



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.





**The Jeffrey Modell Diagnostic Center for  
Primary Immunodeficiencies at  
Ann & Robert H. Lurie Children's Hospital of Chicago**

Invite you to our  
1<sup>st</sup> Annual Balloon Release  
in Honor of  
Primary Immunodeficiency Awareness Week  
Monday, April 22, 2013 at 4:30 p.m.

Location:  
225 E. Chicago Avenue  
Main Lobby

Sponsored by:

*We Love you!*



Semana Mundial  
de las  
Inmunodeficiencias  
Primeras  
22 al 29 de Abril

**Suelta de  
Globos**

Hospital de Niños  
Ricardo Gutiérrez  
22 de Abril - 11 hs.

Evento de lanzamiento dentro del  
Hospital de Niños Ricardo Gutiérrez y  
Parque de la Salud  
Buenos Aires



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 every where 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.

4/22/13 Jeffrey Modell Foundation joins with 32 countries to launch World Primary Immunodeficiency... -- NEW YORK, April 22, 2013 /PRNewswire-USNewswire/ --



Send a release  
Become a member For journalists  
Member sign in For bloggers  
Global sites

Search  
Advanced Search  
Products & Services News Releases

Products & Services Knowledge Center Browse News Releases Contact PR Newswire

See more news releases in Medical Pharmaceuticals | Not For Profit

## Jeffrey Modell Foundation joins with 32 countries to launch World Primary Immunodeficiency Week



More -

Embed



World PI Week 2013

NEW YORK, April 22, 2013 /PRNewswire-USNewswire/ -- The Jeffrey Modell Foundation, in collaboration with physician experts and patient groups from 32 countries, launched World Primary Immunodeficiency Week beginning today.

Primary Immunodeficiencies (PI) are genetic defects of the immune system that are often chronic, serious, and can be fatal. The disorder affects 10 million people worldwide and most are not aware of their condition.

Vicki and Fred Modell established the Jeffrey Modell Foundation 26 years ago, in memory of their son Jeffrey, who lost his battle with Primary Immunodeficiency (PI) at the age of 15. The Foundation (JMF) is a global organization dedicated to Research, Physician Education, Patient Support, Public Awareness, Advocacy, and Newborn Screening. There are 196 Jeffrey Modell Centers in 68 countries spanning six continents.

Weeklong events will bring 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.

"To affirm our dedication, passion, and commitment to our mutual mission, Jeffrey Modell Diagnostic, Research, and Referral Centers throughout the U.S. and abroad will be participating in this event by launching balloons on the same day. This will signify how since inception, WPIW has 'ballooned' into a global movement," said Vicki Modell, Co-Founder of the Jeffrey Modell Foundation. She added, "We need to be sure that each child and adult has the best chance of being diagnosed early and effectively treated. Awareness is critical, and World PI Week is an excellent opportunity to drive this global movement to educate the medical community and the public about Primary Immunodeficiencies."

The Jeffrey Modell Foundation also sponsored a global competition for the most innovative, creative, unique, and cutting edge idea to create awareness of Primary Immunodeficiencies during World PI Week. JMF has awarded three winners with a prize of \$5,000 each to fund their events during World PI Week.

### About Jeffrey Modell Foundation

Vicki and Fred Modell established the Jeffrey Modell Foundation in 1987, in memory of their son Jeffrey, who died at the age of fifteen from complications of Primary Immunodeficiency -- a genetic condition that is chronic, serious, and often fatal. JMF is a global nonprofit organization dedicated to early diagnosis, meaningful treatments, and, ultimately, cures through research, physician education, public awareness, advocacy, patient support, and newborn screening.

For more information about PI, visit [www.info4pi.org](http://www.info4pi.org) or email the Jeffrey Modell Foundation at [info4pi@jmfworld.org](mailto:info4pi@jmfworld.org).

### Media Contacts:

Vicki Modell, Jeffrey Modell Foundation, (212) 819-0200  
Fred Modell, Jeffrey Modell Foundation, (212) 819-0200

### Related Link:

[To learn more about the Jeffrey Modell Foundation](#)

SOURCE Jeffrey Modell Foundation

### RELATED LINKS

[www.info4pi.org](http://www.info4pi.org)



Next in Medical Pharmaceuticals News

### Custom Packages

Browse our custom packages or build your own to meet your unique communications needs.

Start today.

### PR Newswire Membership

Fill out a PR Newswire membership form or contact us at (888) 776-0942.

### Learn about PR Newswire services

Request more information about PR Newswire products and services or call us at (888) 776-0942.

### More by this Source



Bill & Melinda Gates Foundation and Jeffrey Modell Foundation Announce Collaboration to Eradicate Polio Worldwide  
Nov 28, 2012, 09:00 ET

[View All News by this Source](#)

### Featured Video

### Journalists and Bloggers



Visit PR Newswire for Journalists for releases, photos, ProNet experts, and customized feeds just for Media.

View and download archived video content distributed by MultiVu on [The Digital Center](#).

[www.prnewswire.com/news-releases-test/jeffrey-modell-foundation-joins-with-32-countries-to-launch-world-primary-immunodeficiency-week-202423081.html](http://www.prnewswire.com/news-releases-test/jeffrey-modell-foundation-joins-with-32-countries-to-launch-world-primary-immunodeficiency-week-202423081.html)

1/2

240 Media outlets ran the [World PI Week](#) release distributed by the [Jeffrey Modell Foundation](#). It appeared on television, radio, newspapers, Websites and blogs. The largest number of visitors per day were Wall Street Journal, Yahoo News, Reuters, The New York Business Journal and Washington Business Journal.



On Monday, April 22<sup>nd</sup>, 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 25<sup>th</sup>, 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 25<sup>th</sup>, 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.

 *Semana Mundial de las Inmunodeficiencias Primarias (IDP)*  
22-29 de Abril de 2013

**Ceremonia:**

**“Presentación de los pacientes con IDP del HNERM”**

**Día:** 25 de Abril de 2013  
**Hora:** 12:00 – 14:00 horas  
**Lugar:** Auditorio N°1 (Guillermo Kaelin) - HNERM

**Organizadores:**

- Servicio de Alergia e Inmunología del HNERM
- Jeffrey Modell Foundation

**Programa:**

- 12:00 Palabras de bienvenida
- 12:15 Conferencia: Importancia del diagnóstico y tratamiento de las IDP
- 12:30 Conferencia: ¿cuándo sospechar IDP?
- 12:45 Presentación de los pacientes con IDP
- 13:45 Palabras de despedida / break final

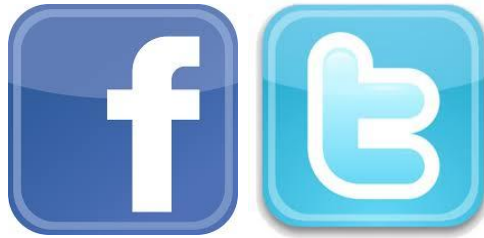




➤ **Andy & Sofia – Boston, Massachusetts**

- 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:



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:



**Congressional Record**  
PROCEEDINGS AND DEBATES OF THE 103<sup>rd</sup> CONGRESS, SECOND SESSION

Designating the week beginning April 18, 1993, as  
**"Primary Immune Deficiency Awareness Week"**

Around the country, children and adults are suffering unnecessarily because their primary immune deficiency has not been diagnosed or their physician is not sure how to treat it. We must increase public awareness of this condition so diagnoses can be made, treatment begun, and support provided for the families suffering this debilitating condition.

**April 18, 1993**

Dear Colleague:

Primary Immune Deficiency is a congenital defect in the immune system which affects over 500,000 people in this country which affects over 500,000 people in this country.


Primary Immune Deficiency affects more children than leukemia and lymphoma combined. The first symptoms can be recurring ear infections, sinus infections, repeated incidence pneumonia, failure to gain weight, or two or more infections meningitis. Patients with primary immune deficiency often do not respond to prophylactic antibiotics.

**The Jeffrey Modell Foundation**

Around the country, children and adults are suffering unnecessarily because their primary immune deficiency has not been diagnosed or their physician is not sure how to treat it. We must increase public awareness of this condition so diagnoses can be made, treatment begun, and support provided for the families suffering this debilitating condition.

**Primary Immune Deficiency Awareness Week**

Sincerely,  
*Joseph I. Lieberman*  
 Joseph I. Lieberman



In six years, the Foundation, a symbol of two parents' love and tireless dedication, has proven to be much more than a worthy endeavor. It has served the victims of primary immune deficiency, providing them with critical information and assistance, and has devoted efforts to medical research directed at treating and one day curing this dreaded disease.

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!