

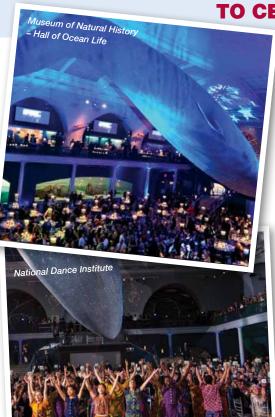
leffrey Modell

# IMMUNEWS





### 1,000 GUESTS FILL NEW YORK'S MUSEUM OF NATURAL HISTORY TO CELEBRATE JMF'S 25 YEARS



The Jeffrey Modell Foundation celebrated its 25th Anniversary at New York City's landmark American Museum of Natural History. The sold out event — "25 Years and Still Reaching for the Stars" honored David W. Levinson, Chairman and CEO of L&L Holding Company. Levinson, together with his partner Rob Lapidus, founded L&L 11 years ago. It is a privately owned real estate investment & development company that owns more than 5½ million square feet of commercial office space valued at over \$3 billion.

Longtime generous supporters from the real estate industry, pharmaceutical companies, government officials, board members, donors, physicians, family and friends filled the Museum's Hall of Ocean Life to capacity.

"The Real Estate community and their generosity have supported our Foundation since the very beginning," said Fred Modell, Co-Founder of the Jeffrey Modell Foundation.

"We know this group has the ability to write checks and attend galas, but what people don't realize is that their commitment has gone far beyond that. They want to know how they have changed the lives of the patients, especially the children." The evening was filled with high spirits, great energy, and good company in a magical and majestic setting. "Spring Ahead" raised funds for meaningful research and comprehensive patient programs dedicated to Primary Immunodeficiency (PI).



### **WORLD IMMUNOLOGY CONFERENCE**

"A Global Get-Together" June 1st - 5th

360 Expert Immunologists from 64 countries, convened at Rockefeller University, for the Jeffrey Modell Foundation's first World Immunology Conference — "A Global Get-Together." The Conference began with a Keynote Address delivered by Nobel Laureate, Dr. David Baltimore, President Emeritus, California Institute of Technology. The world meeting was a perfect blend of clinical and basic science with the goal of enhancing education and expanding dialogue on Primary Immunodeficiencies globally. The collective expertise and efforts of all invited Expert Immunologists will help further research, advance treatments, encourage new discoveries, and ultimately, lead to cures.

The entire Conference was Webcast in real-time to physicians throughout the world. This provided an opportunity for physicians, scientists and medical students to interact with more than 40 speakers on a vast array of topics including Primary Immunodeficiencies, Autoimune Diseases, Cancer, Bone Marrow Transplantation, and Gene Therapy. Physicians from 38 countries participated in the Webcast.



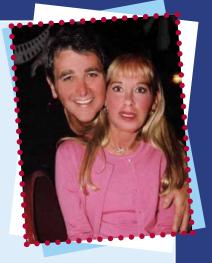


## Vicki and Fred...

### **Some Thoughts**

#### **BUDGETS AND BABIES**

You wouldn't normally think about budgets...Federal, State, City... or perhaps even household budgets, when you and your family are celebrating the joyful experience of bringing a healthy newborn baby into the world. But somehow, in the current environment, we actually find ourselves appearing before Members of Congress and Government Agencies, trying our best to justify an investment of \$4 to screen a newborn baby for Severe Combined Immune Deficiency (SCID), a life threatening disease. The discussions absolutely defied logic as we brought to their attention the following:



- 1. Babies born with SCID will die before their first birthday. But, with newborn screening they can be diagnosed and cured with a bone marrow transplant.
- 2. Science has actually developed a cure for a child with a fatal disease who can now live a healthy and productive life.
- 3. JMF, in collaboration with government, has funded 10 states including California and New York. We are now screening 2 million newborns or about 50% of the babies born in the US.
- 4. The cost for this screening is \$4 per baby.

We were astonished to receive word that government would no longer continue to fund the screening programs, because of budgetary constraints. We are still in discussions with federal and state officials, but the future for this program is very uncertain. We realize that decisions need to be made and priorities need to be addressed, but when it comes to saving the life of a newborn baby, we believe that there are serious and dire consequences to such decisions. As supporters of the Jeffrey Modell Foundation, you are entitled to know what kind of decisions and priorities our lawmakers and government officials are making with respect to the citizens whom they represent and their families.

We hope to change their minds! Stay tuned...

### Vicki and fred

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#### JMF APPOINTS EXECUTIVE DIRECTOR

The Jeffrey Modell Foundation announced that Vanessa Tenembaum has been appointed as Executive Director. The new position responds to the dramatic expansion of the Jeffrey Modell Centers Network.

Vanessa returns to the Foundation where she began 11 years ago. During the past five years, she worked with Russell Simmons as Director of Marketing for his jewelry brands. "I am excited to return to the Jeffrey Modell



Foundation and reunite with physicians, families, patients, and friends, many of whom I have kept in touch with over the past 5 years. I believe that working with Russell was an invaluable experience, and I can bring those skill sets back to the Foundation."

Vicki Modell, Co-Founder of the Jeffrey Modell Foundation said, "Vanessa joins us at an important moment in the Foundation's history. I am thrilled to have Vanessa back with us as Executive Director. She has the heart, compassion, and skills to lead this Foundation, as we embark upon exciting new initiatives planned all over the world."



## JMF'S NEWBORN SCREENING PROGRAM — ALREADY SAVING LIVES!!

#### **NEWBORN SCREENING FOR SEVERE COMBINED IMMUNE DEFICIENCY (SCID)**

JMF continues in its quest to screen every newborn for Severe Combined Immune Deficiency (SCID). Babies born with SCID will not survive to their first birthday but with Newborn Screening they can be identified, diagnosed, and cured with a stem cell transplant. JMF's efforts have led to screening more than two million newborns in 10 States including California, New York, Wisconsin and Massachusetts or about 50% of all Newborns in the United States. **Not a single baby has been lost to SCID in the states currently screening for the disorder.** As of publication date, 10 more states are prepared to go forward subject to availability of funds.



- When detected in the first few months of life, SCID can be cured with a bone marrow transplant.
- Late diagnosis of SCID costs an average of \$2.2 million.
- Early diagnosis & treatment, in the first 3 months of life, ranges in cost from \$10,000 to \$100,000.
- The cost to screen using the TREC's assay is \$4 per baby.
- We Can Screen! We Can Treat! We Can Cure! We Can Do This Economically!
- The results priceless.



## ANGEL FLIGHT TAKES OFF WITH Roots & Wings

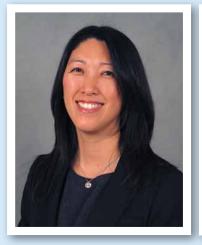


The "Roots & Wings" Program was established by the Jeffrey Modell Foundation to provide travel and related support to families whose child has been identified with a potentially life threatening Primary Immunodeficiency, and requires lifesaving medical care. These little patients often require transportation to specialized centers where they might reside for several months, while undergoing treatment. "Roots & Wings" will make life easier, reduce the burdens, and enable these children to have a second chance at life.

Angel Flight has joined with JMF to provide free air transportation by their volunteer pilot network for the patients and their families, especially those living in rural areas that need specific care at urban hospitals.

Vicki Modell, Co-Founder of JMF said: "With this new partnership, we can provide hope to families across the nation and the necessary 'Roots and Wings' to save many precious lives."

#### MEETING INDUSTRY LEADERS



Julie Kim General Manager, Biotherapeutics Baxter's BioScience Business



Ludwig Hanston
President,
Baxter's BioScience Business

Julie Kim has been with Baxter for more than ten years in various roles of increasing responsibilities within the BioTherapeutics commercial team; Ludwig Hantson recently joined the Company as the President of Baxter's BioScience Business. Julie and Ludwig share a deep passion with the entire Baxter Team to understand the needs of the PI community and work collaboratively to meet those needs and improve the lives of patients worldwide.



Julie Kim and Ludwig Hantson at Jeffrey Modell Center Dedication in Leuven, Belgium

# "In their own words"

We're committed to positively impacting patients' lives through our innovative therapies, support and education.

Baxter's BioScience business is a leader in recombinant and plasma-based protein replacement therapies to treat a variety of life-threatening and often difficult to diagnose conditions. In support of our commitment to deliver life-saving and life-sustaining therapies, we have a long-standing relationship with our patient communities, including our close, twenty-five year collaboration with JMF, which began when Baxter attended the first KIDS day in Central Park in 1986. Since those early days, we have been an ardent supporter of JMF's mission to raise awareness and increase diagnosis of primary immunodeficiency disorders worldwide through supportive educational programs, involvement in market access and diagnosis campaigns, funding of primary research through the Jeffrey Modell Centers Network and delivery of novel therapeutic solutions and services that continue to ease the burden of the disease on patients.

Over the years, Baxter has become actively involved in programs and events with JMF. It's through these programs that we have the opportunity to understand the needs of our community and to deliver solutions that can make a meaningful difference to patients, families and caregivers.



Baxter worked together with JMF to raise awareness of PI at the EU Parliament this past year. In addition, we sponsor 23 Jeffrey Modell Diagnostic and Research Centers at prestigious medical institutions around the world, and a new Center was just recently dedicated at Children's Hospital Los Angeles.

Recently, we had the pleasure of attending the JM Diagnostic and Research Center opening in Leuven, Belgium. The dedication and passion of Prof Meyts and everyone involved in the center was reflected in the opening with over 150 patients, families and treaters in attendance. It was truly inspirational to hear some of the patient stories and gave us an eye into the community and the continued progress that is needed to improve the lives of those suffering from the disease. It is personally fulfilling to know that we're a part of this progress.

As a market leader for the past several decades, Baxter has always held a strong commitment to consistently providing the highest quality therapies to our patients. We have a robust history of introducing therapies that improve the lives of patients with PI, continually delivering projected clinical outcomes, consistent safety and tolerability profiles, and more convenient options that allow patients to lead a more normal lifestyle while managing their PI.

Our team at Baxter has been actively involved in the PI community for more than 25 years and plans to make a positive difference in patients' lives well into the future. As part of our efforts to advance innovation in this space, Baxter's BioScience team is actively investigating new opportunities and listening to feedback from the patient community and our partners, like JMF, to improve our current product portfolio. We're looking at new therapeutic combinations, new delivery mechanisms and new ideas to support PI patients around the world. We look forward to continuing to support JMF and PI patients for many years to come.

Our team at Baxter has been actively involved in the PI community for more than 25 years and plans to make a positive difference in patients' lives well into the future.



Dr. Joseph Church with the Baxter team and Vicki and Fred Modell at dedication of Jeffrey Modell Center at Children's Hospital Los Angeles

Baxter enthusiastically supports the JMF mission of advancing awareness and diagnosis of PI.



# "When I Grow Up..."

### DONATED MEDIA TOPS \$175 MILLION TO SUPPORT JMF'S NATIONAL PUBLIC SERVICE ADVERTISING CAMPAIGN AND STILL CLIMBING

To coincide with this year's 25th Anniversary, JMF launched its seventh year of Public Service Advertising with an all new Campaign, "When I Grow Up." The PSA's have been prominently featured on TV, radio, airports, shopping malls, magazines, and even large billboards in Times Square. Vicki Modell, Co-Founder of the Jeffrey Modell Foundation, described the new Campaign as "one that allows a child to dream of days without hospital visits, sleepless nights, and without fevers. It encourages a child to be whatever they want to be...playing baseball, fighting fires, becoming a chef, and even a glittery rock star. These children now have a chance."



# ONE MILLION UNIQUE VISITORS VIEW WWW.INFO4PI.ORG

JMF's National PSA Campaign continues to encourage visits to our website. **info4pi.org** is the PI "hub" for patients throughout the world. JMF continues to update the Website with the most current information and "Breaking News". The Website offers easy access and referrals to Expert Immunologists in the Jeffrey Modell Centers Network, as well as grant opportunities for physicians and patient groups.

Since the Website was established, it has received more than 62 million hits from more than one million unique visitors. 23,000 calls have been logged by our hotline and 36,000 patients are now registered in our database. The activity has been tracked from all 50 states and 66 countries around the world.



### incm Newly Published Manuscript

"Global Study of
Primary Immunodeficiency Diseases (PI) —
Diagnosis, Treatment and Economic Impact:
An Updated report from
the Jeffrey Modell Foundation"

In 2011, the Jeffrey Modell Centers Network expanded by more than 40%.

JMF reached out to our Network physicians with a newly developed questionnaire and survey.

76% of our Center Directors responded.

The data was collated, the results were included in a newly developed manuscript and the study sustained vigorous peer review.

This manuscript was accepted and published

and is now available online at Do1:10.1007/s12026-D11-8241-y,
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**112**%

increase in the patients identified with PI defects in the past two years

**107**%

increase in patients requiring IgG therapy in the past two years

**70**%

decrease in the number of infections, pneumonias, emergency room visits, days in hospital, days on antibiotics and school/work days missed one year after diagnosis

**\$108,462** 

reduction in healthcare costs for patients diagnosed and treated one year after diagnosis

1:583

patients scored as high risk for PI with the new Spirit Analyzer Software®

# JEFFREY MODELL ENDOWED CHAIR DEDICATED AT CHILDREN'S HOSPITAL OF PHILADELPHIA



Fred Modell, Dr. Jordan Orange, Dr. Steven Altschuler and Vicki Modell

JMF continues on its mission to assure expert research and clinical care for Primary Immunodeficiency in perpetuity. The fourth Jeffrey Modell Endowed Chair in Pediatric Immunology Research was recently dedicated at Children's Hospital Philadelphia (CHOP). The first endowed professor holding the Chair is Jordan Orange MD, PhD. Endowed Chairs have also been

established at Boston Children's Hospital, Seattle Children's Hospital, and New Orleans Children's Hospital.



### U.S.News

### WHERE ARE THE JEFFREY MODELL CENTERS?

US News and World Report recently rated children's hospitals for excellence in pediatrics. More than 5,000 hospitals in the US were examined and rated.\* 10 of the top 11 "Best Children's Hospitals" and 22 of the top 30 are Jeffrey Modell Centers.

In a separate report the best Immunology and Infectious Disease Programs at Graduate and Medical Schools were rated.\*\* **8 of the top 10** programs, including the #1 rated, Harvard University are Jeffrey Modell Centers. The Foundation is proud that the newly constructed Jeffrey Modell Immunology Center, centrally located on the Harvard Medical School campus, has become the Immunology focal point at Harvard.

\* Best Pediatric Hospitals 2011. U.S. News & World Report, May 17, 2011 \*\* Best Graduate Schools 2011. U.S. News & World Report, May 15, 2011

### RECENT JEFFREY MODELL CENTER DEDICATIONS











Buenos Aires, Argentina



Hope ★ Advocacy ★ Action









# Kids will be "KIDSS"

Created in 1988, KIDS DAYS started in New York City. The KIDS Day program, for Kids with Immune Deficiencies, has spread from Seattle to St. Louis, Sáo Paulo to Shanghai, Miami to Morocco, Oslo to Omaha, Chicago to Colombia and all that's in between. Kids Days provide PI patients and their families, along with their doctors and nurses, an opportunity to relate and form friendships in a casual and fun environment outside of the hospital. Events have been held at a range of great locations, including baseball games, museums, aquariums, zoos, carnivals, and bowling alleys, just to name a few. There have been clowns, face painting, balloons, magicians, and other fun activities... not to mention lots of food!

Thanks to our generous sponsors, Baxter, CSL Behring, Grifols and Octapharma, this program continues to thrive and has an important impact on so many patients and their families.

It's a special fun-filled, festive, incredible

and unforgettable day for all!



Los Angeles
Miami
Milwaukee
New Orleans
New York
Omaha
Philadelphia
Seattle
St. Louis
Stanford
Tampa/St. Pete

Atlanta

Boston Buffalo Chicago Cincinnati

Cleveland

Dallas

Houston

Irvine



#### International

Argentina
Brazil
Chile
Colombia
Mexico
Morocco
Norway
Serbia













# "IT'S A WIN, WIN" FOR PATIENTS AND PHYSICIANS

JMF's WIN Program has awarded 131 grants to patient groups worldwide, and continues to expand every year. WIN grants fund medical Conferences and workshops, Websites, KIDS DAYS, as well as educational materials.

Recent WIN grants supported a Conference on Rare Diseases in Cyprus, a SCID Symposium in the US, the 7th annual Ataxia-Telangiectasia (AT) meeting in Poland, a Physician Education conference in Morocco, a manuscript for a medical journal in France, awareness programs in Iceland and Germany, KIDS Days in Mexico, Brazil, Netherlands and Canada, as well as many other events and activities in South Africa, United Kingdom, Argentina, Colombia, Serbia, Chile, United States and more. Many activities celebrated "World PI Week" in April, including a special education event for patients in Norway and Cyprus.



### NEW Program – winMD – Offers Grants to Physicians Worldwide

This year JMF introduced **winMD**. The Program was established to continue JMF's mission to enhance physician education. **winMD** offers grants to medical students, fellows, researchers and physicians to support travel to national and international medical conferences that highlight Primary Immunodeficiencies. There is a great demand for these grants and **winMD** will be a vital funding source. Grant applications are available at www.info4pi.org.



# Lots of "FUN" RAISING

### Dina Lavigna "Breath of Life" Triathlon

The "Breath of Life" Fund was established by the family of Dina LaVigna, who died at the age of 33, after a courageous battle with Primary Immunodeficiency. In her memory, the family organizes and hosts the Dina LaVigna "Breath of Life" Triathlon and recently held their 13th annual event in Ventura, California. This year's Triathlon attracted more than 800 registrants and over 100 volunteers. Since its inception, the Triathlons have raised more than \$7.5 million. These funds are used to build and enhance infusion facilities in children's hospitals, fulfilling Dina's wish for brighter, happier surroundings while the patients receive treatment.

This year, the LaVigna Family chose to have the proceeds go toward JMF's new "Roots & Wings" Program, which provides travel and related support to families whose child has been identified with a potentially life threatening Primary Immunodeficiency, and requires specialized or lifesaving medical care.





### More "FUN" RAISING

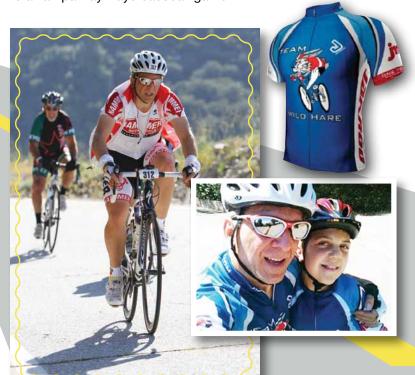


### Wiffle Ball Tournament

Connie and James Ramos have done it again! The 3rd annual Wiffle Ball Tournament took place on St. Pete Beach in Florida. The day began with Beach-Side Meet-and-Greet. The Tournament had a fantastic turnout with more than 600 attendees, over 250 children, raising funds to benefit All Children's Hospital and the University of South Florida Department of Allergy and Immunology.

The three day event was filled with fun, food, families, and fireworks. Guests and players tried their luck at a Home Run Derby, and a lucky winner won 4 box seat tickets







Steve Bursley has begun his second year as "One Tough Guy" for his yearly Fundraiser "One Tough Ride". Steve endures the challenges of many ultraendurance cycling competitions to honor his son, Nicholas, and all children who live with Primary Immunodeficiency. The Jeffrey Modell Foundation is proud to support Steve for his courage and commitment throughout the season. Steve has completed the L'Etape Du California and the Tour de Starbucks and looks forward to the Santa Cruz Mountains Challenge and the Furnace Creek 508. Good Luck Steve!!



#### Hope ★ Advocacy ★ Action



The Jeffrey Modell Foundation has been on an extraordinary twenty-five year journey of hope, advocacy and action — to alleviate suffering, improve the quality of life and, ultimately, find cures for patients with Primary Immunodeficiencies.

Our inspiration comes from the brilliance and compassion of the physicians, the resolve and dedication of the researchers, the perseverance of the quiet, unsung heroes working days and nights in their laboratories, the bravery and courage of the families, and most of all, the patients who inspire us and encourage us to continue our incredible journey.

"The Global Get-Together", held at Rockefeller University, was our gift to all participants... With special thanks and appreciation to our Conference Chairpersons: Doctors Jean-Laurent Casanova, Alain Fischer, Raif Geha & Chaim Roifman whose expertise, love of medicine and brilliant efforts produced the exquisite program... Our esteemed Faculty for sharing their intellect and knowledge... Our prominent and preeminent Physician Delegates that represented countries around the world... And our Sponsors whose constant and consistent generosity, encouragement and hearfelt compassion make everything possible.

The Conference opened with a warm and festive "Welcome to New York" party at the Waldorf=Astoria Hotel. It was an opportunity for more than 360 Expert Immunologists from 64 countries to interact and connect with old friends and new. The next evening, they enthusiastically participated in the "Spring Ahead" Gala at New York's Museum of Natural History.

The Conference concluded with a "Fun Farewell" event, "Watching the Sunset with Miss Liberty in New York Harbor". Everyone enjoyed a fun sing-along with "the Pogies", a live band of Immunologists from Harvard Medical School led by Dr. Fred Alt. It was an unforgetable four days!



"Thinking about some Numbers such as the number of new diseases presented, the number of countries participating, the number of guests, the number of possibilities to relieve the children around the world ... I found a figure simply impossible to calculate by my computer." - Casablanca, Morocco

#### **Hope \* Advocacy \* Action**



"I attended too many meetings in my life, but I never enjoyed a meeting of such a high scientific and emotional level. The most clever immunology people in the world were there, all really participating with their best attitude to achieve our common aim, to cure PID worldwide. I'll continue to do my best to contribute on my side." - Rome, Italy







"The science was outstanding, discussions with colleagues were fruitful, opportunities have been great. These are things which create links and bridges between people for the benefit of patients and knowledge."

- Tunisia







"Thank you for your generous, tremendous and incredible worldwide contribution to the field of PI; for reminding us, day by day how dedication, determination and passion can save lives; for providing me the great opportunity to be part of the "JMF Family" from both a professional and humanity point of view."- Israel





#### **Hope \* Advocacy \* Action**

"I keep going through my notes and I cannot stop thinking what a fantastic meeting this was!!!! The best ever in my life! None of this would have been possible without your continuous strenuous effort to bring together the PI community worldwide, with no barriers! The venue was fantastic and the friendly and very warm hospitality marked one more time your generosity. I want to thank you from the deepest of my heart and please be reassured that I will continue to work beside you to help you raise the world PI community!!!" - United States





"You made miracles and history! ... you motivate us finding and creating new ways to help out patients. All our patients know you indirectly. We cannot thank you enough for paving ways we could never dream to walk through." - Cairo, Egypt



"...thanks again for a really exceptional event you organized in NY. I was impressed even more when I found myself sitting with my coffee in JFK Delta terminal on my way back just in front of JMF poster!" - Prague, Czech Republic



### **Hope ★ Advocacy ★ Action**











"What a special event, organized by very special people."
- The Netherlands





### **IMMUNOLOGISTS AWARDED NOBEL PRIZES**

The Jeffrey Modell Foundation congratulates Drs. Bruce Beutler, Jules Hoffman and Ralph Steinman as recipients of the 2011 Nobel Prize in Medicine, for their research on the immune system and its relationship with infectious diseases. We were honored to have Dr. Bruce Beutler as a Speaker at the World Immunology Conference in June and for the past 15 years, the JMF has had a long relationship with the laboratory of Dr. Ralph Steinman at Rockefeller University. Sadly, Dr. Steinman died three days before the announcement.

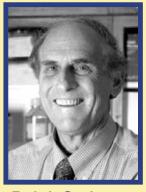
Every year since 1901 the Nobel Prize is awarded for achievements in physics, chemistry, physiology or medicine, literature and for peace. The Nobel Prize is an international award administered by the







Jules Hoffmann



Ralph Steinman

Nobel Foundation in Stockholm, Sweden. Since 1901, 34 of all Nobel Laureates in physiology or medicine were awarded for their research and discoveries in Immunology.

The Jeffrey Modell Foundation is pleased to honor these outstanding scientists on our Wall of Immunology at the Jeffrey Modell Immunology Center, Harvard Medical School.

## JMF RECEIVES HIGHEST "4 STAR" RATING FOR SOUND FISCAL MANAGEMENT \* \* \* \*

Charity Navigator, America's largest and most utilized independent evaluator of charities, announced that the Jeffrey Modell Foundation has earned its highest, and most coveted, 4 star rating for sound fiscal management. The notification letter pointed to JMF's "ability to efficiently manage and grow its finances, and execute its mission in a fiscally responsible way. JMF outperforms most other charities in America, and this exceptional designation differentiates JMF from its peers and demonstrates to the public that it's worthy of their trust."

Charity Navigator evaluates the financial health of over 5,000 charities in the United States annually.



# The Jeffrey Modell Foundation has moved!

CHARITY NAVIGATOR

Your Guide To Intelligent Giving

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www.info4pi.org

