

UPDATE



JEFFREY MODELL CENTERS FOR PRIMARY IMMUNODEFICIENCIES

Atlanta • Beijing • Berlin • Boston • Cleveland • Debrecen • Düsseldorf • Haifa • Hannover • Los Angeles • Miami • Milwaukee
Munich • New Haven • New York City • Paris • Philadelphia • Seattle • Stanford • Stockholm • Toronto • Vienna • Zurich



JMF SPANNING THE GLOBE

A new Jeffrey Modell Diagnostic Center has been established in Beijing, China. This is the 30th Jeffrey Modell Center worldwide. The Center will be led by Dr. Xiao-Ming Gao of Peking University and supported by Hong Kong Vigconic

International and the Beijing Council of Science and Technology. An International Symposium on Primary Immunodeficiencies was part of the Center's launch in May 2006 where leading experts from all over the world were invited to speak to treating physicians in the region. The speakers included Drs. Alain Fischer, Paris; Amos Etzioni, Haifa; Edvard Smith, Stockholm; Jean-Laurent Casanova, Paris; Hans Ochs, Seattle; Lennart Hammarström, Stockholm; and

Richard Gatti, Los Angeles. The meeting was sponsored by JMF, the Luk's Group of Hong Kong, and the Beijing Municipal Science and Technology Commission and it was organized in collaboration with the Chinese Society

for Immunology, Beijing Society of Immunology, and Beijing Association for Science and Technology. Dr. Gao is working in close collaboration with the Beijing Children's Hospital which sees over 2.8 million patients per year.



In a related development, Dr. Xiaochuan Wang, Children's Hospital of Fudan University in Shanghai, conducted the first ever JMF KIDS Day in Asia, funded by a WIN Grant. The Beijing and Shanghai Centers will work together in close collaboration.

Over the past year, new Jeffrey Modell Diagnostic Centers were established in Atlanta, Miami, and Milwaukee, bringing the number of Centers worldwide to 30. To date, the JMF Centers overall have reported a 79% increase in the number

of diagnosed patients, 54% increase in patients receiving treatment, and 57% increase in the number of patient referrals.

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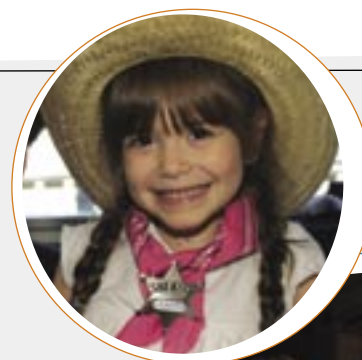
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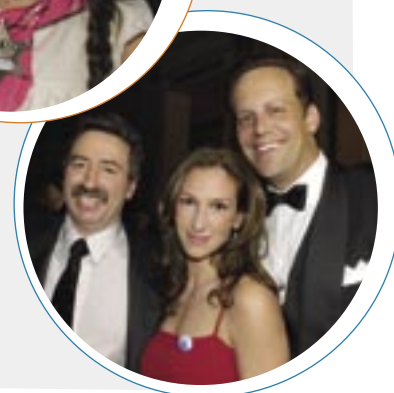
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KIDS DAY
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A QUESTION FOR VICKI & FRED



It was a simple question...
then an awkward pause...
and finally serious reflection.

The question came from a member of Congress who has been a long time supporter of the Foundation's activities. He said "you have both done a very good job in raising awareness and educating doctors about the Primary Immunodeficiency diseases, but ultimately what happens to that initiative? Who will look out for the patients? Who will support the research? Who will encourage young investigators to enter the field?"

We looked at each other a bit unsure with an awkward pause, fidgeted, reflected, and tried to recover with an acceptable response. "Congressman, those are very good questions. We're going to give this some serious thought and get back to you." Our answer sufficed for that moment, but obviously was a bit light on content.

When we returned to the office, we reached out to many of you, our most trusted supporters. Board members, physicians, pharmaceutical companies, hospitals, medical schools, patients, and families. We listened and then developed a strategic plan that would hopefully provide answers to those important questions. We reviewed all of the JMF activity, both current and planned, and tried to construct a meaningful response. **The results of these efforts can be found in the accompanying article entitled "Securing the Future".** And that is what we did by providing endowed support for program activities at leading academic medical centers throughout the nation. All of these endowment funds are "in perpetuity", and co-funded with you... our stakeholders who believe in the mission.

The member of Congress who posed those questions energized and inspired us to keep an eye on the future. The endowments will benefit patients, researchers, and physicians, and will assure all of us that funding will be firmly in place to support the Primary Immunodeficiency community. NIH budgets may go up and they may go down, but the Jeffrey Modell Foundation is now providing endowment funds "in perpetuity" so that the important research in Primary Immunodeficiencies will go forward and be sustained. And, we can all look back proudly, that these efforts will create an eternal legacy to the life of Jeffrey Modell.



SECURING THE FUTURE

JMF endowed programs:

Jeffrey Modell Immunology Center Harvard Medical School, Boston, Massachusetts
Jeffrey Modell Endowment Fund to award an annual prize for the best graduating student thesis in Immunology at Harvard Medical School Boston, Massachusetts
Jeffrey Modell/Sidney Sheldon Endowed Chair in Immunology, Mattel Children's Hospital at UCLA Los Angeles, California
Jeffrey Modell Endowed Division of Clinical Immunology at Mount Sinai Medical Center New York City
Jeffrey Modell Endowment Fund to award an annual prize in Clinical Immunology at Mount Sinai Medical School, New York City
Jeffrey Modell Endowed Chair in Pediatric Immunology Research at University of Washington Seattle, Washington
Jeffrey Modell Endowed Fellowship in Immunodeficiency Research at University of Washington Seattle, Washington



A VISIT WITH BILL & MELINDA GATES

Vicki and Fred Modell, co-founders of the Jeffrey Modell Foundation, were invited to the home of Bill and Melinda Gates in Seattle. The Modells were joined by major supporters of the Children's Hospital in Seattle. After a brief boat ride on Lake Washington, the Gates welcomed each guest individually and urged their visitors to tour their beautiful home. A reception and sumptuous dinner followed.

The Jeffrey Modell Foundation has supported the Children's Hospital for nearly 10 years, funding research and clinical care under the expert leadership of Dr. Hans Ochs.



A MESSAGE FROM THE DEAN

The following is a message from Dr. Joseph B. Martin, Dean of the Harvard Medical School.

HARVARD MEDICAL SCHOOL



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Dear Friends,

Harvard Medical School welcomes the opportunity to collaborate with the Jeffrey Modell Foundation in establishing the Jeffrey Modell Immunology Center at Harvard. Since announcing this initiative, more than 100 donors have participated, including an unprecedented response from the Harvard Medical School immunology faculty with support totaling over \$500,000.

Centrally located on the Harvard Medical School Quadrangle, the Jeffrey Modell Immunology Center will provide a "home base" for immunologists from throughout the Harvard medical and scientific community. It will be an operative and geographic focus for both faculty and graduate students working in immunology from the Medical School, the 17 teaching hospitals, and Harvard University science departments. Most importantly, it will facilitate the collaboration of immunology researchers from both clinical and basic research departments and profoundly enhance discovery and productivity.

Please join us in this exciting, unique journey that will make such a prominent contribution to the development of a new generation of highly trained immunologists at a time in history when research in immunology has emerged as the key to the treatment, prevention, and cure of a host of deadly and debilitating diseases.

On behalf of Harvard Medical School and the Jeffrey Modell Foundation, we extend our sincerest appreciation for your consideration of support.

Joseph B. Martin
Joseph B. Martin, M.D., Ph.D.

Dean of the Faculty of Medicine
Harvard Medical School



JMF AT EU PARLIAMENT

In June, JMF was invited to participate at the European Union Consensus Conference. JMF presented data supporting the hypothesis that physician education and public awareness campaigns in the EU countries could lead to earlier diagnosis, treatment and cures. Policy makers, healthcare managers and representatives of the EU countries attended. This is the second appearance for Vicki and Fred Modell at the European Union Parliament.

ADVOCACY AT WORLD HEALTH ORGANIZATION

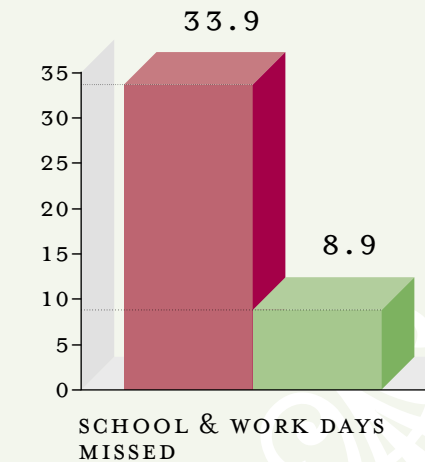
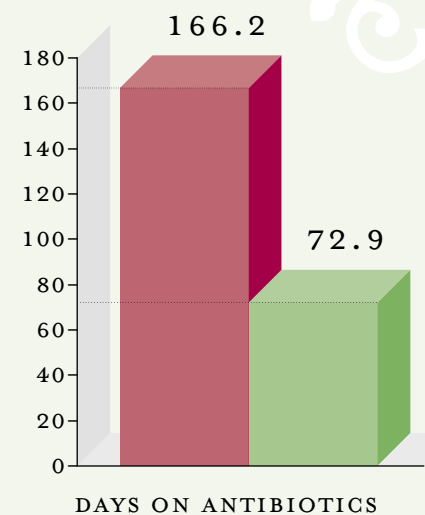
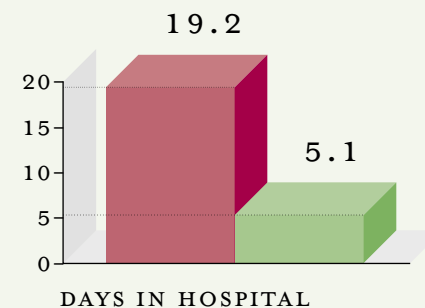
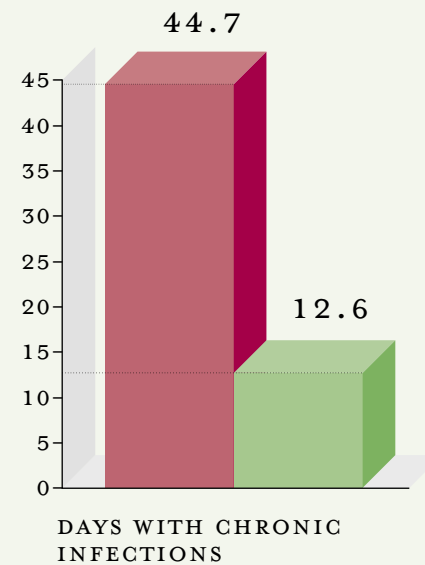
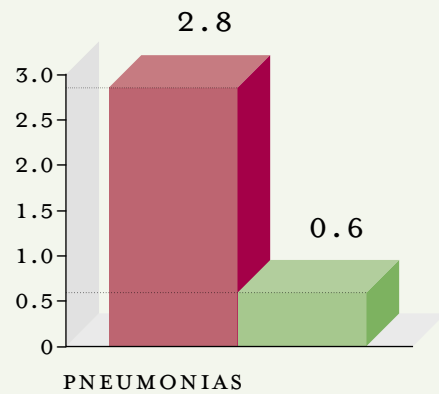
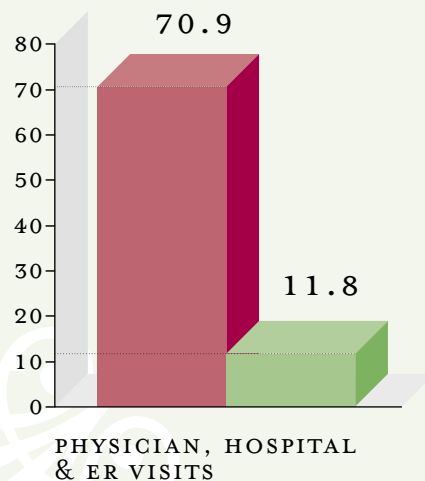
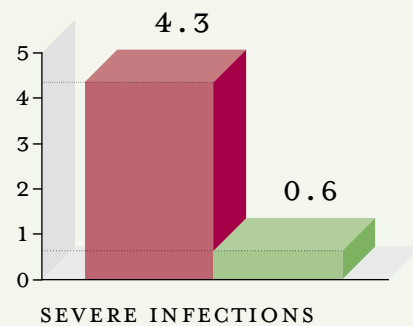
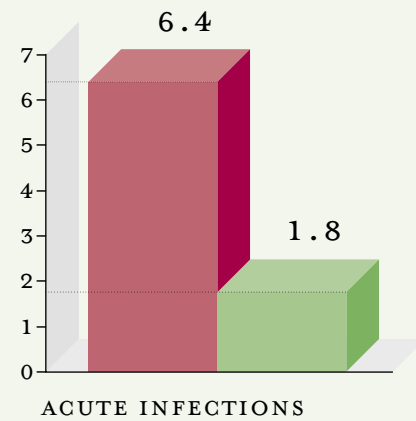
A group of the world's leading immunologists signed a letter that was brought to the World Health Organization (WHO) concerning the vital importance to reinstate Immunoglobulins to the WHO List of Essential Medicines. The signatures were obtained at a meeting of Jeffrey Modell Center Directors in New York City.

Therapeutic Immunoglobulins were removed from the WHO Essential Medicine list in 1999. Since there are no alternative therapies for antibody deficiencies, these plasma derived products are vital for infection prevention and before and after stem cell transplantation. The hope is that with the combined efforts of the Jeffrey Modell Foundation, European patient groups, PPTA, and the physician community, the World Health Organization will reinstate these important therapies onto the Essential List to assure patient access to treatment.

FIRST EVER QUALITY OF LIFE SURVEY ON PI

The JMF is conducting a physician education and public awareness campaign on Primary Immunodeficiencies in collaboration with the NIH and the CDC. The program targets pediatricians, family practitioners, emergency rooms, nurses and daycare centers, as well as the public. Components include CME physician symposia, publications, public service advertising and patient programs. Physician experts were asked to examine patient records before diagnosis and subsequent to diagnosis and treatment. Records of 532 patients were included in the study.

Survey Results from Physician/Experts at 76 Jeffrey Modell Diagnostic and Referral Centers Comparing Undiagnosed and Diagnosed Patients with Primary Immunodeficiencies



■ UNDIAGNOSED PATIENTS
■ DIAGNOSED PATIENTS

\$65 MILLION PSA CAMPAIGN

Major media outlets across the nation have donated over \$65 million in air time and advertising space for public service ads on Primary Immunodeficiency. Television networks and local stations, radio, national magazines, airport dioramas, and internet sites have brought attention to the PI diseases and stressed the importance of earliest possible diagnosis.

JMF's latest campaign is targeted to reach the African American and Hispanic communities. Since first running in November, 2005, the new campaign has generated over \$15 million in donated media and has aired on National networks including CNN and Telemundo. The ads can now be seen in airports nationwide including Atlanta, Boston, Dallas, Miami, Orlando, Philadelphia, San Jose, Seattle, Tampa, and JFK and LaGuardia in New York.





NEW FEATURE! MEETING INDUSTRY LEADERS

In this issue, meet Larry Stern, Talecris Executive Chairman, in his own words...

My name is Danielle Stern, and my father is the Executive Chairman of Talecris Biotherapeutics. When I met Fred and Vicki in Budapest last summer, I immediately knew there was something special about them. That trip has inspired me to learn more about PI and the industry that my dad has been dedicated to for the past couple of years. This summer, I had the privilege of interning at the Jeffrey Modell Foundation, and once again, it has been an experience I will never forget.

Danielle: "Hi Dad. I'd like to ask some questions that others may not be as comfortable discussing with you. I remember a number of your

previous jobs from building chemical plants in Texas to running businesses for Lyondell and Bayer. This job seems different. From the company mission, to your sense of urgency, to the number of industry events you and mom attend, what's special this time?"

Larry: "Danielle, just the fact that you too saw the value in helping Fred and Vicki is a testament to what is different about this industry. Helping patients in need makes all the travel, conference calls, and stress worthwhile. In my previous jobs, I helped make the plastics and fibers that went into clothes, sneakers and playgrounds. Now I help provide a life-saving therapy. I feel lucky to have a job and a career that can literally help thousands of people with life-threatening chronic diseases. As the Executive Chairman of Talecris, I feel a tremendous responsibility to ensure we strive every day to achieve our mission as a leading supplier of premium products. That responsibility is driving a greater sense of urgency than any other job I've had before."

Danielle: I've noticed a significant increase in the number of industry events you attend. Mom even joins you on occasion. How do you account for this change?

Larry: "Since acquiring the business from Bayer about 16 months ago, I've probably been to a dozen events for PI, GBS (Guillain-Barré Syndrome), Alpha-1 Foundation, and others. At first I went to learn more about the industry, to make contact with key opinion leaders, and to show that the new ownership would not change the 60 year legacy of support from Bayer and now Talecris. Your mom and I have been truly impressed with the people we've met. They're dedicated. They're focused. They're analytical. They're driven... as if it was their child in search of a cure."

Danielle: "Are there one or two events which were particularly memorable?"

Larry: "They've all been memorable, but let me point out two. Let's start with the International Union of Immunological Societies (IUIS) event that you attended in Budapest along with your brother Jason. I remember us talking as a family about how Vicki and Fred were the inspiration and the glue. They not only brought everyone together, they also developed a nurturing community in which everyone openly shares results for the benefit of patients everywhere. Your mom and I also attended the opening of a JMF Center at the University of Miami. What a great institution. We were really impressed with their care for children, including physical therapy with equipment designed for children. So yes, I could always get a report from Talecris employees who attend, but how can you absorb the feeling and inspiration without going yourself?"

Danielle: "I've learned that newborn screening for SCID is now being developed. If an infant were to test positive for SCID, a bone marrow transplant could potentially cure this child. This might lead to a reduction of sales and demand for Gamunex and other brands of immune globulins. Does Talecris support this prospective SCID cure?"

Larry: "Talecris strongly supports newborn screening, even if it ultimately reduces the number of patients requiring treatment with Gamunex. Diagnosing SCID in newborns enables doctors to consider a bone marrow transplant, which has nearly a 100% success rate for well matched donors and recipients. In fact, we've even made some contributions to the JMF specifically to support their advocacy work for newborn screening. The tireless work by Vicki and Fred with CDC, CMS, Congress and individual state governments in this field deserves more support and funding."

"Helping patients in need makes all the travel, conference calls, and stress worthwhile."



Larry Stern, Vicki & Fred Modell, and Becky Stern at University of Miami dedication.

Danielle: "The gene chip technology being developed by Affymetrix to screen newborns seems very interesting. Do you support the technology development?"

Larry: "We sincerely hope that Affymetrix is not only successful in completing the technical development, but that the government supports the commercial implementation... including mandates or requirements for testing."

Danielle: "I know you've made a number of trips to Washington DC given the changing policies on reimbursement. Why are you and Talecris getting so involved? And without being too controversial, is this in the best interest of patients or the company?"

Larry: "Wow, you are tough. Ultimately, the patients, the medical community and the companies like Talecris that produce these life-saving therapies need each other. So it's fair to say that the advocacy

"I feel lucky to have a job and career that can literally help thousands of people with life-threatening chronic diseases"



"Ultimately, the patients, the medical community and the companies like Talecris that produce these life-saving therapies need each other."

positions from Talecris on reimbursement are for the benefit of the patients, the healthcare system, and for Talecris. We believe that reimbursement policies should allow the patient to choose the location of care. We believe that reimbursement should not only cover the cost of the drug, but the cost of the infusion set, the infusion nurse and other administrative costs. And we believe that each IGIV on the market is different, that the doctor should choose which therapy to prescribe, and that the reimbursement for each brand should be independently set to avoid having reimbursement formulas influence a prescribing physician."

Danielle: "What is the extent of the relationship between Talecris and The Jeffrey Modell Foundation?"

Larry: "Danielle, this year (2006), Talecris is supporting the Yale Diagnostic Center, Miami Diagnostic Center, Harvard Immunology Center, the JMF's media outreach plan, physician mailings, KIDS Day events, cartoon book, JMF's Spring Gala, 20th Anniversary Celebration, and American Academy of Pediatrics (AAP) Program."

Danielle: "One final question. When the company was acquired from Bayer Corporation, was there pressure to prove yourself in the industry, and to what extent have you accomplished that objective?"

Larry: "I felt tremendous pressure. We inherited a great legacy. We have excellent technology and assets. But business is all about people. In this case, it starts with our patients. It includes relations with doctors and researchers. It includes our distributors and customers, and of course, our talented employees. We had to show by our actions, not our words, that we were building upon our legacy and not resting upon it. In effect, we've tried to emulate the passion and success that Vicki and Fred have had with the JMF. In terms of our results, we'll let others be the judge, now and over time."

Danielle: Thank you very much for taking time out of your busy schedule to do this interview, and I owe you a dinner.

In future issues of UPDATE, we will highlight industry leaders who are providing life saving IVIG Therapy for our patients.



JMF TURNS 20

JMF celebrated its 20th Birthday at the annual "Spring Ahead" Gala in April. The Grand Ballroom of the Waldorf=Astoria was filled to capacity as JMF took the opportunity to honor all past "Spring Ahead" Honorees. Over 700 guests joined in the high-spirited celebration including physicians, patients and pharmaceutical companies. The 2006 Gala was JMF's most successful event ever! The night featured entertainment by Le Clique, music by the Valerie Romanoff Orchestra, and raised a record-setting \$1.5 million for education, research, and awareness of Primary Immunodeficiency.

SAVE THE DATE
 THURSDAY, APRIL 26, 2007
 JMF'S 21ST "SPRING AHEAD" GALA
 CIPRIANI 42ND ST, NEW YORK CITY



*Celebrating
 our 20th
 Birthday*



1 Joseph Fabrizi (Cushman & Wakefield); Robert Freedman (GVA Williams); Richard Farley (RFR)
2 Jack Irushalmi (Tri-Star), Jon Mechanic (Fried Frank). Fred Modell, Wendy Frank (Tri-Star),
 Brad Gerla (CBRE) **3** James Emden (CBRE) pulls winning raffle ticket with JMF Kids **4** Fred Modell
 addresses more than 700 attendees **5** The crowd joins in the dancing with Le Clique! **6** Vicki & Fred
 Modell join with JMF board members: Max Lebersfeld, Frann Francis, Debbi Lebersfeld and Eric
 Francis **7** Dr. Propa Ghosh, Nikhil Kumar, Fred & Vicki Modell and Dr. Hans Ochs **8** Yalda Miller
 (Intermune) **9** Todd Bassen (Vornado), Stephen Farber & Michael Stoler (First American Title),
 Barry Langer (Vornado) **10** Gospel Choir offers moving solo **11** Brian Robin, Gary Armstrong,
 Mr. and Mrs. Anthony Westreich (Monday Properties) **12** Cece Cord and Dr. John Baldwin (CBR
 Institute, Harvard Medical School) **13** Arnold Penner (Penner & Co.), Jon Mechanic (Fried Frank),
 Allyson Waterman, Todd Waterman (Reckson Associates) **14** Wendy Siegel and Jared Siegel
 (CBRE) **15** Vicki Modell, Laureine and David Greenbaum (Vornado) **16** JMF Kids



AMERICAN ACADEMY OF PEDIATRICS/JMF COLLABORATION

The Jeffrey Modell Foundation has launched the "PREP Audio program on PI" together with the American Academy of Pediatrics. Funded by Talecris and organized by the JMF, this educational online course will reach 36,000 pediatricians who can participate in the CME course in the comfort of their own office or home. Drs. Rebecca Buckley of Duke University School of Medicine, Thomas Fleisher of the NIH, and Melvin Berger of Case Western Rainbow Babies and Children's Hospital, convened in a studio in Miami to record the audio portion of the program. A CD-Rom, accompanying booklet, and tear-out poster of the 10 Warning Signs and Physician Algorithm were sent to the entire American Academy of Pediatrics membership.

HARVARD KEYNOTE

Dr. Joseph B. Martin, Dean of Harvard Medical School, introduced Fred Modell as the Keynote speaker at the annual Council for Harvard Medicine. The Keynote address highlighted new discoveries and scientific developments relating to immunology. Fred Modell described how new medical breakthroughs are creating important developments in vaccines, transplantation, and a host of diseases relating to immune response. "I began to think about this very moment in our understanding of science, discovery, genetics and immunology. If you step back and take a broad overview of these complex disciplines, I think you will agree that we are embarking upon an era that will produce spectacular achievements and unprecedented accomplishments in the near future."

The Council consists of prominent business and scientific leaders, including Fortune 500 CEO's, Nobel Prize winning scientists, leaders of pharmaceutical and biotech companies, and major supporters of the Harvard Medical School.

HIGHEST RATING TO JMF

Charity Navigator, America's largest premier independent charity evaluator, announced that JMF has again been designated with the agency's highest 4-star rating for the second consecutive year. JMF was cited for its sound fiscal management, including its ability to efficiently allocate and grow its finances. The online service of Charity Navigator applies data driven analysis to the charitable sector and evaluates the financial health of over 5,000 charities.

Trent Stamp, Executive Director, stated in a letter to JMF, "Less than 12% of the charities we have rated have received 4-star evaluations, indicating that JMF outperforms most charities in America."

This 'exceptional' rating differentiates the Jeffrey Modell Foundation from its peers and proves that it is worthy of the public's trust."

NEWBORN SCREENING 1ST GENE CHIP FOR SCID (BUBBLE BOY DISEASE)

JMF, NIH, and Affymetrix are continuing a program to develop a confirmatory newborn screening test for X-Linked SCID with Dr. Jennifer Puck as the principal investigator. To date, using this new microarray technology, Affymetrix has developed the first gene chip for SCID and Dr. Puck is developing the confirmatory screening test. This innovative technology will help accelerate more comprehensive detection and diagnosis of Severe Combined Immunodeficiencies and other serious genetic diseases.

PLANNING WHO/IUIS



The JMF is honored to have been selected once again to organize the World Health Organization/IUIS expert meeting on PI (WHO/IUIS). Past meetings have been organized by JMF in England, Austria, Switzerland, Portugal and Hungary. The 2007 Conference will be held June 6-10, in Jackson Hole, Wyoming. As in the past, this year's meeting is a collaboration of the World Health Organization and the International Union of Immunological Societies, with emphasis on molecular biology and the genetics of Primary Immunodeficiency disorders. The 3-day meeting will be comprised of 100 physicians and scientists from all over the world who are selected to speak or participate as invited delegates. Subjects will include: Innate Immunity; T Cell Deficiencies; Disorders of Immune Regulations;

JMF IMMUNOLOGY PRIZE AT MOUNT SINAI

Dr. Kelly Leigh West was awarded the prestigious Jeffrey Modell Prize in Clinical Immunology at New York's Mount Sinai School of Medicine Commencement last May. Kelly is in the dual degree program pursuing an MD/PhD. She earned her PhD in Biomedical Sciences and will now finish her MD degree. Kelly has already published papers in various science journals including Immunity and MOL Cell Biology. She recently defended her dissertation "Rag2: Protein Interactions and V (D) J Recombination".

AAI PUBLIC SERVICE AWARD

Vicki and Fred Modell were presented with the American Association of Immunology's 2006 Public Service Award at the Hynes Convention Center in Boston. The Award was given in recognition of their extraordinary support for, and advocacy of, immunological research. AAI is a professional association of more than 6,500 research scientists and physicians dedicated to understanding the immune system, resulting in an improved means to prevent, treat, and cure diseases. Previous AAI Public Service Award Recipients include:

- Sam Donaldson, ABC Newsman
- Dr. Anthony Fauci, Director of the National Institute of Allergy & Infectious Diseases
- Sen. Tom Harkin (D-AI), Chairman and/or Ranking Member of the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee
- Sen. Edward Kennedy, Chairman and/or Ranking Member of the Senate Health, Education, Labor and Pensions Committee
- Sen. Arlen Specter (R-PA), Chairman and Ranking Member of the Senate Labor, Health and Human Services, and Education Appropriations Subcommittee



reaching
for the stars

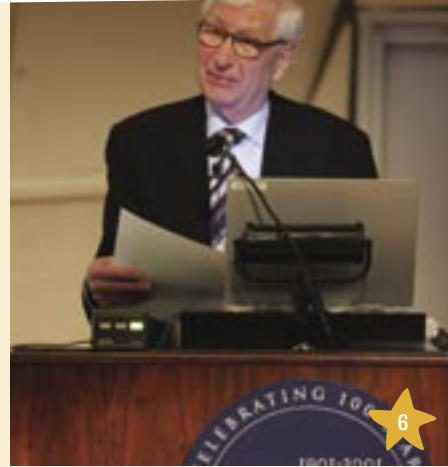
ROCKEFELLER SYMPOSIUM APRIL 25TH



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JMF recently conducted a full day symposium on Primary Immunodeficiencies at Rockefeller University. The scientific meeting, entitled "A Twenty-Year Perspective: Past, Present, Future", featured presentations by 30 of the world's leading immunologists. More than 400 physicians, fellows, students, scientists and researchers from 8 different countries, participated.

Dr. Max Cooper, University of Alabama Howard Hughes Medical Institute, delivered the Keynote Address entitled "Evolution of Immunology—Where is the Future?" Dr. Irving Weissman, Stanford University, offered a special address entitled "The Big Picture: Politics and Science." Other speakers included Dr. Fred Alt of Harvard Medical School; Dr. Alain Fischer of Hospital Necker Enfants Malades;



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and Dr. Charlotte Cunningham-Rundles of Mount Sinai Medical Center. The meeting was sponsored by the Jeffrey Modell Foundation, in collaboration with the New York Academy of Sciences, and focused on current scientific understandings, as well as future treatments, therapies and cures.

The next morning, for the first time ever, there was a meeting of Jeffrey Modell Center Directors from around the world who shared their experiences in conducting awareness and physician education campaigns. Thirty expert physicians were joined by pharmaceutical company representatives that currently support these Centers. It is anticipated that Jeffrey Modell Center Directors will meet on an annual basis.

CELEBRATING 20 YEARS



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1 Dr. Richard Stiehm (UCLA) 2 Dr. Alessandro Aiuti (San Raffaele Gene Therapy Institute, Milan) and Dr. Richard Gatti (UCLA). 3 Dr. Chaim Roifman (Hospital for Sick Children, Toronto) and Fred Modell. 4 Dr. Raif Geha (Children's Hospital, Boston) 5 Vicki Modell and Dr. Robert Goldstein (Juvenile Diabetes Research Foundation) 6 Dr. Walter Hitzig (University Children's Hospital, Zurich) 7 Dr. Max Cooper (University of Alabama) and Dr. Irving Weissman (Stanford).

PATIENT NEWS

44 WIN GRANTS AWARDED

The World Immunodeficiency Network (WIN), established by JMF, supports 60 patient groups in 51 countries throughout the U.S., Latin America, Canada, Europe, Eastern Europe, the Middle East, and Asia. An esteemed Advisory Board reviews all grant applications and monetary awards are made within 30 days. WIN is supported by JMF, multiple U.S. government agencies, and global pharmaceutical corporations.

WIN has awarded 44 grants to patient organizations around the world, providing them with financial and technical support to enhance education and awareness within their community. Just this past summer, WIN helped fund a Family Day organized by a newly established patient group in Shanghai – the first ever in China! In the past year, funds from WIN have contributed to:

- Printing of educational materials for distribution at medical conferences
- Sponsoring bone marrow testing for potential donors
- Publishing of posters, pamphlets, booklets, and books in a series about PI
- Sponsoring Immunologists at medical conferences
- Mailings to physicians and media outlets to raise awareness
- Website development with information and links as a resource for doctors and patients
- KIDS Days and family events



world immunodeficiency network
One voice for PI patients worldwide

WIN grant applications are offered on the JMF website at www.info4pi.org
Simply click to WIN!

10 Warning Signs of Primary Immunodeficiency

Primary Immunodeficiency (PI) causes children and young adults to have infections that come back frequently or are unusually hard to cure. In America alone, up to 1/2 million people suffer from one of the 140 known Primary Immunodeficiency diseases. If you or someone you know are affected by two or more of the following warning signs, speak to a physician about the possible presence of an underlying Primary Immunodeficiency.

- | | | | |
|---|---|---|----|
| 1 | Eight or more new ear infections within 1 year. | Recurrent, deep skin or organ abscesses. | 6 |
| 2 | Two or more serious sinus infections within 1 year. | Persistent thrush in mouth or elsewhere on skin, after age 1. | 7 |
| 3 | Two or more months on antibiotics with little effect. | Need for intravenous antibiotics to clear infections. | 8 |
| 4 | Two or more pneumonias within 1 year. | Two or more deep-seated infections. | 9 |
| 5 | Failure of an infant to gain weight or grow normally. | A family history of Primary Immunodeficiency. | 10 |

Presented as a public service by Jeffrey Modell Foundation JMF
This publication was supported by grant funds from the United States Centers for Disease Control and Prevention (CDC) and the generosity of the following organizations:
PPTA, Baxter, GE Healthcare, Baxter/Mundipharma, Octapharma, Talecris, ZLB Behring
For information or referrals contact the Jeffrey Modell Foundation: 1-888-INFO-4-PI • www.info4pi.org
These warning signs were developed by the Jeffrey Modell Foundation Medical Advisory Board • © 2008 Jeffrey Modell Foundation

The 10 Warning Signs poster has been distributed in 25 countries and is available in 20 languages.



KIDS DAYS GO NATIONWIDE

Jeffrey Modell Foundation KIDS Days began in 1988 and were created to provide a joyous occasion for Primary Immunodeficient patients, their families and their doctors and nurses. It is a valuable opportunity to meet one another, share personal experiences and form supportive, long-lasting friendships. Patients can also get to know their physicians and nurses in a casual environment away from the hospital. Just this year, KIDS Days have been held in 12 cities nationwide. Plans are already underway for 20 Regional KIDS Days in 2007. Cleveland's first ever JMF KIDS Day drew more than 450 people!



Buffalo
Philadelphia



Cleveland



Stanford



Indianapolis



Boston



Los Angeles



Miami



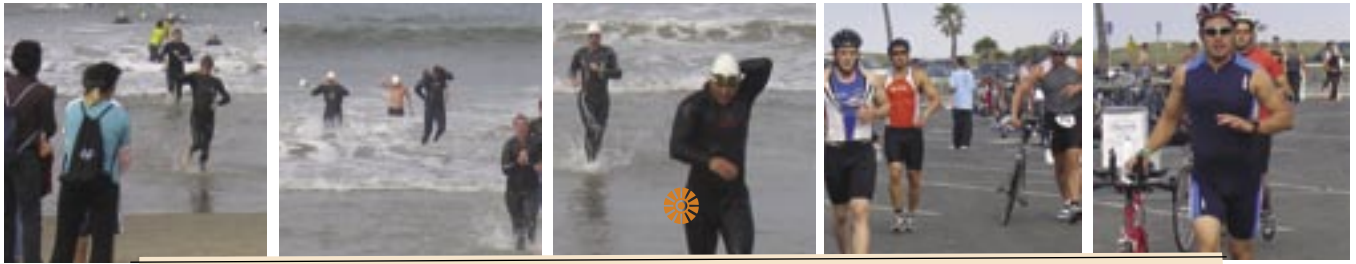
Atlanta



NYC



Seattle



8TH ANNUAL TRIATHLON

SAVE THE DATE! Next Triathlon: June 26, 2007. To register or volunteer visit www.triforlife.com

The Dina LaVigna “Breath of Life” Triathlon was held in Ventura, California. The triathlon attracted more than 1,000 athletes competing in a 1.5k ocean swim, 40k bike ride, and a 10k run. This USAT (USA Triathlon) sanctioned event is considered to be the best of its kind in the entire Western Region. The enthusiasm of the participating athletes is testimony to this, as is the Resolution passed by California State Assembly this year, honoring the Dina LaVigna “Breath of Life” Fund.

All proceeds will benefit the Dina LaVigna “Breath of Life” Fund, created by her family together with the JMF, in the memory of Dina, who died at the age of 33 from complications of Primary

Immunodeficiency. The purpose of the Fund is to improve the conditions and the experience for patients undergoing their treatments. The current focus of the “Breath of Life” Fund is to create “Dina’s Room,”

a treatment suite at UCLA’s Mattel Children’s Hospital. The record \$200,000 raised by this year’s Triathlon will go a considerable way toward the \$750,000 pledged by the fund to UCLA, Dina’s alma mater. Previously the Fund provided support to establish “Dina’s Room” at Mount Sinai in New York City. The infusion centers are bright, uplifting and cheerful spaces for patients undergoing treatment.



1ST ANNUAL “LINKS FOR LIAM”

The first annual “Links for Liam” golf event and dinner was a huge success!

Thanks to the support of friends and family, the golf outing raised \$18,000 and had 140 people in attendance at the Stone Creek Golf Club in Phoenix, AZ. The event is held in honor of Liam, a little boy who was diagnosed with SCID at 6 months of age and had a bone marrow transplant (BMT) when he was 10 months. At the time, his parents were told he had a 50% chance of survival. It pained them to learn that babies with SCID, who receive a BMT in the first 3 months of life, are given a 90% survival rate, because it was too late for Liam. The transplant for Liam was not successful and he succumbed to his disease. His lungs were unable to “heal” themselves. His father says “Liam is in a better place now; looking down on his twin brother and his older sister.”

“Links for Liam” hopes to raise funds for research and awareness in future years, in partnership with the Jeffrey Modell Foundation. The



hope is to advance newborn screening, because while a bone marrow transplant is a successful treatment, it is much more successful when performed during the first few months of life.

Next year’s event will be held on April 28 at the Sanctuary Golf Course in Scottsdale, AZ.