# **World Psoriasis Day 2010**

## **General summary**





#### **World Psoriasis Day**

#### What is World Psoriasis Day?

World Psoriasis Day, October 29, is an annual day specially dedicated to people with psoriasis and/or psoriatic arthritis.

Conceived by patients for patients, World Psoriasis Day is a truly global event that sets out to give an international voice to the more than 125 million people with psoriasis/psoriatic arthritis around the world.

In 2004 members and non-members of psoriasis associations around the world launched World Psoriasis Day to raise awareness of psoriasis and psoriatic arthritis. MerckSerono was the founding sponsor of this day.

#### **Aims and Objectives**

- Raise awareness about psoriasis.
- Encourage healthcare decision makers to give psoriasis suffers better access to the most appropriate therapies for their condition.
- Deliver relevant information and knowledge to interested parties.
- Provide a patient voice platform.

#### **Key Communication Messages**

- · Psoriasis and psoriatic arthritis are serious and chronic, non-communicable and disabling diseases
- People with psoriasis should have access to appropriate treatments
- We are more than 125 million people with psoriasis and we want to be heard
- Psoriasis is not contagious, stop stigmatization and discrimination

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### **Concept of World Psoriasis Day 2010**

#### WPD Theme 2010

Childhood psoriasis: a challenge for all

#### **Key Communication Messages**

- Psoriasis affects all ages
- Childhood psoriasis is a big challenge for the whole family
- Appropriate treatment for children with psoriasis is important
- Claim your rights for a





Activities 2010 – "Childhood psoriasis - a challenge for all"
On the theme for 2010: "Childhood psoriasis – a challenge for all" a new campaign with activities both on a national and global level were introduced. The purpose was to involve as many children as possible from all over the world to participate in this activity and competition.
Global drawing contest for children and the WPD Teddy bear campaign
Introduction of a new symbol/mascot: the WPD Teddy bear with psoriasis and an International Drawing Competition for Children were launched for World Psoriasis Day 2010.
The MDD To delections
The WPD Teddy bear
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#### WPD Teddy bear campaign - Objectives

- Get children with psoriasis (or with a relative or friend with psoriasis) from all over the globe involved and interactive in an activity that is tailored for them.
- Strengthen the national psoriasis associations in their activities for children by offering the kids to participate in a global contest. Hopefully create new relations between children and the association.
- Create awareness about Childhood psoriasis and WPD in the medical profession by doing this event that appeal to emotions at the EADV Congress. (The European Academy of Dermatology and Venerology)
- Create an activity that is directed to all target groups: to children, to parents, to the general public, to the medical profession and to the pharmaceutical industry.
- Create a cost efficient activity that can be conducted in all countries at a low cost and that also be taken to a global level with a strong effect and attention

#### WPD Teddy bear campaign - Communication Messages

- Empowering story
- Give hope
- · Happy ending
- · You can do anything
- Information is solving many problems
- Everybody is welcome to join!

#### **Emotional benefits with the WPD Teddy bear**

- A teddy bear moves everyone emotionally just by the way it looks
- The teddy bear has been the best friend of humans from all over the world for centuries
- It is someone you always can rely on

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- Communicates a feeling of coziness and feeling secure
- Communicates and appeals to kids in all ages as well as to adults
- A nice friend to identify with and relate to
- Makes the tough situation to have psoriasis and to talk about psoriasis a bit softer and more
- Even a sweet teddy bear can have psoriasis and he is still sweet and cuddly
- It is a new idea that appeals to a large audience/general public
- It creates a feeling
- Psoriasis can happen to everybody even to a teddy bear
- If the teddy bear can cope with it so can I
- It can make a difference for kids with psoriasis from any country

#### **Step 1 National level**

IFPA encouraged all national psoriasis associations to launch and kick off the contest in their own country. Children of all ages were asked to send in a drawing in a specific format (A4) to a national drawing contest.

The drawing should include 3 items:

- 1. Psoriasis
- 2. Teddy bear
- 3. A feeling (shall be reflected by the drawing)

Either be a teddy bear with psoriasis or a teddy bear in relation to psoriasis with the picture reflecting a feeling of any choice, such as: happy, sad, angry, powerful, hopeful, and so on.

The children were asked to send in the drawings to the national psoriasis association who then selected a national winner to compete in the global contest.

The winning drawing from each competing country was then sent on to the IFPA Secretariat to compete in the global contest. Together with the drawing was a short presentation of the young artist with name, age and photo.

#### Step 2 Global level

All the drawings were collected and prepared for an art exhibition at the EADV Congress. Twenty-one





drawings were sent in from all over the world. The drawings were numbered and a voting procedure took place among the delegates of the EADV Congress.	
The World Begins Boy. Obildren's Art subibition at EABY Commerce	
The World Psoriasis Day – Children's Art exhibition at EADV Congress	
The art exhibition took place in the IFPA Booth at the EADV Congress, October 6-10, in Gothenburg and the more than 8 000 delegates /TT2 g/TT2 g0ee teeesleges ee0e s, October 5.955 59TQD 7014.955 596735.4751 Tm()6g/	TT3 1
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World Psoriasis Day IFPA Secretariat, Box 5173, SE-121 18 Johanneshov, Sweden	

To be the most effective advocate for the psoriasis community we need to present facts and relevant information.
We also need to encourage healthcare decision makers, for example governments, physicians and all those responsible for psoriasis care/ medicines, to allow psoriasis sufferers access to the most appropriate therapies.
The WHO Strategy – the global campaign
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through contact with WHO national, regional and headquarter representatives and mobilizing psoriasis stakeholders in a global WHO/World Psoriasis Day campaign.
The WHO approach – a brief of the global political WPD activity
On World Psoriasis Day, Oct 29 2009, IFPA delivered an inclusive packet of information about psoriasis to the WHO Noncomm-35(t)/60a737(O)-41941(e)-47(o(r)-27(i)-47ei)-47(v)-36(i)thopoliaretwap
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World Psoriasis Day

Unfortunately, the arrangement of the round table meeting has not been possible within the set timeline for IFPAs promised reply to WHO. The draft proposal and related documents have instead been distributed by email to the leadership representatives of the organisations in the psoriasis and psoriatic arthritis field, to give the experts and key persons from the leading organisations the opportunity to view and comment the draft proposal. IFPAs intention herewith was to present a consolidated view of the proposal, reflecting aspects representing the broad spectra of the global psoriasis movement.

IFPA EC asked the representatives of the organisations to send the consolidated comments, advice and eventual amendments on the draft proposal to the IFPA Secretariat. The organisations were also encouraged to support IFPA in this activity by sending a supportive letter from their organisations of the IFPA action and the proposal of collaboration between IFPA and WHO. The signed letters of support from all the organisations was then to be enclosed in the final consolidated reply and proposal from IFPA to WHO.

It is with great honour and appreciation that IFPA EC have received exclusively encouragement and support from all the partner organisations that have been approached for review of the proposal.

The International League of Dermatological Societies (ILDS), European Academy of Dermatology and Venereology (EADV), American Academy of Dermatology (AAD), International Psoriasis Council (IPC), Group for Research and Assessment of Psoriasis and Psoriatic Arthritis (GRAPPA), Sociedad Latinoamericana de Psoriasis (SOLAPSO) and Psoriasis International Network have given their unanimous endorsement and ensured their willingness to lend IFPA their expertise.

IFPA are proud of the statements of support provided by IFPAs professional partner organisations who all are respected and established international and regional associations and societies within the scientific medical profession and research area of dermatology and rheumatology, all with special dedication and expertise in the psoriasis and psoriatic arthritis environment. The supportive statements as well as the proposal of collaboration between IFPA and WHO and related documents will in the near future be published on the IFPA website were you also will be able to follow the progress of this activity.

IFPA EC wants to direct a special thank you to all the partner organisations that have given IFPA their important support in this activity for psoriasis recognition.

The consolidated reply to WHO including the proposal and supportive statements was sent to WHO in the end of February 2010.

In October 2010, Dr. Shanthi Mendis, WHO Coordinator for Chronic Disease Prevention and Management, suggested that one possible way that IFPA and WHO could collaborate is by means of a psoriasis patient "self-care" program, which could be initiated in the Spring of 2011.







#### **Activities**

#### Awareness raising activities

Psoriasis is a systemic disease with huge impact on people's lives.

It is important to let people with psoriasis know that they are not alone and raise the profile of this devastating disease and the misery it can cause. World Psoriasis Day should provide a platform from which the 'patient voice' can be heard and from which people with psoriasis can be encouraged to speak out about their needs and wants.

World Psoriasis Day should aim to provide information and knowledge to those who are affected by psoriasis/psoriatic arthritis as well as the general public, in order that people can be better informed about the condition, develop a better understanding, enabling them to be more confident to speak about it.

The goal is to dispel myths about the condition, such as the mistaken view that psoriasis is contagious. Awareness raising activities to educate and give information about psoriasis and psoriatic arthritis are of enormous importance for all groups in the society.

Target groups

- Politicians
- Public
- Health care professionals
- Psoriasis community

#### **National WPD activities 2010**

For World Psoriasis Day 2010 a wide variety of activities took place, everything from seminars to meetings with politicians and decision makers. Every year the interest and the success of World Psoriasis Day increases and we are proud to present some example of all the awareness raising national activities that have been taking place all over the world. This year the International Drawing Competition for Children raised a lot of interest, both nationally and globally. Please see the document "Summary of national activities World Psoriasis Day 2010" for detailed information.

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#### **Examples of national activities WPD 2010**

**ARGENTINA** Distribution of 100 000 postcards and 5 000 posters to schools in Buenos Aires.

**BELGIUM** All primary schools in Flanders informed about psoriasis; new brochure "1001 questions about psoriasis".

BRAZIL Urban actions, seminars, conferences.

**CANADA** Psoriasis patient meetings, advertisements.

**COLOMBIA** Urban actions, seminars, activities for children at hospitals.

**CROATIA** "Open day" for psoriasis patients at hospital with information and discussions.

**ECUADOR** Launch of educational video, release of book on psoriasis.

EL SALVADOR Educational video, seminars.

ESTONIA Information and schooling day.

FINLAND Posters on buses and billboards on trams.

**FRANCE** Illustrated short story "The Red Scarf", seventeen conferences in hospitals, shopping malls, etc.

**GEORGIA** Free consultations for patients with psoriasis in three different regions of Georgia.

**GERMANY** Youth camp for young psoriatics. Twenty-five regional events all over Germany.

**INDONESIA** Meeting with national WHO office, creation and distribution of flyer on WPD 2010 theme.

JAPAN Gatherings in ten different cities.

**KENYA** PAK members participated in the Nairobi International Marathon. Lectures and seminars.

**LEBANON** Meeting for psoriatics and medical professionals with the theme "WE HOPE".

**MEXICO** 7th National Congress for psoriasis patients and families.

**NETHERLANDS** Glossy magazine about psoriasis.

**NORWAY** Photo project on youths with psoriasis, exhibition at Oslo Central Station.

**PANAMA** 5<sup>th</sup> Psoriasis Informative Conference, urban actions.

**POLAND** Conference with the theme "A decent life with psoriasis".

**PORTUGAL** Video with testimonies from public figures who suffer from psoriasis.

**PHILIPPINES** PsorPhil's Caravan of Hope; Hug-me campaign with celebrities.

**SINGAPORE** WPD 2010 road show with the theme "Will you hold my hand.

**SOUTH AFRICA** Inserts into newspapers, circus event.

**SPAIN** Conferences on the theme "Towards new horizons" were held in nine different cities.

**SWEDEN** WPD Conference in Stockholm for health care professionals.

**SWITZERLAND** New brochure in French and German about psoriasis, possible treatments and helpful tips.

**TANZANI A** Appointment with Commissioner of Social welfare to inform about psoriasis.

**UKRAINE** Flyers, calendars and booklets on psoriasis handed out in the town squares of the major cities.

**USA** National media release on results of bullying survey secured a total of 200 media hits.

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# Media The media activities on World Psoriasis Day were full of variety and all over the world huge efforts were made to gain attention and raise awareness about psoriasis, and especially the WPD 2010 theme of childhood psoriasis, and to promote World Psoriasis Day. World Psoriasis Day is presented by IFPA, and supported by A Prorise for Life Schering-Plough

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#### WPD 2010 Theme and teddy bear campaign, examples



#### From the left hand corner:

Postcard from Sweden, ad from Panama, boy with WPD Teddy bear t-shirt in Argentina, press conference in Ukraine, handing out flyers in Indonesia, celebrating WPD in Brasil.





#### **WPD** Website

World Psoriasis Day official website www.worldpsoriasisday.com

The WPD website works as an important channel to promote and spread information globally about psoriasis and World Psoriasis day. On the website you can do also find presentations of the national activities in the participating counties.

#### **External communication channels**

- Facebook
- Youtube
- Blogging

By using Facebook, YouTube or other social networks we could reach thousands of individuals in a short span of time to a minimal cost.





Facebook
<ul><li>www.facebook.com</li><li>World Psoriasis Day have a group on Facebook. The purpose of the group is to raise awareness about psoriasis and World Psoriasis Day.</li></ul>
Youtube
www.youtube.com On Youtube a lot of the videos from national WPD events can be found. There are also many other videos about psoriasis and psoriatic arthritis. The large coverage and the popularity among young people is an advantage with this social media.
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World Psoriasis Day

Blogging
Blogging is one of the new ways to communicate. This is a quick way for people to express their views and start debates. Blogs are often read by many and is considered to have large coverage. Blogging is a more personal way of drawing attention to World Psoriasis Day and how it is to live with psoriasis.
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#### PRESS RELEASE - October 29th, 2010

#### Childhood psoriasis - a challenge for all!

October 29 is **World Psoriasis Day**. Conceived by patients for patients, World Psoriasis Day is a truly global event focusing on the burden of living with psoriasis. There are more than 125 million people with psoriasis/psoriatic arthritis in the world. Many are children. Psoriasis is a severe chronic inflammatory disease that effects all ages, genders, races and ethnicities.

The theme of World Psoriasis Day 2010 is: Childhood psoriasis - a challenge for all

"Childhood psoriasis is difficult in many ways and affects the whole family. Treatment options are much fewer than for adults. Getting a child with severe psoriasis in the family, who needs constant care, is a concern for all; parents, siblings, relatives and friends. In preschool and primary school relationships with class mates will be very important, sometimes including the risk of bullying and discrimination. This is why awareness raising about the disease must be prioritized and repeated again and again, since new generations are coming and growing up all the time." Lars Ettarp, President of IFPA says.

Encouraging all children in the world to join, IFPA arranged the World Psoriasis Day International Drawing Competition for Children. The drawing competition which took place both a national and global level was launched together with the new mascot for World Psoriasis Day; the World Psoriasis Day Teddy Bear called Ted, who suffers from psoriasis.

The IFPA Member associations asked children in all ages to send in a drawing to a national drawing contest. The drawing should feature 3 things: Psoriasis, a Teddy bear and a feeling (to be reflected in the drawing.) The national Psoriasis association selected a drawing as national winner to be competing for the country in the global contest. The winning drawing from each competing country was sent to the IFPA Secretariat to compete on a global level. A short presentation of the young artist and a description of the drawing in the artist's own words were also enclosed.

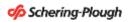
At the EADV Congress in Gothenburg Oct 7-10, the winning drawings from all over the world were presented as an Art Gallery in the IFPA Booth in the exhibition. The almost 8 000 delegates of the EADV Congress; professors, doctors and scientists from all over the world, were invited to vote for the global winner.

We are today, at World Psoriasis Day 2010, happy to announce and warmly congratulate the winner.

Congratulations Faya Priem, from the Netherlands

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Faya is six years old and she has had psoriasis since she was three years old. She says: Sometimes it is worse; sometimes it gets a bit better. Sometimes it gives her big problems.

Faya wrote a poem on her drawing:

'Hello Sun, Hello Sea, Please, take the spots away from me....'

The word on the sailing boat means: 'itching'

Please visit <a href="https://www.worldpsoriasisday.com">www.worldpsoriasisday.com</a> for more information and to see the winning drawing and the finalists. The story of our WPD Teddy bear and his psoriasis, teddy postcard and illustrations can also be downloaded there.

Happy World Psoriasis Day!

#### For more information, please contact:

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#### World Psoriasis Day

Since 2003 October 29 is the World Psoriasis Day. Its primary purpose is to act as a focus for people - patients, doctors, nurses and the general public - to raise awareness of psoriasis and psoriatic arthritis and to give people with psoriasis and/or psoriatic arthritis the attention and consideration they deserve. World Psoriasis Day is also a channel to encourage health authorities to offer better access to the most appropriate treatments. Read more at <a href="https://www.worldpsoriasisday.com">www.worldpsoriasisday.com</a>

#### IFPA

The International Federation of Psoriasis Associations (IFPA) is a nonprofit organization made up of psoriasis associations from around the world, representing more than 125 million people who suffer with psoriasis and/or psoriatic arthritis.

More information about IFPA: www.ifpa-pso.org

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