

# Update



A Publication of  
the Jeffrey Modell  
Foundation

Winter 2004

JEFFREY MODELL CENTERS FOR PRIMARY IMMUNODEFICIENCIES:

Boston • New York • Seattle • Stanford • Berlin • Haifa • Munich • Paris • Stockholm • Toronto • Vienna

## First National Public Awareness Program on PI Launched

### JMF AND AD COUNCIL DEVELOP PUBLIC SERVICE CAMPAIGN

JMF, in collaboration with the Ad Council, has created a Public Service Campaign to increase public awareness of PI. The central theme of the ads is that a pattern of recurring illnesses may be explained by an underlying Primary Immunodeficiency disease.



The campaign launched in June, 2003 and has already aired in

major markets across the United States.

In just the first two months, 3,039 television ads were run on 268 stations in 192 markets. During the same period, 4,195 radio spots were heard on 105 stations in 57 markets. As a result, the JMF web site traffic increased 55% in the first month, and 81% in the second month, bringing monthly web site hits to over 400,000. JMF hotline calls have increased by more than 300% since the campaign started.

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A video news release (VNR) accompanying the PSA campaign was also produced and featured a family and physician. The VNR was picked up by 92 stations, airing 143 times in 72 markets. The awareness campaign will continue through at least 2005.

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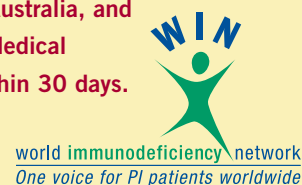
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## JMF Establishes World Immunodeficiency Network

### GRANT SUPPORT OFFERED TO 57 PATIENT ORGANIZATIONS IN 50 COUNTRIES

The Jeffrey Modell Foundation announced an exciting new initiative on behalf of patient groups around the world... the World Immunodeficiency Network. WIN offers funding support through grant applications as well as "know how" and assistance in preparing publications, disseminating information, web site development, family days, advocating for product safety and availability and much more. WIN connects 57 patient groups in 50 countries, including the US, Canada, Mexico, Central and South America, Europe, Eastern Europe, Asia, Africa, Australia, and New Zealand. WIN has established a world renowned Medical Advisory Board who will review and act upon grants within 30 days.

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



**A NEW LOOK FOR UPDATE** If you haven't noticed, let us be the first to announce that "Update" is now 4-color and has a completely new format. As you can see on these pages, there is so much to report that we needed a fresh layout to fit everything in. We always like hearing from you, so let us know what you think by e-mail at [Vicki@jmfworld.org](mailto:Vicki@jmfworld.org). We hope you like the new format and will enjoy reading about the latest developments at JMF.

## MESSAGE FROM VICKI AND FRED

### *“Symphony”*

Recently we were invited to attend a performance of the Vienna Philharmonic. We were seated in one of the first few rows and were able to closely observe Sir André Previn lead more than 100 gifted musicians.

The strings, woodwinds, brass and percussion sections all performed with precision and impeccable timing, creating a variety of moods, range of emotions and breathtaking harmony. Sir André Previn conducted the Tchaikovsky Concerto with vigor, energy, enthusiasm and absolute brilliance. But without the instruments, the talented musicians, and the precise coordination of their efforts working together, there would be no music, no matter how brilliant the conductor.



We began to think that you too have created beautiful music by working together in harmony to make a better life for patients with Primary Immunodeficiencies. In this issue of Update, we celebrate the cooperation and collaboration among the physicians and thought leaders, global pharmaceutical companies, patient groups and treasured friends who support Spring Ahead (pgs 8-9), Kid's Days (pgs 6-7), JMF triathlons (pg 16), the WHO/IUIS meeting (pgs 14-15), the 11 Jeffrey Modell Centers in the U.S., Canada, Europe and the Middle East (pgs 12-13), the World Immunodeficiency Network (pg 1), government initiatives by NIH to establish a PI research consortium and CDC to continue a collaborative education and awareness campaign (pg 5).

It is you who have produced a symphony—working together in cooperation and coordination to open new chapters for progress and unity; you have our profound thanks. Finally, we need to publicly express our sincere appreciation to the International Union of Immunological Societies (IUIS). We are humbled and frankly a bit embarrassed by the announcement that IUIS will present a special award to us at the World Immunology Congress on July 18th in Montreal (pg 5). Such recognition rightly belongs to all of you. We are blessed and honored to be out front receiving recognition, somewhat like the symphony conductor, but it is you who have made the music... who have produced for the world a beautiful symphony... indeed a masterpiece... and together we should all rejoice in its beauty.

*Vicki and Fred Modell*

# School Nurse Campaign to Be Launched

## JMF REACHES OUT TO 38,000 SCHOOL NURSES NATIONWIDE

A new program to further educate every school nurse in America about Primary Immunodeficiency will be initiated by JMF in collaboration with Lifetime Learning Systems (LLS), a division of Weekly Reader®.

A newly developed poster kit will include:

- A 17" x 22" 4 color wall poster guide describing the immune system and how it relates to PI in bold, captivating colors and images.
- A panel listing the 10 Warning Signs of PI
- A letter directed specifically to the school nurse suggesting strategies for limiting absenteeism, and ways to distribute the information through the PTA, Open Houses and mailings
- A letter to parents providing a thorough explanation of PI—what it is and what it isn't, and suggested questions to ask while at the doctor's office
- A fact sheet including information and common misconceptions, where to find additional information and web sites,

contact information to the JMF web site, hotline, and appropriate links.

- Survey for nurses to determine program effectiveness

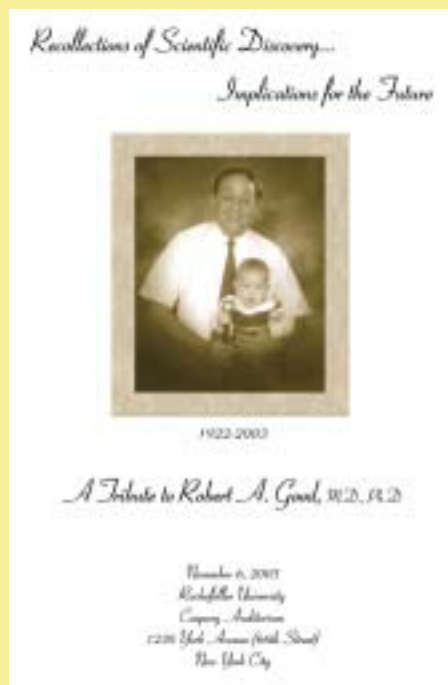
The program is scheduled to launch during the first quarter of 2004. Distribution to all school nurses nationwide in elementary, middle and high schools, is targeted towards those who are on the front line of observing over 7 million children daily.

Over the past 25 years, LLS has created 1,800 programs for more than 600 non-profit organizations, government agencies and corporations.



## JMF and Rockefeller University Host Robert A. Good Symposium

### FOUNDER OF MODERN IMMUNOLOGY RECEIVES SPECIAL TRIBUTE IN HIS MEMORY



Considered by the scientific community to be one of the most influential figures of the last half century, Dr. Robert A. Good was the focus of a science symposium entitled "Recollections of Scientific Discovery...Implications for the Future" A Tribute to Robert A. Good M.D. Ph.D.

Dr. Good's achievements require more than 40 pages to chronicle. He authored or co-authored over 2000 scientific papers, 50 books, received 13 honorary degrees and mentored and trained more than 300 scientists who have become professors or department chairmen throughout the world. His research achievements include the discovery of the function of the thymus and definition of the two distinct, major cellular components of immunity systems now called T and B lymphocyte systems. In 1968, he per-

formed the first successful bone marrow transplant to cure a fatal genetic disease, SCID. He was also the first to cure the enzyme deficiency ADA through bone marrow transplantation. He identified and defined for the first time at least 9 human primary immunodeficiencies, including what is now called Chronic Granulomatous Disease. In 2001, he was cited as one of "America's Top Doctors" in a national guide to outstanding medical specialists throughout the United States.

The symposium featured world-renowned physician/researchers, all of whom had a special close connection with Dr. Good. His passing in June 2003 left a great void in the science community, and he will be missed by us all. The event took place at Rockefeller University in New York City on November 6th.

## JMF WELCOMES SENATOR ARLEN SPECTER TO NEW YORK

Senator Arlen Specter (R-PA), the Chairman of the Senate Appropriations Subcommittee on Labor, Health and Human Services and Education visited the Jeffrey Modell Division of Clinical Immunology at the Mount Sinai Medical Center in New York City, and toured the JMF laboratories. The day concluded with a luncheon at the Park Avenue Café which was well attended by many JMF Board members and pharmaceutical industry representatives. Senator Specter continues to champion increased research and education for Primary Immunodeficiencies.

CLOCKWISE FROM TOP LEFT: Pharmaceutical sponsors Dennis Jackman (Aventis Behring), Terry Tenbrunsel (Bayer) and Gunnar Riemann (Bayer) listen to the Senator's comments on healthcare legislation.

Senator Specter addresses luncheon attendees.

Dr. Charlotte Cunningham-Rundles tours her laboratory with Senator and Mrs. Arlen Specter.

Dr. Charlotte Cunningham-Rundles offers insight to Senator and Mrs. Specter on recent trends in research and diagnosis.

Vicki and Fred Modell greet Senator Specter outside of the Mount Sinai Medical Center.

Senator & Mrs. Specter and Fred & Vicki Modell outside the Mount Sinai Medical Center.

Mrs. Joan Specter, Senator Arlen Specter and Fred & Vicki Modell at the Jeffrey Modell Center for Research & Comprehensive Care at Mount Sinai Medical Center.

Vicki Modell thanks Senator Specter and all luncheon attendees for extending their support.

JMF Board members Debbi & Max Lebersfeld with Senator Specter.



## CDC Awards \$2 Million to JMF for Awareness Program

The United States Centers for Disease Control and Prevention (CDC) have awarded, for a second year, a single source contract to JMF totaling \$2 million. The grant provides for continuing education programs directed to primary care physicians, new initiatives to reach school nurses, and continuing outreach to the public.



In the official notice of the grant award, the CDC reaffirmed its support of JMF.

**“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 impressive array of public and private support in the medical, industry, and government areas and Centers of Excellence in North American, Europe, and the Mid-East.**
- **JMF has a history of “making this happen” and the organizational commitment to achieve their stated purposes this National Campaign.**

**JMF has demonstrated that they have the management, talent, professional expertise, and broad-based support to successfully complete the proposed activities.”**

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## NIH Awards \$12.8 Million To Research Consortium

The study of Primary Immunodeficiency diseases has been dramatically bolstered by a \$12.8 million initiative sponsored by the National Institutes of Health (NIH). The program establishes the Primary Immunodeficiency Research Consortium (PIRC), a coalition of the world’s most prominent researchers in the field of Primary Immunodeficiency diseases, to help prioritize and coordinate research directions and develop new resources for the study of these disorders. The initiative is co-sponsored by the National Institute of Allergy and Infectious Diseases (NIAID) and the National Institute of Child Health and Human Development (NICHD).

For the past 7 years, JMF has vigorously advocated in the U.S. Congress to give greater recognition and resources for research in Primary Immunodeficiency diseases. The initiative is a direct result of a 2001 NIH Advisory Panel’s recommendations to accelerate research in Primary Immunodeficiency diseases and attract new investigators to the field.

**“Until now, a relative scarcity of study subjects has limited a researcher’s options for investigating these lesser known diseases,” says Anthony S. Fauci, M.D., Director of the NIAID. “The consortium will help advance our understanding by focusing research priorities, uniting established researchers with new investigators, funding small-scale clinical and preclinical projects, and creating or expanding research resources, including a cell line repository and Web-based patient registry to which all researchers will have access.”**

## Twelfth International Congress of Immunology to Convene in Montreal

PRESENTATION OF IUIS

AWARD ANNOUNCED

10,000 clinical and basic immunologists, researchers, scientists and investigators from all over the world will gather this July in Montreal, Canada for the International Congress of Immunology. This meeting is held every three years; the last was held in Stockholm in 2001. This year, the meeting is being hosted by the Canadian Society for Immunology.

Participating in this event of unprecedented scope for the immunology field is the International Union of Immunological Societies (IUIS), which is comprised of 58 organizations worldwide. The IUIS will present a special award to Vicki and Fred Modell at the opening ceremony and welcome reception. This award, created and designed by world renowned artist Niki de Saint-Phalle, was given only once before, to Bill and Melinda Gates of the Gates Foundation. News of the award was announced at the WHO/IUIS meeting in Portugal, by Dr. Fritz Melchers, past president of IUIS.



**The IUIS will present a special award to Vicki and Fred Modell at the opening ceremony and welcome reception. This award, created and designed by world renowned artist Niki de Saint-Phalle, was given only once before, to Bill and Melinda Gates of the Gates Foundation.**

## Kid's Days

From New York to New England, South Florida to Seattle, JMF Kid'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.





kid's  
day



**Save the Date**  
Spring Ahead  
April 21, 2004  
Plaza Hotel



## 17th Annual “Spring Ahead” Gala Honors Tod Waterman

The Grand Ballroom of the Plaza Hotel was sold-out for the 17th Annual “Spring Ahead” Gala. Tod Waterman, Senior Vice President and Managing Director of Reckson Associates Realty Corp., New York City, received JMF’s “Man of the Year” Award. The night featured a crowd pleasing Brazilian dance troupe, bringing everyone to their feet and complimenting the event’s exotic Carnival theme. The event raised more than \$800,000.

CLOCKWISE FROM TOP LEFT:  
Fred Modell presents JMF “Man of the Year” Award to Tod Waterman.  
Neil Clark, TSNY and Arnold Penner (Penner & Co.)  
Fred & Vicki Modell and Kara & Josh Freedman (CNBC and Lehman Brothers)  
Ric Clark (Brookfield Properties), John Nugent, (CB Richard Ellis), and Robert Alexander (CB Richard Ellis)  
Jon Mechanic (Fried, Frank, Harris, Shriver & Jacobson), Bruce Mosler (Cushman & Wakefield), Joseph DeLuca (Gensler), Steve Siegel (CB Richard Ellis)  
Howard & Amy Rubenstein (Rubenstein & Associates)



TOP ROW, L-R:  
JMF Honoree, Tod Waterman  
(Reckson Associates), with  
Gala Chairperson, Harvey Schulweis  
(Schulweis & Company)  
Vicki Modell and JMF Staff

MIDDLE ROW, L-R:  
Paul A. Galiano (Tishman Speyer),  
Geoffrey Wharton (Douglas Elliman),  
Robert Speyer (Tishman Speyer),  
Jon Mechanic (Fried, Frank, Harris,  
Shriver & Jacobson)  
  
Jason Shuman and many other  
patients and families share in  
the celebration.  
  
Wendy & Jon Mechanic (Fried, Frank,  
Harris, Shriver & Jacobson)

BOTTOM ROW, L-R:  
The Samba beat enhances the  
evening activities.  
  
Vicki & Fred Modell and Allyson and  
Tod Waterman pose for a group shot  
before the gala begins.  
  
Vicki Modell gives a big welcome  
to the Spring Ahead crowd.  
  
Steve & Wendy Siegel  
(CB Richard Ellis)

# JMF Selects "Spring Ahead" Honoree for 2004

CBRE NEW YORK CHAIRMAN TO LEAD APRIL 21ST GALA



Robert J. Alexander, New York Region Chairman of real estate giant CB Richard Ellis has been selected as JMF's 2004 "Man of the Year." Formerly the President of Insignia/ESG, he is widely recognized as the top-producing broker in New York, the nation, and the world, having arranged nearly 3

million sq. ft. of transactions in 2002 worth an aggregate of \$2 billion. In 2001, Mr. Alexander transacted a mammoth 7 million sq. ft. of deals estimated to be valued at \$13 billion.

At Insignia, Mr. Alexander was honored as the firm's top producer four years in a row beginning in 1999.

"Mr. Big," as he was dubbed by New York Post Executive Editor Steve Cuzzo for both his stature and his accomplishments, is a veteran real estate broker with over 22 years in the business. During his illustrious career, Mr. Alexander has arranged more than 50 million sq. ft. of real estate lease and sales transactions for such corporate financial giants as Lehman Brothers, Deutsche Bank AG, J.P. Morgan Chase & Co. Fleet Bank, KPMG, The Bank of America, The Port Authority of New York and New Jersey, New York Life Insurance Company and The Bank of New York, to name a few. JMF hopes to make Spring Ahead 2004 our best ever, led by "Mr. Big," Robert J. Alexander.

## PRIMARY IMMUNODEFICIENCY SYMPOSIUM NOW AVAILABLE VIA WEB CAST

Online Now!

Educational CME Symposium for:

- Physicians
- Nurses
- Medical Students
- Public Health Professionals

Visit [www.info4pi.org](http://www.info4pi.org) for the link to the CME Symposium.



## JMF Sponsors Physician Symposia Across the Nation

The Jeffrey Modell Foundation sponsored a series of physician symposia throughout the United States in 2003. Created for physicians, physician 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, Internists, Pediatricians, Pulmonary Specialists, Allergists and other related medical professionals.

The courses, available for CME credit, informed attendees about the components of the immune system, the types of infections that can arise when an immune system is impaired, how to distinguish between the different types of immune defects in pediatrics, and recognition of defects found in adults. In addition, the symposia provided physicians with laboratory information, steps to diagnosis, and new treatment options.

The CME courses took place 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



PICTURED LEFT TO RIGHT: Kenneth Weinberg, M.D., Philip Pizzo, M.D., Fred Modell, David Lewis, M.D., Vicki Modell, Irving Weissman, M.D., E. Richard Stiehm, M.D., and John Curnutte, M.D., PhD.

# NIH and JMF Collaborate to Reach Pediatricians and Family Practitioners Nationwide

## NATIONAL SURVEYS DEMONSTRATE NEED FOR GREATER AWARENESS

Alarmed by the numbers of people with chronic infections who are not being screened for their underlying cause, a new national campaign was launched by the Jeffrey Modell Foundation (JMF) in partnership with the National Institute of Child and Health and Human Development (NICHD) of the National Institutes of Health (NIH), and other federal and private agencies and supported by grant funds from the U.S. Centers for Disease Control and Prevention (CDC).

The first initiative of the campaign was a mailing sent to more than 100,000 physicians nationwide about Primary Immunodeficiency (PI). It reached every pediatrician who is a member of the American Academy of Pediatrics and every practitioner affiliated with the American Academy of Family Practice Physicians.

“Unfortunately, a significant number of cases are undiagnosed until those

affected are very sick or chronically debilitated,” wrote Duane Alexander, M.D., Director of the NICHD.

In connection with the national campaign, a new study by Opinion Research Corporation International in Princeton, New Jersey found that not a single American could name any of the more than 100 PI diseases. Yet, one third of Americans know someone, child or adult, who suffers

from unexplained repeated ear infections, sinusitis, pneumonia, or similar recurring infections. A second nationwide survey with pediatricians and family practice physicians revealed that virtually every physician respondent (96%) had patients with 2 or more of the 10 warning signs of PI. Yet, only 1% of those patients were suspected of having a PI disease and only 2% were referred to an immunologist for follow-up. Asked to rate the prevalence of PI, 85% of the physicians surveyed characterized PI to be “rare” or “extremely rare” (1 in 5,000-10,000).

However, the US National Institutes of Health (NIH) indicate that, taken together, PI diseases affect 1 in 500 Americans and estimate that at least another 1 in 500 Americans are affected but undiagnosed,

due to a lack of awareness.

“When I first met with Fred and Vicki Modell of the Jeffrey Modell Foundation, I was disturbed to

hear the results of the physician survey indicating such a lack of awareness about the PI diseases,” said Dr. Alexander. “These new survey results confirm the need for a PI awareness campaign to better inform the medical community. This is an extraordinary issue and the NICHD is pleased to lead this effort to reach as many pediatricians and family physicians as possible.”

**“Unfortunately, a significant number of cases are undiagnosed until those affected are very sick or chronically debilitated,” wrote Duane Alexander, M.D., Director of the NICHD.**



## JMF Diagnostic Centers Established in Europe

BERLIN, MUNICH AND VIENNA BRING JEFFREY MODELL CENTERS TO 11

JMF recently dedicated Diagnostic Centers in Berlin, Munich, and Vienna, bringing the established Jeffrey Modell Research and Diagnostic Centers to 11.

The JMF Diagnostic Centers include physician education programs, patient support events such as family days, and regional public awareness campaigns. Newly diagnosed and suspected patients can now be referred to the Diagnostic Centers for laboratory testing and "work-ups." These initiatives have led to improved and earlier diagnosis, and generated additional referrals to the 47 Jeffrey Modell Referral Centers in the US, Canada, Europe, the Middle East and Latin America.



#### LEFT PAGE

CLOCKWISE FROM TOP LEFT:  
Dr. Volker Wahn examining a patient at the Immundefekt Centrum Charite-Berlin.

Dr. Ulrich Wahn (Director of the JMF-Berlin Diagnostic Center) and Dr. M. Dietl (Clinical Director of the Children's Hospital-Charite, Berlin) accept signage for the new Jeffrey Modell Center in Berlin.

Families await diagnosis and treatment at the Immundefekt Centrum Charite, Berlin.

Fred and Vicki Modell join clown unit touring the pediatric hospital in Munich.

Dr. Hermann Wolf, Dr. Martha Eibl, Vicki Modell & Fred Modell accept signage for the new JMF Center in Vienna, Austria.

Children interviewed by the press at the Berlin Center.

Dr. M. Dietl addressing the press at a Berlin press briefing announcing the new JMF Diagnostic Center.

#### RIGHT PAGE

CLOCKWISE FROM TOP LEFT:  
The PI team at the Kinderklinik und Poliklinik im Dr. von Haunerschen Kinderspital in Munich, Germany.

Dr. Belohradsky and Fred Modell share information for the education and awareness campaign.

Fred Modell describing strategies for the new JMF Center in Munich.

Family Days at the Berlin Jeffrey Modell Center have already begun!

Kristina Schmid (Assistant Director of the JMF Center in Munich), Wolfgang Vogel (ZLB Bioplasma), Vicki Modell, G. Grundl (DSAI, the German patient organization), Fred Modell, Eva Sorgel (DSAI), Dr. Bernd. Belohradsky, (Director of the Jeffrey Modell Center in Munich).

Professor Reinhardt, Head of the Children's Hospital in Munich seals partnership with Vicki & Fred Modell.

Dr. Belohradsky provides a tour of the facilities at the Kinderklinik und Poliklinik im Dr. von Haunerschen Kinderspital in Munich, Germany.

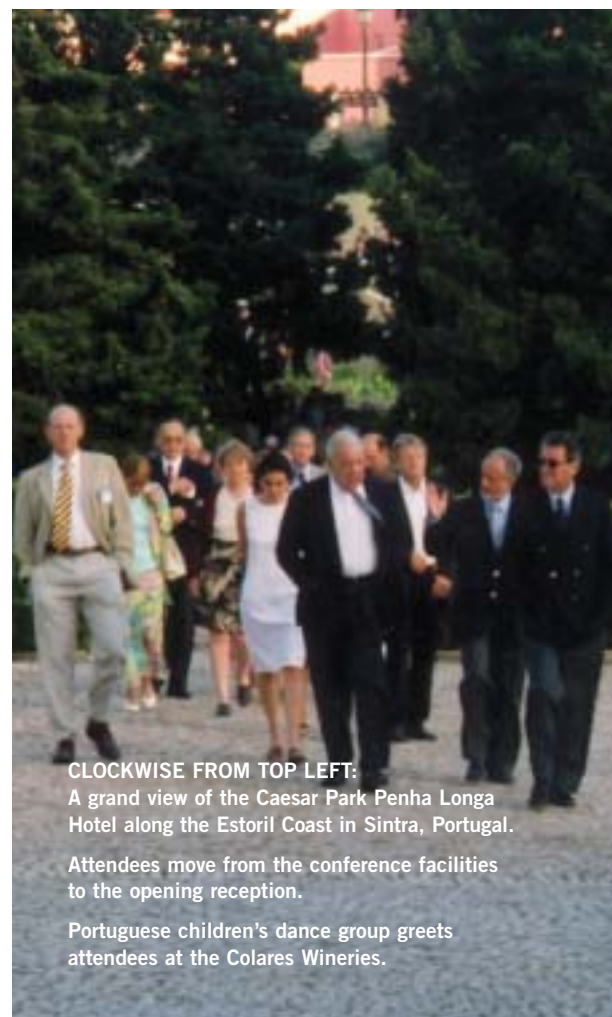
## World Health Organization/IUIS Conference held in Sintra, Portugal

### JMF ORGANIZES ITS FOURTH WORLD SCIENCE CONFERENCE

In a very unique setting along the Estoril coast, a few miles from Lisbon, the Jeffrey Modell Foundation hosted the meeting of the International Union of Immunological Societies (IUIS) Symposium on Primary Immunodeficiency Diseases (formerly the World Health Organization Symposium).

Since the early 1960's, the Committee on Primary Immunodeficiency Diseases has met every two or three years in various worldwide settings to define and classify the Primary Immunodeficiency Diseases. The resulting report not only provides vital information to the medical community, but is also used by various governments to help determine health care policy. The committee believes that scientific progress and information is moving forward so rapidly that it is important to convene regularly.

This year's meeting follows the very successful past meetings organized by JMF in Bristol, England, Baden Bei Wein, Austria and Lucerne, Switzerland. The scientific proceedings were organized by Dr. Raif Geha, Harvard Medical School and Dr. Luigi Notarangelo, University of Brescia, Italy. More than 100 of the world's leading Immunologists attended and delivered new breakthrough scientific findings in identifying, diagnosing, and treating PI disorders. The proceedings will be published in the first half of 2004.



CLOCKWISE FROM TOP LEFT:  
A grand view of the Caesar Park Penha Longa Hotel along the Estoril Coast in Sintra, Portugal.

Attendees move from the conference facilities to the opening reception.

Portuguese children's dance group greets attendees at the Colares Wineries.



#### TOP ROW LEFT TO RIGHT:

JMF Staff Members, Kristen Henderson and Vanessa Tenenbaum enjoy the Portuguese barbecue with Vicki Modell.

L-R, Dr. Fred Rosen (Center for Blood Research, Harvard Medical School) sharing a light moment with Dr. Max Cooper (Birmingham, Alabama)

The Modell's with Drs. Martha & Hans Eibl.

#### SECOND ROW LEFT TO RIGHT:

L-R, Fred Rosen (CBR), Fred Modell, Vicki Modell, Kathy & Allan Lock (National Institutes of Health)

The IUIS attendees enjoy the evening festivities.

#### THIRD ROW LEFT TO RIGHT:

Dr. Raif Geha welcoming the crowd at the conference gala.

IUIS 2003 Expert Committee Chairpersons, Dr. Raif Geha and Dr. Luigi Notarangelo officially open the conference at the traditional Portuguese barbecue.

Dr. Hans Ochs participating with the Tuna ensemble school orchestra.

#### BOTTOM ROW LEFT TO RIGHT:

Dr. Lennart Hammarstrom (Stockholm, Sweden) & Dr. Richard Gatti (Los Angeles, CA) share a light moment during the reception.

L-R, Fred Modell, Ursula Melchers, Vicki Modell, and Fritz Melchers (former President of the IUIS)

## DINA LAVIGNA TRIATHLON



The 5th Annual Dina LaVigna “Breath of Life” Triathlon was held in Ventura County, California. Participants were challenged by a half-mile swim, 40K bike ride and a 10K run. This year there were winners for best overall time, best female competitor, and best team time. The event was organized by the family of Dina LaVigna, who died five years ago of complications from her Primary Immunodeficiency. The “Breath of Life Fund” has been supported by Dina’s friends, family members, and colleagues. The fund has already improved and enhanced the infusion room at Mount Sinai Medical Center in New York and UCLA Mattel Children’s Hospital. This year’s triathlon raised more than \$50,000.

## Jeffrey Modell Immunology Prizes Awarded at the Mount Sinai School of Medicine Commencement Ceremonies

Ayotunde Dokun and Carol Ming Lewis received Jeffrey Modell Immunology Prizes, awarded at the Mount Sinai School of Medicine commencement ceremonies.

Dr. Dokun’s research, conducted at Mount Sinai, resulted in 6 publications including *Science*, *Nature Immunology* and the *Journal of Immunology*. He was the recipient of a national research service award and Pre-Doctoral Fellowship. He will continue his training in Internal Medicine at Duke University Medical Center in Durham, NC.

Dr. Lewis graduated with Distinction in Research. She is the recipient of many scientific awards including a Howard Hughes Medical Institute CME Scholarship, a Howard Hughes Fellowship supporting two years of basic science research at NIH and the Albert Schweitzer Fellowship for Community Service. Her work resulted in publications in *Nature Immunology* and *Current Opinion in Immunology*. She will continue her training at Harvard Medical School.

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## Patient Starter Kits Now Available

An educational resource kit for newly diagnosed patients with Primary Immunodeficiency (PI) is now available through JMF. The kit includes an interactive CD-ROM that provides the viewer with the opportunity to hear from patients and families successfully coping with PI. There is an easy to understand tour of the human immune system, as well as comprehensive information on diagnosis and treatment. Sample letters for school officials and employers, support services available for patients, insurance issues and a variety of web site resources are included. The educational resource kit was developed in collaboration with the JMF and Baxter Healthcare Corporation. Patients can receive kits from their specialists/physicians or from the Jeffrey Modell Foundation at 1-866-INFO-4-PI or [www.info4pi.org](http://www.info4pi.org). Patients can also contact Baxter at [www.baxter.com](http://www.baxter.com).

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## New Physician Algorithm from JMF

### FOUR STAGES OF IMMUNOLOGIC TESTING CREATED BY JMF MEDICAL ADVISORY BOARD

In an effort to advance diagnosis, the JMF has now developed a Physician Algorithm poster. The algorithm identifies four specific stages of immunologic testing. The earlier stages are generally appropriate for primary care physicians before the necessity of a specialist referral. The algorithm, reflecting a consensus of the JMF Medical Advisory Board, is presented as a public service by JMF and is supported by grant funds from the CDC, the generosity of the NIH, the PPTA and several global plasma producers. The algorithm is available on the JMF website, [www.info4pi.org](http://www.info4pi.org), or by calling the hotline 1-800-INFO-4-PI.