



Patients for Patient Safety News

April 2008



Welcome to another edition of PFPS News! This edition is *packed* with champion activities from across the regions as well as a feature interview with Nittita Prasopa Plaizier from the Research programme of the World Alliance for Patient Safety.

CHAMPION ACTIVITIES around the world!

South East Asia

Opening Doors: News from Sri Lankan Patients for Patient Safety team!

- Christine Perera, Patients for Patient Safety Champion, Sri Lanka

Last month I was invited to present as part of a session on Patient Safety, to the Sri Lankan Medical Association by Dr. Eugene Corea. This offered a great opportunity to have the patient voice included and Dr Corea worked incredibly hard to get Patient Safety onto the agenda. He is a Council Member of the College of General Practitioners of Sri Lanka and a member of the Ethics Committee of the Sri Lanka Medical Association. He has been promoting patients' interests for as long as I have known him and was extremely keen to work with the Patients' Safety Team on our return from the Patients for Patient Safety Regional Workshop in Jakarta last year. Although patient safety is a very new topic in Sri Lanka some GP's have been promoting safety measures for quite sometime. After much persuasion by Dr. Corea and the College we were given a session at the 121st Scientific Session of the SLMA to present what the doctors have already put to practice and the patients' point of view and the work done so far. The topics touched on can be seen in the side panel of this page.

After the discussion most of the questions were directed at the medical professions but some of the key points discussed included

- The limited time doctors spent with patients. We too have to share the blame.
- Since there is no referral system in Sri Lanka patients consult any doctor/specialist they please, very often unnecessary on the recommendation of family, friends or even the receptionist in private hospitals.
- Health Policy - although Sri Lanka has many excellent regulations, implementation is a serious problem.
- Data Collection of adverse incidents - this is another issue to be taken up in the future.

The Patients for Patient Safety Champions and our group in Sri Lanka are working on a poster campaign aimed at educating patient on the very severe problem of referrals.

We will be repeating the whole session at the monthly meeting of the Independent Medical Practitioners Association next month. Only time will tell how successful we were?

To find out more you can email Christine at: christinesbp@sltnet.lk

PATIENT SAFETY AND SAFETY IN PRACTICE

Introduction to patient safety

Dr Aruna Rabel

Learn ethics to practice safety

Dr Eugene Corea

The safe prescription

Dr Prasanna Siriwardena

A home based patient held record

Dr Dushyanthi Weerasekera

Preventing a death in the family

Dr Seneth Samaranayake

Making mistakes apparent

Dr Jayantha Jayatissa

Promoting safety and learning from experience

Ms Christine Perera

Safety in an institutional primary care setting

Dr Aruna Rabel

Roles of the community & professional bodies in improving safety

Discussion



Presentation given by Christine Perera to the Sri Lankan Medical Association (SLMA)

PROMOTING SAFETY AND LEARNING FROM PATIENTS' EXPERIENCES "PATIENTS FOR PATIENT SAFETY"

"FIRST DO NO HARM"

is every health care provider's responsibility. But what about the patient? Even though today's patients are better informed about healthcare than any previous generation we have yet to come to terms with our role and responsibility in preventing adverse incidents and improving the safety of health care.

HOW BIG IS THE PROBLEM

The facts are shocking. In industrialised countries alone, an estimated one in every 10 patient admitted to hospital suffers some form of unintended harm. As there is a lack of data available on adverse incidents in Sri Lanka as is the case in most countries in our region where the problem is likely to be worse. But the good news is that an estimated 50% of these could be prevented.

Most of us now recognize that the majority of errors in patient care are the result of a failure in the system of care rather than a specific individual. We are moving from the 'blame game' (fuelled by medical malpractice) to identifying and correcting the root causes of the errors so that they will not occur again.

Preventing adverse incidents requires a team effort. We therefore request you to involve us in every aspect of the health care process. After all, "Patients are the only ones who see the medical error from the very beginning to the very end" (Susan Sheridan, External Lead, Patient for Patient Safety, WHO World Alliance for Patient Safety).

The only person that stays the course is the patient. Therefore the patient has a unique insight and taking their experiences into consideration is crucial.

Around the world, the most successful healthcare systems are not necessarily those that are the best financed, staffed and resourced, but those that encourage close cooperation with patients and their families.

When harm occurs the cost to the patient comes in the form of increased pain, disability, psychological trauma, loss of trust in the health care system, loss of independence and loss of functionality and productivity. Human costs to health care professionals include a loss of morale and confidence, depression, stress, and feelings of frustration, shame, guilt and inadequacy. There are many other indirect costs, but human loss to both patients and health care professionals is the most important.

When harm occurs this is what we expect you to do: **Talk to us; Explain what has happened; Control the extent of the damage; Control the long term effects; Offer counseling; Report and analyse the incident; Encourage us to report the incident; Consider us as team members and Explain to us what you will do, so it does not happen again.**

We are here today to give a voice to patients. I was a member of the Sri Lankan team that participated in the "Patients for Patient Safety" workshop organised by WHO SEARO in Jakarta, Indonesia, last year. This three-day event, the first of its kind, in our region brought together patients, health care professionals, and policy makers in an open dialogue. We shared experiences and perspectives and discovered how to work together to make health care safer in the region. Together, we drafted the "Jakarta Declaration".

Inspired by the workshop we formed into a group to advocate for patient safety.

Our overall aim is to work with health care providers and policy makers to improve the safety of health care in Sri Lanka. We will accomplish this through:

Patient education; Strengthening the patient-doctor relationship (including communication and team work); Advocacy; Networking; and Data collection

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PARTICIPATION IN WORKSHOPS RELATED TO PATIENT SAFETY

Since the Jakarta meeting, we had the opportunity to contribute patients' perspectives in two WHO regional workshops that were hosted by Sri Lanka.

Last December, we were invited to the First Meeting of the Regional Network of Medical Councils which was held in Colombo. One of the key items on the agenda was to discuss the roles and responsibilities of medical councils in ensuring patients' safety. The key action points identified by the working groups were:

- Ensure transparency in the proceedings of Medical Councils
- Improve the efficiency of the grievance procedures for patients
- Include non-medical representatives in Medical Councils

In January, we attended a WHO regional workshop in Bentota. The overall purpose was to strengthen emergency and essential surgical care at the district level to ensure patient safety. Because we believe that the blood donors will be able to contribute a great deal about other donors, we proposed including non-medical representatives on Blood Transfusion Committees although we do not have the necessary technical background. We are very grateful to have been included in these workshops.

OUR ACTIVITIES WITH THE COLLEGE OF GENERAL PRACTITIONERS

We are happy to say that we are already actively engaged in patient safety activities with the College of GP's. We are developing two patient educational posters which could be displayed in surgeries island-wide. The originals were compiled in the Sinhala language and are being translated into English and Tamil. Here are some extracts.

Your doctor

Is your doctor kind and sympathetic?
Does your doctor spend enough time with you?
Do you understand the answers to your questions?
Is your treatment cost effective?
Is your doctor registered with the SLMC?

You

Respect other patients

Talk to your doctor – you should open your mouth, and not just to say “ahh”. Experts agree that communication is the easiest way for people to help prevent medical harm.

Please tell the doctor everything – sure you may not want to give away how many cigarettes you went through last week, and it may be tempting to fib your estimate of how much you drink.

Check your personal details and keep track of your medicines and medical records – carry them around like your life depends upon it because it does sometimes.

Make sure you can understand the writing on your prescription.

We are also working on a project to translate the relevant cautionary labels which are contained in the British National Formulary into Sinhala and Tamil. The intention would be to make this list available to all pharmacies so that the appropriate cautionary labels could be noted in the medical drug cover as a safety measure.

Very soon we will be setting up a post box for the collection of good and bad experiences of both patients and professionals. This data will be used for future reference.

Our hope is that the other professional colleges and associations will give us the opportunity to work and cooperate with them.

We leave you with this thought :

Together we could strive for excellence, so that all involved in healthcare are as safe as possible as soon as possible.

To contact Christine and the Sri Lankan team you can email : christinesbp@sltnet.lk



Blood Transfusion should be safe and not transmit HIV or Hepatitis B, C infections

- Dr J S Arora, Patients for Patient Safety Champion, India

No Patient should suffer preventable HIV and Hepatitis B & C infections with Blood Transfusion

Thalassemia is a serious inherited blood disorder. In this, blood formation is defective since early childhood. When the child is born he/she is absolutely hail & hearty. By the age of 3 month to 2 years the child starts showing the symptoms of severe anemia which does not improves with medicines [iron, vitamins, etc] and he/she is diagnosed as Thalassemia major by a special blood test. The child requires regular, repeated life-long blood transfusions for his/her survival. As the age grows the blood requirement also increases. The multiple transfused Thalassemics always carry high risk being infected with serious transfusion transmitted infections like HIV, Hepatitis B & Hepatitis C.

National Thalassemia Welfare Society formed in 1991 by the patients, parents, doctors and well-wishers committed for the welfare of Thalassemics conducted a survey on 551 multiple transfused Thalassemics of age ranging from 1yr to 49 yrs from 10th Dec2006 to 29th Aug 2007. 33 of them were found HIV positive 89, Hepatitis C (Anti HCV) positive and 43 Hepatitis B (HBs Ag) positive i.e. approx 6% of them are HIV, 8% Hepatitis B, & 16 % HCV infected

Out of 89 infected with Hepatitis C 5 were born after 2002, the year when HCV screening was made mandatory in all blood banks in India and out of 33 infected with HIV 28 were born after 1989, when HIV screening was made mandatory. It clearly indicated that at least 28 Thalassemics got HIV & 5 Thalassemics got HCV infected after mandatory screening. However actual figure is much more because many Thalassemics were HIV/HCV negative before these tests were made mandatory since they are regularly tested for these infections once a year.

The above facts suggest that

1. either testing kits are substandard
2. or human error
3. or window period transmission

None of the blood bank will accept first two reasons and people will continue to be infected with excuse “**window period transmission**”.

So let us focus on this issue. The ELISA kits used by blood banks in India cannot detect HIV before 22 days of infection, Hepatitis B before 59 days and Hepatitis C before 82 days.

Leave aside US & Europe; Hong Kong & Singapore are using NAT [Nucleic Acid Test] in addition to conventional ELISA method for over five years. Even in less developed countries like Thailand, Malaysia & Indonesia, Red Cross has started NAT testing for approximately a year.

In India a study was done on 21731 units of donor's blood from 8 different blood banks of different states & cities. It was found that 1 in 1811 was positive with NAT but negative with ELISA for at least one of the three infections HIV, Hepatitis B or Hepatitis C.

Apparently 1 in 1800 figure looks very small but if we consider total consumption of blood 3.5 to 4 lac units in Delhi, say 3.6 lac units then 200 units are issued infected with at least one of three - HIV, Hepatitis B or Hepatitis C infections with “best” ELISA kits and “no” human error. These days each unit of blood is divided in 2 or 3 components, i.e. RBCs, Plasma and Platelets, that means 400 to 600 persons are infected with one or more of these three dreaded infections in Delhi. If we replicate this calculation with National annual requirement of blood, 9 million units then 10,000 to 15,000 people are being infected with at least either of the three infections under best current system of testing. These figures are not small for any city or country and **necessarily not acceptable for any individual who gets either of these infections.**

It has been found that with NAT (Nucleic Acid Testing) window period is reduced to 11 days in case of HIV; 23 days in case of HCV & 34 days in case of Hepatitis B in comparison to 11, 82 and 59 days with ELISA respectively. That is approximately 50% reduction in window period of HIV, 72% in Hepatitis C and 34% in Hepatitis B Infection.

The above window period (the time when one is infected but does not test positive with a particular testing method) is based on the NAT by pool method i.e. when we tested blood by pooling samples of 12 units of blood. But if we do ITD [Individual Donor Testing] the window period is further reduced to 5.6 days in case of HIV, 4.9 days in Hepatitis C & 35.4 days in Hepatitis B. It is not irrelevant to mention here that during first 3 days of infection [window period] viral load is so less that transmission of infection is almost negligible. That means with ITD with NAT. We can reach to “Near zero risk blood transfusion.”

1st October is observed as National Voluntary Blood Donors day in India. I raised the above issue on this day last year at India Habitat Centre, where it was celebrated jointly by NACO (National Aids Control Organization), ISBTI (Indian Society of Blood Transfusion & Imuno-haematology), SBTC (State Blood Transfusion Council), and Apollo Hospital. Our above study and my suggestion to include the NAT in donors blood was widely covered by media. Study was covered by Sahara news on 1st October and again on 5th Oct. with myself on phone line, and live telecast with Zee News on 4th Oct'07 with questions put by anchor to Dr Yogan and Shastri, Hon'ble Minister of Health Govt. of Delhi. It was twice covered by IBN7 on 4th Oct'07 with former union Minister of Health Dr C.P. Thakur and with Dr Yoganand Shastri for their comments. The study was also widely covered by print media.

Through PFPS I want to raise awareness of Thalassemia and this serious transfusion transmitted hazard. I hope NAT can be mandatory in all blood banks in India.

To find out more about the work that Dr Arora is doing on Thalassemia and in his role with the National Thalassemia Welfare Society & Federation of Indian Thalassemics you can email him at drjsarora@gmail.com



Europe

Serena a Palermo

- Paola Acquaro, Patients for Patient Safety Champion, Italy

Serena a Palermo, is part of Europa Donna(ED), a non profit organization whose members are from all over Europe. Serena a Palermo shares the same goals as ED. They work to diffuse information on different aspects of breast cancer, including prevention, screening, psychological support, medical and legal advice. The members of Serena a Palermo are men and women with heterogeneous professions, many of them are affected by the disease. The association tries to involve young people and cultural mediators because they are good mediators between the health care system, families and immigrants. It is important that everyone has equal opportunities to treatment independently of their social class and where one lives.

Sicily is becoming a melting pot that welcomes immigrants that face constant international cultural changes. Serena a Palermo has many members that are cultural mediators that make possible the access to healthcare service, according to the law in force not only for the urgent cases but also for essential level of assistance (LEA) and prevention.

On January 13th Serena a Palermo, thanks to the collaboration of many people organized a Social event at the Politeama Theater of Palermo to raise awareness on patient safety, prevention of breast cancer. In the event participated Mary Salvato, a well know musician, Prof Bonadonna, a worldwide teacher of oncology. This event had a successful result with over 1,200 people participating.

To find out more contact Paola Acquaro at paolaacquaro@hotmail.com

Patients for Patient Safety moves forward in England and Wales!

Patient involvement in patient safety activities took another step forward recently when following a two year pilot project in involving patients in safety a recruitment campaign was launched to recruit 'patient safety champions'

Initially, 22 patient 'champions' will be recruited to work with 11 NHS champions across England and Wales. The patient 'champions' will be drawn from patient activists, including people who have been affected by medical accidents, and we hope the NHS champions will be drawn from Patient Safety Action Teams and Regional Health Boards. (Regional teams that focus on patient safety).

The project is a joint initiative between the National Patient Safety Agency which is part of the NHS and Action against Medical Accidents ("AvMA" – the charity that supports people affected by medical accidents and promotes patient safety and justice). It implements recommendations in 'Safety First' which was the Department of Health's blueprint for improving patient safety, published at the end of 2006.

Rita Lewis, Chair of AvMA, whose own family has been affected by medical accidents said,

"For 25 years AvMA has championed the cause of patient safety and justice. This is an exciting opportunity for individual patients who have unique experience and perspectives to offer, to help address what is the most pressing issue facing the NHS today".

The project is proud to be part of the global Patients for Patient Safety initiative spearheaded by the World Health Organisation and hopes to contribute to the wider ambitions of the World Alliance.

European Regional Patients for Patient Safety Workshop, Dublin September 2007

Report now available to download!

Please visit our website:

www.who.int/patientsafety/patients_for_patient



Progress through Partnership and Listening

Adoración Carpintero – Patients for Patient Safety Champion, Spain

In February I went to Talavera de la Reina (Toledo, Spain) as representative of the "Allergic to Latex Spanish Association" for the beginning of the official works for the "First Latex-free Health Care Centre" in Castilla-la-Mancha region.

This news is very important for all allergic to latex patients because it means the result of a hard work and collaboration during a lot of months among our Association and the Castilla-la-Mancha Government.

In several meetings we explained the consequences for allergic to latex patients in case of attending at a Health Care Centre where latex materials are being used, because it means a big danger for our health. At the same time, we also told them that all the materials with latex (as gloves, bandages, etc) can be substituted for other alternative materials, and in that way possible adverse effects are avoided as well as the emerging of new cases is prevented.

The policy makers of Castilla-la-Mancha Government understood our problem and they decided to build the "First Latex-free Health Care Centre". It will include the structure itself, as well as all materials and furniture being totally latex free. This Centre is going to have a surface of 3151 sq. meters with a cost of 5.000.000 € and the building is going to be finished in 15 months time.

This is an example of safe health care for allergic to latex patients as well as an example of partnership among one Patient Association and a Government with good results for listening, understanding and solving the mentioned problem.

To find out more you can contact Adoración Carpintero at: Info@alergialatex.es



Stockholm Patient Safety Conference, March 7 2008

- Christina Fleetwood, Patients for Patient Safety Champion, Sweden

Issues around Patient Safety have been highly prioritised by the current majority in Stockholm County. A one-year project was started up to break ground for more permanent activities. This project ended with a most successful conference directed towards persons active within the county, policy makers, health care workers, researchers etc. The county holds 1,9 million inhabitants (20%) on approximately 2 percent of the Swedish geographical area. The Swedish capital, the City of Stockholm, is part of Stockholm county. The conference had about 600 persons attending and a total of 25 different seminars.

Our seminar was presented under the title "Patient Safety – more than statistics", emphasizing that patients are necessary co-partners in the work to achieve patient safety. It was the most popular seminar of the conference, with more than 150 persons attending. I did first a presentation of WHO World Alliance for Patient Safety / Patients for Patients Safety program and brought up some of the most important issues, using a power point presentation so that people could read and reflect as I was talking. After this I introduced two of my colleagues who had time to tell their "patient safety stories".

First was Anna Westerberg, a consultant/advisor at the Young Disabled Division of the Swedish Federation of the Disabled in Stockholm. She had had a mishap with a saucepan spilling boiling water into her lap while she was sitting anchored in her motorised wheelchair – leading to a seven week long hospital treatment for burns including two grafts surgeries. There were many "incidents" that had to do with other kinds of support than just taking care of her burns, and she had had a lot of trouble in dealing with them. Anna has cerebral palsy and is dependent on daily assistance for eating, walking, talking on the phone, paying bills etc. One of the problems was that the social services assumed that because she was in an institution/hospital, that she didn't need her special assistants. The assumption was that the nurses and hospital assistants could take over that function, which was major misjudgement on their part. So Anna, in the midst of having great pains and not access to communication had to fight to get her regular special assistants back. There was a lot of confusion around practical ways of solving problems that the personnel were not prepared for. Anna was caused a lot of unnecessary pain and her parents extra burdens, including back problems after having to carry her.

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Then Bengt Stenström shared his experience. He went through a traumatic medical incidence after having been hit by a falling construction crane at his work place in the mid-sixties. He had extensive head injuries and after being operated by neuro-surgeons he “returned to a life that I didn’t remember”. The diagnosis of Aphasia was not clear at that time so his lack of words and communication skills led to a decision to transfer him over to what was called “long-term-care”, where you didn’t get any treatment, just survival care. So – “just having survived I lost my right to live!” The prognosis was that his condition was irreversible, since “It was impossible to rehabilitate brain injured persons” - a verdict that was commonly accepted until 1994!

By a “safety error” Bengt managed to leave the hospital and went home to his family. Treated as an out-patient – keeping his patient-status - he received a lot of unnecessary medication, e.g. very strong epilepsy-medicine that was not indicated by any seizures but held the confusion going. He was falsely diagnosed as ‘Psychotic’. The insurance company were very interested in avoiding the possible diagnosis of aphasia. So, instead of investigating his cognitive problems, memory problems and the possibility of aphasia they ended up writing a medical judgement based on a false diagnosis of “psychosis”. This was done without informing the patient, which at that time could be done according to then existing law. Based on this judgement the insurance company managed to avoid having to provide Bengt his economic compensation.

He has since lived an interesting life, raised a family with four children, working on rehabilitation as an out-patient together with persons in the medical field who have been willing to try new treatments and challenges. He has been involved in starting a patient support organisation (BrainPower) for persons with brain injuries and he writes and gives speeches based on his life experiences. The message that he wants to convey is that you have to have the patient themselves involved in all the treatments and the decisions over what kind of treatment that is to be started.

Finally in the program came Lene Lindberg, psychologist and head of the administrative department of psychiatric health care in the county. Lene talked about empowerment, how it can be described and the importance it has on future health care. She gave many good examples, specially mentioning children who have gone through traumatic experiences. Empowerment is a very important but tricky concept – one of the reasons being that it defines both a state of being and a process at the same time.

During the session we also carried out a mini survey to establish perceptions and opinions from those attending. Most of these were care-givers, policy makers, health care administrators or university teachers/researchers. Based on the recent Patients for Patient Safety and First Global Patient Safety Challenge survey on Hand Hygiene we asked them as care-givers if they thought it was a good idea for them to ask patients to remind them to wash their hands and 77% agreed this was a good idea. They also felt strongly that showing by example and washing their hands in front of patients would encourage compliance, along with promoting hand hygiene in all health care facilities, not just at a tertiary level.

Also we asked them about structures of support. Only 32% felt that if they were involved in unintended harm to a patient they knew of, or had in place, appropriate support structures to help them to cope with the aftermath of the event. Finally, looking at Anna's experience we asked participants if there were mechanisms in place in their work places to bring in additional expertise and social worker support when patients need a wider scope of care to meet their daily needs while in hospital. Although 30% felt this infrastructure was in place, 25% felt it wasn't and they would not be able to bring in that additional support that some patients do require.

Participating and running the session was a lot of fun and the applause from the audience after the seminar was heart warming.

To find out more you can contact Christina at: Christina.Fleetwood@gmail.com





Eastern Mediterranean

New Partners in Egypt

- Riham Elasadly, WHO Eastern Mediterranean Regional Office, Cairo

It has been a pleasure for WHO/EMRO to welcome a group of new patient safety champions in Egypt. WHO/EMRO was recently approached by a group of Egyptian medical students who are affiliated with the International Federation of Medical Students Association (IFMSA), which has several international partners, including WHO.

The group has several on-going projects pertaining to public health, infectious diseases, patient safety, medical research and education. In a remarkable large-scale endeavour, the students are currently undertaking a project with the aim of advocating for patient safety-related issues, and potential areas of patient harm in medical school university hospitals in Egypt. They have been performing ad hoc studies to determine potentially harmful practices and avoidable areas of patient harm in Egyptian Medical Schools over the past 3 years (heavily depending on interviews with doctors). Now that they have a large body of data, they would like to prioritize areas of avoidable harm and initiate campaigns targeting medical students, junior doctors and residents, to convey such areas and possible mechanisms of promoting safety.

They will also approach patients and communities in their local hospitals for awareness raising campaigns. Our colleagues at WHO/HQ, especially Dr Agnes Leotsakos, have been unyielding in their efforts to support patient safety, supporting the provision of pertinent advocacy posters, flyers, brochures etc., advocating for patient safety, hand hygiene and other activities of the World Alliance for Patient Safety. Mrs Nagwa Metwally, Lead Patients for Patient Safety Champion in Egypt, has joined forces with the group to implement planned activities and plan for other proposed activities.

Another prominent champion in Egypt, Dr Mahmoud El-Damaty, has recently contributed at the 2nd International PS congress, Antalya, Turkey. Dr Damaty delivered a talk on the Patient Safety Friendly Hospitals in Egypt. A full report will be in the next edition of PFPS News.

Partnership to make change in Lebanon

- Mohamad-Ali Hamandi, Patients for Patient Safety Champion, Lebanon

In Lebanon, the Patients for Patient Safety Champion Mohamad-Ali Hamandi is executing a project to improve the culture of safety among Lebanese nurses. The project is a partnership between the Syndicate of Hospitals and World Health Organization.

This project is divided into three phases:

Phase 1: Data collection/needs assessment

A self administered questionnaire is addressed to nurses in all hospitals in Lebanon inquiring about patients' safety culture. The sample size is 1,000 registered nurses which constitutes 15% of the total number of nurses working in the country.

Independent variables are: region, bed size of hospital, ownership, teaching status, and work area and staff position.

Dependent will be: patient safety grade, teamwork, culture of blame, statistical analysis of errors, No. of events reported, training, presence of policies, and presence of safety officer.

The participation of hospitals is voluntary. The Syndicate of Hospitals has sent a memo to all hospitals urging their participation in the survey.

The results will be analyzed and deficiencies will be identified. As soon as the results of the survey are published, the Syndicate will have a role of disseminating the results to all stakeholders and through their webpage. In addition, they will be discussed to recommend appropriate actions.

Phase 2: Training

Hospital nurse will be trained on how to address priorities found in the analysis.

The magnitude of training depends largely on the results of the survey. The training will be conducted by a group of experts in full coordination with the Syndicate of Hospitals. It will consist of training at least one person from each hospital to become a trainer for all staff.

Phase 3: Evaluation

The impact of the training will be evaluated by another survey. Similarly, the Syndicate will be involved in disseminating the results and recommending appropriate actions.

The project duration is 6 months to end by June 30, 2008

To find out more about this piece of work you can email Mohamad-Ali Hamandi at: mhamandi@hotmail.com



The Americas

Patients for Patient Safety Canada Network: UPDATE

The Steering Group from Patients for Patient Safety Canada (PFPS) met in Edmonton, Alberta at the beginning of February for 2 days of productive meetings. The goal of this work was to define a governance charter, affirm the PFPS's goals, and begin action planning.

After an overview of the formation of PFPS and its relationships with WHO, IAPO, PAHO, CAPS and CPSI, work commenced in creating specific action plans for the four primary goals that were identified as consistent with PFPS's Vision (*"Every Patient Safe"*) and Mission (*"We Champion The Patient Voice To Advance Safe Healthcare"*).

The Steering Group worked to further prioritize and establish specific strategies and time-lines for the following:

- To realize full disclosure about all adverse events
- To incorporate the patient experience in patient safety research

- To involve patients and families in all care decisions
- To be continual learners and educators about patient safety

Productive work continued towards the creation of a draft governance charter which included a governance structure, work structure, milestones and objectives, and a vision of what success will look like.

After review by the membership of PFPS, the work of the Steering Group will be finalized and it is anticipated that positive progress towards its vision and mission will commence.

PFPS looks forward to sharing its strategies, actions and successes with other patient safety groups around the world.

If you want to find out more you can contact Erin Pollack at: epollack@cpsi-icsp.ca

LAUNCH OF THE PERUVIAN PATIENT NETWORK

- Mario Rios, Patients for Patient Safety Champion, Peru

The Peruvian National Network of Patients, Healthcare Users and Citizens for Health Service Quality, Safety, Rights and Responsibilities (The Peruvian Patient Network) was launched on March 13th. This initiative was created after several months of intense mobilization by patient organizations, human rights non-governmental organizations, and other civil society groups.

The Peruvian Patient Network is articulated into 8 local patient platforms. The local platforms are located in the regions of Junín, Tacna, Arequipa, Cuzco, La Libertad, Ica, Loreto and Uyacali. The Peruvian Patient Network integrates individual patients and patient organizations, such as the National Coalition of Cancer Patients, Mental Health Patients, and Patients Living with HIV/AIDS. The National Patient Network integrates also groups of patients with TB and persons who have suffered adverse events in the health care system, including: people infected with HIV/AIDS through blood transfusion, family members of people deceased as consequence of the yellow fever vaccine, and others.

The National Patient Network is supported by the Ombudsman of Peru, the Ombudsman at the Ministry of Health, the Peruvian Medical Association and the Pan American Health Organization. The Strategic Framework of the National Patient Network, approved previously to the launch ceremony, establishes as a main deliverable the celebration of the 1st National Patient Network Workshop.

Currently, the National Patient Network is promoting a bill on the Rights of Health Care Users, and is designing a National Campaign for Health Care Quality, Safety, and Patient Rights. The campaign is under joint design with the associations of health care professionals. This campaign is expected for approval at the 1st National Doctor – Patient Workshop to take place on April 7th.

Please refer to <http://www.forosalud.org.pe/reddepacientes/index.html> for further information.





Updates from Mexico Champions!

MONTERREY PROJECT. Diffusion and Prevention of Kernicterus

- Tomas Flores, Patients for Patient Safety Champion. Mexico



Activities for Kernicterus prevention are well underway in Monterrey –capital city of the State of Nuevo Leon, Mexico. I'm proud to announce that on February 22nd "El Norte", a major newspaper in the country, has published an article about Kernicterus. This article reports the case of my son Chris, and provides families in Northern Mexico with valuable information on this topic.

On the other hand, our group has carried a search in therapeutic clinics for kids with high bilirubin levels and diagnoses related to jaundice. During that search my wife Rosy met Argelia, the mother of Aaron, an affected 20-month-old boy affected who suffered delays in health care during severe jaundice. The delays resulted in a 45 day period of phototherapy and two blood transfusions. Both Argelia and Aaron have joined our Kernicterus dissemination campaign.

Community Centres

Once the Monterrey Community Centres (community-based institutions supporting poor neighbourhoods) learned about our activities and work with PAHO/WHO, we gained access to their installations in order to present about Kernicterus. The project focuses on informing low-resource populations, who are the most vulnerable groups to this condition due to a lack of awareness amongst parents.

The Project Comes True

On February 09, 2008, Rosy, Argelia, and myself presented at these Community Centres for the first time. The presentation started off with technical information. However, when both mothers expressed their experience, most participants felt the confidence to openly express doubts; their interest on this matter elicited naturally. Therefore, the Communitarian Project was a successful start, as it reached people who do not typically receive this type of information.

Additional Community Centres are organizing similar events in other areas with the objective of spreading the word about the risks posed by high levels of bilirubine in newborns. We hope this project will help eliminate further cases of Kernicterus, by preparing future parents with the skills to receive or request medical attention of affected babies.



Working Collaboratively!

Patients for Patient Safety Champion, Evangelina Vásquez-Curiel has been very active in Mexico. Currently, her activities concentrate on the following:

- In collaboration with CONAMED (National Health Arbitration Agency), Evangelina has elaborated a brochure for hospitalized patients.
- Also in collaboration with CONAMED, Evangelina has designed a questionnaire for the research of the emotional consequences of adverse events on patients. The questionnaire has been pre-tested with her patient/researcher colleagues Socorro Campos, Alicia Herrera, and others.
- Evangelina's group is in the last stages of an estimation of the number of kernicterus cases and other types of cerebral palsy in newborns. The cases included in this estimation are related to medical malpractice.
- In collaboration with the National Autonomous University of Mexico (UNAM) and CONAMED, Evangelina is coordinating the celebration of a cycle of lectures on possible complications during pregnancy and delivery. These lectures will take place over three days (April 14-16th) in the mountainous region of the state of Guerrero (Mexico), and are intended for young mothers from modest and indigenous backgrounds. In a next step, these lectures will be delivered at nursing schools.



World Alliance for Patient Safety – RESEARCH PROGRAMME

Interview with Nittita Prasopa Plaizier *Small Research Grants Manager, World Alliance for Patient Safety*



What do you feel are some of the key issues and challenges in patient safety research globally?

Patient safety research is still underdeveloped. Very little targeted research has been conducted in this field. This is largely due to the lack of awareness of patient safety issues. As the problems are under-recognized and poorly-understood, they do not yet gain full attention from either researchers or policy-makers as public health priorities.

Other important issues in patient safety research are resources and research expertise. This is especially true in developing countries and countries with economies in transition, where research evidence is most needed.

The Research for Patient Safety has worked collaboratively with experts and key take-holders to implement several projects and programmes to address these issues.

The Small Grants for Patient Safety Research project is a new initiative that aims to stimulate research activities in patient safety by providing seed funding for small research projects. The grants will encourage research projects in developing countries and countries with economies in transition, and will have a particular focus on young researchers. This may help contribute to the building and strengthening of research capacity among local researchers.

We are aiming to fund between 20 and 30 projects in the first round of funding and will start accepting proposals between July and September this year. All the details of the grants are available on our website: www.who.int/patientsafety/research/grants/en.

How do you think patient engagement in the research field can/is adding value?

Patient safety research is about finding solutions to make health care safer for patients. Thus, patient involvement is crucial in identifying which solutions are effective, practical, appropriate and acceptable.

We believe that patient involvement will be very valuable in promoting the Small Grants for Patient Safety Research initiative. Many of you who are qualified researchers may consider teaming up with other colleagues or with clinicians in submitting a research proposal for funding.

You can also help spread the word about the grants by sharing the information with relevant researchers, government officials or research institutions in your countries. In doing so, please ensure that your colleagues are aware that grants are awarded on a competitive basis. Proposals will be reviewed by a panel of experts and the success of the proposals will depend on the merits of the applications.

What role do you think patients can play in moving forward the research agenda and become more involved in Patient Safety research?

You can help raise awareness of the issues and correct some misunderstanding about patient safety problems. This will help people to understand that adverse events are often caused by organizational or system factors rather than individuals' errors. Your involvement may also help support a positive safety culture that will promote greater communication and enable the learning from patients' experience.

In addition, you can also play an important role in advocating for more effective use of research evidence. You can do this by sharing the information with relevant researchers, policy-makers or practitioners and encourage them to apply the evidence into policy and practice.

You may also participate in research projects either as study participants or, for some, as co-investigators. If you do not wish to take a direct role, you may take part in committees or advisory bodies that oversee the design, development and the conduct of research projects. Your role will help ensure that research studies take into account patients views and values and that the research processes respect and empower patients

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How do we align researchers' research agenda with the research agenda generated by patients and their needs?

The most important thing is to keep communicating. Achieving a common research agenda will require understanding from both parties, each understanding the other's limitations and vice versa. The good thing is, many researchers want to engage patients. They just do not know how best to do this. Patients can find ways to help the researchers to understand this. It may not be straight forward, but communication is the beginning.

Is there any other information that you would like to share?

We hope that the Small Grants for Patient Safety may present an opportunity for patients and researchers to collaborate and discuss their agenda.

The Research for Patient Safety has worked collaboratively with several patient champions. We appreciate your inputs and look forward to more opportunities for collaboration. We would encourage you to visit our website regularly to gain up-to-date information on the small grants.

To find out more about the Research programme you can visit the website at: www.who.int/patientsafety/research/

Coming up in the next edition! – June 08

2nd International Patient Safety Congress, 25-29 March 2008, Antalya Turkey

Just last week several of the Patients for Patient Safety team along with many Patients for Patient Safety Champions from across the world participated at the 2nd International Patient Safety Congress in Turkey.

There has been great feedback from this event and it was a huge success for the organizers which included our two Patients for Patient Safety Champions based there. There were great contributions, presentations and workshops led by Patients for Patient Safety Champions.

The next edition of PFPS News in June will have a major feature on the event and its outcomes, including pieces from PFPS champions who attended sharing their learning, perspective and experiences.

Don't forget if you have any news you want to share or events you want to alert others to, please send them through to safetyadmin@patientsorganizations.org for forthcoming editions.

The next edition will come out at the start of June. Deadline for contributions is 26 May 2008!