



International Alliance of  
Patients' Organizations

A global voice for patients



# Patient Solidarity Day 2014: a review

# Background

Patient Solidarity Day was started by the Morris Moses Foundation in Kenya, in 2011. The initiative was aligned with IAPO's vision and mission: to ensure that patients throughout the world are at the centre of healthcare. IAPO members in the African region felt the importance of engaging, and therefore in 2012, several celebrated the day. 2013 saw a dramatic increase in solidarity and activities, with 17 members across 10 countries holding a diverse range of activities to show their support.

Building on previous successes, on 6 December 2014, IAPO launched Patient Solidarity Day as a global campaign, encouraging members, supporters, and like-minded organizations to endorse one key message: the need for universal health coverage.

## One voice. United. Universal.

Following the launch of IAPO's **Universal Health Coverage principles** at the Global Patients' Congress in 2014, the theme for Patient Solidarity Day was created with the aim of promoting and raising awareness of the need for all people to have access to equitable, high quality and affordable healthcare, which is centred on the patient.

When participating in the campaign, we asked supporters to endorse our message:

**“High quality, equitable and affordable healthcare; nothing more than a dream for so many people around the world. This needs to change. We have all been a patient at some point in our lives, or cared for one. It's time to stand together in solidarity to call for truly patient-centred healthcare.**

**Every person, every patient is equal and all have the right to access healthcare that they need, when they need it. We have to unite to ensure that all people, across the world, have fair and impartial access to quality healthcare.”**







## Tools and resources

To help members engage with the day, we developed a range of capacity building resources, all of which were made available, free of charge, on the **Patient Solidarity Day website**. These included, in both English and Spanish:

- A flyer for the public to increase awareness of the campaign issues
- A toolkit for members, with activity suggestions, and guidance on how to campaign
- Logos for use in campaigning, websites, social media (see below)
- Example letters for members to alter to send to external stakeholders, such as their Ministries of Health



## Member involvement

An estimated 80 organizations from 32 countries supported the day, with over 50 officially endorsing the campaign on IAPO's **Supporters Wall**, and publicity on over 20 websites. The WHO African Regional Office officially supported the day, and the WHO Euro office recognised its importance.

Although IAPO provided the theme, capacity building resources, and the principles of Universal Health Coverage, the real impact was that our members took ownership of Patient Solidarity Day, and adapted the campaign to their own needs and circumstances. Because of this, members held a diversity of activities to show their support.

A new way of showing support through the 'gesture' of holding hands was launched: photos of supporters holding hands were uploaded onto social media sites, a symbol to show solidarity and unity.

# Member activities

- Public awareness raising: flyers, posters, and t-shirts, marches, public rallies, and walkathons
- Meetings with Ministries of Health and healthcare professionals, and deliveries of letters and petitions to government, calling for patient-centred healthcare
- Health and community engagement workshops, offering opportunities for patients to speak
- Free health screenings
- Hospitals and care centre visits, including handing out toys and food at a children's hospital
- Press conferences
- A poster competition at a school to engage youth audiences

See examples of specific activities and pictures below.

## Evaluation and the future

Members who responded to an evaluation survey felt that the day was a positive endeavour, which successfully achieved its objectives by:

- Raising awareness and community engagement
- Communicating a strong, united patient voice
- Building cross-sector alliances

Based on your feedback, we plan to make Patient Solidarity Day even better in 2015, with a range of tools, more engagement with decision-makers, and a strong online and media presence.

Thank you for all of your support and we look forward to 2015!





# Member activities

An estimated 80 organizations from 32 countries all across the world supported Patient Solidarity Day. See a few specific examples below.



## Latin America

Asociación Procrece Guatemala attended a conference with a Minister of Health representative, in conjunction with the Heroes of Hope Association. As a result, the Minister requested that more patient organizations are engaged and integrated, and recommended an alliance be created in order to have a stronger, united voice with the authorities.

Psoriasis Chile reported a successful dissemination of information through the use of street banners and flyers to raise awareness of PSD amongst the general public. The organization also made visits

to health authorities and publicly distributed information about IAPO, the need for Patient Solidarity Day, and its key messages on public media in the country.

Corporación del Trasplante in Chile effectively raised awareness of the campaign through the distribution of information on stickers, flyers and social media. They also met with the head of Histo-compatibility, a representative from the National Drug Agency, and the Institute of Public Health to raise the importance of the issue of patient-centred healthcare.

## Africa

The Patients' Alliance of Ghana in Engagement published a statement highlighting the serious threats of Ebola in West Africa and the recent cholera outbreak in Ghana affecting many communities. The organization helped highlight the necessity to uptake proper hygiene practices in order to minimise risk of exposure to these diseases. Also, health workers were reminded that the patients' involvement is an essential part of healthcare.



In Uganda, the National Organisation for People Living with Hepatitis B offered education and free screenings for Hepatitis B. Additionally, they joined with other organizations under the umbrella name of the Uganda Alliance of Patients' Organisations to highlight and promote Patient Solidarity Day. Key partners such as WHO, Ministry of Health and patients engaged in this event.

The Uganda National Health Consumers Organisation also joined alliances with other organizations under the Uganda Alliance of Patients' Organisations. They offered health screenings for communicable and non-communicable diseases to the general public and donated various medical supplies including 'mama kits' for pregnant mothers.



## India

In India, the Blood Patients Protection Council held a rally in which the parents of patients participated to raise awareness about blood disorder conditions. They also hosted a function to celebrate the life and death of a supporter of the organization,

who suffered from a rare blood disorder. The organization was able to raise demands at separate haematology and oncology departments at Medical College Hospital in Calicut.



The Association of Community Pharmacists in India organised a 'walkathon' to raise awareness of HIV/AIDS, and in support of those affected by the condition. Staff, students and patients joined together in a meeting where patients were able to discuss their day-to-day problems and concerns about being HIV positive. Thanks to this safe forum, some patients stated that they felt able to overcome the stigma that is attached to the disease.



# Día de la Solidaridad con el Paciente

Una voz. Unida. Universal.



ASOCIACIÓN PERUANA  
VIDAS SIN CÁNCER





# List of organizations who supported PSD 2014

1. Accion Psoriasis (Spain) IAPO member
2. Action for Humane Hospitals (Cameroon) IAPO member
3. Africa Psoriasis Organization (Kenya) IAPO member
4. Alzheimer's Bangladesh (Bangladesh)
5. Alzheimer's Disease International (International) IAPO member
6. Alzheimer's Ghana (Ghana) IAPO member
7. Alzheimer's Pakistan (Pakistan) IAPO member
8. American Chronic Pain Association (USA) IAPO member
9. Asociación Argentina Lucha contra la Enfermedad Fibroquística del Páncreas (FIPAN) IAPO member
10. Asociación Civil Para El Enfermismo De Psoriasis (AEPSo) (Argentina) IAPO member
11. Asociación Guatemalteca de Pacientes con Enfermedades Autoinmunes Reumáticas (ARTRILUP) (Guatemala) IAPO member
12. AS - Center for the Empowerment Youth of people who are living with HIV and AIDS (Serbia)
13. Asociación de Talasemia Argentina (Argentina) IAPO member
14. Asociación Peruana Vidas Sin Cáncer (Peru) IAPO member
15. Asociación Procrece (Guatemala) IAPO member
16. Asociación Salvadoreña para la Prevención del Cáncer: Luz de Esperanza (El Salvador) IAPO member
17. Asociación Venezolana para la Hemofilia (AVH) (Venezuela) IAPO member
18. Association of Community Pharmacists of India (India) IAPO member
19. Associazione Italiana Endometriosis (Italy) IAPO member
20. Blood Patients Protection Council (India)
21. Cáncer Vida Fundación (Peru) IAPO member
22. CHEN Patient Fertility Association (Israel) IAPO member
23. Cherchen Yaich Trabajar para Escuchar (Argentina) IAPO member
24. Concebir (Grupo de apoyo para personas con trastornos en la reproducción) (Argentina) IAPO member
25. Consumer Health Forum of Australia (Australia) IAPO member
26. Consumer Online Foundation (India) IAPO member
27. Corporación del Trasplante (Chile) IAPO member
28. Corporación de psoriasis de Chile (CORPSO) (Chile) IAPO member
29. Dhakshama Health and Education (India) IAPO member
30. Esperanza Asociación (Peru) IAPO member
31. European Lung Foundation (Europe) IAPO member
32. European Patients Forum (EPF) (Europe)
33. Federación de Hemofilia de la República Mexicana (México) IAPO member
34. Fibromyalgia Awareness (India)
35. Fundación Metamorfosis (Guatemala) IAPO member
36. Fundación Comunicología- Bienestar Juntos (Chile)
37. Fundación de apoyo al paciente con psoriasis (FUNDAPSO) IAPO member
38. Fundación Psoriasis de Panamá (Panama) IAPO member
39. Fundación Red de Apoyo Social de Antioquia (RASA) (Colombia) IAPO member
40. Fundación SIMMON (Colombia) IAPO member
41. GIST Foundation Chile (Chile) IAPO member
42. Global Colon Cancer Alliance (International) IAPO member
43. Hecho Con Amor (Peru) IAPO member
44. Hong Kong Alliance of Patients Organisations (KHPO) (Hong Kong) IAPO member
45. International Bipolar Federation (international) IAPO member
46. International Diabetes Federation (international) IAPO member
47. International Patient Organisation for Primary Immunodeficiencies (IPOPI) IAPO member
48. Irish Patients Alliance (Ireland) IAPO member
49. Jahandad Society for Community Development (Pakistan) IAPO member
50. LiveWell Foundation (Nigeria) IAPO member
51. Lupus Europe (Europe) IAPO member
52. Luz de Esperanza: Asociación de personas oncológicas con esperanza de vida (Peru) IAPO member
53. Morris Moses Foundation (Kenya)
54. National Organization for People Living with Hepatitis B (Uganda) IAPO member
55. Osaka City Universal Hospital Cancer Patient Support Club (GINNAN) (Japan) IAPO member
56. PARADIGMA XXI (Argentina)
57. Patients Alliance of Ghana in Engagements (PAGE) (Ghana)
58. Patients Safety Foundation (Poland) IAPO member



59. Pro Salutem (European Society for Health Promotion) (Poland) IAPO member
60. Red Latinamericano de psoriasis (LATINAPSO) (Latin American) IAPO member
61. Red Peruana de Pacientes y Usuarios (Peru) IAPO member
62. Regional Society for Blood Transfusion Kenya (Kenya) IAPO member
63. Respiratory Decade (International)
64. Safe Medicines India (India)
65. Salud Derechos Y Justicia A.C (Mexico) IAPO member
66. Students' Scientific Society (Egypt)
67. Tamiz Neonatal y Fenilcetonuria (Mexico) IAPO member
68. Thalassemia Society of Pakistan (Pakistan) IAPO member
69. The American Chronic Pain Association (USA) IAPO member
70. The European Federation of Crohn's and Ulcerative Colitis Associations (Europe) IAPO member
71. The Liver Foundation (UK)
72. The NCD Alliance (International)
73. The Thalassemia International Federation (TIF) (International) IAPO member
74. The World Confederation for Physical Therapy (International)
75. The World Health Organization (Africa and Europe regional offices)
76. The World Self-Medication Industry (International)
77. Ugandan Alliance of Patients' Organizations (UAPO) (Uganda) IAPO member
78. Uganda National Health Consumers Organisation (Uganda) IAPO member
79. Uniao sad associacoes de portadores de psorise do Brasil (UNAPSO) (Brazil) IAPO member
80. World Hospice Palliative Care Alliance (International)

## List of known media coverage of PSD 2014

1. The European Federation of Crohn's and Ulcerative Colitis Associations posted a PSD announcement on their **website**.
2. The NCD Alliance posted an **announcement** as a news item on their website.
3. A PSD **news article** was included on e-Hospice, a globally run news

and information resource about hospice, palliative and end of life care. This also included a statement highlighting the support from the Worldwide Hospice Palliative Care Alliance.

4. The World Self-Medication Industry included an **announcement** on their website.
5. Consumer Health Forum of Australia announced their **support**.
6. Respiratory Decade highlighted PSD in a **blog post**.
7. Alzheimer's Ghana shared PSD on their **website**.
8. PAGE Ghana and their support of PSD were covered in a **news article** on Ghanaweb.
9. Fibromyalgia Awareness did two blog posts, **one highlighting PSD as an important campaign**, and another on the **PSD event held in Mumbai**, India by Consumer Online Foundation.
10. Safe Medicines India also covered the event in India in an **article** on their website.
11. This event got much media attention, including several blog posts such as **The Common Man Speaks**, on **Privy Trifles** blog, and on **Dr Kaggarwal** blog.
12. Articles that had been covered in the media, on the Indian event and on PSD, were included on **Drug Today Online**, as well as in the **Afternoon Dispatch and Courier of India**.
14. Lupus Europe covered the campaign on their **website**, showing their support.
15. The World Confederation for Physical Therapy included a PSD blurb in their **e-letter**.
16. The American Chronic Pain Association released an **online announcement** highlighting PSD.
17. The Thalassemia International Federation included PSD **announcement** in their December 2014 newsletter.
18. The Liver Foundation, West Bengal held an event celebrating PSD at the Iran Society Hall, Kolkata, which was covered **online**.
19. Ugandan Alliance of Patients' Organizations (UAPO) had an event in Uganda that was covered by the newspaper **New Vision**, Uganda's leading daily newspaper (7 December 2014).
20. Action for Humane Hospitals, Cameroon, launched a **patients' declaration** in French and promoted this online.
21. AS Center for the Empowerment Youth of people who are living with HIV and AIDS, in Serbia posted **photos of their PSD event** on Facebook.