

World PI Week ~ April 22 - 29, 2015



World Primary Immunodeficiency Week  
Update



## World PI Week ~ April 22 - 29, 2015

The Jeffrey Modell Foundation once again celebrated World Primary Immunodeficiency Week in April 2015. We have Jeffrey Modell Research and Diagnostic Centers in 79 countries that were invited to participate in World Primary Immunodeficiency Week. In 2015, 110 sites worldwide participated in the Jeffrey Modell Foundation "Global Balloons & Bubbles Launch", to celebrate World Primary Immunodeficiency Week. (24 states within the United States and 76 countries in Africa, Asia, Australia, Europe, Eastern Europe, Latin America and the Middle East). This year's Balloon Launch; with the help of our friends from all corners of the world, was our biggest, best, and strongest global movement in creating awareness of Primary Immunodeficiency. This truly has turned into a "Global PI Village".

As thousands of balloons were set free, around the world, all of us, as one strong voice, affirmed our dedication, passion and commitment to our mutual mission...to continue 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 patient...newly diagnosed, living with PI, or discovered through Newborn Screening.



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**Jeffrey Modell Foundation**

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April 22 · Edited · 🌐

On the first day of #WPIW, we want to start our week by honoring our Founder, Jeffrey Modell, for his courage, determination and strength. Because of him, 29 years later, we still continue to create Awareness, Education, and Advocate for all the lives he may not have met, but has touched around the world. Jeffrey inspires us to continue our mission of Hope, Advocacy and Action each and every day! #JMF

📍 Tag Photo   📍 Add Location   ✎ Edit

Unlike · Comment · Share

👍 Jeffrey Modell Foundation, Cindi Krisei, Grant Ginsberg, Rachel Bass and 131 others like this.

↻ 40 shares

- 

**Connie Fohl** You are awesome for doing what you do! We appreciate it!  
 Unlike · Reply · 👍 1 · April 23 at 5:18pm
- 

**Deb Gaudet Duxbury** Thank you Fred and Vicki for all you do  
 Unlike · Reply · 👍 1 · April 22 at 11:59pm
- 

**Lily Masey Leiva** And you, Fred and Vicki have done an amazing job with awareness about primary immunodeficiency diseases around the world  
 Unlike · Reply · 👍 2 · April 22 at 9:51pm
- 

**박정우** miss you, Jeffrey. you are always living peoples' heart as my son. ✕  
 Unlike · Reply · 👍 2 · April 22 at 8:22pm
- 

**Tamara Staines Boone** Hermosa Sonrisa inspiración para el mundo ...  
 Unlike · Reply · 👍 1 · April 22 at 4:40pm
- 

**Claudia Moreno García** Gracias Jeffrey!!! El amor y compromiso que tus Padres siguen dando por todo el mundo, es en tu honor! Dios los bendiga siempre!!! México.  
 Unlike · Reply · 👍 3 · April 22 at 8:50am

- 

**Jamie Sharp** Look at that precious boy and his big, beautiful smile!!  
 Unlike · Reply · 👍 2 · April 22 at 8:27am
  - 

**Nickie McCloskey** What an adorable smile. It is amazing how the love of a child can inspire so much.  
 Unlike · Reply · 👍 2 · April 22 at 7:59am
  - 

**Rachel Simoneau** I'm with you JMF and Jeffrey! #WPIW #JMF  
 Unlike · Reply · 👍 1 · April 22 at 6:51am
- Write a comment... 📷 😊





## World PI Week ~ April 22 - 29, 2015

### SOCIAL MEDIA REPORT:



Follow us  
**@info4pi**

The Jeffrey Modell Foundation communicates with all its followers over all Social Media Outlets - through the Foundation's Facebook, Twitter and Instagram platforms. This year, patients, their families, and patient organizations participated in contests, interacted with each other, made new friends, and helped us "Burst the Bubble" on PI - creating greater awareness than ever! Today, we have more than 158,000 "likes" on JMF's Facebook page, 245 followers on Instagram and 814 tweeting with us!

**WPIW**

Where are you celebrating around the world?

**jm** Jeffrey Modell Foundation  
Curing PI. Worldwide.

Alabama, USA

Mississippi, USA

Illinois, USA

Missouri, USA

Belgium

Iceland

Sweden

New York, USA

Connecticut, USA

Uganda

Rio de Janeiro, Brazil

PINSA, South Africa

Israel



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

"In five words or less, tell us what #WPIW means to you! We will take all of your words, and put them into a word cloud at the end of the week. We look forward to hearing from you. #JMF #PIAwareness #Global"

This is the representation of all of their words. We are moved by the voice they have given the PI Community.





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**Global Balloon Launch:**





# World PI Week ~ April 22 - 29, 2015



Leuven, Belgium



Shanghai



Palestine



Ukraine



Iceland





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The Painted Turtle, California



Slovenia



**Meeting of Patients with Primary Immunodeficiencies**  
**Balloons and Bubbles**  
Seč, Czech Republic  
25.-26.4.2015  
Department of Immunology, Motol University Hospital, 2nd Medical Faculty, Charles University, Prague  
Interest group for Primary Immunodeficiencies, Czech Society for Allergy and Clinical Immunology  
Jeffrey Modell Foundation Center for Primary Immunodeficiencies, Prague, Czech Republic  
**jmcn** Jeffrey Modell Center for National  
World PI Week  
Your Chicago, Friend



Czech Republic

Biotest, New Jersey





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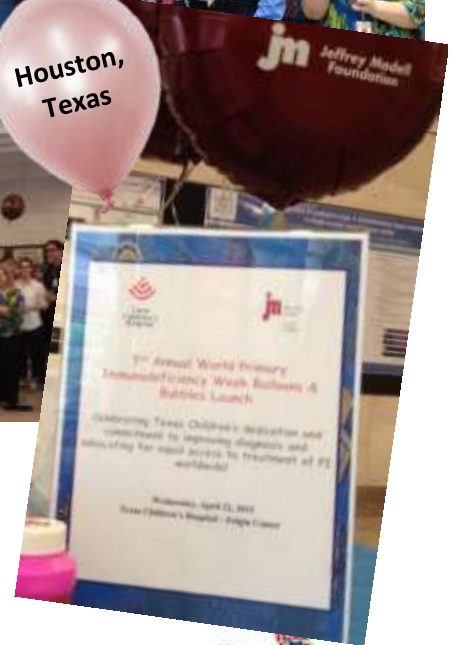


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**Vienna, Austria**



**Bosnia & Herzegovina**



**BRAGID, Brazil**



**Fortaleza, Brazil**



**Corinthian, Texas**



**Campinas, Brazil**





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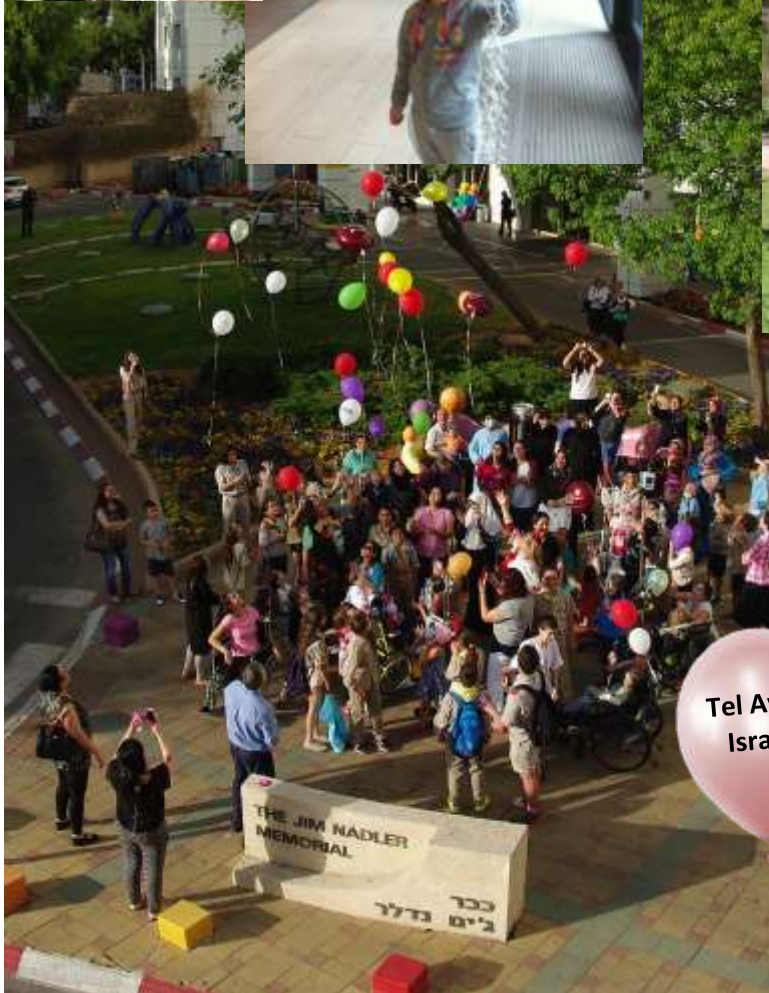
Vilnius,  
Lithuania



Ghent,  
Belgium



France



Tel Aviv,  
Israel





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Mexico City, Mexico



Staten Island, New York



Sydney, Australia



Washington DC



Chicago, Illinois



Sofia, Bulgaria

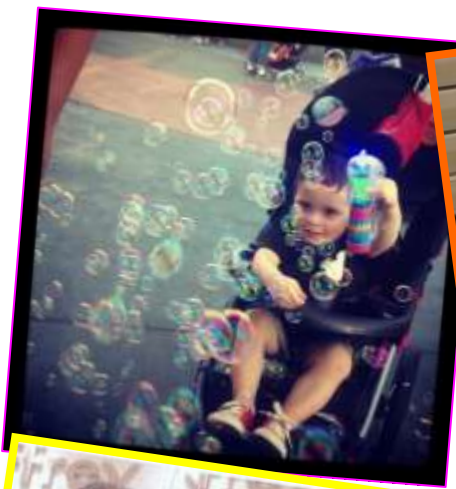




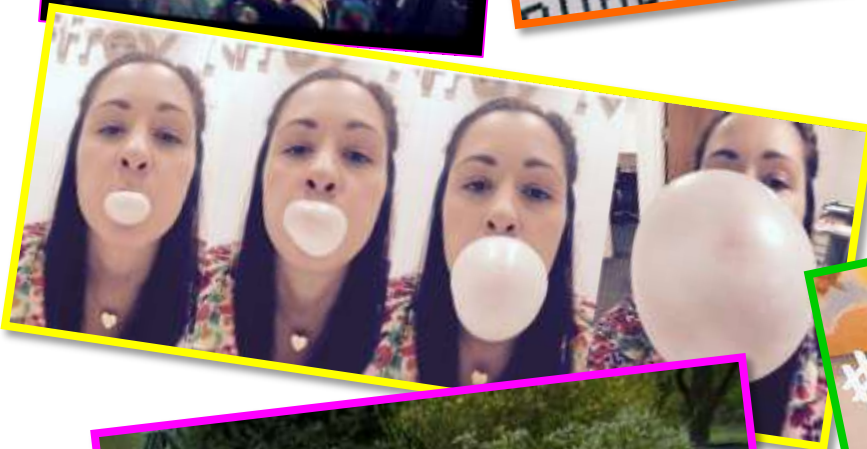
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This year JMF wants to \*Pop\*, \*Explode\*, and “Burst the Bubble” About Primary Immunodeficiency!



I'm joining the Jeffrey Modell Foundation to help “Burst the Bubble” about PI! Learn the 10 Warning Signs of Primary Immunodeficiency and much more by visiting [www.INFO4PI.org](http://www.INFO4PI.org)! #JMF



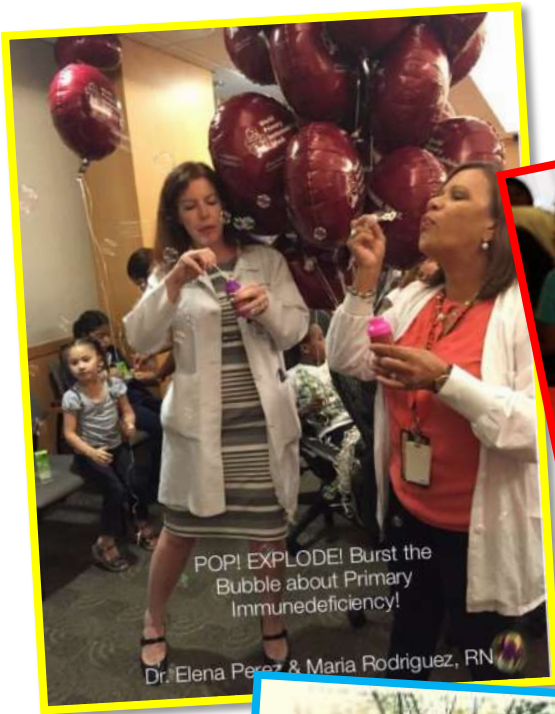


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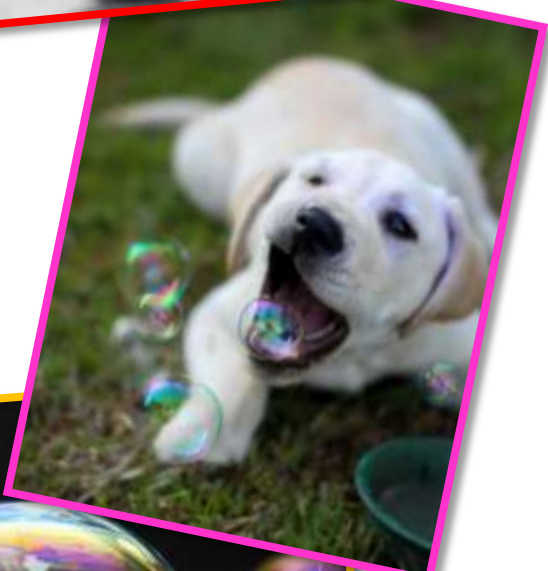
Jeffrey Modell  
Foundation

Curing PI. Worldwide.

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Don't forget to take a picture of you  
"Bursting the Bubble" about PI!







Jeffrey Modell  
Foundation

Curing PI. Worldwide.

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You are cordially invited to attend

# JMF's WPIW Virtual Party!!

Join us as we celebrate  
**World PI Week!**  
April 22 — April 29, 2015

Together we can further spread awareness and  
education about Primary Immunodeficiency  
and our amazing community!





## World PI Week ~ April 22 - 29, 2015

Below are a few images created for this special week:



**wpiw**



**Together We Will  
Raise Awareness!**



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**Test.**

**Diagnose.**

**Treat.**





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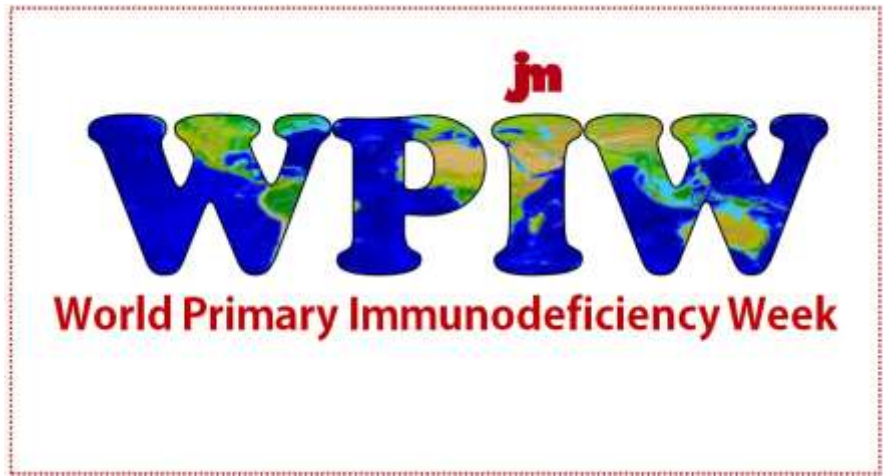
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**·WPIW·WPIW·WPIW·WPIW·WPIW·**





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## World PI Week ~ April 22 - 29, 2015

Jeffrey Modell Foundation Advertising in Times Square - Donated Space for WPIW:





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FlashBack Friday on Social Media:

[#FBF](#) - 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 declaring Primary Immunodeficiency Awareness Week. The goal and mission was earliest possible diagnosis and access to appropriate treatment.

[#JMF](#) [#WPIW](#) [#Historic](#) [#FlashBackFriday](#)

**Congressional Record**  
 PROCEEDINGS AND DEBATES OF THE 103<sup>rd</sup> CONGRESS, SECOND SESSION  
 Vol. 140

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

United States of America

**U.S. HOUSE OF REPRESENTATIVES**

Washington, DC 20510

**United States Senate**

WASHINGTON, DC 20510

Whereas early intervention and treatment can save lives and prevent permanent damage to lungs and other organs; and whereas many forms of treatment are available once a specific diagnosis is made, procedures such as BMT may result in cure, and other treatments like monthly infusions of gamma globulin dramatically reduce a patient's risk of infection and enable him or her to lead a normal life; and whereas patients may have long periods of normal health then be struck by severe fevers and infections; and whereas public awareness can lead to a better diagnosis, isolated and confused; and whereas education is essential to make the general public aware of this condition;

Dear Colleague:

Primary Immune Deficiency is a congenital defect in the immune system which affects over 500,000 people in this country. It can cause permanent damage to lungs and other organs. In order to increase public awareness of this condition, I hope you will join with me and Senators Dodd, Cohen and D'Amato in supporting legislation to designate the week of April 18, 1993 as Primary Immune Deficiency Awareness Week.

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

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 that a diagnosis can be made, treatment begun, and support provided for the families suffering this debilitating condition.

**Primary Immune Deficiency Awareness Week**

0414.

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.

**The Jeffrey Modell Foundation**

Whereas primary immune deficiency is a congenital defect in the immune system such that the body cannot adequately defend itself from infection; and whereas primary immune deficiency is most often diagnosed in children and affects more children than leukemia and lymphoma combined; and whereas primary immune deficiency is hereditary; and whereas there are currently considered to be 22 forms of primary immune deficiency;

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Our Final Social Media Post for WPIW - April 29, 2015

On the last day of WPIW, we thank everyone around the world for participating in such an extraordinary week of awareness and education...and a little fun too launching our balloons and "bursting the bubble".

We are so thankful for all of you and your dedication to make life better for all PI patients worldwide!!!

[#JMF](#) [#Thankful](#) [#Community](#) [#GlobalPIAwareness](#)

