

\$2 Million CDC Grant Awarded to JMF

CDC Funds will address Primary Immunodeficiency Education and Awareness

“Congratulations! The CDC is proud to inform you that the Jeffrey Modell Foundation has been awarded a \$2 million contract to create, develop, and enhance physician education and public awareness of primary immunodeficiencies.”

So said **Mike Smiley**, Grants Management Specialist at the CDC together with **Timothy G. Baker**, CDC Deputy Director, Office of Genetics and Disease Prevention, on a recent telephone conference call to JMF.

This is the first-ever federally funded program addressing physician education and public awareness of PI. It is the culmination of years of dialogue between the JMF, lawmakers, and federal agencies. The

“Health Communication Campaign on PI,” as it is now known, is a Congressionally mandated program. It is designed to increase knowledge of primary immunodeficiency diseases for primary care physicians, educate the public about the disease and available resources, and when appropriate, increase referrals to Centers of Excellence specializing in primary immunodeficiency. Targets for the first phase of this program will be America’s pediatricians, family practitioners, and the general public. Baseline surveys, printed materials, public service announcements, CME educational conferences, and website enhancements will all be included in the campaign. Evaluation studies will take place regularly and special attention to public health con-

cerns will lie at the core of the program.

In the official Notice of 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. The Foundation has an impressive array of public and private support in the medical, industry, and government areas and Centers of Excellence in North America, Europe, and the Mid-East. The Jeffrey Modell Foundation has a history of “making things happen” and the organizational commitment to achieve their stated purposes in this National Campaign.” ♦

Ad Council selects JMF for Official Campaign

National media will carry public service advertisements on PI

The very fabric of American culture is filled with Ad Council slogans familiar to all of us. Smokey Bear’s “Only You Can Prevent Forest Fires;” The Crash Test Dummies’ “You Could Learn A lot from a Dummy;” McGruff the Crime Dog’s “Take A Bite Out of Crime;” “Friends Don’t Let Friends Drive Drunk;” and of course, “A Mind is a Terrible Thing To Waste;” just to name a few. After September 11, the Ad Council launched the highly emotional and effective “I Am An American” campaign.

For over 60 years the Ad Council has been producing, distributing, and promoting public service campaigns on behalf of non-profit organizations and government agencies in areas such as quality of life, health, education, and family. Beginning in 1995, the Ad Council launched a ten-year initiative focusing on children with the intention of helping all of our children achieve their full potential. Overall, the Ad Council’s mission is to identify a select number of significant public issues and stimulate action on those issues through communications programs that make a measurable difference in our society. The Ad Council imprimatur is well known throughout the world and significantly enhances a public service campaign.



JMF and Ad Council senior management recently met to discuss the possibility of creating an Official Campaign on PI. In such a campaign, the creative and strategic development is provided pro bono by members of the American Association of Advertising Agencies. Millions of dollars worth of advertising space and time are donated by the media on behalf of Ad Council’s public service advertising campaigns. After submission of a comprehensive proposal, the Ad Council selected JMF for an Official Campaign to be launched in early 2003.

JMF received an acceptance letter from **Patricia Carbine** and **Tim Love**, Co-Chairpersons of the Proposals Review Committee:

“The Committee was overwhelmingly positive and approved this new campaign unanimously. It is with great pleasure that we welcome you to the Ad Council. The Committee shares your firm belief that a public service campaign can help you realize your important goal of achieving the earliest possible diagnosis for children who may be affected by primary immunodeficiency. We are truly impressed with your program and believe that a partnership with the Ad Council can help further your efforts to ensure that all children receive the proper diagnosis and care for PI. Again, we admire your dedication and congratulate your entire organization.” ♦

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SAVE THE DATE
“SPRING AHEAD”

APRIL 9, 2003
PLAZA HOTEL

A Message From Vicki & Fred

Friendship... what a powerful force in our lives, too often overlooked, generally taken for granted, and usually under-appreciated. For both of us and for Jeffrey's Foundation, friendships are not only something we treasure, but they are woven into the very heart and soul of the Jeffrey Modell Foundation.

A brief look at the most recent accomplishments says so much about the power of friendships. For the first time ever, the U.S. government has appropriated funds to address PI education and awareness. For the first time ever, the U.S. Centers for Disease Control and Prevention have characterized Primary Immunodeficiency Diseases as a public health concern for all Americans. For the first time ever, our National Institutes of Health have funded a grant to detect underserved and uninsured patients with primary immunodeficiencies through a system of matching the ICD-9 hospital codes with the JMF 10 Warning Signs. For the first time ever, the Ad Council will launch a major national media campaign on PI. The accomplishments go on and on.

How did this happen? The only consistent thread through all of this has been your unwavering friendship. We started this journey together 16

years ago, not knowing where it would take us. You gave us your support and your encouragement to move forward. In turn, that gave us the courage to scale unimagined heights, so that together we would have a chance to really make a difference. Friends — Friends at pharmaceutical companies, in the U.S. Congress, at the NIH, at the CDC, Friends who are patients and parents, Friends who are physicians, researchers, real estate executives, and even some very good friends within the media. The one common bond between all these groups has been unconditional support for JMF. We cannot think of a single moment when any of you said “no” to us. In fact, you always gave us a little push to do better, to reach higher, and you were always right there with us, rooting us on.

So, as we stop for a moment to celebrate some of these accomplishments, we also want to thank each and every one of you for being so supportive, for giving us your encouragement, and most of all for being such good friends. Yes, together we are really starting to make a difference. ♦

Vicki and Fred Modell

New York City Health and Hospitals Corporation in Collaboration with JMF

New York City's Health and Hospitals Corporation (HHC) is the largest public hospital system in the country. HHC operates:

- 11 acute care hospitals;
- 4 long term care facilities;
- 6 diagnostic and treatment centers;
- More than 100 community health clinics;
- A certified home health care agency.
- A wholly owned subsidiary managed care plan, Metroplus

New York City's Health and Hospitals Corporation reports:

- \$4 billion in revenue;
- 1 million emergency room visits;
- 5 million walk-in visits to outpatient and community based clinics;
- 2 million primary care visits.

Mary E. Medina, Chief of Staff in the Office of the Chairman, organized a meeting with HHC Medical Directors, JMF, **Dr. Charlotte Cunningham-Rundles**

of Mt. Sinai Medical Center, and HHC President, **Dr. Benjamin K. Chu**. The JMF Education and Awareness Campaign was carefully examined and fully discussed. A decision was reached to establish a formal partnership between the New York City Health and Hospitals Corporation and the Jeffrey Modell Foundation. The program will include distribution throughout the system of the 10 Warning Signs Poster, a physician algorithm, a “slim-jim” brochure, NIH booklets, and website links. The physician education component will include Grand Rounds at HHC facilities to be presented by expert immunologists, as well as CME symposia. According to **Dr. Van H. Dunn**, Senior Vice President and Chief Medical Officer,

“This is a very exciting time for New York City's Health and Hospitals Corporation. We are delighted to move forward with the Jeffrey Modell Foundation. Our communities will be very well served with a meaningful education and awareness campaign and we are enthusiastically looking forward to working with JMF on this program.” ♦

Sarah Ferguson, the Duchess of York, joins physicians and patients to kick off National PSA Campaign

The Duchess of York joined representatives of the Jeffrey Modell Foundation to launch a new public service campaign designed to alert the public to the warning signs of primary immunodeficiency. The announcement took place at a press conference in New York City. Joining the Duchess were JMF Medical Advisory Board Member, **Dr. Charlotte Cunningham-Rundles** of the Mount Sinai Medical Center and several patients.

"I feel so strongly that greater awareness of PI will finally help the many children who spend their lives locked in a cycle of chronic illnesses," said the Duchess of York. "Diagnosis and treatment can mean the world to a child, so it's vitally important for parents and physicians to know the warning signs."

Network affiliates in all of America's major markets requested the PSA, which was produced by the Disney Company and features the Duchess of York. It was carried by 14 ABC affiliates, 16 CBS affiliates, 9 NBC affiliates, and 13 Fox affiliates. If you would like to view the PSA, please visit the JMF website at www.jmfworld.org and click on NPI. ♦



The Duchess of York addressing the media at New York press conference.



Debbe Longo, who lost her four year old son, Christopher; the Duchess of York, Sarah Ferguson; Jason Shuman, a 10 year old patient prospering with regular immunoglobulin therapy; Yarnell Blackman, a 25 year old patient recently diagnosed as part of the NIH Outreach Program; and Dr. Charlotte Cunningham-Rundles of the Mount Sinai Medical Center.

National Institutes of Health Community Outreach Grant Generates Remarkable Early Results

JMF and Mount Sinai Target PI in Underserved Populations

Dr. Charlotte Cunningham-Rundles, of the Mount Sinai Medical Center, has provided preliminary data based on the first year results of an NIH grant to detect primary immunodeficiency diseases in underserved and minority populations. New technology was developed at Mount Sinai for the East Harlem and Harlem communities in connection with this grant. By using a database of hospital records, the ICD-9 hospital codes were matched up to the JMF 10 Warning Signs of PI. Medicaid patients who had at least one hospital admission and more than two of the Warning Signs/ICD-9 codes were targeted. HIV patients, chemotherapy recipients and the elderly were excluded from the patient database.

Using these criteria, at the end of the first year Dr. Cunningham-Rundles identified 187 patients in the East Harlem Community, more than 50% of which had an identifiable immune deficiency. Most of these patients required and initiated treatment intervention and therapy. Dr. Cunningham-Rundles reported that the minority population of her patient base has increased from a level of 8% to over 30% in just one year, which demonstrates an astonishing under-diagnosis of this population. The three-year grant project was conceived and developed by the Jeffrey Modell Foundation and the Mount Sinai Medical Center, together with Dr. Charlotte Cunningham-Rundles, the Principal Investigator. ♦

JMF Meets with European Union Members of Parliament

The European Union (EU) is made up of 15 member countries serving 375 million citizens. Currently, there are 13 applicant countries in Central and Eastern Europe with 175 million citizens awaiting admission. The European Parliament is the legislative body that represents the citizens of the European Union.

Vicki and Fred Modell, Co-founders of the Jeffrey Modell Foundation, met with the following members of the EU at the Parliament in Strasbourg, France.

- **Ms. Minerva Malliori** (Socialist Group/Greece), Public Health Committee
- **Dr. Guiseppe Nistico** (Conservatives/Italy), Public Health Committee
- **Dr. Paul Rubig** (Conservatives/Austria), Research Committee
- **Ms. Astrid Thors** (Liberals/Finland), Research Committee
- **Ms. Mel Read** (Socialists/United Kingdom), Research Committee
- **Dr. Peter Liese** (Conservatives/Germany), Public Health Committee
- **Ms. Emilia Muller** (Socialists/Germany), Public Health Committee
- **Mr. Armin Macher** (Socialists/Germany), Advisor to Social Group for Research and Public Health Committees

An agreement was reached to initiate an awareness campaign with government support in three steps:

- 1) A letter from each Member indicating their support
- 2) An Awareness Day to be held in the Parliament
- 3) Inclusion of Primary Immunodeficiency on the European Medical Research Agenda

The Awareness Day in Parliament took place in October 2002 in Strasbourg, France. ♦



Dr. Paul Rubig, Member of EU Parliament (Austria) and Member of Medical Research Committee with Vicki and Fred Modell at the Parliament, Strasbourg, France.

In a letter to the JMF, **Dr. Paul Rubig** (Austria) stated:

"I would like to encourage a physician education and public awareness campaign on PI for the European Union to be held at the European Parliament to further inform and educate members and the public about this disease. I look forward to working with patient organizations such as the Jeffrey Modell Foundation and industry representatives to help implement this important initiative."

Jeffrey Modell Diagnostic Centers for PI established in France and Sweden

A comprehensive campaign to bring greater awareness of primary immunodeficiencies to Europe has been launched by JMF. Diagnostic Centers have been created at the Hospital Necker – Enfants Malades in Paris, France and the Karolinska Institute/Huddinge Hospital in Stockholm, Sweden. The campaigns have been under-

written by the Baxter Pharmaceutical Corporation. It is anticipated that similar centers will be established in England, Germany, Switzerland, Italy and Austria. JMF wishes to express its profound gratitude to Baxter for their generosity, compassion and vision on behalf of PI patients worldwide. ♦

JMF Supports New Canadian Center for Primary Immunodeficiencies

Children from across Canada will benefit from the newly established Canadian Center for Primary Immunodeficiencies supported by the Jeffrey Modell Foundation. The central diagnostic facility at The Hospital for Sick Children in Toronto includes a patient registry, and is the only Center of its kind in Canada. Patients, including children with complex disorders such as SCID that cannot be treated anywhere else, will be referred to the Canadian Center for Primary Immunodeficiency. Basic and clinical research in immunobiology is at the core of the Center's activities. ♦



Dr. Chaim Roifman, MD of The Hospital for Sick Children presents Vicki and Fred Modell with dedication plaque



Vicki Modell delivers a thank you on behalf of the Jeffrey Modell Foundation



Dr. Roifman with Fred and Vicki Modell in the Jeffrey Modell Research Laboratory



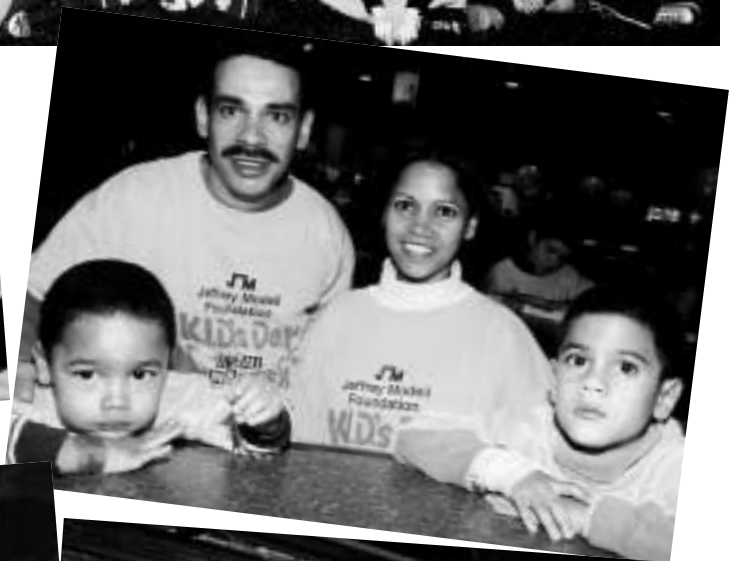
Dr. Alan Goldbloom, Executive Vice President and Chief Operating Officer of The Hospital for Sick Children enjoying a light moment with Dr. Roifman



Dianne Lister, President and CEO of The Hospital for Sick Children Foundation makes a special dedication

JM KID'S Day

Broadway City and Fenway Park Host New York & New England Kids



Over 200 children and their families shared a joyous family day at New York's **Broadway City**, an interactive arcade. The day included motorcycle rides, baseball games, car racing, boxing, games of skill, and exciting events. Everyone left with prizes. The Commodities Exchange Center's "Futures & Options for Kids" sponsored the event.

At Boston's **Fenway Park**, the 5th Annual K.I.D.'s Day for New England patients and their families was organized by the New England Primary Immunodeficiency Network (NEPIN) and JMF. Led by **Stan and Nancy Graziano**, Co-Founders of NEPIN, the day was a high-spirited event that included a lunch reception, t-shirts, tote bags, and baseball. As always, K.I.D.'s Day (**K**ids with **I**mmune **D**eficiencies) was supported extensively by the pharmaceutical industry and home care companies. ♦



SPRING For a Brighter Tomorrow AHEAD

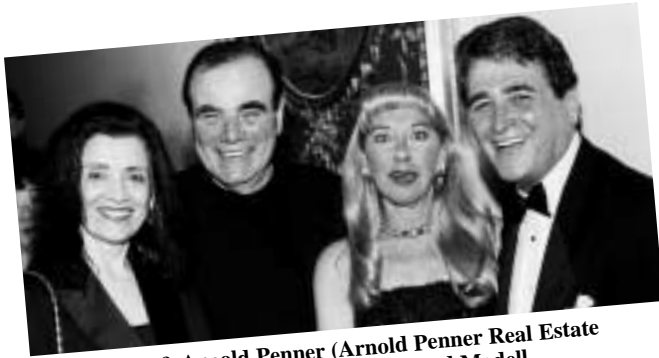


Mount Olive Baptist Church Gospel Choir

High Spirits at 16th Annual Spring Ahead Gala

The Grand Ballroom of the Plaza Hotel was sold out for the 16th Annual Spring Ahead Gala to benefit JMF. Ric Clark, President and CEO of Brookfield Properties, received JMF's "Man of the Year" Award. The event opened with the inspirational

Mount Olive Baptist Church Gospel Choir celebrating New Yorkers' renewed commitment to rebuild. The event raised over \$800,000. All of the proceeds benefited immunology research supported by JMF. ♦



Mimi & Arnold Penner (Arnold Penner Real Estate Investments), Vicki and Fred Modell



Fred Modell presenting JMF "Man of the Year Award" to Ric Clark (Brookfield Properties)



Josh Mermelstein (Fried, Frank, Harris, Shriver & Jacobson), Ric Clark, Dennis Friedrich (Brookfield Properties), and Jon Mechanic (Fried, Frank, Harris, Shriver & Jacobson)



Michael Berman (Reckson Associates), Mr. & Mrs. Josh Mermelstein (Fried, Frank, Harris, Shriver & Jacobson)



Ric Clark (Brookfield Properties), David & Simone Levinson (Insignia/ESG)



John Moore (Lazard Freres & Co.), John Zuccotti (Brookfield Properties)



John Cefaly (Cushman & Wakefield), Ric Clark (Brookfield Properties), and Jon Mechanic (Fried, Frank, Harris, Shriver & Jacobson) with Jason, Joey, Scott, and Kyle



Wendy Siegel, Wendy Mechanic



Neil Clark (TSNY), Wendy Mechanic, Paul Pariser (Taconic), Phil Altheim (Forest Electric)



Lynne Koepfel, Fred Modell, Caleb Koepfel (Koepfel Tener), Vicki Modell



Mr. & Mrs. John Cefaly (Cushman & Wakefield), Mr. & Mrs. Neil Goldmacher (Newmark), Mr. & Mrs. Ric Clark (Brookfield Properties)



Howard Rubenstein (Rubenstein Associates), Trevor Davis (Davis & Partners)



Pat Ahern (Ahern & Partners), Corrinne Ball, and John Moore (Lazard Freres & Co.)



Steve Siegel (Insignia/ESG) and John Cefaly (Cushman & Wakefield)



John Cefaly (Cushman & Wakefield), Ric Clark (Brookfield Properties), Jon Mechanic (Fried, Frank, Harris, Shriver & Jacobson)



Yoron Cohen (Insignia/ESG), Jason Brown (RFR Holdings), Aby Rosen (RFR Holdings)

JMF Selects "Spring Ahead" Honoree for 2003

Reckson Associates Executive, Tod Waterman to lead April 9th Gala

Philip M. Waterman III ("Tod") is the Senior Vice President and Managing Director for Reckson Associates Realty Corp.'s New York City division. Reckson is one of the largest publicly traded owners and managers of Class "A" office and industrial properties in the New York "Tri-State" area with over 20 million square feet in its portfolio. The Company closed on the \$700 million acquisition of Tower Realty Trust in June of 1999 and immediately followed that transaction with the \$277.5 million purchase of the first mortgage note secured by 919 Third Avenue, effectively giving Reckson control of that property. In early 2000, Reckson acquired 1350 Avenue of the Americas. Reckson's holdings in Manhattan currently include 100 Wall Street, 810 Seventh Avenue, Tower 45, 919 Third Avenue, and 1350 Avenue of the Americas.

Prior to joining Reckson Associates, Mr. Waterman spent 12 years with Tishman Speyer Properties. He served as a Managing Director of Tishman Speyer Properties and sat on the company's Management Committee, which was responsible for investment and acquisition decisions. He was responsible for the oversight of Tishman Speyer's domestic leasing and marketing efforts for approximately 38 million square feet, including Rockefeller Center and the Chrysler Building in New York. Past responsibilities included oversight of Tishman Speyer's Los Angeles and San Francisco offices. He also spent two years in the Company's Chicago office.

Mr. Waterman received his B.A. from the University of Michigan. His professional affiliations include The Young Men's and Women's Real Estate Association of New York, The Real Estate Board of New York where he serves as a Governor, NACORE, ICSC, the International Development Research Council, and the Urban Land Institute. Mr. Waterman's charitable activities include involvement in Riverdale Country School, The Fresh Air Fund, where he sits on their Council, and the Downtown School (in formation) where he is a member of the Board of Trustees.



Tod Waterman
JMF 2003 "Man of the Year"

SAVE THE DATE
"SPRING AHEAD"
APRIL 9, 2003 • PLAZA HOTEL

Jeffrey Modell Center established at Stanford University School of Medicine and Packard Children's Hospital

Lucile Packard Foundation Joins in Funding Collaboration

Dr. Philip Pizzo, Dean of the Stanford University School of Medicine invited **Vicki and Fred Modell** to tour the facilities at the Stanford University Medical Center, Lucile Packard Children's Hospital, and Stanford School of Medicine. The Palo Alto, California complex is one of the world's leading biomedical research and clinical centers. Two outstanding researchers principally lead the team addressing primary immunodeficiencies, **Dr. Alan Krensky**, Chief of the Division of Immunology and Transplantation Biology and **Dr. David B. Lewis**, Associate Professor of Pediatrics and Immunology/ Transplantation Biology. After an exchange of information and examination of JMF's mission, an expansive plan for research, clinical care, education, and awareness was developed.

As a result of these meetings, a challenge grant was offered by the Lucile Packard Foundation for Children's Health to join in a funding collaboration with the Jeffrey Modell Foundation. The two Foundations agreed to establish a \$1 million center to be named The Jeffrey Modell Center for Research and Comprehensive Care for Primary Immunodeficiencies. Dr. Alan Krensky stated,

"We are honored to collaborate with the Jeffrey Modell Foundation and the Lucile Packard Foundation to advance knowledge, access to care, and treatment strategies for children who suffer from these devastating diseases. We look forward to working with your outstanding organization and collaborating scientists from around the world." ♦

Members of Congress overwhelmingly support JMF Awareness Campaign on Primary Immunodeficiency

Senators Charles E. Schumer and Hillary Rodham Clinton of New York expressed their strong support for JMF in a joint communication to the U.S. Centers for Disease Control and Prevention (CDC):

"The JMF, located in our state, has established an education and awareness program which has been in operation since 1998. It is our strong belief that the Foundation has created an exceptional campaign that would meet the Centers' standards of excellence while saving the Center millions of dollars and valuable resources in development."

Members of the House Appropriations Subcommittee on Labor, HHS, and Education added their support including **Representatives Rosa L. DeLauro** (Connecticut), **Patrick J. Kennedy** (Rhode

Island), **Nita M. Lowey** (New York), **Jesse L. Jackson, Jr.** (Illinois), and **Steny H. Hoyer** (Maryland). The Ranking member of the Senate Appropriations Subcommittee on Health, **Senator Arlen Specter** (Pennsylvania), Senate Appropriations Subcommittee Chairman, **Tom Harkin** (Iowa) and House Chairman **Ralph Regula** (Ohio), added their strong support to expand the physician education and public awareness program for primary immunodeficiency diseases. In communications with the CDC, the Members enthusiastically supported the Jeffrey Modell Foundation as the sole source contractor to implement this program.

JMF expresses its profound thanks to the members of Congress who have encouraged and supported this program for patients with primary immunodeficiencies. JMF enthusiastically looks forward to working in close collaboration with the CDC. ♦



Senator Hillary Rodham Clinton (New York) with Vicki and Fred Modell at New York Reception.



Congressman Ralph Regula (Ohio), Chairman House Appropriations Subcommittee on Health, at Congressional Hearings on PI.



Senator Clinton sharing a light moment with Fred Modell.



Vicki Modell provides testimony at Congressional Hearings on the importance of the Awareness Campaign.

"We've Got Your E-mail"



"My heart breaks for you for the loss of your darling son. I admire the strength and courage you work so hard to keep. Thank you for all of the work you are doing for everyone suffering from PI. My son has had three surgeries this year and 6 months of a picc line for antibiotics. He seems to be slipping month by month, it is a difficult thing to watch. I hope I will be as kind and brave as the two of you if I must also face parting with my child. Bless you both and thank you for your inspiration"

Gini, Belmont, Michigan

"This is a really great site for information. I am glad to see more PI related sites and attempt to educate the general public about PI and how these diseases affect patients."

Shelly

"Yes, you seem to be on the right track for me. I just received a call from my immunologist 2 days ago and he said I do indeed have Common Variable Immune Deficiency. He recommended that I see Dr. Charlotte Cunningham-Rundles at Mount Sinai and that I will need to be put on Intravenous Immunoglobulins, but I feel now I am going to the proper professional and where the experts are located. Hopefully she will get my body back on the right track."

"Again, thank you so much for your help I think your website is awesome! Very informative, very attractive, easy to use and access information. Thanks for being there for me."

Carol

"Thank you for all you do for those of us who suffer with this illness."

Kathi, Seattle, Washington

"I am just very happy that this illness is being publicized and that treatment is becoming available. When I was a child and young adult, I suffered from constant ear infections, sinus infections, bronchitis and various types of skin infections. For years, I was told it was all in my head. It nearly drove me mad. I wish more PCP's and general practitioners were aware of the signs of PI. If only they would have known what it was in my case, it would have saved me years of needless suffering. I am happy that children today will have a better shot at a "normal" life."

Mary, Orlando, Florida

"If I didn't stumble across the "10 Warning Signs of PI," I probably still would be searching for answers... instead, I found an immunologist and received a hard-won diagnosis. Thanks to the JMF I am not alone (or aching) anymore."

Linda, Madison, Wisconsin

"I just wanted to thank you for your web site. My younger sister, age 22, has been suffering since she became ill at age three weeks. She was not correctly diagnosed until her teens. Before that, a number of physicians recommended psychiatric care...that she was a spoiled child, that she just hated school, that she was a hypochondriac...all while prescribing one antibiotic after another for infections that she couldn't possibly conjure up on purpose. She had a difficult time in school with teachers, administrators and peers. She is currently having the same problems with college professors and administrators, but at least she knows what her illness is and that it is real, even if they don't believe her or her doctor. Thank you for the good work!"

Kellie

JMF will host World Meeting of Experts in Portugal

World Health Organization/IUIS Conference, June 25th-29th

The Expert Committee on Primary Immunodeficiencies meets every two years to update its report that defines and classifies PI diseases. The report not only provides vital information to the medical community, but is also used by various governments to determine health care policy. Plans are now underway to hold the conference in Sintra, Portugal in June 2003. This year, the World Health Organization (WHO) meeting will be held in collaboration with the International Union of Immunological Societies (IUIS).

The Jeffrey Modell Foundation previously sponsored the WHO/IUIS meetings in Bristol, England, Baden bei Wein, Austria, and Lucerne, Switzerland. Those meetings were considered outstanding scientific conferences on immunodeficiencies, generating important breakthrough findings and dialogue among scientists from around the globe. The academic program has been funded by the Baxter Corporation. To date, the Foundation has received delegate support from American Red Cross and Aventis Behring. ♦

Visit the National Primary Immunodeficiency ResourceCenter (NPI) at www.jmfworld.org.

All you need to know about Primary Immunodeficiency in one place

For: Physicians Researchers Scientists Patients Families Industry Government

Lots of new features include a research library, referral centers, expert locator, FAQs, and K.I.D.'s Korner. Be sure to visit today!

Message Board

Want to chat with others in the PI community? Ask a question? Provide an answer? Make new contacts? Find new resources? Go up on NPI's Message Board. Visit NPI at www.jmfworld.org, click on Patient to Patient and you will find the link for the Message Board.

Survey

You can help promote awareness, encourage earlier diagnoses, and create the possibility of new treatments. Just take a few minutes to complete the NPI survey. It's quick, it's simple, it's confidential, and you will be helping yourself and the PI community worldwide. Visit NPI at www.jmfworld.org and click on Survey. ♦

**Over
5 Million Hits**

"We've Got Your E-mail"

"My son was diagnosed with CVID at age 12. He was pretty ill before we received the diagnosis. He has been getting IVIG since Sept. 99 and seems to be doing better. Thank you for all of the info that you have provided. We wish that it was known to us back when we didn't understand why our son was so sick. We hope that now that this info is available, other families who are newly diagnosed can use this to help them understand. When our son was so sick, right before he was diagnosed, the doctors really didn't go into detail about what was wrong. We were very confused. This site is very well set up. Good Job!"
Karen, Northampton, Pennsylvania

"Great site! Easy to read & access valuable & much needed information!"
Beth, Grosse Pointe Park, Michigan

"I just wanted to take a moment to thank you for your wonderful website. My daughter Morgan is 6 years old and was finally diagnosed with Common Variable Immune Deficiency about 8 months ago. From birth she has experienced one illness after another requiring multiple courses of antibiotics, surgeries for infections and a general unfulfilling life due to constant illness. The diagnosis trail began with allergies, asthma, chronic sinusitis, recurrent infections and finally Hypogammaglobulinemia. She has been receiving IVIG every 3 weeks since the end of January 2002 and we are able to see the benefit this has for her. She has been able to attend her first year of school, only missing 35 days. Knowing there is help out there and other parents who are doing just as I am gives me hope that I will achieve all that can and should be achieved for my daughter. Thank you again for all your information and helpfulness in dealing with our situation."
Sonya, Fort Wayne, Indiana

More E-Mails Follow ➔

1st International Symposium on PI for Eastern European Physicians

JMF presents comprehensive program in Debrecen, Hungary

More than 100 physicians from 12 Eastern European countries convened in Debrecen, Hungary for the first international symposium on primary immunodeficiency diseases. The conference was organized and led by **Dr. Laszlo Marodi**, Department of Pediatric Immunology at the University of Debrecen. Speakers and delegates in attendance were from:

- Austria
- Bulgaria
- Czech Republic
- Estonia
- Hungary
- Lithuania
- Macedonia
- Poland
- Romania
- Russia
- Ukraine

Representatives from each of the countries met with JMF

to exchange ideas and communicate their problems and their needs. All confirmed the serious under-diagnosis of primary immunodeficiencies in their countries and the critical lack of treatments. JMF shared its education and awareness campaign currently underway in the U.S. and the programs that have begun in Europe. There was consensus among the attendees that a single, fully developed Diagnostic Center in Europe would be able to serve these countries at this time. JMF presented a comprehensive proposal designed specifically for these countries and it is expected that the Diagnostic Center serving Eastern Europe will be launched in mid 2003. JMF provided sponsorship for the three-day meeting. ♦

“We’ve Got Your E-mail”

“Thank you so much for the public awareness campaign! I didn’t have any knowledge as a consumer of PI, nor did the many physicians I saw (family practice, ear/nose/throat/allergist). My diagnosis was made 10 years after the onset of symptoms, reducing the quality of my life, and leading me to a point now in which I’m unable to work outside the home due to frequent and disability infections.”
Lorinda, Hurst, Texas

“More awareness of the difference between AIDS and PI, and more information for physicians who rarely see PI.”
Lynn, Rancho Murieta, California

“The doc who manages my PI is an Infectious Diseases Specialist. It might be worth asking what type of specialist is managing the PI, as many of the people I’ve made contact with are treated by hematologists or ID docs rather than immunologists. In my case, there’s not a clinical immunologist close enough for dealing with hospitalization etc. I was glad to see the new PSA with the Duchess of York as spokesperson—it’s been airing on ABC in the DFW area. I think the JMF is doing a wonderful job and well thought out work on behalf of those of us who have PI. Thank you so much. Your info has been helpful to my friends and family, and to my home care nurses as well as my docs.”
Sherri, Dallas, Texas

“Thank you for your patient advocacy.”
Sarah, Texas

“I just found your website after hearing a brief mention on ABC TV today and how I wished I had known it existed before.”

I am the mother of a 21 year old son who has had PI all his life and I really didn’t know there were so many others in the same situation. He wasn’t diagnosed correctly until he was 4, after many serious illnesses, pneumonias, meningitis, and other rare complications. He, especially, needs help to deal with the emotional/social issues.

I really appreciate all the info that I found out on your website and will access some of the organizations to help. I sincerely thank the Modells for their dedicated work to the children with PI and will keep this organization in mind to help in any way I can.”

AnnMarie

“I really appreciate all the work JMF does for those of us with PI, and I particularly like the new NPI website. Thanks for all the lobbying and encouragement of researchers that you do on patients’ behalf. Thanks to you and the IDF, the medical community is becoming more aware of both the existence and serious nature of living with PI, and of the need for appropriate and aggressive treatment of infections in combination with IVIG.”

Sherri, Ft. Worth, Texas

“Thank you for this site. Information on PI is much more easily located now than when I was diagnosed, or in the prior years when I should have been diagnosed. The PI commercial with The Duchess of York is wonderful. Perhaps adults with PI should also be mentioned.”

Kay, Pickens, South Carolina

Triathlon Benefits Dina LaVigna “Breath of Life” Fund



The 4th Annual Dina LaVigna “Breath of Life” Triathlon was held in Ventura County, California. Participants were challenged by a half-mile swim, a 25-mile bike ride, and a 6-mile run. This year there were winners for best overall time, best female competitor, best team time, and many other categories. The event was organized by the family of Dina LaVigna, who died five years ago from complications that developed from an undiagnosed 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 City and Mattel’s Children’s Hospital in Los Angeles. ♦

THE WINNERS!

	<i>FIRST</i>	<i>SECOND</i>	<i>THIRD</i>
OVERALL	C.J. Castle 1:54:33	Harry Friedman 1:55:41	Henry Layne 1:59:00
FEMALE	Anissa Sequin 1:59:42	Jessica Gillett 2:05:10	Rowena Spence 2:09:01
TEAM	TRIX 2:03:12	Noe Rules 2:09:03	Star Tribe 2:10:39



New York Academy of Medicine Hosts PI Symposium

Dr. Charlotte Cunningham-Rundles, of the Mount Sinai Medical Center, and the Jeffrey Modell Foundation organized and sponsored a one-day CME course entitled "Recognition of Primary Immune Defects in Clinical Practice". A full program featuring experts on the immune system and immune defects was presented at the NY Academy of Medicine, a distinctive and historical New York landmark. Primary care physicians and medical students from the entire metropolitan area attended the event. Aventis Behring and Bayer Corporation generously provided sponsorship of this event. The JMF wishes to thank them wholeheartedly for their ongoing generous support. ♦

University of Washington School of Medicine Hosts PI Symposium

Dr. Hans Ochs, Children's Hospital of Seattle, and the Jeffrey Modell Foundation organized and supported a regional research symposium entitled "Primary Immunodeficiency Disorders". The program included experts on immunodeficiency with presentations on T-Cell and B-Cell development, IPEX, and Stem Cell Transplantation. A follow up conference is planned for May 2003. ♦

"Hopes and Dreams" reach children with PI

New York's Mount Sinai Hospital and Seattle Children's Hospital receive thousands of gifts and toys

Brand new stuffed animals, toys, books, candies, videos, and much more were included in "Kids Kare" packages sent by JMF to New York's Mount Sinai Hospital and Seattle Children's Hospital. The program was made possible through JMF's partnership with Children's Hopes and Dreams Wish Fulfillment Foundation.

In a letter to both organizations, **Pearl V. Johnson**, Mt. Sinai's Community Liaison, expressed her thanks:

"Because of your generosity, the hopes and dreams of the population we serve have come true. The stuffed animals will allow us to offer a special program throughout the year; our teddy bear clinic uses stuffed animals to teach children

about medical examinations. There are no words, thoughts, or deeds that I can use or express to thank JMF and the Hopes and Dreams Foundation for their generosity."

In a letter to JMF, **Genie Higgins**, Trustee of Seattle Children's Hospital, wrote:

"Your generous gift will enhance the experience of the many children across the Pacific Northwest, who require hospitalization. In addition to serving the needs of seriously ill children, our mission goes beyond the walls of the hospital to every corner of the region. All of us at Children's send our deepest gratitude for your thoughtfulness." ♦

The Jeffrey Modell Foundation was established by Vicki and Fred Modell in memory of their son Jeffrey, who died at the age of 15 of a genetic condition known as primary immunodeficiency—a chronic, serious and often fatal disease.



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