



Patients' Voice

August 2024



NEWS



77th WHA Highlights: The Seventy-seventh World Health Assembly (WHA), the main decision-making body of the WHO, convened from May 27 to June 1, 2024, in Geneva, Switzerland. With the theme "All for Health, Health for All," the Assembly gathered delegates from 194 Member States to discuss and decide on global health priorities & strategies.

[Read more](#)



Historic Resolution on Social Participation in Primary Health Care:

This significant resolution empowers people, communities, and civil society to have a more substantial influence on health decisions that impact their well-being.

[Read more](#)



Global Self-Care Summit:

Global Self-Care Federation hosted the inaugural Global Self-Care Summit in Geneva, Switzerland. Themed "Self-Care in Action: Empowering Health and Well-Being," the event took place at College Sismondi Chemin Eugène-Rigot 3, drawing health leaders and advocates from around the world.

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WPA Advocates for Safer Medications at PDA Good Aseptic Manufacturing Conference:

Hussain Jafri, Executive Director, WPA delivered a compelling presentation at the 2024 PDA Good Aseptic Manufacturing Conference, emphasizing the critical role of aseptic manufacturing in ensuring patient safety and building trust in the pharmaceutical industry.

[Read more](#)



World Patients Alliance Statement

Ethical Principles Involving Vulnerable Individuals in Research

Munich, 14 May, 2024

WPA Statement on Ethical Principles for Medical Research Involving Vulnerable Groups and Individuals:

The statement was presented on 14 May, 2024 at Munich, Germany by Hussain Jafri, Executive Director of the World Patients Alliance in the context of the revision of the Declaration of Helsinki to The World Medical Association (WMA).

[Read more](#)



WEBINAR

UNDERSTANDING AND MANAGING PAIN

22 JULY 2024 | 9 AM ET



More information:
WorldPatientsAlliance.org

Pain is something that we all have experienced at one time or another. But do we really understand what pain is, how to treat it and most importantly, how to live with pain when it becomes part of your daily life. The WPA hosted an important webinar titled "Understanding and Managing Pain" on July 22, 2024, at 9 AM ET to raise awareness and provide valuable insights into pain management.

[Read more](#)

Partners' Insight

Getting to the Heart of Hypertrophic Cardiomyopathy (HCM):

The Power of the Global Patient Voice

A piece written by:



Erica Crawford, MBA
Director, Cardiovascular Patient
Advocacy, Global Patient Outreach

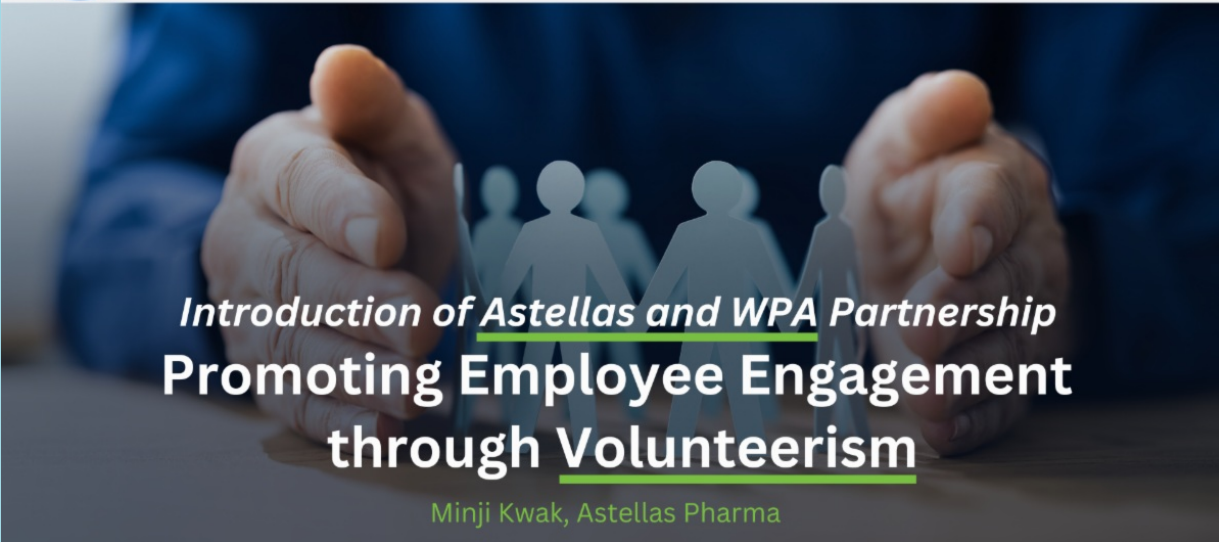


Babak Abbaszadeh, MD, MBA
Vice President, Worldwide Medical,
Intercontinental



Many of us are familiar with important principles of improving cardiovascular health – eating a heart healthy diet, managing stress, getting regular exercise, and knowing your cardiovascular risk numbers. But did you know that up to 1 in 200 people are living with a serious and frequently misdiagnosed cardiovascular condition called Hypertrophic Cardiomyopathy (HCM)?

[Read More](#)



Patient-centered care is a shared goal between Astellas and World Patients Alliance (WPA). A primary feature of the partnership is promoting patient engagement through volunteer opportunities for Astellas employees. The initial idea was to globalize the Astellas Access to Health team’s patient engagement (**Star Light Partner Activities**) component and find an appropriate international partner to elevate from Japan-focused patient engagement activities to the global level for all employees. World Patients Alliance was the best fit as it is the biggest patient umbrella organization in the world.

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Partners' Events

- **ISQua's 40th International Conference 2024** (ISQua, 24-27 September, Istanbul, Türkiye)
- **47th IHF World Hospital Congress** (IHF, 10-12 September, Rio de Janeiro, Brazil)

Getting to Know the WPA Team

In this issue of Patients' Voice, we are privileged to feature Mecciya Majrashi, Member, **WPA Advisory Board** and **Asia-Pacific Region Steering Committee**, a prominent figure in patient advocacy and a leading contributor to the patients' cause. Patients' Voice thanks Mecciya for sharing her story. Click 'Meet Mecciya Majrashi' to read more.



Mecciya Majrashi

WPA Advisory Board Member & WPA Asia-Pacific Region Steering Committee Member

Mecciya Majrashi completed her MBA in Total Quality Management in 2012 From University of Leicester, Leicester, United Kingdom and holds a rich 20-year experience in healthcare sectors. She has been appointed as the President of Saudi Patient Experience since January 2022. She is also the part of a team working with the Patient Advocacy Council since 2019 representing a group of individuals committed to engaging with one another, sharing ideas and expanding the engagement of Patient Advocate Leaders in The Beryl Institute community from different entities around the world.

[Read more](#)

[Meet Mecciya Majrashi](#)

Members' News

WPA has launched a campaign to promote and highlight the excellent work its member patient organizations are doing globally. Please [click here](#) to see members news all over the world.

- [Meningitis Awareness Campaign On Public Transport by the Helping Hands Foundation, Pakistan](#)
- [Diabetes and Liver Diseases Screening Campaign on Global Fatty Liver Day by Dialeb, Lebanon](#)
- [C. difficile Infection Survey by Gastrointestinal Society, Canada](#)
- [#ACTNOWSCREEN TODAY# Event on Global Fatty Liver Day by Empowerment for Sustainable Livelihood, Ghana](#)
- [World Hand Hygiene Day by Institute of Neurosciences Kolkata, India](#)

If you are interested in showcasing your event on WPA social media, website, and newsletter. Please [click here](#) to submit your event details.

Members' Announcements



21 Sep 2024

Czechia

Pacienti IBD

[St. Wenceslas IBD Conference](#)



26-27 Oct 2024

USA

International Pemphigus and Pemphigoid Foundation (IPPF)

[2024 Patient Education Conference](#)



26 Oct 2024

Mozambique

Associação Moçambicana de Hemofilia (AMH)

[VI Conferência Nacional de Hemofilia](#)

New WPA Members

WPA is very pleased to welcome our 91 new members, who have joined the organization in the last three months:

- Vitiligo Support And Awareness Foundation Vitsaf, Nigeria
- Fundación Colombiana Para La Fibrosis Quística – Fiquires, Colombia
- Fundación Colombiana Para Cáncer De Pulmón, Asma, Epoc Y Otras Enfermedades Respiratorias – Inspirat, Colombia
- Familias Ame Perú, Perú
- Public Foundation Together Against Cancer, Kyrgyzstan
- Fundación Grupo De Apoyo Hap Carabobo, Venezuela (Bolivarian Republic of)
- Vitiligo Support And Awareness Foundation, Ghana
- Asbestos Disease Awareness Organization (Adao), USA
- Educating Girls And Young Women For Development-Egyd, Zambia
- Hungerndthirst Foundation, Netherlands
- Myeloma Friends Charitable Trust, India
- Africa Healthcare Network, Rwanda
- Royal Patches, Kenya
- PORMIKI, Indonesia
- Stevens-Johnson Syndrome Canada, Canada
- Uganda Non Communicable Diseases Alliance, Uganda
- A Pen for Africa, Uganda
- Tshimollo home, South Africa
- China Mutual Assistance of Psoriasis Patients, China
- Sickle Cell Uhuru Trust (SCUT), Kenya
- Ebenezer Women Social Entrepreneurship Trust, Zimbabwe
- Chithuen Phendhey Association, Bhutan
- Symbol of hope warriors, Kenya
- South African Psoriasis Association, South Africa
- Jen Ai Foundation, Taiwan
- Psoriasis Indonesia (Yayasan Bercah Merah Indonesia)
- Psoriasis Association of Kenya
- IBD Patient Support Foundation, India
- National Association of Non-Governmental Organizations (NANGO), Zimbabwe
- Mpumalanga Mental Health Society, South Africa
- Instituto Nacional de Saúde, Guinea-Bissau
- The E-Center For Women'S Cancers & Maternal Health, South Africa
- Stroke Association Of Kenya
- Apn – Associação Portuguesa De Neuromusculares, Portugal
- Henzo Kenya
- Hope On Feet CBO, Kenya
- Stowelink Foundation, Kenya
- Bahrain Society For SCD Patients, Bahrain
- Instituto Camaleão, Brazil
- Kayula Childhood Cancer Foundation, Zambia
- Mission Society Care For The Infected And Affected With HIV/Aids Network, South Africa
- Fundacion Sicklemia, Colombia
- Suomen Sklerodermayhdistys Ry, Finland
- Multiple Sclerosis South Africa
- Narcolepsy Africa Foundation, Kenya
- Tunisian Hemophilia Association, Tunisia
- Rare Diseases South Africa (NPC)
- Asociacion De Desordenes Del Ciclo Urea Y Enfermedades Metabolicas Peru, Perú
- Eyomphakathi Foundation, South Africa
- Corporacion De Ayuda Al Niño Con Artritis Cronica Juvenil Anacroj, Chile
- Diabetes & Limb Salvage Foundation, Nigeria
- Hope For Kids Zimbabwe
- Asociacion Costarricense De Hipertension Pulmonar, Costa Rica
- Federacion Costarricense De Enfermedades Raras, Costa Rica
- Funarp - Panamanian Rheumatoid Arthritis Foundation, Panama
- Multiple Sclerosis Namibia (Wo293)
- Thalassemia And Sickle Cell Society, India
- Foro Español De Pacientes, Spain
- Asociación Salvadoreña Para La Prevención Del Cáncer, Al Salvador
- SCDP Community Of Tanzania, United Republic of Tanzania
- Association Of Rheumatic Patients For Targeted Therapy, Hungary
- Community And Family Aid Foundation-Ghana
- Medindia4U Pvt. Ltd., India

- Cure Blau Syndrome Foundation, Canada
- Fundacja Carita im. Wieslawy Adamiec, Poland
- Mohan Foundation, India
- Federación peruana de enfermedades raras, Perú
- Fadhili Cancer Support Organization, Kenya
- Renal Patients Society of Kenya
- International Alliance of ALS/MND Associations, Canada
- V Care Foundation, India
- Tumaini Sickle Cell Organization, Kenya
- Союз Пациентских сообществ, Кыргызстан
- MOWHA (Women@40), Uganda
- Shepherd Best Care Initiative Taraba (SBCI), Nigeria
- Cankids Kidscan, India
- My Skin Global, Kenya
- Solace Cancer Foundation&/ Solace Cancer Community Based Organization, Kenya
- Association Des Malades Atteints De Leucémies, Morocco
- Lélek-Zet Egyesület, Hungary

- Nile Health, Australia
- Cancer Survivors Association Of Kenya
- Theta Uganda
- Cancer Care Egypt Foundation, Egypt
- Rahma Foundation Algeria - RFA
- National Organization Of Users And Survivors Of Psychiatry In Rwanda (Persons With Psychosocial Disability (Nouspr), Rwanda
- Zivai Community Empowermenttrust-Zicet, Zimbabwe
- Mission Society Care For The Infected And Affected With Hiv/Aids Network, South Africa
- BMT Support Foundation, India
- Plan Health Advocacy And Development Foundation (Plan Foundation), Nigeria
- Youth on The Move, Kenya

For more information on WPA member organizations, please visit our [members](#) section.

World Patient Safety Day 2024



World Patient Safety Day (WPSD), one of WHO's global public health initiatives, was established in 2019 by the Seventy-second World Health Assembly through the adoption of resolution [WHA72.6 – "Global action on patient safety"](#). Observed annually on 17 September, it is a pivotal event to promote global health and safety, firmly grounded in the core medical principle: "first, do no harm." The day aims to raise public awareness, enhance global understanding, and foster solidarity and action among Member States to promote patient safety. Each year, a new theme is chosen to address a critical area in patient safety that demands urgent attention.

[Read More](#)

WPA Announcements

World Patient Safety Day 2024 Grants

The WPA is pleased to announce Grants to WPA member organizations to celebrate the World Patient Safety Day 2024. There are limited grants of USD 300 to USD 500 available to be used for organizing WPSD **in-person** events.

[Apply for Grant](#)

[Learn More](#)

Cape Town 2024: 2nd World Patients Conference



19-20 Oct, 2024 | Cape Town, South Africa: We are excited to share that registrations for the 2nd World Patients Conference have exceeded 900! Your enthusiasm and support mean the world to us. Thank you for joining us on this incredible journey. The 2nd World Patients Conference will provide patients the platform and opportunity to network, exchange information, share experiences, learn from each other, raise your voice, and advocate for patients cause internationally. Join us as we provide the international platform to empower and raise the patients' voice for the provision and access to safe, quality, and affordable healthcare globally. Secure your spot now by registering through the below link.

[Register Now](#)

WPA Webinars

The WPA will be organizing the following webinars during the next quarter. Visit [announcements](#) page.



[Register Now](#)

[Learn More](#)




WEBINAR
HEART OF HEALTHCARE
CELEBRATING OUR NURSES

OCTOBER 03, 2024 | 9 AM ET

[REGISTER NOW](#)

worldpatientsalliance.org



[Register Now](#)

[Learn More](#)

WPA Patient Videos

How do you raise concerns about a patient's condition in the hospital?



English Version



Spanish Version

Article



Advancing health literacy through AI in patient care

By **Hussain Jafri** | Executive Director, WPA

The ever-increasing pressure of Non-Communicable Disease (NCDs) is estimated to cumulate in a global economic loss of \$47 trillion over the course of the next two decades. In addition to the prevalence of chronic disease, we are also predicted to witness a global shortfall of 10 million physicians, nurses and midwives by 2030. What this makes clear to me is that the sheer number of patients in the world can't be seen by primary care professionals alone.

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