

## World PI Week ~ April 22 - 29, 2014



**World Primary Immunodeficiency Week**  
**April 22 - 29, 2014**

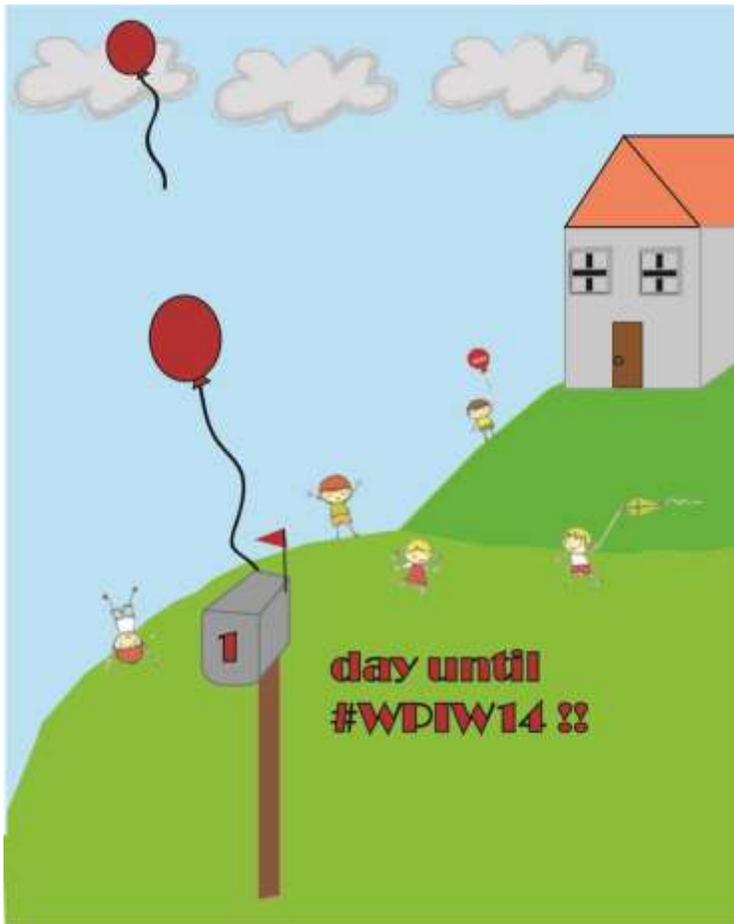
**Jeffrey Modell Foundation**  
**Update**

## World PI Week ~ April 22 - 29, 2014

The Jeffrey Modell Foundation organized World Primary Immunodeficiency Awareness Week in April, 2014. The celebration featured a simultaneous launch of specially designed balloons and bubbles that the Foundation provided to Jeffrey Modell Centers in 75 locations, 20 states within the United States and 50 countries in Africa, Asia, Australia, Europe, Eastern Europe, Latin America and the Middle East. This year's Balloon Launch was bigger, better, and bolder, with an even stronger reach than last year! It was a memorable and magical global movement to raise awareness of Primary Immunodeficiencies.

As thousands of balloons were set free, all of us, as one voice, affirmed our dedication, passion and commitment to our mutual mission...to raise awareness, improve diagnosis, and advocate for equal access to treatment for patients worldwide. We stood together, each in our own part of the world, and set our balloons free, each balloon symbolizing a newly diagnosed patient!

We are pleased to share some 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.

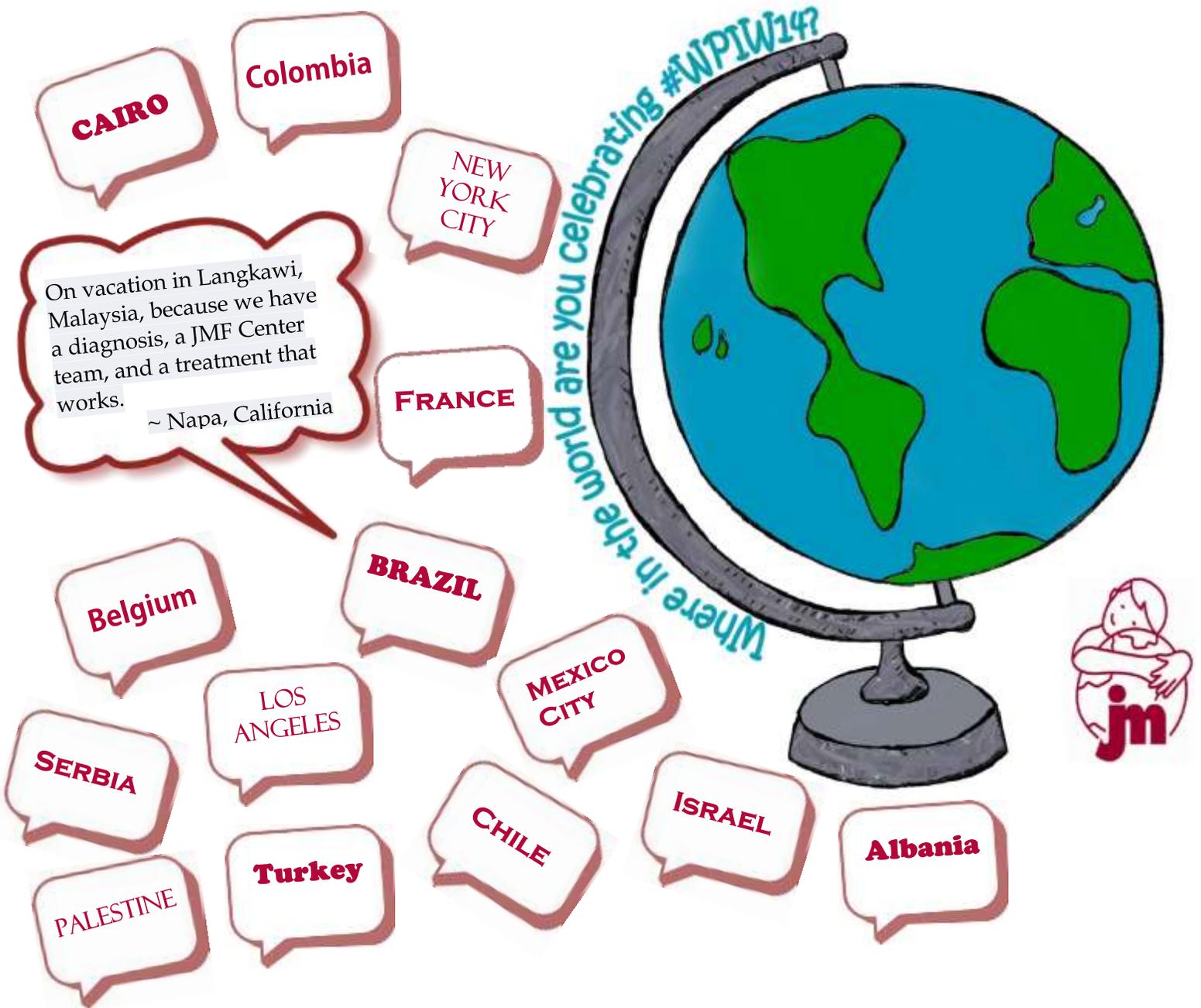


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### Social Media Report:



The Jeffrey Modell Foundation communicates with all of its followers over all Social Media Outlets - through the Foundation's Facebook, Twitter, and Instagram platforms, patients, their families, and patient organizations participated in contests, interacted with each other, and today more than 145,000 "Likes" are on JMF's Facebook page, with more than 23 million views. During the Awareness Week, the average number of visitors per day to our posted media releases was more than 48 million.



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Below are a few images created for this special week:

### World PI Week is important because...

...it creates awareness that helps undiagnosed patients worldwide find closure...it helps these patients find treatments that give them a happier and healthier lifestyle...it gives our community the chance to tell health officials that PI is a top priority...it inspires innovative research...it provides hope...it unites families all around the globe...it reminds us that we can make a difference...and have fun doing it...it reminds us to never give up...it empowers us to stand up for what's important...it reminds us to appreciate each and every day...and to cherish each moment, working hard towards our goal...it could save lives...share this with the world...create awareness...and remind one another, that no matter where in the world you are, we are in this together.

JMF created specialized hashtags for World PI Week, asking our entire community to tweet these hashtags in an effort to create awareness and spread the #word



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People are connecting, sharing their stories and becoming friends!



Jeffrey Modell Foundation gets recognition for World PI Week in Times Square!



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### World PI Week Press Release

#### Jeffrey Modell Foundation to Host Events for World PI Week in 50 Countries



NEW YORK, April 22, 2014 /PRNewswire-USNewswire/ -- From April 22<sup>nd</sup> to April 29<sup>th</sup>, the Jeffrey Modell Foundation (JMF) and 75 locations across 50 countries, will join together to celebrate the annual World Primary Immunodeficiency Week (WPIW).

JMF will host their simultaneous balloon launch in New York City and around the world to represent their commitment to this global movement to raise awareness for Primary Immunodeficiency (PI). Each balloon symbolizes a newly diagnosed patient; a person that with the help of the Foundation and its colleagues, will experience a better quality of life, or even, life itself.

These defects of the immune system are thought to be rare. However, PI affects 10 million people worldwide.

"We have organized this Global Get-Together so that doctors, nurses, patients, families, friends, and staff will set free thousands of balloons to affirm, as one voice, our dedication, passion, and commitment to patients with PI. It is not only about awareness, but a worldwide Call to Action for both government and health officials to recognize PI as a top priority," says Co-Founder, Vicki Modell.

Event participants are spread across the globe in Africa, Asia, Australia, Europe, Eastern Europe, the Middle East, and right here in the United States. JMF unites these organizations not only through the balloon launch, but through their growing social media community.

Through the Foundation's Facebook, Twitter, and interactive events like this year's Photo Contest, patients, their families, and patient organizations are provided with the opportunity to get involved in this year's celebrations. Through these social media platforms, contests, and additional advocacy and awareness efforts, the Foundation has grown to over 137,000 members and continues to grow at a rapid pace with the goal of reaching as many countries as possible.

20 years ago, Co-Founders, Vicki and Fred Modell, sought out congress and lobbied for an awareness week for Primary Immunodeficiency. Their dedication to this cause resulted in the last week of April being declared World Primary Immunodeficiency Week.

"We could never have imagined the progression and growth of our community. Had you told me we would have 50 countries and 20 states join Vicki and I in this global movement, I would have never believed it," says Co-Founder, Fred Modell.

The Jeffrey Modell Foundation is dedicated to public awareness, physician education, and to bring Primary Immunodeficiency to the forefront of health officials concerns in each of these countries. This awareness week will continue to enhance these efforts and continue to change the quality of life for patients around the world.

#### 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:

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

Photo - <http://photos.prnewswire.com/prnh/20140417/76370>

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#### More by this Source

**jm** Why Newborn Screening has Economic Benefits  
Dec 16, 2013, 09:00 ET

**10** "He's a Kid" is not a Diagnosis, Could it be Primary Immunodeficiency?  
Dec 04, 2013, 09:00 ET

**jm** Global Polio Study Begins  
Nov 18, 2013, 09:00 ET

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Buenos Aires  
Argentina



Rosario  
Argentina



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Dublin  
Ireland



Hollywood  
Florida  
USA



Debrecen  
Hungary



Freiburg  
Germany



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Madrid  
Spain



Mexico City  
Mexico



Miami  
Florida  
USA



New Orleans  
Louisiana  
USA



Lima  
Peru



Prague  
Czech Republic



Timisoara  
Romania

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Milwaukee  
Wisconsin  
USA



Vienna  
Austria



Istanbul  
Turkey



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### Photo Contest

We asked all of our participating locations all around the world to send us their photographs from World PI Week. The JMF team will choose the best photo to win a \$1,000 grant to fund an awareness or educational event! That photo will be featured on our Facebook page! Second place winners will receive 25 JMF hats for their organization or friends and family! All the photographs are special, inspirational, and meaningful and will be a part of a slideshow to commemorate World PI Week 2014!

#### 1st Place

**Dr. Shereen Reda**  
 Ain Shams University  
 Cairo, Egypt



#### 2nd Place

**Dr. Anna Sediva**  
 University Hospital Motol  
 Prague, Czech Republic



#### 3rd Place Tie

**Dr. Ludmila Siziakina**  
 Rostov State Medical University  
 Rostov on-Don, Russia



**Dr. Elisabeth Foerster-Waldl**  
 Medical University of Vienna  
 Vienna, Austria



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



During World PI Week the Jeffrey Modell Foundation reached out to government officials, health professionals, schools, daycare 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!