



UPDATE

A Publication of
The Jeffrey Modell Foundation

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SPRING 2001

NIH and JMF Launch Education and Awareness Campaign

50,000 Physicians Receive New Ten Warning Signs Poster

At the Rayburn House Office Building on Capitol Hill, Congressional Leaders joined with NIH officials and the Jeffrey Modell Foundation to announce the launch of a new national awareness campaign for primary immunodeficiencies. At the press briefing, Dr. Duane Alexander, Director of the National Institute of Child Health and Human Development, announced a groundbreaking grant from the NIH to the Jeffrey Modell Division of Clinical Immunology at the Mount Sinai School of Medicine that will increase detection of primary immunodeficiency disorders in minority and economically disadvantaged communities (see story below).



Vicki Modell addresses government officials and media at the Press Briefing



Joining Dr. Alexander at the announcement were Fred and Vicki Modell, founders of the Jeffrey Modell Foundation (JMF), Rep. Nita Lowey (D-NY), Member of the House

Appropriations Subcommittee on Health, and Charlotte Cunningham-Rundles, MD, PhD., Director of the Jeffrey Modell Center at Mount Sinai

Continued on page 2

JMF Receives \$1.3 Million NIH Grant

Award to Focus on PI in Minority and Underserved Population



Dr. Duane Alexander, Director, NICHD, announces the NIH Grant Award

Primary immunodeficiency diseases—until now little known disorders caused by genetic flaws—appear less often among members of minority groups in the United States than among non-minorities. Scientists suspect that difference may be due to under-diagnosis of those disorders in minority populations. Why so few cases are discovered

among minorities remains unclear, but now a three-year, \$1.3 million study funded by the National Institutes of Health (NIH) and awarded to the Jeffrey Modell Foundation could help doctors and nurses recognize and treat primary immunodeficiency diseases earlier among African Americans, Hispanics

Continued on page 11

I N S I D E

Congress Offers Strong Support	3
JMF Symposia	4
First Ever Symposium on PI and Cancer	4
Grand Rounds on PI Seen Worldwide	4
JMF International Centers	5
K.I.D.'s Days	6-7
Spring Ahead 2000	8-9

JMF's "First Friend" Selected as Veep	11
Chairman Porter Tours JMF Division	12
Rock & Roll Dance Party	13
New Infusion Facility	14
Industry Advisory Council	15
First JMF Prize at Harvard	16
WHO Conference on PI	16

SAVE THE DATE

14TH ANNUAL SPRING AHEAD

Waldorf-Astoria
Tuesday, April 24, 2001

A Note From Vicki & Fred

A year after we lost Jeffrey to the ravages of primary immunodeficiency disease, we established the Jeffrey Modell Foundation. Our goals were modest. We proceeded cautiously. We had absolutely no experience in the non-profit sector. All we had were family and good friends who gave us encouragement and enthusiastic support. By the end of the first year, the JMF was able to fully fund two Jeffrey Modell Fellows at Mount Sinai. From those early days we could never have imagined what this past year has brought to this effort. The early encouragement of family and friends has now been expanded to the pharmaceutical industry, the US Congress, the National Institutes of Health, the Centers

for Disease Control, and the media. All of this was made possible by the early commitment of good friends. Now we can look with pride at our accomplishments and most importantly, the impact we are having on patients, families, and physicians, who are coping with this insidious disease and working for a cure. We have met with countless number of families who have benefited from the progress in research, education, and new treatments. With your help, the cures will come and our journey together will have made a tremendous difference.

Vicki and Fred Modell

NIH and JMF Launch Education and Awareness Campaign (continued from Page 1)

and principal investigator.

Also speaking was Debbe Longo, whose 4-year-old son Christopher died last year from a misdiagnosed primary immunodeficiency disease (PI), and Lawrence Jackson, whose correctly diagnosed PI has been treated successfully for 18 years.

Dr. Alexander announced the results of a national survey conducted by Opinion Research Corp for the Jeffrey Modell Foundation. The survey showed that not a single respondent could identify any of the 80 primary immunodeficiency diseases. However, after hearing a description of the symptoms of these diseases, more than one third of respondents reported knowing someone with more than one of the 10 warning signs of PI. Dr. Alexander went on to say, "The first goal of the awareness campaign is to make doctors and parents alike aware of the warning signs of PI and to urge them to screen or intercede when appropriate."

"You cannot imagine the scope of this basically hidden problem until you speak with the families that are affected," said Fred Modell. "We continually receive phone calls and letters from people who suffered with PI for years, even decades, without the benefit of a proper diagnosis. This is especially tragic because now, many forms of PI are treatable when diagnosed properly."

In connection with the launch of the campaign, more than 50,000 pediatricians and family practitioners received the "10 Warnings Signs" of PI in an NIH mailing. In an accompanying



Debbe Longo addresses the attendees as Dr. Duane Alexander looks on



Representative Nita Lowey (D-NY) describes the government collaboration with the JMF



Dr. Charlotte Cunningham-Rundles, MD with Kareem Edwards



Vicki Modell enjoying the comments of Theresa Jackson

Continued on page 10

Congressional Appropriations Sub-Committee Offers Strong Support

Chairman Porter and Congressman Hoyer Laud JMF Initiative

Congressional Record of Wednesday, March 8, 2000

Mrs. Vicki Modell, Vice President and Co-Founder, Jeffrey Modell Foundation

Mr. Porter. Congressman Hoyer.

Mr. Hoyer. Thank you very much, Mr. Chairman. I understand it is now time for Fred and Vicki Modell to join us again. Vicki is going to testify. I try to be here every time they testify. Unfortunately, because of schedules, we cannot always be present for everybody. But I think the Modells, Mr. Chairman, whose son died of primary immunodeficiency affliction, represent why we have done so well in the United States. Certainly, the public sector has been involved, but those in the private sector, individuals who have a particular focus and passion, who take the time and devote extraordinary amounts of both resources in financial terms, but much more importantly, in terms of their heart and their beings and soul into educating the rest of us about what can be done if we will, as you have done, Mr. Chairman, invest sufficient resources to determine how we can overcome the various afflictions that mankind faces.

And I always want to be here because as a couple, as individuals, they demonstrate the very best in private effort in this country in partnership with public effort. I know that you share that view as you have come to know them and hear them. And I appreciate very much everything they do. My children do not suffer from this particular affliction. But, again, none of us know what afflictions will affect our children, our grandchildren, our successors, and therefore it is important that we focus on all of the diseases and all of the weaknesses in our own makeups that can turn a happy, productive life into one not so happy, not so productive, and in fact, in many cases, end in the termination of life.

So, I want to thank Vicki and Fred for their constancy and their conviction and their contributions. Thank you, Mr. Chairman.

Mr. Porter. Thank you Mr. Hoyer. Vicki, it is nice to see you. Tell me how many times you've testified.

Mrs. Modell. I believe it is my fourth.

Mr. Porter. Fourth, yes. Well, what Mr. Hoyer said is exactly true. Your commit-

ment to overcoming this disease has been absolutely constant and strong and you have inspired us to try to be of help as well. I think you are right Mr. Hoyer, that I believe that 20 or 25 years from now we will see most of the funding for biomedical research come through foundations, like the Modell Foundation, that are aimed at conquering certain diseases and we will see Government filling in the gaps and coordinating the research. And I think it is absolutely wonderful that what Vicki and Fred represent is going to be the way of the future in their commitment to providing private funding as well as public funding to direct the research that will unlock the key eventually.

So, Vicki, it is good to see you again. Please proceed with your statement. And then if we have any questions, we will follow with the questions.

Mrs. Modell. Thank you very, very much. And, as always, it is such a pleasure to be here. Good morning, Mr. Chairman, and good morning, Congressman Hoyer. I am truly privileged to be here and I am deeply humbled and really quite touched and emotional by your beautiful, beautiful words. It makes it all worthwhile when we hear something like that from the two of you, such strong individuals. To say that to us, it gives us the courage to continue, and I thank you very, very much.

Now I am a little emotional but I will continue.

Mr. Hoyer. While you are getting yourself together, I want to say to the rest, who may somewhat cynically say, "well the Modells live in Hoyer's district and he wants their votes." Not only do they not live in my district, they don't live in my State. But all of you, I think many of the comments that I made about Fred and Vicki apply because you are taking of your time, your considerable talent and educating us. Obviously, no one of us can know the breadth of human experience particularly as it relates to disease and afflictions.

So I do not want you to take my com-

ments as I am here just because Vicki and Fred happen to be from my district. They are not. And, frankly, I did not know them before they started testifying here. But like so many of you that I will not know as personally as I know Vicki and Fred, and for the Chairman, we really do appreciate it. Even if we are not here, your comments are kept in the record and they really do make a difference. Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Hoyer. Please proceed, Vicki.

Mrs. Modell. Thank you very much. I am honored to have the opportunity to speak to you on behalf of The Jeffrey Modell Foundation

(Vicki's Testimony proceeds)

Mr. Porter: Vicki, thank you for those very generous and very kind words. One of the rewards of this chairmanship is the chance that I get to understand more about the real world, hearing from people like you who are going through these terrible experiences and have made the kind of commitment that you have made and are making a difference through your work through the Foundation.

We were talking yesterday about what good is it to do research if we don't translate it into public health. And today we will talk about what good is it to do the research if we don't translate it into practice so that physicians know what to look for. And I think your point is a very, very strong one. I am sure the sub-committee will be willing to put language in urging NIH to do exactly that, to raise public awareness. It used to be that NIH's role was simply to perform the research. But they understand now and they do a great deal of outreach into practicing physician community on a number of diseases. They should do it here as well. I think we have to ensure both ends of the pipeline. It is very, very important, and we are going to do our best to do just that.

Mrs. Modell. Thank you. That is all I can ask. Thank you.

Mr. Porter. Thank you very much. ♦

JMF SYMPOSIA

Physician Conferences Highlight Medical Breakthroughs

Boston and Seattle Symposia Describe Genetic Disorders and Gene Therapy Cures

Recently, in two different cities on the same day, physicians gathered to discuss the genetic basis of primary immunodeficient disorders and potential gene therapy cures. In the morning, at a joint meeting in Boston of the major pediatric academic societies, and the American Academy of Pediatrics annual meeting, a plenary session sponsored by the National Institute of Child Health and Human Development addressed, "Gene-based understanding of X-Linked Primary Immunodeficiency Disorders." Experts from Duke University Medical Center, Harvard Medical School, the University of Washington School of Medicine in Seattle and the NIH brought the pedia-

tricians up-to-date on the astounding information explosion in genetics and pointed out how correction may be possible for most of the diseases in which the molecular basis is known. The session emphasized the key role of pediatricians in identifying these patients prior to the development of serious infections.

Later that day, in Seattle, physicians and researchers gathered at the Fred Hutchinson Cancer Research Center to hear of progress made on successfully achieving the world's first gene-therapy cures. A physician group in France, led by JMF Medical Advisory Board member Dr. Alain Fischer, effectively treated children born with a fatally defective

gene for a vital blood component, by artificially inserting the correct DNA into their cells. Physicians said that if the present course continues on the patients treated, it will be the first clear demonstration that gene-therapy has corrected a condition, thereby making medical history. The advancement is important because in the future, rather than treating symptoms, doctors could re-write the DNA blueprint for life. Tackling the cause of genetic immune deficiency conditions by re-writing, or replacing, defective genes has long been a dream of researchers and physicians.

The conferences in Boston and Seattle were sponsored by the Jeffrey Modell Foundation. ♦

First Ever Symposium on PI and Cancer

National Institutes of Health collaborate with JMF

In an extraordinary meeting sponsored by the National Cancer Institute, National Institute of Allergy and Infectious Diseases and National Institute of Child Health and Human Development in collaboration with the Jeffrey Modell Foundation, leading immunologists convened in Washington DC at a meeting entitled "Advances in the Diagnosis and

Treatment of Primary Immunodeficiency Diseases: Risk of Cancer." Although patients with chronic PI appear to be at greater risk for lymphoid cancers and leukemia, the genetic mechanisms and molecular pathogenesis of this interesting relationship have not been systematically studied. As more patients with primary immunodeficien-

cies survive longer because of improved treatments, their risk for developing lymphoid and blood cell cancers increases later in life. This meeting afforded an opportunity for basic and clinical scientists to examine the relationship of primary immunodeficiency and cancer and to develop a plan and strategy to address it going forward. ♦

NIH Clinical Center Grand Rounds Beamed to Worldwide Audience

15,000 Sites Connected to Med TV Net

The NICHD sponsored a Grand Rounds on Severe Combined Immunodeficiency (SCID), using a "Bench to Bedside" format, at the Clinical Center of the NIH in Bethesda, Maryland, on September 20, 2000. The purpose of this event was to increase the awareness of this disease among researchers, physi-

cians, and other health professionals. In addition, the Grand Rounds provided an update of the recent advances in the diagnosis and treatment of SCID. All health care professionals attending were able to receive continuing medical education credits. In order to expand and extend the proceedings beyond the live

viewing audience, the Grand Rounds was multicast to personal computers on the NIHnet Mbone and INTERNET, and was televised to hospitals and medical centers throughout the United States. Overall, more than 15,000 sites were connected to The NIH Grand Rounds symposium by Med TV Net. ♦

JMF International Centers Established in France and Israel

Gene Therapy Laboratory in Paris Holds Out Hopes for a Cure

The New York Times

New York, Friday, April 28, 2000

In a front-page story in the New York Times, the medical world celebrated the world's first ever gene therapy cures. The physician in charge of this breakthrough therapy was Dr. Alain Fischer, longtime member of the JMF Medical Advisory Board. Shortly after the announcement, Dr. Fisher and the JMF entered a comprehensive collaboration by establishing "The Jeffrey Modell Laboratory for Gene Therapy." The partnership is intended to accelerate the pace of gene therapy as a potential cure for certain primary immunodeficiencies. Dr. Fischer has been a frequent speaker at the World Health Organization (WHO) Meetings sponsored by the JMF and is scheduled to update scientists from around the world at the WHO meeting in Lucerne, Switzerland in July. ♦



The first successful gene therapy has been reported by Dr. Alain Fischer and Dr. Marina Cavazzano-Calvo and colleagues in Paris

Technion Institute in Haifa, Israel A Partner in Creating Jeffrey Modell Center



Dr. Amos Etzioni, Division Head, Pediatrics
at the Rambam Medical Center, Technion, Haifa, Israel

The Jeffrey Modell Foundation and the Technion Institute of Haifa, Israel have agreed to international collaboration. Dr. Amos Etzioni, member of the JMF Medical Advisory Board initiated a plan to build a regional center for diagnosis and treatment of primary immunodeficiencies. He met with the Modells in Seattle and New York, and a blueprint was quickly developed.

The Center will include a primary immunodeficiency laboratory, reception area, game room, three examination rooms, a transfusion room, a genetic research laboratory, an immunological and clinical laboratory, a testing facility, equipment, technicians, and Fellows. All of this is scheduled for the first phase of the collaboration. The second phase will include a gene therapy laboratory, along with technicians, doctoral fellows and a series of educational conferences and symposia directed to physicians in that part of the world. According to Dr. Etzioni, "What made this especially important is that there is no immunodeficiency center of this type between the west coast of Italy and Japan. That is too big a region to miss patients with unexplained recurring illnesses. And that is why I felt so strongly about establishing a Jeffrey Modell International Center for this region."

Fred Modell, co-founder of the Jeffrey Modell Foundation, stated, "This is truly a collaborative effort. The Foundation and the American Society for Technion will raise the necessary funds to make this center a reality. We are extremely touched and humbled by the initiative and encouragement received from Dr. Etzioni and Technion." ♦

New Englanders Celebrate in Boston

NEPIN, The New England Primary Immunodeficiency Network, under the superb leadership of Nancy and Stan Graziano, held the 3rd Annual New England K.I.D.'S Day at Prouty Garden in Boston. The day included a puppeteer, karaoke, face painting, and a wide array of games and competition for kids of all ages. Pharmaceutical industry support came from Aventis Behring, Baxter, and Caremark, Inc. As always the New England K.I.D.'S Day was a joyous and highly energized event. ♦

K.I.D.'s



Days

New York Families "Bowled Over"

During the past holiday season, the JMF celebrated its 8th Annual K.I.D.'S Day in New York at Bowlmor Lanes. This unusual environment for bowling, music and psychedelic lighting drew more than 200 children and their families. The day was sponsored by the Commodities Exchange Center's "Futures & Options for Kids." As always, K.I.D.'S Day provides a welcome opportunity for families to share personal experiences with one another in an informal and fun setting. ♦



New York's Real Estate Industry Honors Aby J. Rosen

The JMF celebrated its 13th Annual Spring Ahead Gala at the Waldorf=Astoria in New York City. Over 1200 guests participated to honor Aby J. Rosen, co-founder of RFR Holdings, as JMF's "Man of the Year." The evening was the most successful fundraising event in JMF history, raising over \$1 million for the support of children with primary immunodeficiencies. The JMF has received enormous support from New York's real estate community throughout the years. ♦

**SPRING
20
BREAKS**



(L-R) Neil L. Kennedy, Kennedy Capital LLC; Aby Rosen



(L-R) Costas Kondylis, Costas Kondylis Associates; Steven Witkoff, The Witkoff Group; David Edelstein, Sutton East Associates



(L-R) David Levine, Davis and Partners; Steven A. Karpf, Fremont Realty Capital; Stephen Siegel, Insignia/ESG; Keith Locker, Bear Stearns



(L-R) Ian Schrager, Ian Schrager Hotels; Aby Rosen; Jon Mechanic, Fried, Frank



(L-R) Jennifer Wechsler, Aby Rosen, Liz Rosen



(L-R) Gary Jacob, Glenwood Management Corp; Richard "Bo" Dietl, Beau Dietl & Associates; Robert J. Ivanhoe, Greenberg Trauric



(L-R) Michael Fuchs, RFR Realty, LLC; Sam Giarrusso, M&T Bank; Jason Brown, RFR Holding LLC; Rich Kamerman, Classic Realty



(L-R) Fred Modell, Man of the Year, Aby Rosen; Vicki Modell



(L-R) William G. Cohen, Newmark & Co. Real Estate; Wendy Mechanic; Stephen B. Siegel, Insignia/ESG; Jon Mechanic, Fried Frank



(L-R) Brad Gerla, Insignia/ESG; Meghan Culklin, R.K. Futterman; Steve Yalof, Gap Inc.; David Greenbaum, The Mendik Company; Robert Futterman, R.K. Futterman



(L-R) Jack S. Irushalmi, Tri-Star Construction Corp; Carin Lesser; Mr. & Mrs. Mitch Konser, Cushman & Wakefield



(L-R) Mr. & Mrs. Steven Witkoff, The Witkoff Group

AHEAD OO RECORD

Celebrities Join High Energy Party

Actress Holly Robinson Peete and her husband, NFL Quarterback Rodney Peete, and New York Giant Jason Sehorn kicked off JMF's new National Public Awareness Campaign during a press conference at the Spring Ahead Gala. The celebrities met with some of the children, shared stories, autographed footballs, and posed for pictures with the kids. Earlier that day the Peetes appeared on Lifetime TV live, WCBS TV's newscast, and NY1's Sport Studio. Jason Sehorn, Giants defensive star, also appeared on NY1's Sport Studio, as well as Gary Apple's WCBS TV's Sunday Night Sports Program. All of the celebrities emphasized the importance of public awareness for primary immunodeficiencies. ♦



Pro-football star Rodney Peete signs footballs



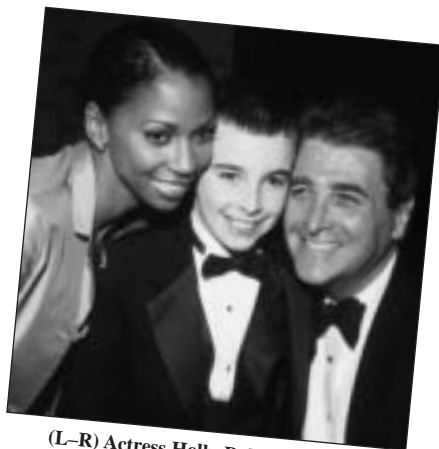
New York Giant Jason Sehorn signing footballs



(L-R) Celebrities Rodney Peete, Holly Robinson Peete, Jason Sehorn, with Vicki Modell, Fred Modell, Bo Dietl



(L-R) Fred Modell, Jon Mechanic



(L-R) Actress Holly Robinson Peete, Scott McGuire, Fred Modell



Pro-football star Jason Sehorn with actress Holly Robinson Peete, The Modell family, and the JMF Kids



JMF Kids join raffle winner Scott Major



Aby Rosen and Jason Shuman



The kids make a big play for good health

letter, Dr. Alexander indicated that the campaign will include a new NIH publication "Primary Immunodeficiency: When the Body's Defenses are Missing." Campaign plans include widespread distribution of the 10 Warning Signs poster, substantial interaction with the broadcast and print media, a parent information kit, an expanded website and more. The 10

Warning Signs poster explains that when two or more signs are present, blood screenings by a physician are warranted to confirm or rule out PI.

The new awareness campaign is a unique joint effort by government, private industry and a non-profit that will reach out to pediatricians, primary care physicians and specialists, HMOs/PPOs, schools, school nurses, pharma-

cies, blood banks and the media. The press briefing was attended by representatives of all five major industry partners that appear on the Warning Signs poster including American Red Cross, Aventis Behring, Baxter Healthcare Corporation, Bayer Corporation, and Novartis Pharmaceuticals Corporation. Also in attendance was Dennis Jackman, Executive Director of the Plasma Protein Therapeutics Association. ♦



(L-R) Fred Modell, Debbe Longo, Vicki Modell, Dr. Duane Alexander, Kareem Edwards, Lawrence Jackson, and Theresa Jackson introducing the new "10 Warning Signs of Primary Immunodeficiency"



Debbe Longo chats with Kareem Edwards and Lawrence Jackson at the Press Conference



(L-R) Vicki Modell, Dennis Jackman, Executive Director of the PPTA

JMF's "First Friend" Selected as Veep Nominee

Senator Joseph Lieberman was First Public Official to Assist JMF

Much of the attention paid to Senator Joseph Lieberman (D-CT) has ignored the human side of a man who has made a great impact on the lives of those afflicted with primary immunodeficiencies. In 1993, Senator Lieberman was the first elected official to respond to JMF inquiries concerning research, education, patient support, and public awareness. He invited Vicki and Fred Modell to Capitol Hill and introduced them to elected officials. He later hosted a reception for physicians, families, and industry in the Senate's office building and called for more public awareness of primary immunodeficiency diseases. Finally, he spoke eloquently on the floor of the U.S. Senate about patients with primary immunodeficiencies and the work of the JMF.

Because of his help, the new national public awareness campaign is supported by the federal government, and information will alert physicians, healthcare workers, and families to the warning signs of PI. The JMF is proud that Senator Lieberman has had the opportunity to bring his sensitivity, humanity, and compassion to the entire nation. ♦



JMF Co-Founders Fred and Vicki Modell
with Sen. Joseph Lieberman (D-CT)

NIH Grant Awarded to Mount Sinai (continued from Page 1)



John McGrath of NICHD with Whitney Stuart, Linda Voss of
the American Red Cross, and Vicki Modell



Dr. Denise Wiesch, Program
Officer NIAID announcing
the NIH Grant

and other ethnic populations.

Director of the Immunodeficiency Program at Mount Sinai and JMF Medical Advisory Board Member, Charlotte Cunningham-Rundles, M.D., Ph.D., will direct the new study at Mount Sinai School of Medicine in New York City. She and a team of computer scientists, statisticians, nurses and health educators will develop a computer-assisted method for health care workers serving minority populations.

The central theme of the new grant is that PI is not recognized in minority and economically disadvantaged individuals because of different factors including: the fact that many families in these populations are not in regular contact with a primary physician; many families receive their medical care in emergency rooms and clinics where physicians

rotate schedules; and, patients are treated for the obvious symptoms (when treated), such as ear or sinus infections, and are not tested for possible underlying causes of the recurring illness.

The Mount Sinai study should help develop standards to assist health care workers in identifying people with primary immunodeficiencies. One phase of the project will involve reviewing hospital records from the past five years, which contain universal codes used by all physicians to define their patients' conditions. By examining records for codes commonly related to primary immunodeficiency diseases, this survey will help define a more precise profile of the combinations of the disease codes that indicate probable primary immunodeficiencies. The review will also help uncover where in the health care system

such patients might typically be found, such as pediatric emergency rooms, where children are treated for related conditions.

Other clinical investigators will work with community clinics and hospitals in New York City to identify current patients whose records indicate more than one of the relevant disease codes. Those patients will be invited to receive clinical tests to see if they have primary immunodeficiency.

The study team also will develop educational materials for wide distribution to doctors serving minority populations in order to increase awareness and improve diagnoses of these diseases.

The study is co-funded by the National Institute of Allergy and Infectious Diseases (NIAID), the National Institute of Child Health and Human Development, and the National Cancer Institute. "It is an example of increased collaboration among NIH components to fund research that addresses health disparities," noted Denise Wiesch, Ph.D., the NIAID program officer overseeing the award.

It is anticipated that if the hypothesis is demonstrated in the New York City region, the project will be replicated in several other communities with different ethnic populations throughout the United States. ♦

Congressman John Porter Tours Jeffrey Modell Division at Mount Sinai **Meets with Divisional Chief Dr. Lloyd Mayer**

Representative John Porter (R-IL), Chairman of the House Appropriations Sub-Committee on Health, recently toured the Jeffrey Modell Division of Clinical Immunology at the Mount Sinai Medical Center. Chairman Porter has been, for years, a strong advocate for increased research and education of primary immunodeficiencies. Selected to receive an Honorary Degree of Human Letters at the Mount Sinai Commencement, Congressman Porter spent the morning

hours meeting with research scientists at Mount Sinai, and Dr. Lloyd Mayer, Division Chief. He also had the opportunity to greet Sandro Santagata, recipient of the first Jeffrey Modell Prize in Immunology at the Mount Sinai School of Medicine. Chairman Porter was impressed with the facility and indicated that this gave him a heightened awareness of the basic and clinical research being advanced for the diagnoses and treatment of primary immunodeficiencies. ♦



Rep. John Porter (R-IL) visits the JMF Center at Mount Sinai



Chairman Porter in the Laboratory with Division Chief, Dr. Lloyd Mayer, as the Modells proudly observe



Dr. Mayer describing the medical research at the Division to Chairman Porter



(L-R) Fred Modell, Vicki Modell, Dr. Lloyd Mayer, JMF Prizewinner Dr. Sandro Santagata, and Rep. John Porter.

First Jeffrey Modell Prize in Immunology at Mount Sinai School of Medicine

At the Mount Sinai School of Medicine Commencement Awards Ceremony, Dr. Sandro Santagata received the first Jeffrey Modell Prize for Excellence in Immunology at Mt. Sinai. Making the presentation was Dr. Arthur Rubenstein, Dean, Mount Sinai School of Medicine, and Dr. Lloyd Mayer, Chief of the Division of Clinical Immunology. Dr. Santagata graduated from Amherst University in 1993 and is currently enrolled

in the MD-PhD program at the Mount Sinai School of Medicine. He recently defended his thesis. Earlier in the day, Dr. Santagata and Dr. Mayer had an opportunity to give Representative John Porter (R-IL), Chairman of the House Appropriations Sub-Committee on Health, a tour of the Jeffrey Modell Division of Clinical Immunology. ♦

(See photo above)

ROCK & ROLL DANCE PARTY

**"Doo-Wop" Groups Join
JMF Supporters at NY's Copa**



The fabulous Coasters sing "Charlie Brown" at the Doo-Wop Party



WCBS-FM Dee Jay, Bobby Jay, emcees the night



The Shangri-Las sing "Leader of the Pack"



The crowd was entertained throughout the night



The Tokens sing "Lion Sleeps Tonight"



(L-R) Dr. Stuart Orsher, Mel Paikoff, and JMF Board Member Ed Gutman help the Shangri-Las with "Do-Wah-Ditty-Ditty"



Alexandra is the party's youngest Rock & Roller



Hula Hoop contest challenges the crowd



The dance party had everyone up and on their feet!



JMF Board Member Trish Backal and "Mom" show off their poodle skirts



Rock & Roll memories dress the tables

New Infusion Facility Dedicated at Mount Sinai

"Dina's Room" Honors the Memory of a Young Mother

A new state of the art infusion facility was recently dedicated at Mount Sinai Medical Center. The new room, "Dina's Room," was named for Dina LaVigna, a young mother who passed away last year from complications of a PI disorder. Funds for this room were raised by Dina's family, friends, and her husband Jeff Schmitt. A special fund called the "Breath of Life" was established in Dina's memory. The infusion room, more than double the size, is a comfortable and welcoming environment, and includes reclining chairs, TVs, VCRs, computers with internet access, patient desks and chairs, coffee maker, refrigerator,

tor, magazines, videos, children's toys, arts and crafts and much more.

"Dina LaVigna's friends and family watched her live courageously with her disease for many years and wanted to make sure her legacy would bring a better life for the thousands of others with this disorder," said Fred Modell, co-founder of The Jeffrey Modell Foundation. "The Breath of Life Fund," established in Dina's memory, fulfilled her dream to enhance the infusion room at Mount Sinai, and improve the experience for other patients who have to endure 4-6 hour infusions." ♦



Dina and Jeff Schmitt's son Zack "cuts the ribbon" as the family looks on



The new infusion facility "ready to go"



Vicki Modell celebrates at the opening of "Dina's Room"



A picture of Dina La Vigna that will stay in the new infusion room permanently



(L-R) Nancy & Stan Graziano, founders of NEPIN (New England Primary Immunodeficiency Network) and Whitney Stuart of American Red Cross



"The Baxter Boys" (L-R) Jim Hauert, David Bond, and Kyle Bush at infusion room dedication.

Los Angeles Triathlon Raises Funds for Dina's Room

The second Annual JMF Triathlon in the Los Angeles area raised significant funds for the enhancement of "Dina's Room." Spearheaded by JMF Board member Jeff Schmitt and the LaVigna and Schmitt families, there were more than 150 contributors raising nearly \$20,000. The "Breath of Life Fund" will be used to improve and enhance the infusion room at Mount Sinai and other facilities across the nation. Plans are underway for next year's triathlon. ♦

Over 1.5 Million Hits On JMF Website

Expanded Format Generates More Than 100,000 Visitors Per Month

In January 2000, the JMF embarked upon a completely revamped website as part of its new efforts at physician education and public awareness. Since that time, website visits have risen from an average of 74,000 per month to 115,000 per month. This repre-

sents an increase of over 50%. It also is worth noting that the average length of a viewer's visit has increased from just over 5 minutes to more than 12 minutes. The JMF will continue to update and enhance the website in the future. ♦

Please visit us at: www.jmfworld.com



Jeff Schmitt proudly dedicates Dina's Breath of Life Room



(L-R) Dr. Charlotte Cunningham-Rundles, Dr. James Bussel, and Fred Modell

Pharmaceutical Industry Advisory Council Established

The leading pharmaceutical industry companies have been enthusiastic supporters of the JMF for many years. Recently, as a result of blood shortages and concerns for blood safety, industry officials communicated regularly with the JMF on assuring quality and availability for patients. In order to continue the dialogue on pharmaceutical subjects relevant to patient care, the companies and the JMF have agreed to form an Industry Advisory Council. At this time, members of the council include:

American Red Cross

Aventis Behring

Baxter Healthcare Corporation

Bayer Corporation

Novartis Pharmaceuticals Corporation

A Big Welcome to New JMF Board Members

The incredible growth of the JMF is due in large part to the enlightened, enthusiastic, and generous Board of Directors. The JMF is proud to welcome the following new Board members:

Tony Della Salla

Kris Fuchs

Michael Fuchs

Liz Rosen

Aby Rosen

Susan Woods

Brian Woods



How to Get Involved



The JMF is a "grassroots" operation. We keep our expenses under control and we try to be efficient while accomplishing our goals. All of this requires the support of good friends who believe in our mission.

Now the Jeffrey Modell Foundation has received an exciting opportunity from Citigroup—Citibank Private Bank and Salomon Smith Barney Philanthropic Services Group. You can immediately receive financial benefits and at the same time support research and

patient programs of the JMF. This unique and innovative program is not complicated and can be implemented in complete confidence. Citigroup has assigned a specialized financial advisory team that will offer you a personalized strategic planning consultation, without cost or obligation. These tailored solutions can provide you and your family with extraordinary financial and tax benefits. For more information, just call the Jeffrey Modell Foundation office at (212) 819-0200 ext #28. ♦

First Jeffrey Modell Scholarship Prize at Harvard Medical School

Dr. Robert J. Monroe received the first Jeffrey Modell Prize in Immunology at the Harvard Medical School. Presenting the award was Dr. Frederick Alt, Senior Investigator at the Harvard Medical School, and Dr. Fred Rosen, President of the Center for Blood Research, at Harvard. The annual prize will recognize "the outstanding thesis in Immunology" at Harvard Medical School. Dr. Monroe was chosen by the graduate committee in Immunology. His research, in Dr. Alt's laboratory, was in RAG Expression and Regulation of the TCR Locus. ♦



Dr. Robert Monroe, Prizewinner, with Dr. Fred Rosen, President, CBR, Harvard Medical School



(L-R) Dr. Raif Geha, Chief, Department of Immunology, Boston Children's Hospital, Dr. Robert Monroe, and the Modells



Fred Modell shares a light moment with Dr. Fred Alt, Senior Investigator at the Harvard Medical School

World Health Organization Conference on PI Planned for July JMF Will Host Expert Meeting in Lucerne, Switzerland

Plans are currently underway for the JMF to host the World Health Organization Conference on PI in Lucerne, Switzerland in July. The Organization meets every 3 years, and the JMF is honored to have been selected once again to sponsor this important world conference and scientific report. The

Jeffrey Modell Foundation previously sponsored the WHO meeting in Bristol, England and Baden bei Wein, Austria. These meetings were considered to be the outstanding conferences on PI worldwide, and generated important breakthrough findings that heightened dialogue with scientists around the

globe. The meeting in Switzerland will be heavily geared toward molecular biology and genetics of primary immunodeficiency disorders. Similar to the last meetings in England and Austria, this will bring together experts from Europe, the United States, and Asia. ♦

The Jeffrey Modell Foundation was established in 1987 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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