



World Patients Alliance

WPA Members Newsletter: January 2021

Dear WPA Member,

Recently, we hosted the first ever World Patients Alliance (WPA) global member webinar. This inaugural webinar featured presentations from Mike Ybarra, MD (Vice President and Chief of Medical Affairs at PhRMA) and Dr. Rashid (Patient Advocate, Social Activist, Pakistani Politician) on COVID-19 vaccine, new developments and response. The entire video will be made available on the WPA website and is currently available on [WPA YouTube](#). We will continue with a Webinar series throughout 2021, keep an eye out for more information.

Successes of 2020

Launch

On September 25th 2020, the World Patients Alliance officially and publically launched as a global patient advocacy non-profit. This public launch received much media attention and was highlighted, featured and discussed in the following publications: Newspapers, Online New Sites & Other Influencers, Broadcast Media, Financial News Service, Twitter, LinkedIn and others

“Too often, healthcare policy fails to consider patients’ actual needs,” said Hussain Jafri, founding director of the World Patients Alliance and secretary general of Alzheimer’s Pakistan. “The World Patients Alliance will work to make health care universally accessible and affordable.”

As the WPA, we will advocate for policies that ensure equal and affordable access to optimal healthcare, empower patients to express their needs and play a larger role in deciding their treatments, and improve patient education and healthcare literacy.

“The World Patients Alliance unites thousands of advocates across various countries and disease areas,” said Andrew Spiegel, chair of the World Patients Alliance and executive director of the Global Colon Cancer Association. “We’re eager to help patients make their voices heard and promote policies that will improve their quality of life.”



World Patients Safety Day (WPSD)

September 17th 2020, the World Patients Alliance



marked the WHO's World Patient Safety Day with a series of events and initiatives to raise awareness of this important day.

WPA invited all of its patient groups around the world, to participate in the various activities listed below. In addition to the this, WPA provided each member patient group with a social media tool kit which they could utilize in amplifying messaging regarding the day and its event priorities.

Conferences for WPSD

WPA participated in the organization of two conferences in collaboration with other WPA member groups, and other healthcare organizations. One of WPA's founding board members, Jolanta Bilinska organized and hosted a conference in Lodz, Poland to mark WPSD. This conference had over 40 attendees who were education in the importance of health worker and patient safety.

WPA hosted and participated in a conference in Pakistan at Fatima Jinnah Medical University in Lahore on Patient Safety - in collaboration with WHO Pakistan and Health Department Punjab. Dr. Yasmin Rashid, Health Minister Punjab was the keynote guest at this seminar.

WPA's Dr. Jafri discussed patient safety and how it is the priority of the government in Pakistan, additionally, Dr. Jafri highlighted a number of new patient safety initiatives which have been started in Punjab.



Awareness Walks

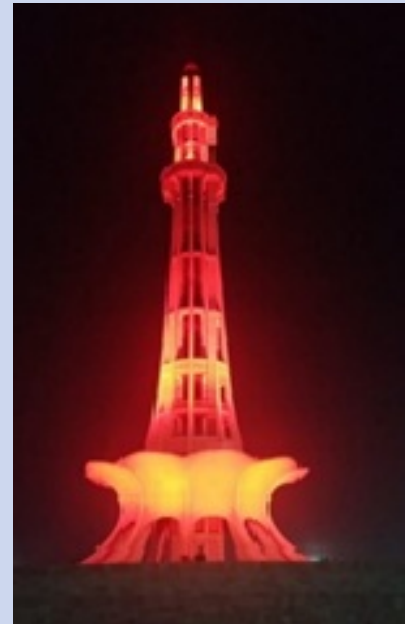


WPA and WPA member groups; Alzheimer's Pakistan, Thalassemia Society of Pakistan and Jahandad Society for Community Development, in collaboration with Government College University, Lahore came together for a WPSD awareness walk. Dr. Yasmin Rashid, Health Minister Punjab attended and participated as the guest of honor.

In Lodz, Poland, WPA and WPA member groups organized and participated in an awareness walk to mark WPSD. In addition to this, participants of this WPSD walk were also instructed in other physical exercises which pertained directly to personal health and wellbeing.

Illumination of Monuments:

Joining other cities around the world in lighting up prominent monuments to mark WPSD, many buildings across the Punjab province and capital city, Lahore participated in turning buildings orange to mark patient safety with the most notable being; Minar e Pakistan, and Summit Minar.



Media Coverage:

Efforts by WPA and its member groups celebrating WPSD in around the world achieved wide social media, print and electronic media coverage. The inaugural seminar, hosted by WPA in collaboration with others in Pakistan was covered and broadcast live by leading national TV channels.

Representation at events in 2020:

Despite 2020 being a year where COVID-19 changed the landscape of global convening's, conferences and other events, WPA continued to represent, present at and attend multiple meetings around the world, to ensure that the patient voice was represented. Below you will find a list of few where WPA Board Members were present (either virtually or safely in person):

- IV Patients Empowerment Congress Warsaw - online in Press Club - Foksal
- Ukraine, Kyiv - online participation in the HTAi Regional Meeting - Panel Discussion 4 as speaker on the theme: "What should stakeholders expect from HTA: can we work together for an integrated efficient system?"
- Patients Safety Day - Conference in Columna medica - dedicated specially NCD
- IV Congress Health Vision - Warsaw
- PhRMA Health Technology Assessment Discussion panels
- WHO panels and discussions

Upcoming Events in 2021

Webinar Series:

The WPA will be hosting a Webinar

Survey:

In late December, 2020, the WPA

series which will occur every two months and be open to all member organizations to attend. This Webinar series will feature outside experts presenting on and addressing topics which will be highlighted from the WPA member survey responses. These Webinars will also provide the opportunity for participation to WPA member organizations, please keep monitoring our emails for more information regarding this. January's webinar can be found [here](#).

posted an online membership survey which was shared with all WPA member organizations for them to participate in and complete. This survey is important because it provides the opportunity for your needs to be heard and for the WPA to best support your organization. *Complete the Survey by clicking the button below.*

The Survey is also available in French and Spanish please contact office@worldpatientsalliance.org if you have any difficulties.

Survey

Regional Meetings:

The inaugural regional meetings will take place virtually later in 2021. These regional meetings seek to provide value to each member organization through the provision of opportunities to hear subject-matter experts discuss member relevant topics, learn of advocacy efforts, education surround new treatments/medicines/therapy opportunities, provision of practical strategies, and enablement of collaboration and partnership building amongst regional peers. Each WPA member organization will be given the opportunity to help shape debate, build networks and partnerships, and to inspire action.

Want us to highlight your events?

WPA will also be offering each of its member organizations the opportunity to apply and submit an application for WPA to celebrate its event. These application forms will be vetted by WPA staff and voted upon by the WPA board to ensure that the event is in line with WPA principles, mission and vision. Once approved, WPA will work in partnership with the member organization to ensure that it's event is highlighted and celebrated across the wider organization. These events will need to be reapplied for on a yearly basis.

If you would like for the WPA to *highlight your specific, feature events* throughout the year, please let us know. Please email office@worldpatientsalliance.org to register your organization's interest.

Additionally, if your organization has recently *published an articles, opinion pieces* or will be in the future and would like to have WPA highlight your work, please email office@worldpatientsalliance.org to register your interest.

**We look forward to continuing to work with each of you
To make 2021 a huge success**

For achieving recognition for the global, patient voice.

Corporate Sponsors:

Warmest Regards,

Andrew Spiegel, Esq., Chair
Hussain Jaffri, Chair Elect
Penney Cowan, Secretary
Jolanta Bilinska, Treasurer
Karla Ruiz de Castilla, Board Member
Regina Kamoga, Board Member

