Harvard Medical School Establishes Jeffrey Modell Immunology Center

Newly Constructed Building Will Be Focal Point For Immunologists Worldwide

The Harvard Medical School, in collaboration with the Jeffrey Modell Foundation, completed construction of a new immunology building centrally located on the Harvard Medical School campus. The Jeffrey Modell Immunology Center at Harvard is a unique endeavor serving as a focal point for the most dynamic and diverse community of immunologists in the world. The Center will include:

- Dr. Fred S. Rosen Lecture Hall
- Dr. Robert A. Good Library
- Reception Facilities
- Conference Room
- Visiting Professor Office
- Program Director & Faculty Offices
- Graduate Student “Idea Exchange”
- Graduate Student Reading Room

The Center will maximize collaboration between faculty, postdoctoral fellows and students in the graduate program in Immunology, as well as throughout the Longwood medical area.

Architectural rendering of the new Jeffrey Modell Immunology Center at Harvard.

Harvard has been rated the #1 medical school in the United States for the past 19 years. There are more than 7,000 full time faculty working at 17 Harvard teaching hospitals and

To be continued on page 2…

Networking…

35 Centers Worldwide Form Jeffrey Modell Network

At the Jackson Hole, Wyoming Expert Meeting on Primary Immunodeficiencies, 35 Jeffrey Modell Center Directors and industry supporters convened to address the ever-expanding Jeffrey Modell Diagnostic and Research Centers. There was a consensus to set up a new network that would frame the scientific agenda; including best practices, clinical guidelines, outcome measures, data capture, novel therapies, and a research platform. A Steering Committee was formed, and several sub-committees are now being organized. The Jeffrey Modell Centers Network is comprised of expert Immunologists from 28 cities, 14 countries and 4 continents.
A Message from Vicki & Fred Modell

Sincerely,

They create about hope and dreams for the future. and, listen to the music wait to go back and participate in the new Brazilian all so similar and have so much to share. We can't a child live with hope for a better tomorrow. We are Parents, brothers, sisters, and friends trying to help We are constantly amazed at the similarities. Miami and then Budapest, Beijing and Shanghai. It was so inspirational to us, and brought to mind memories of our very first meetings with patients in the past. We provided answers as best as we could. Then, almost miraculously, one family began talking to another and soon, they came to life, smiling and laughing with heads held high. Before long, they were planning a "Kid's Day." They formed a patient organization, found volunteer leadership, established a name, a logo, t-shirt design, and one they were never able to speak about their diseases in the past. We offered answers as best as we could. Nevertheless, one family began talking to another and soon, they came to life, smiling and laughing with heads held high. Before long, they were planning a "Kid's Day." They formed a patient organization, found volunteer leadership, established a name, a logo, t-shirt design, and one of the fathers, a musician, even promised to write a song about hope and dreams for the future.

Harvard Medical School Establishes Jeffrey Modell Immunology Center

(Continued from page one)

research institutes. The Harvard Medical School has produced 12 Nobel Prize winners. According to Joseph B. Martin, MD, PhD, retiring Dean of the Faculty of Medicine, "This Center will make a prominent contribution to the development of a new generation of highly trained immunologists at a time when research in immunology has emerged as the key to the treatment, prevention and cure of a host of deadly and debilitating diseases"

Future programs at the Jeffrey Modell Immunology Center will be announced in early 2008.

2nd Robert A. Good Society Symposium

The Robert A. Good Society conducted its Second Annual Symposium entitled "Immune Reconstitution of Primary Immunodeficiencies," at Harvard Medical School in Boston.

The two day conference focused on unresolved problems of Stem Cell Transplantation (SCT), long-term analysis of immune reconstitution, and novel strategies to expedite immune reconstitution post-SCT. The meeting honors Dr. Robert A. Good, considered to be one of the greatest immunologists of the 20th century. Forty years ago, Dr. Good conducted the first successful Bone Marrow Transplant to cure Severe Combined Immune Deficiency. It has emerged as the treatment of choice for many congenital and acquired blood disorders.

Did You Know?

The National Institute of Allergy and Infectious Diseases (NIAID), at the U.S. National Institutes of Health, stated in a recent grant announcement:

“While individual Primary Immunodeficiency Diseases are rare, as a group they may affect 1-2% of the population.”

This translates to between 3 million and 6 million Americans, a prevalence far greater than most health agencies have estimated in the past.

Jeffrey Modell Foundation Endows Chair at Seattle Children’s Hospital

Dr. Hans Ochs Selected to Hold Chair in Pediatric Immunology Research

The Jeffrey Modell Foundation has established its first Endowed Chair to support pediatric immunology research. It will assure continuing scientific investigation in Primary Immunodeficiency and Immunology, and bring attention to this field in the medical community. Dr. Hans Ochs, a long-time collaborator with the Foundation, has been selected as the recipient of the Chair. Dr. Ochs is a distinguished professor of Pediatrics at the University of Washington and an acclaimed researcher and clinician.

JMF Initiates Collaboration with the State of Wisconsin

Although there are more than 150 Primary Immunodeficiency defects identified, Severe Combined Immune Deficiency (SCID), or “bubble boy disease,” will end a child’s life before his or her first birthday if not precisely diagnosed and treated within the first weeks of life. This is the reality for the most severe Primary Immunodeficiency disease, and therefore, there is a great need to initiate a screening program. Experts indicate that SCID can be treated and cured with a better than 95% success rate.

Are We All Immunodeficient?

Dr. Jean-Laurent Casanova, a world-renowned and respected physician at Hôpital Necker Enfants Malades, Paris, France, published a most provocative study in a recent issue of Science. The article, entitled “Primary Immunodeficiencies: A field in its infancy,” expressed the hypothesis that “a paradigm shift is occurring in the field of Primary Immunodeficiencies, with revision of the definition of these conditions and a considerable expansion of their limits. It now appears that most individuals suffer from at least one of a multitude of Primary Immunodeficiencies.” The article appeared in Volume 317 of Science, dated August 3rd, 2007. Dr. Casanova has collaborated with the Jeffrey Modell Foundation frequently over the past decade.
The U.S. National Institutes of Health (NIH) estimates that at least 500,000 cases of PI remain undiagnosed in the United States. The economic impact of undiagnosed PI to the healthcare system in the United States totals over $40 billion annually.

Quality of Life Data Compares Undiagnosed and Diagnosed PI Patients

"Immunologic Research," a scientific journal published by Humana Press, features data compiled by JMF comparing quality of life issues for diagnosed and undiagnosed patients. The information was provided by physicians/experts at 76 JMF Diagnostic and Referral Centers worldwide. Surveys were collated by JMF and reviewed by members of the Foundation’s Medical Advisory Board. 532 Patients were included in the study. JMF assigned economic values to the conditions assessed based on publicly accessible information.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Cost per episode</th>
<th>*of episodes</th>
<th>Cost prior to diagnosis</th>
<th>*of episodes post-period</th>
<th>Costs after diagnosis</th>
<th>Annual savings</th>
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<tbody>
<tr>
<td>Acute Infections</td>
<td>$2,950 per episode</td>
<td>6.4</td>
<td>$18,880</td>
<td>1.8</td>
<td>$5,310</td>
<td>$13,570</td>
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<tr>
<td>Severe Infections</td>
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<td>$24,544</td>
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<td>$3,424</td>
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<td>Bacterial Pneumonia</td>
<td>$7,529 per episode</td>
<td>2.8</td>
<td>$21,081</td>
<td>0.6</td>
<td>$4,517</td>
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<td>Chronic Infection</td>
<td>$36.33 per day</td>
<td>44.7</td>
<td>$1,623</td>
<td>12.6</td>
<td>$457</td>
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<tr>
<td>Physician/ Hospital/ ER Visits</td>
<td>$125 per visit</td>
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<td>$8,862</td>
<td>11.8</td>
<td>$1,475</td>
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<td>Hospitalizations</td>
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<td>19.2</td>
<td>$22,233</td>
<td>5.1</td>
<td>$5,905</td>
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<tr>
<td>Antibiotics</td>
<td>$4.25 per day</td>
<td>166.2</td>
<td>$706</td>
<td>72.9</td>
<td>$309</td>
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<td>School/ Work Days Missed</td>
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<td>$4,623</td>
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<td>Totals per patient</td>
<td></td>
<td></td>
<td>$102,552</td>
<td>$22,610</td>
<td>$79,942</td>
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Results

The U.S. National Institutes of Health (NIH) estimates that at least 500,000 cases of PI remain undiagnosed in the United States. The economic impact of undiagnosed PI to the healthcare system in the United States totals over $40 billion annually.
In this issue, meet Larry Guiheen, Baxter BioPharm President

In the beginning...

The 10 Warning Signs campaign was one of the first signs that Baxter and the Jeffrey Modell Foundation (JMF) were going to have a long and successful partnership together. That was the first major awareness and early diagnosis initiative we worked on with Fred and Vicki. Fred had approached the Plasma Protein Therapeutics Association (PPTA) for support to launch the JMF’s awareness campaign nationally. Baxter led the way in pledging support, and helped influence others in the industry to join the effort. It was a big victory since the Centers for Disease Control and Prevention (CDC) was matching the contributions. Fred had succeeded in bringing patients, industry and the government together to tackle what was clearly a major problem, lack of Primary Immunodeficiency (PI) awareness and a significant delay in diagnosis.

Ever since that time it has been a huge honor for me, and many people at Baxter to be involved with Fred and Vicki, and all the wonderful initiatives that JMF drives. We support their mission and respect their willingness to work with Baxter, and the plasma industry as a whole. They do things that make sense for the community and the country, and we’re proud to be a part of that.

For example, Baxter and JMF are long-standing partners in the effort to raise awareness and increase diagnosis of PI globally. Throughout the years we’ve supported the JMF’s newborn screening program and its highly successful efforts to create awareness, resulting in early diagnosis and treatment. Even today, it takes an average of nine years for many patients to receive an accurate diagnosis. When patients finally get diagnosed, it can make such a big impact on their ability to work, go to school and to enjoy life. To us, these are all the right reasons to help. I’m saying this not only as an executive, but more importantly, as a father who understands how precious it is to have a healthy, thriving child.

Supporting the PI community today...

SPONSORSHIP OF JMF DIAGNOSTIC CENTERS

When Fred and Vicki first told us about their plan to provide the regional resources communities need to educate healthcare professionals and get patients diagnosed earlier through the opening of JMF Diagnostic Centers, we immediately pledged Baxter’s support. Baxter is a sponsor of nine JMF Diagnostic Centers at prestigious medical institutions around the world.

Providing resources for patients and families

Through the years many people at Baxter have had the opportunity to work with the PI community and meet patients and families at JMF events. In fact, Pete O’Malley, a Vice President in Baxter’s BioScience division, was at the very first JMF Kids’ Day in Central Park. Our encounters with patients and families always bring great insight into the programs and resources Baxter can provide.

That’s how Charlie and Emma’s books came about. Our product manager for Gammagard®, David Bond, met Dayna, the mom of three children with PI, at a conference. They got to talking and as a result, Baxter became aware of a book that Dayna wrote for her son, Charlie. Dayna’s goal was to help eliminate some of the anxiety Charlie was having about going for his IVIG infusions. Baxter supported Dayna and Charlie’s wish to publish the book and share it with other families.

Another PI patient, Emma, approached Baxter about publishing her book, The ABCs of Kids Like Me. Emma used each letter of the alphabet to create an inspirational tale about the courage and determination needed to succeed in managing life with PI. Both books are available free of charge on Baxter’s ImmuneDisease.com website.

Working with policymakers to assure access and choice

In my almost 30 years at Baxter, I’d have to say that one of the most rewarding parts of my job is the advocacy work we do with patients in Washington D.C. Patients need access to all brands at all points of care. We work with the JMF and other patient organizations, government agencies and members of Congress to create awareness about the insurance and reimbursement needs of patients and healthcare professionals. Our mutual end goal is to be sure PI patients can access the IVIG they need, regardless of brand or site of care.

When I go to Washington, it’s easy for me to speak passionately, because we have met so many PI patients, and I personally know the hurdles they’ve had to overcome.

For example, JoJo was 13 years old when we first met her. She was a state-ranked soccer player and honor roll student. But from the time JoJo was born she was in and out of the hospital constantly with pneumonia and severe sinus infections. JoJo was finally diagnosed with CVID and prescribed Gammagard. Now, at age 17, she is looking forward to entering a pre-med program and becoming a trauma surgeon.

Addressing the needs of special patient populations, such as those requiring a low IgA IVIG therapy, is important to us too. In fact, we are the only manufacturer who offers an IVIG therapy with IgA levels less than 1mcg/mL in a 5% solution. That was important for Evin, a young girl I met many years back. Throughout her childhood Evin was often ill with various infections. After months of severe reactions to her original treatment regime she was offered Gammagard S/D. She tolerated it well and regained her zest for life. Evin has kept in touch with us over the years as she went to college, pursued a career and got married. It means a lot to us that she considers Baxter part of her extended family.

Commitment into the future

I think what I am most proud of is Baxter’s history of providing Gammagard to patients who depend on it. In fact, Baxter is the only name that has remained constant in the IVIG market over the last 20 years and we’re going to continue to be here for patients into the future.

As a market leader, Baxter has always taken its responsibility of consistently providing the highest quality IVIG to our patients very seriously. First we introduced Gammagard, then Gammagard S/D and then Gammagard Liquid. And we’re dedicated to continually advancing the science of IVIG. We’re investigating other opportunities, both in SubQ administration and other novel ways of delivery of this product. Baxter continues to look at formulations, packaging and enhancements that would make IVIG even more pure and utilization, even more convenient.

The PI community can continue to expect great things from Baxter. Fred and Vicki’s dedication and seemingly endless energy to make strides in research and awareness has inspired us to pursue our own excellence in meeting the needs of PI patients and families. We look forward to many more victories we can accomplish together.

Larry Guiheen is the president of Baxter Healthcare Corporation’s BioScience BioPharmaceuticals business. In this position, he is responsible for setting the strategic direction for Baxter in the North American region including sales, marketing, manufacturing expansion and new product requirements. Larry joined Baxter in 1978 and through the years he has held various senior management positions in sales, marketing and operations. In 1997, Larry became president of Hyland Immuno U.S., which is now known as Baxter BioScience.
Philip Altheim, principal of Belway Electric, received the Foundation’s “Man of the Year” award at JMF’s 21st Annual “Spring Ahead” Gala. Cipriani 42nd Street in New York City was sold out once again. The night featured high-spirited entertainment by Le Clique, music by Valerie Romanoff, and a dazzling entertainer known as “Mirror Man,” who thrilled the crowd suspended from the ceiling as a human disco ball. The event raised over $1.4 million. Be sure to “Save the Date” for the next exciting “Spring Ahead,” April 24, 2008 honoring Jeff Blau, President, Related Companies.
We're Hearing from You

Mandy in Milwaukee, Wisconsin:
“Park! The Foundation gave an evening to all the families to thank for all the help and generosity of the Jeffrey Modell Foundation and for giving us hope for the future.”

Marciol in Thiensville, Wisconsin:
“I want to thank you for trying to reach out to the community, especially the Spanish speaking community, because that is how I found out about PI. I believe it to be the answer to my child’s illness. He never gets rid of the cough and the cold. Thank you so much and I hope I find the answer and that you keep up the great work.”

Dana in Sedalia, Missouri:
“Your website and radio ad, truly saved us. I didn’t know what was going on with our little one and finally we have an answer. I had never heard of PI so I took the 10 warning signs to our pediatrician and our first pediatrician told me it was so rare that most children die and therefore our child could not have it. Thank you for airing the radio ads and having the website available. Grace does have PI and I could have never found out if it wasn’t for info4pi.org. Thanks so much. We appreciate you so much.”

Anne in Fayetteville, Arkansas:
“Grace does have PI and I could not have it. Thank you for airing the radio ads and having the website available. Grace does have PI and I could have never found out if it wasn’t for info4pi.org. Thanks so much. We appreciate you so much.”

Terry in Houston, Texas:
“Your website and radio ad, truly saved us. I didn’t know what was going on with our little one and finally we have an answer. I had never heard of PI so I took the 10 warning signs to our pediatrician and our first pediatrician told me it was so rare that most children die and therefore our child could not have it. Thank you for airing the radio ads and having the website available. Grace does have PI and I could have never found out if it wasn’t for info4pi.org. Thanks so much. We appreciate you so much.”

Winnie in New Hope, Pennsylvania:
“I’ve been researching for years to try to help my kids stay well and I found your site along the way. Unfortunately, we are still in the dark ages of immune deficiency. It’s still not on the doctors’ radar. I know it takes time for change and your PSA, print and radio ads will certainly help. I think there’s little emphasis in today’s medicine on recurrent infections, especially if they seem benign, I have hope in doctors again. Thank you Jeffrey Modell Foundation. Keep at it, spread the word, educate the doctors. Keep the faith and hope alive.”

Tim in Minneapolis, Minnesota:
“I just received my first Jeffrey Modell ‘Update’ and wanted to thank you for the wonderful work you have done for those of us with immune system diseases. I am so glad that there are people like you who are out there educating not only the public, but the medical community. My heartfelt thanks for all that you have accomplished and for giving us hope for the future.”

JMF Receives 4 Stars... 4th Year in a Row
Once again, the Jeffrey Modell Foundation has received the highest 4-star rating from Charity Navigator, America’s largest independent evaluator of charities. This on-line service applies data-driven analysis to the charitable sector, evaluating the financial health of over 4,000 charities.

In a letter to the Foundation from Trent Stamp, Executive Director, “Charity Navigator salutes JMF’s commitment to prudent financial management and congratulates the JMF on receiving our highest 4-star rating. A 4-star rating from Charity Navigator gives your supporters confidence in JMF’s ability to maximize its charitable return on its donations and demonstrates that it is worthy of the public’s trust. And this exceptional 4-star rating means that the JMF is able to efficiently manage its funding, exceed industry standards and outperform most charities in its cause.”

Charity Navigator evaluated two broad areas of financial health: Organizational Efficiency and Organizational Capacity. These two areas combine to contribute to the overall rating. Fundraising efficiency, administration, program expenses, and working capital ratio all received the exceptional 4-star rating.

JMF Dedicates 4 New Centers of Excellence

New Initiative in Brazil will be 36th Center Worldwide
Four new Jeffrey Modell Diagnostic Centers have recently been dedicated in New Orleans, Seattle, San Francisco, and Oxford, England. Currently, plans are underway to establish the first new initiative in South America, in São Paulo, Brazil.

The most recent survey of the existing Jeffrey Modell Diagnostic and Referral Centers reports:

- 98% annual increase in diagnosed patients
- 79% annual increase in referrals
- 492% annual increase in diagnostic tests
- 65% annual increase in patients receiving IVIG

WIN “W” Grant Awards

“WIN,” the World Immunodeficiency Network established by JMF, supports over 65 patient groups in 50 countries around the world. An esteemed Advisory Board reviews all grant applications, and monetary awards are made within 30 days of approval.

WIN is supported by JMF; multiple U.S. government agencies, and global pharmaceutical corporations.

WIN has awarded grants to patient organizations worldwide, providing them with financial and technical support to enhance physician education and public awareness within their communities.

WIN International Network
Support for PI patients worldwide
JMF was honored to have been selected once again to organize the World Health Organization / IUIS Expert meeting. Previously, JMF organized these high-science events in England, Austria, Switzerland, Portugal and Hungary. This year’s meeting in Jackson Hole, Wyoming was a collaboration of the World Health Organization and the International Union of Immunological Societies (IUIS). The three day meeting addressed molecular biology and the genetics of Primary Immunodeficiency Disorders. Subjects included innate immunity, T and B cell deficiencies, disorders of immune regulation, genetic instability and cancer.

The prestigious meeting drew expert immunologists from 21 countries including Australia, China, Iran, Israel and Japan.
Program expands to 22 regions in the United States

JMF “KIDS DAYS” began in 1988 and were created to provide a joyous occasion for Primary Immunodeficient patients, their families, doctors and nurses. It has become a valuable opportunity for patients to meet with one another, share personal experiences and form supportive, long lasting friendships. JMF has helped organize more than 60 “KIDS DAYS” across America and many others in Europe, Middle East, Asia and Latin America. Plans are already underway for 22 regional “KIDS DAYS” in 2008.
To Becky Wilson’s Fifth Grade Class,

On behalf of the Jeffrey Modell Foundation, we would like to express how thankful, surprised, happy and honored we were to receive your donation of $1,354 from the “Pay It Forward” program at the Village Green Elementary School. There are no words to completely describe our gratitude and appreciation, so please accept a simple, yet heartfelt, thank you.

We are so proud of all of you for expressing your kindness, working hard to achieve your goals and caring so deeply about other children like your “class buddy”, Tanner, who has to cope with and deal with health problems each day. Each and every one of you is special—and we promise you that we will do something very special with your hard earned money.

We have asked Tanner’s doctor to make a “wish,” and we will grant his wish with your donation and in honor of the Village Green Elementary School Fifth Grade Class. It will be used for a special research project to improve the lives of children with Primary Immune Deficiency and to buy some game boys and DVD’s that the children can use while they receive treatment.

With Thanks & Love,

Vicki & Fred Modell
Jeffrey Modell Foundation

What a beautiful gift—what a difference you will make in so many precious lives. We will end with our favorite quote and one that is very meaningful:

one hundred years from now...

☐ it will not matter what my bank account was, the sort of house I lived in, or the kind of car I drove, but the world may be different because I was important

☐ in the life of a child

With Thanks & Love,

Vicki & Fred Modell
Jeffrey Modell Foundation

“Personal Best”– Reaching the Optimum for Dina

In June, the Dina La Vigna “Breath of Life” Triathlon was held once again in Ventura, California. The event 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 competition is considered to be one of the best of its kind in the entire Western Region.

All proceeds benefit the Dina LaVigna “Breath of Life” Fund, created by her family, her friends, and the JMF in 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 facility at UCLA’s Mattel Children’s Hospital. The funds raised by this year’s Triathlon have made the new infusion facility a reality. Congratulations to all participants!