

UPDATE

A Publication of Jeffrey Modell Foundation Jeffrey Modell Centers in

Boston • New York • Seattle • Paris • Haifa

National Hotline 1-800-JEFF-844 www.jmfworld.org

SPRING 2002

JMF Celebrates its 15th Year

JMF Kids Salute 15 Years of Honorees

PAGES 8-10



CDC Partners with JMF

Public Health Agency Addresses Primary Immunodeficiencies

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• CDC and JMF will jointly support a Public Health Fellow and assign a Public Health Officer from the CDC to study primary immunodeficiency disorders. The project will be led by Tim Baker, Deputy Director of the Office of Genetics and Disease Prevention (OGDP) - Project Planning and Oversight. Also joining the team is Senior Medical Officer, Dr. Mary Lou Lindegren, Medical Epidemiologist and Project Director

at the Office of Genetics and Disease Prevention (OGDP), and Dr. Lisa Kobrynski, a Clinical Immunologist at Emory University in Atlanta with a large PI patient base.

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Continued on page 3

INSIDE

A Message from Vicki & Fred2	K.I.D.'s Days 6–7
Gene Therapy Conference on PI3	Spring Ahead 2001 8–10
National PI Interactive Data Center 3	JMF Selects 2002 Honoree11
Dr. Robert Good Honored4	WHO/IUIS Conference in Lucerne 12–13
Triathlon for "Breath of Life" Fund 4	Looking Back
Bubble Boy Movie Controversy 5	JMF Prizes in Immunology Presented 16

SAVE THE DATE SPRING AHEAD THE PLAZA HOTEL WEDNESDAY, APRIL 24, 2002



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SAVE THE DATE SPRING AHEAD THE PLAZA HOTEL WEDNESDAY, APRIL 24, 2002

A Message From Vicki & Fred

As we look back on the first 15 years of the Jeffrey Modell Foundation, we are in awe of the tremendous support we have received. From the very first day that we considered establishing an organization in memory of Jeffrey, you have responded with encouragement, and an abundance of emotional and financial support.

At the same time that we count our blessings, all of us must look ahead to the future. The

tragic events of September 11, 2001 remind us so graphically of how helpless we can be and how little control we can have over our future. We think long and hard about our children and what kind of world they will face. While we pray for their well-being as parents, grandparents, aunts, uncles, cousins and friends, all of us know we must do our very best to keep our children healthy. It is that effort that still resides within our control. And that is the mission of the Jeffrey Modell Foundation.

Today, with research and clinical care centers at New York's Mount Sinai Medical Center, Boston Children's Hospital, Center for Blood Research at the Harvard Medical School, Seattle Children's Hospital, University of Washington Medical School, and The Gene Therapy Laboratory at Hospital Necker in Paris, cutting edge dis-



Jeffrey Modell

coveries are now generating novel, meaningful, and exciting new therapies that have already changed the lives of so many. They have produced real cures, and foster hope for the more than 500,000 children affected by PI in the United States and the estimated 10 million worldwide.

The Foundation now reaches patients and scientists around the globe in the areas of research, physician education, patient support and public advocacy. By way of example, the "Ten Warning Signs" poster, developed by the JMF, is now widely circulated in 19 countries and in 14 languages.

We have gained so much momentum. We stand at the edge of so many more possibilities. If you believe that these first 15 years represented the best that we could do, then let's commit to future generations and continue this work, until every child is cured, and each of our children can enjoy a full, productive, happy and healthy life.

Victiona Fred Modell

JMF Celebrates its 15th Year

JMF Kids Salute 15 Years of Honorees



atta now IME

Scott McGuire, star of the new JMF video, greets crowd

JMF Kids Salute 15 Years of Honorees

JMF celebrated its 15th Annual Spring Ahead Gala at New York's Waldorf=Astoria. The event theme was "A Journey from Commitment to Cure." In an inspiring presentation, each of the previous honorees received a special award from one of the JMF K.I.D.S. Among the evening's honorees were leaders from the real estate industry, pharmaceutical industry, and expert physicians and researchers. The JMF Lifetime Achievement Award was presented to Dr. Alain Fisher of Paris whose groundbreaking success in gene therapy has offered hope to patients worldwide.



Dr. Alain Fischer is congratulated by Scott McGuire



Lifetime Achievement Award Winner Dr. Alain Fischer



Aby Rosen, RFR Holdings, is presented award by Scott McGuire



CBR President Dr. Fred Rosen is presented award by Joey Graziano



Bruce Mosler, Cushman & Wakefield, receives award from Jamie Hall



Doug Loocke, American Red Cross, and Jason Shuman



Paul Perrault, Aventis Behring, and Jacqueline Plumey



Jon Mechanic, Fried, Frank, Harris, Shriver & Jacobson, and Ray Plumey bask in the warmth of the crowd



Jason Shuman presents Steve Witkoff, The Witkoff Group, with his award...



...along with a big hug



Steve Seigel, Insignia/ESG, receives his award from Steven Lozano...



...there were lots of big hugs between old friends

JMF CELEBRATES **ITS 15TH YEAR**







Honorees Bruce Mosler, Cushman & Wakefield and Steve Seigel, Insignia/ESG



Jon Mechanic and his wife Wendy dancing cheek to cheek



Neil Clark, TitleServNY, Jon Mechanic, Jill Block, Mark Shapiro, Shapiro & Block LLP



Board Members James Emden, Insignia/ESG and his wife Bettina



Mr. and Mrs. Paul Glickman, Cushman & Wakefield



Longtime buddies, Evin Bail, Kyle Bush and Susan Newman of Baxter



Drs. Lloyd and Jill Mayer, Fred and Vicki Modell toast the evening's honorees



Mr. and Mrs. Jack Irushalmi, TriStar Construction, Bruce Mosler, Cushman & Wakefield



Honorees Jon Mechanic and Steve Seigel share a good chuckle

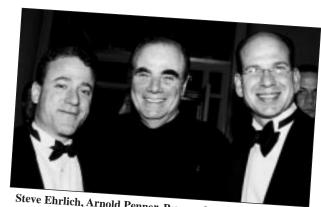


JMF Board Members, Susan and Barry Stein with Fred Modell

15th Year Gala continued



Mitch Konsker, Cushman & Wakefield, Jon Mechanic, Fred Modell, Lisa Konsker



Steve Ehrlich, Arnold Penner, Penner & Co., Keith Locker, Deutsche Bank



Trevor Davis, Davis & Partners, Vicki Modell, Steve Witkoff, Bo Dietl, Fred Modell

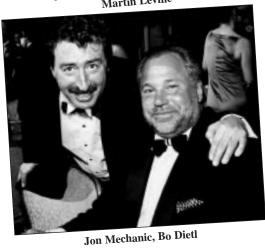


Chris Fuchs, Fred Modell, Michael Fuchs, RFR Holdings, Vicki Modell



Norman Baker, Insignia/ESG and Martin Levine







15th Year Gala continued



NEXT SPRING AHEAD SAVE THE DATE APRIL 24, 2002 THE PLAZA HOTEL

Scientists, physicians, and leaders of the pharmaceutical industry honored by the JMF KIDS

JMF Selects Spring Ahead Honoree for 2002

Brookfield Properties Chief to Lead April 24th Gala

Richard Clark, President and Chief Executive Officer of Brookfield Properties U.S. Commercial Operations, will be this year's "Man of the Year" at the upcoming Spring Ahead Gala. Brookfield owns interests in 60 premier commercial properties comprising 46 million square feet. Its major markets include New York City, Boston, Denver, Minneapolis, Toronto and Calgary. Brookfield also runs a property management operation with over 100 million square feet under contract and develops master-planned residential communities.

Ric has been with Brookfield since 1984 in various senior roles. He currently oversees all of Brookfield's United States commercial operations and has been designated to become CEO of the parent company in March 2002.

He is a member of the Board of Directors of Brookfield Financial Properties, a member of the Investment Advisory Committee for PRIMUS (a real estate investment fund sponsored by Deutsche Bank), a member of The Real Estate Board of New York's Board of Governors, and a member of the Lincoln Center Real Estate and Construction Council.

The JMF will be returning once again to the Grand Ballroom of the Plaza Hotel in New York City. As always, it will be a "high energy party," and we hope for an enthusiastic outpouring of support from our good friends who have participated over the past 15 years. ◆



Richard Clark
JMF 2002 "Man of the Year"

CDC Partners with JMF

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- An expert workshop will be held November 7–9 to develop recommendations for addressing PI within the general populace.
- The proceedings of this conference will be published in a major medical journal.

Vicki Modell's testimony before the Congressional Sub-Committee included the following statement:

"Individuals with undiagnosed Primary Immunodeficiencies are a source of viral and bacterial infection. When they are left undiagnosed and unprotected, this population harbors serious viruses, bacteria, and deep-seated infections such as Cryptosporidia, Polio, Enterovirus, Parainfluenza, and E-Coli to name a few. When they are left undiagnosed and untreated, they become a delivery system of infection to the general public. This poses a serious threat to schools, daycare centers, workplaces, and the often-overlooked environment of hospitals. Delayed disgnosis leads to increased morbidity and inflated global medical costs. It also leads to racial disparities and a host of social and economic costs. The most overlooked, undiagnosed group is 5-10 year olds who present with frequent illness. If left undetected, by the time they are identified they already suffer with serious life threatening infections, and it is often too late."

The partnership is a response to ongoing testimony delivered by Vicki Modell to the **House Appropriations Subcommittee on Health.** At the WHO/IUIS meeting in Lucerne, Switzerland, (see page 12) Dr. Mary Lou Lindegren held a breakfast meeting with leading immunologists from around the world to help formulate the CDC role worldwide. Many of those researchers and scientists will be contributing to the Expert Conference November 7-9.

In addition to these steps, the CDC sent out letters on agency letterhead accompanied by the JMF "10 Warning

Signs" poster to every state, county, and local public health department in the United States. Nearly 16,000 copies of the poster were received by health officials nationwide.

According to Dr. Richard Jackson, Director for the National Center for Environmental Health, "We look forward to developing this partnership between the CDC and the Jeffrey Modell Foundation. We applaud the Foundation's efforts in educating physicians and parents on Primary Immunodeficiencies, and we are committed to working with the Foundation to improve awareness of these disorders.

Gene Therapy Conference on Pl

JMF Supports Breakthrough Meeting

The Jeffrey Modell Foundation cosponsored an important meeting in Bethesda, MD on "The Status of Gene Therapy for Primary Immunodeficiency Diseases." JMF joined three of the National Institutes of Health: the NIAID, NICHD, and NCI, as well as the Office of Rare Diseases (ORD) in helping to organize the conference.

Co-chaired by Dr. Rebecca Buckley of Duke University and Dr. Hans Ochs of the University of Washington in Seattle, the meeting included clinicians, transplanters, gene therapy experts, ethicists, and representatives of regulatory agencies, to explore the need for clinical trials and determine the optimal approaches to assess the

safety and viability of this new therapy.

The meeting generated a report of recommendations and study considerations. A number of researchers and scientists who attended the JMF sponsored WHO/IUIS meeting in Lucerne (see page 12) delivered papers at this NIH Gene Therapy conference.

JMF Establishes National Primary Immunodeficiency (NPI) ResourceCenter

Electronic Interactive Center Will Begin Operations Soon

The Jeffrey Modell Foundation is establishing an interactive resource center that will centralize research, and serve as an electronic communication center. The NPI ResourceCenter will coordinate many resources of information for patients, primary care physicians, specialists, researchers, treatment providers, and government health agencies. It will provide links to the JMF website (www.jmfworld.org), which has been referenced by more

than 3 million users, as well as the JMF Centers of Excellence and Referral Centers, National Institutes of Health, and Centers for Disease Control and Prevention.

The center will also feature six interactive new specialized sections, including a Patient-to-Patient portion, an Expert Locator, a K.I.D.'s Center, a resource for health professionals posting online symposia, a section for FAQ with responses from experts,

and a Dynamic Link Library.

It is anticipated that this interactive communications center will become recognized as the foremost central resource on Primary Immunodeficiency on the Internet, providing expansive information to researchers, physicians, patients and government agencies.

The National Primary Immunodeficiency ResourceCenter is expected to commence operations in early 2002. ◆

JMF Website Receives Over 3,000,000 Hits!!

Dr. Robert Good Honored at USF Tribute

JMF Supports Science Symposium

The Jeffrey Modell Foundation participated in and supported a two-day science symposium at the University of South Florida and Children's Hospital of St. Petersburg in honor of Dr. Robert Good.

Dr. Good is truly one of the most accomplished and foremost leaders of medical research in the past half century. His list of accomplishments includes completion of the very first successful bone marrow transplant ever performed. As a physician, researcher, and professor, he has published more than 2000 scientific papers and authored 50 books. He is the recipient of 13 honorary degrees from medical schools around the world.

Dr. Good began his career in medicine at the University of Minnesota Medical School and devoted the next 50 years to groundbreaking research and clinical application in many areas of medicine, including bone marrow and stem cell transplantation, and other forms of cellular engineering. Dr. Good appeared on the cover of Time Magazine and has often been lauded in public media, scientific publications, and medical journals. He has pioneered advances in several different areas of medicine, but is most recognized for his accomplishments in the field of immunology.



Dr. Robert Good with Fred and Vicki Modell

An enthusiastic gathering of more than 400 leading scientists and former students met in St. Petersburg for a deserving tribute to Dr. Good. The JMF sponsored the science symposium and tribute event.

Triathlon Benefits Dina LaVigna "Breath of Life" Fund

Third Annual "TriForLife" Event Supports Infusion Facility at UCLA



Friends of the Dina LaVigna "Breath of Life" Fund participated in a triathlon, raising funds to enhance a state-of-the-art patient care infusion facility at UCLA. The participants of the race began with a 6.2 mile run in beautiful Marina Park, followed by a .5 mile swim in the neighboring Ventura Harbor. They finished with a 40K (24.8 mile) bike ride, ending in Marina Park.

First Place winner was Mr. Shigy Suzuki, with a time of 2:00:48, followed by Dave Romero and Mark Kajiwara who came in at 2:06:37 and

2:07:55 respectively. Many participants teamed up to complete the race. Prizes for the winners included a gym membership, a weekend getaway, dinner for two, a \$100 gift certificate, and plane tickets to the destination of choice anywhere in the continental U.S.

The race has already generated over \$30,000 toward the new facility. The JMF contributed a matching grant, bringing the total to \$60,000.

According to Jeff Schmitt, JMF Board Member, who together with the LaVigna family helped organize the event, "This is just the beginning. We are hopeful that additional matching funds and support from the pharmaceutical industry will make one more of Dina's dreams a reality in a very short time. We're already planning next year's event, which will be even bigger and better."

The "Breath of Life" Fund was established in memory of Dina LaVigna, a young mother who passed away in 1997 from complications of a PI disorder. Her dream was to have a comfortable, welcoming infusion room environment with toys and games for the children, arts and crafts, computers, magazines and much more. She is lovingly remembered for her optimism, vision, and tremendous spirit. She is survived by her son Zack, her husband Jeff Schmitt, and so many friends. All proceeds of the event will be allocated toward patient care projects. For more information, log onto their website, www.triforlife.com.

Bubble Boy Movie Creates National Controversy

JMF Challenges Disney Co. to Join Education and Awareness Campaign

A national media blitz came to the JMF following the Disney Company release "Bubble Boy." The film is a comedy about a young man who spends his whole life confined to a bubble because he was "born without immunities and a single germ would kill him." Although the movie is a mockery and is tasteless, the JMF did not call for a boycott, protest, pickets, letter writing campaign, or any other adversarial action to block the opening of the movie. Instead, the JMF reached out and challenged the Disney Company to work together to coordinate a public awareness and education campaign. The purpose of this campaign would be to promote greater public awareness and familiarity with Primary Immunodeficiencies for parents, patients, schools, employers, physicians and managed care organizations.

At a New York press conference, major television networks and national wire services packed the JMF offices to hear patients and their families express their displeasure concerning this movie. 10-year-old Jason Shuman of Sudbury, MA said, "When I saw the movie, I was furious. I was crying. They were taunting me about my disease."

Scott McGuire, a 10-year-old from North Attleboro, MA wrote a letter to Michael Eisner, Chairman and CEO of Disney, to voice his feelings about the movie. He wrote, "It's called a comedy, but we don't think it's funny to make jokes about serious diseases...I spend many hours a month getting transfusions at the hospital so I can try to stay healthy. It would make me really sad to think that while I am at the hospital, lots of people are sitting in a movie theatre laughing about a serious disease."

Ironically, Scott was honored by Disney last year as one of the "Millennium Dreamer Award" winners. He was chosen because of a book that he wrote about his disease called "The Difference I Make." Sadly, he wrote to Eisner, "The book I wrote helped people understand that being



TV cameras and reporters pack the JMF offices



16-year-old, Summer Krisel describes to the media what it is like to live with primary immunodeficiency



10-year-old Jason Shuman calls the Disney Company to express his displeasure at "Bubble Boy"



The panel of patients and parents explain that primary immunodeficiency is no laughing matter

immune deficient is not funny. But now with this movie coming out, my book and the award I won for it don't mean as much anymore."

All the major national media outlets covered this story. These included: ABC, Associated Press, Bloomberg, CBS, CNN, Reuters, FOX, NBC, WB, WPIX, and WWOR, as well as stories

on Entertainment Tonight and the CBS Morning Show.

The controversy was also covered by WINS and CBS national and local radio, and articles appeared in the Boston Globe, Entertainment Weekly, Newsday, Newsweek, NY Daily News, the NY Post, the NY Times, Time Magazine, and USA Today. ◆



New York K.I.D.S Day Celebrated at Bowlmor Lanes

K.I.D.'s Day







K.I.D.S Day is an annual event devoted to KIDS with IMMUNE DEFICIENCIES and their families. It provides a welcome opportunity for families to share personal experiences with one another in a fun, informal setting. Once again the event was held at Bowlmor Lanes in New York City, and attended by over 200 of the JMF K.I.D.S and their families. The day included not only a full afternoon of bowling, but also featured clowns, face painters, disco music and fun food. The day was sponsored by the Commodities Exchange Center's "Futures & Options for Kids."



New York K.I.D.S Day continued



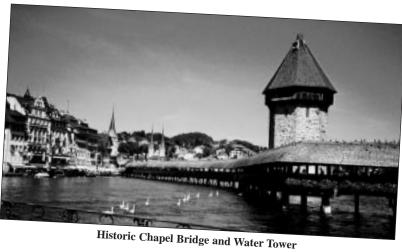
JMF HOSTS WORLD MEETING **OF EXPERTS IN SWITZERLAND**

WORLD HEALTH ORGANIZATION/IUIS CONFERENCE HELD IN LUCERNE

The Expert Committee on Primary Immune Deficiency Diseases meets every three years to update its report that defines and classifies the PI diseases. This year, the World Health Organization (WHO) meeting was held in collaboration with the International Union of Immunological Societies (IUIS). The Report not only provides vital information to the medical community, but is also used by various governments to determine health care policy. The Jeffrey Modell Foundation previously sponsored the WHO/IUIS meetings in Bristol, England and Baden bei Wein, Austria. Those meetings were considered outstanding scientific conferences on immunodeficiencies, generating important breakthrough findings and dialogue among scientists from around the globe.

This year's keynote address was delivered by Dr. Rolf Zinkernagel, Director of the Institute of Experimental Immunology in Zurich, Switzerland. His paper was entitled "On Immunity: Survival and Disease." Dr. Zinkernagel was awarded the 1996 Nobel Prize in Physiology and Medicine for the discovery of how the immune system recognizes virus-infected cells.

In addition to the three-day series of scientific papers, there was an extensive social program that included a colorful evening of dinner and music at a working Swiss farm, a twilight boat ride on Lake Lucerne, and a festive gala at the Park Hotel Vitznau. The highlight of the meeting was a special tribute to Dr. Fred Rosen by his peers, recognizing his



26 years of leadership as Chairman of the Committee on Primary Immunodeficiency Diseases.

The academic program and support for the speakers, delegates and social events were underwritten by the enthusiastic support of the American Red Cross, Baxter Healthcare Corp., Bayer Inc., Novartis, and ZLB Bioplasma. The JMF wishes to express sincere thanks and recognition for their overwhelming generosity.

Experts at the meeting were from Austria, Belgium, Canada, France, Greece, Iran, Israel, Italy, Japan, Russia, Scandinavia, Spain, Switzerland, Turkey, United Kingdom, and the United States. The next world meeting of experts is now being organized by JMF and is set for June, 2003. ◆





Swiss folk singers provide great entertainment



Dr. Chaim Roifman, the Hospital for Sick Children, Toronto, Canada, Mrs. Perach Roifman, Dr. Amos Etzioni, Technion Institute, Haifa, Israel



Dr. Rolf Zinkernagel, Institute for Experimental Immunology, Zurich, Switzerland, our keynote speaker



Dr. Alain Fischer, Hospital Necker Enfants Malades, Paris, France with Host Dr. Reinhard Seger, Kinderspital Zurich, Switzerland



Farmhouse "Herligsberg," a unique setting for the social program



Dr. Luigi Notarangelo, University of Brescia, Brescia, Italy helps musicians ring the cow bells



Dr. Dick Gatti, UCLA School of Medicine, and Dr. Teresa Espanol, Hospital Vall d'Hebron, Barcelona, Spain enjoying the alphorns

JMF Hosts World Meeting continued





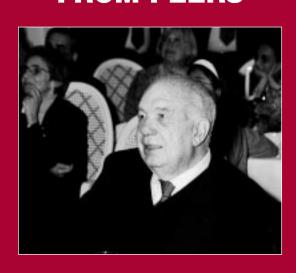
Vicki Modell presenting Dr. Dick Gatti with special award



Dr. Fred Alt, Center for Blood Research, Boston, MA



Dr. Helen Chapel, Oxford Radcliffe Hospital, Oxford, UK



FOR 26 YEARS OF LEADERSHIP



Dr. Max Cooper, University of Alabama, Birmingham, AL



Dr. Tom Waldman, National Institutes of Health, Bethesda, MD



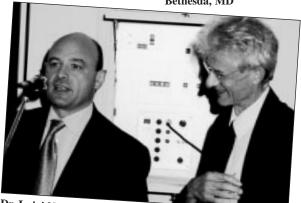
Dr. Walter Hitzig, Zurich, Switzerland



Dr. Jennifer Puck, National Human Genome Research Institute, Bethesda, MD



Dr. Raif Geha, Children's Hospital, Boston, MA



Dr. Luigi Notarangelo, Dr. Hans Ochs, Children's Hospital, University of Washington, Seattle

Looking back...Our First 15 Years





Jeffrey Modell Prize in Immunology Presented at Mount Sinai and Harvard Medical Schools

Scholars Recognized for Excellence in Immunology

The 2nd Annual Jeffrey Modell Prize for the best thesis submitted in the field of immunology to a graduate student at Harvard Medical School was awarded to Ben Gewurz. Dr. Gewurz, is an M.D., Ph.D. pre-doctoral candidate in the graduate program in immunology. His work is entitled "Antigen presentation subverted: Structure of the human cytomegalovirus protein US2 bound to the class I molecule A2." This work was performed in the laboratory of Hidde Pleogh, in collaboration with Don Wiley.

At the Mount Sinai School of Medicine Awards and Prizes Ceremony, Dr. Azza Idris received the second annual Jeffrey Modell Immunology Prize for Excellence. Her breadth of leadership at the Medical School includes Student Council Representative and advisor for the Admissions Committee and Cultural Diversity in Medicine Program. She has also taught college physiology, as well as mentoring high school students in the Mount Sinai Scholars program. Dr. Idris will continue her training in pediatrics at Emory University. •