Jeffrey Modell Foundation
Curing PI. Worldwide.

World Primary Immunodeficiency Week
April 22 – 29, 2013

Jeffrey Modell Foundation
Update
During World PI Week, the Jeffrey Modell Foundation asked its friends on Facebook the following question:

In five words or less, what is your hope for patients who have a Primary Immunodeficiency?
This is a representation of all of their words.
We are moved by the voice they have given the Primary Immunodeficiency community.
The Jeffrey Modell Foundation, in collaboration with physician experts at the Jeffrey Modell Centers Network (JMCN) and patient groups from the World Immunodeficiency Network (WIN), in 12 States and over 30 countries joined together for World Primary Immunodeficiency Week (WPIW), April 22 – 29, 2013 to create awareness, dialogue and activities for PI.

We are pleased to share our weeklong efforts that brought together patients and their families, healthcare professionals, scientists, and industry, empowering all stakeholders to raise awareness for earliest possible diagnosis and appropriate treatment.

One of the highlights of World PI Week is a simultaneous launch of thousands of specially designed balloons at Jeffrey Modell Diagnostic and Research Centers throughout the U.S. and around the world.
Children’s Hospital Los Angeles partnered with the Jeffrey Modell Foundation to improve the diagnosis and treatment for children with Primary Immunodeficiency Disorders and to serve as a local resource for physicians in Southern California. They hosted a virtual balloon “lift off” on their Facebook page – with more than 18,000 followers learning about Primary Immunodeficiency. It was immediately followed by a symposium led by Dr. Steven Holland of the National Institutes of Health to educate physicians.
The balloons were launched in Louisiana, Argentina, New York, Belgium, Texas, United Kingdom, Illinois, Colombia, Florida, Canada and everywhere that is in between. To coincide with our launch, we ran a press release announcing the start of World PI Week, and our initiative to “Lift off” thousands of balloons around the world.

On Monday, April 22nd, our efforts to launch World PI Week also appeared in New York City’s Time Square!

The Jeffrey Modell Foundation also sponsored a global competition through our World Immunodeficiency Network (WIN) to award the most innovative, creative, unique and cutting edge idea to create awareness of Primary Immunodeficiency during World PI Week. We had over 20 grants come into the Jeffrey Modell Foundation. There were so many creative ideas, that the JMF awarded three winners with a prize of $5,000 each to fund their events during World PI Week. Here are the winners:

→ Romanian Association of Patients with Primary Immunodeficiencies in Collaboration with Association “Pro Primary Immunodeficiencies” and Jeffrey Modell Center in Timisoara, Romania
  “Planting Trees for a Better Immune System”
Planting Trees for a Better Immune System:

→ 2500 Maple Trees and 64 Willow Trees were planted in Romania on Monday, April 22, 2013. The amount planted was based on an estimated number of patients they believe exist in Romania. Currently, they have over 350 patients diagnosed and being treated.

→ They had local, national and TV attend their event – which created a lot of media attention for the start of World PI Week in Romania.

Dissemination of educational materials:

→ The Romanian patient organization also disseminated posters about Primary Immunodeficiency and posted them in elementary schools, high schools, universities and hospitals

Education tools for physicians:

→ On Thursday, April 25th, 2013 – the Romanian patient organization hosted an educational event for the physicians.

→ They sent an email blast to all family practitioners including the 10 Warning Signs poster and information about Primary Immunodeficiency.

➢ Edgardo Rebagliati Martins National Hospital in Lima, Peru

→ April 25th, 2013, patients, families, physicians and the Peruvian Health Authorities gathered for a two hour meeting about the importance of Primary Immunodeficiency awareness, early diagnosis and treatment. The 10 Warning Signs were distributed and real life presentations were presented to the Peruvian Health Authorities.

→ From April 25 – 26, 2013 – 500 t-shirts with the 10 Warning Signs illustration were distributed to patients, families, physicians and the public around the National Hospital create awareness.
Andy & Sofia – Boston, Massachusetts

→ Andy & Sofia have created a very comprehensive and expansive Social Media Network. Twitter is a vital part of their extraordinary following. Every day, millions of people turn to Twitter to connect to their interests, to share information, and find out what’s happening in the world right now. Andy & Sofia created a Twitter Campaign, using key messages, during World PI Week promoting “tweets” by a targeted search and geographically.

→ Andy & Sofia’s Twitter page also links to their Facebook page which has over 12,000 followers.

Jeffrey Modell Foundation Social Media Outreach during World PI Week:

As of: (Facebook July 2012) (Twitter March 2013)

As a result of this weekly celebration, every day and every hour, the Jeffrey Modell Foundation posted images of events held during World PI Week, fun and interesting facts on Primary Immunodeficiency, old photos of how World PI Week was started in 1993 by JMF, educational materials and tried to engage our followers to participate in the excitement of World PI Week.

Here are some of our Awareness outreach results from Facebook:

1049 “Likes”

648% increase in Weekly Total Reach

400% increase in People talking about us

Through our efforts and constant postings on our Facebook Page – for the week of April 22 – 29, 2013 – our Facebook total outreach was 33,701. And on average we had 15 new “likes” per day!

The “People talking about us” come from all around the world; Brazil, U.S. Australia, Japan, Venezuela, The Netherlands, Ireland, South Africa, India, Israel, Germany, Canada, Uruguay, Mexico and so many more.

Our demographics show 72.8% of visitors are female, with the largest age group spanning 35 – 44 years old.
Below are a few images created for this special week:

World Primary Immunodeficiency Week is here!!!

JMF is thrilled to be a part of this global celebration!

Let’s all join together to raise awareness for PI around the world!

WORLD PRIMARY IMMUNODEFICIENCY WEEK
April 22 - 29, 2013
On April 18, 1993, Vicki and Fred Modell, together with Senator Joseph Lieberman, Dr. Duane Alexander, Director of the National Institute of Child Health and Development, and Dr. Anthony Fauci, Director, National Institute of Allergy and Infectious Diseases received a congressional resolution (photo above) declaring Primary Immunodeficiency Awareness Week. The goal and mission was earliest possible diagnosis and access to appropriate treatment.

This week, the Jeffrey Modell Foundation has reached out to government officials, health professionals, schools, day care centers, media, scientific journals and much more. Our promise to the community is that our efforts will not only last this week - we will continue every day to educate and create awareness for Primary Immunodeficiency – we will continue our mission of Hope, Advocacy and Action.

We had a great week with our entire network of friends and family of the Jeffrey Modell Foundation, and continue to wish all of them good health this year, and every year to follow!