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### Upcoming Events

Lebanese Society for Quality & Safety in  
Healthcare Congress in Hamra, Beirut,  
19 September 2015.

## Welcome!

*Margaret Murphy, External Lead Advisor, Patients for Patient Safety (PFPS)*

Welcome to PFPS News Summer 2015 edition. Following a busy end to 2014, there has been no rest in our momentum and drive of events and activities in the programme at Geneva HQ and among our PFPS advocates (champions) across the world.

If you want something done, ask a busy person”, or so the saying goes. This is certainly true of the advocacy and patient safety promotional work, carried out by our PFPS champions. Like all networks, the levels of individual activity are not uniform but, the sincerity, passion and commitment of our PFPS champions is never in doubt. Our work is appreciated by those who have the vision to include patients and families as a relevant resource, which will add value to health care at all levels.

As individuals, we are different men and women to what we would have been had we not encountered PFPS and embraced the collaborative/partnership model out of which our network operates. Sometimes we can become victims of our own success in that we find it difficult to make that space in our lives to engage more proactively with the PFPS community of practice. But we must try harder to stay engaged. That engagement is important to sustain momentum, not only for ourselves, but for the whole network.

When we first engaged with WHO, we never dreamed of realizing the depth and breadth of possibilities and opportunities that have opened up to us in the intervening years. Our association with WHO has given credibility to us as individuals. It has endorsed our sincerity of purpose as collaborative partners who are striving to be ‘critical friends’ of our national health-care systems.

So, be informed by staying engaged with PFPS and be inspired to broaden your own scope of practice as an advocate. Most importantly, be conscious of and truly appreciate the unique added value each of you brings to the health-care area with which you engage – be that policy, regulation, research, education, standard setting or presenting to different fora. You are the voice of those who are unheard and you do speak in honour of those who have died, those who have been left disabled – many of them members of our own families. We will continue to strive for that excellence that will make all patients as safe as possible as soon as possible. It is our pledge, our intrinsic identity and our grounding mission and vision.

I hope you enjoy the Newsletter and I hope you continue to derive real satisfaction in your work as agents for change in 21<sup>st</sup> century global health care.



*Figure 1: Margaret*  
Our work is appreciated by those who have the vision to include patients and families as a relevant resource, which will add value to health care at all levels.

# Updates from WHO PFPS in Geneva

## 1. Global perceptions of engagement and empowerment

*Ellen Houston*

PFPS has launched a project that aims to create an advocacy tool for global engagement and empowerment, conducted by Ellen Houston, an intern under Nittita Prasopa-Plaizier's supervision. The team has disseminated a 'call for contributions' through the PFPS global network, other professional networks and also across social media. Participants are offered the option of making a video 'selfie' of themselves, answering questions regarding their perceptions of meaningful engagement. The PFPS team encourages contributions from patients, family members, health-care providers, policy-makers and the general public from all around the world, who will then be represented in the final advocacy video. We are still accepting contributions. So if you have not done so and are interested in being part of global engagement efforts, please contact the PFPS team or visit [http://www.who.int/patientsafety/patients\\_for\\_patient/en/](http://www.who.int/patientsafety/patients_for_patient/en/).



Figure 2: Ellen Houston

The second component of this project has been conducted internally at WHO in Geneva. The PFPS team has been interviewing WHO staff members to better understand their perspectives and approaches of engaging and empowering people in their projects and programmes. Both components of this project aim to help define what meaningful engagement is and to inform the development of the WHO Global Framework on Patient and Family Engagement.

## 2. PFPS website

*Ellen Houston*

WHO PFPS is updating its website to make the contents current and robust, as well as the format reader-friendly. The revised PFPS website will consist of four key pages, including news/events, projects and activities, a tool box and programme information. New projects and initiatives will be announced through this website. The PFPS team hopes that the revised website will facilitate navigation and will retrieve key information, tools and resources. Any new projects or initiatives will be announced through the 'What's new' page. See our new webpage at: [http://www.who.int/patientsafety/patients\\_for\\_patient/en/](http://www.who.int/patientsafety/patients_for_patient/en/).

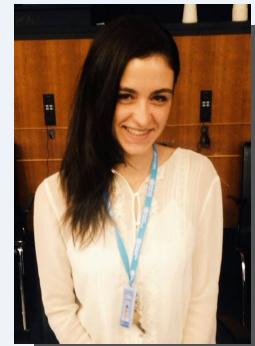


Figure 3: Katie Hayes

## 3. Calling for contributions for a resource library

*Katherine Hayes*

The PFPS team is compiling examples of engagement and empowerment approaches as a resource for patients, patient advocates and other key stakeholders, as well as to help inform the WHO Framework on Patient and Family Engagement. This involves reviewing PFPS champion interviews and drawing from their wisdom and expertise. We are also creating a compendium of tools and resources, as well as key players on the topic of patient and family engagement. The compendium will be made available for PFPS advocates on the PFPS community of practice. So this is another incentive for you to join the PFPS CoP! We want the PFPS compendium to be as comprehensive as possible. So we invite all PFPS champions to share with us any tools and resources (publications, reports, details of organizations etc.) on the community of practice.

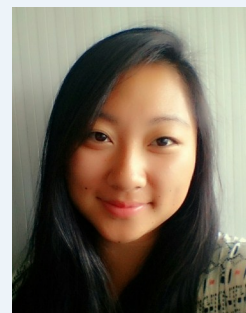


Figure 4: Ning Shi Xie

## 4. New PFPS Community of Practice (CoP)

*Ning Shi Xie*

The PFPS team has just completed revising the PFPS Community of Practice (CoP). As part of this process, we are updating the CoP membership to determine active members within the community, reorganize the library materials and create a sub-community for the PFPS Advisory Group, to be moderated by Helen Haskell. The team has invited all contactable PFPS champions to register themselves in the newly revised CoP, if they wish to continue being part of the PFPS global.

We thank everyone for your patience during this transition time. We hope to count on your continuous contributions and stimulating discussions in the PFPS CoP. The revision involved changing the platform over to the WHO community service, which has more space for discussion and resource sharing and is more user-friendly while retaining interface features with which you are already familiar. If you have not yet switched over to the new CoP and would like to, please email [pfps-admin@ezcollab.org](mailto:pfps-admin@ezcollab.org) or contact Katthyana Aparicio on [pfps@who.int](mailto:pfps@who.int).

## 5. PFPS Webinar: “How to care for yourself when representing the patient voice”

*Felicity Pocklington, Kathyana Aparicio*



Figure 5: Collaborating teams who organised the webinar. From left; WHO, Sick Kids, PFPS Canada

The WHO PFPS programme collaborated with the SickKids Hospital (Canada), PFPS Canada and the Canadian Patient Safety Institute (CPSI) to deliver a webinar on 7 May 2015. This interactive session discussed the journey of PFPS champions as partners in patient safety and the ways they could care for themselves. The session was designed by and for patients, families and PFPS champions, and aimed to share examples, tools and guidance to help patient advocates care for themselves and to help liaisons or coordinators of patient advocate groups understand the needs of advocates.

Three themes were discussed during the webinar:

1) ‘*Knowing when you are ready to partner: good questions to ask yourself*’. This theme revealed multiple issues, including considering how an advocate would want to be involved, issues they would want to work on and reflecting on what drives them.

2) ‘*Concrete steps for making it easier to partner*’. This theme discussed practical steps that the advocates should take to prepare themselves before and during giving presentations and talks, to ensure that their voice is heard and understood. For example, they should try to know the audience and their expectations of the advocate’s involvement, what support is available from the organizers and whether media will be present.

3) ‘*Harness your passion: take good care of yourself to be the best you can be*’. This theme discussed how telling a patient’s story can be emotionally draining for the PFPS advocates themselves. The panel advised that the advocates should adopt a mindful practice, be aware of this personal grief and be aware of the possible impact on their own health, from revisiting this adverse experience.

Big thanks go to Theresa Malloy-Miller (PFPS Canada) for sharing the session and to Sharon Nettleton (PFPS Canada), Sabina Robin (PFPS Canada), Manvir Jesudasan (PFPS Malaysia and member of the PFPS Advisory Group), Martin Hatlie (PFPS USA and member of the PFPS Advisory Group), and Sitara de Gagne (a family advisor working at SickKids

hospital) for their excellent presentations.

## 6. WHA68 Side Event: ‘Imaging for Saving Kids—the Inside Story about Patient Safety in Paediatric Radiology’

*Felicity Pocklington, Kathyana Aparicio*

The PFPS team collaborated with colleagues in the WHO Department of Public Health, Environmental and Social Determinants of Health, through Dr Maria Perez, to facilitate a side event at the 68<sup>th</sup> World Health Assembly (WHA68). This WHA68 side event was jointly organized by the Governments of Kenya, Malaysia, Spain and Uganda together with the following NGOs in official relations with WHO: Diagnostic Imaging, Healthcare IT and Radiation Therapy Trade Association (DITTA), International Commission on Non-Ionizing Radiation Protection (ICNIRP), International Commission on Radiological Protection (ICRP), International Organisation of Medical Physics (IOMP), International Society of Radiology (ISR), International Society of Radiographers and Radiological Technologists (ISRRT), RAD-AID International, World Federation for Ultrasound in Medicine and Biology (WFUMB), and the World Organization of Family Doctors (WONCA).

The side event was co-chaired by Dr Edward Kelley, Director of the WHO Department of Service Delivery and Safety and Dr Maria Neira, Director of the WHO Department of Public Health, Environmental and Social Determinants of Health. Margaret Murphy, the External Lead Advisor to Patients for Patient Safety (PFPS) was among the panellists. She gave contributions and input on behalf of PFPS. The event raised awareness and advocated for appropriate use of radiation in children’s health care. We would like to thank all contributors for their support and effective collaboration.



Figure 6: Participants of the WHA68 side event



# Update from AFRO

## Uganda

### Injection Safety Campaign, Experience of Community Health & Information Network (CHAIN), Uganda

*Regina Kamoga*

Injections are among the most common health-care procedures. According to WHO, every year, at least 16 billion injections are administered worldwide. The vast majority – around 95% – are given in curative care. But unsafe injections can result in the transmission of blood-borne pathogens from patient to patient (through the reuse of syringes), patient to health-care worker (through needle-stick injuries) and more rarely, health-care worker to patient. Patients have been found to be at risk when using injection equipment that has not been safely sterilized and/or disposed of. Unsafe injection practices have also been the cause of outbreaks of viral hepatitis B and C and HIV in health-care settings.

In Uganda, health-care providers still unnecessarily prescribe injections to patients, respond to patients' requests or preference for injections as they perceive them to be a more effective treatment than oral medicines. Ugandan patients also perceive injections as a therapeutic norm and standard practice. Patients are not often aware of the risks associated with overuse of injections or safe practices. It is against this background that the Community Health and Information Network (CHAIN), a civil society organization in Uganda embarked on a medication and injection safety campaign to ensure that patients are more aware and become more engaged in efforts to improve safe injections.

#### Objectives

- To raise awareness on unsafe injections.
- To raise awareness about the appropriate disposal of all injection waste.

#### CHAIN's progress in 2013/2014

- 1020 patients acquired knowledge about the safe use of medicines and injection safety through workshops and community outreach programmes.
- Training and dialogue conducted with patient leaders and health-care professionals in order to share knowledge and discuss their role in promoting patient safety. Ten patient leaders and 30 village health teams (VHTs) received training on injection safety.
- Held regular meetings with the bio-ethics committee of

Mulago/National Referral Hospital to update them on patient issues and needs and how patients, families and communities can work together to address them.

- Conducted advocacy meetings with health policy and decision makers at all levels of health service delivery, for instance the Ministry of Health (MoH), World Health Organization (WHO) and the National Drug Authority (NDA).
- Organized two press conferences and disseminated materials highlighting patient safety concerns, via radio and TV talk shows.
- Encouraged patients living with HIV to share their testimonials and information within their spheres of influence.



*Figure 7: Regina Kamoga conducting a capacity building workshop.*



*Figure 8: Session with health workers of Komamboga health center in Kawempe division, Kampala, Uganda*



*Figure 9: A health worker demonstrates safe injection*

This campaign has received positive feedback from all stakeholders. It has demonstrated the need to educate and engage patients, patient organizations, the media and health professionals around medication safety and injection safety. Public dialogues, meetings and the media have been seen to be powerful educational tools. As Regina commented:

“Our strength lies in having close engagement and collaboration with key health-care stakeholders. Scaling up this project requires the participation of multiple stakeholders and the community”.



Figure 10: Village Health teams (VHTs) and community health workers attending a one day seminar organized by CHAIN



Figure 11: Nurses and patient leaders in a dialogue on injection safety. Standing, a male nurse shares a testimony on challenges/risks faced while administering injection. Some of the risks include exposure to HIV, Hepatitis etc.

informed parents can become active agents for preventative and safe medicine, regardless of their socio-economic and cultural status, the programme aims to use evidence and resources (lectures and workshops) to educate parents, expectant parents and professionals on child care in the first year of life, in a patient-friendly language (“the mother’s language”). Videos, music and songs were presented in order to emphasize the messages and reflections of the programme.

It was anticipated that this educational programme could help mothers build a positive, healthy and secure life and environment, as well as a positive impact on the child-parent interactions in reducing stress. Dr Jorge César Martínez said, “this programme engages children, families and health-care providers to work towards realizing the intervention’s goals and help us to dream of a better world, as an old Chinese proverb teaches us:

*Many little things... done by many little people... in many little places... could change the face of the world”.*

Dr Martínez also participated in the 10th Latin American Congress of the International Radiation Protection Association (IRPA) that took place in Buenos Aires, Argentina, on 12-17 April 2015. The congress was organized by IRPA, co-sponsored by the Pan-American Health Organization (PAHO), WHO and the International Atomic Energy Agency (IAEA). He represented WHO PFPS to bring the patient’s voice to the discussion. He commented, “...during and after my presentation, I felt a very sensitive understanding of the safety culture and the importance of patient-centred care, as well as consideration of the patient as a partner”.



Figure 12: “An invitation to life programme” launch

## Update from AMRO/PAHO

### Argentina

*Dr Jorge César Martínez and Felicity Pocklington*

Dr Jorge César Martínez, PFPS champion from Argentina, launched the programme called ‘An Invitation to Life – The Science, the Child and a Safe World’ at del Salvador University, supported by the Bagó family. Inspired by the concept that



Figure 13: Dr Martínez at the “An invitation to life programme” launch



## Canada

*Update from Patients for Patient Safety Canada (PFPS)*

### Passing the Patient Safety Baton

Change is always bittersweet, however, it is always healthy for any organization. It brings about an opportunity to pause, look back, and appreciate the journey and accomplishments with the leaders who made it happen, and an equally valuable opportunity to dream about what the ongoing journey and future accomplishments could be with new leaders at the helm. Both Patients for Patient Safety Canada (PFPS), a patient-led programme of the Canadian Patient Safety Institute (CPSI), and CPSI have recently passed the leadership baton.

After eight years as Co-Chair of PFPS together with Carol Kushner, Donna Davis has left her leadership role (according to the PFPS succession planning process). Donna commented,

*“One of the greatest achievements I have seen in the Patient Safety community during my tenure as Co-chair, is the movement to include the patient/family voice when discussions on patient safety and quality improvement take place. They are frequently equal partners at the table, (as in the National Patient Safety Consortium), being included in all discussions from the beginning and bringing the valuable perspective that only they can provide. Our goal is to remove “frequently” from the above sentence and replace it with “always”. From having to invite ourselves, in 2007, to be participants at conferences, on working committees etc, in 2015 we now have more requests to participate with our health-care partners than we can fulfil. I am so proud that PFPS is very visible as a respected, go-to patient/family group on the national landscape, bringing the patient/family voice forward to achieve our mission of “Every Patient Safe”.*

Denice Klavano, who is also a member



Figure 14: Donna Davis



Figure 15: Hugh MacLeod

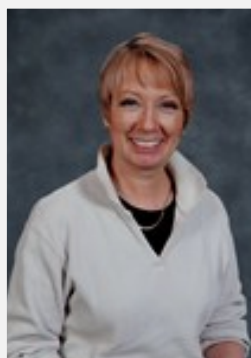


Figure 16: Denice Klavano



Figure 17: Chris Power

of the WHO PFPS Advisory Group, and Sharon Nettleton (who has transitioned in from Carol Kushner) are now the PFPS Co-Chairs and can be reached at [info@patientsforpatientsafety.ca](mailto:info@patientsforpatientsafety.ca). The term of a Co-chair is two years with six months transitioning in and six months transitioning out to ensure optimal orientation for the incumbent and a seamless transition of duties. The PFPS Co-Chairs are volunteers.

CPSI is thrilled to welcome Chris Power as CPSI's new CEO. Chris, a former nurse, is an exceptional leader with a proven track record of valuing patients as partners. She will be carrying on even stronger patient engagement at all system levels at the helm of CPSI. PFPS, CPSI and our common vision of “every patient safe” can only thrive under the leadership of such amazing individuals and we are thrilled to be working by their side.

Patients for Patient Safety Canada would like to thank Hugh MacLeod, former CEO of CPSI, who has promoted patient engagement in an unprecedented way. Hugh retired at the end of 2014 and is now enjoying sunny California with his grandchildren. Hugh's vision to accelerate patient safety involved strengthening the collaboration among the key stakeholders in patient safety, including patients and families.

## Mexico

*Author: Evangelina Vazquez Curiel*

*Reviewer: Felicity Pocklington*

Evangelina was invited to participate in several events in the different provinces of Mexico. Firstly, the Regional High Specialty Hospital located in the town of Zumpango, State of Mexico, hosted the “Quality Symposium: the key component for health organizations”, where Evangelina spoke on “co-responsibility of patients in Clinical Safety” on 24 April 2015. The symposium represented a great opportunity to share with health-care professionals and health-care providers who pledged to support the participation of patients in the task of improving patient safety.

Secondly, the first International Conference on Quality in Health Children's Hospital DIF-Hidalgo, in the city of Pachuca, Hidalgo, was held on 30 May, and Evangelina spoke on “the patient as a co-responsible partner in their safety”. The event enabled policy-makers to meet and network. The audience was very receptive of the messages; some even showed empathy and enthusiastic support to the patient networks.

Until recently, these events were reserved exclusively for health-care professionals. Evangelina was impressed to have seen that patients were invited not only to present, but also to start to engage with them and look for ways to collaborate in the future through the local networks.



Figure 18: Evangelina speaking at an international congress

## USA

*Jeanine Thomas*



Figure 19: World MRSA Day Poster

Raise awareness in your country about the MRSA epidemic, health care-acquired infections and antibiotic resistance! 2 October 2 is the World MRSA Day and October is the World MRSA Awareness Month.

The 7th Annual World MRSA Day Kickoff Event and Global C. difficile Summit, an annual awareness event will be held on 26 September 2015 at the Community House in Hinsdale, Illinois, from 10:30am – 12:30pm and is open to the public with free admission and parking. This annual event is informative for both the public, health-care professionals and industry and all are invited to attend.

The keynote speaker will be William R. Jarvis, M.D, president of Jason & Jarvis Associates, LLC – a world renowned MRSA expert and infectious disease specialist, formerly with the CDC. Others presenting will include Michael S. Pulia, M.D. from the University of Wisconsin/Madison, along with MRSA survivors sharing their stories. A panel discussion will follow with the public and media asking questions to the experts concerning MRSA, Livestock-acquired MRSA, C. difficile in health-care facilities and in the community and antimicrobial resistance (AMR).

Plan your event in your community to help raise awareness to the global MRSA epidemic in your country. Downloadable posters, brochures and banners are available at [www.WorldMRSAday.org](http://www.WorldMRSAday.org) and a public service announcement can also be viewed on MRSA Survivors Network YouTube Channel and websites. See: [www.MRSAsurvivors.org](http://www.MRSAsurvivors.org) and [www.WorldMRSAday.org](http://www.WorldMRSAday.org).

## Update from EMRO

### Egypt

*Author: Nawga Metwally*

*Reviewer: Felicity Pocklington*

Nagwa has been immersed in community involvement campaigns in Cairo, promoting hand hygiene. In June Nagwa participated in a community meeting with approximately 30 community actors and health experts in infection control, who lead the quality teams in their local hospitals to discuss the importance of hand hygiene. The meeting aimed to educate and train the locals and students on the steps to safe and efficient hand washing. The local people were supplied with 1000 small soaps to facilitate further training from themselves to members of their household. The community involvement campaign also facilitated shared learning on the importance of safe and clean hands in an orphanage in Cairo. As Nagwa commented:

“I am trying to get NGOs to include WHO campaigns on patient safety into their own programmes in the community. I have started this year by focusing on the hand hygiene campaign. I am very happy that I have started to involve the community as well as the hospitals. We go out to a larger community of patients and families and the volunteers are very optimistic and excited to start their work for this campaign”.



Figure 20: A community involvement campaign in Cairo



Figure 21: A community involvement campaign in Cairo





Figure 22: Nagwa Metwally attending a community meeting in Cairo

## Israel

*Sara Yaron*

“Shevet”, Israel’s Organization for patient safety has expanded its operations, both nationally and internationally. Shevet’s activities in 2014-2015 included having one of its members appointed as a permanent member of the Ethics Committee of a large hospital in central Israel, participating in all the meetings as a representative of the concerned public.

Another activity has been having representation on ISQua advisory forum. ISQua is an international organization dealing with quality in health care. The advisory forum, is made up of patients, care-givers and policy-makers. Sara’s role involves participation in regular conference calls, expressing opinions and writing responses to conference calls.

## Tunisia

*Hussain Jafri*

### EMRO regional workshop on capacity-building of patient safety and health care quality from assessment to improvement

From 14-16 June 2015, the WHO Eastern Mediterranean Regional Office (EMRO), hosted the Regional workshop on “Capacity building of Patient Safety and health-care quality: from assessment to improvement” in Tunisia. This workshop aimed to build the capacities of Ministry of Health officials, who are the national patient safety and quality focal points, on use of WHO quality and safety tools and interventions, including the updated patient safety assessment manual, the patient safety toolkit, the WHO patient safety initiatives such as the prevention and control of health-care associated infections, the Patients for Patient Safety (PFPS) programme, the new injection safety strategy as well as the quality tool for primary care.

EMRO has developed specific initiatives that target patient safety and quality as normative approaches that refer to the use of evidence-based standards and indicators for the assessment and monitoring of quality of care and patient safety, at both primary care and hospital levels. From this, the patient safety

assessment manual has been updated. The Patient Safety Toolkit includes practical guidance on implementation of a patient safety programme at the operational level. It also covers generic and specific patient safety tools that the local teams can refer to when addressing patient safety priorities.

The workshop was chaired by Dr Sameen Siddiqi (Director, Health Systems Development, WHO-EMRO, ) and Dr Mondher Letaief (Technical Officer, Quality and Safety, WHO-EMRO) was the technical lead and facilitator of the workshop. The PFPS Programme Manager, Nittita Prasopa-Plaizier participated in the workshop along with three PFPS Champions from the region including Hussain Jafri (Pakistan), Nagwa Metwalli (Egypt) and Said El Kharrazi (Morocco). Special emphasis was given to patient engagement and how PFPS’s experience could be used to engage patients in EMR’s quality and safety interventions. In this regard, a session on “Patients and community empowerment for patient safety” was also held during the workshop. Mr Hussain Jafri explained, in his presentation, the importance of patient engagement and how patients in partnership with health systems have contributed towards improving quality and safety in health-care globally as well as in the Eastern Mediterranean Region. Case studies from Egypt and Morocco were also presented by Nagwa Metwalli and Said El Kharrazi respectively, to illustrate the diverse opportunities that patient empowerment and engagement could contribute towards quality and safety at national and local levels. Dr Huda Amer Al-Katheeri (Director, Health Care Quality Management and Patient Safety, Qatar) shared Qatar’s experience of engaging patients in the fields of quality and safety.



Figure 23: The participants of the Tunisia conference



Figure 24: Panellists from left to right: Sameen Siddiqi, Nittita Prasopa-Plaizier, Hussain Jafri, Nagwa Metwalli, Hada Amer Al-Katheeri, Said El Kharrazi.



The recommendations of the workshop included a commitment to develop instruments to facilitate the empowerment and engagement of patients in the work of quality and safety at national and EMR levels.



Figure 25: Nittita Prasopa-Plaizier presenting on patient and family engagement

## Update from EURO

### Poland

*Jolanta Bilinska*

In June, Regina Kamoga, PFPS Champion from Uganda visited Poland to take part in collaborative work with Jolanta Bilinski (PFPS Champion from Poland). The work aimed to increase awareness of patient safety in health-care systems and the general public. A number of activities were held, including sessions on knowledge building and sharing between patients and health professionals: how to prepare tailor-made patient safety materials, how to improve the health worker-patient relationship and how to help an elderly patient navigate the health system.

Jolanta and Regina participated in a meeting held with a group of patients and board members of the Patient Safety Foundation that discussed models of patient safety in hospitals and the formation of national networks of patient safety advocates in both Poland and Uganda. They were also invited to talk about non-communicable diseases (NCDs) in an elementary school in Lodz. Regina talked about the need to adopt healthy lifestyles, including eating healthy diets, doing regular exercise, and avoiding smoking and alcohol. She emphasised the important role of patients in preventing and managing NCDs in order to avoid preventable death. Regina and Jolanta also gave a hand-washing demonstration to promote hand hygiene among the

school children. A quiz was conducted to determine and increase the level of knowledge on hand washing. The children fully participated in the day and acquired valuable patient safety knowledge.

## Update from SEARO

### India

*J.S. Arora*

On 8 May 2015, Dr JS Arora and his team organized a patient and parent interactive session for the International Thalassemia Day. The patients and care-givers had the opportunity to interact face-to-face with experts in the field to understand the complexities of their conditions and treatment. They were free to ask any questions from availability and safety of blood, side effects of medicines, risk factors, the cure rate and possible complications of bone marrow transplants.

The Health Minister of Delhi & Union Minister of Chemicals were also invited to provide information on and possible solutions to blood safety issues. The Health Minister promised to provide safe blood by introducing “NAT technologies” (Nucleic acid amplification test technologies) on donor’s blood at all Delhi government hospitals. The Chemicals Minister, who also looks after Pharmaceuticals, assured the participants that Iron Chelating agents would be brought under the National Pharmaceuticals Pricing Authority to make adequate treatment affordable.

The Health Minister released a concise book authored by Dr JS Arora, entitled “Florilegium of Thalassemia” that focuses on thalassemia management. The book is written in the national language, Hindi, covering all aspects of practical management of thalassemia so that patients and care-givers can easily understand what needs to be done at what stage to enable them to expect the best possible care from their health-care providers. An English version was released in April 2014.

### Thailand

*Piyawan Limpunyalert and Felicity Pocklington*

Patients for Patient Safety (PFPS) Thailand was formally launched in August 2014, following the first PFPS Thailand workshop with the support of WHO. Since then, PFPS Thailand has made impressive progress expanding their network and activities across the country, with the mission to encourage, support, and drive quality improvement and a safety culture in Thailand’s health-care system (see figure 26).

In October, the network established their strategy for improving patient safety, that included four key components: raising

awareness of patient safety issues, sharing knowledge between service providers and patients, promoting health and safety strategies and driving and expanding cooperation between stakeholders.

The network developed action tools such as the one entitled 'Patient Experience' to engage public and private health-care facilities to improve patient safety. They have also piloted two initiatives: the 'Patient Experience Survey' and the 'Remind Card' across 90 hospitals.

By February 2015, PFPS Thailand had enrolled 148 hospitals in their Safe Hospital programme, an initiative aimed at improving patient safety at the hospital level. Eleven expert groups that include patients and health professionals, were established to share knowledge, and experience through a Community of Practice and to develop practical guidance and facilitate the implementation of the Safe Hospital programme.

On 10-13 March 2015, the Healthcare Accreditation Institute in Thailand (HAI Thailand) held a national forum that for the first time involved patients and the public as key stakeholders. The Minister of Health and Deputy minister were present, as well as Nittita Prasopa Plaizier and Dr Nima Asgari-Jirhandeh. The forum advocated for public participation in health care. Patients and the public were involved in workshops to help improve use and understanding of the Patient Experience toolkit, in health-care facilities that help to build and extend their collaboration with other stakeholders such as the National Health Security Office (NHSO), as well as the network of patients with chronic diseases.

Overall, PFPS Thailand has shown the sort of remarkable progress that a network can make in a short amount of time by successfully coordinating with several agencies and sectors within the health-care community. We congratulate them on their progress and wish the network all the best in their future ventures!



Figure 26: PFPS Thailand's key activities, August 2014 - July 2015

## Update from WPRO

### Australia

*Stephanie Newell*

Embedding the patient voice into all levels of health care has continued to be a systemic focus in Australia, especially while the current National Safety and Quality Health Service Standards (NSQHSS) have been undergoing review. The NSQHSS was developed in 2013 by the Australian Governments' statutory body and the Australian Commission on Safety and Quality in Healthcare to protect the public from harm and improve the quality of care provided by health-care organizations. The NSQHSS covers 10 mandatory health standards across eight clinical areas, which are underpinned by two overarching standards for governance and partnering with consumers. These two standards are:

- 1) Ensuring leadership and the involvement of health-care users in their own care and secondly, guaranteeing consumers and consumer representatives are in the governance structures and mechanisms of health care service organizations.
- 2) Ensuring health-care users' participation in governance and safety and quality-related committees, and require that the organization ensures ongoing support for their involvement in the areas of governance, patient safety and quality improvement. In addition, health-care users are to be involved in all aspects of planning, design, monitoring and evaluation of an organization's services, including involvement in the education of staff on the patient experience of patient-centred care, patient safety and the quality of care experience.

The inclusion of health-care users has been highlighted as critical to ensuring that each level and area of a health service includes the health-care user perspective and oversight to maintain services that are safe, meaningful and targeting what matters to the patient and their carers and family.

### Malaysia

*Rosmini Omar*

The journey towards advancement and sustainability of the entire health-care system, in which patients and societies in every part of the world could understand risks and benefits and can value the right treatment and care, may take a long time. Optimistically, fusions of efforts and collaboration from distinct and critical stakeholders could accelerate this journey. This spring of 2015 weaved another strand of milestones on the journey. The WHO Patients for Patient Safety (PFPS), the International Association for Radiation Research (IARR), the



Japanese Association for Radiation Research (JARR), the National Institute of Radiological Sciences, Japan (NIRSJ) and Patients for Patient Safety Malaysia (PFPS Malaysia) successfully engaged a PFPS champion from Malaysia to participate in the 15th International Congress of Radiation Research (ICRR 2015) in Kyoto, Japan. ICRR 2015 was held from 24-29 May 2015. With the theme 'Radiation Science Shaping the Future of the Earth and Mankind', the ICRR 2015 congregated high levels of expertise and examined the latest technology in the field of radiation science.

Rosmini Omar, a PFPS champion from Malaysia represented PFPS global to present the patient's voice at a symposium that specifically discussed Benefit Risk Communication in Paediatric Radiology, sharing a podium with renowned experts in pediatric radiology. Dr Madan Rehani (visiting scientist at Harvard Medical School and Massachusetts General Hospital, Boston, USA and Director of Radiation Protection, European Society of Radiology) suggested the importance of identifying suitable approaches and strategies to communicate with different profiles of patients and families. Osamu Miyazaki (Paediatric radiologist, Department of Radiology National Center for Child Health and Development) highlighted the increasing importance of risk communication in Japanese paediatric radiology after the Fukushima nuclear disaster.



Figure 27: Rosmini Omar talking at the ICRR conference 2015

Rosmini shared real-life stories of parents whose children experienced radiological diagnosis and treatment. In the context of Malaysia, she explained the gap between the 'too-brave' and 'too-scared' patients and families. She touched on the importance of the 3-Cs (correct, clear and cordial) in communicating information of the children's needs for radiology to parents and families. Rosmini also highlighted the development of paediatric radiology in Malaysia, which significantly merited strong partnership between patients, health-care providers and policy-makers. Both moderators, Kazuo Sakai (Consultant, International Atomic Energy Agency) and Lawrence Lau (Chair, International Commission on Radiological Quality and Safety) offered insights on the way towards creating a more inclusive and understanding health-care community, inclusive of the scientific community, health-care providers and patients and families.

On reflection, the Benefit Risk Communication symposium provoked a significant point to consider, which is that health-care systems need to find the right platforms and approaches to educate patients and families on their roles and responsibilities towards achieving the correct radiological diagnosis and treatment.



Figure 28: Speakers and moderators of Benefit Risk Communication, ICRR 2015. From left: Osamu Miyazaki, Madan Rehani, Rosmini Omar, Kazuo Sakai and Lawrence Lau.

## Future events

*Katthiyana Aparicio, Felicity Pocklington*

### September

The "Lebanese Society for Quality & Safety in Healthcare Congress" will take place in Hamra, Beirut, on 19 September 2015. This year's theme is "Patient Engagement" and Mary Vasseghi, a PFPS champion from Ireland has been invited to speak at the conference about her experience as a patient and how she has helped to improve the health-care system and at the institutional level.

In the second half of September, WHO PFPS will host its 2nd webinar in collaboration with PFPS Canada and CPSI. The webinar, entitled, "Tips to engage with the health authorities of my country", will share different experiences from different settings. Keep an eye open on the PFPS website and community of practice for more information regarding this event!

## PFPS Champion feature

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**Helen Haskell**

Vice Chair, PFPS Advisory Group

Helen has been a representative of the patient voice in American health-care policy for many years. Her work with policy-makers and health-care professionals in her home state of South Carolina led to a state-wide journey of patient safety improvement that includes the universal implementation of patient-activated rapid response systems and use of the WHO Surgical Safety Checklist, among other changes. Helen writes patient educational materials and teaches classes for patients on navigating the health-care system. She regularly addresses medical and nursing students and has collaborated with professional educational organizations to produce videos that are widely used to teach nursing and medical students and health-care professionals about patient safety, nursing safety, and medication safety.



*Figure 29: Helen Haskell*

**PFPS Skype:** If you wish to speak to us interactively, our Skype name is pfps.geneva.

**WHO/PFPS Editorial Group:** Nittita Prasopa-Plaizier, Katthyana Aparicio, Felicity Pocklington and Laura Pearson.

### Disclaimer

*The information, comments and opinions expressed in this newsletter do not necessarily reflect those of the World Health Organization, and incidents described have not been verified by WHO. The authors of the articles take the responsibility for the content of their contribution and the opinions expressed.*

## Future PFPS News

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**Share your news with us!**

**PFPS News:** Contributions for the next PFPS News are invited. The deadline for submissions is 30th September.

**PFPS Community of Practice:** You can also continue to ask questions, share experiences and learning on the PFPS platform at: <http://ezcollab.who.int/pfp scop>. If you have problems accessing the CoP, please contact Katthyana Aparicio at [pfps@who.int](mailto:pfps@who.int).