

## NEWS

#### **World Health Assembly Starts**



The 76<sup>th</sup> World Health Assembly has begun at Palais des Nations. Geneva, Switzerland, which will run from 21 to 30 May 2023. The World Health Assembly is the decision-making body of the World Health Organization (WHO). A number of important healthcare issues faced by the world will be discussed at the World Health Assembly this year, which include the ongoing health and humanitarian emergencies, thus driving forward WHO's focus towards health for all.

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#### 5th Global Ministerial Summit on Patient Safety

Switzerland hosted the **5th Global Ministerial Summit on Patient Safety** from 23-24 February 2023 at Montreux. The Global Ministerial Summits on Patient Safety have been very successful in raising awareness on Patient Safety issues all above the world. The Summit covers patient safety in different technical domains through a broader, public health policy perspective.



# 17th World Congress on Public Health

WPA participated in the **17th World Congress on Public Health (WCPH)** in Rome from 2-6 May 2023. More than 3,000 public health professionals and researchers, policymakers, and students attended the global event organized by the World Federation of Public Health Associations (WFPHA) in association with the Italian Society of Hygiene, Preventive Medicine and Public Health (SItI) and the Association of Schools of Public Health in the European Region.

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## **Getting to Know the WPA Board Members**



#### Meet Andrew Spiegel WPA, Board Chair

To help our members get to know each board member a little better and understand why we give our time and talents freely to support and grow the World Patients Alliance, we will be featuring an interview with each board member over the next few issues.

Andrew Spiegel co-founded the Colorectal Cancer Alliance, a US-based national patient advocacy organization dedicated to colon cancer. Today he is co-founder and CEO of the Global Colon Cancer Association (GCCA). Mr. Spiegel is a co-founder and Board Chair of the World Patients Alliance since its inception in 2019. He has been a driving force in the success and growth of the World Patients Alliance working closely with our Executive Director, board, and staff.

**WPA:** When did you first get involved in the nonprofit world/community?

**A.S.:** My first encounter with the nonprofit world was in 1998.

WPA: What lead you to get involved?

A.S.: In the summer of 1998, my mother was diagnosed with metastatic colorectal cancer and as I began to do a little bit of research, I learned that this disease was the second leading cause of cancer deaths. Surprising to me, despite this startling statistic there were no patient advocacy groups in the United States for colorectal cancer. It was that revelation that was my motivation to get involved in the patient advocacy world. I began by cofounding the first patient group for colorectal cancer in the United States, The Colorectal Cancer Alliance. The mission of the CCA is to empower a nation of allies who work with us to provide support for patients and families, caregivers, and survivors; to raise awareness of preventive measures; and inspire efforts to fund critical research.

**WPA:** Is your background in nonprofit management or were you involved in a career when you began your work with colon cancer?

**A.S.:** Before getting involved in the colorectal cancer community, I had no nonprofit experience. My career was as a self-employed attorney. I was driven by my passion to bring the importance of early screening and education about colorectal cancer to the public.

**WPA:** What would you say is the most rewarding part of working with a nonprofit?

**A.S.:** Everything I do, every decision I make, every conversation or Zoom I have, every email I read or respond to is helping make the world a better place. Everything I do has only good intentions behind it. There are very few positions where that reward exists. It is my sincere hope that together we can raise awareness about the importance of early screening to identify the disease in the early stages and save lives.

**WPA:** What is the most challenging part of working with a nonprofit?

**A.S.:** Nonprofits are businesses and are run as such, yet many believe that NGOs work with little expense and with only volunteers. The reality is the opposite. NGOs fill a significant gap in society and to be effective, they must be run as a business and attract talented experienced professionals to make the business a success. Fundraising should not be the greatest challenge for a nonprofit organization but sadly I feel most would agree that having sufficient funds to accomplish one's mission remains the most

#### challenging part of NGO running.

**WPA:** What would you tell someone who was thinking about working or being involved with a nonprofit health organization?

**A.S.:** First, do your research to see who is already in that disease area. See what they are doing, get involved or partner with an existing organization rather than recreate the wheel. Second, determine what unmet need you want to address and remain focused on that as your mission. Third, just do it! Don't be afraid that you lack experience or expertise. We all did at one point. You will learn and grow every day.

**WPA:** What are you most proud of because of your work in the nonprofit world?

A.S.: Impact. It's almost impossible to measure the real impact NGOs have on improving the health of society. Usually, many stakeholders are involved in effecting change so it's difficult to determine whose efforts led to success and its usually the combined efforts that actually cause the change to occur. But I know that if you remain on mission, you can take comfort in knowing you contributed to the success you hoped to achieve. For over two decades I've personally witnessed the colorectal cancer movement in the United States. Its arguably one the biggest public health success stories in decades. We have gone from having zero Americans screened for this preventable disease to nearly three-fourth of the population now getting screened. We have gone from one highly infective drug for this disease to now over thirty FDA approved therapies and this has resulted in life expectancy of the metastatic colorectal cancer patient tripling since I got involved in the cause. And now I work in the global arena and I'm working with stakeholders around the world who are committed to needed awareness and change for a disease that will soon be the leading cause of cancer death worldwide. So, what I'm most proud of is I know my efforts have had impact.

**WPA:** If you want, you can share a little bit about you. The number of kids, pets, and anything things else that would put a more personal spin on the article.

**A.S.:** I am married and have three children, all teenagers. I also have three dogs.

We want to thank Mr. Spiegel for sharing his story with our readers. We hope this will help you understand the passion and commitment that each of the World Patients Alliance board members have to see the WPA succeed in its mission.

# **Events**



#### World Day of the Sick 2023

World Patients Alliance (WPA) in collaboration with the Polish Patients Safety Foundation organized the World Day of The Sick on 12 February, 2023 at Lodz, Poland.





#### Workshop on Person-centered Care System

World Patients Alliance (WPA) & International Society for Quality in Health Care (ISQua) jointly hosted a workshop based on the recently published white paper "Person-Centered Care Systems: From Theory to Practice".

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### **Members'** Corner

### **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.

- Managing People with Chronic Diseases in The Work Environment by Malta Health Network. (Malta)
- National Thalassemia Welfare Society organized "10th National Thalassemia Conference" (India)
- The Thalassaemia Federation of Pakistan (TFP) organized a Seminar and an online Thalassemia clinic to commemorate the International Thalassaemia Day 2023. (Pakistan)

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**



#### National Incontinence Day June 28, 2023

Incontinence is a devastating problem in Italy affecting nearly 5 million people - 60% of which are women facing impact on social, psychological, professional, familial, physical, sexual, economical, school and sports related aspects of their lives. FINCOPP is celebrating national day for the prevention and treatment of Incontinence on June 28, 2023. For more information please visit http://www.fincopp.org



Patients Day 8 October 2023 Arrhythmia Alliance is organizing Patients Day on 8 October 2023 sharing great learning about the latest developments in arrhythmias, syncope care and treatment options from leading medical experts. Patients Day provides the opportunity to hear the latest developments in arrhythmias (including AF), syncope

care and treatment options, from leading medical experts. For more information please visit ttps://beattrbuthmalliance.org/aa/uk/brc2023.pa-

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## **New Members**

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

Member Organization	Country
Greek Carers Network Epioni	Greece
Down Syndrome Foundation	Uganda
The Josiah Centre	Ghana
MD Healthcare	UK
La ASOCIACIÓN DE PACIENTES CON ANGIOEDEMA HEREDITARIO DEL PERÚ	Peru
Organización de Pacientes con Hipertensión Pulmonar	Peru
King Hussein Cancer Foundation	Jordan
La Universidad del Paciente y la Familia	Spain

# **Collaborations**

WPA is pleased to announce partnership with the **Universidad del paciente y la familia**, Spain (The University of the Patient and the Family). It is a center of academic innovation with an objective to offer accredited training to patients, relatives, caregivers, volunteers and the professionals in collaboration with universities, scientific societies and foundations. A partnership MOU has been signed between the two orgnazations.

World<br/>Patients<br/>AllianceWorld<br/>Patients<br/>Patients<br/>Patients

# World Patient Safety Day 2023



"Engaging Patients for Patient Safety" has been selected as the theme for World Patient Safety Day 2023. Evidence shows that when patients are treated as partners in their care, significant gains are made in safety, patient satisfaction, and health outcomes. Resolution WHA72.6 urges Members States "to put into place systems to support the active engagement, participation, and empowerment of patients, families, and communities in the delivery of safer health care".

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# **WPA Announcements**

### 1st WPA Asia Pacific Regional Meeting



### Workshop on Patient Safety: Diagnostic Errors



Workshop on Sustainability



# Article



The Patient's Role in Patient-centered Care By Penney Cowan | Co-founder WPA

Each of us is a patient at some point in our lives. It is unavoidable, even if it is for a simple annual checkup or injury. But how engaged are you with your health care professional (HCP) during your visit? Do you ask questions? Or are you one of those who think of all the things you should have said and questions you did not ask on the way home from your HCP visit?

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