



World Patients Alliance



2021 ANNUAL REPORT

www.worldpatientsalliance.com



World Patients Alliance

WPA is the largest global patient umbrella organization working across all disease areas, in all regions of the world.

347

patient member organizations

111

countries representing all disease areas

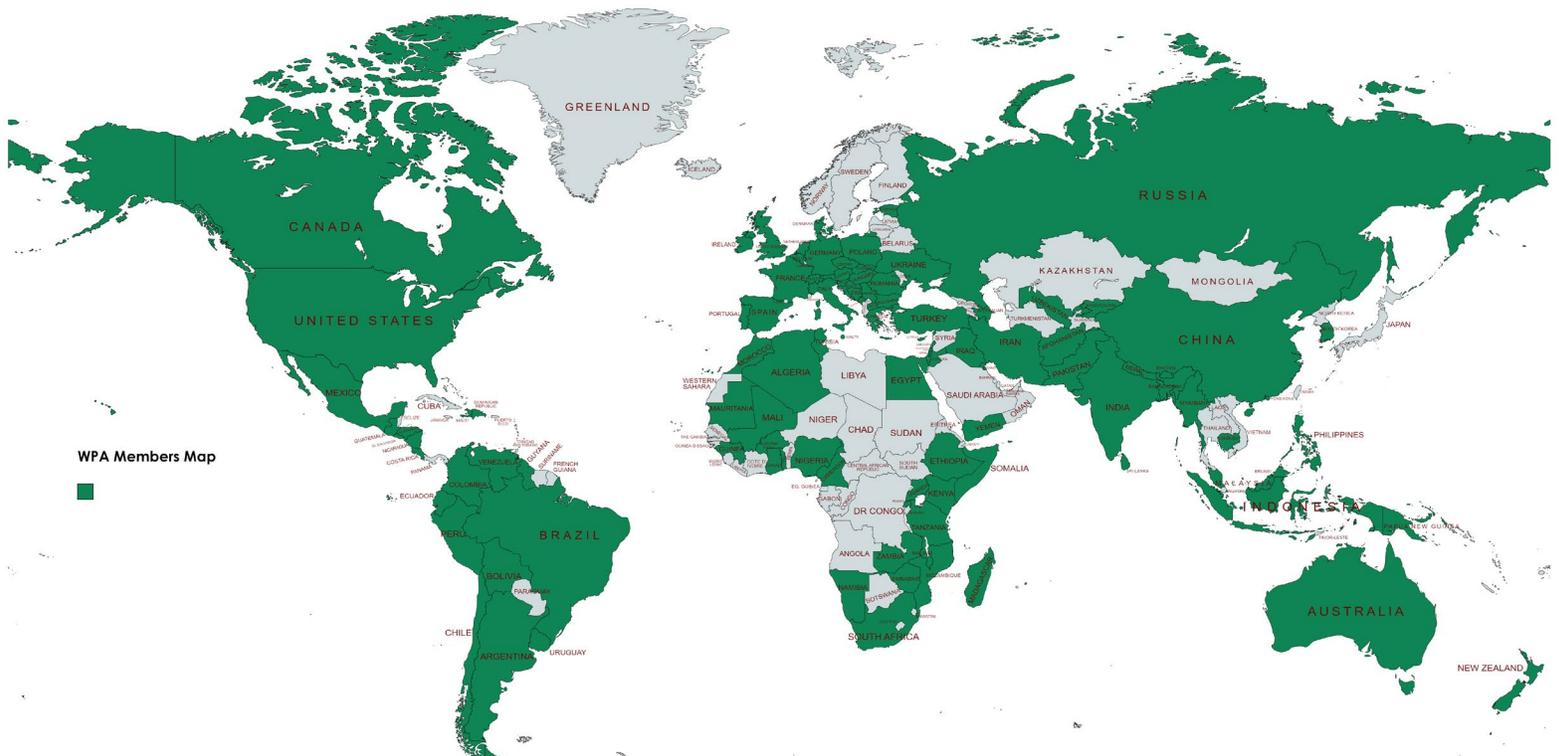


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Message from the Chair



As Chair of the World Patients Alliance, I am proud of how far our organization has come in such a short time. The WPA began as an idea in the summer of 2019 and was officially launched in September 2020 as a group of patient advocacy organizations who saw an urgent need to collaborate globally on important issues affecting patients worldwide, not the least of which was the COVID-19 pandemic. By the time of our first Membership Survey nine months later, our membership had grown to more than 200 patient organizations. In the year since that survey, our membership has grown significantly, currently standing at nearly 350 member patient advocacy organizations. In this short time, the WPA has become the largest patient advocacy coalition in the world covering all disease areas and all geographic regions.

I believe this tremendous success is due in large part to WPA's focus on the needs of its members. Our programs, including webinars, workshops, and in-person/hybrid events, are all developed based on the requests of members. We seek to provide our members with the information and tools they tell us they need to be effective patient advocates in their regions. We are proud of the great content we have developed with help from our members. As you will see in this Annual Report, these include webinars about COVID-19 vaccine safety and equitable vaccine distribution, health technology assessments and other issues important to patient organizations.

Our success is also due to the hard work and dedication of our members, who are among the most engaged patient advocates I have seen in my 20+ years in patient advocacy.

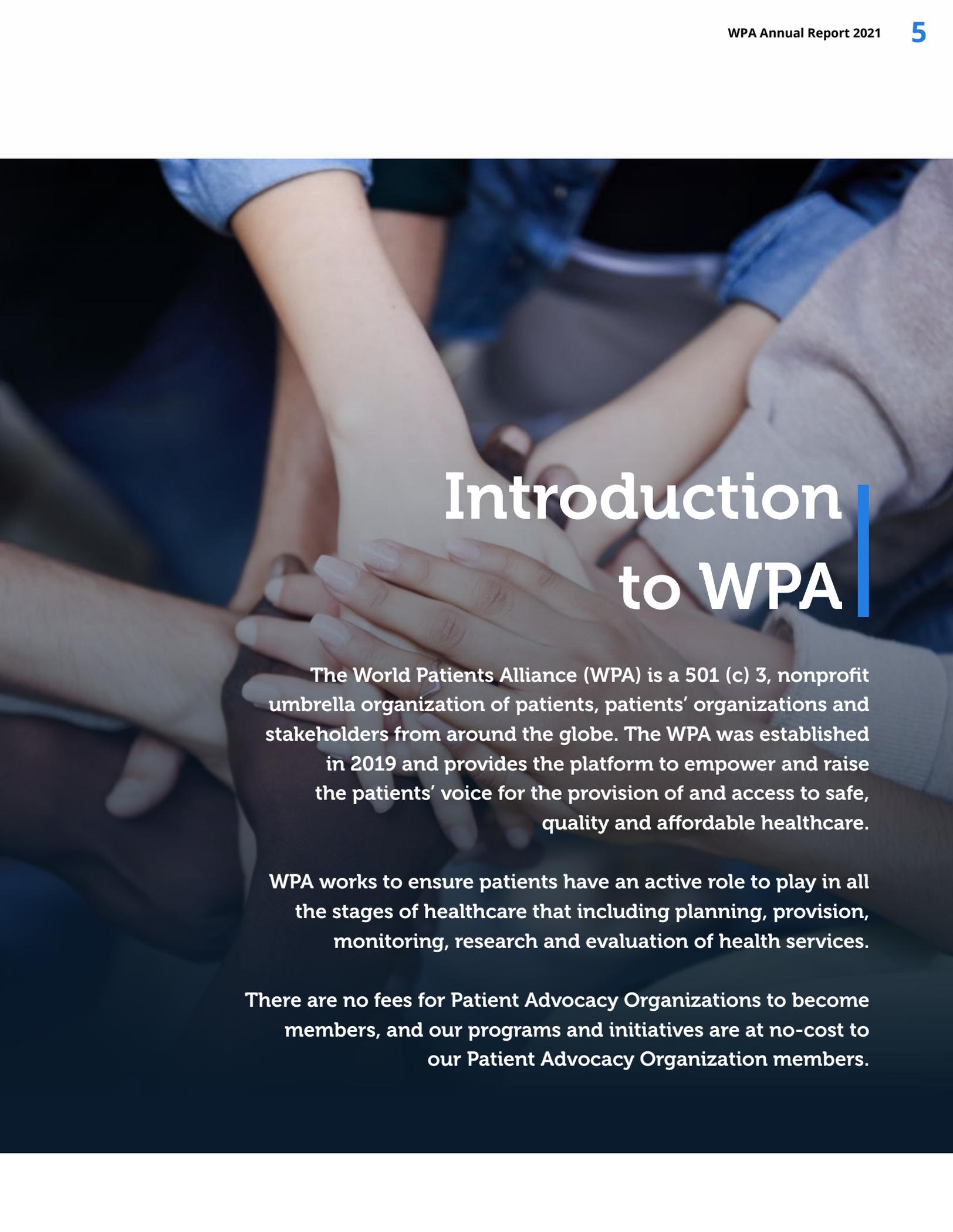
Together, our reach is not merely global, but grassroots as well. Our members have shown they can work collaboratively not only across country lines, but at the local level with partners in their communities, to reach large numbers of patients with our educational programs. For example, on the WHO's World Patient Safety Day, (September 17th, 2021) our members were able to host more than 800 educational events worldwide...on a single day. This achievement was made possible, in part, through educational grants that WPA provided to our member organizations in countries including Cameroon, Ghana, Greece, India, Israel, Lebanon, Malawi, Mali, Nepal, North Macedonia, Pakistan, Uganda, and the United States.

As we plan programs and activities for the next year, I encourage all of our members to participate in our 2022 Membership Survey so we may continue to provide programs targeted based on the interests and needs of the patients our members represent. I also hope that you will consider joining us, either virtually or in person, at our 1st World Patients Conference, to be held in Rome, Italy on October 15-16th, 2022. Learn more at our website www.WorldPatientsAlliance.org.

Enjoy reading about our successes!

Sincerely,

Andrew R. Spiegel,
Chair, World Patients Alliance



Introduction to WPA

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.

World Patients Alliance

Mission & Vision



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.



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



WPA Statement of Rights on Patient Safety, Quality of Care, and Access to Information

1. Right to safe, timely medical care that upholds the standard of care.
2. Right to be treated with respect, with regard for personal dignity, and without discrimination as to age, race, gender, sexual identity, social status, economic status, disability, or medical condition.
3. Right to know the name, purpose, risks, and benefits of the treatments and medications you are offered.
4. Right to be informed of your healthcare status and the plan for your care, in language that a reasonable person can be expected to understand.
5. Right to make your own healthcare decisions, including the decision to decline recommended care.
6. Right to have a family member or supporter present with you when receiving healthcare and to name a person to speak for you at times you cannot.
7. Right to access your medical record upon request.
8. Right to know the names and credentials of the persons providing your care.
9. Right to be treated by healthcare personnel who are adequately trained to provide the services they perform in a safe and effective manner.
10. Right to a healthcare environment that is clean and safe for you and for the persons providing your care.
11. Right to honest, timely and complete information about what has happened in the course of your care.
12. Right to have your opinion heard on the safety and quality of your care.

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 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.

WPA's Global Call to Action for COVID-19

The COVID-19 is the biggest health challenge that the world's nations have faced in the last 100 years. COVID-19 has affected nearly all countries of the world; both high-income as well as low- and middle-income countries found it hard to cope adequately with this crisis. There is no medicine available to cure COVID-19, which has resulted in millions of deaths globally.

Thankfully, several vaccines are now available to fight the spread of this deadly virus. Prevention strategies such as hand washing, sanitization and social distancing also have a role to play. But our governments and health systems cannot cope with this pandemic alone. They must continue working with patients and communities to overcome this global crisis.

The WPA requires that:

1. The governments and healthcare systems around the world must put in place effective strategies to ensure that all patients and communities have access to Covid-19 vaccines. The WHO and the UN must also ensure that there are global collaborative efforts for equal and immediate access of Covid-19 vaccine to all the people of the world without financial hardship.
2. The governments and healthcare systems must also ensure access to safe and appropriate diagnostic, preventive and treatment services. The high-risk individuals such as patients with pre-existing medical conditions, like hypertension, diabetes, heart disease, elderly and other vulnerable groups should be given special attention and access to appropriate services.
3. The governments must provide all the possible resources and support to their respective health systems and work towards the provision of adequate services to patients with no financial hardship.
4. There must be no discrimination by the governments and health systems on the basis of patient condition, age, language, religion, ethnicity, income level, legal status, etc.

5. The governments and health systems while dealing with the crisis must respect the values, preferences and needs of the patients. Moreover, individuals' rights, dignity, privacy & confidentiality and freedom should also be respected.
6. Patients organizations should be empowered as an important stakeholder for creating awareness and supporting patients & caregivers to make informed decisions and healthcare choices.
7. The patients and communities must be given comprehensive, appropriate and simplified information about the diagnostic, preventive, treatment and any other services. The patients and community members should be involved in the production and dissemination of this information.
8. The patients, patient advocates and patients' organizations should support their governments and healthcare systems by providing accurate information to the public that will help in timely diagnosis, prevention, treatment and vaccination at local levels. Moreover, they should also refer the public to reliable information resources such as World Health Organization (WHO) and other leading organizations' websites and other resources.
9. The patients and communities must cooperate with healthcare providers and authorities in not only dealing with their own health but also to help the community at large. In this regard, the regular advices of governments and healthcare authorities must be followed at all times.
10. The patients and communities must avoid public gathering, social distancing or any other activities that may help in increasing the virus spread.
11. The governments must ensure the human rights of the patients and communities during isolation, quarantine and any other such measures. The governments must engage with the populations and inform them about the goals and processes of isolation and quarantine. The values and concerns of the population should be taken into account in the planning, implementation, and utilization of such activities. No one should be kept in unnecessary isolation and quarantine. There should be constant monitoring and in the case of any problems, systems should be in place to take immediate correct measures. The patients and individuals should also take all the precautions as recommended by the health authorities. It is better to stay at home and self-isolate as it helps in preventing the spread of the disease.
12. The governments should ensure to the best of their ability that appropriate services are provided for comprehensive diagnostic, preventive treatment and vaccination services to people. Moreover, the patients feedback systems must be in place with authorities taking any corrective measures accordingly. Communication to the public needs to be updated on continued basis so that each person is informed about the progression of COVID-19 and what their responsibility is.
13. The WHO should coordinate global efforts and ensure the provision of diagnostic, preventive, treatment and vaccination services in all countries of the world so that no patient or community remains underserved. Moreover, the countries should also be provided any required support related to the supply of vaccine, medicines, equipment strengthening of the health systems as well as the capacity building of the healthcare providers.
14. The WHO and the UN must take the lead and devise a mechanism through which countries work collaboratively to deal with this pandemic. There should be global collaboration to ensure sharing of experiences, knowledge and expertise, as well as any other resources like financial help and provision of lifesaving medicines, equipment and vaccination.

Member Survey Results 2021

WPA created a shared a survey with all of our 200 plus member organizations. The results of this survey have informed us how to best serve and understand all of our member organization's needs. WPA patient organization members represent hundreds of millions of patients globally and through this survey, we were able to gain insight into their needs.

Survey Key Findings:



Access to healthcare was the highest reported issue

1 billion+

WPA Patient Organization
Members represent billions
of **patients globally**

50%

50% of WPA members said
advocacy was a priority and
over 70% of those respondents
are **requesting assistance** from
WPA in advocacy efforts

76%

76% of surveyed members
are seeking assistance from
WPA with **Education Devel-
opment** (toolkits, webinars,
trainings)

95%

COVID-19 has impacted 95%
of WPA Member organizations. The
highest reported numbers indicate
that organizations have **not been
able to continue services** the way
they did before the pandemic.



World Patient Safety Day

17 September 2019

WPA conducted the largest WPSD campaign globally as over 800 events were organized all over the world.

World Patient Safety Day (WPSD) is observed globally on September 17 every year. 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. The theme of WPSD 2021 was “Safe Maternal and Newborn Care” and all stakeholders were urged to “act now for safe and respectful childbirth!”. Maternal and child mortality is one of the major health issues of the current times. Every day we lose 810 women due to pregnancy-related complications, 6,700 newborns lose their lives, and there are 5,400 stillbirths globally. The tragedy is that most of these deaths are avoidable through the provision of safe care.



World Patient Safety Day 2021

WPA organized a regional webinar Series in the month of September 2021, some of which are described here.

Euro



The WPSD Regional Webinar for European region was held on 06th Sept 2021. The webinar was attended by patients and organizations from all over the European continent. Jolanta Bilinska, WPA founding Board member and President Polish Patients Safety Foundation moderated the webinar.

Asia



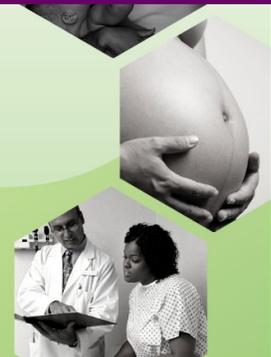
On Sept 13, 2021, the WPA Regional Webinar on WPSD was held for the Asian Region (including EMRO). It was a very successful event in which renowned speakers from the region participated, including WHO regional officials, patients' safety experts, and patient advocates from all over the region.

Latin America



The Spanish-language WPSD webinar for Latin America was held on September 9. The webinar was organized by Helen Haskell and hosted and moderated by WPA Board member Karla Ruiz de Castilla and the Peruvian NGO Esperantra.

Afro



On 14th September, the Ministry of Health Uganda in partnership WPA, WHO country office, and Community Health and Information Network (CHAIN) organized the AFRO region webinar. The event was a scientific meeting of 20 people at Golden Tulip Hotel, Kampala with 100 online participants from all over Africa.

WPA member organizations around the world held a number of events to educate and advocate on maternal & child health and medication safety.



PAKISTAN



GHANA



CAMEROON



NEPAL



POLAND

View full WPSD 2021 newsletter report online at: www.worldpatientsalliance.org/wpsd-2021-newsletter

WPA Webinars

Right from the beginning, we ensured to actually deliver on what our member patients organizations needed. So in 2021, when we had around 200 members, we created and launched a members survey to understand the members needs and how can we best serve. The vast majority of WPA members wanted assistance from us regarding educational development, which is why we launched Webinars and Workshops series.

We started our webinar series in late 2020 and continued them into 2021. Initially we focused on COVID-19, because that's what our members asked for. We brought in leading healthcare experts including policy makers such as health ministers, leading patients advocates & patients organizations, healthcare providers, the WHO and drug manufacturers. We were pleased to see very active participation from WPA members in these educational events.

WPA Global Members Webinar



Michael Ybarra MD
*Vice President and Chief
of Medical Affairs at PhRMA*



Dr. Yasmin Rashid
*Patient Advocate &
Health Minister, Pakistan*

Access to Healthcare during the COVID-19 Pandemic Webinar



Ravi Prasad
*Psychologist, Clinical Professor
and Director of Behavioral Health
at the University of California*



Anna Sliwinska
*President of the Polish
Diabetes Association*

COVID-19 Vaccine: Safe & Equitable Distribution Webinar



Laura Mann
*Director, Global Government
Affairs, AstraZeneca*



Sinan Atlig
*Regional President, Vaccines,
International Developed Markets,
Pfizer*



Dr. Marta Lomazzi
*Executive Manager, World Federa-
tion of Public Health Associations*

WPA Webinar on Health Technology Assessments



Jennifer Austin
*Chief Executive Officer (interim),
International Alliance of
Dermatology Patient
Organizations (GlobalSkin)*

World Patients Alliance Workshop

Workshop on Managing Stress During the Pandemic

WPA conducted Workshop on Managing Stress During the Pandemic on November 9, 2021. The main idea of the workshop was to discuss that how to Manage Stress During the Pandemic because over the past 18 months everyone dealt with increased stress because of COVID-19. For many, life was stressful enough without having a pandemic to cope with. Knowing how to deal with the stress of everyday life is directly connected to your overall health and wellbeing. The World Patient Alliance thought it important to provide our member organizations with a workshop on managing stress during such challenging times. During this workshop different experts on a variety of topics shared with participant how to recognize and manage stress in everyday life. WPA Board members Penney Cowen and Jolanta Bilinska also participated as a speaker in the Workshop. The entire workshop videos are currently available on YouTube.

Workshop recordings available for online viewing at YouTube:

📺 [WPA Workshop on Managing Stress During the Pandemic Part 1](#)

📺 [WPA Workshop on Managing Stress During the Pandemic Part 2](#)



Christopher Shannon
*Doctoral Candidate in
Counseling Psychology,
University of Missouri*



Bini Sebastian
*Doctoral Candidate in
Counseling Psychology,
University of Missouri, USA*



Aliya Jafari
*Academic Coach
& Yoga instructor*



Sarah Burns
*Professional Landscape Painter
and Art Teacher*

WPA Board of Directors



Chair: Andrew Spiegel, Esq.
*Global Colon Cancer Association,
USA*



Secretary: Penney Cowan
*American Chronic Pain
Association, USA*



Treasurer: Jolanta Bilinska
*Patient Safety Foundation,
Poland*



Director: Regina Kamoga
*Community Health and
Information Network,
Uganda*



Director: Karla Ruiz de Castilla
Esperanza, Peru



Director: Hussain Jafri
Alzheimer's Pakistan

WPA 2020 Financial Report

Revenue	\$236,248
Program Expense Areas:	
Growing and supporting the international Patient community	\$18,463
Advocating for patient-centered policy	\$25,624
Education	\$14,555
Total for Program Expense Areas	\$58,642
Management & General Expenses	\$13,504
Total Expenses	\$72,146

Amounts shown in USD



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