



ANNUAL REPORT 2023



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### MESSAGE FROM THE CHAIR

With immense pleasure, we present the World Patients Alliance's Annual Report 2023, a celebration of the remarkable growth and impact we've achieved over the past year. It fills me with pride to share our collective accomplishments, showcasing the World Patients Alliance's dynamic journey. Throughout the year, our Alliance's membership has flourished, culminating in a diverse community of nearly 467 patient organizations spanning over 124 countries. Our engaged members, representing over one billion patients globally, have actively participated in WPA events and programming, embodying the vibrant spirit of our Alliance.

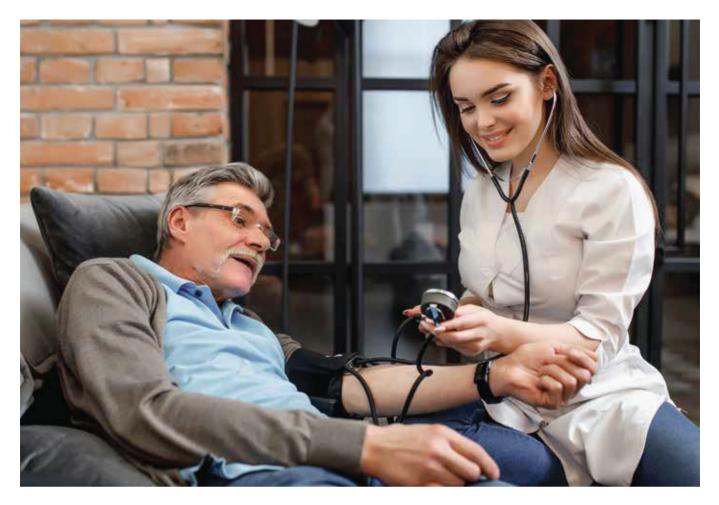
This report is a reflection of the impactful events that have shaped our journey where, the Asia Pacific Regional Meeting stands out as a milestone, fostering connections and insights that contribute to the global dialogue on patient-centric healthcare. Our journey included world's largest WPSD awareness campaign. WPA, in collaboration with our member organizations, organized over 400 events all over the world benefiting the public at large. Last but not the least, our Joint Workshop on Sustainability with the International Hospital Federation (IHF), the enlightening webinar on Patient-Centered Care & Patient Engagement, and the significant collaborations with Universidad del paciente y la familia and the International Council of Nurses (ICN) along with many similar endeavors imply our commitment to our objectives and therefore, a full of excitement terrain ahead.

Our annual member survey has been instrumental in understanding and addressing the evolving needs of our members. The depth of engagement we've cultivated underscores our commitment to providing tailored solutions and meaningful support.

As we forge ahead, the World Patients Alliance remains resolute in serving patients globally through our dedicated members. Our commitment extends beyond this report; we are poised to expand our programming, ensuring our impact resonates even more profoundly. Dive into the pages of our report to relish the details of what has been an undoubtedly successful and transformative year.

Thank you for being an integral part of the World Patients Alliance's incredible journey.

Warm regards, Andrew Spiegel, Esq. Chair, World Patients Alliance



## **WHO WE ARE**

World Patients Alliance is a nonprofit world's largest umbrella patient organization that works across all disease areas and in all world regions. The WPA provides the platform to patients, patient organizations and stakeholders from around the globe to empower and raise the patients' voice for the provision of and access to safe, quality and affordable healthcare.

WPA works to ensure patients have an active role to play in all the stages of healthcare including planning, provision, monitoring, research and evaluation of health services.

There are no fees for Patient Advocacy Organizations to become members, and our programs and initiatives are at no-cost to our Patient Advocacy Organization members.

## **MISSION**

Our mission is to be the global voice of patients working toward patient empowerment and engagement, improved access to safe innovative treatment and patient centered healthcare throughout the world.

## **VISION**

Our vision is that all patients will have access to safe, high quality and affordable healthcare everywhere in the world.

## WPA PRINCIPLES

### **ACCESS TO HEALTHCARE:**

Every patient should have access to healthcare that includes timely, effective, affordable, optimal, and innovative treatments for their condition.

### **PATIENT CENTERED HEALTHCARE:**

Patients and healthcare providers must work in partnership to ensure the patient's individual specific health needs and desired health outcomes are the focus for all healthcare decisions including physical, emotional, psycho-social, and economic aspects.

### **FINANCIAL HARDSHIP:**

Patients should have health coverage options that provide them with healthcare while protecting them from financial hardship.

### **EMPOWERED PATIENTS:**

Patients should be supported and empowered to express their needs, concerns, and preferences and provided with the opportunity to have a voice in the decision making of their treatments

### PATIENT SAFETY AND QUALITY:

Patients should be provided with treatments that are safe, high quality and appropriately monitored.

### PATIENT EDUCATION AND INFORMATION:

Stakeholders should ensure patients are educated in understandable and accessible ways about their condition and treatment options. They must be provided with information that is simple, relevant and comprehensive.

### PARTNERSHIP AND COLLABORATION:

Patients should partner and collaborate with all stakeholders for the provision and access to safe, quality, and affordable healthcare.

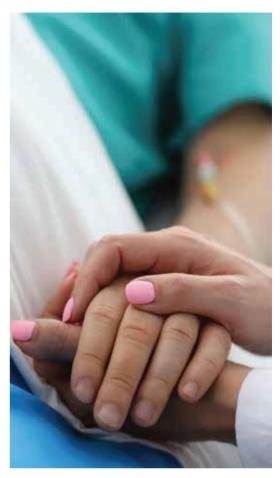
### **PATIENT ENGAGEMENT:**

Patients should be supported and provided the opportunity to be engaged at all levels of decision making concerning their healthcare.

### NO DISCRIMINATION:

Patients seeking care must not be discriminated against on the basis of age, gender, sexual orientation, religion, ethnicity, income, health status, education, geographic location, legal status or other similar factors.

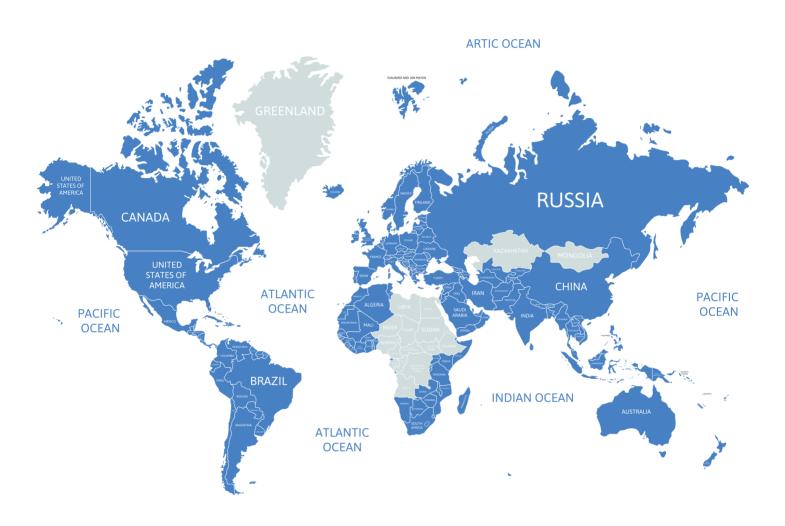
For details, please visit: https://www.worldpatientsalliance.org/principles/





## **MEMBERS MAP 2023**

We are delighted to announce that WPA is the largest international umbrella Patients' organization that is working across all disease areas and in all regions of the world.



Map: Blue color show countries with WPA member organizations

## **Total Global Members: 467 Countries:124**

Membership Continent-wise

Europe	132
Americas	112
Africa	110
Asia	99
Australia	14

## **WELCOMING NEW MEMBERS**

The membership of the WPA continues to grow. The WPA welcomed 73 new members in 2023. We look forward to working with our new members to establish the WPA as the global voice of patients. The new members joining WPA include:

- Saudi Patient Experience Club under Saudi Health Administration Association
- 2. Unidos pela Vida Brazilian Institute for Cystic Fibrosis Care
- 3. National Kidney Foundation
- 4. Pakistan Down Syndrome Association (PDSA)
- 5. Acufade
- 6. Estonian Stroke Patients Society
- 7. Hidradenitis Suppurativa Australia
- 8. Greek Carers Network Epioni
- 9. Down Syndrome Foundation Uganda
- 10. The Josiah Centre
- 11. MD Healthcare
- 12. Asociacion De Pacientes Con Angioedema Hereditario Del Peru
- 13. Organización de Pacientes con Hipertensión Pulmonar
- 14. King Hussein Cancer Foundation
- 15. Universidad del paciente y la familia.
- 16. Sree Renga Hospital
- 17. FEMINA M-Association for help and support of patients with gynecologic diseases
- 18. Cyprus Stroke Association
- 19. Nepal Stroke Association
- 20. Thalassaemia & Sickle Cell Society of Bangalore
- 21. Panhellenic Heart Disease Association
- 22. Associação Ação Avc
- 23. Non-communicable Diseases Alliances Kenya
- 24. Cyprus Federation of Patients' Associations
- 25. National Organization of Persons with Disabilities of Serbia (NOOIS)
- 26. FNAAF
- 27. HOPE Qatar Centre for Special Needs
- 28. Egyptian Thalassemia Association ETA
- 29. Myeloma Euronet Romania
- 30. Brainstrust the brain cancer people
- 31. Global Healthy Living Foundation (GHLF)
- 32. Bhutan Kidney Foundation
- 33. GIST Cancer UK
- 34. Patient Safety Learning
- 35. Patients and Citizens Involvement in Health
- 36. VStrong Vitiligo Support Community
- 37. Eczema Society of Kenya
- 38. FOKUS Patient

- 39. Center for Ichthyosis Related Members CIRM
- 40. Rheumatology Educational Trust Foundation, Inc.
- 41. Helping Hands Foundation
- 42. Scleroderma Awareness Philippines (SAP)
- 43. NPO-Kakehashi
- 44. Hong Kong Psoriasis Patients Association
- 45. Albinism Fellowship of Australia
- 46. Bhutan Cancer Society
- 47. Vietnam Psoriasis Association PSORVIET
- 48. Vietnam Vitiligo Association
- 49. Shweta Association
- 50. Eczema Association of Australasia Inc.
- 51. Rare Skin Disease Nepal
- 52. The Honeybee Childrens Clinic
- 53. Institute of Neurosciences Kolkata
- 54. China Chronic Skin Disease Fund
- 55. Pahuja Trust for Blood Disorders and Thalassemia
- 56. Africa Cancer Foundation
- 57. Lok Bandhu Raj Narayan Combined Hospital Lucknow
- 58. Axios International
- 59. Center of Excellence for Patient Safety and Quality
- 60. General authority for Healthcare accreditation and regulations GAHAR
- 61. Africa Access Health
- 62. Global Alliance of Partners for Pain Advocacy (GAPPA)
- 63. Pseudomyxoma Survivor
- 64. Psoriasis Association of Singapore
- 65. Manzil Home Healthcare Services
- 66. VIPOC Vitiligo International Patient Organizations Committee
- 67. QUAD A (The American Association for Accreditation of Ambulatory Surgery Facilities)
- 68. Sankalap Voluntary Organization
- 69. Psoriasis Australia Inc.
- 70. Bahrain MS Patients society
- 71. Yemen Society for Thalassemia & Genetic Blood Disorders
- 72. The National Multiple Sclerosis Society
- 73. BASMA-Association for Supporting Children with Cancer and Their Families



The vibrant city of Dubai played host to the World Patients Alliance's much-anticipated Asia-Pacific Regional Meeting on November 04 and 05, 2023. This gathering brought together global leaders from patient organizations and key healthcare stakeholders. The WPA Asia Pacific Regional Meeting is an important component of the World Patients Alliance's regional strategy, aligning with our commitment to addressing the unique needs of members across diverse regions. This meeting specifically focused on the Asia Pacific region, aimed to identify and address regional healthcare challenges, capture key insights, and achieve strategic milestones outlined in our regional objectives.

The event boasted a stellar lineup of speakers from national and international health organizations, each bringing their unique perspectives to the forefront. The insights shared by Mondher Letaief (WHO), Shin Ushiro (Kyushu University Hospital, Japan), Lamya Alhazani (Saudi Patient Safety Center, KSA), Candace Henley (Global Colon Cancer Assoication, USA), Christiane El Ferzli (Children's Cancer Hospital, Lebonan), Nicole Sheahan (Global Colon Cancer Association, USA), Kimberly Galia (Oracle, USA), and the in-house speakers Andrew Spiegel Esq., PenneyCowan, Jolanta Bilinska, Regina Kamoga and Hussain Jafri added depth to the discussions.

Asia-Pacific Regional Meeting had a hybrid format: a dynamic blend of in-person and virtual engagement.



**94**COUNTRIES REPRESENTED

518 PARTICIPANTS

40
IN-PERSON PARTICIPANTS

478
ONLINE PARTICIPANTS



### **Key Meeting Sessions:**

- 1. Advocacy and Communication
- 2. **Fundraising**
- 3. Patient Safety
- 4. Equity and Access to Healthcare
- 5. Asia Pacific Regional plan
- 6. WPA Members' Disease Specific / Regional Meetings

Each session was followed by a diverse panel discussion with panelists sharing their insights further exploring the topic.

The Asia-Pacific Regional Meeting provided a fertile ground for forging connections, sharing best practices, and exploring solutions that resonate across borders in the region. The impact of this event extended far beyond the two days, as the global community returned to their respective countries better equipped and more inspired to advocate for patients. Notably, a key outcome was the development of the Asia Pacific Regional Plan, marking a strategic milestone among several impactful initiatives emerging from the event.

Special Thanks to Sponsors: WPA extends heartfelt gratitude to our sponsors Pfizer and Sanofi at the Silver level and IFPMA at the Patron level for making this impactful event possible.

information on the meeting, please https://www.worldpatientsalliance.org/wpa-asia-pacific-regional-meet ing-2023/





### **MEETING SPONSORS**







## **MEMBERS SURVEY 2023**

WPA conducts an annual membership survey to know what our members' needs are and how can we best serve them? All the yearly activities are designed keeping in view the results of the annual survey to ensure that we are actually delivering what our member patient-organizations needed. The results of the WPA Membership Survey 2023 showed an excellent turnover of WPA members responding to the online survey.





#### THE KEY FINDINGS OF THE SURVEY SHOWED:

- WPA Member Organizations represented hundreds of millions of patients globally.
- 95% said advocacy was a priority and over 57% of the respondents requested assistance from WPA in advocacy efforts.
- 100% said awareness was a priority and over 54% of the respondents requested assistance from WPA in awareness efforts.
- 98% said fundraising was a priority and over 85% of the respondents requested assistance from WPA in fundraising efforts.
- 96% said access to healthcare was a priority and over 83% of the respondents requested assistance from WPA in access to healthcare efforts.
- 97% said information to patients and families was a priority and over 49% of the respondents requested assistance from WPA in information to patients and families efforts.
- 97% said education of patients was a priority and over 55% of the respondents requested assistance from WPA in education of patients efforts.
- 87% said educations of healthcare providers was a priority and over 68% of the respondents requested assistance from WPA in educations of healthcare providers efforts.
- 96% said capacity building of organization was a priority and over 83% of of the respondents requested assistance from WPA in capacity building of organization efforts.
- 90% said universal healthcare was a priority and over 68% of the respondents requested assistance from WPA in universal healthcare efforts.



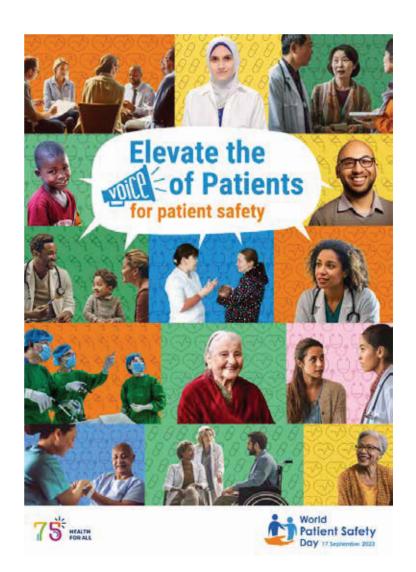
17 September 2023

# WPA ORGANIZED 400 EVENTS GLOBALLY LARGEST WPSD CAMPAIGN IN THE WORLD

World Patient Safety Day 2023 was observed on 17 September under the theme "Engaging patients for patient safety", in recognition of the crucial role patients, families and caregivers play in the safety of healthcare. Evidence shows that when patients are treated as partners in their care, significant gains are made in safety, patient satisfaction and health outcomes. By becoming active members of the healthcare team, patients can contribute to the safety of their care and that of the healthcare system as a whole.

Our member organizations celebrated World Patient Safety Day 2023 worldwide by conducting a range of awareness events, community mobilization meet-ups, walks, seminars, training events, workshops, conferences, etc.

WPA empowered the voice of the patients through the provision of WPSD2023 Grants, supporting numerous events and aligning with its premier objectives of enhancing patient safety, fostering engagement, and promoting access to high-quality healthcare worldwide. WPA successfully organized and facilitated more than 400 events on a global scale.



## WPSD GLOBAL CAMPAIGN

### THE THEME OF WPSD 2023 WAS

### "Engaging Patients For Patient Safety"

WPA member organizations around the world held a large number of events to educate and advocate patients, communities and other healthcare stakeholders on medication safety.



Pateint Engagement Conference in Poland



Patients & Citizens Educational Event in Zambia



Pateint Engagement Conference in Ecuador



Social Mobilization in Rural Pakistan



Awareness Marathon in Nepal



Community Event at Bosnia & Herzegovina

13

For details, please

visit: https://www.worldpatientsalliance.org/world-patient-safety-day-2023/wpsd-2023-collaborated-events/

## WPSD WEBINAR

### PATIENT ENGAGEMENT IN PATIENT SAFETY AROUND THE WORLD

### 20 SEP 2023 | ONLINE

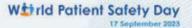
The World Patient Safety Day 2023, observed on September 17, centered around the theme "Engaging patients for patient safety." Recognizing the pivotal role patients, families, and caregivers play in healthcare safety, the event emphasized that treating patients as active partners in their care results in significant gains in safety, patient satisfaction, and health outcomes. The day highlighted the importance of patient engagement in decision-making, understanding medical procedures, and contributing valuable insights to enhance healthcare safety. A webinar organized by the World Patient Alliance (WPA) featured international patient advocacy champions and healthcare experts who shared perspectives on patient engagement in patient safety, offering a global outlook on the evolution of patient safety initiatives. Dr. Neelam Dhingra, Unit Head, WHO Patient Safety Flagship was the keynote speaker at the webinar. Dr. Dhingra highlighted the imperative of patient and family engagement in improving global patient safety, emphasizing the transformative impact of collaborative, patient-centered healthcare approaches.

#### For details, please visit:

https://www.worldpatientsalliance.org/allevents/webinar-patient-engagement-in-patient-safety-around-the-world/







### Webinar:

## PATIENT ENGAGEMENT IN PATIENT SAFETY AROUND THE WORLD



20TH SEPTEMBER 2023



11 AM TO 12 PM EDT



DR. NEELAM DHINGRA WHO

Unit Head, WHO Patient Safety Flagship



HELEN

Chair, WPA Patient Safety & Quality Council



JOLANTA BILINSKA

Poland

Founding Director WPA / Patient Safety Foundation



STEPHANIE NEWELL

Australia

Australian Consumer Advocates



CAROL

Australia

Australian Consumer Advocates



NAGWA METWALLY

Egypt

Patients for Patient Safety



## **PATIENTS VIDEOS**

#### **HOW MANY MEDICATIONS ARE TOO MANY?**

In our latest video, we addressed a crucial aspect of healthcare for individuals aged 65 and above who are managing five or more medications. Medication safety is paramount, and this video emphasizes the importance of staying informed, learning about each medication, its purpose, and exercising vigilance for potential side effects or overdoses. Prioritize your health by taking only what's necessary in the correct amounts.

Check out the video for essential insights: https://youtu.be/Vh\_oW05piYo



### HOW DO YOU TALK TO YOUR HEALTHCARE PROVIDER?

Embarking on a medical appointment can be a crucial step in managing your health effectively. In this video, we guide you through the art of articulating your concerns to your healthcare provider. Learn how to concisely describe your symptoms, highlight changes over time, and address the impact on your daily life. Discover the importance of expressing your desired outcomes and being receptive to your provider's suggestions. This video equips you with valuable insights to make the most out of your healthcare appointments.

Check out the video for essential insights: https://youtu.be/K3\_CdWnaZwc



## WPA EVENTS

### **WORLD DAY OF THE SICK 2023**

12 February 2023 | Poland

WPA and the Polish Patients Safety Foundation organized the World Day of the Sick in Lodz, Poland. The global event focused on supporting those with illnesses under the theme "Illness is part of our human condition." The event featured presentations by healthcare professionals on various health topics, providing practical guidance and scientific insights. Participants, including patients and healthcare practitioners, received information on cardiovascular diseases, sepsis, blood diseases, exercise benefits, and nutrition. The conference aimed to raise health awareness and promote compassionate care for the sick

For details, please visit: https://www.worldpatientsalliance.org/allevents/world-day-of-the-sick-2023/





## WORKSHOP ON PERSON-CENTERED CARE SYSTEMS: FROM THEORY TO PRACTICE

20 April 2023 | Online

The World Patients Alliance and the International Society for Quality in Health Care (ISQua) organized a workshop on embedding Person-Centered Care (PCC) as the standard in healthcare systems. The workshop aimed to address the challenge of making PCC the norm in healthcare.

Speakers highlighted the need for respect in healthcare and shared the successful integration of PCC at Sree Ranga Hospital, India. Patient advocates emphasized patients' active role in care decisions.



For detail, please visit:

https://www.worldpatientsalliance.org/allevents/workshop-on-person-centred-care-systems-fro-theory-to-practice/

### TODAY YOUNG, TOMORROW ELDER WORKSHOP FOR HEALTH

25 June 2023 | Poland

WPA, in collaboration with the Patient Safety Foundation Poland, organized a workshop in Zgierz, Poland. The workshop aimed to promote healthier lifestyles and empower individuals for disease prevention. Jolanta Bilińska, WPA Board Director, highlighted the importance of patient engagement in prevention and treatment, emphasizing the significance of preventive health measures. Medical experts addressed topics such as obesity, movement for health, and dietary habits. Focused on the importance of a healthy lifestyle, the event attracted patients, doctors, therapists, and nutritionists.



For details, please visit:

https://www.worldpatientsalliance.org/allevents/today-young-tomorrow-elder-workshop-for-health/

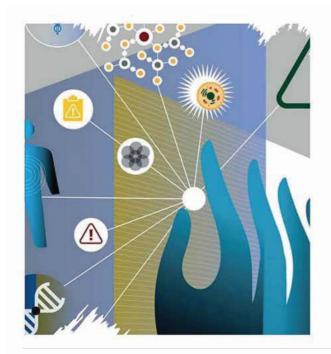
### **WORKSHOP ON PATIENTS SAFETY: DIAGNOSTIC ERRORS**

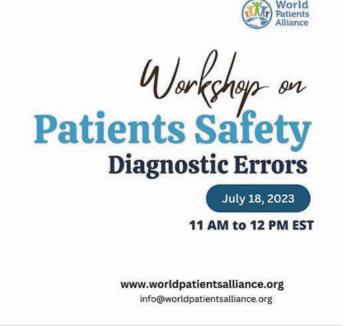
18 July 2023 | Online

WPA organized a workshop on diagnostic errors, addressing their global impact on patients and healthcare. Expert speakers, including Dr. Hardeep Singh, highlighted the frequency and factors contributing to diagnostic errors. Patient advocates shared personal experiences, underscoring the importance of patient engagement in diagnosis. The event, moderated by Helen Haskell, Chair WPA Patient Safety & Quality Council, emphasized collaboration and open communication to enhance diagnostic accuracy and patient care. Attended by around 175 participants, the workshop provided valuable insights into mitigating diagnostic errors and promoting patient-centered healthcare.

### For details, please visit:

https://www.worldpatientsalliance.org/allevents/workshop-on-patients-safety-diagnostic-errors/





### WEBINAR: WHAT IS A CLINICAL TRIAL AND WHY SHOULD I BE INVOLVED?

5 September 2023 | Online

WPA hosted a webinar on "What is a Clinical Trial and Why Should I be Involved?" for World Patient Safety Day 2023. Eminent speakers, including Dr. Sean Mackey, Dr. Lembit Rägo, and Dr. Vasee Moorthy, provided insights into clinical trials, ethical considerations, and the World Health Assembly's 2022 resolution. Patient advocates Christin Veasley and Ruth Nankanja Mukiibi highlighted the importance of patient engagement, challenging traditional research models, and advocating for strong regulatory systems. The objective of the webinar was to address the misconceptions about clincial trials and how can patients engage in clinical trials For details,

please visit:

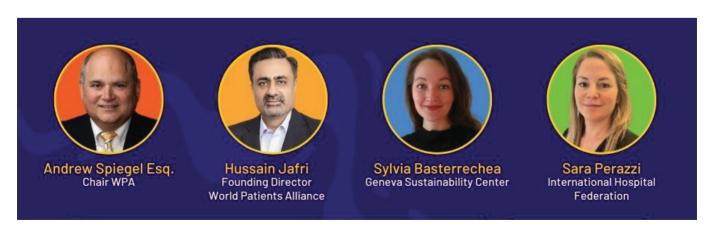
https://www.worldpatientsalliance.org/allevents/webinarwhat-is-clinical-trial-and-why-should-i-be- involved/



### **WORKSHOP ON SUSTAINABILITY**

16 November 2023 | Online

In collaboration with the International Hospital Federation (IHF) and the Geneva Sustainability Center, the WPA organized a groundbreaking sustainability workshop featuring enlightening presentations by Sylvia Basterrechea and Hussain Jafri. Sylvia emphasized healthcare's crucial role in tackling climate change, offering actionable strategies from the Geneva Sustainability Center. Hussain underscored patient involvement in driving sustainability, outlining impactful contributions. The workshop aimed to inspire global healthcare initiatives centered on sustainability and patient engagement, marking a significant step toward a more resilient and patient-centric future.



For details, please visit: https://www.worldpatientsalliance.org/allevents/workshop-on-sustainability/

### WEBINAR: PATIENT CENTERED CARE AND PATIENT ENGAGEMENT

1 December 2023 | Online

In collaboration with International Council of Nurses (ICN), WPA hosted a groundbreaking webinar on Patient-Centered Care & Patient Engagement featuring distinguished speakers. Dr. Cipriano illuminated the role of nurses in Patient-Centered Care, emphasizing the need for a robust nursing workforce to address global health challenges. Lisa Morrise explored patient engagement, stressing collaboration, transparency, and education for effective healthcare relationships. A panel discussion and insightful wrap-up by Howard Catton concluded the event, marking milestone in advancing patient-centric healthcare globally.



For details, please visit:

https://www.worldpatientsalliance.org/allevents/webinar-patient-centered-care-and-patient-engagement/

### 5TH GLOBAL MINISTERIAL SUMMIT ON PATIENT SAFETY

23-24 February 2023 | Switzerland

Switzerland hosted the 5th Global Ministerial Summit on Patient Safety in Montreux. With over 600 participants, the summit emphasized global efforts to enhance patient safety, highlighting the WHO's Global Patient Safety Action Plan 2021–2030. WHO Director-General Dr. Tedros Adhanom Ghebreyesus stressed the need for a culture of safety and patient engagement. WPA actively contributed to discussions, providing the patients' perspective and engaging with international healthcare stakeholders



For details, please visit:

https://www.worldpatientsalliance.org/allevents/5th-global-ministerial-summit-on-patient-safety/

## **COLLABORATIONS**

In a year marked by significant strides towards our mission, WPA proudly announces two new strategic collaborations that reinforce our commitment to patient-centric healthcare and global well-being.



WPA is excited to announce a partnership with the International Hospital Federation (IHF), a membership association reprsenting the interests of hospitals and healthcare organizations across the world. IHF's mission is to connect healthcare leaders through international knowledge exchange and showcasing of the good practices. Its vision is healthy communities served by well-managed hospitals and healthcare services, where individuals can reach their highest potential for health. An MOU has been signed between the two organizations that authorizes a framework for joint initiatives, information exchange, and addressing crucial healthcare issues. This partnership aligns with WPA's commitment to elevate patient voices globally.



WPA is thrilled to partner with Spain's Universidad del paciente y la familia, known as The University of the Patient and the Family. This academic center focuses on accredited training for patients, caregivers, volunteers, and professionals, emphasizing patient empowerment through education and active participation. The university is now an associate member of WPA, aligning with our commitment to global health and well-being.

## WPA BOARD OF DIRECTORS



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MECCIYA MAJRASHI SAUDI ARABIA



MOE A. K. NAING MYANMAR



IBRAHIMA MADOUGOU MOUBARAK NIGER

## WPA FINANCIAL REPORT 2022

Revenue	\$ 204, 615
Program Expense Areas:	
Growing & Supporting The International Patient Community	\$47,868
Advocating For Patient-centered Policy	\$77,467
Education	\$52,542
Total For Program Expense Areas	\$177,877
Management & General Expenses	\$23,045
Total Expenses	\$200,922

Accounts shown in USD

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## Write to us at: office@worldpatientsalliance.org



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