

# Update



JEFFREY MODELL CENTERS FOR PRIMARY IMMUNODEFICIENCIES

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Paris • Philadelphia • Seattle • Stanford • Stockholm • Toronto • Vienna

## National Public Service Advertising Campaign for Primary Immunodeficiency (PI) Generates \$16 Million in Donated Media

The 1st National Public Service Advertising Campaign for PI was launched by the Jeffrey Modell Foundation (JMF) in collaboration with the Ad Council. It had 43,089 television airings, 16,945 radio airings, appearing on 2000 television and radio



The "Face" of the New Campaign

stations in the first year.

The PSA's aired during primetime hours on *ABC World News Tonight*, *NBC*, *Fox News*, *Good Morning America*, *Today*, *Fox and Friends*, *O'Reilly Factor*, *Tonight Show*, *Yes Network*, *USA Network*, *National Geographic*, *Lifetime*, and *NY1*. The PSA's aired throughout Westwood 1 Syndication and 328 radio airings were heard during peak listening hours of the afternoon and morning drive. 4-color print PSA's appeared in *Time*, *U.S. News and World Report*, *Newsweek*, *Sports Illustrated*, *Parade*, *Readers Digest*, *the Hill*

and the *National Association of School Nurses* official publication.

The JMF website traffic increased from 223,736 to 565,527 hits per month, and the JMF hotline activity increased from 29 calls to over 500 calls monthly, as a result of \$16,641,822 donated media.

A new campaign, developed by a leading New York ad agency, Korey Kay and Partners, will build upon the successes of the first campaign. It will be launched in late fall of 2004, and features a 6 year old boy (left).

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## WIN Awards 16 Grants to Patient Organizations

### WORLD IMMUNODEFICIENCY NETWORK SUPPORTS PATIENTS WORLDWIDE

Patient groups from Latin America, U.S., Canada, Europe and Eastern Europe are receiving grants under JMF's WIN program. Within the last year, WIN has provided assistance, support and funding to 16 patient organizations to assist them with publications, educational materials, translations, website development, website links, family days, newsletters, and government advocacy. The JMF 10 Warning Signs poster is now distributed in 21 countries and is available in at least 14 languages. An esteemed Medical Advisory Board reviews WIN grant applications and awards are made within 30-45 days. WIN is funded by JMF, multiple U.S. government agencies and global pharmaceutical corporations. JMF has received a very positive response from grantees (see page 4).

WIN patient grant applications are offered on the JMF website: [www.info4pi.org](http://www.info4pi.org). Simply click to "WIN."



world immunodeficiency network  
One voice for PI patients worldwide

## MESSAGE FROM VICKI AND FRED

### *“What It Was Like”*

No one told us that the room would have 7000 seats...or that another 1000 would be standing in the aisles. No one told us that the award ceremony would be viewed on 6 jumbo screens in a meeting auditorium that would easily hold 6 football fields. No one told us we would receive the IUIS award surrounded by the world’s most renowned immunologists, scientists, Nobel Prize winners, investigators, physicians, pharmaceuticals, press and dear friends. If they did, we might have been tempted to board a flight to Miami rather than Montreal.



It was awesome! It was humbling! It was definitely a little scary! It was a kind of “out-of-body” experience. It was a great night, and we accepted the beautiful IUIS Melchers Award with pride and humility. This was an honor we could never have imagined when we started the Foundation 17 years ago. The event touched us profoundly, and we will always cherish this occasion. But it also galvanized us to work harder with renewed vigor, dedication, resolve and focus, giving a voice to families struggling with Primary Immunodeficiencies and the physician / scientists who take care of them.

The devastating disease that ended Jeffrey’s life is beginning to find a place on the public’s radar screen. The Public Service Advertising Campaign has been aired on T.V. and radio more than 60,000 times (pg.1). Collaborating with the United States National Institutes of Health, JMF just sent its Warning Signs Poster and Physician Algorithm to 200,000 pediatricians, family practitioners and sub specialists nationwide (pg.10). Even the EU Parliament wanted to know more about the Awareness Campaign (pg. 5). All of this is beginning to make a difference. We are getting reports from our Diagnostic and Referral Centers, showing significant increases in referrals, diagnoses, treatments and in some cases, even cures (pg.12). The work goes on and the breakthroughs are within our grasp.

For the rest of our lives, we will never forget the night we received the IUIS Award. It was an incredible honor, but for us, of even greater importance, is our unwavering commitment to never forget a single child or adult struggling with this devastating disease. We will now continue on our journey, filled with optimism, renewed energy and passion. Yes, it was quite a night.

*Vicki and Fred Modell*

Co-Founders of the JEFFREY MODELLE FOUNDATION



## IUIS Award Presented to the Modells

At the opening ceremony of the 12th International Congress of Immunology (ICI) held in Montreal, Canada, Vicki and Fred Modell received the International Union of Immunological Societies (IUIS) 2004 Award in honor of their contributions to the field of immunology.

The IUIS currently totals 54 membership groups encompassing Europe, Latin America, Africa, and Asia. There are 30,000 members of IUIS, most of them scientists and physicians in basic, applied, and clinical immunology with major applications in immunodeficiencies, autoimmune diseases, allergies, cancer and vaccines. An estimated 10,000 participants attended this year's triennial International Congress in Montreal.



Congress President, presided over the presentation ceremonies:

**"The Award Committee recognizes that Vicki and Fred Modell have dedicated the last 17 years supporting research and physician education, developing patient support and raising public awareness for Primary Immunodeficiencies. The International Immunological**

**community honors and pays tribute to Vicki and Fred Modell's selfless and optimistic commitment, their unwavering energy and endless generosity."**

The award has been given only once before, to Bill and Melinda Gates of the Gates Foundation.

The IUIS award was presented by Professor Fritz Melchers and Mrs. Ursula Melchers. Professor Melchers is the former President of the IUIS. He and his wife donated the gold sculpture, which is in the form of an antibody molecule and designed by Nikki de St. Phalle. Dr. Emil Skamene,



TOP LEFT TO RIGHT: Professor Fritz Melchers delivers laudation for IUIS prize; Vicki Modell offers her thanks on behalf of the Foundation. BOTTOM LEFT TO RIGHT: Vicki and Fred Modell receive the IUIS Award; Fred Modell showing the award laudation to friends; Vicki Modell proudly displays the gold sculpture in the form of an antibody molecule, designed by Nikki de St. Phalle.

# JMF Joins with Senator Arlen Specter to Champion Stem Cell Issue

## VAST MAJORITY OF AMERICANS SUPPORT EMBRYONIC STEM CELL RESEARCH

According to a national survey conducted in late July 2004, 69% of American voters support stem cell research with a majority (51%) of voters saying that they strongly favor this research. Support cut across party lines, as a majority of Democrats (77%), Independents (67%) and Republicans (60%) encourage the government to continue this research.

Embryonic stem cells, that would otherwise be discarded, have the potential to differentiate into any human cell type. The cells can potentially be used to create vital organs such as kidneys, livers or even hearts and could hold promise to cure diseases such as Juvenile Diabetes, Parkinson's, Alzheimer's, Multiple Sclerosis, Cancer and Immune System Disorders.

Senator Arlen Specter, (R-PA), Chairman of the Labor, Health and Human Services Appropriations Subcommittee, has championed this cause in the United States Congress. 58 U.S. Senators signed a letter sent to President George W. Bush urging the President to modify current embryonic stem cell policy. Most Democrats signed on to the letter, as well as Republicans such as John McCain, Orrin Hatch, Trent Lott, Ted Stevens, Lamar Alexander, Kay Bailey Hutchinson and Thad Cochran.

Senator Specter has worked closely with the Jeffrey Modell Foundation to increase funding for physician education and public awareness for Primary Immunodeficiency diseases.



Senator Arlen Specter (R-PA) and the Modells

## Kind Words from WIN Grantees

IN ITS FIRST YEAR, JMF HAS RECEIVED VERY POSITIVE "FEEDBACK" FROM WIN GRANTEES. HERE ARE A FEW:

"The WIN funds make it possible for us to soon have our own newspaper. All the members of our support group are grateful for your generous help."

— *Germany*

"WIN funds have allowed us to establish a website dedicated to raising awareness and meeting the unique needs of individuals affected by Primary Immunodeficiency. The site is now "live". Thanks for all of your support."

— *Canada*

"We want to thank you and WIN for the approval of our grant application. Your support will help us a lot to improve the information we want to give to every French speaking patient. Thank you so much for your great job for patients with PI!"

— *France*

"Our website is almost finished and visitors are informed that we were able to create and open our website because of WIN. Our dreams have come true."

— *Iceland*

"Our book is now completed. Many thanks to WIN for making this happen. You cannot imagine how happy we are."

— *Denmark*

"The Kid's Day supported by WIN allowed parents and children an opportunity to discuss their treatments and conditions in a non-medical setting. It showed them that they are not alone. The patients are still talking about their wonderful experience. Thank you so much, and keep up the good work."

— *USA*

# Jeffrey Modell Foundation Addresses EU Parliament

The Jeffrey Modell Foundation was invited to speak before the Scientific and Technical Options Assessment (STOA) meeting held at the European Union (EU) Parliament. Fred Modell, Co-Founder of the Jeffrey Modell Foundation addressed EU Members:

“The EU Parliament has an opportunity to encourage and support a physician education and public awareness campaign in the EU countries.

We are asking the EU to do for National Member Organizations (NMO’s) and the International Patient Organization for Primary Immunodeficiencies (IPOPI) what the U.S. Congress, the NIH, and the CDC did for the Jeffrey Modell Foundation.

We are not asking for a handout, but we do need a hand and a signal that this extraordinary and powerful body has heard the voices of these affected children and young adults and fully supports this initiative. The EU Parliament initiative will reverberate

throughout the 25 member countries at the health ministry level, hospitals, medical schools, primary care physicians, specialists, patients, parents, nurses, schools, and the workplace. Your support is critical and we are asking for your help.”



LEFT TO RIGHT: Dr. Cees Kallenberg (the Netherlands), David Watters (Great Britain), Dr. Janne Bjorkander (Sweden), Ann Gardulf RN, PhD (Sweden), Dr. Lennart Hammarstrom (Sweden), Dr. Luigi Notarangelo (Italy), Dr. Reinhold Schmidt (Germany), Dr. Helen Chapel (Great Britain), Vicki and Fred Modell

## School Nurse Poster Campaign

In a further effort to identify undiagnosed PI patients, the JMF launched a new program to educate school nurses in America, totaling 38,650. A poster kit was mailed to all school nurses, and there has already been a vigorous, positive feedback through emails and hotline calls.

1116 school nurses completed a survey on this program for JMF:

- 75% of respondents shared the program with other teachers, nurses and students.
- 72% of the respondents believed that parents/ guardians and teachers were better informed after reviewing the materials.
- 48% of respondents believed Primary Immunodeficiencies were common or fairly common, after reviewing the materials.
- 65% of respondents would urge parents to ask the doctor to do further testing of students suffering from unexplained recurring illnesses or infections.
- 7.8% of respondents indicated that they currently have students diagnosed with PI.
- 59% of respondents are aware of students suffering from unexplained, recurrent ear infections, sinus infections, pneumonia or similar recurring problems, without a specific diagnosis.
- 87.28% of the respondents indicated that they displayed the wall poster.

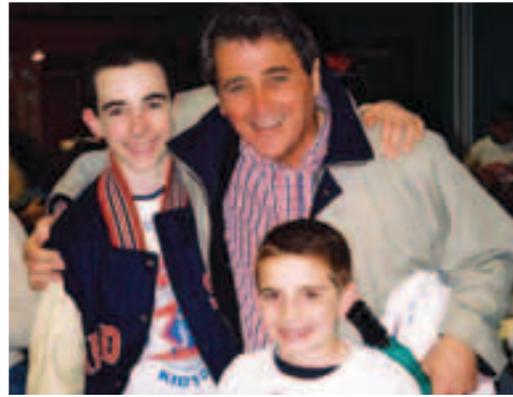
The program had an overall reach of 718,504 nurses / educators and 12,522,600 students (average reach of 324 students and 18.59 teachers).

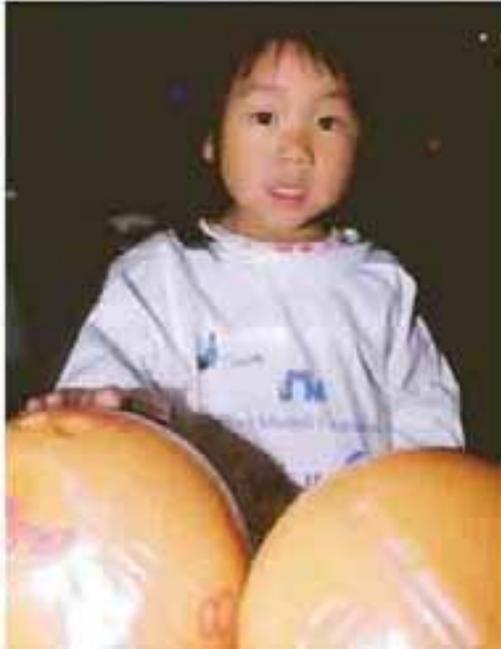
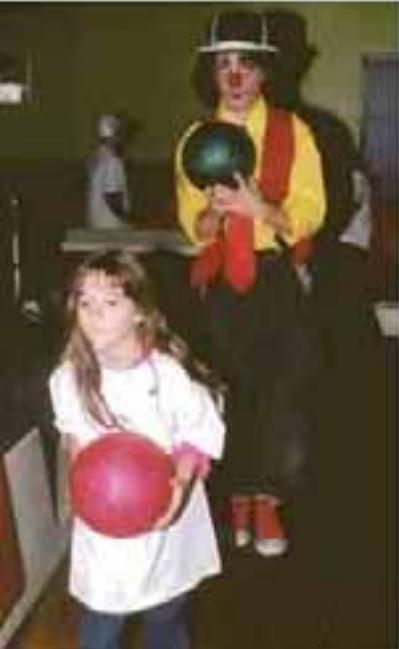
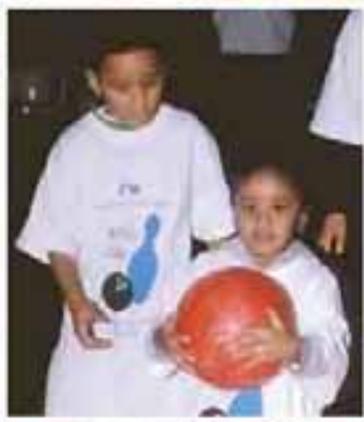
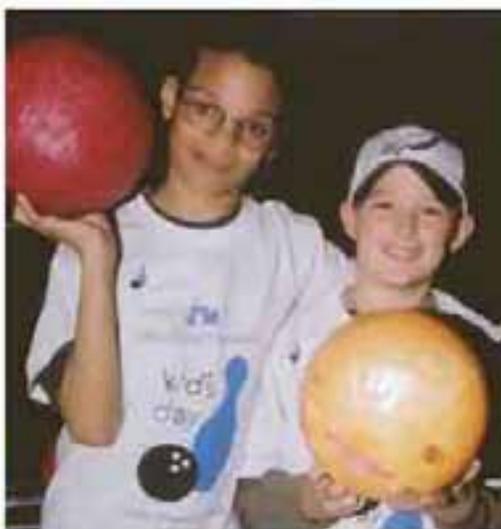


From New York to  
New England,  
South Florida to

# kid's day

Seattle, JMF K.I.D.'s Days are fun-filled events for families across the country. Hundreds of K.I.D.'s (Kids with Immune Deficiencies) along with their families and communities participate in these events throughout the year.





# Annual "Spring Ahead" Gala Held on April 21, 2004

The Grand Ballroom of the Plaza Hotel was sold-out for the Annual "Spring Ahead" Gala. Robert J. Alexander, New York Region Chairman of real estate giant CB Richard Ellis (CBRE) was selected as JMF's "Man of the Year."

The first Jeffrey Modell "Dare to Dream" Award was presented to Senator Arlen Specter and Mrs. Joan Specter for their vision and support of research, physician education and public awareness of Primary Immunodeficiency diseases.

The "Hot Havana Nights" theme featured the Valerie Romanoff Starlight Orchestra, and included a strolling mariachi band to welcome partygoers. Guests enjoyed a lively and colorful evening featuring a crowd-pleasing dance troupe, which brought everyone to their feet. This year's event raised more than \$1 million dollars for education, research, and awareness of Primary Immunodeficiency.

SAVE THE DATE  
Spring Ahead  
April 19, 2005  
Cipriani  
42nd Street





OPPOSITE PAGE:

1. Fred and Vicki Modell with Mrs. Joan Specter
2. Mr. And Mrs. Terry Tenbrunsel (Bayer HealthCare) with Mr. and Mrs. John Walsh (Alpha 1 Foundation)
3. Steven M. Chermiak (Solow Realty), Steve Siegel (CBRE) and Sheldon Solow (Solow Realty)
4. Craig Reicher (CBRE), John S. Moody (HRO International), James S. Doran (Vornado), Bob Alexander (CBRE) and Steve Siegel (CBRE)
5. Dr. James Bussel, Shelby Modell, Dr. Lloyd Mayer, and Bill Modell
6. Jon Mechanic (Fried, Frank, Harris, Shriver & Jacobson), Alice DiMarzio (Newmark & Co.), James Stifel (Benenson Capital), Lawrence Benenson (Benenson Capital), Richard Kessler (Benenson Capital)
7. Richard Farley (RFR Holdings), Nicole Schumann (Atlantic Group), Jeffrey Roseman (Newmark New Spectrum), Steve Marrow (RFR Holding) and Marc Leber (Newmark New Spectrum)

THIS PAGE:

8. Gala Chairman Tod Waterman (Reckson Associates) entices Honoree Bob Alexander (CBRE) with chocolate chip cookies to receive his award.
9. Vicki Modell gives a big welcome to the Spring Ahead crowd.
10. David and Simone Levinson (CBRE)
11. David Greenbaum (Vornado Realty Trust), Tod Waterman, Josh Mermelstein (Fried, Frank, Harris, Shriver & Jacobson) and Brad Gerla (CBRE)
12. Wendy Mechanic, Wendy Siegel, and Bonnie Rudin
13. Mitchell Konsker (Cushman & Wakefield), Wendy Siegel, Lisa Konsker, Keith Locker (Inlet Capital)
14. Standing: Andrew Sussman (CBRE) and Brian Burget (Lehman Brothers), Seated: Jamie Fuertes (Lehman Brothers), Chris Cox (Aurora Loan Services) and Joe DeGregoria (Lehman Brothers)
15. Board Members Debbi Lebersfeld, Jim Emden, Bettina Emden, and Dr. Barry Stein
16. Dr. and Mrs. Alberto Martinez (ZLB Behring) with Mr. and Mrs. Paul Perreault (ZLB Behring)

# JMF and NIH Collaborate on Physician Mailing

JMF, in collaboration with the National Institute of Child Health and Human Development (NICHD), sent a mailing to pediatricians and specialists in pediatric pulmonology, pediatric emergency medicine, pediatric otolaryngology (ENT), family practice, internal medicine, infectious disease, pulmonary disease and genetic counselors. The mailing consisted of a letter from the Director of the NICHD, Dr. Duane Alexander, and a 2-sided poster of the 10 Warning Signs and Physician Algorithm.

In the letter, Dr. Alexander explains, "The purpose of the PI Awareness Campaign is to alert physicians, other health profes-



National Institute of Child  
Health and Human Development

sionals, and parents to the warning signs of PI, so that affected children and adolescents receive appropriate, care and treatment. Unfortunately, a significant number of cases are still undiagnosed — until those affected become very sick or chronically debilitated.

The PI Awareness Campaign is sponsored

by the JMF, in collaboration with the NICHD, a component of the National Institutes of Health, U.S. Department of Health and Human Services, as well as other federal agencies and several private partners.

Through this multi-faceted education program, the JMF, the NICHD and partners hope to significantly raise awareness of PI. Early diagnosis of PI can help those affected receive appropriate treatment and may prevent them from becoming more seriously ill. We are pleased to join with the JMF on this worthwhile endeavor." An estimated 200,000 physicians were reached.

## NEW LOOK FOR JMF WEBSITE

The JMF website continues to undergo modifications in order to allow for better organization, easier access to information, and faster and better response to website visitors.

Additional resources have been posted to the website and are continually updated. Please check out the new look at:

[www.info4pi.org](http://www.info4pi.org)



## CDC Renews \$2 Million Award to JMF for Awareness Program

**"JMF is a world recognized leader in efforts to improve the recognition, diagnosis, treatment, and quality of life of persons with PI. JMF has an array of public and private support in the medical, industry and government area and Centers of Excellence in North America, Europe, and the Middle East. JMF has a history of "making this happen" and the organizational commitment to achieve their stated purposes in this National Campaign. JMF has demonstrated that they have the management, talent, professional expertise, and broad-based support to successfully complete the proposed activities."**

So stated the United States Centers for Disease Control and Prevention (CDC) in awarding, for a third year, a single source contract to JMF totaling \$2 million. The grant provides for continuing medical education (CME) courses for primary care physicians, new initiatives to reach school nurses, and educational outreach to the public.

## Public Television Program on Primary Immunodeficiency Diseases

JMF, together with iTV, produced a 30-minute educational program focusing on Primary Immunodeficiencies to air nationally on public television, for three years on 350 stations in 211 markets. It will reach 99% of American television households averaging 92.4 million people per

week. The project is supported with a 4-color full-page ad placed in 13 targeted journals / publications. The program is linked to journals' and publications' websites for physician viewing and will be encoded for Internet viewing.

# JMF Participates in 3rd Annual Urban Health Conference

NEW YORK CITY HEALTH AND HOSPITALS CORPORATION ADDRESSES RACIAL DISPARITIES IN HEALTH OUTCOMES

The Jeffrey Modell Foundation has formed a partnership with New York City's Health and Hospital Corporation (HHC), the largest public hospital system in the nation. The JMF participated in and supported the 3rd Annual Conference on Urban Health organized by HHC. Dr. Francisco (Tony) Bonilla, Assistant Professor of Pediatrics at Harvard Medical School and Boston Children's Hospital, was one of the speakers and delivered the lecture, "Racial Disparities in PI Disease Outcomes." As a result of this initiative, JMF is planning an additional education and awareness campaign specifically addressed to underserved minorities.

According to Mary Medina MSW, JD and Executive Director of the New York City Health and Hospitals Corporation Foundation,



"Through the participation and leadership of Vicki and Fred, the conference was truly a success. As I was leaving, I received a series of thanks from physicians and community residents for Dr. Bonilla's outstanding presentation. Comments focused on his eloquent and understanding style of presenting his subject, and HHC physicians have acquired an appreciation of the need to screen for PI."



## JMF Sponsors Physician Symposia Across the Nation

The Jeffrey Modell Foundation sponsored a series of CME physician symposia throughout the United States over the past 18 months. Created for physicians, medical assistants and nurses, the symposia were directed to all medical professionals who wanted to increase their knowledge of Primary Immunodeficiency disorders. The events were well attended by Family Practitioners, Specialists, Allergists and other health-care providers. The conferences were held at:

- Emory University; Atlanta, GA
- George Washington University School of Public Health; Washington, DC
- Stanford University School of Medicine; Stanford, CA
- University of Washington School of Medicine; Seattle, WA
- Rainbow Babies and Children's Hospital; Cleveland, OH
- Children's Hospital of Philadelphia; Philadelphia, PA
- Children's Hospital Medical Center; Cincinnati, OH
- University of Miami; Miami, FL

# JMF Diagnostic Centers Dedications



JMF has recently added Diagnostic Centers in Munich, Stockholm, Stanford, Los Angeles, and New Haven to bring the established Jeffrey Modell Centers to 16. There are 8 in the U.S. and another 8 throughout the world. The Referral Network totals 45 academic medical centers in the U.S. and 56 in Canada, Europe, Middle East and Latin America.

In many of these regions, JMF has already conducted physician education and public awareness campaigns. The JMF initiative has led to improved and earlier diagnosis.

**Reports received from 31 centers indicate that in the first year, there has been an 85% increase in the number of patients diagnosed, a 45% increase in the number of patients receiving some form of treatment, a 67% increase in the number of PI patients receiving Immunoglobulin therapy, a 31% increase in the number of PI patient referrals and a 22% increase in the number of diagnostic tests performed.**



## KINDERKLINIK UND POLIKLINIK IM DR. VON HAUNERSCHEN MUNICH PHOTOS

TOP: Plasma Donor, Director of Aventis Plasma Center Collection, Patient Moritz, Martin Kastler (EU), Eva Soergel (DSAI) and André Sarrasani

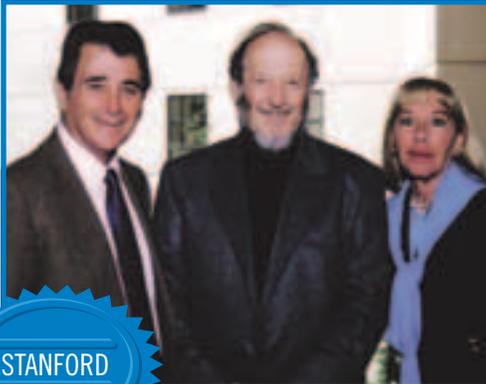
BOTTOM LEFT: Fred Modell presents new signage for Jeffrey Modell Diagnostic Center to Dr. Bernd H. Belohradsky (Director, Jeffrey Modell Diagnostic Center at Children's Hospital)

BOTTOM RIGHT: Dr. Uwe Wintergerst (Pediatrician, Children's Hospital), Fred and Vicki Modell, Dr. Dietrich Reinhardt (Director, Pediatric Clinic at Children's Hospital) and Dr. Bernd H. Belohradsky

## KAROLINSKA UNIVERSITY HOSPITAL STOCKHOLM PHOTOS

TOP: Mrs. and Dr. Lennart Hammarstrom (Professor, Center for Biotechnology at Karolinska University Hospital, Karolinska Institute), Dr. Harriet Wallberg-Henriksson (Dean, Karolinska University Hospital, Karolinska Institute) and the Modell's

BOTTOM: Ann Gardulf, RN, Ph.D (Associate Professor, Karolinska University Hospital, Karolinska Institute) presenting new signage to Vicki and Fred Modell



STANFORD



**STANFORD UNIVERSITY SCHOOL OF MEDICINE  
STANFORD PHOTOS**

TOP LEFT: Fred Modell, Dr. Irving Weissman, and Vicki Modell

TOP RIGHT: Dr. Kenneth Weinberg, Dr. Philip Pizzo, Fred Modell, Dr. David Lewis, Vicki Modell, Dr. Irving Weissman, Dr. E. Richard Stiehm, and Dr. John Curnutte

BOTTOM: Kelly Gordon, Ginger Gradeff, Ann Rose, Dr. Ron Rosenfeld, Dr. David Lewis, the Modells, and Vanessa Tenenbaum



LOS ANGELES

**UCLA SCHOOL OF MEDICINE / MATTEL CHILDREN'S HOSPITAL  
LOS ANGELES PHOTOS**

TOP LEFT: Vicki and Fred receive plaque from Dr. Edward McCabe (Physician in Chief, Mattel Children's Hospital UCLA)

TOP RIGHT: Dr. Talal Chatila (Chief, Division of Pediatrics at UCLA)

BOTTOM: Fred Modell, Dr. Talal Chatila, Dr. Edward McCabe, Vicki Modell, Dr. Gerald Levey (Vice Chancellor of UCLA Medical Sciences, Dean of David Geffen School of Medicine UCLA) and Paul Perrault (Vice President and General Manager of North American Operations, ZLB Behring)



**YALE UNIVERSITY MEDICAL SCHOOL  
NEW HAVEN PHOTOS**

LEFT: Dr. Margaret K. Hostetter (Chairman and Professor of Pediatrics / Microbial Pathogenesis, Yale University School of Medicine), Dr. Ramsay Fuleihan (Director, Jeffrey Modell Diagnostic Center), Matthew Rowell (10 year old patient), Dr. Dennis Spencer (Interim Dean, Yale School of Medicine), Vicki and Fred Modell, Gabriella Maselli (7 year old patient) and Terry Tenbrunsel (Vice President of Sales and Marketing, Bayer Healthcare Corp.)

RIGHT: Vicki Modell, Dr. Ramsay Fuleihan, and Fred Modell

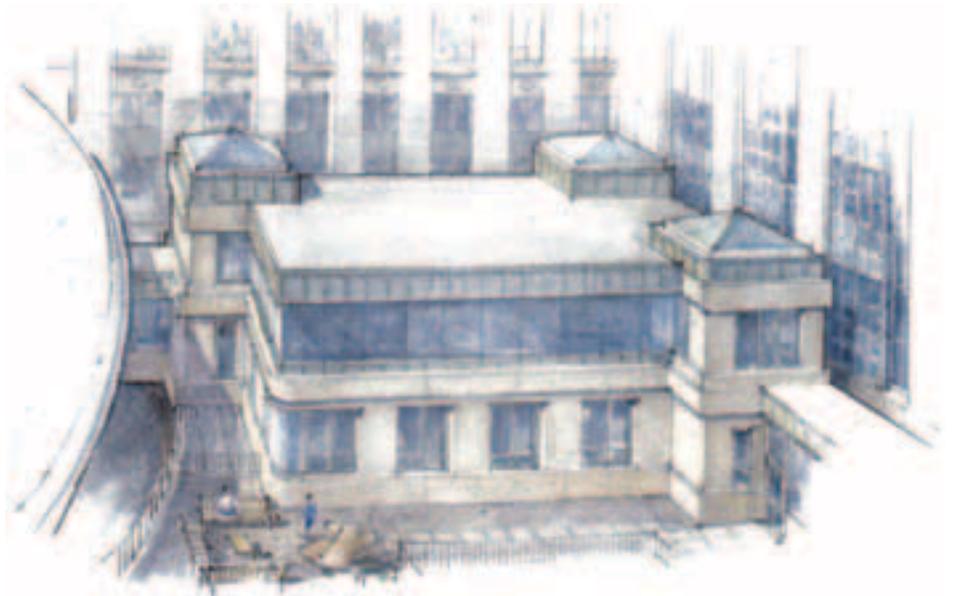


NEW HAVEN

## JMF Organizes 2005 World Health Organization Meeting in Budapest

Since the early 1960's, the World Health Organization (WHO) has convened an Expert Committee to define and classify the Primary Immunodeficiency diseases. Since then, the committee has been meeting every 2-3 years in various parts of the world to update the Report. Recent meetings have taken place in Italy, Japan, the United States, England, Austria, Switzerland and Portugal. The report not only provides vital information to the medical community, but is also used by various governments to determine healthcare policy.

The Jeffrey Modell Foundation is honored to have been selected once again to organize the WHO expert meeting on Primary Immunodeficiencies. The next meeting is scheduled to be held in Budapest, Hungary June 15-19, 2005. The Foundation previously sponsored the WHO meetings in Bristol, England, Baden bei Wein, Austria, Lucerne, Switzerland and Sintra, Portugal. Those meetings were considered the outstanding scientific conferences on immunodeficiencies worldwide, generating important breakthrough findings, identifying new molecular and genetic defects and encouraging dialogue with scientists from around the globe. The Budapest meeting will once again be held in conjunction with the International Union of Immunological Societies and will be heavily geared toward molecular biology and genetics of primary immune deficiency disorders.



## JMF Collaborates with Harvard Medical School to Establish a Center for Immunology

“The Center for Immunology is a unique endeavor. It is absolutely the first of its kind,” says Richard L. Cosnotti, Director of Development Dana-Farber / Harvard Cancer Center, Harvard Medical School. “The Center will become the focal point for the most dynamic and diverse community of immunologists in the world. We are delighted to work with the Modells and make this dream a reality.”

The Jeffrey Modell Foundation challenged the Harvard Medical School by pledging to match every dollar contributed to the Center for Immunology. The new 2-story, 73,000 square foot building will be located in a prime location in the Harvard Medical School quadrangle.

It will feature much needed space for teaching, lectures, receptions, seminars, special education events, conference rooms, study areas, lounge, library and new office space for immunology faculty.

“The Center for Immunology will provide a meaningful contribution to the development of a new generation of highly trained immunologists at a time when research in immunology has emerged as the key to treatment, prevention, and cure of a host

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**“The Center will become the focal point for the most dynamic and diverse community of immunologists in the world. We are delighted to work with the Modells and make this dream a reality.”**

*— Richard Cosnotti,  
Harvard Medical School*

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of deadly and debilitating diseases,” says Dr. Fred S. Rosen, President of The Center for Blood Research Institute for Biomedical Research at Harvard. “We enthusiastically support this collaboration.”

**FOR MORE INFORMATION  
ON THIS INITIATIVE PLEASE  
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rcosnotti@hms.harvard.edu

Fred Modell  
Jeffrey Modell Foundation  
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fmodell@jmfworld.org

# 6<sup>th</sup> Annual Dina LaVigna Triathlon



This year's 6th Annual Dina LaVigna Breath of Life Triathlon was held at San Buena Ventura State Beach in Ventura, California in June. More than 800 athletes participated. This picturesque park is located on the Pacific Ocean just south of the Ventura pier.

There were two triathlon courses; the Olympic course and the Sprint course. Olympic course participants were challenged by a 1.5k swim, 40k bike ride and a 10k run. Sprint course participants were equally challenged by sprinting a 400m swim, 20.4k bike ride and running a 5k to the finish line. Winners were declared by best overall time, best female and male competitor, and best team time.

The Dina LaVigna Breath of Life fund is named for a young woman who died of complications from Primary Immunodeficiency. "The Jeffrey Modell Foundation Funds research, education, patient support and public awareness of PI," says David LaVigna, Dina's brother. "The Breath of Life Fund focuses on improving the environment in which children with PI receive their treatment. The end result of the most recent triathlon was that we added about \$180,000 toward our ability to fund important patient care projects."

Current funds are being applied to build a new, world-class PI treatment center at Mattel Children's Hospital, UCLA.

"The Mattel Children's Hospital has added significance to us because my sister graduated from UCLA," LaVigna says. "Our success with the triathlon will help us reach our goals sooner rather than later."



## JMF ESTABLISHES ENDOWED FELLOWSHIP IN IMMUNODEFICIENCY RESEARCH AT UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE

The University of Washington School of Medicine (UW) and the Jeffrey Modell Foundation have created a collaboration to support an endowed fellowship in immunodeficiency research. The program will support full time fellows (graduate or MD / Ph.D students) in the division of immunology within the Department of Pediatrics. Under the agreement, UW will contribute an additional 50% for all funds provided by the Jeffrey Modell Foundation. According to Dr. Paul G. Ramsey, UW Vice President of Medical Affairs and Dean of the School of Medicine, "I appreciate the Modells' dedication to pediatric immunology at UW Medicine, as well as, their significant volunteer commitment to the Institution. We are grateful for their support of our work."



The Modells share a proud moment with Harvard Medical School JMF prize winners

## Jeffrey Modell Immunology Prizes awarded at New York's Mount Sinai and Harvard Medical School Commencements

This year's Jeffrey Modell Immunology Prize at New York's Mount Sinai School of Medicine Commencement was awarded to Dr. Joe F. Lau. In 1996, Dr. Lau was accepted into Mount Sinai's Medical Scientist Training Program (MD / PhD dual degree program), through which he was awarded his Ph.D degree in Biomedical Sciences in 2002.

While a graduate student in the laboratory of Dr. Curt Horvath, Associate Professor, Center for Immunobiology, Dr. Lau studied the mechanism of gene activation involved in the innate immune response to viral infections.

The Harvard Medical School Jeffrey Modell Immunology Prize was awarded to three outstanding students. The recent graduates of Harvard Medical School's graduate program in immunology received cash awards and will move into the post-doctoral phases of their scientific careers. Receiving Jeffrey Modell awards at Harvard were Dr. Dong Lee, who worked in the lab of CBRI Senior Investigator Anjana Rao; Dr. Sean Rooney, in the lab of CBRI Senior Investigator Fred Alt; and Dr. Brandon Sullivan in the lab of CBRI Senior Investigator Laurie Glimacher.

## Kid's Wish Fund

### A NOTE OF THANKS

*"Dear Jeffrey Modell Foundation,*

*Throughout the past month or so my mom has been asking me if I could have anything, what would it be. I said a laptop. Little did I know that this wish was in the progress of being granted! The laptop will stay with me through the years. First playing games, then doing homework, writing college papers, and maybe writing a dissertation. I would like to thank you all at the Jeffrey Modell Foundation. You have granted my wish."*

If you are a patient, under the age of 21, and would like to apply for a "Wish," please have your physician complete the application on our website at [www.info4pi.org](http://www.info4pi.org)



Happy recipient of Kid's Wish Fund