A new Jeffrey Modell Diagnostic Center has been established in Beijing, China. This is the 30th Jeffrey Modell Center worldwide. The Center will be led by Dr. Xiao-Ming Gao of Peking University and supported by Hong Kong Vigconic International and the Beijing Council of Science and Technology. An International Symposium on Primary Immunodeficiencies was part of the Center’s launch in May 2006 where leading experts from all over the world were invited to speak to treating physicians in the region. The speakers included Drs. Alain Fischer, Paris; Amos Etzioni, Haifa; Edvard Smith, Stockholm; Jean-Laurent Casanova, Paris; Hans Ochs, Seattle; Lennart Hammarström, Stockholm; and Richard Gatti, Los Angeles. The meeting was sponsored by JMF, the Luk’s Group of Hong Kong, and the Beijing Municipal Science and Technology Commission and it was organized in collaboration with the Chinese Society for Immunology, Beijing Society of Immunology, and Beijing Association for Science and Technology. Dr. Gao is working in close collaboration with the Beijing Children’s Hospital which sees over 2.8 million patients per year.

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

Over the past year, new Jeffrey Modell Diagnostic Centers were established in Atlanta, Miami, and Milwaukee, bringing the number of Centers worldwide to 30. To date, the JMF Centers overall have reported a 79% increase in the number of diagnosed patients, 54% increase in patients receiving treatment, and 57% increase in the number of patient referrals.
It was a simple question... then an awkward pause... and finally serious reflection.

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

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

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

The member of Congress who posed those questions energized and inspired us to keep an eye on the future. The endowments will support the research? Who will encourage young investigators to enter the field? The question came from a member of Congress who has been a long time supporter of the Foundation’s activities. He said “you have both done a very good job in raising awareness and educating doctors about the Primary Immunodeficiency diseases, but ultimately what happens to that initiative? Who will look out for the patients? Who will support the research? Who will encourage young investigators to enter the field?”

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

The Jeffrey Modell Foundation has supported the Children’s Hospital in Seattle for nearly 10 years, funding research and clinical care under the expert leadership of Dr. Hans Ich.
FIRST EVER QUALITY OF LIFE SURVEY ON PI

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

Survey Results from Physician/Experts at 76 Jeffrey Modell Diagnostic and Referral Centers Comparing Undiagnosed and Diagnosed Patients with Primary Immunodeficiencies
In this issue, meet Larry Stern, Talecris Executive Chairman, in his own words...

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

Danielle: “Hi Dad! I’d like to ask some questions that others may not be as comfortable discussing with you. I remember a number of your previous jobs from building chemical plants in Texas to running businesses for Iynfeld and Bayer. This job seems different. From the company mission, to your sense of urgency, to the number of industry events you and mom attend, what’s special this time?”

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

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

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

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

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

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

Larry: “Wow, you are tough. Ultimately, the patients, the medical community and the companies like Talecris that produce these life-saving therapies need each other. So it’s fair to say that the advocacy positions from Talecris on reimbursement are for the benefit of the patients, the healthcare system, and for Talecris. We believe that reimbursement policies should allow the patient to choose the location of care. We believe that reimbursement should not only cover the cost of the drug, but the cost of the infusion set, the infusion nurse and other administrative costs. And we believe that each IOV on the market is different, that the doctor should choose which therapy to prescribe, and that the reimbursement for each brand should be independently set to avoid having reimbursement formulas influence a prescribing physician.”

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

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

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

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

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

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

“‘Business is all about people. In this case, it starts with our patients.’”

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

“‘I feel lucky to have a job and career that can literally help thousands of people with life-threatening chronic diseases’.”
JMF celebrates its 20th Birthday at the annual “Spring Ahead” Gala in April. The Grand Ballroom of the Waldorf=Astoria was filled to capacity as JMF took the opportunity to honor all past “Spring Ahead” Honorees. Over 700 guests joined in the high-spirited celebration including physicians, patients and pharmaceutical companies. The 2006 Gala was JMF’s most successful event ever! The night featured entertainment by Le Clique, music by the Valerie Romanoff Orchestra, and raised a record-setting $1.5 million for education, research, and awareness of Primary Immunodeficiency.
HIGHEST RATING TO JMF

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

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

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

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

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

HARVARD KEYNOTE

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

The Council consists of prominent business and scientific leaders, including Fortune 500 CEOs, Nobel Prize winning scientists, leaders of pharmaceutical and biotech companies, and major supporters of the Harvard Medical School.
This publication was supported by grant funds from the United States Centers for Disease Control and Prevention ... and Hospitals Corporation National Heart, Lung, and Blood Institute (NHLBI).

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

Dr. Max Cooper, University of Alabama Howard Hughes Medical Institute, delivered the Keynote Address entitled ‘Evolution of Immunology: Where is the Future?’ Dr. Irving Weissman, Stanford University, offered a special address entitled ‘The Big Picture: Politics and Science.’ Other speakers included Dr. Fred Alt of Harvard Medical School; Dr. Alessandro Aiuti (Children’s Hospital, University of Rome); Dr. Raif Geha (Massachusetts General Hospital, Harvard University); Dr. Cha; Dr. Richard Stiehm (UCLA); Dr. Robert Goldstein (Boston); Dr. Richard Gatti (University of Pennsylvania); Dr. Cha; and Dr. Charlotte Cunningham-Rundles of Mount Sinai Medical Center. The meeting was sponsored by the Jeffrey Modell Foundation, in collaboration with the New York Academy of Sciences, and focused on current scientific understandings, as well as future treatments, therapies and cures.

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

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

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

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

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

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

The 10 Warning Signs of Primary Immunodeficiency

- Persistent or recurrent sinuses
- Persistent or recurrent ear infections
- Two or more serious sinus infections
- Two or more pneumonias
- Eight or more new ear infections
- Persistent or recurrent mouth ulcers
- Deep-seated infections
- Gluten-sensitive enteropathy
- Deep vein thrombosis
- Chronic fatigue or unexplained weakness

Simply click to WIN!
Jeffrey Modell Foundation KIDS Days began in 1988 and were created to provide a joyous occasion for Primary Immunodeficient patients, their families and their doctors and nurses. It is a valuable opportunity to meet one another, share personal experiences and form supportive, long-lasting friendships. Patients can also get to know their physicians and nurses in a casual environment away from the hospital. Just this year, KIDS Days have been held in 12 cities nationwide. Plans are already underway for 20 Regional KIDS Days in 2007. Cleveland’s first ever JMF KIDS Day drew more than 450 people!
The Dina LaVigna “Breath of Life” Triathlon was held in Ventura, California. The triathlon attracted more than 1,000 athletes competing in a 1.5k ocean swim, 40k bike ride, and a 10k run. This USAT (USA Triathlon) sanctioned event is considered to be the best of its kind in the entire Western Region. The enthusiasm of the participating athletes is testimony to this, as is the Resolution passed by California State Assembly this year, honoring the Dina LaVigna “Breath of Life” Fund.

All proceeds will benefit the Dina LaVigna “Breath of Life” Fund, created by her family together with the JMF, in the memory of Dina, who died at the age of 33 from complications of Primary Immunodeficiency. The purpose of the Fund is to improve the conditions and the experience for patients undergoing their treatments. The current focus of the “Breath of Life” Fund is to create “Dina’s Room,” a treatment suite at UCLA’s Mattel Children’s Hospital. The record $200,000 raised by this year’s Triathlon will go a considerable way toward the $750,000 pledged by the fund to UCLA, Dina’s alma mater. Previously the Fund provided support to establish “Dina’s Room” at Mount Sinai in New York City. The infusion centers are bright, uplifting and cheerful spaces for patients undergoing treatment.

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

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

“Links for Liam” hopes to raise funds for research and awareness in future years, in partnership with the Jeffrey Modell Foundation. The hope is to advance newborn screening, because while a bone marrow transplant is a successful treatment, it is much more successful when performed during the first few months of life.

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