increased our global outreach and began to build the GIST Collaborative Tissue Bank to give researchers the opportunity to share tissue and coordinate all of their sophisticated technologies.

Much still remains to be done to find a cure for this deadly cancer. Clearly, we haven't finished the job. And we won't be finished until we have brought education, support and, ultimately, the cure to every GIST patient.

Thank you for all you have helped us to achieve in 2008. Our success is possible only through the generosity and support of our donors and the dedication of our volunteers and members. Together we can continue our vital mission to ensure the survival and well-being of GIST patients.

Sincerely,

Jerry Cudzil President

Jernen andgil

Norman J. Scherzer Executive Director

Morman J. Scherge

Providing Help

The mission of the LRG is to ensure the survival of GIST patients while maintaining the quality of their lives. To accomplish this mission, the Life Raft Group devotes its efforts to the following major priority areas.

Information & Support

The LRG provides information and support to the GIST community including patients, families, friends and medical professionals.

Most notably, this year brought the LRG's fourth international information and education meeting for patients and caregivers. Hosted in Chicago, Life Fest, aptly named by GIST survivors, brought patients and their families together with experts on GIST. There is truly no substitute for gathering with others who are in the same boat as you and gaining critical knowledge and perspective on battling such a rare and deadly cancer.

This year, the LRG focused on redesigning the LRG website with new content and a user-friendly attitude. We also launched a new site, www.GISTNews.org, to create an easier way to search and share newsletter articles. More educational materials have been developed to address specific needs such as Managing Your Care and Financial and Logistical Assistance. Some of these educational materials are also translated into languages like Farsi, Hebrew and Spanish. The LRG also hosted many webcasts on topics such as GIST in the Family: Understanding and Managing Risk; Navigating GIST Clinical Trials; Pediatric GIST: Breaking New Ground; The Link between Dosage and Survival; and Balancing your Needs and Role as a Caregiver. These webcasts are also available for viewing on demand, after they air, on our website.

The LRG continues to provide patient support through our email communities. This year, the LRG also launched a Spanish email community to meet the needs of many more GIST patients.

GIST Outreach

GIST outreach is important because it is such a rare cancer. A pamphlet found in a doctor's office could literally save someone's life. Patients depend on our newsletter, webcasts, website, email community, and volunteers to get this much needed information into their hands. Our volunteers distribute materials

"Seven years ago I heard those words that no one EVER wants to hear:

"You Insert sound of squealing brakes *here* as you realize that life as you knew it is now a chapter in history, as have you will never be quite the same person, ever again. cancer." Over the years I just kept surviving ... surviving cancer, and surviving life. I'm looking forward to another 7 years...and another 7 beyond that...and I know in my heart that I will continue to face adversity, yet I will continue to overcome those adversities & come out stronger and smarter."

Financial &

Logistical

Assistance for

GIST patients

A guide for programs

and assistance in:

Reimbursement

Prescriptions

Managing

Your GIST

Care

Creating Hope

and host local groups that meet inperson across the United States to share their knowledge with every GIST patient they meet. LRG now has local representatives in 36 states!

We also work with international chapters and sister groups through the Global GIST Network. These volunteers help GIST patients with treatment issues specific to their countries. We have a total of 44 country representatives to date. In 2009, we intend to dramatically intensify our efforts to ensure that physicians understand and apply the very latest information for treating GIST.

This year the LRG also reached out to the entire world to ask, "What does a cure

What Does a Cure Mean For You?

a cure for cancer is in our reach

I'll have the energy to finish my beautiful garden. And then enjoy it.

Sand castles..
Lots and lots of sand castles

We won't just wait for a cure
We are taking action
You can toe

mean for you?" We know that GIST is rare, but cancer is cancer and all of the emotions that surround it are the same regardless of molecular make-up. We invite you to imagine a world without cancer as well. If you would like to participate, go to www.ACurelsInOurReach.org

Research

This year marks the two-year milestone for the LRG Research Project, *Pathway to a Cure*. (See *Pathway to a Cure* for more details– pages 5-6.)

LRG GIST Patient Registry

The LRG maintains a GIST-specific patient registry, tracking patients' medical status to allow us to provide information to the GIST community. We use this data to give timely updates on what could be life-saving advances in treatment before clinical trials are able release that information.

The LRG was founded by patients and caregivers. Those pioneers have become patient scientists by ne-

cessity with a belief in leaving no stone unturned when it comes to survival. In 2008, the LRG updated and published the 2007 Gleevec dosage study and yet again the data showed that patients on a higher dose of imatinib had significantly higher overall survival rates than those on a lower dose when we looked at the dose the patient was actually taking. We continue to advocate that this is no coincidence and that many patients may be at risk of being under-dosed.

Treatment and Surveillance

In 2008, the LRG launched its clinical trials database. Clinical trials are still published in the newsletter but



Longtime GIST survivor Alice Sulkowski (center) holds the record for number of PET scans at Mountain States Health Alliance, in Johnson City, Tennessee.

Pictured with Alice are Darlene Blackhurst (left) and Diane Cohee (right), her trusted PET scan technologists.

Taking Action



LRG at ASCO 2008!

The American Society of Clinical Oncology meeting is the largest gathering of oncologists in the world with Dir. of Operations Tricia McAleer and LRG Member Doris Dallow.

the online database makes it easier for patients to search for trials that may serve their particular need. This is the most up-todate GIST-specific listing of clinical trials in existence.

The LRG continues to encourage patients to get mutational testing in order for their physicians to take advantage of that information when developing treatment strategies. This year, plasma testing has provided a new tool in exploring whether patients are getting an effective amount of drug in their system to ensure optimal response. We also provide insight gained from our internal research that tracks trends and preliminary reports so that patients can make better-informed decisions regarding their care.

Advocacy

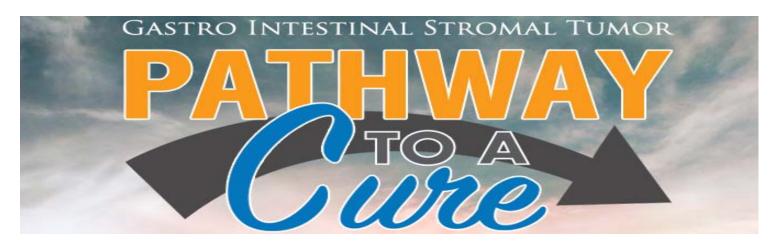
The LRG continues to stand as a strong advocate for GIST paover 30,000 in attendance! Pictured (left to right): LRG | tients. This year marked another call to arms on the issue of placebo use in clinical trials for terminally ill patients. We believe placebos are often an unethical and unwise approach to clinical trial design. Instead, we want to know not whether a new drug is

better than nothing but whether it is better than the best available treatment. The LRG also supports general advocacy efforts for cancer patients such as supporting the Abigail Alliance's argument that terminally ill patients who have run out of options have a right to try experimental drugs without FDA approval.

In 2007, the LRG worked with the global GIST community in the adoption of the Bad Nauheim Declaration, which aims to improve standards of care for all GIST patients in any healthcare system across the world so that all patients are treated equally. The LRG has taken a step further in 2008 by adopting the Baveno Declaration, the cornerstone of which was to introduce routine plasma level testing of imatinib as a practical way of determining which of the low dosage patients actually might require an increase.

Patients contact the LRG, from all over the world, for help because of issues like access to treatment. The LRG works hard to make sure these patients gain that access to a drug that could help them survive.





July 2008 marked the launch of Phase II of the Life Raft Group's "Pathway to a Cure" research program. Building upon the success of its first two years, LRG's innovative research initiative has expanded.

Pathway to a Cure began in 2006 with the creation of a five-year strategic plan to identify priority projects needed to overcome GIST treatment resistance. The goal was to find a cure for GIST within five years. The LRG brought together the world's best GIST researchers and introduced cooperation, coordination and accountability as key building blocks of this historic effort. We created tissue banks, both for adult and pediatric GIST to support this research process. Most significantly, after two successful years, our plan is beginning to work.

The LRG's cutting-edge research model is representative of a new direction among disease-focused organizations to find cures by becoming actively involved in the research process. The LRG is part of a select group of innovative organizations, collectively known as The Redstone Acceleration and Innovative Network (TRAIN), all of whom share a sense of urgency to keep their members alive by identifying new treatment options and ultimately finding cures. The Life Raft Group is working together with other organizations to support each other's efforts to produce better and faster research results. The collective goal is to shorten the time from "bench-to-bedside" by funding targeted research that has the highest probability of finding a cure.

Why the need for innovative research models? Traditionally, most cancer research decisions are made by three key players: the Pharmaceutical Industry, the Researchers and the Government. Each year, billions of dollars are contributed by government, charities and individuals to States alone, hundred alone, hundred search Phase II of the Life Raft Group's each year but there has been no significant change in can-

High on the list of obstacles to finding cancer "Pathway to a Cure." cures and new treatments is the nature of biomedical research itself. There are three phases in the therapeutic drug discovery pipeline. First is basic research or discovery. This is the research carried out by researchers in labs with minimal direct application to treatment in humans. The second phase is "translational research", which applies the basic biological discoveries to the treatment and prevention of human disease. It includes steps like the identification of biomarkers, target and pathway validation and testing in animal models. The third and final phase is clinical research in humans and approval of drugs. Despite scientific advancements in the discovery phase, the amount of time it takes to bring new treatments to market is still ten to 15 years.

Based on an analysis of the barriers to finding a cure and because GIST patients are dying faster than new treatments can be developed, the Life Raft Group decided not to follow traditional rules and simply hand over money to cancer centers for GIST research. The LRG decided to carve out a seat for itself at the cancer research decision-making table and create a partnership with the research community. Out of this collaborative process came the LRG's "Pathway to a Cure" and a five-year plan committed to finding ways to counteract Gleevec-resistance in GIST, prevent Gleevec resistance altogether and identify and validate new targeted therapies. Despite remarkable clinical responses to Gleevec, we are increasingly seeing relapses of GIST, even in patients with initial response to Gleevec. Many GIST patients currently benefiting from Gleevec treatment will eventually develop resistance on the single-regimen therapy. We are indeed in a race to find a cure before patients develop resistance.

The LRG identified a core group of the world's leading GIST cancer researchers whose complementary expertise and combined

personalities would permit them to work together synergistically and invited them to join the team. We challenged them to

create a strategy which consisted of specific prioritized projects with the greatest chance of success to guide GIST cancer research and to commit to a collaborative, rather than a competitive philosophy. Great pains have been taken to enable collaboration while eliminating redundant research efforts. In return, the LRG committed to allocate our research funds to implement that strategy and to support and enhance the team's collaborative efforts.



The LRG Research Team is presented with a two million dollar check!

Phase I results

In Phase I (March 2006-June 2008), LRG research funding has seen progress in identifying novel treatment strategies for GIST by studying new treatment methods in GIST surgical specimens, GIST cell lines, and mouse models of GIST. The urgent aims in all these studies are to identify therapies that function synergistically with Gleevec in destroying GIST cells. Each of the funded scientists performs GIST research that is coordinated with the efforts of the other scientists in this LRG program in an effort to identify treatment approaches that synergize with Gleevec and other KIT kinase inhibitors in enabling a higher cure rate for patients with GIST.

Gleevec-resistance studies are essential to therapeutic progress in GIST. These studies will likely reveal that combinations of GIST therapies are needed to consolidate initial remissions, forestall the emergence of clinical resistance, and lead to increased cure rates. Each of the priority projects funded by LRG in Phase I have substantial, near-term potential for enabling development of novel GIST therapies. Detailed progress for each of these high-priority projects may be found at www.liferaft group.org or in the 2007 Annual Report.

What's new for Phase II?

Building on Phase I successes, Phase II will see an expansion into two new areas and the addition of two new researchers. Dr. Anette Duensing of the University of Pittsburgh Cancer Institute and Dr. Sebastian Bauer, West German Cancer Center, University of Essen in Germany will round out the Life Raft Group's GIST Research team for Phase II. Dr. Duensing will be advancing the understanding of apoptosis, or how cancer cells die. Dr. Bauer extends the team's translational research ability and opens up the potential for testing new compounds and drugs.

On a parallel track, the LRG continues to expand both the scope and the content of its GIST Patient Registry with medical updates provided by patients. The Life Raft Group utilizes the data from this registry to identify critical areas not being covered in a timely way by clinical trials or by the traditional cancer research community, including understanding the non-toxic, but life-altering side-effects of cancer drugs and understanding how dosage levels impact survivorship. In the coming year, the LRG will be conducting a new study examining long-term side effects as well as the cutting-edge area of Gleevec plasma levels.

GIST cancer research provides a perfect model for demonstrating how to cure other cancers. GIST is a relatively simple cancer and has an increasingly understood mechanism of cancer mutations. Further, there is a growing list of targeted drugs to address these mutations.

We are approaching a critical intersection on the road to finding a cure for GIST. We have the right scientific tools and the right researchers at the perfect time and place. We have achieved a historic understanding of the fundamental genetics driving GIST and the know-how to identify and overcome the remaining downstream pathways of resistance. We have two approved targeted drugs, Gleevec and Sutent, and a number of other promising ones in the pipelines. This opportunity to complete the "Pathway to a Cure" is unprecedented and well within our grasp. For if we don't find a cure, who will?



Life Fest 2008

The Life Raft Group's fourth Life Fest meeting, held in Humanitarian of the Year September at the Hyatt Regency O'Hare in Chicago, Dr. Lee Helman III., was a great success.

The goal of Life Fest meetings is to bring together GIST patients, families, physicians and researchers in a comfortable environment to learn more about disease management, survival and supporting each other through the process. This is the largest gathering of its kind. It is always a memorable event for all who attend.



The LRG recognized several people, during this meeting, for their valuable contributions to the GIST community. The Association of Online Cancer Resources (ACOR) received a Certificate of Appreciation, graciously accepted by President, Gilles Frydman. Steve Rigg, who worked diligently with the LRG to create a new custom-designed database for the LRG Patient Registry, received an Allan Tobes Volunteer Award. Kendra Tobes

Allan Tobes



presented the award after a touching speech about her late husband who Volunteer Award Recipients acted as Chief Financial Officer, board member and local area coordinator for the LRG. The Master of Ceremonies himself, Dick Kinzig, was also presented with a Volunteer Award for his work as a local chapter coordinator and countless GIST outreach efforts. Finally, the Hu-Steve Rigg manitarian of the Year Award was presented to Dr. Lee Helman, by Board

Member, Ray Montague, for his role in the creation of the National Institutes of Health (NIH) Pediatric GIST clinic.

General sessions and workshops proved to be very informative. Attendees were offered sessions on topics like GIST 101, a LRG Research Team update, GIST survival strategies, nutrition, drug development, coping, side -effects and building a personal survival plan.

Special thanks must go out to the LRG Chicago Chapter for all their help, Phil Vettel for organizing a lovely evening on the town for everyone, Dr. Bruce Brockstein of Evanston Hospital and Donna Mazzone, RN of Lutheran General Hospital who filled in at the last minute for Dr. Jonathan Trent and Pat Neal, RN, respectively, both of MD Anderson in Houston, Texas who had to cancel due to severe weather conditions.



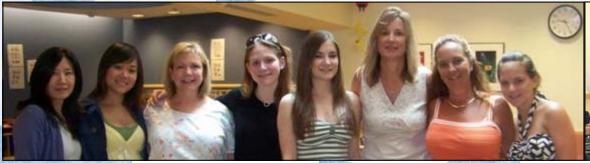
"It is wonderful to see people from all over...interacting. I particularly like to see new GISTers seeking advice from 'old' GISTers," said one member.



PEDIATRIC GIST

Neither our age nor our cancer defines us.

A Monumental Year for the Life Raft Kids!



Mothers & daughters unite: Jennifer & Sile Bao, Toni & Ashley Young, Stephanie & Patty Kastner, Phyllis & Kara Gay at the National Institute of Health Pediatric & Wildtype Clinic.

Top row from left: Dr. Constantine Stratakis, Nora Winstead, Stefanie Peyk, Sile Bao. Bottom row from left, Jacqui Bromberg, Liz Skree, Jason DeLorenzo & Stephanie Kastner.

Three Cheers for the NIH!

Pediatric GIST differs from adult GIST because of a lack mutations within the tumor. Although generally slower growing than adult GIST, it has left this group of GISTers with few options for treatment. Furthermore, pediatric GIST is a rare subset of a rare cancer, so finding the right physician and treatment has always been a difficult task for pediatric patients and their families.

However, this year marked a major turnaround for pediatric GISTers as the National Institute of Health (NIH) opened its doors for the first every Pediatric and Wildtype GIST clinic. LRG Pediatric GIST Co-chairs Jacqui Bromberg and Ashley Young along with Phyllis Gay, GSI Pediatric and Wildtype Coordinator and LRG staffers worked on the planning committee for the Clinic. The NIH held two clinics in 2008 and plans to hold clinics on a biannual basis in the future. GIST specialists and researchers flew in from all over the United States to participate in this intensive Clinic. Aside from the astounding clinical care they receive, these patients are participating in research to help further unravel the mystery of this specific type of GIST. We cannot thank Dr. Lee Helman, Dr. Su Young Kim and everyone at the NIH enough for giving these patients a place to turn to.



LRG Pediatric GIST Co-chair Ashley Young (left) and LRG staffer Tricia McAleer (right) prepare at NJ office for the Pediatric GIST webcast.

Liz Skree

Pediatric GISTer Rachel Gilbert speaks out about GIST at a Teenage Cancer Trust meeting in the UK.





Who's on Board?

Robert Book, Director Stanley Bunn, President Emeritus Mia Byrne, Associate Director Christopher Carley, Director

Jerry Cudzil, President Thomas J. Hughes, Director Gerald Knapp, Director Ray Montague, Secretary-Treasurer John Poss, Director Marietta Robinson, Director Rodrigo Salas, Director Silvia Steinhilber, Director

The LRG Board of Directors voted in a new president, Jerry Cudzil, in 2008! Jerry became involved with the LRG after his father-in-law, Bill Roth, was diagnosed in 2003. Bill passed on in October of 2008, but his legacy lives on through Jerry's dedication and commitment. His volunteer efforts include fundraising and work to raise awareness for GIST. He has also served as a co-chair of the Fundraising Committee and Secretary-Treasurer for the LRG.

A little bit about Jerry's professional background: Jerry earned his BA in Economics at the University of Pennsylvania. He is a Managing Director at Dimaio Ahmad Capital. DA Capital is a Hedge Fund that invests primarily in fixed income instruments.

A letter from Jerry Cudzil in response to his appointment:

It is with humility, hope and optimism with which I accept the role of President of the Board of Directors of the Life Raft Group. Over the past six years, the Life Raft Group has accomplished significantly more than most thought possible. We have helped educate the world about a rare form of cancer called GIST. We have provided patient support, in a myriad of ways, to thousands of patients and caregivers. Among many other things, we more recently helped structure a research effort which is second to none and one that has further enhanced our credibility as an organization worldwide. And most importantly, we remain focused on the main goal of survival. We now have the privilege, ability and responsibility to both enhance our past efforts and forge ahead to the ultimate goal of one day soon finding a cure.

I would like to recognize Stan Bunn's efforts as president of the board for the last five years. Stan's tireless efforts— whether mental, emotional or financial— have helped make the organization what it is today. We are fortunate that Stan will play a key role in the organization and the board on a go-forward basis. I am grateful for Stan's efforts thus far and appreciative of his assistance during this time of transition.

I would also like to recognize the indefatigable efforts of the staff and volunteers. I am impressed and encouraged by the team's consistent work ethic. I know if we all put forth that same focus and determination our success will be limited only by our imaginations. My goal as president will not be to change the Life Raft Group. My goal will be to positively influence the group even if only in a small way. We lose friends and loved ones too often. With the collaborative efforts of the Board, along with the staff and researchers, I am optimistic about our ability to accomplish all which we set out to accomplish. Sincerely,





Special thanks to President Emeritus Stan Bunn who served as Board President for over five years and was instrumental in founding the LRG. His leadership and generosity has brought the LRG to where it is today.

JerryM andgil

On November 5, 2008, we lost our five-year board member, Dr. Arnold Kwart. Always an outspoken and devoted GIST advocate, Arnie will be deeply missed.



2008 Contributors

David K. Chene

Above \$100,000

Sacremento Region Community Foundation Novartis Stiftung für Mensch und Umwelt

\$20,000-\$99,000

Jerry Cudzil Arbor Foundation Carlos & Liana Baldor Stan Bunn Pfizer Pharmaceuticals

\$10,000-\$19,999

Amgen Community Foundation SE Michigan Jim Hughes Infinity Pharmaceuticals Jerry Knapp

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OSI Pharmaceuticals Lois Rosen Ulrich Schnorf Lawrence Selkovits

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Timothy Brennen
John R. Brimsek
Bryan Carroll
Lyon Carter III
Health Care Mgmt. Group
Center Radiology
Karl Cerny

Dr. Arnold Kwart (pictured on page 9), LRG board member and retired urological surgeon, reached out to his family, friends and former patients to ask them to support the LRG. So far, their response to their beloved Arnie resulted in an overwhelming \$120,000 in donations to the LRG. Arnie lost his battle with GIST at the end of 2008.

Nick Chiara David Chou John Chrystal **Edward Cleaver** Steve William Cozine **Doris Dallow** Philip Desantis Gina DeStefano Cyril & Risa Drabinsky Steve Edwards Michael Ehrhart Alexis Feliciano David K. Gallagher Stephen D. Gardner William C. Glidden **Andrew Gonedes** Albert Goodman Robert Grillo David Hollander **Douglas Horst** Industrial Railroad Engineering Brian Isaacson Linda Kellly Richard & Sue Kinzig Mark Knopman Mary Kogelschatz Eric Kramer Malcolm Lane IV Carole Lindroth John Lofaso Lai Oy Louie Dennis Lu Joseph Mannello Mohit Marria Sonja McLaughlin Steven Mondry Frank Moretti Matthew Morris Vincent Murray **Anatoly Nakun** Gary Narvaez George Nemphos James Olszowy Raymond Potter Mike Regan Bibiana G. Rigau Ellen Rosenthal Armin Rothauser William & Ellen Shaw

Amer Siddiqui

Charles Sorrentino

Derek Smith

Kelley Suwak

Kendra Tobes

Indiana

Timothy V. Turpin

United Way of Central

A True 'Ironman'

Steven Eldred raised money for the LRG by entering in his first Ironman competition, July 19 in Lake Placid, NY. The money was raised in honor of his father-in-law, Erwin Johnson, an LRG member.

The LRG would like to congratu-

late Steven on completing the grueling two mile swim, 112 mile bike ride and 26 mile run. **Thanks Steven!**

RUN

Daniel Ward
Marc Wasserman
Scott Wede
Glenn Willett
Lawrence J. Wolfson
Chowdhary Yarlagadda

\$250-\$499

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The LRG's top three fundraisers for the 2008 annual campaign tell us what a cure means for them.

Pictured below from left to right: Pat Lemeshka, Rachel Tate, Robert (Butch) Eller



Thanks to all of our generous players Thomas Richetti and guests, the New York City Poker Tournament raised over \$63,000!



The final three players at this year's tournament From left: Dennis Lu, Joe Bonavita & Choudhary Yarlagadda.

Russell & Cindy Kaye Susan Kayler-Daley George T. Keefer Robert Keller Sean & Judy Kelly Matthew Kennedy Stewart Kessler The Mahendra Khatri Family Sam Kirshenbaum Kenneth Klipper Mark Kopec Kathleen B. Kortte Lawrence Kraus Julie D. Kreif Jennifer Kwok Kevin Kynyak Diana & John Lanza David Levene Nancy Levy Catherine Liesman Lincoln Financial Foundation Linda Lipson Anthony Lorello Lucille & Robert Madsen Chet Malhotra Timothy & Gail Mansfield Monish Mansukhani Carol & Richard Margolis Mary Culhane Marre William L. Marre John & Jennifer Marshall Marie A. Marzadri Peter McAree The McCarthy Family McFarren Marketing Inc. Anne McMurray-Wiberg Robert Melillo Nicole K. Menard Omer Mercier Albert Paul Mercogliano

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Chris Rekow

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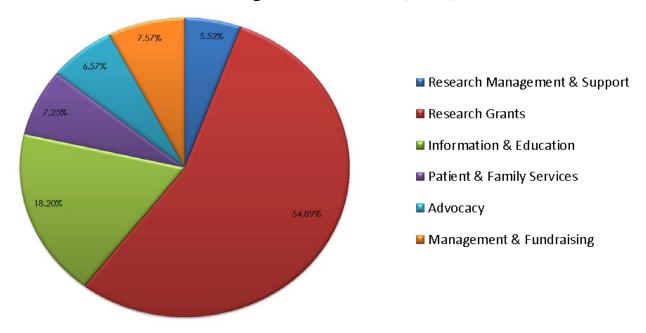
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