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MESSAGE FROM THE CHAIR

We are excited to present the World Patients Alliance’s Annual Report. I am astounded by the growth and impact the World Patients Alliance has had this year and look forward to sharing our accomplishments. As you will read, the Alliance’s membership continued to experience growth all year long and at the end of the year, we had close to 400 patient organizations members from 115 countries. Our members represent hundreds of millions of patients around the globe and are very active in WPA events and programing. Through our annual member survey, we learn about the needs of our members and adjust programs accordingly. It is no wonder we have obtained such significant engagement with our members.

In 2022, the Alliance held its first African Regional meeting with more than 49 Countries in attendance. We held our first Global Conference in Rome, Italy with more than 650 people from 101 countries participated in the hybrid event. At both meetings, leading experts in health policy from multiple disciplines came together to address the needs of patients around the world. I am so proud of the WPA Members, Staff and my fellow volunteer Board of Directors who are committed to furthering the principles of the Alliance through these types of events.

The WPA has been a champion of the WHO’s World Patient Safety Day. Over the past two years, we through our Members hosted more than 1200 World Patient Safety Day events. Take a look at the amazing stories and photos of our grant recipients NGOs who held educational events around the globe in the pages that follow. We also collaborated on a two day Biosimilars Training Program so patient organizations can ensure that people remain at the center of important policy discussions.

I am proud of the partnerships we have made this past year. We know collaboration is the key to change and we have partnered with organizations like ISQUA and World Federation of Public Health Associations. Finally, I thank our partners whose generosity allows us to operate our programs and events.

Moving forward, the Alliance will continue to serve patients worldwide through our members and will expand our programming. Enjoy reading about a most successful year!

Andrew Spiegel, Esquire
Chair, World Patients Alliance
The World Patients Alliance (WPA) is a 501 (c) 3, nonprofit umbrella organization of patients, patients’ organizations, and stakeholders from around the globe. The WPA was established in 2019 and provides the platform 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 that 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.

**VISION**

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

**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.
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 health care 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.
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.

GRAPHIC SHOWS MEMBERS’ LOCATIONS IN BLUE GLOBALLY.

Total Global Members: 393
Countries 115

MEMBERSHIP WORLD REGION WISE

<table>
<thead>
<tr>
<th>Region</th>
<th>Members</th>
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<tbody>
<tr>
<td>European Region</td>
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<td>American Region</td>
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<td>African Region</td>
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<tr>
<td>Eastern Mediterranean Region</td>
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<tr>
<td>South East Asian Region</td>
<td>24</td>
</tr>
<tr>
<td>Western Pacific Region</td>
<td>21</td>
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The membership of the WPA continues to grow quickly. The WPA welcomed 69 new members in 2022. We look forward to working with our new members to establish WPA as the global voice of patients working toward patient empowerment and engagement, improved access to safe innovative treatment and patient-centered healthcare throughout the world. The new members joining WPA include:

1. National Alliance for Rare Diseases Support – Malta
2. Lake Health and Wellbeing
3. Russian association on osteoporosis
4. Charter of “Fighting Leukemia” Public Union
5. SANO, North Macedonia
6. Mathiwos Wondu-ye Ethiopia Cancer Society
7. ASHIC, Foundation for Childhood Cancer
8. Fertility Europe
9. Finzopp – Federazione Italiana Incontinenti E Disfunzioni Pelvico
10. Associazione Italiana Stomizzati A.I.STOM. O.D.V.
11. Campaigning for Cancer
12. Breast Care International (BCI)
13. SEN Slovensko/Cesko
14. Pain Support Organisation
15. Trinity Healthcare Foundation
16. Dup15q Alliance
17. Cancer Association of Namibia Namibia (WO30)
18. Crohn en colitis ulcerosa vereniging vzw
19. Pun Yang Hnin Si (Pink Rose) Breast Cancer Patients Support Group
20. ABRALE – Brazilian Lymphoma and Leukemia Association
21. Oncoguía
22. SAID NGO
23. Lugei Foundation Uganda
24. PTAVC União de Sobreviventes, Familiare e Amigos
25. Australia Alopecia Areata Foundation Inc
26. Por Una Vida Libre de ACV
27. Multiple Sclerosis Association Of Lanka
29. Eczema Outreach Support
30. Alliance Algérienne contre les Maladies rares
31. World Federation of Public Health Associations
32. Associação Portuguesa de Doentes da Próstata
33. Asociación Tejido Azul
34. Federación Colombiana de Enfermedades Raras
35. United Mission to Rural Area (UNMIRA) Nepal
36. Asociación Guatemalteca Héroes de Esperanza
37. ANAQ Foundation for Sickle Cell & Nutrition
38. Ukrainian Hemophilia Association
39. Women’s Hope Foundation (WHF)
40. Pacienti IBD
41. DEBRA South Africa
42. Niger League Figth against Cancer
43. Global media foundation
44. Shared Blessing Alliance (SBA)
45. Vitiligo Support and Research Group
46. Health Improvement and Population Safety Movement (HIPS Movement)
47. Association of Patients with Asthma, Allergies and Atopic Dermatitis – AAA Association
48. Esperantra Centro
49. Linda Afa Society
50. Hope for Cancer Kids (HCK)
51. Pancyprian Association Of Rare Genetic Diseases Unique Smiles
52. Botswana Organisation for Rare Diseases (BORDIS)
53. AFRH – Association Française pour la Recherche sur l’Hidrosadénite
54. Patient Voice Partners
55. Bald Girls Do Lunch, Inc
56. Public Health Education Liaison and Advocacy (PHELA) Foundation
57. Northern Morocco Association for patients with multiple sclerosis
58. Lifeline for Childhood Cancer Ghana
59. Hope & Courage International
60. Public Health Initiative
61. Confraternity of Patients Kenya (Colpax)
62. Epilepsy Warriors Foundation
63. Cancer Survivors Quest
64. Partnership to Fight Chronic Disease
65. Nyankonton Aid Foundation
66. Thalassemia Foundation Ghana
67. Tim Africa Aid Ghana
68. Fundacion SAYANI
69. Vaincre Dunnigan
The theme of the conference was “New Normal, New Challenges for Patients.” The healthcare has changed a lot since the pandemic. Both patients and healthcare providers have experienced unpresented challenges in the last few years and there is a new normal that is emerging. Patients and healthcare providers are adjusting to this new normal.

The 1st World Patients Conference brought together patient leaders from around the world to the beautiful city of Rome from 15 – 16 October 2022. The objectives of the conference were to provide patients the platform and opportunity to network, exchange information, share experiences, learn from each other, raise voice and advocate for patients cause internationally.

101 COUNTRIES REPRESENTED
LARGEST CONFERENCE OF PATIENTS FROM ALL DISEASE AREAS AND FROM ALL REGIONS OF THE WORLD
Delegates consisted of global patients advocates, patient advocacy organizations leaders, patients and caregivers, healthcare stakeholders, healthcare regulators, industry, researchers and scientists. The leading global healthcare stakeholders that attended and presented at the conference included World Health Organization, International Committee of the Red Cross, International Council of Nurses, International Hospital Federation, Food and Drug Administration (FDA), European Medicine Agency (EMA), academic institutions and World Federation of Public Health Associations.

Key Conference Sessions:
1. New Normal, New Challenges
2. What is new Normal: How could patient expectations be met
3. Universal Health Coverage (UHC)
4. WPA Regional Meetings
5. Patient Safety
6. Healthcare Emergencies
7. Patient Engagement with Regulators
8. Digital Health
9. Members Discussion: Open Forum

The conference also provided WPA members, patient advocates and healthcare stakeholders to set up booths both virtually and in person and showcase their services, activities, programmes and initiatives to global audience including patients organizations, leading patients advocates, healthcare providers and international healthcare organizations.
WPA has a large members base in the African region comprising of 101 patients’ organizations in 26 countries. These patients’ organizations mostly serve the underserved patients in the many isolated communities of Africa. WPA’s First African Patients Virtual Regional Meeting brought together leading patients advocates, policy makers, leading healthcare stakeholders, healthcare providers, industry representatives and the World Health Organization. The Regional Meeting provided the platform and opportunity to patients to discuss healthcare issues faced by the African countries and discuss ways to overcome these barriers and promote Universal Health Coverage in the region.

The event participants presented and discussed the underlying issues of why over 615 million people in Africa cannot access essential services and why the services available are of very low quality and why is there a low sense of ownership and trust in the health care systems. Participants presented on current interventions that addressed barriers to quality health care. Based on the knowledge sharing and learnings during the event, the regional meeting participants’ established a road map to bring patients and community organizations, healthcare providers, and other healthcare stakeholders to partner and start contributing to the Universal Health Coverage framework of actions to achieve quality and safe care for African patients, families, and communities.

The meeting resulted in the establishment of a strong platform and network where patient organizations and partners can collaborate to foster interventions for patient engagement and empowerment to achieve quality and safe care in Africa.

View video recordings & presentations of African Regional Meetings: https://www.worldpatientsalliance.org/africa-regional-meeting/
SURVEYS
MEMBERS
SURVEY 2022

WPA conducts annual membership survey to know exactly 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 on what the patient organizations needed. The results of the WPA Membership Survey 2022 showed an excellent response with over 62% of WPA members responding by completing the online survey.

THE KEY FINDINGS OF THE SURVEY SHOWED:

1. WPA Member Organizations represented hundreds of millions of patients globally
2. 94% said advocacy was a priority and over 52% of those respondents’ requested assistance from WPA in advocacy efforts
3. 100% said awareness was a priority and over 41% of those respondents’ requested assistance from WPA in awareness efforts
4. 95% said fundraising was a priority and over 76% of those respondents requested assistance from WPA in fundraising efforts
5. 85% said access to health care was a priority and over 68% of those respondents requested assistance from WPA in access to health care efforts
6. 98% said information to patients and families was a priority and over 40% of those respondents’ requested assistance from WPA in information provision
7. 96% said education of patients was a priority and over 48% of those respondents’ requested assistance from WPA in education of patient’s efforts
8. 94% said education of health care providers (HCP) was a priority and over 72% of those respondents’ requested assistance from WPA for educations of HCP efforts
9. 97% said capacity building of the organization was a priority and over 71% of those respondents’ requested assistance from WPA for capacity building efforts
10. 80% said universal health care was a priority and over 72% of those respondents’ requested assistance from WPA in universal health care efforts
HTA SURVEY

Health Technology Assessments (HTAs) can provide crucial information regarding multiple aspects of healthcare that can have a positive impact on the lives of patients – if the patient voice is heard.

A properly developed assessment process can favor the establishment of a truly patient-centered healthcare system that covers quality and safety comprehensively and promotes a ‘Get it Right the First Time’ culture. WPA believes that patients must have access to healthcare that includes timely, safe, effective, affordable, optimal, nondiscriminatory and innovative treatments, health services, health devices, health products and pharmaceuticals.

WPA conducted a survey of its members and patients to understand what their experiences and thoughts were on health technology assessment (HTA). The survey was held in five languages that included English, Spanish, French, Dutch, and German languages. We had a total of 543 responses received online.

THE KEY FINDINGS OF THE SURVEY SHOWED:

1. Cost of new medicines major concern across all countries
2. More than 50% were most concerned about the cost of new medicines
3. More than 70% say their government had not reached out to their organization regarding the state of healthcare
4. Limited involvement in the decision-making process with health care systems. In the Spanish speaking countries, the majority felt they were not involved
5. 80% agreed that treatment preferences could be better addressed by health care system
Slogan was “Medication Without Harm” and the key action areas are high-risk situations, transitions of care, and polypharmacy.

The objectives of WPSD are to increase public awareness and engagement, enhance global understanding, and work towards global solidarity and action by all stakeholders to improve patient safety. WPA provided Grants to WPA member organizations to celebrate the day.

We all get sick, at some point in our lives, take medications to prevent or treat illness. However, if incorrectly stored, prescribed, dispensed, administered, or monitored, medications can be dangerous.

Medication errors are a leading cause of avoidable harm in health care globally. Medication safety incidents happen because of weak medication systems and human factors and can result in patient injury, disability and even death.

WPA organized 400 EVENTS globally.
MEDICATION HARM ACCOUNTS FOR 50% OF THE OVERALL PREVENTABLE HARM IN MEDICAL CARE.
WPA CONDUCTED THE LARGEST WPSD CAMPAIGN GLOBALLY

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

View full WPSD activities online at:
https://www.worldpatientsalliance.org/world-patients-safety-day-wpsd-2022/
WORLD PATIENT SAFETY DAY WEBINAR

The WPA World Patient Safety Day webinar was held on 14 September 2022. The topic was “Patient Engagement in Medication Safety,” focusing on what patients can do to help keep themselves safe while using medications. This was in keeping with the 2022 World Patient Safety Day theme “Medication without Harm” and the long-running WHO global patient safety challenge on medication safety. Both these WHO campaigns were undertaken in acknowledgement of the fact that adverse events from medications are one of the greatest sources of patient harm in healthcare. Leading medication safety experts globally were the resource persons at the webinar.

To recognize World Patient Safety Day, WPA gathered four of the world’s leading experts on medication safety that included Alpana Mair, Head of Prescribing and Therapeutics for Scottish Government and a global expert on the simultaneous prescription of multiple medications, Dr. Michael Cohen, head of the US Institute for Safe Medication Practices, Professor Phillip Routledge, Cardiff University, UK and Dr. Helen Ndagije, Director of Product Safety at the National Drug Authority of Uganda. Helen Haskell, WPA Patient Safety Committee member and chair of the Patients and Public Working Group of the global challenge moderated the webinar.

View full WPSD Webinar online at: https://www.worldpatientsalliance.org/world-patients-safety-day-wpsd-2022/

MEDICATION SAFETY VIDEO

Everyone especially patients have a key role to play in ensuring medication safety. WPA launched this video for patients and patients’ organizations globally providing them an introduction to medication safety, how to take medicines correctly, the side effects of medicines and how patients can improve medication safety at their homes and communities.

View Videos online at: https://www.worldpatientsalliance.org/world-patients-safety-day-wpsd-2022/
WPA EVENTS

WPA held several events that included workshops, webinars, trainings and conferences in 2022. These events were designed and delivered according to our membership needs as reflected in WPA Membership Survey 2022. World leading patients advocates, patients’ organizations, healthcare providers, policy makers, health ministers, WHO and companies attended these events. There was a very active participation of WPA members and patients advocates from all over the world in these educational events.

WORKSHOP ON PATIENT EMPOWERMENT & COMMUNITY ENGAGEMENT IN PATIENT SAFETY

Patient empowerment is a process through which patients individually and collectively have increased capacity to express their needs, present their concerns and take action to meet those needs in partnership with the healthcare providers. The Jeddah Declaration on Patient Safety highlights the significance of patient empowerment and engagement in the improvement of healthcare globally. The workshop highlighted the WHO Patients for Patient Safety Program’s role in incorporating the patient, family, and community voice into all levels of health care through engagement and empowerment.

WORLD HEALTH DAY CONFERENCE

The WPA in collaboration with the Patients Safety Foundation Poland organized a conference to commemorate the World Health Day on 02 April 2022, at Lodz, Poland. The theme for the World Health Day 2022 was “Our Planet, Our Health.” WPA through the World Health Day 2022 focused global attention on urgent actions to keep people and the planet healthy and to support the movement to create societies focused on well-being.

FUNDRAISING WEBINAR

The WPA held a successful Fundraising Webinar on 03 March 2022. Renowned speakers from around the world participated, including fundraising experts, patient advocates and industry partner representatives. The participants of the webinar were introduced to all aspects of fundraising, including information on fundraising fundamentals. Fundraising resources and examples of successful campaigns were also shared with the participants.
WPA and ISQua collaborated and organized a workshop on Person Centred Care. The objectives of the workshop was to have shared understanding between patients and healthcare providers on the important issue of Person Centred Care. The workshop brought together expertise and insight on person centred care and co-production from countries around the world. The participants were educated about Person Centred Care along with practical examples from both a patient and clinical perspective with speakers drawn from a variety of different countries and settings.

View full Workshop report online at: https://www.worldpatientsalliance.org/allevents/workshop-on-person-centred-care/
A Biosimilar Training Program was held from 10-11 May 2022, which educated patient advocates from all over the world on the health and economic benefits of biosimilars as well as the challenges they create for patients. The WPA partnered with the Global Colon Cancer Association and the Alliance for Safe Biologic Medicines for providing this extensive training program. This virtual event was open to patient advocates worldwide, representing all disease areas and attended by experts including physicians, pharmacists, regulators, and manufacturers. Patient advocates from around the world also shared their advocacy stories and strategies.

The training program highlighted how biologicals offers significant benefits and enhanced quality of life for patients with chronic diseases. However, finding a working treatment regimen may take a long time and involves trial and error for a patient’s individual case. Nevertheless, government policies that force biosimilar switching for non-medical and strictly economic reasons may affect patients’ treatment and their well-being, create mistrust in the healthcare system, undermine competition, increase total healthcare costs, and function as a barrier to innovation and future access to new biological drugs for patients. The attendees were taught how to collaborate with allies, identify champions, make clear policy request, build long-term relationships with policymakers, stay informed and keep your members engaged. The participants were also provided extensive training on the Biosimilars Patient Advocacy Toolkit which includes definitions, questions for your doctor, sample position statements for your organization, sample letters to policy makers, and much more.

View full Webinar online at: https://www.worldpatientsalliance.org/allevents/biosimilars-training-program/
WPA is pleased to announce our strategic partnership with International Society for Quality in Health Care (ISQua), which is a leading international organization dedicated to promoting quality improvement in health care. WPA & ISQua signed a Memorandum of Understanding (MOU) in 2022, which provides a clear framework of partnership between the two organizations. Through this partnership, WPA and ISQua strive to improve the quality and safety of patient-centred healthcare around the world. This framework includes activities such as information exchange, organizing joint projects, promoting, and participating in each other’s activities and publishing joint statements on important healthcare issues.

WPA also entered into partnership with World Federation of Public Health Associations (WFPHA), which is the only worldwide professional society representing and serving the broad field of public health internationally to have influence in the health of the people in today’s globalized world. It represents over five million public health professionals worldwide. Both the organizations joined each other's organizational memberships as WHPHA has become WPA’s corporate member whereas WPA has become WFPHA’s partner membership. We look forward to working together towards our shared goals of protecting and promoting health and wellbeing worldwide.
WPA BOARD OF DIRECTORS

Chair: Andrew Spiegel, Esq.
Secretary: Penney Cowan
Treasurer: Jolanta Bilinska
Director: Regina Kamoga
Director: Karla Ruiz de Castilla
Executive Director: Hussain Jafri
## WPA FINANCIAL REPORT 2021

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<td>Growing and supporting the international Patient community</td>
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<td>Advocating for patient-centered policy</td>
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<td>Education</td>
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<td><strong>Total for Program Expense Areas</strong></td>
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<td>Management &amp; General Expenses</td>
<td>$19,648</td>
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<td><strong>Total Expenses</strong></td>
<td>$124,538</td>
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Accounts shown in USD