



IMMUNENEWS

Jeffrey Modell Centers Network Off And Running

Spanning The World



304

Physicians

138

Academic
Teaching
Hospitals
& Medical
Schools

39

Countries

120

Cities

6

Continents

At the Jackson Hole (WY) Expert Meeting on Primary Immunodeficiencies, 35 Jeffrey Modell Center Directors and industry supporters convened to review advances at our Diagnostic and Research Centers. There was a consensus reached to set up a working Centers Network that would frame the scientific agenda. Areas of specific interest would include best practices, clinical guidelines, outcome measures and data capture, novel therapies, a research platform, an international fellowship program, and expansion of the Physician Education and Public Awareness Campaign (PEPAC).

The Jeffrey Modell Centers Network (JMCN) has initiated the development of a Best Practices Guideline in Diagnosis of Primary Immunodeficiencies. This program will improve standards of care with existing therapies, addressing best clinical practices, therapeutic treatment, and best outcomes. This will include:

- ▶ Physician algorithm
- ▶ Molecular diagnosis and gene sequencing
- ▶ Bone marrow transplantation
- ▶ IVIG trough levels
- ▶ Gene therapy
- ▶ Technology integration
- ▶ Newborn screening

The Robert A. Good/Jeffrey Modell Fellowship in Transplantation and Immunodeficiency is an international fellowship program with a clear mandate to fund the brightest investigators focused on Primary Immunodeficiency and stem cell transplantation. The Fellowship Program will honor one of our greatest immunologists of the last century, Dr. Robert A. Good, and his patient, Jeffrey Modell.

Four of the U.S. National Institutes of Health (NIH) announced a funding opportunity, "Investigations on Primary Immunodeficiency Diseases," soliciting investigator-initiated grants in PI research. JMF is a funding partner with the NIH. The program will support novel clinical strategies to identify the molecular basis of PI diseases and to develop innovative therapies. Investigators who have no prior history of receiving independent NIH funding in this field are encouraged to apply.

Best Practices

International Fellowship

Research Partnership With NIH

Excerpts of remarks delivered by Vicki Modell at the dedication of the Jeffrey Modell Diagnostic Center and the Jeffrey Modell Endowed Chair in Pediatric Immunology Research, Children's Hospital, Boston.



**Co-founders
Fred & Vicki Modell**

A Love Story

When I sat down to prepare some words for this special day, my first thoughts went back to the movie "Love Story" from 1970, the year our son Jeffrey was born. Ironically, the words from the theme song start, "Where do I begin to tell the story of how great a love can be..." Ironically, it is about a young couple, a beautiful romance, which took place in Boston, at Harvard, and then sadly ended in a tearful and heart-wrenching death.

This is exactly how our love affair with Boston Children's began, continued, and was interrupted by two deaths. But in spite of that, it has endured to this day and will survive forever.

We met Dr. Fred Rosen in the 1970s when we brought our son Jeffrey to Children's, seeking answers to his complicated and complex disease. Of course, the wise Dr. Rosen was able to help us and was always available each and every time Jeffrey's doctors in New York sought his advice.

Ten years later, when Jeffrey passed away, Fred and I developed a multi-dimensional relationship with Fred Rosen. He began as our mentor and advisor for Jeffrey's foundation, and that led to unconditional trust, respect, a warm and deep friendship, our traveling companion, and ultimately it led to a profound love affair. This teacher, healer, researcher, wise man, cultured man, a person of excellent taste taught us to always pursue excellence.

That pursuit of excellence brings us here today to the work of Dr. Raif Geha and the extraordinary Division of Clinical Immunology that he has so lovingly and wisely nurtured and enhanced, following in the footsteps of his teacher and mentor, Fred Rosen. We are honored to dedicate the Jeffrey Modell Endowed Chair in Pediatric Immunology Research to be held by Dr. Luigi Notarangelo, a brilliant, insightful, immensely talented and universally respected leader in our community. And only a few steps away is the newly constructed Jeffrey Modell Immunology Center at Harvard Medical School, which completes the picture of a comprehensive commitment to immunology and Primary Immunodeficiencies. Our love affair continues to grow and grow, and we are so proud for Jeffrey's name to flourish here on this campus, surrounded by excellence.

This is a love story that endures. What a great joy and honor for us and for Jeffrey's foundation.

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The Jeffrey Modell Immunology Center at Harvard, dedicated in November 2007, is a unique endeavor serving as a focal point for the most dynamic and diverse community of immunologists in the world.

The Center includes the Dr. Robert A. Good Library and the Dr. Fred S. Rosen Lecture Hall, (named in honor of the founding fathers of modern immunology,) faculty offices, a graduate student area and reading room, a conference room, and reception facilities.

The Center maximizes collaboration between faculty, postdoctoral fellows, and students in the graduate program in Immunology, as well as throughout the Longwood medical area.

"Harvard Medical School is renowned throughout the nation and the world for its outstanding leadership in medical research. The Jeffrey Modell Center will keep Harvard at the cutting edge for years to come in the field of immunology and for prevention, treatment, and cures of a wide range of deadly and debilitating diseases," said Senator Edward M. Kennedy, Chairman of the Senate Health Committee.

JMF and Harvard Medical School Dedicate Jeffrey Modell Immunology Center

Below, from left to right: Dr. Fred Alt, Vicki Modell, Fred Modell, Former Dean Joseph Martin, Dean Jeffrey Flier, Dr. K. Frank Austen.



1. Children's Hospital Boston
2. Children's Memorial Hospital Chicago
3. Children's Medical Center Dallas
4. Lucile Packard Children's Hospital Stanford
5. Federal University Hospital São Paulo, Brazil
6. Medical & Health Science Center Debrecen, Hungary
7. RIKEN Research Center for Allergy and Immunology Yokohama, Japan



Seven New Centers Join Jeffrey Modell Diagnostic and Research Centers Network

New Centers Bring Total Network to 42

Those PSAs Are Everywhere



Media

350,000 Airings/
Placements **2,500** Markets: Television, Radio,
Newspapers Magazines,
Airports, Websites
and **\$95,000,000** In Donated
Media

And

11,126,713 Hits to the
JMF website in the
past year
531,030 Total visits to the
JMF website in the
past year
14,223 Calls to the
JMF Hotline
19,730 Patients registered
in the JMF database

This Campaign Is Working!

112% Annual increase in
patient referrals to
Jeffrey Modell Centers **115%** Annual increase in
patient diagnoses at
Jeffrey Modell Centers **91%** Annual increase in
patients being treated at
Jeffrey Modell Centers



Six studies were conducted by JMF to assess the impact of the Physician Education and Public Awareness Campaign, including Quality of Life and Economic Impact. This data has been accepted for publication in the scientific journal Immunologic Research, published by Humana Press, an imprint of Springer Publishers, NYC. It is anticipated that the article, titled *"From Genotype to Phenotype. Further Studies Measuring the Impact of a Physician Education and Public Awareness Campaign (PEPAC) on Early Diagnosis and Management of Primary Immunodeficiencies"* will be published in early 2009.

JMF Data to be Published in Scientific Journal

Condition	From	To
# of Acute Infections	6.4	1.8
# of Severe Infections	4.3	0.6
# of Bacterial Pneumonias	2.8	0.6
# of Chronic Infections	44.7	12.6
# of Physician/Hospital/ER Visits	70.9	11.8
Hospital Days	19.2	5.1
Days on Antibiotics	166.2	72.9
School/Work Days Missed	33.9	8.9

Changing Patients' Quality of Life in Just One Year

Measuring quality of life data for patients with PI disease in the year before and the year after diagnosis. Provided by expert physicians at Jeffrey Modell Centers, worldwide, in 2008.



The U.S. National Institutes of Health (NIH) estimates that at least 500,000 cases of PI remain undiagnosed in the United States. Using these estimated numbers, the economic impact of undiagnosed PI to the healthcare system in the United States totals more than \$40 billion annually.

Economic Impact

Recently, the National Institute of Allergy and Infectious Disease (NIAID), at the U.S. National Institutes of Health (NIH), stated in a grant announcement: "While individual Primary Immunodeficiency Diseases are rare, as a group, they may affect 1-2% of the population." This translates to between **3 million and 6 million Americans**, a prevalence far greater than most health agencies have estimated in the past. **Can you imagine what the economic impact would be if we used these updated numbers?**

Flemming Nielsen, President, Octapharma USA



Twenty-five years ago, Wolfgang Marguerre was sitting in a rather small office in Paris when he decided to form Octapharma. Mr. Marguerre envisioned a company with the goal of providing patients with the safest, highest-quality plasma products available. Today, Octapharma is still a family-owned business with the goal of helping people live better lives, but at the same time, we have become the largest private plasma products company in the world, and the third largest overall, so we certainly have seized the global opportunity. But our goal is still the same. Patients always come first. In the end, doing what is right for patients has always turned out right for Octapharma as a business.

Octapharma still has that same approach. Safety, integrity, quality, responsibility, loyalty – these are our guiding principles. A good example of this occurred recently when our sales staff became aware of a patient that was on vacation that couldn't get his normal octagam® therapy. The patient was upset because he had previous adverse effects to the alternative that had been presented. Our sales staff went the extra mile to make sure the patient received octagam®. The situation is a good example of how we view our relationship with patients because Octapharma does not look at a sale as being complete when the product leaves our hands and goes to a distributor. Our job is not done until we know the therapy has reached the patient. We are committed to maximizing every patient's quality of life.

Things have changed quite a bit in 25 years – both for our company and the industry. We are now a company of almost 2,000 people in 27 countries, and we are expecting tremendous growth in the U.S. – both in our staff size and product sales. There is no marketplace more important to Octapharma than the U.S., despite continuing supply and access to care issues. Octapharma firmly believes that patients should have access to care at all times and that access to care should not be driven by reimbursement. This is just one of the reasons why it is so important for corporations to collaborate with leading nonprofit organizations like the Jeffrey Modell Foundation.

The efforts of patient-led organizations like the Jeffrey Modell Foundation are vital, particularly in the area of early diagnosis. We stand firmly behind the Foundation because when it comes to ensuring patients have the therapies they need, the PI community is our top priority. Immunoglobulins are the first treatment for PID patients so IVIGs should always be available. It is particularly rewarding for Octapharma staff to see patients get the therapy they need and to be involved with JMF. We consider it a privilege to be able to support the Kids Days programs and the Jeffrey Modell Immunology Center at Harvard Medical School because we get a whole new perspective on what we are working for every day. We look forward to many more joint ventures with Fred and Vicki because Octapharma is committed to giving back to the community when we find opportunities that are consistent with our goal of improving patients' lives each and every day.

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We work closely with JMF and other key healthcare constituencies nationwide because it is critical to our business that we understand the needs of patients. The U.S. market holds the key to Octapharma's future. That is why earlier this year we decided to acquire 33 plasma collection centers throughout the U.S. from International BioResources (IBR).

The acquisition was very significant for a number of reasons. Most important is the fact that demand for Octapharma products continues to rise significantly each year and, to continue to meet the patient demand, we can no longer rely on plasma collected from external sources. Our goal is to have 50 percent of all the plasma we utilize for products coming from Octapharma-owned plasma centers by the next decade. Relying solely on external suppliers for plasma supply is no longer possible, but our relationship with nonprofit plasma suppliers, such as America's Blood Centers, remains as critical as ever to Octapharma's long-term success. Our established relationships with the nonprofit community are very important because working together we can overcome some of the existing marketplace supply issues.

Our anticipated growth in U.S. product utilization in the next few years is based on the continuing strong demand for current products and several new therapies that will be available in the near future. From the beginning, Octapharma has been a strong believer in research and development. What differentiates Octapharma from the rest of the plasma fractionation industry is that Octapharma research is based purely on the development of human proteins; not only are our plasma products of human origin, but so are our recombinant products. Octapharma research focuses on human proteins because we firmly believe that proteins of human origin have optimal tolerability for patients.

Human proteins have been developed over millions of years of evolution, and nature has done a very thorough job of optimizing their efficiency and reducing side effects. Octapharma is focused on bringing these proteins to patients in the form of life-saving therapeutics in a way that respects the integrity of the proteins but at the same time ensures that any potential virus transmission is avoided. With a 130-person research and development team, Octapharma is constantly investing in future therapies as well as optimizing purification and virus inactivation methods, ensuring the safest, highest-quality products available today.

Octapharma is firmly committed to improving the lives of patients in every possible way. Fred and Vicki Modell are true patient advocacy trailblazers, and that is why we respect JMF so much. The formation of JMF was truly a milestone event in advancing the quality of life for the PI community, and we are honored to help advance the JMF mission.

Mr. Nielsen is President of Octapharma USA, a division of Octapharma, the world's largest privately owned plasma products company. Flemming Nielsen joined Octapharma in 2003 when he started his career in the company's Lachen, Switzerland, headquarters as a Finance Controller. In 2004, he moved to the U.S. subsidiary to serve as Vice President of Finance.

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Jeff Blau Challenges More Than 700 Supporters and Raises \$2 Million for Immunology Research



The Jeffrey Modell Foundation held its 22nd Annual "Spring Ahead" Gala on April 24 at Cipriani 42nd Street in New York City. Guests gathered for a "State-Fair" themed evening of dinner, dancing, and live music.

More than 700 guests attended, including Primary Immunodeficiency advocates, educators, patients and their families, supporters from the civic and business communities, and the medical and pharmaceutical fields.

In his remarks to the crowd, Fred Modell, co-founder of the Jeffrey Modell Foundation, highlighted the stories of three young people impacted by PI and read excerpts from the books that each has written. Later in the evening, the young authors held a book signing to autograph copies of their work.

Real estate titan and tireless JMF supporter Jeff Blau, President, Related Companies, was honored as "Man of the Year." He surprised and energized the crowd and the Foundation, when he challenged the supporters to reach the \$2 million mark by offering to match their pledges dollar-for-dollar. The guests responded and achieved an unprecedented milestone - bringing the amount raised to \$2 million for PI research and patient programs.

Please save the date for the 23rd Annual "Spring Ahead" Gala, to be held on April 23, 2009, at Cipriani 42nd Street in New York City.



SAVE THE DATE!

23rd Annual
"Spring Ahead" Gala
April 23, 2009
Cipriani
42nd Street
New York City



In Their Own Words



"If you'd pass me on the street or met me today, you would never know of all the struggles I have been through dealing with PI. Even my life-long friends do not know the extent of my illness, and I prefer to keep it that way. There have been ups and downs, weeks or months where I have been continuously sick, but I have managed to lead a fulfilling, goal-oriented life.

Right now, I cannot complain. I am in my third and last year for my master's degree in architecture at the City College of NY. There are days where I just have to take off because I simply am not feeling well. There have even been weeks I've missed due to hospitalizations, but I always managed to make up the work and stay on track. I know what my limits are and have learned to work around that.

This past summer, I was able to acquire an internship at one of New York's biggest architectural firms. However, the best news of all for me this year is that I am engaged. My boyfriend, Chris, of over 5 years surprised me this past January by taking me on vacation to the Hilton Honolulu and the Four Seasons Resort in Maui, Hawaii where he proposed. The wedding is scheduled for June of 2009, a month after I graduate, god-willing, with my master's degree in architecture. We are now in the process of decorating our home-to-be (the second floor of a brownstone on the Upper East Side).

I have been blessed with a loving family and a fiancé, who has to have been sent from above, who are constantly there for me. Last but not least, the Jeffrey Modell Foundation has made it possible for people like me to dream big, work hard, and accomplish all that I want to do in life. Sure, I might have to work a little bit harder and work around a slightly more complicated schedule, what with treatments and doctor visits, but who says life's easy? If anything, it has made me a stronger and very dedicated person."

–Jacqueline Plumey

"My daughter has CVID. We have enjoyed the opportunities to have the Kids Days sponsored by your Foundation. Just wanted to say thanks. Maggie is an inspiration to all who meet her. I pray for a cure in her lifetime. Thank you for all you do."

–Bebe in Jasper, GA

"I wanted to thank you both for supporting the JMF Kids Day at Hershey Park. It was a great experience and was very well attended. Hershey Park was overrun by people wearing red Kids Day shirts. We had a wonderful time. We were very thankful for the opportunity to allow families to meet and interact with one another. I look forward to seeing you both again. Thanks for your generosity."

–Nicholas in Hershey, PA



"This is to thank you for your support to our Medical Summer School here in Rome. It has been an incredible experience, both for us and the students. During this two-week course, we enjoyed science and Roman heritage! Your travel grants have been very precious for all participants and have rendered this event possible for many of them. Just to give you an idea, I thought you might appreciate a photo with Alessandro, Professor Perricone, the students and myself (third, upper level from the left). Hoping to meet you personally very soon."

–Viviana Moschese and
Alessandro Aiuti

Saving Newborns

SCID or "Bubble Boy Disease" will end a child's life before his or her first birthday, if not diagnosed and treated within the first months of life. The State of Wisconsin is the first in the nation to screen every newborn for Severe Combined Immune Deficiency (SCID). Population screening began in January 2008 in collaboration with the Children's Hospital of Milwaukee, the Medical College of Wisconsin, the Wisconsin State Laboratory of Hygiene, and the Jeffrey Modell Foundation.

To date, 50,000 babies have already been screened, and one or more babies have been identified with a life-threatening PI disease. These babies received appropriate intervention and treatment and are doing fine, according to their physicians. One of the parents expressed their feelings in a letter to the JMF, "Words cannot express our deepest gratitude to all of you for helping with funding for this testing. It is because of you that our little boy has a shot at a great life. Every day he amazes us with his strength and resilience. I think God especially picked him for this journey because he knew he would be strong. I believe there is a purpose for everything and it was not a coincidence that my son received his bone marrow transplant on Jeffrey's birthday. You are all doing so much to raise awareness for immune deficiencies. You played a huge role in saving my baby's life. With thanks and appreciation."

"It isn't a village or hospital that helps these babies. It is people the world over who come together to help children they will never see."

SCID Family Conference



The SCID (Severe Combined Immune Deficiency) Family Conference took place in beautiful Wintergreen, VA, with approximately 175 people in attendance. The conference served as an opportune moment for families affected by SCID and doctors involved in the field to unite and share their ideas and dreams, as well as their experiences and achievements. These achievements include recent developments in SCID research, newborn screening, bone marrow transplantation, gene therapy, enzyme therapy, and other important developments.

The highlights included the participation of Navajo Indian families who traveled across the country to attend this event, as well as a Mennonite family who made a special appearance outside of their community. JMF was proud to participate as a sponsor of this informative and educational weekend.

WIN Grant Awards



WIN, the World Immunodeficiency Network, has had another very successful year, awarding grants to patient organizations across the globe, from Massachusetts to Morocco. To date, WIN has awarded 65 grants, including 12 grants this year alone. WIN was established to provide meaningful support, encouragement and assistance in disseminating information and in developing publications, educational conferences, websites, web links, family days, templates for letters, strategies for more government supported research, and advocacy for product safety and availability. WIN is supported by JMF, multiple U.S. government agencies, and global pharmaceutical corporations.



Jeffrey Modell
World Immunodeficiency
Network



World's Leading Immunologists Gather in Jackson Hole for Expert Meeting Combining Science and Social

In 1970, a committee of international experts in the field of Primary Immunodeficiencies began to meet every two to three years to further classify and define Primary Immunodeficiencies, under the direction of the World Health Organization. These meetings also generated important breakthrough findings through the dialogue and data collected. The resulting reports provided vital information to the medical community as well as to various governments to help determine health care policy.

Beginning in 1996, sponsorship of the meeting was assumed by JMF in collaboration with the International Union of Immunologic Societies (IUIS). Since that time, the Jeffrey Modell Foundation has organized six major scientific meetings on Primary Immunodeficiency Diseases around the world.

1996 - Bristol, England	1999 - Baden bei Wien, Austria
2001 - Luzern, Switzerland	2003 - Sintra, Portugal
2005 - Budapest, Hungary	2007 - Jackson Hole, Wyoming

The next IUIS meeting on Primary Immunodeficiency Diseases will be held in June 2009, in Dublin, Ireland.

Global Impact

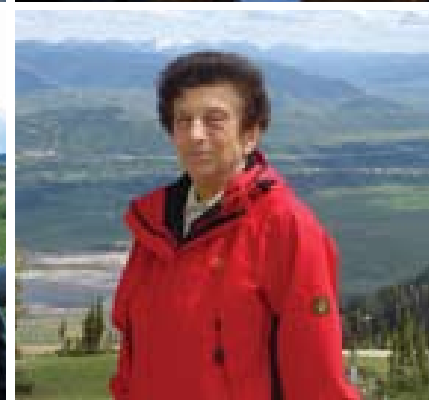
The Expert Meeting, together with the Jeffrey Modell Centers Network, has encouraged the emergence of physician societies around the world. The first meeting of the newly established African Society of Immunodeficiency Diseases (ASID) took place in Casablanca, Morocco and recently Immunologists from the Middle East and Asia convened and agreed to form the Asian Society for Immunodeficiency Diseases. These new initiatives enhance the global community of established organizations including the European Society for Immunodeficiency Diseases (ESID), the Latin American Society for Immunodeficiency Diseases (LASID), and the Canadian Network.

These physician societies, together with support from the U.S. National Institutes of Health (NIH), the U.S. Centers for Disease Control and Prevention (CDC), the U.S. Congress and global pharmaceutical companies, create a platform and springboard for a variety of new initiatives in research, diagnosis and treatment. These collaborations have been applauded by patient organizations around the world.



**SAVE
THE DATE!**

World Health
Organization/IUIS
Expert Meeting
June 3-7, 2009
Dublin



20 JMF Kids Days Reach Communities Nationwide

**Atlanta
Boston
Buffalo
Cincinnati
Cleveland
Dallas
Houston
Los Angeles
Miami
Milwaukee
New Orleans
Omaha
Philadelphia
Seattle
Stanford
St. Louis**

The Jeffrey Modell Foundation Kids Day program offers a welcome opportunity for patients and their families to form friendships with one another, and to get to know their physicians and nurses in a casual environment.

From amusement parks (Atlanta, Los Angeles, Miami) and baseball games (Buffalo Bisons, Milwaukee Brewers, Philadelphia's Camden Riversharks), to zoos (Cincinnati, Cleveland) and museums (Dallas, Houston, Seattle), children and their families are able to share personal experiences in enjoyable environments.

Along with the Jeffrey Modell Foundation, the 2008 sponsors include Baxter, CSL Behring, Grifols, Octapharma, Talecris, and New York Board of Trade.

This year's Kids Day program reached 20 cities throughout the U.S. Recently, similar events were held in Europe, the Middle East, Asia, and Latin America. We eagerly anticipate an even more ambitious program for 2009.





Texas Kids Day Supports "Hurricane Ike" Victims

The September 2008 Kids Day event was cancelled at the last minute due to Hurricane Ike. Remarkably, more than 100 families, led by Dr. Maite de la Morena, arranged for all of the food prepared for Kids Day to go to victims of the hurricane. The food was donated to the Main Street Church of Christ in the Dallas/Fort Worth area. A subsequent Kids Day event has been planned.



**1,200 Athletes
Participate in
"Breath of Life"
Triathlon
to Benefit JMF**

The Dina LaVigna "Breath of Life" Triathlon celebrated its 10th anniversary as a widely recognized premier charity event. Sharing in this successful milestone again this year was a "sell-out" crowd of more than 1,200 athletes and volunteers. This singular Southern California event raised over \$100,000 to be used to improve the conditions and experiences of children undergoing PI treatment.

Of all the accomplishments of the Dina LaVigna "Breath of Life Fund" in the 11 years since its inception, the LaVigna family is perhaps most proud of the special relationship it shares with JMF. With the support of the entire JMF team, the LaVigna family has succeeded in opening two "Dina's Room" state-of-the-art facilities, one at Mt. Sinai in New York City, where Dina lived as a young adult, and most recently, one at Mattel Children's Hospital in Los Angeles.

This year, the LaVigna family celebrates the anniversary of Dina's birth 45 years ago, the 10th anniversary of the "Breath of Life" Triathlon, and its next project to improve PI treatment.

If you are ever looking for a fun way to test your endurance, come out to California in June...and be sure to tell the organizers that the Modells sent you!

This singular Southern California event raised more than \$100,000 to be used to improve the conditions and experiences of children undergoing PI treatment.



**Best Pediatric
Hospitals Partner
with JMF**

Among the 30 Best Pediatric Hospitals in the U.S., Identified by U.S. News & World Report:*

**9 of the Top 10
24 of the Top 30
are Jeffrey Modell Centers**

*Best Pediatric Hospitals 2007. U.S. News & World Report, August 27, 2007

**America's Largest
Charity Evaluator
Gives JMF Highest
Four-Star Rating for
Fifth Year in a Row**

The nation's leading charity rating service, Charity Navigator, has once again awarded JMF its highest evaluation with a four-star rating. Since 2002, JMF has consistently received the four-star rating for excellence in foundation management and appropriation of funds. Charity Navigator is an independent rating service covering more than 5,000 public charities. In a letter to JMF, Charity Navigator stated, "Only 10% of all charities rated have received three or more consecutive four-star evaluations, indicating JMF outperforms most charities in America in its efforts to operate in the most fiscally responsible way possible."