Welcome!

Patients for Patient Safety (PFPS) team, Geneva

Welcome to PFPS News Winter 2015 edition! As we reach the end of the 11th year of the WHO PFPS programme, we have the chance to reflect on our achievements, opportunities and progress as a global team, united to improving health care safety and quality. Through our commitment, dedication and motivation towards being a catalyst for change, we have seen the programme move from strength to strength in all six WHO regions.

As PFPS advocates you have the ability to move hearts and minds, by touching on your powerful experiences to evoke emotions and change beliefs and thoughts. As Gandhi wrote: “Your beliefs become your thoughts..., Your thoughts become your words..., Your words become your actions..., Your actions become your habits..., Your habits become your values..., Your values become your destiny”. When we influence the thoughts and beliefs of key health stakeholders, their habits and values continue to be shaped too.

At times, advocacy can be tiresome, as we are all faced with barriers and challenges. Yet, when we read through this quarterly newsletter, we continue to see health-care system and service improvements, be it in a rural community or an international setting. As Jorge Martinez, PFPS champion from Argentina quoted these wise words; “Many little things… done by many little people… in many little places… could change the face of the world”… So stay engaged, informed and open to new possibilities for the new year.

Thank you to all the PFPS advocates across the world for your hard work, dedication and commitment to patient safety and quality health care throughout 2015. We look forward to a new year of engaging and empowering activities and rewarding opportunities to bring the voice of patients to health care, advocating for those whose voice is still unheard. We also look forward to your continued support and commitment to keep the momentum in this important and rapidly evolving area of work.

Happy Christmas from all the team in Geneva. We wish you all a prosperous, healthy and happy New Year.

Bring on 2016! See you again soon!
Updates from WHO PFPS in Geneva

1. ISQua International Conference, 4-7 October 2015, Doha, Qatar

Nittita Prasopa-Plaizier

Nittita Prasopa-Plaizier, in her role as designated technical officer (DTO) for the official WHO-ISQua relationship, was responsible for coordinating WHO SDS activities at ISQua’s 32nd International Conference this year, held in Doha, Qatar, from 4–7 October 2015. Other WHO staff present at this event were Dr Shams Syed, Nuria Toro Polanco, Dr Neelam Dhingra-Kumar and Dr Mondher Letaief, from our Regional Office in Cairo (EMRO).

WHO SDS organized three technical sessions to engage conference participants in the different areas of work currently being carried out by SDS.

Session 1 entitled “Lessons learned from the Ebola response: how to improve health-care safety and quality” focused on the lessons learned from the recent Ebola virus disease outbreak and invited input from different stakeholders and from the audience, highlighting the critical importance of safety and quality as a precondition for service delivery.

Session 2 entitled “Towards people-centred and integrated health service approaches: how to better integrate the patients’, families’ and communities’ perspectives?” looked at how the “Patient and Family Engagement Framework”, which is being developed by the PFPS team, in collaboration with the People-Centred and Integrated Health Services team (led by Dr Hernan Montenegro), can contribute to realization of the PCIHS Strategy by facilitating meaningful and respectful patient-professional engagement, through empowering and strengthening capacity of both parties.

Session 3 entitled “From engaging for patient safety to empowering for people-centred and quality universal health coverage: what will it take?” got the panellists and participants discussing how to engage patients, families and the community in efforts to reach universal health coverage (UHC).

These three sessions enabled WHO SDS to engage partners and collaborators from 11 countries, including officials from different ministry of health, researchers, health-care professionals, patients and representatives from patients organizations.

2. Radiological Protection Culture in Medicine Workshop

The PFPS team (Nittita and Katthyana) and Sepideh (SDS colleague) participated in the 2nd Regional European Workshop on Radiological Protection Culture in Medicine (RPCM), held in Geneva on 30 November -2 December 2015.

Building on the collaboration developed at the regional Latin American workshop, this workshop aimed to further explore the creation of a RPCM, considering the role of professionals, patients and other stakeholders. It was jointly organized by the International Radiation Protection Association (IRPA), the International Organization of Medical Physics (IOMP) and WHO.

WHO Service Delivery and Safety (SDS) staff played prominent roles and contributed strongly to this event. Sepideh was a panellist providing a scene-setting presentation on safety culture. Nittita was also a panellist, presenting patient perspectives in a separate session, co-chaired by Katthyana, which discussed the role of different stakeholders. Overall, the event demonstrated continued strong collaboration between SDS and the Radiation Programme of the department of Public Health, Environmental and Social Determinants of Health (PHE).
Update from AFRO

Malawi

Author: Ellos Lodzeni
Editor: Felicity Pocklington

Ellos Lodzeni, PFPS advocate (champion) from Malawi has been involved with a nongovernmental organization (NGO) called ‘the Patient and Community Welfare Foundation’ (PAWEM) for the past six years. Prior to 2009, there was no robust organization advocating for patients’ rights in Malawi. Since this was the case, PAWEM was established in 2009, to develop capacity and increase the health literacy of patients, families and communities on their rights and responsibilities.

PAWEM’s main objectives include:

- to advocate for sustainable high quality health services that respect patients’ rights and responsibilities;
- to advocate for humanitarian relief and development for vulnerable populations;
- to build capacity of local structures to ensure effective and efficient delivery of health and community services;
- to stimulate Malawians to be proactive in adhering to good hygiene and sanitation practices;
- to empower vulnerable patients and communities to hold duty bearers accountable.

The key activities implemented by PAWEM since 2009 are summarized below:

- Health governance – This project aimed to rejuvenate and build the capacity of hospital and health facility advisory committees as well as empower communities to hold duty bearers to account. Key outcomes of this project include advisory committees successfully negotiating and mediating disputes between health professionals and the community.
- Promotion of hygiene and sanitation in primary schools – this project implemented a hygiene and sanitation campaign into Mfera and Makhuwira primary schools. The institutions were provided with sanitation buckets and other materials to enhance sanitation activities.
- Eye care awareness – This project included community-based activities such as an open day where awareness-raising speeches regarding the prevalence, cause, prevention and availability of care for eye diseases and blindness were emphasized. Information on early detection of eye disease was provided to patients, families and the community.
- Equity in access to treatment and accountability - This project aimed to developed capacity in patients, families, community actors (including traditional leaders and church leaders) and health professionals in analyzing national policies and reviewing how they affected them; in developing strategies to advocate health systems and service improvements; in conducting income-generating activities for sustainable livelihoods; and in interfacing with duty bearers to hold them accountable for their work.
- Non-communicable diseases (NCDs) - PAWEM spearheaded the formation of a National Alliance of Patient Organizations, Malawi (NAPOM). The aim of the alliance is to engage the Malawi Ministry of Health in collaborative efforts with NCD programmes, and to advocate for the increased availability of medication. NAPOM is an umbrella organization, comprised of the Diabetes Association of Malawi, Epilepsy Association, Mental Health Users and Consumers, Journalist Against Aids and Global Hope Mobilization. PAWEM is the Chair of NAPOM.

It was fantastic to hear of so many positive activities coming from PAWEM. We wish Ellos and the team all the best with their future events, and look forward to representing their voice further in future editions of PFPS news.

Figure 4: PAWEM at work in the community
The PFPS team (represented by Nittita and Felicity) provided technical support to the first Ugandan Patients for Patient Safety (PFPS) workshop on 3–5 November this year. Hosted by the Community Health and Information Network (CHAIN), an NGO founded by PFPS advocate Regina Kamoga, with support from the Ugandan Ministry of Health and the WHO Country Office, the workshop focused on awareness-raising and capacity-strengthening for patient and people engagement and empowerment for patient safety and people-centred quality universal health coverage (UHC). The three-day event brought together approximately 60 participants, including the WHO Country office, Ugandan Ministry of Health, health professionals (including hospital managers, radiologists, surgeons, nurses), patients and family members. Most participants were from Uganda, with the exception of key speakers from Geneva.

With the exception of government officials and workshop speakers, participants were selected through an open call for participants. The call was disseminated through the WHO country office, Ugandan nongovernmental organizations (NGOs), the local media (newspaper, Facebook, radio) and health services.

Mr Mwebesa opened the workshop, on behalf of the Ugandan Ministry of Health. He reported on Uganda’s progress in the area of patient safety and explained how re-orienting health systems for improved quality and safety is a key aim of Uganda’s five-year strategy towards sustainability in the health system. He identified key objectives of this strategy which include:

- Increased access to direct care through improved infrastructure;
- Increased availability of essential medicines;
- Reduced patient to health professional ratios;
- Improved professional training;
- Increased meaningful engagement of patients and families in health systems and services.

We wish to thank all presenters for sharing their experience, knowledge and insights, including the Minister of Health, Dr Wondimagegnehu Alemu, Dr Henry Mwebesa, Dr Jacinto Amandua, Dr Jackson Amone, Professor Freddie Ssengooba, Professor Michael Kawooya, Dr Rosemary Byanyima, Dr Augustine Lubanga, Moses Kirigwajo, Regina Kamoga, Dr Olaro Charles, Dr Odu Benard, Dr Tonny Tumwesigye, James Mwesigwa Lwanga, Dr Martin Ssendyona, Dr Michael Etukoit, Dr Frederick Nelson Nakwagala, Kiguba Ronald, Joshua Wamboga, Lubega Ssubi and Dr Mukuzi Muhereza.

A facilitated ‘story telling’ session was dedicated for patients and other members of the community, many of whom had been affected by an adverse event, had the opportunity to share their experiences, build partnerships with other stakeholders, share learning and challenges, and work in partnership with health professionals, Ugandan policy-makers and WHO staff. The workshop helped to create a Ugandan PFPS network of patient advocates (champions), and all participants were involved in an interactive session to discuss the roles, responsibilities and next steps of a Ugandan PFPS network. The Ministry of Health was very enthusiastic to support this new initiative. This working partnership is expected to help embed the voice of patients and the wider population into the centre of health-care improvement efforts.

Uganda
Sample photos from the PFPS Uganda workshop

Figure 8: Compilation of photos from PFPS Uganda workshop
Update from AMRO/PAHO

Argentina

Author: Dr Jorge César Martínez
Editors: Katthyana Aparicio, Felicity Pocklington

Dr Jorge César Martínez, a PFPS champion from Argentina, has been especially active in the last quarter of the year, participating in several patient safety events in Buenos Aires. Firstly, he delivered an awareness-raising speech on patient safety culture and a more “humanized” approach to health care at the national Nurses Conference. He also participated in the Paediatric Medicine Conference, delivering a speech on safe neonatal care. Thirdly, he participated in a Government-led health conference, discussing issues of adverse events and patient safety – “What are the trends according to WHO”? At another Government led annual conference entitled “Integrated Development of Children”, Jorge presented information on his programme named ‘An Invitation to Life – The Science, the Child and a Safe World’. Inspired by the concept that informed parents can become active partners 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”).

Jorge has been awarded with a distinction of “Maestro de la Medicina Argentina” from the National Academy of Medicine in Argentina. He has also been named an emeritus professor by La Universidad del Salvador of Argentina.

The PFPS team wish to congratulate Jorge on these great awards and achievements.

Mexico

Author: Evangelina Vazquez Curiel
Editors: Katthyana Aparicio, Felicity Pocklington

1) PFPS Mexico workshop

Katthyana Aparicio, representing the PFPS team, provided technical support for a capacity-development PFPS workshop in Mexico City, on 19 November. The workshop was hosted at the Hospital de Ciencias Médicas y Nutrición and was co-sponsored by the Universidad Autonoma de Mexico (UNAM), through Dr Enrique Acosta. The workshop hosted 60 participants, the majority of whom were health professionals, patients, family members and PFPS advocates (champions) from Mexico (Lucía Aguilar Almazan, Evangelina Vazquez Curiel, Tomas Flores) and Costa Rica (Randall Madrigal).

The workshop intended to raise awareness on patient, family and community engagement, to capacity strengthen participants with this knowledge and to foster collaboration between patients, family members and health professionals. The workshop engaged participants in a round table discussion on “how patients can contribute to make health care safer with higher quality”.

The workshop was a great opportunity to expand the Mexican patient safety network, and to train patients, people and health professionals on how they can be engaged and contribute to health care, through advocacy skills, opportunities and techniques. Evangelina presented on the Pan-American PFPS network and the Mexican PFPS network. Katthyana gave an overview of patient and family engagement and empowerment from the WHO perspective. Existing PFPS advocates (champions) in the Pan-American region gave accounts of their experiences in advocacy. Tomas Flores presented on his work raising awareness to parents of children with kernicterus. Lucía Aguilar Almazan presented on the “Inclusion of indigenous (at-risk) groups in accessing health-care services”, Randall Madrigal discussed “Patients’ rights and the experience of Costa Rica”. Furthermore, the workshop provided an overview of WHO global initiatives on engagement and empowerment for patient safety and health-care quality, for people-centred and integrated health services (PCIHS) and for quality universal health coverage. Questions and in-depth discussions followed the presentations.

The workshop was a big success and represented a step forward for Mexico patient safety and quality improvement work. For many participants, this was the first time they had been in the same room as other patients and/or health professionals.

Figure 9: PFPS Mexico workshop participants
Evangelina Vazquez Curiel, patient advocate and PFPS champion worked in collaboration with the PFPS programme to organize a session within the 3rd World Congress on Integrated Care, held in Mexico on 19-21 November. The Congress was hosted by the International Foundation for Integrated Care (IFIC). This session, entitled “Engaging and empowering for health, sharing experiences”, was joined by PFPS advocates and approximately 45 members of the community whose participation was supported by the Congress organizers.

Katthyana provided an overview of the WHO patient, family and community engagement programme, which builds on the PFPS approaches. Lourdes Ferrer opened the session by presenting on “Engaging patients, carers and communities for the provision of coordinated/integrated health services”. He outlined WHO strategies and tools for this engagement, including supporting patient self-management, patients’ shared decision-making and patient peer-to-peer support. He outlined strategies for empowering populations, including protecting people’s rights and shared responsibilities, enabling people’s informed choice, strengthening health literacy and supporting community development.

Other presentations in the sessions included Katthyana discussing patient engagement; Tomas Flores discussing the importance of health literacy in health prevention and promotion; Randall Madrigal discussing the importance of access to medical records as a way to empower patients; Lucia Aguilar Almazan on why it is important for the patient and family to be recognized in health care; and Evangelina Vazquez Curiel presenting on the challenges and opportunities of empowering patients and families in Latin America. She provided case studies on advocacy experiences from Columbia and Argentina.

Peru

Nora Espiritu, PFPS advocate (champion) reported results from two research projects working in parallel, conducted in the Hospital Dos De Mayo, in Lima, Peru, between 2013 –2014.

The first research study involved the adaptation, validation and implementation of the WHO Safe Childbirth Checklist into the gynaecology and neonatal units of the hospital. The checklist was translated and validated by a group of experts, adapting it to the package of services that the hospital provides. The aim of the study was to help health professionals to improve mother and baby health care, and to improve adherence to prescribed checklist recommendations. The research methodology included measuring use of the checklist at four key stages of hospital care; at admission for delivery, at the moment just prior to delivery, throughout the postpartum period and at discharge of the mother and baby from hospital.

The study found that 70% of the participants in the gynaecology and the neonatal units complied with the checklist criteria throughout the four stages of care. However, the study only measured use of the checklist. Recommendations from the study were to carry out further research on effectiveness of the checklist, through indicators of morbidity and patient returns to the hospital. Further recommendations from the study are to institutionalize the checklist across all hospitals in Peru and to provide capacity-building for health-care professionals to use the checklist effectively.

The second research project, aimed to assess the level of academic knowledge and training of patient safety in first year medical students in the same hospital. This was an exploratory descriptive study. The methodology included first year students completing an anonymous questionnaire. The questionnaire included 10 questions, gathering personal data, the students’ knowledge about patient safety, and whether patient safety training was in their medical school curriculum.

The study found that almost half of the participants had patient safety classes and training in their curriculum. 17% of the participants had never heard anything about patient safety. The knowledge-gathering questions revealed that although many medical students had some knowledge of adverse events, they were unaware of the adverse event reporting systems available in their own hospital. Furthermore, knowledge on methods and tools to improve patient safety was very scarce.
We wish to congratulate Jeanine Thomas, founder of the Methicillin-Resistant Staphylococcus Aureus (MRSA) Survivors Network, who has received the prestigious Medically Induced Trauma Support Services (MITSS) organization’s ‘HOPE’ award. The award was presented during MITSS’ annual event, held in November in Boston, with several hundred participants from the Boston medical community. The annual award recognizes people who represent MITSS’ mission of supporting, healing and restoring hope to patients, families and clinicians affected by adverse medical events.

Methicillin-resistant staphylococcus aureus (MRSA) is a deadly bacterium commonly found in health-care settings and the community, which is resistant to many antibiotics. MRSA kills more Americans every year than AIDS. Jeanine, a survivor of MRSA herself, initiated ‘MRSA Survivors Network’, a non-profit organization in 2003. Since then, she has raised awareness about MRSA in the United States and has initiated MRSA legislation in the Illinois House and Senate.

She stated: “I am very honoured and grateful for this award and hope it will draw more attention to MRSA and raise more awareness”.

For more information about MRSA or the MRSA Survivors Network's mission please follow the link: http://www.MRSA surviv os.org.

Egypt

Nagwa has been immersed in patient and family engagement and community involvement campaigns in Cairo throughout 2015. Key recent activities include participating in an honorary ceremony that certified the maternity and gynaecology medical school hospital with an Egyptian accreditation certificate for the first time. She has also been representing the patient’s voice in a medical school hospital board, amongst hospital directors and the hospital chairman; and meeting medical students and teaching them about patient safety and quality improvement advocacy strategies.

We wish Nagwa all the best with her activities in Egypt.

Jordan

The PFPS team provided technical support in the third Quality Health Care Conference and Exhibition called “Building Quality for Safer Healthcare”, hosted by the Health Care Accreditation Council (HCAC), on 23-25 November 2015. The team organized and facilitated a capacity-strengthening workshop, which was a collaborative effort between the WHO PFPS programme, the Health System Development Department, Eastern Mediterranean Regional Office (EMRO), the WHO Country Office for Jordan and the Health Care Accreditation Council (HCAC), Jordan. The workshop focused on awareness raising and capacity strengthening for and provided a forum for the participants to exchange ideas, knowledge and experience in patient safety and quality improvement in the contexts of people-centred health services and quality Universal Health Coverage). It. The session was very well attended and the participants had the opportunity to meet and network with other stakeholders, share learning and challenges, and collaborate with health professionals, organizations and policy-makers.
Although this was a national event, the workshop brought together approximately 60 participants from across the whole Eastern Mediterranean Region, including from Jordan’s Ministry of Health, health professionals (including hospital managers, radiologists, surgeons, nurses), patients and family members. The workshop was co-chaired by Nittita and Dr Mondher Letaief (WHO Cairo Office) with the panellists. Key speakers included Professor Cliff Hughes (President of the International Society of Quality in Healthcare (ISQua) and Mr Mondher Letaief (from WHO’s Regional Office in Cairo).

In addition, Nittita provided two presentations at the HCAC conference entitled “Bridging the gap between quality care and patient engagement” and “WHO driving quality universal health coverage (UHC)”. This was a good opportunity to raise awareness of and share international experiences about integrating patient and health professional engagement and empowerment into the national patient safety health-care quality policy agenda. The conference hosted over 500 participants, many of whom were health professionals and policy-makers.

The workshop represented part of the agreed workplan within the Biennial Collaborative Agreement between WHO EURO and the Polish Ministry of Health, in which patient safety and quality of care was agreed as one of the key priorities. Twenty-seven participants attended the workshop, including patients, a PFPS advocate (champion), Jolanta Bilińska, family members, representatives from civil society and patients organizations, academics, health professionals (including managers of hospitals and health-care providers) and policy-makers. Key organizations in attendance included the International Alliance of Patients Organization’s, the Polish Association of Insurance Medicine, the Urszula Jaworska Foundation, We Patients Foundation, the Center for Quality Monitoring in Healthcare, the Institute of Cardiology, Fundacja NeuroPozytywni, the Polish Association of the Blind, STOMALIFE, Childbirth with Dignity Foundation, the Polish Diabetes Society, Polish Chamber of Physicians and Dentists and the ‘Stroke – Support Counts’ association. The deputy commissioner of patients’ rights, Mr Grzegorz Blazewicz also attended.

This workshop was the first time patients, family members, health professionals and policy-makers had come together under the same roof to discuss how to bring the patients’ voice to health care. The aim was to raise awareness of the role of patient and people engagement and empowerment for health systems and services quality improvement. The PFPS team facilitated the discussion between patients, people and health professionals, enabling understanding and information sharing, to engage and empower all participants. The workshop was very well received by the participants, with active participation throughout.

Update from EURO

Poland

PFPS team

The PFPS team (Nittita Prasopa-Plaizier and Felicity Pocklington) travelled to Warsaw, Poland, to facilitate a capacity-strengthening workshop for patient, family and community engagement and empowerment, held on 3–4 December. The workshop was a collaborative effort between the WHO PFPS programme, WHO’s Regional Office for Europe (EURO), through Dr Juan Tello, WHO’s Country Office, through Dr Paulina Miskiewicz, and the Ministry of Health Poland.

This workshop was the first time patients, family members, health professionals and policy-makers had come together under the same roof to discuss how to bring the patients’ voice to health care. The aim was to raise awareness of the role of patient and people engagement and empowerment for health systems and services quality improvement. The PFPS team facilitated the discussion between patients, people and health professionals, enabling understanding and information sharing, to engage and empower all participants. The workshop was very well received by the participants, with active participation throughout.
Malaysia

PFPS team

Nittita Prasopa-Plazier and Shams Syed, Coordinator (*ad interim*) of the WHO Universal Health Coverage & Quality Unit (QHC) in the Department of Service Delivery & Safety (SDS), attended the 4th meeting on Healthcare Quality Improvement in the Asia Pacific Region, held on 15-17 December, in Kuala Lumpur, Malaysia. This multi-stakeholder meeting was jointly organized by the WHO Western-Pacific Regional Office (WPRO), the WHO South-East Asia Regional Office (SEARO) and the Organization for Economic Cooperation and Development (OECD) in collaboration with Ministry of Health Malaysia.

The goal of the meeting was to gather data to inform the development of the ‘Health at a Glance Asia/Pacific 2016’ report, which will be published in November 2016. More specifically, the meeting had three key objectives, including:

1) to share updates on how countries in the Asia-Pacific region are addressing quality and patient safety challenges in health

2) to agree on data collection tools for quality in hospital services and survey of patient experiences, with reference to established OECD Health Care Quality Indicators; and

3) to learn from and promote Patients for Patient Safety (PFPS) approach, with focus on sharing of patient experiences, programs for family and community engagement in the region, for possible inclusion in the Health at a Glance Asia/Pacific 2016 report.

Nittita co-chaired and presented in the panel session, “Patients for Patient Safety”, which aimed to share WHO global initiatives on patients, family and community engagement and empowerment, as well as discuss how to encourage health professionals to more actively include the patient, family and community’s voice into health care.

Malaysia’s experience in setting up a Patients for Patient Safety Malaysia network was the main case study. The panellists included representatives from the National Institute of Public Health, Japan, Ministry of Health, Malaysia, the Malaysian Society for Quality in Health (MSQH) and the PFPS Malaysia network. Photo credits — OECD Korea Policy Centre, WHO WPRO and Ministry of Health Malaysia.

Future events

Prince Mahidol Award Conference (PMAC) 2016

The WHO Service Delivery and Safety Department (SDS), in collaboration with the Prince Mahidol Award Conference and the Healthcare Accreditation Institute of Thailand (HAI Thailand) will participate in a side meeting on the subject of “Universal health coverage and Quality of care, Part II” . This side event is a follow-on to last year’s PMAC session held on the same subject (which is why it has “Part II” in the title.)

During this session, participants will co-develop thinking on how to stimulate change in improving the quality of health service delivery within the context of universal health coverage (UHC). The session will explore the multiple perspectives on the subject from across the world and examine examples of how national systems and global development partners are contributing to “UHC-quality convergence”. The session will also share details with participants on the recently launched WHO unit on UHC and quality of care, and will seek input from participants to inform the development of a learning laboratory, a think tank that aims to capture and share best approaches in achieving quality UHC at the front line of service delivery.

The experiences from five distinct national health systems, including Thailand’s, as well as development experience from others, will be highlighted. The side event aims to be an interactive session, with participants’ feedback being actively encouraged.
Webinar

WHO PFPS will host a webinar in collaboration with PFPS Canada and CPSI. The webinar, entitled, “Does patient engagement in patient safety and quality committees advance safe care or is it a myth?”, will share global perspectives from patient representatives and provider representatives and/or committee chairs. The session will highlight best or leading practices, tools and resources for patient engagement in patient safety and quality committees.

The date has not been finalized yet, although the webinar will be hosted towards the end of January/early February. Keep an eye open on the PFPS website and community of practice for more information regarding this event!

PFPS advocate (champion) feature

Barbara Farlow
PFPS advocate (champion)

Barb has been a PFPS advocate for patient safety for almost 10 years, subsequent to the death of her infant daughter, Annie. In her own words:

“Annie had a rare genetic condition associated with disabilities and her care was fraught with ethical misdemeanours, for which the hospital has apologized. I discovered that the medical literature was void of the patient and family experience of Annie’s condition. I collaborated with two leading physician-ethicists to undertake original research to complement the literature”.

Since then, Barb has published two research papers in major medical journals and presented the team’s research at many major paediatric conferences as well as grand rounds at leading institutions, including the Boston Children’s and Massachusetts General Hospitals.

Two years ago, Barb co-founded the International Trisomy 13/18 Alliance with a physician, a researcher and another mother. Together, they summarize medical literature and create booklets to empower parents and support physicians with the goal of optimizing decision-making through improved communication. They will be co-hosting a conference in Ireland in January.

Barb commented, “I’m proud to say that the effort has made a difference. We receive heart-warming letters of gratitude from parents. My highlight was at the Paediatric Academic Societies conference where I presented the parents’ voice. A physician waited in line to tell me, “Today, you’ve made me a better physician”.”

Barb is a member of the Patients for Patient Safety Canada, which is supported by the Canadian Patient Safety Institute (CPSI). She served as an advisor to the DeVeber Institute of Bioethics and Social Research and in 2012, became the first Honorary Patient Perspective Board Member of the International Society for Quality in Health Care. Through these roles, she encourages and support policy-makers to engage patients and families in all aspects of health care.

Future PFPS News

Share your news with us!

PFPS team: Nittita Prasopa-Plaizier, Katthyana Aparicio, Felicity Pocklington

PFPS News: Contributions for the next PFPS News are invited. The deadline for submissions is 15th March 2016.

PFPS Community of Practice: You can also continue to ask questions, share experiences and learning on the PFPS platform at: http://ezcollab.who.int/pfpscop. If you have problems accessing the CoP, please contact Katthyana Aparicio at pfps@who.int.

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


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