



9th Global Patients Congress Report

Co-creation in Innovative Healthcare during COVID-19

11th January 2021

Contents

Executive Summary	3
Acknowledgements	5
Partners	6
Message of condolence	7
Background.....	9
Aims and objectives of GPC 2020	11
GPC 2020 Theme	13
Introduction to Programme Sessions	14
Day One	14
Opening Ceremony	14
Keynote Speech.....	16
Sessions.....	18
Day Two	33
Keynote Speech.....	33
Keynote Speech.....	34
Sessions.....	35
Final Remarks.....	53
GPC 2020 Call to Action	56
Resources and Inputs.....	57
Booth Visits.....	58
Outputs, Outcomes and Impact.....	59
GPC 2020 Information	61
Programme	61
Delegates' Attendance.....	68
List of Speakers	70
IAPO Staff	90

“

We have found that the factors that helped countries respond and cope better to the COVID-19 pandemic included strong political leadership, a reliance on science and public health experts to shape the strategy, being open and transparent with the public, having clear communications lines and having citizens involvement and empowerment to act within the guidelines they receive and trust between government and their citizens.

*Dr Soumya Swaminathan, MD,
Chief Scientist, World Health
Organization*

”

Executive Summary

The 9th Global Patients Congress (GPC 2020) was meant to be a celebratory event to mark our twenty first anniversary and the coming of age of patient centred healthcare globally.

However, the COVID-19 pandemic overtook all of us revealing great fault lines in our health systems and shifted all our membership's focus as most of them had to rapidly assist their patient communities and governments to develop effective shielding programmes for very vulnerable patients.

The pandemic was a catastrophe for patient-centred healthcare and the social welfare and mental health wellbeing of our patients was adversely impacted as the unplanned lockdowns ensured that most healthcare services and access to medicines and psychosocial support were disrupted.

The GPC 2020 had to take place virtually under a new theme "Co-creation in Innovative Healthcare during COVID-19" on 16-17 September 2020.

GPC 2020 Virtual brought together 1300 delegates from 101 countries and nearly 400 patient groups. We were also happy to virtually meet representatives from 98 IAPO member organizations live while others accessed the recordings on www.gpc2020.vfairs.com.

The GPC 2020 opened with a Keynote from WHO Chief Scientist Dr Soumya Swaminathan, Chief Scientist who brought everyone up to date on the fast progress being made on World Health Assembly Resolution 73.1 Covid-19 response and the impact COVID-19 was having on existing WHO programmes on Maternal and New Born Health, TB, Malaria and NCDs. Under the umbrella of the International Federation of Pharmaceutical

manufacturers, Industry representatives from the five Covid-19 candidate vaccines then laid out the route plan on how quickly they would be ready and what needs to be done.

Expert patients, policy makers and practitioners coming from 28 countries organised in 27 thematic panels then delivered the remaining 64 insightful presentations. The sessions paved the road to discussing:

- The health crisis provoked by COVID-19 worldwide and its impact on the patient community;
- How to realise the World Health Organization (WHO)'s commitment to "build back better" and ensure the implementation of the World Health Assembly Resolution 73.1 COVID-19 response;
- The next steps for strengthening health systems and preparedness through patient led and co-created innovative solutions post COVID-19 and in future.

Throughout GPC 2020, speakers raised key issues and delivered unique take-home messages. These included the importance of all WHO Member States and pharmaceutical industry to keep cooperating and sharing knowledge and resources in the fight against COVID-19. All Speakers also agreed on the importance of patients' engagement to address the 'infodemic' and vaccine hesitation, and their participation in health systems all over the world.



World Patient Safety Day 17 September 2020

Day 2 of GPC 2020 marked the 2nd World Patient Safety Day (WPSD). At IAPO we know how crucial safety is for all patients seeking healthcare. However, safety in health systems is a global concern because of increasing numbers of people suffering avoidable harm or being put at risk of injury while receiving healthcare.

IAPO invited Hon. Jeremy Hunt MP the Chief Architect of the Global Ministerial Patient Safety Summits and former UK Secretary of State for Health and Social Care to open with a keynote.

Recognising the urgency of the issue, on 17th September 2020, health stakeholders from all over the world stood together, united in observing the WPSD. The COVID-19 pandemic has unveiled the serious difficulties health workers are facing worldwide while responding to this unprecedented global public health challenge. World Patient Safety Day 2020 was an opportunity to emphasize the importance of health worker safety as a priority for patient safety by committing and taking urgent and sustainable action to recognize health worker safety as a prerequisite for patient safe. This was a unique opportunity for patients, patients' groups, carers, civil society organizations and other relevant

stakeholders to stand together in our call for safe patient-centred healthcare as an essential component for the achievement of universal health coverage.

The theme for WPSD 2020 was '**Health worker safety: A priority for patient safety**'. This theme was selected given the current challenges health workers were facing with regards to their physical and mental health and safety amid the COVID-19 pandemic. The slogan 'Safe health workers, Safe patients' reflects the interlinkages between health workers safety and patient safety. Services cannot be delivered safely if health worker safety itself is not prioritized and addressed.

The WPSD 2020 therefore called on WHO Member States and partners to 'Speak up for Health Workers Safety!' urging them to prioritize and address the issue in a holistic manner.

Acknowledgements

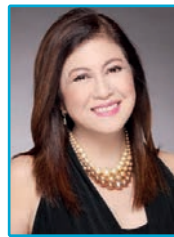
We first want to thank all the health professionals and frontline health workers who have been putting themselves at great risk to take care of patients during the current COVID-19 pandemic.

Many have made the ultimate sacrifice and lost their lives in serving us. We pass our condolences to their families. In this year of the Year of the Nurse and the Midwife 2020, we acknowledge the great support given to us by the International Council of Nurses during this pandemic.

We also want to thank our members, industry partners, collaborating partners and supporters who made the 9th Global Patients Congress a great success despite the difficult circumstances that they are all facing. They stepped forward to help in planning the event by joining our GPC Organising Committee and later as moderators and speakers during the congress.

Our special thanks go to the World Health Organization (WHO) and its Secretariat and specifically the WHO Patient Safety and Quality Improvement Unit in the Service Delivery and Safety Department for helping us mark a great 2nd World Patient Safety Day on 17th September 2020. We particularly want to thank Dr. Soumya Swaminathan, Dr. Neelam Dhingra, Dr. Ivana Knezevic and Joseph Kutzin for enriching our programme and sharing with our members great insight into the COVID-19 pandemic and the WHO Flagship Decade of Patients Safety 2020-2030.

We would like to thank the GPC 2020 Committee:



Karen Alparce-Villaneuva (Chair)



Dr Ratna Devi



Dr Neda Milevska



Kawaldip Sehmi



Sabine Nick



Bisi Bright



Dani Mothci



Rachel Githinji

GPC 2020 Rapporteurs:



Monique Bittencourt Franca

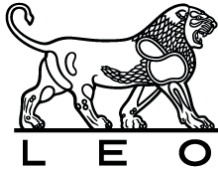


Antonia Gama Da Costa

Partners

Lastly, we thank our Industry Partners without whose partnership and resources we could not have delivered this quality virtual congress.

Platinum Sponsors



Gold Sponsors



Silver Sponsors



Message of condolence

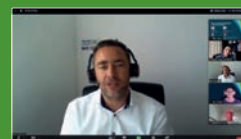
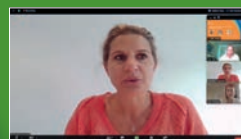
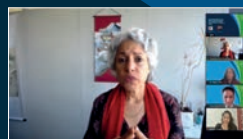
At the time of the Congress, many countries were going through the first wave of COVID-19 infections and bereavements. IAPO and its family of patient organizations shared this pain, and send out our deepest condolences to the bereaved families and friends of those who have lost their lives to COVID-19.

IAPO and its board were directly affected by the loss of Carol Ossai, an incredible patient advocate and board member of IAPO, who passed away in April 2020. She was the Founder and CEO of Sick cell and Young Stroke Survivors UK, a charity founded in 1996 after her personal experience of caring for her son who was a young stroke survivor at the age of six years. Carol was a EUPATI fellow with a keen interest in the research and development of drugs for rare diseases. She was also a selected reviewer with the European Medicines Agency and a selected member of the Innovative Medicines Initiative (IMI) pool of expert patients. Carol founded the Sick Cell in Africa Patient Parent Network (SCAPPN), a network of patients and parents directly affected by Sick cell that led grassroots initiatives in Africa, and the Global Alliance of Sick Cell Disease Organizations (GASCDO), a global sickle cell disease patient organization dedicated to inspiring hope and improving the quality of life of all people with SCD worldwide.

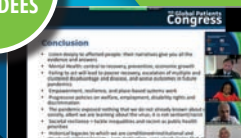
The IAPO family will terribly miss Carol. Now, more than ever, we will endeavour to advocate for the safety of patients at all times, and will continue to stand by the global community in the fight against COVID-19.



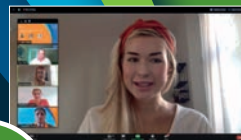
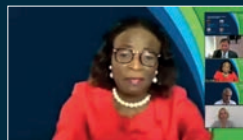
Carol Ossai



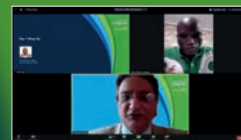
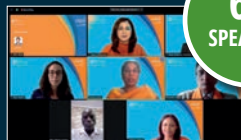
1200
ATTENDEES



26
SESSIONS



64
SPEAKERS



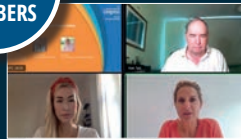
101
COUNTRIES



338
PATIENT GROUPS



83
IAPO MEMBERS



Background

The bi-annual Congress is the International Alliance of Patients' Organizations (IAPO)'s flagship event that brings together our global membership with a variety of high-level global healthcare stakeholders to discuss urgent needs in global health and advocacy needs in driving progress for healthcare that is designed, organised, and practised with the patient at the centre.

With patient advocates coming from all disease areas from across the world, GPCs are a moment that celebrate patient advocacy and patient-centred healthcare. The GPC gives the participants an enabling environment to learn how the newest global trends in healthcare will affect patient centricity, access, safety, quality, and affordability nationally.

More importantly, the GPC is a strategic cross-sector think-tank comprising expert patients and global healthcare stakeholders willing to share their insight over two days to support patient groups in shaping their national health policy, strategies, programmes, projects, and services in order to address the challenges we face.

The Congress acts as a vital step to further the process of developing global patient-centred healthcare by acting

as a platform where patients and policymakers can discuss detailed actions to take to ensure patient-centred healthcare is a reality around the world. Started in 2005, the bi-annual Global Patients Congress continues to facilitate its intended outcome of fostering greater connection among delegates and collective action around urgent needs.

Our 9th Global Patients Congress (GPC 2020) coincided with IAPO's 21st Anniversary. IAPO and the global patients' movement have come of age, and we are an optimistic, confident and a well-informed global patients' movement that is integrated into the global healthcare policy and decision-making infrastructure.



Global patient movement coming of age: 21 years of shaping our healthcare landscape

IAPO was formed in 1999 as a response to developments in healthcare that were increasingly marginalising patients by restricting participation and engagement. IAPO wanted to put the patient back at the centre of all healthcare decision and policymaking.

Modern medicine has lost its touch with its societal roots and has increasingly excluded patients from the centre by creating silos and hierarchies in the healthcare systems.

Medicine forgot that 'A good physician treats the disease; a great physician treats the patient who has the disease.'
(Sir William Osler)

While we have surmounted most of the traditional barriers in healthcare during the past 21 years, the modern healthcare landscape has changed dramatically over the last decade. Rapid globalisation, digitised and innovation within healthcare has created new challenges and barriers for us.

Aims and objectives of GPC 2020

IAPO's overall vision is to see patient-centred healthcare institutionalised globally. GPC 2020 aimed to raise awareness of barriers and challenges faced by our global patient community and provide patient advocates with evidence-based healthcare policy and practice solutions to overcome these challenges and realise our vision.

GPC 2020's main objectives were to ensure that our delegates:

- Understood and appreciated the scale of the COVID-19 and other modern healthcare problems and their location within their healthcare value chain. What was preventing us from achieving our vision and realising the right to health above?
- Participated with the invited keynote speakers, experts, patient organizations, regulators, payers, health technology assessors, academics, and the healthcare industry in identifying the most effective, efficient and evidence-based patient centric strategies, policies, products, services and interventions that are available to our members to influence health policy and decision-makers to address these barriers and challenges.
- Engaged with our members in global advocacy to ensure that 194 heads of the WHO Member States address the WHA Resolution 73.1 COVID-19 Response and respect, promote and protect patients' right to health and act on their political commitment and obligations adopted under:
 1. *The Declaration on Universal Health Coverage which was announced at the UN High-Level Meeting on Universal Health Coverage (UHC-UNGA 2019)*
 2. *WHA 72 resolution 72.6 - Agenda item 12.5 Global action on patient safety (72 WHA 2019)*
 3. *WHO Constitution (2006) Right to Health*

We wanted every delegate to recollect that their country has ratified the WHO Constitution in 1946 and must at all time ensure that:

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, and political belief, economic or social condition.



GPC 2020 Theme

Co-creation in Innovative Healthcare during COVID-19

World Health Organization's Director-General (WHO DG) Tedros Adhanom Ghebreyesus at the historic virtual and de minimis 73rd World Health Assembly in May 2020 said that the world had come together virtually to confront the defining health crisis of our time.

World Health Organization's Director-General (WHO DG) Tedros Adhanom Ghebreyesus at the historic virtual and de minimis 73rd World Health Assembly in May 2020 said that the world had come together virtually to confront the defining health crisis of our time.

Our virtual 9th Global Patients Congress 16-17th September 2020 (GPC 2020) was an equally important moment to reflect upon the impact of the pandemic on our global patient community and our health systems. It was also a moment for patients to engage in focused discussion on health systems strengthening and preparedness through patient led and co-created innovative solutions.

The world now needs a whole-of-government and whole-of-society response to engage and empower people and communities to keep themselves and others safe to control the COVID-19 pandemic. The WHO DG reminded us of the challenge ahead: it will take hard work and high fidelity to science in all decision-making, especially within some exceedingly difficult decisions to come in maintaining effective test, treat, cure and shield programmes without breaching human rights and privacy of patients with pressure to end lockdowns and jump start economies.

From the initial global COVID-19 infection related mortality and morbidity statistics, we saw that patients with chronic conditions, especially those with multimorbidities, had the worst outcomes. It was also noticeably clear that many of our health systems did not have capacity to shield immunocompromised patients behind effective patient centred and evidence based shielding programmes. It is important that we address this failure.

However, we also saw some innovative patient led good practice as many health systems began to provide virtual and digital healthcare services. A lot of primary healthcare reverted to telemedicine and remote peer-to-peer (expert-patient to new patient) supported self-care and home-based care solutions that alleviated some of the mental health pressures affecting those in self-isolation. Patients must continue participating in co-creating other innovative solutions. Nothing about us without us.

Introduction to Programme Sessions

Day One

Opening Ceremony

Dr. Ratna Devi, Chair of IAPO Board, opened the 9th Global Patient Congress by welcoming delegates from across the globe. In these unprecedented times, Dr. Ratna's welcome followed with a prayer for the health workers and those struggling with COVID-19 around the world. She stated that it is only through national unity and global solidarity that the world will be able to overcome the current challenges posed by the COVID-19 pandemic.

Dr. Ratna then introduced the programme: Day 1 focused on topics selected by members and Day 2 was dedicated to World Patient Safety Day. She mentioned the irreparable loss caused by the pandemic to countries, communities, and families, and the great loss to IAPO of its board member Carol Ossai, honored in the programme by the Carol Ossai Talk.

She thanked the World Health Organization, especially the Patients Safety Flagship Team for helping to shape Day 2 and agreeing to speak on various sessions. She

finalized her speech with the announcement of the COVID-19 Response Activity Grant for IAPO members in middle and low-income countries.

Dr. Neda Milevska Kostova, IAPO's Vice-Chair, through her opening remarks attested to IAPO's commitment to improve patient-centered healthcare and presented the three key pillars of IAPO Strategy 2019-2021, which has been developed with and for the members:

1. Empower patient communities globally to advocate effectively for patient-centred universal health coverage for all;
2. Drive research processes and development of evidence base for patient-centred universal health coverage;
3. Shape law, policy and practice at global, regional and national levels.

Dr. Neda then presented exciting partnerships towards achieving the vision for the new roles of IAPO. In February 2020, the governing board reinforced IAPO's new role in creating multi-sectorial partnerships in research. The creation of the Scientific Advisory Board is the first step in this journey, representing diversity in terms of sectors, interests, expertise and geographic regions, just like the global patient community.

The current pandemic has also highlighted the importance of expert patients. Therefore, Dr. Neda also pointed out IAPO's initiative on developing strategies with partners to recruit and train expert patients and equip



Dr Ratna Devi



Dr Neda Kostova



Karen Villanueva

them with new skill set so they are able to engage in research planning and implementation.

Finally, the Vice-Chair also reminded IAPO's initiatives on acknowledging the achievements of contributors for better healthcare, such as achievements of women in science and expert patients.

Karen Villanueva, IAPO's Board Secretary and Congress Committee Chair, welcomed all and introduced the 9th Global Patients Congress, stating its theme is a call for co-creation and innovation, the opportunity to share the patients' experiences and join the whole society and government's efforts to control the current pandemic, as well as rebuild the system as a whole-of-patient-community. The pandemic has proven that without healthcare worker safety there is no patient safety. Therefore, the second day of GPC 2020 was dedicated to the World Patient Safety Day, which kicked off WHO Decade of Patient Safety (2020-2030).

Villanueva then presented the GPC 2020 highlights: 1088 delegates from 69 countries representing all

regions of the world; 338 patient groups of which 83 IAPO members; 64 speakers from 28 countries; 23 booths from 22 organizations. She then thanked all IAPO members and fellow patient advocates, partners and speakers for their participation in this milestone IAPO event.

The Board Secretary closed her welcoming speech stating GPC was an opportunity to co-create safe, innovative and resilient health systems, future-proofed for healthcare challenges. She also reminded that health is an investment, not a cost; it is a prerequisite and not a reward for development; it is a pathway for security, peace and prosperity.

Keynote Speech

WHA 73.1 and Future-Proofing Health Systems: Preparedness for Next Phase of Pandemic COVID-19 and Patient Co-Creation

The COVID-19 pandemic has unveiled that no country or health system is robust enough to face the threats posed by unknown pathogens. As governments, healthcare institutions, researchers, and most importantly the patients themselves are struggling to cope with the current scenario, member States in national unity and global solidarity must act as whole-of-government, whole-of-society and whole-of-patient communities to first strengthen their public health systems, then ensure the patients receive timely and appropriate treatment that is accessible to all.

Dr Ratna Devi, the Chair of IAPO Board and moderator of this panel, introduced the session and pointed out WHO's efforts in bringing together all the knowledge and information into trustworthy guidelines to overcome the current COVID-19 pandemic and avoid others in the near future.

Dr Ratna presented the session panellists:

- The guest of honour and keynote speaker of the session, Dr Soumya Swaminathan, Chief Scientist Officer of the World Health Organization
- The discussant Dr Komal Kanitkar, a diabetic patient and COVID-19 survivor

Dr Soumya Swaminathan started by pointing out that we are all going through a difficult time, and the pandemic encourages us to think jointly about the positive and negative outcomes of this scenario.

The pandemic has brought the global community together: scientists in their research, clinicians in their practice. However, the response to COVID-19 did change from country to country. Among the important factors that contributed to many countries' effective response, Dr Soumya emphasized strong political administration and the citizens' involvement in the development of solutions.

According to her, The second wave of infections in Europe was a result of the increase in testing. On one hand, we are learning how to manage the disease better as time goes by. Data and surveillance about the virus are vital to track the situation in different countries, especially in the overcrowded ones.

On the other hand, essential health services have been severely impacted and countries need to work to provide universal healthcare while responding to a pandemic. For instance, the underlying NCDs make people more susceptible to infections. If these diseases are neglected,



they worsen the impact of pandemics. Therefore, Dr Soumya made a call to break the cycle of panic-and-neglect: we must detect, prevent and respond to infection outbreaks.

Although there is now a vast debate about virus transmission all over the world, there are still important gaps in our knowledge about COVID-19. As the biggest fallout of these times, Dr Soumya pointed out that the pandemic has increased inequities and inequalities all over the world. People are being pushed to poverty and the most vulnerable are suffering the most.



Dr Swaminathan

“

This is a test of global solidarity. All countries must be protected from COVID-19 and we cannot have differences between countries when it comes to vaccines.

This is also important to help us achieve a good level of global immunity.

This only reinforces the need for the kind of advocacy that IAPO does and we need to stay positive and help each other.

Dr Soumya Swaminathan

”

Sessions

COVID-19 Vaccine Development for Future and Current Pandemics and Public and Patient Engagement in Clinical Trials

There is a pressing need for information on the COVID-19 vaccine development. Several candidate vaccines are using various technological platforms from RNA/DNA through to peptide-based/recombinant protein and traditional live attenuated and inactivated virus approaches. Many Phase III trials were coming to an end.

The purpose of this session, one of the most awaited of GPC 2020, was to hear a report of the candidate vaccines clearly highlighting where they were, what was in the pipeline and how we will make these vaccines accessible for all from selected International Federation of Pharmaceutical Manufacturers & Associations (IFPMA) partners.

The IFPMA provides a global collaboration platform to accelerate the development, production and equitable access to COVID-19 diagnosis, therapeutics and vaccines.

One pillar of this joint effort is COVAX, a coalition for epidemic preparedness and innovations at WHO.

The moderator, Karen Villanueva, IAPO Board, introduced the five panellists:

- Thomas B. Cueni, Director General, International Federation of Pharmaceutical Manufacturers & Associations
- Dr Jerald C. Sadoff, MD, Senior Advisor of Clinical Vaccine Development, Janssen Infectious Diseases and Vaccines
- Dr Thomas Breuer, MD, MSc, Chief Medical Officer, GSK Vaccines
- Julia Spencer, Associate Vice President of Global Vaccines Public Policy, Partnerships and Government Affairs, MSD
- Steve Lockhart, Vice President, Head of Europe and Asia-Pacific, Vaccine Clinical Research and Development, Pfizer

Thomas B. Cueni gave a broad view of this unique collaborative effort to develop a vaccine for COVID-19. This effort is unprecedented in many aspects: (1) speed, as the fastest vaccine ever to be developed was Ebola in four years, the attempt now is to cut this down to 12-18 months; (2) volume, as the highest volume ever produced - aside from seasonal flu shots - is polio, 450 million doses, and for COVID-19 it will probably require 15 billion doses (as double dose is required for immunization). These unprecedented numbers require unique collaboration and logistics to make it available and affordable on a global scale.



“ All the companies are firmly committed to doing the vaccine at a great speed, as fast as possible and as slow as necessary.

Thomas Cueni



”

Many countries are trying to meet the expectations of their populations, therefore the importance of COVAX being a connective effort with an extent never seen before. One of the ambitious objectives to be fulfilled by COVAX is solidarity from rich countries to poor countries.

Expectation management is also important as there won't be sufficient quantities of vaccine for everyone in the short term. Hence the allocation principle of WHO, to which countries have signed up through COVAX, is covering 20% of the priority population: 1% of healthcare frontline workers, 8% of elderly people above 65 year old, as well as people affected by comorbidities.

Dr Thomas Breuer highlighted there is only one way to supply the vaccine: several companies will have to supply it. Therefore GSK has decided to work with other companies instead of developing its own vaccine, by providing key ingredients for the production of several

“ Normally we are in fierce competition, but this time I hope my competitors will succeed in their efforts.

Dr Thomas Breuer



”

collaborators, such as Chinese and Canadian companies and including the company's main competitors, Sanofi. Dr Breuer explained GSK has a platform to mass produce key ingredients whereas Sanofi has a platform to mass-produce the vaccine. Most companies are committed to produce vaccines at scale and this has to be done through partnerships.

Dr Jerald C. Sadoff gave a snapshot of the Janssen Infectious Diseases and Vaccines programme. A series of pre-clinical studies have been done with primates and hamsters and Dr Sadoff stated they were positive; their one dose vaccine had a very good chance of being successful.

“ This is probably the first time in my 45 years in the industry that we've been actually cheering on for the other companies as well as ourselves because this is an effort that is very important for the entire world.

Dr Jerald C. Sadoff



”

On their Phase 3 trials with different groups, they are enrolling younger adults as well as the elderly, hoping to have results between late December 2020 and March 2021, committing to provide a billion doses of vaccines in the near future.

Julia Spencer gave a brief overview of MSD's efforts on delivering a vaccine, working with partners towards two vaccine candidates: RV590 and RV591 program. In terms of clinical studies, she assured MSD is not only taking care of scale but also making sure to have diversity.

“Ultimately there is a need for a lot of work now to prepare the systems tomorrow to deliver these vaccines.

Julia Spencer



”

There are a number of measures to ensure minority population across the globe are participating, as this is important to bring trust among these communities and to ensure people understand how these vaccines are being developed.

Steve Lockhart highlighted how encouraging it is to see the broad spectrum of vaccines being developed, as in this stage no one knows which one is going to work and what problems might arrive in the developing or manufacturing area. Pfizer is working very closely with BioNTech and has now advanced to Phase 3 studies, fully committed to applying all of their regular safety standards.

Having an effective vaccine is not the end. Vaccines tested on healthy individuals need further efficacy and

“We want to produce a safe and effective vaccine, we won't cut any corners, and we are working very closely with the regulators to make sure we achieve the high standard they are expecting.

Steve Lockhart



”

safety evaluation amongst vulnerable groups. This session also looked at the need to motivate patients to participate in the clinical trials and the rollout of universal/selective vaccination programmes, questioning how can industry partner with patients and patient organizations to speed up the process.

Karen Alparce-Villanueva questioned panellists about the status of their patients' enrolment. Industry representatives highlighted their strategies to engage more patients in clinical trials, and focus on diversity, involving minority communities, patients with comorbidities, as well as patients from low and middle-income countries. Panellists recognized the need to enhance these efforts in order to involve more people in the most vulnerable groups. Finally, they discussed communication strategies to ensure patients' enrolment in clinical trials and in a broader aspect promoting confidence in vaccines and the systems delivering them.

Thomas Cueni gave the final messages highlighting the up-coming challenges. The session showed the different approaches from the pharmaceutical companies aiming at the common goal of finding protection against the same virus. Cueni said to be reasonably confident that there will be a number of effective and safe vaccines, considering the different approaches on research and the various collaborations being done. He predicted by Spring/Summer 2021 there will be some immunization programs in place but reminded the importance of being cautiously optimistic, as the challenge is not only to produce but also the logistics, as discussed in the session.

Finally the session agreed and recommended on the importance of industry committing to social responsibility and countries committing to solidarity to overcome the unprecedented challenge imposed by the current pandemic.

Mental Health the Forgotten Pandemic – during and after COVID-19

Mental health is a silent pandemic, difficult to diagnose, even more difficult to measure and understand progress, and have very little investment. Before COVID-19, many patients could not access safe, quality, and acceptable mental health services. The lockdowns exasperated this situation. The fear of job losses, lack of social support, stigmatization and domestic violence have impacted upon mental health of many communities. Many mental health conditions will manifest much later.

This session explored general and specific mental health issues, especially within minority ethnic groups and other socially excluded groups. It looked at the global mental health picture discussing what has changed and why due to the pandemic. The session also questioned the role of industry and the capacity of governments on dealing with mental health issues in the future.

Bisi Bright moderated the session and presented the session panellists:

- Dr Kannan Subramaniam, Upjohn Pfizer
- Prof Kamaldeep Bhui, Oxford University
- Annie Bliss, Alzheimer's Disease International

Dr Subramaniam spoke about NCDs and the global failure in ensuring mental health services were maintained before and during the pandemic. He presented the emerging trends for mental health issues, such as spikes in anxiety and depression, highlighting that this is a global issue and the stigma and lack of understanding only worsen the effects. Towards possible solutions, various organizations have psychological first aid that bolsters resilience.

Dr Subramaniam emphasized resilience and provided useful tips, such as taking breaks from the news, taking care of physical health, talking about the financial strain, making time to unwind and connect with others and seeking support.

“COVID-19 impacts all of us and will take all of us to overcome this together.

Dr Kannan Subramaniam



”

Prof Kamaldeep Bhui discussed health inequalities in severe mental illness and COVID-19. Multiple deprivations make people more susceptible to diseases; therefore black and minority ethnic groups are especially affected by COVID-19. These populations have limited access to safe and efficient patient-centric health services and lack trust in health systems for historical reasons. Poverty, financial hardship and unemployment were increased by the pandemic, which subsequently affects people's mental health.

“ The pandemic has to be a wake-up call for a better society - we need to do more for women, migrants, children, refugees. We cannot have economic growth without a good mental health condition of society. ”

Prof Kamaldeep Bhui



Prof Bhui highlighted the need of early prevention on mental illness and stressed the importance of listening deeply to the affected ones. The patients' narratives offer all the evidence and answers we need to empower people on becoming more resilient.

Annie Bliss talked about the specific case of patients with Alzheimer's and the lack of access to the health system for people with dementia. Dementia is a group of diseases that causes brain degeneration and it is increasingly positioned within mental health. Dementia and mental health are often neglected, because one cannot see what's happening necessarily, whereas these should be equally treated as physical illnesses.

She pointed out how particular challenges of COVID-19 – more isolation, anxiety, depression – affect people with dementia. Moreover most people with dementia

are elderly and therefore they are the most threatened and isolated. Patients are deprived from face to face treatment, which for people with dementia is crucial. During the pandemic there is also less diagnosis, even though dementia is progressing a lot quicker in these times.

“ In 2020 the rest of the world suddenly experiences what people with dementia usually experience after diagnosis: stigma, fear, isolation. This is not a struggle of a moment for us, it's a constant struggle. ”

Annie Bliss



This session recommended the importance of having policies and practice more aligned to social complexities. Leadership must be fully engaged in recognizing and tackling inequalities as public health priorities. The session also recommended the need to allow localities to select the solutions that work for them. Looking ahead more preparation is needed not only towards pandemics but also towards mental health. More awareness, more research and more investment are required, so no one will be left behind.

Prioritizing NCDs in Future Pandemic Preparedness

- Addressing Concomitant Risks of the Virus and the Underlying NCDs

The importance of prioritizing non-communicable diseases (NCDs) has been growing over the last few decades as these silent killers have overtaken infectious diseases as the major cause of deaths and disease globally.

Despite NCDs being often preventable and largely treatable, they are responsible for over two thirds of all deaths worldwide each year, also causing significant disability and disproportionately affecting people in low and middle-income countries.

Patients with NCDs are facing four major challenges during the COVID-19 pandemic. First, there is high morbidity and mortality due to COVID-19 within NCD patients globally. Second, the infodemic and conflicting messages from governments create fear within the NCD patients resulting in them not self-referring or visiting their secondary prevention regular clinics. Third, health systems were disrupted and the full range of current preventative, curative, rehabilitative and palliative treatments is compromised. Lastly, patient support groups and organizations were shut down. This all has a long-term impact.

This session explored this context and discussed the necessary steps to mitigate the negative impact of the pandemic on patients with NCDs in future pandemics and other health emergencies. The panel looked at the global context of COVID-19 and its effect on NCDs, both immediate, short term and long term.

Dr Amrit Ray, Global President of R&D and Medical at Pfizer Upjohn, moderated the session inviting the following speakers to share their views and perspectives:

- Dr Mark Barone, Vice-President, International Diabetes Federation
- James Headen Pfitzer, Director, Access Accelerated
- Dr J S Thakur, MD, President, World NCD Federation

Dr Mark Barone spoke about the need to identify high-risk people and protect them, reminding there was knowledge available that a pandemic would impact more severely on NCDs patients and especially people with diabetes. The decrease of physical activity, the increase of food intake and the difficulty of accessing medical treatment result in higher blood glucose and consequently individuals start to migrate to greater risk, leading to severe illness and more deaths from COVID-19.

“ Outbreaks should not be underestimated and being prepared for future pandemics would also bring a number of benefits to health systems worldwide.

Dr Mark Barone



”

James Pfitzer presented a few practical perspectives from the private sector in developing targeted interventions for the prevention and care of NCDs and strategies to help build resilient health systems. There are benefits of taking a multi-sectorial approach in identifying the needs, and ways to tailor interventions to fill some of the gaps in health systems. This health system strengthening approach is valuable in tackling challenges imposed by COVID-19, ensuring to involve communities in tailoring interventions, so patients take ownership of the whole process.

Dr J S Thakur explained the work developed by the World NCD Federation, a professional association launched in India in 2015 to focus on public health approaches for prevention, control and management of non-communicable diseases globally and achievement of the Sustainable Development Goals.

COVID-19 and NCDs combined highly increase the risk of hospitalization and death, both globally and in India, having great impacts on hospitals and medical institutions. He concluded with a call for a healthy lifestyle, which can improve all bodily functions, including immunity.

This session looked at how COVID-19 has affected the diabetic populations and showed that protecting individuals with NCDs would also be a means to protect the health systems and national economies during the current pandemic. Therefore it's important that communities, patient organizations, patients, caregivers, industry and governments continue investing in tackling the challenge of NCDs and in future pandemic preparedness.

Genetic Disorders and Rare Diseases Patient Co-Creation

Rare Disease International has mapped the main issues affecting patients with genetic and rare diseases in their declarations and statements to the World Health Organization/United Nations. There is an acute shortage of accessible and effective diagnostic services. We do not have quality and effective genetic counselling services to support patients and carers. There are many undiagnosed genetic and rare diseases, and syndromes without a name.

While there are major innovative treatments and cures developed or in the pipeline, many patients cannot access these gene therapies, biologic monoclonal antibody, and other new small molecule therapies. During the pandemic, these patients suffered even more.

The moderator Nidhi Swarup, Crohn's & Colitis Society of Singapore, invited three speakers to share their experiences and views:

- Julie Breneiser, Gorlin Syndrome Alliance
- Camilla Krogh Lauritzen, LEO Pharma
- Dr Ivana Knezevic, MD, World Health Organization

Julie Breneiser approached the limited access rare disease patients already had before the pandemic and how they were heavily impacted by COVID-19. She spoke about the specific case of people who suffer from Gorlin Syndrome, a rare genetic disorder which affects many areas of the body and is particularly challenging to diagnose because of the variety of characteristics that it may present. Due to the lack of healthcare provision, patients have to advocate for their own conditions. When it comes to the impact of COVID-19 on people affected by the Gorlin Syndrome, delays on treatment are a main issue, with broader impacts yet to be understood in the future.

Camilla Krogh Lauritzen discussed how industry in the rare diseases area has to now work in co-creating the next generation of solutions for patients. In this process, patients have to transition to partners. They are critical success factors in clinical trials, in terms of input, research and advice. Patients are also innovators and they challenge the set way of thinking, often leading to broad improvements in the whole industry. Industry should therefore welcome patient centricity as an important part of present and future reality.

Dr Ivana Knezevic talked about the WHO approach to support access to cell and gene therapies. The WHO five-year action plan to improve the quality and safety of health products focus on increasing regulatory preparedness for public health emergencies. Cell and gene therapies offer both opportunities and challenges. There is a great potential not previously possible for using traditional treatments, but there are also issues towards safety, bioethics and high prices. WHO has been working in a holistic approach to address these challenges, such as improving biological norms.

This session laid out some of the challenges of living with rare diseases. Many syndromes and diseases are undiagnosed, and the pandemic aggravated the challenges of accessing treatment. The session looked at patient co-creation within gene and cell therapies research and development, and advocacy, using Skin Disorders as a unique case to highlight the issues.

Patient Centricity within Health Technology Assessment, Value Based Healthcare and HTX

World Health Organization's Director-General has rightly stated that "health is not a cost; it is an investment. Health is not a reward for development; it is a prerequisite". This session provided an opportunity to understand how patient engagement in HTA/VBHC/HTx is critical when it comes to accessing innovative and effective healthcare.

Incorporating innovative health technologies needs evidence-based decision making. Traditionally, many health systems use health technology assessment as a bridge between healthcare evidence and policymaking. This is considered to lack patient-centricity. We now have alternatives. Value Based Healthcare (VBHC) is the equitable, sustainable, and transparent use of the available resources to achieve better outcomes and experiences for every person. On the other hand, HTx the Next Generation Health Technology Assessment (HTA), a Horizon 2020 European Union Project, aims to bring both HTA and VBHC together to support patient-centred, societally oriented, real-time decision-making on access to and reimbursement for health technologies throughout Europe.

Jan Geissler, Patvocates, moderated the session inviting the following speakers to share their views and

perspectives:

- David L. Grainger, Biointelect
- Ann Single, Health Technology Assessment International
- Dr Dalia Dawoud, National Institute for Health and Care Excellence

“With effective patient involvement, HTA can inform patient-centered healthcare policy, ensuring fair and transparent allocation of resources informed by the needs, preferences and experience of patients.”



Ann Single

David L. Grainger explained HTA compares the effects of a new health technology with an existing one, usually to assess the value it brings emphasizing the importance of continuing to evolve patient centricity within HTA. Patient perspectives are critical to wider dimensions, interpreting quality of life, rating scales, preferences (side effect profiles, benefit/ risk, delivery and administration). HTA committees need skills in combining a range of diverse evidence, and Multi-Criteria Decision Making (MCDA) is increasingly being explored as an option.

Ann Single emphasized that if HTA is to be patient-centric it must include robust research about patient aspects and/or supporting patients and their representatives to participate during HTA. This complements clinical

research, helps overcome uncertainties in clinical evidence and inform determinations of value with unique, experimental knowledge of patients. Although HTA should support the participation of patients and produce outcomes that matter to them, limitations still remain.

Much of HTA is still done with none or very little patient involvement. Patient knowledge still struggles to find its space, in part because it's still disputed, so it's crucial to find safe spaces to find these conversations. The purpose is to inform decision making to promote an equitable and efficient course of action, under a new paradigm that enables patients to be active in research and development for an improved generation of medicines.

Dr Dalia Dawoud introduced the idea of HTx and its focus on patient centricity. HTx aims to create a framework for the next generation of HTA that supports

patient-centered, societally oriented, real time decision making for integrated healthcare throughout Europe. HTx is revolutionizing how HTA is conducted, involving civil society in decision making. It provides innovative knowledge that could be used not only on research but also in clinical practice. Ensuring patient centricity is in the heart of the debates and NICE's projects, involving patients through meetings, toolbox and fellowship programmes.

This session provided an opportunity to understand how patient centricity is key to the future vision of HTA and therefore the importance of developing methodologies for this participation. In the journey towards this future vision, it's important to start small, looking at the example that countries with similar political and economic circumstances/challenges can offer.

Personalised Healthcare: Can Lessons from COVID-19 Accelerate Adoption?

This session explored how the personalised healthcare (PHC) approach can provide a high-resolution insight into each patient's disease. By leveraging advances in digital health, imaging, digital pathology, genomics and health informatics (electronic medical records, real world data and patient reported outcomes), PHC provides healthcare that is precise and particular for that patient and right for their stage (timely) of the disease. PHC promises that patient lives will no longer revolve around their healthcare facilities, healthcare team, or disease.

Kawal dip Sehmi, IAPO CEO, moderated the session inviting the following speakers to share their experiences and views:

- André Trottier, Roche
- Jan Geissler, Patvocates

André Trottier explained that the pandemic accelerated the digitalization of healthcare worldwide. There has been an unprecedented speed of policy change around the world, and these should be solid sustainable changes that go beyond this moment of crisis. Investing and enabling access to healthcare data improves decision-making and the efficiency of the healthcare system. Technology can impact every step of the patient journey; it impacts on early-personalised diagnosis, rapid access to personalised therapies, personalised care plan and finally personalised remote monitoring and care. At the centre of it all is data and insights, that provide additional information to the patient and creates a whole learning system.

“ COVID, as devastating as it is, it has provided ground to change. The challenge is to make this continue.

André Trottier



”

Jan Geissler stressed that patients want new therapeutic approaches, tailored to their individual biology and preferences. Inequalities are increasing in all countries, even in the richer, but personalised healthcare should not become the privilege of a few. Therefore, it's important to learn from successful experiences in personalised healthcare, make all stakeholders collaborate, overcome institutional resilience and inequalities, and make co-creation with patients and evidence-based advocacy the norm.

This session also highlighted the importance of collaboration and solidarity to make advancements towards Personalised Healthcare. Technology has to be at the service of healthcare provision. A personalised healthcare-enabled world is better for patients.

Launch of MAPS

– Mapping the Patient Journey for NCDs

Worldwide patients wonder if their treatments experience would be the same if people had listened to what they wanted and what they are comfortable with. Many attempts have been made towards this but it's rare that they indeed bring patients' voices to the forefront. MAPS (Mapping the Patients Journey Towards Actionable Beyond the Pill Solutions) is an evidence-driven, patient-centric and action-oriented framework created to identify the NCDs most needed areas in the patients journeys across 12 emerging markets. It provides a look at what the journey might be from a patient's perspective, enabling to understand patient's journey scientifically.

Patients' journeys are often misunderstood as linear, simplified as a transaction between healthcare providers and patients. MAPS takes a critical look at this definition and analyses data in a way to qualify the journey.

Dr Ratna Devi, IAP0 Chair, contextualized the importance of this initiative and invited two speakers to share their insights:

- Dr Amrit Ray, MD, Upjohn Pfizer
- Menassie Taddase, Upjohn Pfizer

Dr Amrit Ray introduced MAPS as a collaborative effort between many functional teams and partners to build

“ Putting people at the centre of the healthcare system is the only way we will be able to tackle the healthcare crisis of our times.

Dr Amrit Ray



”

a patient-centred locally relevant approach towards the care of NCDs. This scientific initiative created a framework to gather access and validate information in a way that shifts the focus from just the disease to the entire journey, involving prevention and quality of life.

Menassie Taddase looked at the significance of MAPS in low and middle-income countries, which are more severely affected by NCDs. Many of NCDs are preventable if treatment starts early, however health systems are not adapted. With ample resources the results are not so different if there's no strategy to match. Data needs to be complemented with local needs, and MAPS helps to address these gaps, enabling patients to be active participants, acknowledging the nuances of particular approaches and particular countries.

“ MAPS is capturing and amplifying the patients' voice.

Menassie Taddase



”

This session provided an opportunity to know MAPS, a scientific initiative that reinforces the importance of patients' voices. It puts patients at the centre of healthcare, enabling them to be active participants while also engaging other actors along the patients' journey, ensuring its relevance for a particular country or patient. None of this would be possible without a multisectorial approach. MAPS offers a simple and powerful solution to achieve tangible results, keeping patient at its centre.

Digital Healthcare: Defragmentation and Integration of Health Systems and Care Pathways

Fragmented healthcare systems are not patient centric and deliver extremely poor health outcomes for patients. Patient experience of navigating fragmented healthcare systems does not inspire trust in the health system as safety and quality is always at risk of being compromised through disjointed services.

This session looked at how digital healthcare can integrate our health systems, making them safer, patient-centred, effective, and efficient. The panellists shared insights on how digital healthcare can advance the World Health Organization's Framework on integrated people-centred health services that has encouraged patient engagement and co-creation and puts the comprehensive needs of people and communities, not only diseases, at the centre of health systems, empowering people to have a more active role in their own health. This session explored how this Framework encourages changing the delivery paradigm.

The session was moderated by, Kawaldip Sehmi, IAPO, who invited three speakers to share their experiences and views:

- Eric de Roodenbeke, International Hospitals Federation
- Siva Singh, Escalla
- Dr Vijay Rawal, NHS England and NHS Improvement (Midlands)

Eric de Roodenbeke looked at integration from the leadership of hospitals in health systems, and hospitals as hubs for digitalization. Digital hospitals empower patients, as they reach widespread evidence-based health behavior interventions, helping to ensure quality in the delivery of supported care, responsiveness to each individual profile of needs, and enabling patients to play leading roles in their own care management. Hospitals need to make place for patient organizations, as steps like this enable and empower patients.



“ Not so long ago patients were only the beneficiaries, from there moving to consumers and now we are being considered as partners. With digital hospitals, we move from partners to stakeholders.

Eric de Roodenbeke



”

Siva Singh and Dr Vijay Rawal discussed the low and middle-income countries experience in integrating services. Fragmentation in healthcare delivery means the systemic misalignment of incentives or lack of coordination that spawns inefficient allocation of resources or harm to patients. Fragmented health systems compromise patient safety, reduce quality, increase costs, leading to inefficiency and poor outcomes for patients.

Possible solutions to fragmentation include commissioning (planned, purchased and monitored by contracts), contracting (legally binding agreement to make sure the organization is working in integration), and the main point: digitalisation tools. Integration ensures that there is overall responsibility and the problem has to be solved collectively.

This session provided an opportunity to better understand how digital healthcare can advance

“ Beyond being a digital system, the most important element is that the patient has access to the data that goes to the primary care physician, read it, ask questions and therefore makes the decisions. ”

Siva Singh



integrated people-centred health services. Integration entails enabling conditions, visionary leaders, empowered patients and collaborative mindsets. Beyond the digital tools provided, there must be a change in the delivery paradigm in order to guarantee patient centricity.

Blood Disorders and Access to Healthcare Services and Therapies (Carol Ossai Talk)

Sickle cell disease (SCD), also known as sickle cell anaemia, is the most common genetic disease in the world, resulting in an abnormal form of haemoglobin. The inadequate care and treatment of children affected by SCD in low and middle-income countries result in many new-borns dying before the age of five years old while others live shortened lives marked by significant morbidity.

Dr Androulla Eleftheriou, Thalassaemia International Federation, moderated the session inviting the following speakers to share their views and perspectives:

- Alexey Salamakha, Novartis Oncology
- Judy Grandison, Global Alliance of Sickle Cell Disease Organizations

Alexey Salamakha made the first remarks starting with a tribute to Carol Ossai, an incredible SCD advocate, evoking her firm belief: “Nothing for the patients can be done without the patients”. On accessing medicines, building infrastructure, research and innovation, the industry has to put patient at the centre of everything, and the same goes to all other stakeholders. Salamakha explored partner perspectives in providing treatment and support for patients with blood disorders and highlighted the Flagship Program in Africa. The continent has the largest amount of people suffering from SCD and significant unmet need for diagnosis, newborn screening, and access to treatment of SCD. Between 50 to 90% of infants born in Africa with SCD will die before their fifth birthday.

The Flagship Program aims to improve outcome for people living with SCD by partnering with governments and organizations to ensure sustainability. The strategy includes accelerating access to SCD treatment, bolstering clinical trial capacity and development pipeline, strengthening healthcare eco-systems, leveraging data science and digital solutions, shaping policy and driving advocacy.

Judy Grandison looked at the specific case of sickle cell disease patients and their needs, including treatment for painful SCD crisis, biotherapeutics and gene therapies. Life with SCD is characterized by painful episodes that occur in the vaso-occlusion in the bone and it's the most frequent complication in many SCD patients. There are many barriers to accessing care, primarily related to human factors, such as knowledge deficits in healthcare providers and patients, suspicion of addiction to painkillers, stigma and bias. While blood transfusion and exchange can be effective treatments for SCD, both come with complications and should be closely monitored by healthcare providers.

This session explored health inequality and the opportunity to deliver better healthcare for people affected by Sickle Cell Disease. Patients suffer with severe pain episodes and there are many barriers to accessing treatment. The Flagship Program in Africa proves crucial to have a multi-stakeholder project to build capacity and infrastructure by partnering with governments and organizations.

Day Two

Keynote Speech

Introduction - World Patient Safety Day 2020

GPC 2020 Day 2 was dedicated to the marking of the World Patient Safety Day 2020. The theme for this year was “Health Worker Safety: A Priority for Patient Safety”.

The COVID-19 pandemic has shown the weaknesses of our health systems, undermining patient and health professional safety. The lessons we learned can be useful not only for better preparedness, but also for reducing the avoidable harm, morbidity and mortality.

The day examined the call to action for ensuring safety across different dimensions of healthcare and from diverse stakeholders’ perspectives. Our distinguished speakers coming from various backgrounds provided insights into the available policies and instruments, offering their valued experiences and sharing their

innovative ideas on how to promote safety culture and wove patient safety into every health system's fabric.

Dr Neda Milevska Kostova, IAPO Vice-chair, welcomed delegates, thanking the positive feedback from social media and e-mail messages regarding the exceptional Day 1 of GPC 2020. She gave a brief overview of WHO's Patient Safety Day and highlighted the event as a platform in which patients can share their expertise and experiences towards co-creation in healthcare. The audience was invited to contribute to the Public Consultation for review of the WHO's draft Global Safety Action Plan 2021-2030.

Dr Neda then invited all to join the exciting sessions ahead.

Keynote Speech

2nd World Patient Safety Day and WHO Decade of Patient Safety 2020-2030

The incidence of patient harm has become a global public health problem.. We must in national unity and global solidarity implement the World Health Assembly 72.6 Resolution and the World Health Organization (WHO)'s flagship initiative "A Decade of Patient Safety 2020-2030" launched in February 2020 to advance the global patient safety movement.

WHO's initiative cuts across all health system structures. It demands a whole-of-government, whole-of-society and whole-of-the-patient community to address patient safety in the whole health system. This session explored concrete next steps for the implementation of the initiative.

The guest of honour and speaker of the session was Rt Hon Jeremy Hunt MP, Chair, House of Commons Health and Social Care Select Committee, who explored the

various dimensions of the 2nd World Patient Safety Day. 2020's theme was "Health Workers Safety", a key topic in a year when thousands of health professionals sacrificed their lives to keep the global population safe during the COVID-19 pandemic. Healthy workers mean healthy patients, preventing hospital infection as well as enabling better healthcare for all. Thousands of deaths worldwide are a result of the lack of protective measures to keep health workers safe. That's why this is the most practical thing we can do whilst living with this pandemic.

Rt Hon Jeremy Hunt recalled that when he started as a politician he didn't know much about health policies, and that his journey started by hearing patients. At that time, what most campaigns had in common was providing relief from tragedies because people didn't want other family members to go through the same suffering. In healthcare, the overwhelming priority is to turn the blame culture into a learning culture, avoiding tragedies to be repeated. Tragedies might happen but we must work to avoid that from happening to other families. There is a need for practical change as much as for a cultural change that allows people on the frontline to talk about the mistakes, and learn from these mistakes.

“ The World Patient Safety Day can not only be about raising awareness, it has to be about a practical change.

Rt Hon Jeremy Hunt MP



”

Sessions

Response to the Keynote: 2019 Jeddah Ministerial Declaration on Patient Safety

This session provided an overview of the commitments and advances from the 2019 Jeddah Declaration proclaimed at the 4th Global Ministerial Summit on Patient Safety. It is an articulation of allegiance to ensuring continuity of action, which was to follow through the postponed 5th Global Ministerial Summit on Patient Safety in 2020 in Switzerland under the slogan “Less Harm Better Care – from Resolution to Implementation”.

Dr Abdulelah Alhasawi, Director-General, Saudi Patient Safety Centre and Chief Responder to the keynote speech, gave an update on the Global Ministerial Summit on Patient Safety as Saudi Arabia was the last hosting country of the Summit. He looked at the global and the country level progress of the implementation of the Jeddah Declaration explaining that the idea was to promote and support patients. Dr Abdulelah contextualized the importance of this agenda in terms of deaths, physical, psychological and financial harm in low/ middle income due to the lack of patient safety.

“ I ask anyone working
in healthcare
- Who is your boss?
The patient is always
the boss.

Dr Abdulelah AlHawsawi



”

Healthcare is one of the most dangerous industries for workers - therefore the importance of improving healthcare resilience. During the pandemic, one of the most important lessons learnt was improving patients and health professionals' safety, which are two sides of the same coin.

The banner features a portrait of Dr Abdulelah AlHawsawi on the left. To his right, the text reads: "2019 Jeddah Ministerial Declaration on Patient Safety" and "17 September 2020 09:30 am BST." On the far right, it promotes the "9th Global Patients Congress" held on "16-17 September 2020" at "GPC2020.vfairs.com". It includes a "Register Now FREE" button, the hashtag "#GPC2020", and the website "#WorldPatientSafetyDay". Logos for the International Alliance of Patient Organizations and the 21st anniversary of the World Patient Safety Day are also present.

AMR: Preventing the Next Pandemic and the AMR Action Fund

This session was organized in two parts. The first part highlighted the history of antimicrobial resistance (AMR) within our health systems and the vision to have an AMR global fund to address this. AMR possesses serious threats to patient safety and will become the next global health pandemic if not controlled now. Our world faces a silent, slow-moving global threat that kills around 700,000 people each year due to the uncontrolled rise of superbugs resistant to antibiotics. These superbugs can affect anyone, of any age, in any country. AMR is a universal issue that impacts us all – we are all at risk. This looming global crisis has the potential to be as large or even larger than COVID-19 in terms of deaths and economic costs.

The second part shared the realisation of this vision in the International Federation of Pharmaceutical Manufacturers & Associations-led USD \$ 1 billion AMR Action Fund that aims to bring 2 to 4 new antibiotics to patients by 2030. The Action Fund will work with partners to create market conditions that enable sustainable investment in the antibiotic pipeline.

Dr Neda Milevska Kostova, IAPVO Vice-chair, moderated the session and invited two speakers to share their perspectives:

- Dame Sally Davies, UK Department of Health and Social Care
- Thomas Cueni, International Federation of Pharmaceutical Manufacturers & Associations

Dame Sally Davies highlighted how the hidden AMR pandemic is already costing many lives and suffering. In addition, it also has a great impact on the health system – AMR doubles the mortality, the patients' time in hospitals, and ultimately the costs. Given that antibiotics are cheap, the pharmacological companies are not investing enough on research despite the recent efforts from this industry.

“There is an unintentional conspiracy of silence around AMR and we need the patients' faces and voices. We have to mobilise this fight, we can find new antibiotics.

Dame Sally Davies



”

Many health conditions depend on the advancement of new and better antibiotics and patients have an important role to play in this struggle. Davies urged patient organizations to put pressure on the companies and investors through the health system worldwide.

Thomas Cueni contextualised the creation of the AMR Action Fund, which aims to bring 2 to 4 new antibiotics to patients by 2030. The Action Fund will work with partners to create market conditions that enable sustainable investment in the antibiotic pipeline. The challenge is



to convince companies to invest in something that has little return. The current pipeline of new antibiotics is insufficient, with private investment shrinking and public investment unable to fully compensate. Antibiotics must be accessible to all and we need policy reforms to support this struggle, as well as a multisectorial effort.

COVID-19 has demonstrated all too well the consequences of the failure to invest in preparedness, and the dramatic impact it has on all sectors. As we continue to tackle the pandemic, we must simultaneously ensure that efforts to stop the spread of antimicrobial resistance are accelerated. AMR is a slow tsunami that threatens to undo a century of medical progress.

A record number of countries are now monitoring and reporting on antibiotic resistance to WHO, and the data they provide reveals that resistance to essential medicines to treat infections continues to spread across the world at an alarming rate.

“

xx

Thomas Cueni



”

This session provided an opportunity to understand the threat imposed by antimicrobial resistance. The AMR Action Fund will be crucial to reversing that trajectory, strengthening and accelerating the research and development of antibiotics through game-changing investments into biotechnology companies around the world.

Patient Co-Creation within Global Patient Safety: Expert Patients and DEEPs

Expert Patients have played a big role in advancing patient safety globally. Disease Experience Expert Panels (DEEPs) have advanced healthcare and patient safety in many disease areas, especially chronic and rare diseases. This session shared this patient perspective with the audience.

Charline Coquerel, Novo Nordisk, moderated the session inviting the following speakers to share their views and perspectives:

- Sara Mobäck, Global Diabetes Advocate
- Ken Tait, DEEPs Member and Diabetes Advocate

Ken Tait is a diabetes patient and became an advocate in 2019 after being invited by Novo Nordisk. He presented the project Hypo-RESOLVE, in which he is involved offering his expertise as a patient and also a psychotherapist, focused on understanding patient's experience. DEEPs offer researchers and professionals in the medical field an opportunity to understand what it's like to live with a specific health condition, and patients need to be part of the process from the beginning, middle and end.

“My hope is that research is more opened to involve patients. Patients are intelligent, beyond our experience as patients, we also have knowledge to offer to the whole healthcare community.”

Ken Tait



“Health workers / researchers wouldn't exist without patients, but patients will always exist, even without health workers/researchers. Keeping this in mind goes a long way to understanding co-creation and co-working.”

Charline Coquerel



Sara Mobäck has lived with diabetes for 18 years and she works through social media and talks online to provide inspiration for people living with diabetes. She is a DEEPs member, a platform that allows her to provide the perspective of living with a chronic disease. Mobäck explained it has been a huge change for her becoming an advocate, due to the new opportunities to share and learn.

During the pandemic, these sharing experiences have been through video chat with doctors and nurses and the global community. People reach out more and more since the pandemic started, allowing an opportunity to give each other emotional support. As a diabetes type 1 patient, Mobäck explained she has to remain positive to keep surviving this condition.

This session shared insights on how Disease Experience Expert Panels (DEEPs) are helping people to share information on their experience of dealing with a disease. Expert Patients' insight and voice have been a powerful game-changer in many health systems.

Partnering to Advance Patient Safety: the Role of Medical Technologies

While becoming more effective, healthcare has also become more complex, with greater use of new technologies, medicines and treatments. Technology, equipment and medical devices are vital for effective delivery throughout the continuum of care.

Medical technologies also help mitigate adverse events of diagnostic procedures, medication errors and harm that patients might experience during provision of healthcare.

But they are also associated with risks. Safety of medical technologies is an inseparable aspect of care, equally important as its access or quality.

The World Health Assembly Resolution 72.6 recognizes the importance of safe medical technologies in prevention of patient harm through early diagnosis and infection prevention, improved medication management, safe surgical and interventional procedures and support for management of chronic conditions.

This session looked into the different stakeholders' perspectives on technology-associated risks. It also explored ways to improve safety of medical devices, and prevent diagnostic and medication errors.

The moderator Melina Raso, Health First Europe, invited three speakers to share their perspectives:

- Fiona Garin, BD Europe
- Kawaldip Sehmi, IAPO
- Dr Neda Milevska-Kostova, IAPO

Fiona Garin explored how patient safety flows through different stakeholders and processes, presenting BD's campaign Safety Flows Through Me. Safety must be a priority through the health journey: maximising clinical outcomes while protecting patients; maximising quality and outcomes while driving sustainability; supplying safe and innovative drugs; and patients taking ownership

“ Risks exist at every step of the patients' journey. However, patient safety is a shared responsibility among all health stakeholders and we all have a unique opportunity to impact healthcare systems in which members of our community will be treated in by ensuring safety flows through us.

Fiona Garin Mc Donagh



”



of their own health while sharing information with others. The medical technology industry has to develop and implement safe and optimised technology and capabilities that help prevent error and adverse events.

This industry is the vector between patients and the adequate cure, looking at the healthcare system through the holistic view. It's also crucial to foster a culture of healthcare worker safety, ensuring that safety flows through every person and every system, changing attitudes and improving accountability. Kawaldip Sehmi shared his personal experience as a patient who was diagnosed late and because of it had to go through surgery.

Only after the event was he able to acknowledge the risks and regretted he didn't act earlier. Safety flow begins with the patient. Empowering patients is also about giving them information, so they act on time to prevent further risks. Dr Neda Milevska-Kostova emphasised the importance of hearing different stories of people who have gone through negative healthcare experiences and learned from these experiences. The COVID-19 pandemic also highlighted the importance of involving patients in the development of medical technology.

Patient safety needs to be about practical changes. Patients need technology and innovation, but there are also risks connected to technology. Patients and healthcare workers have to come together, and demand more investments on safety from policymakers.



IAPO collaborated with BD–Europe to amplify the voices of patients who have been afflicted with healthcare-associated infections (HAIs), sepsis, antimicrobial resistance (AMR) or medication errors. As part of this Voices of Safety campaign, patients from around Europe shared their authentic stories of personal hardship and hope in the face of adversity.

Patient Involvement in Addressing AMR and Sepsis Risks

There are two serious lingering risks in our health systems that simply do not go away: antimicrobial resistance (AMR) and sepsis.

AMR undermines every aspect of medicine today, and by day we are losing one of the most powerful tools for fighting life-threatening bacterial infections: the antibiotics. In 2014, the World Health Assembly Resolution 67.25 brought the issue of AMR to the front.

Sepsis is a global killer, yet largely preventable. In 2017, the World Health Assembly Resolution 70.7 prioritized the improving of prevention, diagnosis, and clinical management of sepsis as a framework for a structured approach to sepsis prevention and management.

“ We must stick to the vow that we borrowed antibiotics from the next generation, we did not inherit them from the past.

Dr Neda Milevska



”

This session explored how the lessons from the current pandemic give us the opportunity to address this jointly as AMR and sepsis present serious challenges amongst patients.

Dr Neda Milevska Kostova, IAPO, moderated the session inviting the following speakers to share their views and perspectives:

- Dr Bruce Altevogt, Pfizer Inc.'s Hospital Business Unit
- Dr Konrad Rheinhardt, MD, Global Sepsis Alliance
- Danjuma Adda, Centre for Initiative and Development (CFID) Taraba & Chagro-Care Trust

Dr Bruce Altevogt presented a brief overview of Pfizer's legacy and commitment to infectious diseases, one of the leading companies in the infectious diseases market. The Davos Declaration and roadmap commitments have changed how industry approaches AMR, and Pfizer was one of the first signatories of this document.

Pfizer's AMR strategy includes five core pillars: education; generate and communicate new data; lead AMR & Sepsis conversation; provide new solutions; strengthen capacity. Dr Bruce Altevogt also mentioned Pfizer's ATLAS Surveillance Database, reminding resistance is a global as well as a local issue. This database allows them to provide the right antibiotics considering the resistance developed within the country. Furthermore, Pfizer is engaged in understanding and meeting the needs of patients, acknowledging that patients from any therapeutic area are impacted by AMR and, therefore, the responsibility to work with all these patients.

Dr Konrad Rheinhardt stressed that sepsis is probably the most likely preventable cause of death and it is still killing millions every year. Every citizen should know the signs

of sepsis. Taking the fight against sepsis to the next level requires ensuring the enactment of the WHO resolution on sepsis, to respond to sepsis with the same vigor and passion as to COVID-19, and finally to learn from countries, health systems and facilities with low mortality rates. It also requires involving top-level policy makers.

Danjuma Adda shared his experience with the CFID's Antimicrobial Stewardship program in Nigeria. Nigeria has some challenging circumstances such as a very large population, high rates of poverty, and the majority lacking access to quality healthcare.

Also specific factors mitigate a successful AMR response in Nigeria: poor public awareness and patient empowerment, high demand for antimicrobials by patients, farmers and the general public, poor hygiene in a community level, and poor regulations on antimicrobials. Adda highlighted the importance of public awareness, stating that if patients had information they would avoid self-medication.

“Bringing the fight against sepsis to the next level can save millions of lives annually and make a major contribution to the achievement of the Sustainable Developmental Goals.”

Dr Konrad Rheinhardt



The challenge imposed by the silent pandemic of AMR has to be addressed globally and demands work in partnership. A high level of advocacy is required for all stakeholders to create extensive awareness. We need concerted effort from the whole-of-health professional and whole-of-patient movement to support the whole-of-industry to eliminate both the risks of AMR and sepsis.

Holistic Patient and Health Worker Safety: Hospital, Care Facility and Self-Care

Patient safety must be considered along the entire continuum of healthcare, irrespective of where it takes place. We must make this care continuum safe throughout. With most patients with chronic conditions shielding in self-isolation, their healthcare has transferred into their homes. Self-care and home-based care have played a big role in reducing pressure on health systems. The use of telemedicine and other digital solutions have helped. This poses serious patient safety risks if your home, carer, or your self-care practice is unsafe.

The uptake of telemedicine and popularisation of home-based care must look at patient safety afresh. This session discussed the next steps in developing a patient safety culture within responsible self-care and self-medication.

The session was moderated by Dr Peter Lachman, MD, International Society for Quality in Healthcare, who invited three speakers to share their experiences and views:

- Dr Neelam Dhingra, MD, World Health Organization
- Judy Stenmark, Global Self-Care Federation
- Monika Lessl, Bayer

Dr Neelam Dhingra explored how 2020's World Patient Safety Day shined a light at workers safety. COVID-19 has caused enormous pressure on the ecosystems of health, society and economy. Now that healthcare has moved to homes, digital tools will be crucial on providing resources. Dr Neelam Dhingra also highlighted patients' organizations are well positioned to discuss patient safety with other stakeholders in the current pandemic.

Judy Stenmark shared her insights on patient safety in self-care. There are some relevant benefits of self-care, such as greater choice of healthcare options for individuals, which can lead to long-term benefits, and it eases the burden on healthcare systems and professionals. However there are some major challenges, such as the 'infodemic', which stresses the priority of creating access to scientific-based information. Stenmark also acknowledged the pivotal role pharmacists and nurses play in self-care as the primary care providers.

Monika Lessl spoke about Bayer's efforts on supporting patient and health worker safety during the pandemic. The company has been investing on raising awareness worldwide, such as in Brazil working to protect vulnerable populations in the Amazonian region, and in Egypt supporting a campaign to prevent and fight the spread of Coronavirus. Lessl also mentioned other measures, such as shifting production to manufacture hand sanitizer; transforming research labs into a diagnostic COVID test station; and offering treatment in Israel and South Africa.

This session provided an opportunity to address patient and health worker safety according to a holistic perspective. The themes discussed acquired even greater relevance during the current times, and those challenges and gaps on the pathway to more safety have to be addressed in the next phases of the pandemic.

Our Expert Panel

9th Global Patients Congress
16-17 September 2020
GPC2020.vfairs.com

Register Now FREE

Holistic Patient and Health Worker Safety: Hospital, Care Facility and Self-Care
17 September 2020 12:35pm BST

Dr Peter Lachman
Chief Executive Officer,
International Society for
Quality in Healthcare
Moderator

Dr Neelam Dhingra
MD, WHO
Coordinator, Patient
Safety and Self-Care
Initiative, World
Health Organization

Judy Stenmark
President, Global
Self-Care Federation

Dr Monika Lessl
Executive Director,
Bayer Foundation

#GPC2020
#WorldPatientSafetyDay

EUPATI Research and Development of Safer Medicines

This session looked at the European Patients Academy on Therapeutic Innovation (EUPATI) and its influence on patient engagement in research and development of safer medicines and healthcare.

In many countries there are national institutes for health research developed to give their Universal Health Coverage (UHC) programmes access to outstanding individuals working in world-class facilities conducting leading-edge research focused on the needs of patients and the public. This has transformed research in and for UHC and helped to shape the health research landscape more broadly. EUPATI has supplied these outstanding patients (EUPATI Fellows) to many health systems.

UHC 2030 programmes need to incorporate patient safety and safe medicines development into its heart. This demands close links between the pharmaceutical industry, capacity builders, researchers and health systems to ensure continued improvement in safe medicines development and medication safety.

Dr Ratna Devi, IAPO chair, moderated the session and invited two speakers to share their experiences and views:

- Lasse Funch Jacobsen, LEO Pharma
- Dr Tamás Bereczky, EUPATI

Lasse Funch Jacobsen spoke about industry and patient engagement in clinical research from a EUPATI perspective. He explained the mentality of LEO Pharma on co-creation, “nothing about you without you”, bringing the patients expertise and voice as early as possible in the process of medicines research and development.

Patient engagement is also supported through education, offering patient expert training courses and serving as an educational source. The opportunity to learn from disease experts can lead to improved clinical trials designs on key parameters such as recruitment, retention and amendments. Therefore this early patient engagement is certainly a collaboration in which all parts involved benefit from.

Dr Tamás Bereczky shared insights on actual patient engagement in clinical research and development of safe medicines. In the last years, many changes in healthcare caused an impact on patients’ communities, such as the advent of new technologies and social media, big data and Google as a resource for patients. Meanwhile, patients are also transitioning to expert patients, conscious consumers and empowered citizens.

Expert patients are multipliers of knowledge and coping strategies. New ways of knowledge production are emerging in patient communities. In research and development they have an active role to inform, tap into



trial populations, understand the situation, spread sound and scientifically established facts, support recruitment and the retaining of patients in trials.

This session provided an opportunity to understand EUPATI as a paradigm shift in empowering patients on medicines research and development. EUPATI educational tools are targeted at different levels and offered worldwide, supporting the empowerment of patients and their communities. Through this accessible institutional mechanism, patients can actually contribute as experts through evidence-based advocacy.

“ Collaboration between patient organizations is essential; if we want to achieve change, we have to do this together, strengthen each other and coordinate policy work of patient communities.



”

Dr Tamás Bereczky

Community Pharmacists - Medication and Overall Patient Safety

Community Pharmacists are often considered the 4th emergency service (after police, ambulance, and fire fighters). During COVID-19 they were placed at considerable risk while serving patients who were shielding. Patient safety is now a concern for all frontline healthcare professionals as well as their employers. All community pharmacists, pharmacy technicians and pharmacy support staff have recognised the importance of safely dispensing medication and providing appropriate advice to patients and the public. This session celebrated their achievement by sharing their experience.

Bisi Bright, LiveWell Initiative LWI, moderated the session inviting following speakers to share their views and perspectives:

- Dr Catherine Duggan, International Pharmaceutical Federation
- Dr Anantha Naik Nagappa, Association of Community Pharmacist of India & Amity Institute of Pharmacy, Amity University of Madhya Pradesh

Dr Catherine Duggan spoke about the role played by the International Pharmaceutical Federation (FIP) and pharmacists during the COVID-19 pandemic. Since the outbreak of the pandemic, FIP have set up a taskforce to develop emergency guidelines to support the pharmacy workforce around the world in helping to minimise and control the impacts and in providing advice and care to patients and communities. Dr Duggan presented the online guidance on FIP's COVID-19 Information Hub which also includes a programme of digital events and an online platform on Facebook for pharmacists. An important part of this guidance is the FAQ and myth busting, and there is also a repository of valuable

COVID-19 related resources developed by FIP's member organizations and partners. FIP's response has been also focused to advocate alongside governments and international organizations.

Outstanding examples of good community and hospital practice were presented, such as the Chinese guidelines and experience at the forefront of the outbreak. They developed a pharmaceutical care framework for COVID-19 hospitalised patients, which included some special considerations for patients within the highly risk groups.

Dr Anantha Naik Nagappa looked at the role played by community pharmacists in India during the COVID-19 pandemic. Community pharmacies represent the first point of contact within the health system for many communities. In some countries, pharmacists play an important educational role in helping people to prevent infections and stay safe. Also, during these times in which routine and elective check-ups with physicians have become unavailable, community pharmacists can assess and manage patients for minor ailments. Normally, community pharmacists (CP) are in direct contact with patients and health consumers for providing services. However, due to the pandemic these CP are being forced to work remotely. In the face of shortages, pharmacists have also been called upon to participate in ensuring adequate supply of health products and medicines.

The pandemic highlighted the importance of community, hospital and clinical biology pharmacists to ensure the continuity of supply of medicines and medical devices, as well as in health education and infection prevention and control measures. Therefore, community pharmacists play a fundamental role especially in these times of crisis, contributing to alleviate the burden on health systems.

Regulatory Harmonisation for Access to Safe Medicines, Vaccines and Health Devices

For truly patient centric healthcare, there must be healthcare that is safe, quality, and effective. The medicines and health devices regulators ensure that this happens.

Within a global world, this means the need for a harmonised global regulatory system and standards that ensure patients get safe and quality medicines, vaccines, and health devices wherever they are. Patients must engage in the regulatory activity to ensure safe and quality medicines, vaccines, and health devices globally.

This session provided an opportunity for the regulators to share their experiences of patient engagement in regulatory affairs and in regulatory reliance as one way to ensure this harmonisation.

David Jefferys, MD, from the International Federation of Pharmaceutical Manufacturers & Associations, moderated the session and invited two speakers to share their views:

- Andrea Furia-Helms, MPH, U.S. Food and Drug Administration
- Nathalie Bere, MPH, European Medicines Agency

David Jefferys introduced the session highlighting reliance as one of the biggest benefits of harmonization. Reliance can give patients timely access to safe effective and quality medical products. He also explored some of the current regulatory trends and the importance of patient's co-creation. Researchers have the opportunity to gain insight into the challenge of living with a particular disease, and patients can better understand the benefits and risks of treatments, which may translate into better health outcomes. Patients must engage in the regulatory activity to ensure we have safe and quality medicines, vaccines, and health devices globally.

“Patients have the real world experience so ultimately they are at the heart of FDA’s work.”

Andrea Furia



”

Andrea Furia presented a brief overview of the importance of patients in FDA's work. Patient and caregivers provide great insights about their needs and priorities that are important to them and to their family members. They have diverse opinions and experiences, and also provide insights on risk tolerance and potential benefit.

She presented an evolution of patient engagement at the FDA, which has been having increasing importance since the 1980's. Furia also explored the Patient Affairs Staff history and activities, always striving to include patients' perspective in FDA's work. FDA has been also working on enhancing their various means of communication to improve patient engagement.

Nathalie Bere shared an overview of how the European Medicines Agency (EMA) engages with patients. She presented patient engagement at EMA as a progressive journey since 1995, when the agency was created.

Current patient participation in regulatory organizations is a result of this journey to ensure safe and quality medicines, vaccines, and health devices globally. Patient Listening Sessions are one of the many ways to include the patient voice at EMA, as well as helping patients

“ We must ensure a strengthened regulatory system that can efficiently integrate patient evidence into its assessments.

Nathalie Bere



”

and their advocates to understand the agency's work. Through committee membership, advisory groups, stakeholders' meetings, public hearings and workshops, patients contribute directly to scientific discussions.

This session provided an opportunity to understand how patients' involvement in regulatory activities is increasing and becoming more varied. In this learning journey, regulatory agencies have been testing different methodologies and working with patients' groups to work out the best solutions.

Flexible engagement methodologies and appropriate support and training are vital elements for this process. The input from these different stakeholders makes a huge difference for the outcomes in the regulatory work.

The Fundamentals of Supporting Health Worker and Patient Safety

Safety must be a top priority for pharmaceutical companies and every action must be considered through the lenses of the people these products are aimed to. The COVID-19 pandemic shines new light on this premise and invites all humanity to a collective responsibility on safety.

Kawaldip Sehmi, IAPO CEO, introduced the session and invited Joanne Waldstreicher, MD, Chief Medical Officer from Johnson & Johnson, to share her insights on health worker and patient safety.

“**Patients and health workers safety are closely connected and we cannot have one without having the other.**
Joanne Waldstreicher”



Joanne Waldstreicher highlighted the importance to speak up for health workers safety. She explored ways health systems can be strengthened by investing in

training for workers, supporting their emotional and mental wellbeing and making sure their equipment is as safe as possible, making sure decisions are oriented by data and science, and following ethical guidelines. Health workers are in the frontline doing the person-to-person work; they are the eyes and ears of the health system.

Johnson & Johnson is committed to collaborate with multiple stakeholders, mobilizing their global reach and international expertise to overcome the pandemic: “our only competitor, our only enemy is the virus”. Healthcare workers are the essential partners in bringing the vaccine through the process and to the public. Real world data monitored by advanced technology will ensure prompt responses to the issues that arise.

The world is coming together to provide a vaccine. These public health crises shine a light on the importance of safety flowing throughout the system. Joanne Waldstreicher closed her speech with a call to action, reminding all public can support healthcare workers safety. Through social distancing, hands sanitizing, keeping well-informed and encouraging trust in science each person can actually take responsibility in overcoming this global crisis together.

Closing Keynote

Financing UHC 2030 and Health System Recovery

Our health systems today need to not only justify investment to repair the COVID-19 related damage, but also investment to accelerate progress towards Universal Health Coverage (UHC). Under the United Nations High Level Political Meeting Declaration on UHC, Member States promised to invest in extending their healthcare services to cover more of their population, enhance their basic healthcare service packages by including comprehensive and innovative services, and reduce the out-of-pocket costs for patients. Health should be perceived not as a reward for development, but as its prerequisite.

This keynote speech provided an overview of challenges and opportunities, as well as lessons learnt from the current pandemic for health systems' financing.

Dr Neda Milevska-Kostova, IAPO, introduced the session and invited Joseph Kutzin, World Health Organization, to share his insights on health financing post-COVID-19.

Joseph Kutzin started his talk exploring Universal Health Coverage as a normative and political concept. According to it, all people and communities are able to get the services they need, with good quality, and without fear of the financial consequences. These values are now more explicitly under threat.

The viability of UHC depends on reducing unmet needs and improving financial protection. The main guiding principle is to move towards predominant reliance on compulsory public funding sources. More public spending on health and better policies reduces the likelihood of people facing financial hardship and it's linked to better service coverage.

The challenges posed by the pandemic within this context are high current spending (expenditure shock) and decline in tax collection (revenue shock). The implications are: at the policy level we have to be concerned with spillover effects: private coverage can conflict with public coverage.

When considering directions for the next 10 years, it's important to design systems to protect the vulnerable. It won't be possible to have "free for all", but tailored measures can reduce severity of impact. Therefore, the need to consider innovations in delivery, through simple financing and locally tailored service delivery approaches.

“ A simple way to think about Universal Health Coverage is a concept not to be implemented but the implementation of health systems reforms by countries in order to make progress on the UHC objectives of reducing unmet needs and improving financial protection.



”

*Joseph Kutzin
Head of Health Financing
Team, World Health
Organization*

Patients Shouting Café

The Patient Shouting Café is a great programme run by IAPO Member Korea Alliance of Patients' Organizations (KAPO). The Patient Shouting Café concluded the virtual GPC 2020 by giving patients an opportunity to share their stories of patient harm, denial of access, discrimination and other challenges they faced in access to or safety and quality of care.

Kawaldip Sehmi, IAPO CEO, moderated the session and invited the following speakers to share their experiences:

- Gi-jong An, Korea Alliance of Patients' Organizations
- Heo Hee-jung, mother of Kim Jae Youn, Leukemia patient
- Flavia Kyomukama, Action Group for Health Human Rights and HIV/AIDS
- Dalilah Kalla, Lupus Alert

Gi-jong An made an introduction to the Shouting Café where Korean patients started gathering in a café to protect their rights and since then it has become a hub for open communication. Patients shout out their troubles and find sympathy and consolation from the audience and seek wisdom to find solutions for their problems. They have formed a committee with doctors,

lawyers, group representatives, and the group suggests solutions to the problems raised by the patients at the shouting café. Patients find tremendous comfort and healing from the audience. This forms public opinion, leading to the making of important regulations, policies and laws. In the process patients learn they can have their voices heard.

Heo Hee-jung, shared her experience with her son Kim Jae Youn, Leukemia patient. Jae Youn had poor physical condition and was administered 4 doses of sleep sedatives in ten minutes while doing a bone marrow examination. His heart stopped and he stopped breathing. This was because no one observed him while doing the examination, although his mother explained his condition and asked a doctor to stay close to him. Heo Hee-jung only wanted medical staff to pay more attention to her son as a patient. She then made a call for doctors to treat patients with full expertise and honesty and for politicians to fulfill responsibilities and change the world with the right policies.

Dalilah Kalla, Lupus Alert, shared her experience as a patient and advocate. Kalla received the diagnosis of lupus at the young age of 13. She was then overwhelmed with feelings of hopelessness. Living with lupus is challenging: pain and other physical restrictions prevent patients from participating in routine activities. The

“ If we can take a closer look on the reason he died and treat the lives of others more safely, I think that was the important message Jae Youn gave to me.

Heo Hee-jung

”

“ The contact with other patients and being open about my disease helped me a lot in this journey.

Dalilah Kalla



”

contact with other patients helped a lot in this process. She also learnt being open with friends, teachers, colleagues and health professionals helped her to deal and cope with the disease. She also understood that sharing her story helped other patients. Kalla became an advocate of lupus and other autoimmune diseases and founded the Lupus Alert organization. When she came out in 1999 about her disease, publicly sharing her pain and traumatic experience, Lupus was actually unheard of in Mauritius. So the impact of awareness, understanding, giving more clinical support, research became a passion for her and the work has touched every individual impacted by lupus in the island. Talking about the disease put the disease on the map and enables patients' personal growth.

Flavia Kyomukama, Action Group for Health Human Rights and HIV/AIDS, shared her personal experience with her pregnant niece needing medical assistance during the COVID-19 pandemic. The current crisis has imposed severe restrictions and challenges for all and especially for patients, due to the difficulties in accessing medical care and medicines. Kyomukama highlighted patients' organizations have been playing a pivotal role in these difficult times, offering guidance, support and a platform for them to have a voice.

Gi-jong An closed the session highlighting the power and importance of patients advocacy in improving the laws and guidelines. Most importantly is that the basic patient safety principle must be adhered. Patients' treatments can be different depending on the efforts by the patient and the family, so patients must raise their voices.

“ Patients' participation can make a difference, and that's why our Patients Shouting Café is meaningful.

Gi-jong An



”

Final Remarks

The collapse of healthcare services round the world, the behaviour of some of the “agencies” enforcing quarantining, and high levels of patient harm during the covid-19 pandemic, undoubtedly warrant a strong response. We need a new agenda for change if we are to address the current threat to patient centred healthcare and patient safety globally.

Day one of the congress saw over 1300 patient advocates participate online and listen to the views of expert patients, policy makers, and practitioners as they discussed the challenges and some of the success stories from the frontline of healthcare. This was then followed by a broad debate on a new road map for global health recovery post covid-19 and how to realise WHO's commitment to “build back better” and ensure implementation of the World Health Assembly Resolution WHA 73.1 covid-19 response.

As the conference proceeded it was evident that every patient organization had adverse experiences to report and stories of patient harm to share as a result of the unprecedented covid-19 health crisis. Mental health related patient organizations spoke out particularly strongly and many speakers underlined the rising crisis in the mental health and wellbeing of patients in most disease groups.

All healthcare services have been affected, from health promotion to prevention, treatment, rehabilitation, and palliative care. Patients who in most settings had previously mostly only endured small hotspots of problems and undertaken firefighting exercises in relation to specific issues such as access to medicine or patient safety concerns, now face a near complete domino collapse of usual services which are causing problems on a massive scale.

Patients with long term conditions and comorbidities have been alarmed by high covid related mortality rates and additional threats to health and wellbeing as a result of shielding and poorly resourced support programmes. Patients with rare diseases faced an additional problem of lack of information on how infection with covid-19 is likely to affect them.

On the positive side pre-meeting posts and virtual chats, as well as dialogue during the congress, made it clear that patient advocates and organizations want to play an active part in national and global efforts to control the pandemic and exchange ideas on “Co-creation in Innovative Healthcare during covid-19” which was the theme of the meeting.

Key conference messages

One loud message from GPC 2020 was that our health systems and healthcare teams do not know their patients as well as they had been telling us. Furthermore (and maybe worse still) many of the healthcare administrators and service delivery teams don't know each other either, nor do they work together well, despite the digital and communications revolution.

Healthcare teams have worked in silos across fragmented healthcare systems for so long that they have become isolated from the overarching aims and

objectives of their health systems—and their patients. Faced with a system-wide and an all-encompassing health crisis they have to learn to talk with each other and work better together. One example where that has happened during the pandemic has been where healthcare managers have to identify and recruit nurses and health workers from across the system who have the skills in respiratory and acute healthcare, as healthcare systems have needed them to cope with patients acutely ill with covid-19.

Expert patients have always been proactive, and many health systems rely upon them for change, renewal, and innovation. So another key message from GPC 2020 was that before health systems can start 'building

back better', they have to ensure meaningful patient engagement and ensure true co-creation in healthcare policy making, service design and delivery becomes a reality. This in turn depends on cultural change among the policy elites.

Day 2 of the congress marked World Patient Safety Day. Dame Sally Davis, UK Envoy on Antimicrobial Resistance and Thomas B. Cueni, Director General of International Federation of Pharmaceutical Manufacturers (IFPMA), spoke about antimicrobial resistance as the second pandemic for which we have to be prepared and the launch of the AMR Action Fund.

Take home messages and a call for action

Over the course of two days debate many issues were raised and important messages sent out. These included the following:

1. WHO Chief Scientist Soumya Swaminathan and the International Federation of Pharmaceutical Manufacturers (a non-State Actor in Official Relationship with WHO) reassured patients that all WHO Member States and all of the pharmaceutical industry are cooperating and sharing knowledge and resources as never before.
2. Strengthening health systems, especially primary health is a priority to lead the effort to vaccinate 8 billion people over a short time span. Patient engagement is vitally important here to address both the infodemic and vaccine hesitation, and help ensure vulnerable patients are vaccinated quickly
3. When effective vaccines come on stream regulators such as the FDA and EMA must maintain their strong stance on patient engagement and co-creation of guidelines and the African Medicines Agency should adopt the same approach
4. The World Health Organization's Global Action on Patients Safety and the WHO Flagship Decade of Patient safety 2020-30 be integrated into all covid-19 control systems and the full spectrum of healthcare
5. Patient engagement and co creation in health systems must be formalised by legal and policy means.

“ It’s a question of values now: are we committed to serve the vulnerable? This needs your voice and influence. Only then we can move to the joys of health financing.

Joseph Kutzin



”

In his closing keynote Joseph Kutzin, a health economist at WHO, highlighted how covid-19 has disrupted the journey towards universal health coverage. To get back on track, he said, we will need to find new ways to raise finance as income tax, VAT and duties, and corporation tax revenues are being severely affected by the economic downturns. And he urged greater investment in health literacy, health promotion, and prevention. Health is central to all policies, he underlined, and it was a lack of investment in global public goods like the International Health Regulation 2005 programmes which had, in his view precipitated this pandemic crisis. The meeting concluded with the launch of a call to action.

Kawaldip Sehmi,
CEO International Alliance of Patient Organizations

GPC 2020 Call to Action

The 9th Global Patients Congress 2020 resolves in national unity and global solidarity, endorsing in acclamation, the global patient community pledge:

- To urge every World Health Organization Member State to engage their whole of patient community within their whole-of-government and whole-of-society efforts to control and eliminate the COVID-19 Pandemic;
- To urge full implementation of the World Health Assembly Resolution 73.1 and request that every Member State during the current pandemic provides equitable and appropriate protection for their populations, in particular people with pre-existing health conditions, other vulnerable groups, as well as groups at risk, including health professionals, and other frontline workers;
- To urge full implementation of the WHA Resolution 72.6 and request each Member State to secure sufficient funding and support for ensuring necessary health system capacity that will provide access to safe and quality care for everyone, in normal state or in an emergency, respecting patient centricity and equity, leaving no one behind;
- and
- To urge Member States to engage expert-patients in research, policy formulation and implementation, so to better respond to their needs.

As the world rethinks responses to protect patients and health workers and rebuild a stronger road to recovery, we pledge for a patient-centred healthcare system with the patient being not only its user, but a contributor and a co-creator to its development for better, more accessible, affordable, dignified, quality and safe care.

Nothing about us without us!

Resources and Inputs

To ensure GPC 2020 was successfully turned into a virtual congress, IAPO staff worked closely with Mustard Presentations, a specialised production agency with years of experience in providing technical support and creative solutions to events and conferences.

Over the course of GPC 2020 we also had the support of two specialised note-takers who produced notes and summarised speakers' presentations in simultaneity with all sessions. These reports were then used to feed the presentations Key Messages and Highlights, which were shared during the closing ceremonies on both days of the congress. These materials have also been useful to the writing up of the present report.

In order to provide the delegates with an interactive experience, as close as possible to a physical conference,

IAPO staff and Mustard team organised GPC 2020 through vFairs, a virtual event platform. Our personalised landing page reproduced a conference environment by providing participants with the following visiting pathways:

1. Lobby
2. Exhibit Hall
3. Auditorium
4. Networking via chat
5. Downloadable resources



Booth Visits

By walking into the conference Exhibit Hall, delegates and speakers had the opportunity to visit a number of booths with different resources and relevant information about healthcare.

GPC Exhibit Hall had 23 booths open to visitors during the 2-day live event and on-demand over one month after that. More than 1500 visits explored the resources provided in the following booths:

Alianza Latina
Bayer
BD
Cell and Gene Therapy Toolkit
Fight the Fakes Campaign
Geneva Health Forum (GHF)
Global Health Progress
Gorlin Syndrome Alliance
IAPO African Pavillion
IAPO Members' booth
IAPO-PAIR AMR Initiative
Indian Alliance of Patients Groups

International Alliance of Patients' Organizations (IAPO)
International Council of Nurses
Johnson & Johnson
LEO Pharma
MSD
Novartis
Novo Nordisk A/S
Roche: Advancing Personalised Healthcare
Thalassaemia International Federation
Upjohn
World Patient Safety Day



Outputs, Outcomes and Impact

Delegates Feedback Survey

For us at IAPO it is extremely important to get delegates' feedback and opinion about GPC 2020 and what they think could be improved in the future. With the support of Survey Monkey online tools, IAPO staff designed a Feedback Survey and kindly asked delegates to briefly fill in the following questions:

1. What did you like the most about the virtual 9th Global Patients Congress?
2. What did you like the least about the virtual 9th Global Patients Congress?
3. What key message(s) did you take away from the virtual 9th Global Patients Congress?
4. How will you apply what you learned at the virtual 9th Global Patients Congress to your work and field?
5. Do you have any suggestions for how our Global Patients Congresses could be improved in the future?

In what follows, we highlight some of the delegates' answers.

Holding our 9th Global Patients Congress in the middle of a pandemic gave our global patient community a strategic opportunity to share our patient experiences and patient perspectives with healthcare policy makers through a global platform. It opened a door for us to join the whole-of-government and whole-of-society effort to control the pandemic and rebuild our health systems as a whole-of-patient community.

The World Health Assembly Resolution WHA73.1 Agenda item 3 (May 2020) gave the GPC 2020 a great mandate

“ In addition to the expertise and knowledge shared during the session, I returned to my day-to-day work knowing who I can turn to for advice and to seek expertise. Time and resources that would have been used to “reinvent the wheel” will be minimized because of the knowledge networks established as a result of Congress.

GPC 2020 Delegate

to call for and ensure that the World Health Organization Member States (MS) quickly strengthen and fix the disrupted healthcare services.

GPC 2020 gave patients hope at a time when things were very bleak due to the pandemic. We heard that delegates felt reassured and gained clarity as a result of the awareness raising that was done by speakers on the reality of COVID-19.

GPC 2020 gave the global patient community an opportunity to mark the WHO World Patient Safety Day through the day 2 programme that was dedicated to this day. The congress provided an opportunity for awareness raising on the scale of avoidable harm linked with medical errors and a platform to examine the call

to action of ensuring safety across different dimensions of healthcare from diverse stakeholders' perspectives to support in reducing the risk of harm, both to health workers and patients.

COVID-19 damaged many services and though the GPC 2020 call to action, patients called on WHO MS to accelerate the implementation of patient centred measures to provide a sufficient quantity of safe, quality,

accessible, acceptable and affordable healthcare services, medicines and devices (including PPE) to all again.

The entire Congress was a moment to remind ourselves of WHO DG's words that health is not a cost; it is an investment. Health is not a reward for development; it is a prerequisite. Health is a pathway to security, prosperity, and peace. We must address this common problem through national unity and global solidarity.

GPC 2020 Information

Programme

DAY 1 – 16 September 2020

🕒 9:00 BST

Opening Ceremony



Dr Ratna Devi, IAPO Chair



Dr Neda Milevska-Kostova, IAPO Vice-Chair



Karen Alparce-Villanueva, IAPO Secretary and Congress Committee Chair

🕒 9:15 BST

Keynote Speech: WHA 73.1 and Future Proofing Health Systems: Preparedness for Next Phase of Pandemic COVID-19 and Patient Co-Creation



Dr Soumya Swaminathan, MD, Chief Scientist, World Health Organization



Dr Ratna Devi, IAPO Chair (Discussant)

🕒 10:00 BST

COVID-19 Vaccine Development for Future and Current Pandemics and Public and Patient Engagement in Clinical Trials



Karen Alparce-Villanueva, IAPO Secretary and Congress Committee Chair (Moderator)



Thomas B. Cueni, Director General, International Federation of Pharmaceutical Manufacturers & Associations



Dr Jerald C. Sadoff, MD, Senior Advisor of Clinical Vaccine Development, Janssen Infectious Diseases and Vaccines



Dr Thomas Breuer, MD, MSc, Chief Medical Officer, GSK Vaccines



Julia Spencer, Associate Vice President of Global Vaccines Public Policy, Partnerships and Government Affairs, MSD



Steve Lockhart, Vice President, Head of Europe and Asia-Pacific, Vaccine Clinical Research and Development, Pfizer

🕒 11:00 BST

Mobility Break

🕒 11:10 BST

Mental Health, the Forgotten Pandemic - during and after COVID-19



Bisi Bright, FPCPharm, FPSN, MPH, MNIM, 1st Vice Chairman, CEO and Founder, LiveWell Initiative LWI (Moderator)



Dr Kannan Subramaniam, Medical Lead for NCD Strategy - Emerging Markets, Pfizer Upjohn



Prof Kamaldeep Bhui, CBE, Professor of Psychiatry, University of Oxford & Editor in Chief, British Journal of Psychiatry Oxford University



Annie Bliss, Communications and Policy Manager, Alzheimer's Disease International

🕒 11:55 BST

Prioritizing NCDs in Future Pandemic Preparedness - Addressing Concomitant Risks of the Virus and the Underlying NCDs



Dr Amrit Ray, MD, MBA, Global President of R&D and Medical, Pfizer Upjohn (Moderator)



Dr Mark Barone, Vice-President, International Diabetes Federation



James Headen Pfitzer, Director, Access Accelerated



Dr J S Thakur, MD, President, World NCD Federation

🕒 12:40 BST

Genetic Disorders and Rare Diseases Patient Co-Creation



Nidhi Swarup, Founder and President, Crohn's & Colitis Society of Singapore (Moderator)



Julie Breneiser, Executive Director, Gorlin Syndrome Alliance



Camilla Krogh Lauritzen, Chief Patient Officer and Head of Patient Engagement, LEO Pharma



Dr Ivana Knezevic, MD, Scientist & Team Leader, World Health Organization

🕒 13:25 BST

Mobility Break

🕒 13:35 BST

Patient Centricity within Health Technology Assessment, Value Based Healthcare and HTx



Jan Geissler, Chief Executive Officer, Patvocates (Moderator)



David L. Grainger, Head of Global Health Outcomes and Policy, Biointelect



Ann Single, Patient and Citizen Involvement Interest Group Chair and Patient Voice Initiative Coordinator, Health Technology Assessment International



Dr Dalia Dawoud, Scientific Adviser, National Institute for Health and Care Excellence

🕒 14:20 BST

Personalised Healthcare: can Lessons from COVID-19 Accelerate Adoption?



Kawaldip Sehmi, Chief Executive Officer, IAPO (Moderator)



Jan Geissler, Chief Executive Officer, Patvocates



André Trottier, Global Head of Personalised Healthcare Policy Strategy, Roche

🕒 15:00 BST

Mobility Break

🕒 15:10 BST

Launch of MAPS - Mapping the Patient Journey for NCDs



Dr Ratna Devi, IAPO Chair



Menassie M. Taddese, President for Emerging Markets, Upjohn Pfizer



Dr Amrit Ray, MD, MBA, Global President of R&D and Medical, Upjohn Pfizer

🕒 15:25 BST

Digital Healthcare: Defragmentation and Integration of Health Systems and Care Pathways



Kawaldip Sehmi, Chief Executive Officer, IAPO (Moderator)



Eric de Roodenbeke, Chief Executive Officer, International Hospitals Federation



Siva Singh, Director EMEA, Escalla



Dr Vijay Rawal, MD, Deputy Medical Director Commissioning, NHS England and NHS Improvement (Midlands) & Subject Matter Expert in Primary Care, Escalla

🕒 16:10 BST

Blood Disorders and Access to Healthcare Services and Therapies (Carol Ossai Talk) ▼



Dr Androulla Eleftheriou, Executive Director, Thalassaemia International Federation (Moderator)



Alexey Salamakha, Director of Global Patient Relations, Novartis Oncology



Issa Ali, Chair, Global Alliance of Sickle Cell Disease Organizations

🕒 16:45 BST

Day 1 Wrap Up ▼



Ellos Ellard Lodzeni, Board Treasurer, IAPO

DAY 2 – 17 September 2020

🕒 9:00 BST

Introduction Day 2 ▼



Dr Neda Milevska-Kostova, IAPO Vice Chair

🕒 9:15 BST

2nd World Patient Safety Day and WHO Decade of Patient Safety 2020-2030 ▼



Rt Hon Jeremy Hunt MP, Chair, House of Commons Health and Social Care Select Committee

🕒 9:30 BST

2019 Jeddah Ministerial Declaration on Patient Safety ▼



Dr Abdulrahman Al-Hawsawi, MD, Director-General, Saudi Patient Safety Centre

🕒 9:45 BST

AMR: Preventing the Next Pandemic and the AMR Action Fund ▼



Dame Sally Davies, GCB, DBE, FRS, FMedSci, UK Government's Special Envoy on Antimicrobial Resistance, UK Department of Health and Social Care



Thomas Cueni, Director General, International Federation of Pharmaceutical Manufacturers & Associations

🕒 10:15 BST

Mobility Break ▼

🕒 10:25 BST

Patient Co-Creation within Global Patient Safety: Expert Patients and DEEPs



Charline Coquerel, Director and Head of Global Patient Relations, Novo Nordisk



Sara Mobäck, Global Diabetes Advocate



Ken Tait, DEEP Member and Diabetes Advocate

🕒 10:55 BST

Partnering to Advance Patient Safety: the Role of Medical Technologies



Melina Raso, Executive Director, Health First Europe (Moderator)



Fiona Garin Mc Donagh, Senior Director for Strategic Marketing, BD Europe



Kawaldip Sehmi, Chief Executive Officer, IAPO



Patient Safety storyteller

🕒 11:40 BST

Patient Involvement in Addressing AMR and Sepsis Risks



Dr Neda Milevska-Kostova, IAPO Vice-Chair (Moderator)



Dr Bruce Altevogt, Vice President and Head External Medical Engagement, Pfizer Inc.'s Hospital Business Unit



Danjuma Adda, Executive Director, Centre for Initiative and Development (CFID) Taraba & Chagro-Care Trust



Dr Konrad Rheinhardt, MD, President, Global Sepsis Alliance

🕒 12:25 BST

Mobility Break

🕒 12:35 BST

Holistic Patient and Health Worker Safety: Hospital, Care Facility and Self-Care



Dr Peter Lachman, MD, Chief Executive Officer, International Society for Quality in Health Care (Moderator)



Dr Neelam Dhir, MD, Coordinator of Patient Safety and Risk Management, World Health Organization



Judy Stenmark, Director General, Global Self-Care Federation



Monika Lessl, Senior Vice President, Head of Corporate R&D and Social Innovation Bayer AG & Executive Director, Bayer Foundation

🕒 13:20 BST

EUPATI Research and Development of Safer Medicines



Camilla Krogh Lauritzen, Chief Patient Officer and Head of Patient Engagement, LEO Pharma (Moderator)



Lasse Funch Jacobsen, Senior Lead of Patient Research and Alliances, LEO Pharma



Dr Tamás Bereczky, Course Coordinator, Content Developer and Trainer, EUPATI

🕒 13:50 BST

Community Pharmacists - Medication and Overall Patient Safety



Bisi Bright, FPCPharm, FPSN, MPH, MNIM, 1st Vice Chairman, CEO and Founder, LiveWell Initiative LWI (Moderator)



Dr Catherine Duggan, Chief Executive Officer, International Pharmaceutical Federation



Dr Anantha Naik Nagappa, President, Association of Community Pharmacists of India & Director, Amity Institute of Pharmacy, Amity University of Madhya Pradesh

🕒 14:20 BST

Mobility Break



🕒 14:30 BST

Regulatory Harmonisation for Access to Safe Medicines, Vaccines and Health Devices



Dr David Jefferys, MD, Senior Vice President for Global Regulatory, Healthcare Policy and Corporate Affairs, Eisai Europe, International Federation of Pharmaceutical Manufacturers & Associations (Moderator)



Andrea Furia-Helms, MPH, Director of the Patient Affairs Staff in the Office of Clinical Policy and Programs, Office of the Commissioner, U.S. Food and Drug Administration



Nathalie Bere, MPH, Patient Relations Coordinator, European Medicines Agency

🕒 15:15 BST

The Fundamentals of Supporting Health Worker and Patient Safety



Dr Joanne Waldstreicher, MD, Chief Medical Officer, Johnson & Johnson

🕒 15:30 BST

Keynote Speech: Financing UHC 2030 and Health System Recovery



Dr Neda Milevska-Kostova, IAPO Vice-Chair (Discussant)



Joseph Kutzin, Head of Health Financing Team, World Health Organization

🕒 16:00 BST

Patients Shouting Café



Kawaldip Sehmi, Chief Executive Officer, IAPO (Moderator)



Gi-jong An, President, Korea Alliance of Patients' Organizations



Heo Hee-jung, mother of Kim Jae Youn, Leukemia patient



Flavia Kyomukama, Executive Director, Action Group for Health Human Rights and HIV/AIDS



Dalilah Kalla, Secretary, Lupus Alert

🕒 16:45 BST

Closing Session



Dr Ratna Devi, IAPO Chair

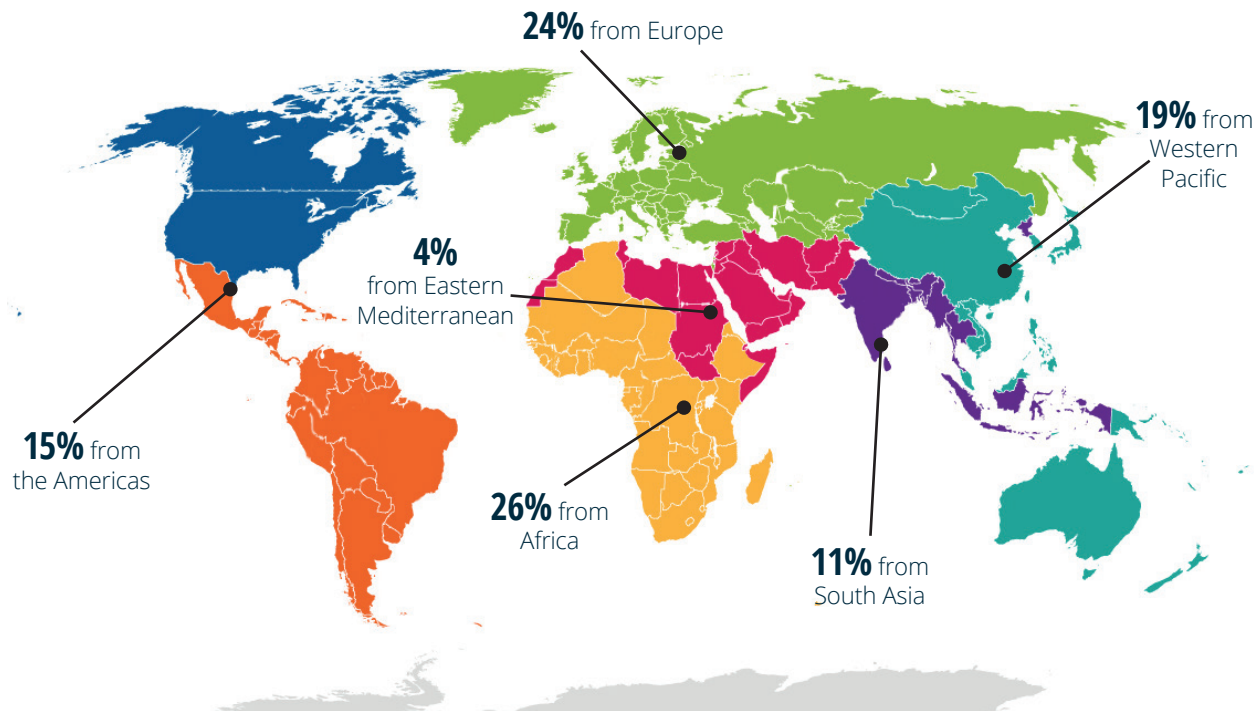
Delegates' Attendance

Delegates were able to join GPC 2020 without having to go through the usual frustrating challenges of face-to-face meetings including having to obtain visas and travel insurance and cope with underlying conditions that some countries and insurance discriminate against.

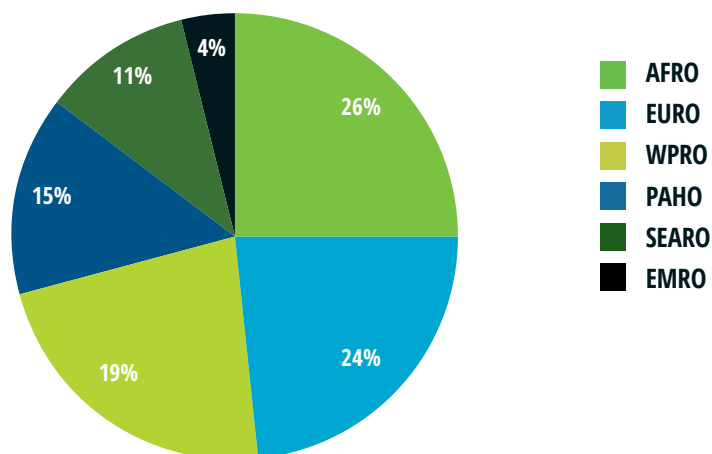
Due to the pandemic, many delegates were shielding, and could not have attended a face-to-face meeting.

The Congress brought together 1300 delegates; a number 10 times higher than the previous Global Patients Congress . Benefiting from the advantages of virtual conferences, delegates were based in 101 countries, an increase of 70 countries when compared with IAPO's previous global conference.

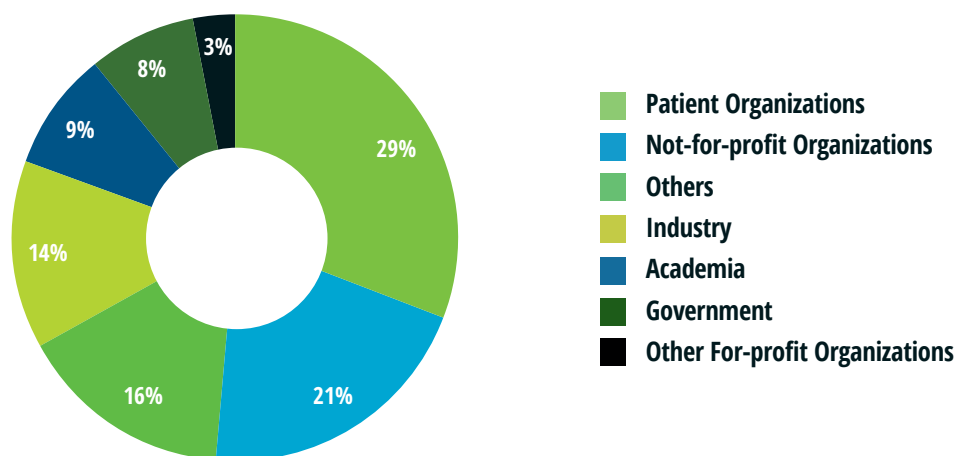
World Map



Delegates by region



Delegates by field



From the 385 patient organizations represented in GPC 2020, 98 were IAPO member organizations, 85 were members of IAPO member organizations, and 202 were other patient organizations. The number of delegates belonging to the health industry was 182, of which 15 are IAPO sponsoring partners.

List of Speakers

Listed in alphabetical order using first name



**Dr Abdulelah AlHawsawi,
MD, Director-General, Saudi Patient Safety Centre**

Dr. Abdulelah Alhawsawi is the founding Director-General of the Saudi Patient Safety Center (SPSC), and MOH Advisor on Patient Safety. He led the efforts to establish SPSC as a WHO Collaborating Center for patient safety policies and strategies (1 of only 5 WHOcc worldwide in this field). He holds Dual Certified Boards (American - Canadian) of general surgery with sub-specialty in Transplant and Hepatobiliary Surgery.

He is a consultant to several national and international quality and safety organizations and recently became an executive committee member of the Global Sepsis Alliance (GSA). He was part of the Expert Panel on the 3rd Global Patient Safety Challenge of the WHO.

He chaired the Organizing Committee for the 4th Global Ministerial Summit on Patient Safety in Jeddah, Saudi Arabia, in 2019. Dr. Alhawsawi has helped introduce Patient Safety as a G20 priority in the 2020 G20 of Saudi Arabia. Currently, Dr. Alhawsawi is part of the WHO's Global Patient Safety Action Plan Taskforce.



**Alexey Salamakha, Director of
Global Patient Relations, Novartis Oncology**



**Dr Amrit Ray, MD, MBA, Global
President of R&D and Medical, Pfizer Upjohn**

Dr. Amrit Ray is a physician researcher and corporate executive committed to advancing scientific breakthroughs and championing patient-focused, ethical healthcare practices. Dr. Ray is Global President of R&D and Medical at Pfizer Upjohn. His instrumental role in developing, launching, and catalyzing access and impact for medicines combatting debilitating diseases has been recognized by patients and governments. Dr. Ray was previously Chief Medical Officer for pharmaceuticals at Johnson & Johnson and a hospital doctor in Britain's National Health Service. He publishes widely on how medical innovation can positively impact patients and society.



**Dr Anantha Naik Nagappa, President,
Association of Community Pharmacists of India &
Director, Amity Institute of Pharmacy, Amity
University of Madhya Pradesh**

Dr A N Nagappa had his education and work experience from BITS, Pilani, Manipal University for 40 years. He is actively engaged in IAPO programs like Patients Solidarity Day. He had participated in several annual conferences of IAPO, ISOPP and ISPOR. His lifetime mission statement is "Pharmaceutical Care Every Where".

He is presently working as Director of Amity Institute of Pharmacy, AUMP, Gwalior Madhya Pradesh. He had pioneered in areas like home medication review, community Pharmacy services, health screening, generic medicine Pharmacoeconomics and Outcome research.

He is participating in patient counseling activity in University Health Center along with the faculty, staff and students of Amity University of Madhya Pradesh.



André Trottier, Global Head of Personalised Healthcare Policy Strategy, Roche

André is the Global Head of Personalised Healthcare Policy Strategy at Roche. He leads a team that engages in developing new policy options as the convergence of medical knowledge, technology and data science is revolutionising patient care.

André has led teams in government (Health Canada and the British Columbia Health Services Authority), the non-for-profit sector (Heart and Stroke Foundation) and the private sector (GlaxoSmithKline Canada and Roche Canada). He has held health policy positions in the therapeutic areas of neuroscience, oncology, and infectious diseases (anti-microbial resistance).

He holds a Master's degree in public administration from the University of Ottawa, Canada. He is the recipient of the Queen Elizabeth II Golden Jubilee Award for his volunteer services with the Lifesaving Society.

André is married and is the proud father of three daughters.



Andrea Furia-Helms, MPH, Director of the Patient Affairs Staff in the Office of Clinical Policy and Programs, Office of the Commissioner, U.S. Food and Drug Administration

Andrea Furia-Helms is the Director of the Patient Affairs Staff in the Office of Clinical Policy and Programs, Office of the Commissioner. In her role, she collaborates with patient communities, the FDA medical product Centers and other offices to incorporate patient and caregiver perspectives in crosscutting regulatory meetings.

Furia-Helms spent over ten years in the FDA's Office of Health and Constituent Affairs where she directed the FDA Patient Representative Program and coordinated patient engagement activities for the agency.

Prior to FDA, Furia-Helms was Director of the Back to Sleep (now Safe to Sleep) campaign, a public-private partnership to educate communities on Sudden Infant Death Syndrome (SIDS), at the National Institutes of Health. She developed SIDS outreach initiatives for African American, American Indian and Latino communities.

Furia-Helms has a B.A. in psychology from Framingham State University, a B.S. degree in community health education from University of Maryland, and a Master of Public Health degree from The George Washington University.



Dr Androulla Eleftheriou, Executive Director, Thalassaemia International Federation

Dr Androulla Eleftheriou obtained her graduate and postgraduate degrees in Biochemistry, Microbiology, Virology, and Business Administration from the University of London and the University of Leicester, UK, receiving fellowships from the World Health Organization and the Fulbright Commission. Her postdoctoral studies were completed at the Centre for Disease Control in Atlanta, GA, USA. From 1990 until August 2006, she was Head of the Virus Reference Centre of the Cyprus Ministry of Health. Since 2006 she serves as the Executive Director of the Thalassaemia International Federation, after 13 years of being a volunteer and Scientific Coordinator of the Federation's renowned educational programme. Dr Eleftheriou is an expert patient advocate, having attended seminars on Patient Advocacy offered by the Harvard University in Boston, MA, USA. She served as Member of the Board of Directors of IAPO, EPHA, President of the Cyprus Alliance for Rare Disorders and participated in several committees and bodies (EUCERD, ESTM, SITA) as both a scientist and patient advocate.



Ann Single, Patient and Citizen Involvement Interest Group Chair and Patient Voice Initiative Coordinator, Health Technology Assessment International

Ann Single is the Coordinator and a Steering Committee Member of the Patient Voice Initiative (Australia) and Chair of the HTAi Patient and Citizen Involvement Interest Group (PCIG). She began in this field directing

patient involvement and communication in Scotland's first Health Technology Assessment (HTA) body. In PCIG she has been involved in the development of numerous tools and resources to support patient involvement in HTA. Her experience includes co-editor of the book Patient Involvement in Health Technology Assessment (2017), lay reviewer for several journals, work in a patient organization, and science and corporate communication for government and research institutions.



Bisi Bright, FPCPharm, FPSN, MPH, MNIM, 1st Vice Chairman, CEO and Founder, LiveWell Initiative LWI

Bisi Bright is a Pharmacist, Lecturer and Public Health Manager. She is 1st Vice Chairman, CEO and Founder of LiveWell Initiative LWI, a self-sustaining non-profit. She is an Internship Preceptor at Harvard T H Chan School of Public Health, Boston USA and, a Doctoral Thesis Co-Supervisor at the University of Helsinki in Finland, with publications in internationally recognised peer reviewed journals. She served as IAPO Regional Steering Committee Member for Africa from 2011-2013; and delivered a paper at the inaugural Africa Regional IAPO Meeting in Johannesburg, in 2013. She led LWI to win the first-ever IAPO Global Photocontest at PSD 2013 with a photo titled TRIPLETS. At the global level, Bisi Bright served on the FIP as HMiS Africa/Middle East Rep and served on 3 International Working Groups including Patients as Partners Working Group, an IAPO-Partnered Project. Bisi founded another Patients Organization, Women in Hepatitis Africa WIHA in 2017, and doubles as Deputy National Coordinator of the Hepatitis national chapter in Nigeria, Exco of the Healthcare Federation of Nigeria HFN. Her latest work is in relation to COVID-19 Study Protocols and Prophylaxis Clinical Trials Research

and Covid Resilience for greater impact. Bisi Bright is happily married and well-travelled.



Dr Bruce Altevogt, Vice President and Head External Medical Engagement, Pfizer Inc.'s Hospital Business Unit

Bruce Altevogt is Vice President and Head External Medical Engagement within Pfizer Inc.'s Hospital Business Unit. In this role Dr. Altevogt is responsible for the business unit's patient engagement strategy and oversees Pfizer's industry leading AMR surveillance program, ATLAS. Prior to this role he was a Senior Director of Science Policy, where he was responsible for managing policy issues in support of Pfizer's research & development enterprise, vaccines and was lead for AMR policy. Dr. Altevogt serves as member of the AMR Alliance Board, an organization that measures and drives the life-sciences industry progress to curb antimicrobial resistance. Dr. Altevogt received a doctorate from Harvard University and a B.A. from the University of Virginia.



Camilla Krogh Lauritzen, Chief Patient Officer and Head of Patient Engagement, LEO Pharma

Anchored in the Research organization at LEO Pharma, Camilla is responsible for driving key deliveries to LEO's 2025 strategy that targets development of intervention against some of this World's most painful and life-threatening genetic and autoimmune diseases for which no treatment or cure currently exist.

To that end, Camilla has established the Patient Engagement function at LEO, implying a responsibility for the strategic and operational patient engagement activities. This is to ensure that all key decisions are informed by patient KOLs and communities, as well as executed in partnership with the mentioned.

Prior to joining LEO in May 2018, Camilla established and led the Patient Engagement function at Abbott, AbbVie and Novo Nordisk. Prior to joining pharma, Camilla worked for science/patient alliances and for patient organizations. In her view and experience, 'Patients' are indeed disease experience experts, and at LEO this translates into a 'Nothing About You Without You' mantra and commitment that shapes our approach, and her team at LEO strives daily to develop solution for people affected by rare disease with severe skin manifestations (click here for more information on what our commitment looks like in practical terms). She holds a Master degree in Molecular Biology, Corporate Communication and Business Administration.



Charline Coquerel, Director and Head of Global Patient Relations, Novo Nordisk

Charline Coquerel is director and head of Global Patient Relations at Novo Nordisk. She is responsible for Novo Nordisk's corporate patient engagement and advocacy strategy, ensuring there is a systematic approach for soliciting and integrating patients' insights across the product development value-chain. She joined Novo Nordisk four years ago. Coquerel has over 16 years of industry experience in public affairs with a strong focus on advocacy and patient engagement, both at a global and local level.



**Dr Dalia Dawoud, Scientific Adviser,
National Institute for Health and Care Excellence**

Dr Dalia Dawoud is Scientific Adviser at the National Institute for Health and Care Excellence (NICE). She holds a PhD in pharmaceutical policy and economics from King's College London. Her current work is focused on the use of real-world evidence to inform drug development and healthcare decision making.

Key research projects that Dalia works on include the IMI GetReal Initiative and Horizon 2020-funded HTx (Next generation Health Technology Assessment) project. She serves as Associate Editor for ISPOR journal Value in Health and for Elsevier's journal Research in Social and Administrative Pharmacy. Dalia holds adjunct position as Associate Professor at Faculty of Pharmacy, Cairo University.



Dalilah Kalla, Secretary, Lupus Alert

Growing up on the small island of Mauritius, Dalilah received the unexpected diagnosis of lupus at the very young age of 13. She was overwhelmed with feelings of despair, helplessness and hopelessness. Her mother made her realise that living a life paralysed with fear was really not living at all. She adjusted her life to accommodate lupus and its demands and to the impact of strong daily medications.

In 2000, she founded Lupus Alert, the only registered non-profit organization dedicated to improving the lives of people with lupus and other autoimmune diseases through advocacy, education, public awareness, genetic

research and clinical trials. Lupus Alert is a learning non-profit organization that is constantly looking for new knowledge and achieving good results without much financial assistance. It is an organization that is filled with passion, vision, commitment, motivation and determination. They are ordinary people who do extraordinary things!



**Dame Sally Davies, GCB, DBE, FRS,
FMedSci, UK Government's Special Envoy on
Antimicrobial Resistance, UK Department of Health
and Social Care**

Dame Sally Davies was appointed as the UK Government's Special Envoy on AMR in 2019. She is also the 40th Master of Trinity College, Cambridge University. Dame Sally was the Chief Medical Officer for England and Senior Medical Advisor to the UK Government from 2011-2019.

She has become a leading figure in global health including serving as a member of the World Health Organization (WHO) Executive Board 2014-2016 and as co-convenor of the United Nations Inter-Agency Co-ordination Group (IACG) on Antimicrobial Resistance (AMR) reporting in 2019.

In the 2020 New Year Honours, Dame Sally became the second woman (and the first outside the Royal family) to be appointed Dame Grand Cross of the Order of the Bath (GCB) for services to public health and research, having received her DBE in 2009



**Danjuma Adda, Executive Director,
Centre for Initiative and Development (CFID) Taraba
& Chagro-Care Trust**

Danjuma is a Nigerian prince and accomplished Public health expert on a mission to raise awareness about Hepatitis. Danjuma was infected with Hep B while in clinical rotations and then lost his own mother to the disease several years later.

Even though Hepatitis kills more people per year than HIV/AIDS, it receives just a fraction of the global health funding. Danjuma is a leading voice for Hepatitis patients in Nigeria and uses his platform to advocate for the most vulnerable populations across Africa. He wants to change the narrative about Hepatitis and raise awareness about the deadliness of the disease.



**Dr David Jefferys, MD, Senior Vice
President for Global Regulatory, Healthcare Policy
and Corporate Affairs, Eisai Europe, International
Federation of Pharmaceutical Manufacturers &
Associations**

Senior Vice President, Global Regulatory, Government Relations, Public Affairs and European Product Safety Eisai Europe Ltd on behalf of IFPMA. Previously practising as a physician/cardiologist, with additional interests in metabolic medicine/clinical toxicology and since spending 21 years as a senior regulatory in the UK/Europe.

Previously executive director of licensing in MCA, CPMP member, chairman of the MRFG and PER committees. Previously CEO and Director of the UK Medical Devices Agency and on creation of the MHRA acting joint chief

executive. Also working on secondment at the EMEA / EMA on benefit risk methodologies. Currently chairman of the ABPI regulatory committee and a member of the Innovation Board.

David also chairs the EFPIA Regulatory Committee and sits on the International Regulatory Board. Chairman of the IFPMA Regulatory Science Committee, a member of the IFPMA Council and of the ICH Committee and General Assembly. He is a past chairman of the CMR Advisory Board and currently sits as a member of the CIRS Scientific Advisory Council.



**David L. Grainger, Head of Global Health
Outcomes and Policy, Biointelect**



**Ellos Ellard Lodzeni, Board Treasurer,
IAPO**

Ellos is a health rights, social justice and governance advocate as well as a patient for patient safety champion with an enormous passion on health matters.

He is the patron and founder trustee of Patient and Community Welfare Foundation of Malawi, the only cross-disease patient movement in Malawi which articulates and amplifies the patient voice and drives the crusade for patient-centered healthcare in Malawi.



Eric de Roodenbeke, Chief Executive Officer, International Hospitals Federation

Dr. de Roodenbeke assumed the position of Chief Executive Officer of the International Hospital Federation in June 2008. Between July 2007 and May 2008, he was Senior Health Specialist at the World Health Organization (WHO) for the Global Health Workforce Alliance (GHWA) during which time he was involved in support country action programs to develop a response to the HRH crisis; development of strategies for regional networks in support of HRH development and was the focal point for follow-up actions in Francophone countries.

He was Senior Health Specialist at the World Bank (AFTH2 & WBI) from 2004 to 2006 in which time he was Team leader (TL) for various health intervention, educational, management and capacity building programs mostly in Africa. He was Director of the 700-bed University Hospital of Tours, and Senior Officer responsible for hospital and health financing interventions at the French Ministry of Foreign Affairs from 2001 to 2003 and 1999 to 2001, respectively.

Between 1996 and 1998, he was Senior Officer on hospital policy expertise at the French Ministry of Cooperation. From 1994 to 1996, he was Deputy Director of the 870-bed University Hospital of NANTES.

Dr. de Roodenbeke has published widely on hospital organization, health systems reforms human resources and health facility management, health policy, insurance and financing in developed and developing countries.



Fiona Garín Mc Donagh, Senior Director for Strategic Marketing, BD Europe

Fiona Garín has more than 25 years of experience in the health sector, with an international track record working in and across public and private sector organizations in developed and developing countries. She is currently the Senior Director for Strategic Marketing for BD Europe, responsible for leading cross-business, cross-functional and cross-country strategies and programmes in the region (including Healthcare Worker Safety, patient safety, efficiency, Marketing communications, and BD's Center for Innovation and Engagement).

Fiona also leads the European BD Marketing Council and Health Economics and Outcomes Research efforts, and is a member of the European Leadership team and the Global Marketing Council. Fiona has also held several other positions within BD, being the Strategic Marketing and Innovation Director for BD Medical Procedural Solutions, BD's director for influenza preparedness in Europe as well as BD's worldwide director for strategic marketing for the immunization platform, responsible for directing overall strategic and marketing efforts to meet developing country safe immunization needs. Prior to joining BD, she was a Health Specialist at the World Bank, managing Health Reform Projects under preparation and implementation in Central America, and a consultant for several years in Price Waterhouse's Strategic Consulting Group.



Flavia Kyomukama, Executive Director, Action Group for Health Human Rights and HIV/AIDS



Gi-Jong An, President, Korea Alliance of Patients' Organizations

Gi-Jong An was born in South Korea in 1970 and studied Law at the Hanyang University of Korea. His wife received a diagnosis of chronic myeloid leukemia in 2001 and he received a diagnosis of thyroid cancer in 2009. He has been working for Korean patients' rights since 2002 when he was involved in the issue of patients' access to the 'Gleevec' anticancer drug. He is a representative of the Korea Leukemia Patient Group which involves 10,000 members as well as the Korea Alliance of Patients' Organizations, representing 35,000 patients from seven patients' organizations.

Gi-Jong is proactively participating in various public health activities and governances including the National Health Insurance Policy Deliberation committee (a Healthcare-related top decision-making body in Korea), the Korea Medical Dispute Mediation and Arbitration Agency and the Korea Patient Right Ombudsman.

Heo Hee-jung, mother of Kim Jae Youn, Leukemia patient

6-year-old Leukemia patient Jae Youn Kim, who has been on Chemotherapy at the age of 3, died due to overdose of sleeping pill in an injection room with poor oxygen and emergency kits.

Heo launched a campaign to demand the government to establish a measure to prevent recurrence by issuing cautionary warnings and improve guidelines for "safe use of paediatric sleep sedatives" and "compulsory report of critical patient's safety accident".



Issa Ali, Chair, Global Alliance of Sickle Cell Disease Organizations

Issa Ibn Abraham Ali hails from the Caribbean, the Twin Island Republic of Trinidad and Tobago. He started his professional career as a licensed/registered pharmacist in the public health sector and later moved to being CEO (Pharmacy Manager) in the private sector. This International Master of Business Administration (Health Management) holder has been the President of the Society for Inherited and Severe Blood Disorders Trinidad and Tobago Ltd.) (SISBDTT) (Hemophilia; Thalassemia and Sickle Cell Disease) for the past eight years. Championing and advocating for persons living with inherited and severe blood disorders inclusive of Sickle Cell Disease, has become his life cause.

In his capacity as President, he has represented SISBDTT at several International Conferences, namely hosted by internationally recognized organizations like the World Federation of Hemophilia (WFH) and the Thalassemia International Federation (TIF).



Dr Ivana Knezevic, MD, Scientist & Team Leader, World Health Organization



Dr J S Thakur, MD, President, World NCD Federation



James Headen Pfitzer, Director, Access Accelerated

As the Director of Access Accelerated, he leads on the overall strategy and implementation for this multi-year initiative. Prior to joining Access Accelerated, James spent 10 years at the World Health Organization Headquarters in Geneva, Switzerland, where he handled strategy, engagement and policy for the Assistant Director Generals of Health Systems and Innovation and Global Health Security.

Issues covered by James included AMR, pandemic preparedness, IHR, R&D, innovation, universal health coverage, health systems strengthening, intergovernmental negotiations and consensus building. James also worked to implement capacity building activities at country and community levels and was appointed by the WHO Director General as the health advisor in the UN Secretary General's Office in New York for the Post-2015 Development Agenda and adoption of the SDGs.



Jan Geissler, Chief Executive Officer, Patvocates

As a CML patient since 2001, Jan co-founded the patient advocacy organizations LeukaNET, European Cancer Patient Coalition, CML Advocates Network, Acute Leukemia Advocates Network and Workgroup of European Cancer Patient Advocacy Networks (WECAN).

Jan was Director of the European Patients' Academy (EUPATI) and manages the German EUPATI platform.

Jan represents patient perspectives in committees e.g., in the EU Cancer Mission Assembly, European Cancer Organization, EHA, EuroBloodNET, ISPOR, Berlin Institute of Health, iCMLf, German National Decade Against Cancer and the Ethics Committee of the Bavarian Chamber of Physicians.

Jan is CEO of Patvocates, a think tank, consultancy and social enterprise on patient advocacy, health policy and patient engagement in research. He is work package leader in the IMI big data project HARMONY.



Dr Jerald C. Sadoff, MD, Senior Advisor of Clinical Vaccine Development, Janssen Infectious Diseases and Vaccines

Dr. Jerald C. Sadoff is the Senior Advisor, Clinical Vaccine Development, Janssen Infectious Diseases and Vaccines where he helps supervise the clinical development of vaccines against CoVid-19, RSV, Universal Influenza, HPV, HIV and Ebola. He is currently the Medical lead for the Janssen COVID-19 Phase 1, Phase 2 and Phase 3 clinical trials sponsored by the Office of Warp Speed.

He has spent his entire career developing vaccines against many bacterial, viral and parasitic diseases, 13 of which have been approved for human use with several others currently in Phase I, IIB and Phase III clinical studies. He is currently on the NIAID AIDS Vaccine Research Working Group where he has been a member for the past 14 years and has served on numerous other advisory and international committees.

Over the last 50 years, he has authored and co-authored over 400 articles, book chapters, abstracts and holds 18 issued patents.



Dr Joanne Waldstreicher, MD, Chief Medical Officer, Johnson & Johnson

Joanne Waldstreicher, M.D., is Chief Medical Officer, Johnson & Johnson. In this role, she has oversight across pharmaceuticals, devices and consumer products for safety, epidemiology, clinical and regulatory operations transformation, collaborations on ethical science, and technology and R&D policies, including those related to clinical trial transparency and compassionate access.

Joanne chairs the R&D Development Pipeline Review Committee for The Janssen Pharmaceutical Companies of Johnson & Johnson, and supports the Device and Consumer Development Committees. Joanne is also a faculty affiliate of the Division of Medical Ethics, Department of Population Health, New York University School of Medicine.

Among her prior roles, Joanne was responsible for late-stage development in neuroscience, cardiovascular disease and metabolism at Janssen. Before joining Johnson & Johnson in 2002, she headed endocrinology and metabolism clinical research at Merck Research Laboratories, overseeing development programs in atherosclerosis, obesity, diabetes, urology and dermatology. She was honored with the Key Innovator Award, among other distinctions.



Joseph Kutzin, Head of Health Financing Team, World Health Organization

Joe Kutzin leads WHO's health financing team in Geneva. He is a health economist with 35 years' experience,

working in Africa, Asia, the Caribbean, Europe, and the United States. Since joining WHO in 1994, he has served as WHO policy advisor to the Ministry of Health of Kyrgyzstan, and also as the European Region's Lead Advisor on Health Financing. Prior to that he worked at the World Bank.

Joseph was a contributor to the World Health Report 2010 on financing for universal coverage and has published numerous conceptual and empirical articles on health systems, health financing and Universal Health Coverage.



Judy Stenmark, Director General, Global Self-Care Federation

Judy was appointed Director General for the association on September 1, 2018. She has a long-standing career leading global and national associations with her recent five-year tenure as the head of the International Osteoporosis Foundation in Geneva, and nine years leading Osteoporosis Australia.

An Australian national, Judy has spent the last eight years living and working in Switzerland. In this time, she established a strong network within global healthcare institutions, including the World Health Organization, United Nations, international scientific academia and among many global pharmaceutical and consumer health companies.

She will be an invaluable addition to WSMI, and lead the organization into its next phase.



Julia Spencer, Associate Vice President of Global Vaccines Public Policy, Partnerships and Government Affairs, MSD

Julia Spencer serves as the Associate Vice President, Global Vaccines Public Policy, Partnerships, and Government Affairs at Merck. In this role, she leads global public policy, partnership, and advocacy efforts to expand and sustain access to Merck vaccines and to strengthen the immunization systems delivering our products. Julia also currently serves as the Chair of the International Federation of Pharmaceutical Manufacturers and Associations' (IFPMA) Vaccine Committee.

Julia brings to this role more than 25 years of public health and health policy experience at the local, state, national, and international levels. Julia joined Merck in 2014 as the lead for International Vaccines Public Policy. In this role, she oversaw the formation of a dedicated, internationally-focused policy team charged with strengthening partnerships and developing new platforms for evidence-based policy engagement on critical vaccines issues.



Julie Breneiser, Executive Director, Gorlin Syndrome Alliance

Julie Breneiser is the Executive Director of the Gorlin Syndrome Alliance. Previously, she was on their Board of Directors.

In the past, she worked as a Physician Assistant. Until 2007, Julie was not a "support group kind of person". As her affected children developed manifestations, she

contacted the Basal Cell Nevus Syndrome Life Support Network (now the GSA) to learn if the signs were part of the syndrome. The rest is history!

It is Julie's feeling that there is nothing better than this work with its purpose, improving the quality and quantity of the lives of people with Gorlin syndrome.



Prof Kamaldeep Bhui, CBE, Professor of Psychiatry, University of Oxford & Editor in Chief, British Journal of Psychiatry Oxford University

Professor Bhui is editor of British Journal of Psychiatry, and College Editor chairing the publications management board of the Royal College of Psychiatrists.

He is Director of the Synergi Collaborative Centre on ethnic inequalities, severe mental illness and multiple disadvantage; Director of the Cultural Consultation Service at QMUL and Director of MSc Creative Arts & Mental Health. He is a member of the Deanery of the School of Medicine and Dentistry; Deputy Lead of the Mental Health Theme of the North Thames CLAHRC/ARC; Member of the QMUL Arts and Cultural Strategy Committee, He is former Public Health Lead at the Royal College of Psychiatrists (2012-2015) and now Chairs PHE's Advisory Committee on Mental Health Campaigns. He is a member of the advisory group of the Mental Health Policy Research Unit at UCL and KCL. He is also the co-founder of Careif (www.careif.org), an international mental health charity that promotes work for young people and their health through culture, sport and arts. He was a founding member of the World Association of Cultural Psychiatry and President of WACP 2012-2015, when QMUL hosted the World Congress of Cultural Psychiatry. He qualified in Medicine at the United Medical Schools of Guy's & St Thomas in 1988, and subsequently

worked at the Maudsley, Institute of Psychiatry, Guy's, King's, St Thomas' Hospitals and Medical Schools being appointed to his first consultant clinical academic post as a senior lecturer in 2000. He was appointed Professor in 2003 at QMUL. Previously he was a Wellcome Training Fellow in Health Services Research and Senior Medical Officer in the policy research programme at Department of Health.



Dr Kannan Subramaniam, Medical Lead for NCD Strategy - Emerging Markets, Pfizer Upjohn

Kannan Subramaniam leads the non-communicable disease (NCD) strategy for Research, Development & Medical at Upjohn in the Emerging Markets. He is a physician with specialist training in psychiatry and has over a decade of clinical experience across emerging and developed nations.

Prior to joining Pfizer in 2010, Kannan served on governance boards of healthcare, biotechnology and health information technology organizations fostering the growth of innovative companies that aim to improve health outcomes. Kannan's focus now is to first understand and then, bridge knowledge and practice gaps through scientific transformation of NCD care, while maintaining and fostering patient centricity.



Karen Alparce-Villanueva, IAPO Secretary and Congress Committee Chair

Karen Alparce-Villanueva is currently a Board Member and Secretary of the International Alliance of Patient Organizations (IAPO) as well as Board Member

and Treasurer of the Philippine Alliance of Patient Organizations (PAPO). She has over 30 years' experience in the private sector specializing in communications & policy work, 20 of which were spent in the healthcare industry. Karen left her corporate job in 2015 to devote her long experience in health advocacy to advancing patient rights.

Karen also served in government as Board Member of the Philippine Health Insurance Corporation (Philhealth) and as consultant for the Health Promotions and Communication Services of the Department of Health (DOH). She was previously External Affairs Director of MSD and was also Corporate Affairs Director of Pfizer Philippines. Karen also runs a communications consulting firm called Health PRx Communications Inc.



Kawaldip Sehmi, Chief Executive Officer, IAPO

Kawaldip previously held the position of CEO at Richmond Psychosocial Foundation International and worked as Managing Director of Coram Children's Legal Centre. He has European and international public health experience as Director of the Global Health Inequalities Programme and as Chairman of the European Network of Quitlines.

Kawaldip's qualifications include an MSc in the Public Health International Programme from the London School of Hygiene and Tropical Medicine, an MBA in Business Administration from the London Business School and Open University, and an LLB (Hons) from the London College of Law



Ken Tait, DEEP Member and Diabetes Advocate

Ken Tait is originally from Edinburgh, Scotland where he worked and lived for many years as an electronic engineer, project manager and management consultant. Ken now resides in Bromley, Kent where he has been working as a psychotherapist and hypnotherapist, in which he has over twenty years' experience.

Ken Tait was diagnosed with type 2 diabetes in March 1999. In 2015, Ken started up a peer support group to help those with diabetes to better manage their diabetes and now is the Chair of Diabetes UK – Bromley.

As a psychotherapist Ken Tait has given talks about the effects of stress, anxiety and depression has on diabetes. Ken became a DEEP member in 2019 and is now a Diabetes Advocate, involved in projects locally, nationally, and internationally.



Dr Konrad Rheinhardt, MD, President, Global Sepsis Alliance

Konrad is recognised as an international champion of sepsis. He is chair of the Global Sepsis Alliance and one of the key initiators of World Sepsis Day. He is a member and was chairman of the International Sepsis Forum and a member of the Council of the World Federation of Societies of Intensive & Critical Care Medicine from 2008-2013.

In Germany he is member of the German National Academy of Science Leopoldina and Chairman of the Sepsis-Foundation. He was funding President of the

German Sepsis Society and its president from 2001-2009. As speaker of the nation-wide German research network SepNet he initiated landmark studies on the efficacy and safety of therapeutic approaches in sepsis as well as on the epidemiology of sepsis in Germany. He was initiator of the Center for Sepsis Control & Care (CSCC) at Jena University Hospital.

Konrad's research activities in the field of sepsis and intensive care medicine led to more than 750 peer reviewed publications and the Research Award of the Federal State of Thuringia/Germany. As Senior Professor at the CSCC, his publicly funded research is focused on quality improvement of sepsis management and long-term sequelae of sepsis.



Lasse Funch Jacobsen, Senior Lead of Patient Research and Alliances, LEO Pharma

Lasse brings 10 years of experience from working in pharma – the last 4 years in Patient Engagement teams across two different pharma companies. Lasse has helped establish functions that ensures that the patient's voice is not only heard, but also implemented throughout the value chain from early research to product.

Lasse has been part of numerous initiatives and coalitions across Academia, Patient Organizations and Industry working together to help improve the lives of people living with chronic diseases.



**Dr Mark Barone, Vice-President,
International Diabetes Federation**

Dr. Mark Barone (Brazil) is Vice-President of the International Diabetes Federation (2020-21). He has previously served on the Organising Committee of the IDF Young Leaders in Diabetes Programme (2011-2015).

Diagnosed with type 1 diabetes at the age of 10, Dr Barone became actively involved as a youth volunteer for ADJ Diabetes Brasil, coordinating diabetes camps and monthly support groups for young adults with diabetes. He was subsequently invited to attend and collaborate with diabetes camps throughout the IDF South and Central America Region, including in Argentina, Chile, Paraguay and Uruguay. This led him to become a member of the Organising Committee of the Diabetes Education and Camping Association (DECA). Over the last 15 years, Dr. Barone has initiated, coordinated and supervised partnership building initiatives, public health and leadership building programmes. In 2016, he started collaborating with the Public Health Institute (PHI) as Technical Director for Brazil. He also founded the Intersectoral Forum to Fight NCDs (ForumDCNTs) in Brazil, which aims to develop and implement cost-effective and sustainable solutions to tackle diabetes and other NCDs in the country.



**Melina Raso, Executive Director, Health
First Europe**

Since 2013, Melina has been working on EU issues regarding Health & Safety, and ICTs. She has experience

in managing of European associations, planning and implemented tailor made events and outreach campaigns. She holds a Master degree in European and International Law from the University of Trieste, and an Executive Master in Communication and EU politics from the IHECS in Brussels.



**Menassie M. Taddese, President for
Emerging Markets, Upjohn Pfizer**

Menassie M. Taddese is an accomplished bio-pharmaceutical executive leader with extensive experience and success in the health industry. He leads with a focus on unlocking value and boosting performance at all levels, organizational effectiveness, impactful decision-making and culture which has enabled him to grow and transform businesses of all sizes.

Menassie is currently the President for Emerging Markets Upjohn – A Pfizer Division and is a member of Upjohn's Executive Leadership Team. In his current role, he has the privilege of leading an organization of approximately 2,000 colleagues across ASEAN, Africa, the Middle East and Latin America in the fight against non-communicable diseases (NCDs). Menassie believes in the power of partnerships to address the NCD burden and is focused on leading the conversation with multiple partners to shape policies and improve NCD care.

He has over 23 years in the pharmaceutical industry with vast experience and increasing scope covering general management, finance, treasury and commercial in multiple geographies across all continents. The breadth and depth of his experience includes country, regional and global roles in the United States, Europe, International Developed Markets and Emerging Markets.

Menassie holds a bachelor's degree in Economics and Accounting from Virginia Tech and a Finance MBA from Penn State's Smeal College of Business, where he graduated with distinction. Menassie lives in Dubai with his wife and three kids.



**Monika Lessl, Senior Vice President,
Head of Corporate R&D and Social Innovation Bayer
AG & Executive Director, Bayer Foundation**

Monika Lessl is Head of Corporate Innovation, R&D and Societal Engagement at Bayer AG and Executive Director of the Bayer Foundation. Her focus is on driving organizational and societal transformation by leveraging the power of Innovation and strengthening sustainability. In her role she is promoting new scientific technologies and data science, Open Innovation and Social Innovation to find news solutions in health and nutrition addressing the needs of a growing and aging population. Monika Lessl is also a member of the supervisory board of the Berlin Museum "Futurium" and jury member of the European Innovation Council.



**Nathalie Bere, MPH, Patient Relations
Coordinator, European Medicines Agency**

Nathalie has been working with the European Medicines Agency in London for over 20 years and is currently responsible for its engagement with patients and consumers. Patients bring specific knowledge and expertise from their real-life experience of the condition and its treatment to the scientific discussions, and their contributions have led to better outcomes for everyone

involved. Over the years, she has been dedicated to creating opportunities for the inclusion of the patient's voice in every aspect of the regulatory lifecycle of a medicine. Experience at EMA has demonstrated that it is essential to be flexible and to test and implement a range of engagement methodologies to best suit the various activities.

As a steady increase in patient engagement at EMA has been observed, Nathalie will look to further strengthen these activities through constant exchanges with all stakeholders to ensure interactions are as mutually beneficial as possible. Nathalie holds a Master's in Public Health from the University of East London (UEL) and has a Bachelor of Science in Psychology.



**Dr Neda Milevska-Kostova, IAPO
Vice-Chair**

Dr Neda Milevska-Kostova is president of Studiorum, a regional think-tank working on research and policy aspects of health and wellbeing in Europe. Neda has over 20 years' experience in health research, policy and patient advocacy. She holds a MSc in functional pharmaceuticals (University of Tokyo), MA in public policy (University of Pittsburgh, USA), and a PhD in public health (University of Sheffield, UK).

Neda is also a Vice-president of Health First Europe, an umbrella organization based in Belgium working on improving access to innovative health technologies in Europe. In 2018, she was awarded the title Primarius by the Minister of Health for exceptional and long-term commitment to the advancement of health system and population health in Macedonia.



Dr Neelam Dhingra, MD, Coordinator of Patient Safety and Risk Management, World Health Organization

Dr Dhingra leads WHO's efforts at providing strategic leadership on patient safety and risk management within the context of improving people-centred integrated health services delivery and UHC. Dr Dhingra coordinates WHO's work for improving patient safety and managing risks in healthcare, including Global Patient Safety Challenge on medication safety; leadership; safety culture; education and training; patient safety standards, assessments, research and measurement; global patient safety networks; safety and quality tools and checklists (Safe Childbirth & Surgical Safety); reporting and learning systems; patient and family engagement including Patients for Patient Safety; safer primary care; diagnostic safety; standardizing care processes; and patient safety solutions. Since joining WHO in 2000, Dr Dhingra has been providing strategic leadership and facilitating multi-country support for strengthening blood transfusion services. From 2015, Dr Dhingra is coordinating WHO global efforts in the areas of patient safety, quality improvement and risk management. Prior to joining WHO, Dr Dhingra served as a medical faculty in a large, tertiary care university teaching hospital in New Delhi, India for 14 years, also coordinating transfusion and laboratory services, after medical and specialist qualifications from New Delhi and UK fellowships.



Nidhi Swarup, Founder and President, Crohn's & Colitis Society of Singapore

Nidhi Swarup is the Founder and President of the Crohn's & Colitis Society of Singapore (CCSS) since 2012. Nidhi is an active member of the SingHealth Patient Advocacy Network (SPAN). She also serves on the Management Committee member of Shree Lakshminarayan Temple. Nidhi has two Masters Degrees; one in Operations Research from University of Delhi, India and the other in Finance from Leicester University, UK. She also has a Graduate Certificate in Professional Counselling from the Swinburne University of Technology, Australia. As the President of the Rotary Club of Raffles City she organized a workshop where Chromoendoscopy experts from USA trained 100 Gastroenterologists. Nidhi has facilitated the formation of IBD Patient Support Groups in Thailand, Malaysia and Philippines. She has made presentations at the Asia Pacific IBD Alliance, APARDO, EFCCA and AOCC.



Dr Peter Lachman, MD, Chief Executive Officer, International Society for Quality in Healthcare

Peter Lachman M.D. MPH. M.B.B.Ch., FRCPC, FCP (SA), FRCPI assumed the position of ISQua Chief Executive Officer on 1st May 2016. He has great experience as a clinician and leader in quality improvement and patient safety. Dr Lachman was a Health Foundation Quality Improvement Fellow at IHI in 2005-2006, and developed the quality improvement programme at Great Ormond Street Hospital where he was the Deputy Medical Director with the lead for Patient Safety. Prior to joining ISQua, Peter was also a Consultant Paediatrician at the Royal Free Hospital in London specialising in the challenge of long term conditions for children. Dr Lachman has been the National Clinical Lead for SAFE, a Health Foundation funded RCPCH programme which aims to improve situation awareness in clinical teams.

In Ireland he is Lead International Faculty at the RCPI in Dublin, where he co-directs the Leadership and Quality programme to develop clinical leaders in quality improvement. He is co-founder and Chairperson of PIPSQC, the Paediatric International Patient Safety and Quality Community.



Dr Ratna Devi, IAPO Chair

Dr. Ratna Devi is the CEO and Co-founder of DakshamA Health and Education, an organization that is dedicated to working for access to health, patient education and advocacy. DakshamA aims to create a network of caregivers and patient groups, and work with them on knowledge sharing as well as providing essential feedback for managing long term and chronic diseases. She leads a cross disease Patient Alliance in India called Indian Alliance of Patient Groups (IAPG), Board member HIA (Healthy India Alliance – the National NCD Alliance in India) and I – ORD (Indian Organization for Rare Diseases). She holds an MBBS degree from Sambalpur University and a dual MBA from SYMBIOSIS and Manipal Institute of Distance Education. Dr. Devi also holds advisory positions at several NGOs and has contributed to research as well as publications.



Rt Hon Jeremy Hunt MP, Chair, House of Commons Health and Social Care Select Committee

Jeremy Hunt has been a Conservative Member of Parliament for South West Surrey since May 2005. In May 2010 Jeremy was appointed Secretary of State for Culture, Olympics, Media and Sport, during which time he

oversaw a successful Olympic and Paralympic Games in London in the summer of 2012. From September 2012 to July 2018, Jeremy held the position of Secretary of State for Health. In June 2018, Jeremy became the longest serving Secretary of State for Health in British history. In July 2018, Jeremy was appointed Secretary of State for Foreign and Commonwealth Affairs, a position he held until July 2019. He was elected Chair of the House of Commons Health and Social Care Select Committee in January 2020. Born on 1 November 1966, Hunt studied Philosophy, Politics and Economics at Oxford University. He lives in Godalming and London with his wife Lucia and their three young children.



Sara Mobäck, Global Diabetes Advocate

Sara was diagnosed with type 1 diabetes at age 13. A few years later, due to own internal pressure, she stopped eating carbs and exercised daily. This led to a 2016 diagnosis of anorexia.

Now Sara wants to encourage a positive perspective and way of living for people with diabetes. She regularly speaks at events and gives talks, and her blog about type 1 diabetes reaches thousands of people globally.



Siva Singh, Director EMEA, Escalla

Siva has worked in the healthcare sector for over 25 years and has a wealth of knowledge from a UK perspective and internationally. He worked directly with foreign Government agencies, the Department of International Trade and also in collaboration

with global consultancies this was to develop truly bespoke role specific learning programmes in support of change and transformation. The programmes incorporated leadership and cultural changes aside learning interventions to change behaviours and embed change. It led on the Sepsis recognition and treatment programme in the Kingdom of Saudi Arabia. This won the Global Sepsis award in 2018 and is forecast to save 32,000 lives annually. It led on various projects in Egypt to develop bespoke solutions for family physicians, nursing teams and other healthcare engagements. Leadership and management learning models in Egypt and Saudi Arabia. Siva has also delivered guest lectures on healthcare leadership and patient safety in the UK and overseas, including Saudi Arabia, Egypt.



Dr Soumya Swaminathan, MD, Chief Scientist, World Health Organization

Dr. Soumya Swaminathan has been appointed Chief Scientist heading the division created to strengthen the organization's core scientific work and ensure the quality and consistency of its norms and standards. She was previously Deputy Director-General for Programmes (DDP). A paediatrician from India and a globally recognized researcher on tuberculosis and HIV, she brings with her 30 years of experience in clinical care and research and has worked throughout her career to translate research into impactful programmes. Most recently, Dr Swaminathan was Secretary of the Department of Health Research and Director General of the Indian Council of Medical Research. From 2009 to 2011, she also served as Coordinator of the UNICEF/ UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases (TDR) in Geneva. She has sat on several WHO and global advisory

bodies and committees, including the WHO Expert Panel to Review Global Strategy and Plan of Action on Public Health, Innovation and Intellectual Property, the Strategic and Technical Advisory Group of the Global TB Department at WHO, and as Co-Chair of the Lancet Commission on TB. She received her academic training in India, the United Kingdom of Great Britain and Northern Ireland, and the United States of America, and has published more than 250 peer-reviewed publications and book chapters.



Steve Lockhart, Vice President, Head of Europe and Asia-Pacific, Vaccine Clinical Research and Development, Pfizer

Biotechnology R&D Director. Experienced in both strategic and operational aspects of biopharmaceutical product development through registration and launch. Innovative approaches to development and registration routes. Successfully built and led teams, with both line and matrix management experience. Medically qualified, with over 30 years in the pharmaceutical industry, following 6 years in hospital medicine. Recognised leader in vaccine development. Experience spans support for Europe, North America, China, Japan, Australia, South Africa, Singapore and other markets around the world, including both developed world and global health products. Worked in large pharma, small to mid-size biotech and start-up joint ventures. Led strong collaborations with academic and non-profit groups. Member of Medical Research Council infection and Immunity Board (MRC IIB).



**Dr Tamás Bereczky, Course Coordinator,
Content Developer and Trainer, EUPATI**

Tamás currently works as the course coordinator, content developer and trainer of EUPATI The European Patients' Academy for Therapeutic Innovation. Before that, he was member of the European AIDS Treatment Group, the largest European network of individuals living with HIV for 15 years, also working as its communications officer between 2015 and 2018. HIV positive since 2003, he served as a member of the board of directors of the EATG for almost 4 years, and also served the co-chair of the European Commission's Civil Society Forum on HIV/AIDS between 2013 and 2015. Tamás also works as a partner and consultant in the patient-led and focused strategic advisory Patvocates.



**Dr Thomas Breuer, MD, MSc, Chief
Medical Officer, GSK Vaccines**

Thomas is the Chief Medical Officer of the extended GSK Vaccine's company (post integration of Novartis Vaccines in 2015) as well as accountable for all Global Health activities of the company including COVID-19.

He leads the global Medical Affairs organization in its newly created vertically integrated configuration (global, regional, local), Medical Governance & Compliance, Safety & Pharmacovigilance and patient access functions such as Health Economics & Epidemiology globally or in the regions.

Passionate advocate for improving life of individuals of all ages, as well as overall public health, by turning vaccines into vaccination.

With a career spanning both the public and private sector, Thomas flexes science and a focus on the patient into a business context (and vice versa), synthesizing my public health experience into know-how for developing and commercializing vaccines.



**Thomas B. Cueni, Director General,
International Federation of Pharmaceutical
Manufacturers & Associations**

Thomas B. Cueni is Director General of International Federation of Pharmaceutical Manufacturers (IFPMA), the global association of research-based pharmaceutical companies and associations. Based in Geneva, IFPMA has official relations with the United Nations and contributes industry expertise to help the global health community find solutions that improve global health. Cueni is Secretary of the Biopharmaceutical CEO Roundtable (BCR), a policy forum of the global CEOs of IFPMA member companies. He is also Chair of the Business at OECD Health Committee, and also serves on the Board of Directors of the City Cancer Challenge (CCan), an initiative aiming to improve cancer care in major cities in low- and middle-income countries. In addition, Cueni serves as Industry Co-Chair of the APEC Biopharmaceutical Working Group on Ethics and Chair of the Board of the cross-sectoral AMR Industry Alliance, a group comprising more than 100 companies and associations representing Rx pharma, generics, biotech, and diagnostics committed to tackling the threat of antimicrobial resistance



Dr Vijay Rawal, MD, Deputy Medical Director Commissioning, NHS England and NHS Improvement (Midlands) & Subject Matter Expert in Primary Care, Escalla

Dr Vijay Rawal is a practicing General Practitioner in the UK, Deputy Medical Director Commissioning for NHS England and NHS Improvement (Midlands), Subject Matter Expert in Primary Care for Escalla, a GP Appraiser, a trained Mentor in Healthcare Organizations, a Specialist GP Advisor for the Care Quality Commission and Director of Rawal Consultancy Limited. His past experiences include being a GP principal, Medical Director of a Primary Care Federation and Provider Company, Clinical Lead for NHS England and Local Medical Committee Medical Secretary/Director. His areas of interest are System Integration, Digitalisation, Clinical Governance, Education, Quality and Efficiency.

IAPO Staff



Kawaldip
Sehmi, Chief
Executive
Officer



Dani Mothci,
Member
Engagement
Manager



Rachel Githinji,
Communications
Manager



International Alliance of Patients' Organizations

A global voice for patients



49–51 East Road, London N1 6AH, UK



+4420 7250 8280



info@iapo.org.uk



www.iapo.org.uk



www.twitter.com/IAPOvoice



www.facebook.com/IAPOvoice



www.youtube.com/IAOPatientVoice