



Patients for Patient Safety News

July 2011

Welcome to the 20th edition of PFPS News, with a feature on patient safety in Africa, following the first African Regional PFPS Workshop held in March. Also read about a new patient rights project in Europe and latest PFPS activities in Egypt!

Make patient safety a priority in Africa, patients urge



The first African regional Patients for Patient Safety Workshop was held in Uganda from 16 - 18 March. Patients, family members and advocates from Ethiopia, Ghana, Kenya, Malawi, Uganda and Zambia, joined health-care workers and policy-makers to share experiences of harm in health care to work together to improve health-care safety in their countries. Participants urged Member States and health-care providers to make patient safety a priority in Africa.



Participants now join the existing network of PFPS Champions around the world advocating for the belief that patients' and family members must be empowered and placed at the centre of care.

PFPS Champion and advocate, Mrs Robinah Kaitiritimba called on the group to work together and take action. She said: "We have been waiting for this workshop. Now that we have a network we are going to move. We emerge from our time together with a shared passion to listen, learn and progressively improve patient safety in our countries"



In 2008, the WHO African Regional Committee highlighted the problem of patient safety and endorsed a number of recommendations to facilitate improvement. One was to promote "...partnerships between patients, family members, health professionals and policy-makers to effect meaningful change in patient safety..." The Committee also stressed that the involvement of patients in raising awareness and campaigning for the development and implementation of health-care safety measures, would be crucial if systems are to improve.

Medical errors result in many preventable injuries and deaths every year. Strengthening patient partnerships in Africa is of particular importance. Weak health-care delivery systems, including sub-optimal infrastructure, poor management capacity and under-equipped health facilities have brought about a situation where the likelihood of medical errors is high.

Prevalence studies on health care-associated infection from a number of African countries report high infection rates (Mali 18.9%, Tanzania 14.8% and Algeria 9.8%) and that patients undergoing surgery were the most frequently affected. Inappropriate funding of health-care systems, unavailability of critical support systems including strategies, guidelines, tools and standards, remain major concerns in the African Region.

The WHO representative for Uganda, Dr Joaquim Saweka, officially opened the workshop by emphasizing the importance of addressing patient safety in the African Region. He welcomed the involvement of patients and civil society in these efforts.

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Look inside:

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- Mexican Workshop



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The WHO focal point for patient safety in Uganda, Mr Joseph Mwoga, stressed that this network would "...bring the human face to all our work..." and envisioned all stakeholders working more closely than ever before. He urged patients' and patient organizations to take the initiative and share their powerful stories with health ministries and professional councils.

The participants worked together to capture the spirit of the workshop by drafting a Declaration which calls for patient safety to be made a priority in Africa and for patients to be empowered as meaningful partners. Participants also developed action plans to improve the reporting of medical errors, to prevent injuries and deaths due to infection, to raise awareness among patients and ensure their voices are heard, and to strengthen partnerships between patients and health-care workers. The Entebbe Declaration and a meeting report will be finalized in the coming months and we will have an article in the next newsletter on the activities the new Patient Champions have been participating in since the workshop.



For more information please email Anna Lee leea@who.int, Marty Hatlie mhatlie@p4ps.net, or Garance Upham fannie.upham@gmail.com.

Patient Safety & Patient Engagement in Africa

Patient Safety in Kenya

Margaret Mungai, Nurse Manager, Moi Teaching & Referral Hospital, Kenya

Moi Teaching Hospital is the second largest referral hospital in Kenya, that serves a catchment area of approximately 15 million people. Patient safety is not very well formalized but there are various activities in the hospital aimed at enhancing patient safety, including infection control, clinical audits, nursing research, incident reporting, monitoring of hospital acquired infections and child life support activities.

Of all the above activities, I wish to elaborate on the child life support service, which has made a lot of progress regarding the quality and safety of paediatric patients care at the hospital. The service was initiated by Mrs Sara Mamlin through an initiative called the Sally Test Centre. She started with a group of volunteers interested in children's welfare, who made visits to children in the hospital each day.

It is easy for such volunteers to identify with the children as they wear bright flowery clothes unlike the white medical personnel uniform feared by all patients, especially children. Through their rapport with the children, they are able to explain the sole intention of any painful procedures required for them to improve their illnesses. The two-hour sessions also include play therapy, which has been observed to cultivate a more understanding relationship between paediatric patients and medical personnel and they also meet children from other wards.

The therapeutic effect of these child life activities in our hospital is notable as children are more receptive, understanding, friendly to each other and do not continuously display signs of separation anxiety. With the children understanding their treatment, they are able to be more co-operative, adherent to instructions and overall benefit from enhanced patient safety.

As child life activities expand, the Sally Test Centre has embarked on establishing satellite centres within the hospital. This Sally Test Centre model is an exemplary concept for adoption in other Kenyan public hospitals.

For more information please email margiemungai@gmail.com



IAPO meeting in South Africa

On 18 - 20 April, the International Alliance for Patients' Organizations (IAPO) held a Regional Network Meeting for its members in Africa. Through an interactive workshop, members discussed health-care challenges in the region to identify common concerns and priority areas to develop an action plan for their work together as a regional network. An action plan was drafted at the event and is now being reviewed by members in the region.

The programme included a multi-stakeholder seminar on building cross-sector partnerships to meet patients' needs in Africa, which provided an opportunity to share information and initiatives and to discuss and debate two current challenges for patients and all those involved in health care in Africa: non-communicable diseases and access to safe medicines.

A full meeting report with information on the outcomes of this event will be available soon.

For more information please see www.patientsorganizations.org/africa



Sickle Cell Disease in Uganda

Foulata Kwena, PFPS Champion & Advocate for Children's Sickle Cell Foundation, Kenya

When I heard I had been selected to attend the PFPS workshop in Entebbe, I saw this as a good chance to visit and learn from our counterparts at the Uganda Sickle Cell Foundation.

There are two sickle cell associations in Uganda: The Uganda Sickle Cell Foundation and Uganda Sickle Cell Rescue and they work closely together. Ruth Nakanja is the Founder of the Uganda sickle cell foundation, a 38 year old mother living with sickle cell disease (SCD) who dedicates her time to serving the foundation. Sickle Cell Rescue is driven and supported by the Mulumba family, Ugandans currently living in the US and parents to a sickle cell child who successfully underwent a bone marrow transplant. They are dedicated to help better the lives of sickle cell patients in Uganda.

The current sickle cell clinic is housed in a container at Mulago hospital in Kampala. All services are free. There is a first aid area for people needing immediate attention and a waiting area for others. There is rotation to ensure doctors availability at the clinic. They are planning to have an adult clinic once a week.

They have developed brochures to help patients with SCD manage it at home to lessen the crises. The centre is closed over the weekends and nights, and sometimes patients arriving after lunch are turned away so that hospital employees are sure to finish by 5pm. These hours are insufficient as a crisis can come at anytime.

During the workshop, fellow participant Gertrude Nakigudde asked me to go and meet a family with three children with SCD. A son in secondary school and identical twins, six years old. The mother was depressed and needed encouragement from someone who understood. We visited the family and met their twins, one girl who has suffered six strokes so far, and the other two strokes. The children cannot support themselves in a chair, eat by themselves or talk, but mental reactions were good. The parents expressed difficulty to afford treatment. Ruth suggested they follow up with the centre at Mulago, request frequent transfusions and physiotherapy.



Ruth told me the Mulumba family have bought land to build a comprehensive sickle cell clinic in Uganda. The vision is to have a fully fledged clinic complete with wards for patients. This clinic would be visited and assisted by volunteer doctors from the US periodically. It is hoped the new clinic will have genetic counselling to minimize the number of babies born with SCD and if they find donors, tests will be subsidized and free in the long run. DVDs have been produced for sale to raise funds and to raise awareness and they will also produce educational videos. They plan to develop magazines and run sensitization programmes to reduce the stigma surrounding the disease.

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I gave Ruth an update on what we had done during the PFPS workshop, and we talked about the need for an umbrella body that brings together different disease groups to speak with one voice.

Ruth shared their many challenges, including the change in government priorities, and the lack of information held by the Ministry of Health on SCD. Recently, however, Ruth met President Museveni, who had made a great effort to understand SCD, and gave a contact name to work with.

For more information please email foulata.kwena@undp.org



News from PAHO

Mexican Workshop

Evangelina Vazquez, PFPS Champion, Mexico

Mexico's first PFPS workshop was held back in November 2010, as part of the International Week for Integration and Development of Mexico's Health Ministry.

Dr Jacques Girard of PAHO Mexico, welcomed attendants while Mr Antonio Heras gave a beautiful speech about patient safety in Mexico, the importance of health-care professionals' sensitization, breaking paternalism and the importance of human rights and listening to patients.

I presented on "Fundamentals of the Mexican Network of Patients For Patient Safety", where I described the importance of involving patients who have suffered adverse events in patient safety improvement work. Susan Sheridan then spoke to us about the PFPS movement and participation of patients at the global level.

Dr Walverly Morales presented on patient engagement at the Metropolitan Hospital of Nuevo Leon. He spoke about the great benefits of actively involving patients that had experienced adverse events, as a positive mechanism to improve the safety culture. The hospital also has a policy of *open disclosure*. Detecting and openly discussing the adverse event, apologizing to the patient and providing the proper follow-up. So there is no circle of blame, but learning and analysis of the case from both perspectives, all bringing resilience and improvements to safety.

Dr Miguel Pezzotti, from Centro Medico 20 de Noviembre, described work being done in the area of paediatrics, particularly around Kernicterus and prescription errors. A project is being implemented in the hospital, "Relatives and Medical Equipment for the Safety and Integral Health of the Child", focussed on the integration of the paediatric patient's family. So far the results point to a decline in nosocomial infections, less risk of having to return to hospital and a reduction in the length of stay in hospital.

Dr Mahli Cho, from PAHO Headquarters, spoke about patient empowerment, and proposed models of strategies for the prevention of adverse events, particularly of patients suffering from chronic illness.

The participation of the Hospital de la Mujer was very illustrative, presenting patient safety strategies and they performed a scene where an identification mistake happens with a newborn patient, showing all the emotional consequences to the family. The performance was interactive and educational in a touching way.

The first Mexican PFPS Workshop was a success.

For more information please email curiel@servidor.unam.mx



Patient Rights

Mary Vasseghi, PFPS Champion, Ireland

Other Regions

Latest Activities in Egypt

Nagwa Metwally, PFPS Champion, Egypt

On May 5, I attended the meeting run by the Egyptian Association of Infection Control, to mark the international hand hygiene day. I presented my experiences in the hospital and the importance of hand hygiene for infection control, the efforts to reduce infection and challenges, etc. In this meeting, the creation of the Egyptian Association of Patient Safety was mentioned, of which I'm one of the founding members. We are in the process of finalizing the structure, vision and mission of the association. We will soon be running a workshop for orientation for those who are interested in working with us and we are hoping to launch the association soon. Dr Riham Elasady, WHO EMRO, is also a founding member.

As a first step, we are hoping that this association will be the reference to all that concerns patient safety in Egypt and we hope to gradually spread to the rest of the Eastern Mediterranean region. I will send more details once the association is established. This association is an important step, it was one of my goals which I wanted very much to achieve. I hope we can achieve good things for patient safety through it.

Another meeting I attended was the Scientific day for Infection Control in the Medical School of Einshams, where I work in its Maternity department. I chaired a session about seeking excellence in infection control practices. There were various presentations including on antibiotic stewardship, zero level of health care associated infections, patient safety, towards a safe hospital environment and more. I was happy about the presentations and the degree of awareness of patient safety, which is growing. There is also more awareness of the importance of the patient voice, and many organizations are contacting me to learn about our activities and to go to their hospitals to replicate our project, so the patient's voice is heard more and more.

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There is a very exciting WHO Patient Safety and Rights project currently under way, which aims to produce policy guidance and an applied tool, supporting patient empowerment, focused on patient rights and safety.

The project is based on the themes of blood transfusion, hospital infections/hand hygiene, elective surgery and medication prescriptions. Additional contribution concerning communications during patient handovers is expected to be brought through the deliverables of the EU-funded dedicated project (HANDOVER), which is currently finalizing its work.

The expert group on which I am honoured to sit, involves multi sectoral representatives including policy-makers and patient representatives from several EU countries .

This project (running until the third quarter of 2011) is exploring the links between patient rights and patient safety, and how/whether strengthening and empowering patients can become an important element of patient safety itself. A conceptual model where the patient is positioned as an active (as opposed to a reactive) participant in his/her care is aspired to. "Patient Participation: Current Knowledge & applicability to Patient Safety" (Mayo Clin Proc. 2010) is relevant to this work.

www.ncbi.nlm.nih.gov/pubmed/20042562

I feel it is positive, practical and feasible to engage the patients in these three areas. These are areas where no specific medical knowledge is required of the patient. Implementation would be facilitated as considerable work on the health system side has already occurred in these issues. This type of engagement will cause a culture change in a gentle way. I look forward to the next steps of the availability of simple tools for trial. I am very excited by this project and see it as having a widespread positive and powerful impact on patient engagement and safety worldwide.

I have also been appointed as patient representative to the recently formed Clinical Effectiveness Committee, composed of 26 members, representing the Irish health-care system. This committee was commissioned by the Minister of Health & Children to develop/adapt and adopt guidelines and audit programmes in priority areas which align with defined national priorities. I was also appointed as patient advocate to the recently created Irish Medical Council Professional Competence Committee and am also a member (with Margaret Murphy) of a steering group to create an Irish Patient Safety network of patients and clinicians.

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WHO Patient Safety

SAVE LIVES: Clean Your Hands: 5 May 2011

The focus of 5 May this year was to encourage health-care facilities to track progress in hand hygiene promotion, plan their actions and aim for hand hygiene improvement and sustainability through the use of the WHO Hand Hygiene Self-Assessment Framework. www.who.int/gpsc/country_work/hhsa_framework

Engagement in using the Framework is evident from the feedback and WHO has launched a survey to obtain a global picture of progress in hand hygiene and identify areas for further improvement.

Registrations for this year's campaign reached 13 527 in 153 countries. There is ongoing engagement around the globe and it is clear that we can all contribute to this every day, every year. New health-care facility registrations are still welcomed and are a powerful message to governments, administrators and clinicians alike. We still want to achieve registrations in all 192 WHO Member States, so please continue to spread the word, using this global annual campaign to help achieve clean hands at the point of patient care.

For more information please email savelives@who.int

SAVE LIVES: Clean Your Hands **News & Resources**

In April, a comprehensive WHO Report on the burden of endemic health care-associated infection worldwide was released. The report describes the advantages and challenges of surveillance, reports available data on the burden of health care-associated infection and its impact in high, middle and low income countries, and points out lessons learned and future perspectives. www.who.int/gpsc/country_work

If you couldn't join the special WHO hand hygiene teleclass on 5 May, you can access the recording and slides from the following link; www.webbertraining.com/schedulep1.php

WHO Hand Hygiene improvement tools can be downloaded at any time to support health-care facilities. www.who.int/gpsc/5may/tools

Mother Baby 7Day mcheck tool

Patients for Patient Safety, in collaboration with WHO Reproductive Health Research, is creating a patient safety tool which aims to empower mothers and their family members to improve safety in the first seven days after the birth of their child. This tool reminds women to seek care for themselves and their newborn if either is experiencing any of several danger signs, such as fever or heavy bleeding, which result in major morbidity and mortality during this high-risk period. The paper-based checklist-style tool will be complemented by a decision support system that is accessed by mobile phone. This system will be largely automated but will also include the option to connect to the community health-care worker or emergency services.

WHO estimates that more than 350 000 women between the ages of 15 and 49 die each year from complications associated with pregnancy and childbirth. Globally, nearly four million newborns die each year within the first month of life. Three-quarters of these deaths occur in the first week, with the highest risk of death on the first day of life. To improve the health and survival of both the newborn and the mother, the early postnatal period is the ideal time to deliver an intervention that empowers women to access health care when needed.

The 'by patients for patients' approach being used to develop this tool is led by a small group of PFPS Champions across the world. By harnessing their local networks of stakeholders including mothers, fathers, grandmothers, midwives, obstetricians and community health-care workers, it is hoped that the tool will truly respond to a global patient need.

Once the latest round of tool refinement is complete, planning for official piloting will begin. We will highlight progress made on this project later in the year.

For more information please see www.who.int/patientsafety/patients_for_patient/mother_baby or email pfps@who.int

Announcements!



New IAPO Toolkit

The International Alliance of Patients' Organizations have created a new toolkit for patient groups, "*Working with Partners and Stakeholders*".

The toolkit provides examples and guidance on how to develop long-term partnerships while retaining independence. The toolkit also gives tips and information to help with some of the challenges that can occur when working with external partners. It also contains materials to help guide organizations on developing infrastructure and capabilities.

The toolkit is available at www.patientsorganizations.org/showarticle.pl?id=1312&n=1091

For more information please contact IAPO at info@patientsorganizations.org

MRSA Survivors Network - Public Service Announcements

Please see the link below to our new PSA's (public service announcements) for MRSA awareness, with Rob Stafford of NBC Chicago and NBC Dateline. These will be running on NBC stations, our YouTube channel and both of our web sites.

Please visit www.youtube.com/mrsasurvivors to check them out.

For more information please email jeanine@ameritech.net

Patients for Patient Safety Canada

The Patients for Patient Safety network in Canada have made a film to highlight their work. This powerful film features four patient experiences of medical error and these families' efforts to improve patient safety. It also gives a brief history of the PFPS network in Canada and how they are hoping to grow and expand their work in the future.

For more information see link; www.youtube.com/watch?v=JB1Us_B5vhM

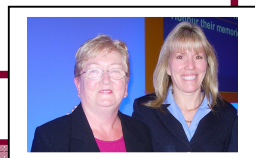
Changes in Patients for Patient Safety

After six years as Expert Lead of the Patients for Patient Safety programme, Susan Sheridan has stepped down from the role for a period of two years, so she can spend more time with her family.

WHO Patient Safety is extremely appreciative of Susan, she has been an inspirational and committed lead and although Susan is stepping back as Expert Lead and its associated commitments for two years, she will remain involved, staying part of the PFPS Steering Group and supporting a number of initiatives.

Margaret Murphy has agreed to step into the role of Expert Lead for the next two years. Margaret has been a committed and passionate member of the steering group for the past six years and is looking forward to taking on this additional responsibility. We are extremely grateful to Margaret and look forward to working together to move forward with the development of PFPS.

If you have any questions please email pfps@who.int



Next time...

If you have any news to share for the next newsletter please send your contributions to Anna, at leea@who.int before 25 August 2011.