



**Volume 9, Number 2, Special Issue: INCTR Palliative Care PAX Program — Inside:**  
 REPORTS: INCTR's PAX Program: a 10-year Journey of Collaboration - **5** - The Nurse's Role in Palliative Care: Meeting an Educational Need - **6** - PAX Psychosocial Care: Updates on Social Work Education and Clinical Practice - **7** - MNJ Palliative Care Program Makes Enormous Strides - **10** - Palliative Care Program at MNJ: Reflections from a Visiting Canadian physician - **12** - BPKMCH Bharatpur, Nepal/Victoria Hospice, Canada Twinning Project - **13** - Bhaktapur Twinning Project Builds on the Work of INCTR - **14** - Palliative Care Program at Santa Marcelina Hospital System - **15** - Building Capacity for Palliative Care Services in Tanzania - **16** - PAX Collaboration with BCCA - **17** - CASE REPORTS: A Case Study from Brazil - **18** - A Selection of Case Studies from India - **20** - REPORT: INCTR Palliative Care Handbook - **22** - NEWS - **23** - PARTNER PROFILE: B.P. Koirala Memorial Cancer Hospital, Bharatpur, Nepal - **24** - PROFILE IN CANCER MEDICINE: Palat Directs INCTR Palliative Care India Program - **26**

## GUEST MESSAGE

### PAIN RELIEF: A HUMAN RIGHT

by Diederik Lohman

In September 2008 a classified ad appeared in a newspaper in Colombia. It read: "Cancer is killing us. Pain is killing me because for several days I have been unable to find injectable morphine in any place. Please Mr. Secretary of Health, do not make us suffer any more..."

The ad was placed on behalf of Sabina (not her real name), a 36-year-old woman with advanced uterine cancer. As is common with advanced cancer, Sabina was suffering from a lot of pain. She had a constant throbbing in her spine, extremities, head and, especially, stomach. The pain had made her completely bedridden, prevented her from ever sleeping more than twenty minutes at a time, and, maybe most significantly, made meaningful interaction impossible with her 13-year-old and soon-to-be orphaned daughter. In an interview with Human Rights Watch, Sabina's mother told us that towards the end of her life Sabina could not even touch her daughter because of the pain.



**A 55-year-old woman holds her husband, a 67-year-old lung cancer patient. He receives palliative care and pain treatment from an NGO in South Kerala, India. © 2009 Brent Foster. Photo courtesy of Human Rights Watch.**

Sabina's doctor had prescribed morphine, a strong analgesic that can relieve most cancer pain. But Sabina couldn't get it. Pharmacists told her mother that they had run out and said she might be able to get morphine in Bogota. But how could her mother make a 480-kilometer trip to Bogota when her dying daughter needed her at home? Driven to desperation by her

daughter's suffering, Sabina's mother repeatedly wrote to the local health department asking for help and, when nothing changed, placed the newspaper ad.

The newspaper ad was noticed. Officials in Bogota, Colombia's capital, promised to look into the situation and make sure Sabina got her morphine. Unfortunately, these efforts came too

# NETWORK

late. After months of suffering, it was death—not morphine—that finally relieved Sabina of her pain.

Sabina's story could have happened in almost any developing country. Morphine and other strong pain medications are virtually unavailable in more than 150 countries around the world. The World Health Organization (WHO) estimates that tens of millions of people worldwide suffer from moderate to severe pain without access to treatment every year, including 5.5 million people with terminal cancer.

What makes Sabina's story particularly devastating is that her suffering was entirely preventable. If she had had access to inexpensive morphine, she should not have spent her last two months wracked in agony. She would have been able to spend time with her mother and daughter instead of isolated in a world of pain and suffering.



A community health worker checks on a child during a home visit in Mathare, Nairobi, Kenya © 2010 Brent Foster.

## UNDERSTANDING THE PALLIATIVE CARE AND PAIN TREATMENT GAP

Morphine is an inexpensive, safe and highly effective medication that is generally not hard to administer. According to the WHO, "most, if not all, pain due to cancer *could* be relieved if we implemented *existing* medical knowledge and treatments." Pain relief as a part of palliative care is an effective and relatively low-cost health service aimed at improving patients' quality of life. The need for palliative care and pain management in developing countries is enormous because most patients present with advanced cancer and can benefit only from such services. So how can it be that 5.5 million cancer patients, like Sabina, die in unnecessary, excruciating pain every year?

Human Rights Watch research has found that one of the key reasons is the failure of many governments around the world to take even basic, low-cost steps in the three areas that WHO has said are essential to palliative care development:

- Education of healthcare workers about palliative care and pain management;
- Ensuring availability of morphine and other strong pain medications;
- Developing government policies related to palliative care and pain management.

## EDUCATION OF HEALTHCARE WORKERS

Surprisingly, a wealth of literature suggests that doctors—although bound by their Hippocratic Oath to relieve suffering in patients—are the biggest obstacle to improving palliative care in many countries. The problem is that most doctors never receive even basic training on the management of chronic pain. Moreover, the emphasis in pharmacology classes is that morphine can be addictive or lead to respiratory failure. Imagine how doctors would feel about chemotherapy if, as medical students, they learned that chemotherapy can cause serious damage to healthy bone marrow cells, cause vomiting, diarrhea and a whole host of other side effects but not that

# INCTR

## EDITORIAL STAFF

Ian Magrath, Editor  
Marcia Landskroener, Managing Editor  
Alison Brown, Guest Editor  
Bénédicte Chaidron, Assistant Editor  
Sophie Lebedoff, Lay-out

## ADDRESS CORRESPONDENCE TO:

INCTR aisbl  
Rue Engeland 642  
1180 Brussels • Belgium  
+32 2 373 93 23 • bene@inctr.be  
www.inctr.org

Volume 9, Number 2,  
December 2009-2010

Views, comments and statements are not necessarily shared or endorsed by INCTR. All patients' photographs are published with their consent.

these side effects are acceptable since chemotherapy can also be very effective in treating cancer?

The absence of pain management from medical curricula is particularly startling given that WHO introduced its Cancer Pain Relief Ladder almost 25 years ago. The ladder (see figure 1) is a simple tool that recommends the use of increasingly potent pain killers as pain becomes more severe, starting with over-the-counter non-steroid anti-inflammatory drugs like ibuprofen and ending with strong opioids like morphine.

In India, Human Rights Watch interviewed many doctors who told us they had never received any training in pain management. One doctor, for example, said: "I was never taught how to treat pain. I know how to treat a fever, but not pain." Recently we came across the case of a medical doctor in India who was in severe pain, dying of cancer, but who refused to take morphine because of her fear of addiction. In fact, research shows that drug dependence is extremely rare in patients who receive opioid medications.

## DRUG AVAILABILITY

A second major problem is the poor availability of opioid medications. While the health systems generally can be weak, the lack of availability of pain medicines is often due to the fact that these medications are controlled substances and are closely regulated under international and national law. Our research identified three common types of obstacles.

First, because of the need to prevent their misuse, there is no free market in controlled medications. Governments have to estimate how much of the medications they will need and supply this to the UN before any controlled medications can be brought into the

country. While this does not have to be an obstacle to drug availability, many countries submit estimates that are so low that almost no patients can be treated for pain. For example, in 2008, Burkina Faso, a country in West Africa, informed the UN that it would need 153 grams of morphine in 2009, an amount that would suffice to adequately treat about eight terminal cancer patients for severe pain. Yet, an estimated 23,000 people died of cancer in the country in 2009. There are many other countries that, like Burkina Faso, request extremely low quotas of morphine and thus condemn patients to suffering. The reasons for these low estimates are probably a combination of weak health systems, a lack of official attention to the issues of pain and palliative care, and exaggerated fears of addiction or misuse.

A second obstacle emerges once morphine is in the country: healthcare institutions must have a license to handle the drug. Unfortunately, many countries have adopted regulations that are so restrictive they make it hard for healthcare institutions to obtain the drug. For example, in India, healthcare institutions in many states have to obtain five different licenses from two differ-

ent government agencies to purchase morphine. The licenses all have to be valid at the same time, no small task as each has its own application procedure and often a short time period before they expire. As a result, most simply do not stock morphine. In China, only larger hospitals can stock opioid medications, meaning that many people who live far from these hospitals cannot obtain them. In Sabina's case, the health department in her region had failed to ensure a supply of morphine, making it unavailable. This problem was addressed after Sabina's mother placed the newspaper ad.

Finally, in sometimes overzealous efforts to prevent misuse of opioid medications, drug regulations in many countries severely restrict prescription practices. Some regulations only allow certain types of doctors, usually oncologists or anesthesiologists, to prescribe opioid medications. Other countries require prescriptions to be signed by multiple doctors or approved by the ministry of health. Yet other countries require that prescriptions are written on special prescription pads that doctors have to purchase at their own expense. Lastly, many countries strictly limit the amount of opioid medica-

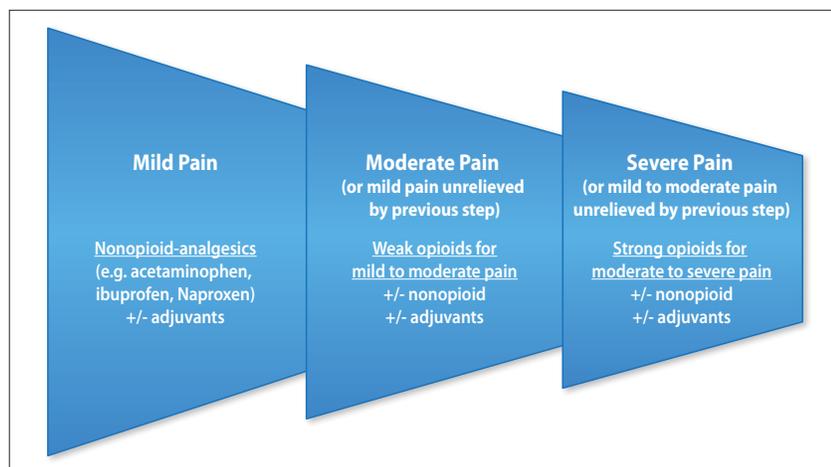


Figure 1. A pain relief escalation system adapted from "WHO's ladder".

# NETWORK



A nurse with ORCI's palliative care team makes a home visit.

tions that can be prescribed, meaning that gravely ill patients in chronic pain have to regularly visit their doctors to obtain new prescriptions.

## GOVERNMENT POLICIES

The third reason for the lack of availability of pain medicines is the absence of government policies to promote palliative care. The WHO recommends that countries develop national palliative care policies and integrate palliative care into national cancer and AIDS control programs. Unfortunately, national palliative care policies do not exist in most countries and often even national cancer control programs do not include a meaningful palliative care component. Given that the vast majority of cancer patients in developing countries have advanced cancer at diagnosis, this means that the cancer care system simply abandons large numbers of patients.

Government leadership is particularly important because palliative care policy development requires coordinated efforts to address both drug availability and educational barriers in parallel.

The experiences of countries like Uganda, Vietnam and Colombia—although there are still stories like Sabina's, the Colombian government has made important progress in improving palliative care—show that where governments develop and implement robust plans of action to address barriers, real improvements follow.

## HUMAN RIGHTS AND PAIN TREATMENT

The failure of governments to take steps to ensure access to pain medicines is a violation of their obligation to fulfill the right to health. It can also be a violation of the prohibition of torture and cruel, inhumane and degrading treatment. This is particularly true when governments know that patients are experiencing severe suffering, have the means to relieve that suffering, but willfully fail to take the necessary steps to do so.

Human Rights Watch documented an example of this in India. Our research there found that more than half of the country's government-supported regional cancer centers do not offer pain

management or palliative care, despite the fact that more than 70 percent of their patients have advanced cancer and need pain treatment. The government has failed to take reasonable steps to make sure that these patients get access to pain treatment. It could make the availability of palliative care a condition for receiving the designation of a regional cancer center, earmark government funding for palliative care, or

**The weak opioid analgesic codeine has traditionally been recommended for use in managing mild to moderate cancer pain. Recent research, however, suggests that it may not be an effective or safe pain medication in certain groups of patients. D.G. Williams, A. Patel and R.F. Howard, "Pharmacogenetics of codeine metabolism in an urban population of children and its implications for analgesic reliability," *British Journal of Anaesthesia*, vol. 89, no. 6 (2002), pp. 839-45; Catherine Ciszkowski, "Codeine, Ultrarapid-Metabolism Genotype and Postoperative Death," *New England Journal of Medicine*, vol. 8, no. 36 (2009).**

initiate palliative care training for doctors at these cancer hospitals, but it has chosen not to. The result is that many thousands of patients are abandoned to excruciating pain even though the government had clear means to prevent their suffering.

Human Rights Watch interviewed dozens of cancer patients who had experienced severe pain but did not have access to treatment. Many of them expressed a sentiment we usually hear from victims of torture: all they wanted was for the pain to stop. With government commitment, in many cases it can. ■

References available on [www.inctr.org](http://www.inctr.org)

## INCTR'S PAX PROGRAM: A 10-YEAR JOURNEY OF COLLABORATION

In the opening article Diederik Lohman describes the suffering caused by the paucity of palliative care and pain-relieving medicines in developing countries. The PAX program's vision is to remedy this where we can. The journey has been characterized by international partnerships combined with hard work and sacrifice by colleagues from many countries. Our success is due to them.

It all began over 10 years ago at INCTR's first Annual Meeting in Antwerp when we decided to press forward with a palliative care initiative. The first step along the road, working with the Nepal Network for Cancer Treatment and Research (NNCTR), was to develop a collaborative project to introduce palliative care at two hospitals in the Kathmandu area. We soon learned that training by itself was not enough to make a major difference and that what was needed was action over a broad front.

So with our Nepali friends we developed a program that combines educational and technical assistance together with engagement with government officials to effect changes in health policy and ensure adequate supplies of essential medicines. Most importantly, however, the model program includes the establishment of palliative care centers that become the focus for delivering actual patient care. Encouragingly, over the years, and as originally planned, the centers have themselves become providers of training courses and activities that raise awareness of palliative care throughout the community.

In spite of many challenges the program in Nepal continues to grow with

the help of our INCTR PAX "partners" Mid Island Hospice and Victoria Hospice Society, which provide both financial and practical support (see articles by Drs. Black and Love). Morphine is now being produced in Nepal, and access to both oral and parenteral preparations has improved. In addition, the Nepalese Association of Palliative Care (NAPCare), an organization of professionals and lay people, is currently

(MNJ). MNJ is now recognized as the center of excellence for palliative care in Andhra Pradesh and one of the leading programs in India. We have many plans for developing the Indian component of PAX, including working with a hospice in Pune to develop a new regional center there, and establishing a pediatric palliative care fellowship program in association with the IPM International Program (at San Diego Hospice).



**INCTR's Pax team; from left to right, Stuart Brown, Director, Gayatri Palat, Director India, Virginia LeBaron, nurse consultant, Fraser Black, Associate Director, Doug Ennals, psychosocial consultant.**

working with the government to have palliative care included in the national health system which provides financial assistance for very poor people. The lessons learned in Nepal have helped us move forward.

The next stage of our journey was the creation in 2006 of a very successful program in Hyderabad, Andhra Pradesh, India. In the following article Dr. Gayatri Palat, Director of INCTR PAX India, describes in more detail the great strides made in establishing the regional palliative care center based at the Mehdi Nawaz Jung Institute of Oncology and Regional Cancer Center

The INCTR PAX team is also working in São Paulo to help set up the first Brazilian collaborating center. In brief, this project is based at the Santa Marcelina Hospital System, which is responsible for the care of around seven million people in the eastern district of São Paulo. After PAX's visit, a palliative care program, including six designated beds, was rapidly established along with a pediatric palliative care program and an outpatient service. Other projects are in the pipeline, including a large community project (see article on the Brazilian project). On a bigger scale, we are planning

# NETWORK

to work with the Brazilian National Cancer Institute to expand population access to palliative care across Brazil. The new Canadian branch of INCTR is taking a special interest in this.

In Tanzania, PAX personnel have worked with the palliative care team at Ocean Road Cancer Institute, Dar es Salaam, for some time. The service there was developed by Drs. Twalib Ngoma and Diwani Msemu, Hospital Director and Director of the Palliative Care Program respectively (please see Dr. Msemu's report of their recent activities). Our work in Tanzania is part of a relationship with the International Atomic Energy Agency's Program of Action for Cancer Therapy (IAEA/PACT). PAX has also provided consultative services for IAEA/PACT in Yemen, Nicaragua and Sri Lanka.

Since starting on the journey 10 years ago, PAX has both organized and participated in many workshops and symposia. These provide us with opportunities for increasing awareness of palliative care and providing education. But more importantly, they are often the first point of contact with others working in developing countries with whom we go on to form very productive partnerships.

PAX also undertakes international faculty visits to INCTR collaborating institutions, during which we exchange ideas and experiences in areas such as clinical and psychosocial care, education and administration. Out of these visits new ventures frequently arise, such as the twinning partnerships in Nepal.

In more general terms, the PAX team has published the INCTR Palliative Care Handbook (see article by Dr. Black) and is working to introduce a Web-based symptom assessment system, a nursing curriculum and a psychosocial support program, all of which will be made available for any institution

starting palliative care.

Overall, thanks to the hard work of the volunteers that make up the PAX team, colleagues in many countries and the support of INCTR, significant headway has been made since our first tentative steps in Nepal. We feel that what we have learned along the way can be adapted to the needs of diverse settings and help tens of thousands of people. ■

*Stuart Brown*

*INCTR PAX Program*

*Abbotsford Regional Hospital & Cancer Center*

*Abbotsford, Canada*

## THE NURSE'S ROLE IN PALLIATIVE CARE: MEETING AN EDUCATIONAL NEED

As the readers of this magazine are well aware, the global cancer burden is increasing dramatically, and expected to continue for the foreseeable future. This burden will be disproportionately shouldered by developing countries, where patients typically present with late-stage cancer and limited viable treatment options. Patients with advanced cancer around the world require competent palliative care to manage their pain and suffering, and nurses are most often the front-line providers of this care. Palliative care is a philosophy and approach to care that involves comprehensive attention—physical, social, emotional and spiritual—to patients and families coping with the multiple stressors of advanced disease. The guiding principles of palliative care are highly congruent with the mission and vision of the nursing profession, which is to relieve suffering and care for patients holistically.

Although mandates issued by the World Health Organization and the International Council of Nurses call for increased healthcare provider knowledge of palliative care, current education of physicians and nurses rarely adequately prepares clinicians to meet this need. Barriers to palliative care education are many, and can include full and inflexible curricula, lack of qualified faculty, failure to view palliative care as a healthcare priority, and the inherent difficulties in teaching the subtleties and complexities that characterize end-of-life care. This is particularly unfortunate for nurses, who are in a unique and powerful position to influence the quality of palliative care delivered at the bedside.

An additional barrier to palliative care education in resource-limited settings is that preexisting curricula are often Western-oriented and presume access to certain therapies and technologies that may not be available. In an effort to address this educational gap, the INCTR Palliative Access (PAX) Program, in collaboration with the British Columbia Cancer Agency (BCCA), is developing a novel nursing palliative care educational framework. The goal of this project is to create a generalist guide to a palliative approach in nursing that is flexible, sustainable, context-specific, transportable to INCTR target countries and other severely resource-limited sites, and appropriate for nursing instruction at a grass-roots level.

At the outset, this nursing workgroup investigated and researched existing nursing palliative care curricula with the goal to avoid unnecessary, and unproductive, duplication of effort. Dialogue with leaders of the International Association for Hospice and Palliative Care (IAHPC), the European Association of Palliative Care (EAPC), and the End of Life Nursing

## REPORTS



**Working group discusses formation of INCTR nursing program at INCTR 10th Anniversary meeting.**

Educational Consortium (ELNEC) confirmed that the INCTR project would help fill a gap in international nursing palliative care education, and was met with enthusiastic support.

Currently, the development of the INCTR Nursing Palliative Care Curriculum is underway. A key feature of the project is a high sensitivity to context, with particular mindfulness regarding available resources, the political landscape (both within the country itself and the specific organization) and the context of the nursing role. Another unique feature is that this curriculum will incorporate content related to building capacity for nurse leadership and advocacy, with a strong emphasis on context-relevant case-based learning. Additionally, relevant content of this palliative care curriculum will articulate with an INCTR oncology nurse educational project that is concurrently in development. Ultimately, it is hoped that this curriculum will help give a stronger voice to nurses, whose role is sometimes overshadowed by that of physicians or more vocal members of the interdisciplinary team.

The crucial role of the nurse in the delivery of palliative care cannot be underestimated, and it is helpful to remember that the founder of the modern palliative care movement, Dame Cicely Saunders, was first trained as a nurse. Nurses, when compared to other disciplines, spend by far the largest amount of time at the bedside delivering direct patient care. This intimate and sustained relationship with the patient and family places the nurse in an extremely vital position as patient advocate and physician liaison. Unfortunately, not all settings and healthcare cultures foster and support this collaborative role of the nurse, which in turn can compromise the delivery of effective palliative care. An overarching goal of the INCTR palliative care nursing curriculum project is to build internal capacity for nursing knowledge and skills, and empower nurses to effectively provide quality palliative care to those most in need. ■

*Virginia LeBaron  
INCTR PAX Program  
University of Arizona College of Nursing  
Tucson, USA*

### **PAX PSYCHOSOCIAL CARE: UPDATES ON SOCIAL WORK EDUCATION AND CLINICAL PRACTICE**

Psychosocial care is an essential component of palliative care. It attends to the diverse psychological, spiritual, social, emotional and practical needs and wishes of people - both children and adults - within the context of their communities. From diagnosis to advanced disease, at the end of life and into bereavement, psychosocial support systems including social workers, counselors, psychologists, spiritual care providers and volunteers play a vital role within healthcare teams.

An essential component of psychosocial care is about relationships. This involves understanding the web of relationships among and between healthcare teams, patients, family/caregivers, medical systems, and the social and cultural context in which these interactions occur. Integrated into this web are the lived experiences of people. Psychosocial care also attends to the relationships between the psychosocial and physical aspects of pain, suffering and quality of life. Thus, psychosocial care invites curiosity. Who is this person before me? What is his story? What is important to him? What gives meaning to his life? What are his goals, hopes, fears, needs?

Psychosocial care can be viewed as both a distinct clinical practice and a philosophy of care. Often identified as a unique discipline, psychosocial care is not separate from physical care. When individuals are seen and heard within the perspective of their lives, they will ultimately be cared for differently.

Resources for psychosocial care services within palliative care systems around the world vary. Economic conditions, medical systems, and social

# NETWORK



**Doug Ennals poses with MNJ social worker Bhuvneshwari, social work practicum students and a pediatric patient.**

and cultural practices influence both the specifics of the care required and the capacity for the delivery of care in various communities. INCTR PAX continues to work in collaboration with regional partners and programs to meet these diverse needs. Here are some of the highlights of our most recent regional visits and initiatives.

## **TRIVANDRUM, INDIA**

The INCTR/PAX visit to India in September 2009 began with a visit to the team at Trivandrum Institute for Palliative Sciences (TIPS), including Dr. Rajagopal, Ms. Aneja (social worker), Dr. Bijou and the TIPS home care team. Dr. Rajagopal, Ms. Aneja and I reviewed ongoing plans and curriculum development needs for a TIPS certificate course in psychosocial care. This pilot course is intended to provide skills in palliative and psychosocial care to community healthcare workers and community leaders in rural regions that are currently served by the TIPS home-care program. The goal is three-fold: build capacity for thorough assessment and supportive care skills of care workers, enhance con-

tinuity of care between TIPS and outlying communities, and increase community education and awareness of palliative care.

This visit also highlighted some key issues expressed by psychosocial care providers in India and other INCTR PAX-affiliated regions. These include the complex role of social work, challenges in supporting the socio-economic needs of patients and families, ensuring conti-

nuity of care and patient adherence, the need for professional development, and ongoing collaboration and networking with other social workers and psychosocial care providers.

## **HYDERABAD, INDIA**

The advancement of psychosocial care services for children and adults living with cancer, HIV and other diseases and chronic health conditions is growing in many regions of India. Healthcare teams and organizations are developing and implementing innovative programs, services and educational opportunities to address the diverse palliative care needs of communities in sustainable ways.

A partnership between the Department of Palliative Care, Mehdi Nawaz Jung (MNJ) Cancer Hospital and Research Centre, Hyderabad and Roda Mistry College of Social Work and Research Centre (RMC), Hyderabad was established in 2007. This program, under the vision and leadership of Dr. Gayatri Palat and Dr. Durga Prasad of MNJ, and Dr. Anna Mathew, Director of RMC, is a model for future collaborations between educational institu-

tions and healthcare facilities in other regions of India.

To date, over 20 social work students, both at the Bachelor's and Master's levels, have completed field work training at MNJ. Students rotate and gain skills and experience in the Pain and Symptom Management Clinic, female and male inpatient wards, and pediatric unit. Students also co-facilitate patient and family support groups, a pediatric arts group and participate in palliative care awareness programs in the community. As a component of the field work placement, students are also required to complete a research project related to their clinical work at MNJ. These endeavors serve as an opportunity to integrate theory and practice, and also contribute to ongoing capacity building of psychosocial services at MNJ.

During an INCTR PAX visit to India in September 2009, Dr. Gayatri Palat and I delivered a two-day workshop at RMC. The first day was an introduction to palliative care and psychosocial care and the role of social work on palliative care teams. The second day we covered areas of communication, assessment, distress and anxiety, clinical interventions, ethical considerations, pediatric populations and self-care. Twenty BSW (Bachelor of Social Work) and MSW (Master's of Social Work) students, faculty, and five practicing medical social workers from the Hyderabad region were in attendance.

Another INCTR PAX, MNJ, RMC joint project currently underway is the development of a field work handbook specific to the needs of future social work students on practicum at MNJ. This handbook will serve as a tool for students new to the field of oncology, palliative care and psychosocial care and will provide foundational resources to assist their learning experience at MNJ.

## REPORTS

Dr. Anna Mathew of RMC has been a strong advocate in developing awareness, skills and knowledge of palliative care in social work education. Over the next year, RMC will be integrating an introductory module on these concepts within mandatory health courses for both BSW and MSW students. RMC attracts students from throughout India and abroad; several individuals from the most recent field work placement at MNJ were from Somalia and Ethiopia. The skills and knowledge they gain from their experiences at MNJ are of great benefit to the people and communities with whom they work.

Discussions were also held with colleagues in both Trivandrum and Hyderabad regarding the development of a Palliative Care Social Workers' Network to facilitate collaboration, professional development, organizational development and research capacities of psychosocial care providers throughout India. Networking has been an ongoing expressed need for some time. INCTR PAX is hopeful these preliminary connections will continue to expand to other regions in response

to the growing need for psychosocial care services.

Thank you to Ms. Bhuvneshwari, Ms. Evangeline, Ms. Aneesa and health-care teams at MNJ, Hyderabad and Trivandrum Institute for Palliative Sciences for your continued commitment and dedication to patients and family/caregivers and the advancement of psychosocial services. You are very much appreciated.

### SÃO PAULO, BRAZIL

The INCTR PAX team has been collaborating with Santa Marcelina Hospital (SMH) and the INCTR Brazil branch for several years on program development and educational initiatives. The advancement of psychosocial care has been a key component of this work and figured prominently during a team visit in October 2009.

INCTR PAX participated in two educational programs for primary healthcare teams working with Santa Marcelina Hospital and palliative care practitioners from São Paulo and region. Participants included physicians, nurses, social workers, volunteers, admin-

istrators, psychologists and spiritual care providers. Topics ranging from psychosocial clinical interventions, grief and loss, spirituality, role of social work and self-care figured prominently in both programs.

One of the many highlights of this trip involved visiting several of the Primary Health Care (PHC) clinics that have been established by Santa Marcelina Hospital (SMH). SMH is located within a district of São Paulo that supports the healthcare needs of over two million people. SMH Primary Health Care clinics provide a comprehensive arrangement of invaluable services to some of the region's most impoverished communities. SMH has developed an innovative program with the utilization of Community Health Agents who operate from these regional clinics. One of the primary roles of these agents is to interact directly with patients and families, most often in their home, to provide assessment and screening for health-related issues. INCTR PAX met with a team of agents to discuss their experiences, skills and confidence in communicating with people facing life-limiting illnesses and conditions. Agents said that finding language to talk about death, dying and bereavement with patients and families was challenging and that training courses directed towards developing communication and counseling skills in these areas would be valuable.

SMH has taken a leadership role in building psychosocial capacity within its hospital and community-based health care teams. INCTR PAX looks forward to its continued involvement in these endeavors. ■

*Doug Ennals  
INCTR PAX Program  
Vancouver Island Health Authority 21  
Victoria, Canada*



**PAX members Doug Ennals and Ruth Ting with Santa Marcelina's Primary Health Care Clinic team.**

# NETWORK

## MNJ PALLIATIVE CARE PROGRAM MAKES ENORMOUS STRIDES

Flashback. Year 2003. The bustling city of Hyderabad with its minarets and lake-rimmed skyline. 10,000 patients suffering from cancer, with fewer than 200 accessing palliative care. Flash forward. Year 2010. The same city, with one marked difference—accessible



**MNJ has taken palliative care to the community—here, an outreach program in a village near Hyderabad.**

palliative healthcare. The difference was made possible with the creation of the Palliative Care Department at the Mehdi Nawaz Jung Institute of Oncology and Regional Cancer Center (MNJ). If actions do not speak for themselves, the statistics definitely will. More than 10,000 patients have been treated over the last four years. It has been a steadily upward moving graph.

Today the MNJ Palliative Care Department has gained acceptance as the regional palliative care center for treatment and training by both the government and the public.

The department has a staff of three doctors, four nurses and three social workers. The range of services being offered includes outpatient and inpatient consultations and home-based

care of sick patients in the twin cities of Hyderabad and Secundrabad, the latter in partnership with Dr. Reddy's Health Foundation. The last two years also saw the development of a unique pediatric palliative care program. In addition to their clinical work the department is very actively involved in training, education and advocacy both at the regional and national levels. It has evolved to become an important center for practical training in palliative care for nurses, oncologists, residents and social work students from the Roda Mistry College Social Workers.

There were many programmatic milestones in the last two years.

### REGIONAL

- 2255 and 2236 new patient consultations, and 5639 and 5096 follow-up consultations, in 2008 and 2009, respectively
- 229 and 369 new pediatric patient consultations in 2008 and 2009 (as well as 1500 follow-up consultations)
- 5.2 kgs of morphine consumed in 2008 and 4.02 kgs in 2009
- 6 doctors, 20 nurses, 8 social workers and 5 volunteers trained in one-month certificate courses
- 45 doctors and 4 nurses participated in the Essentials of Palliative Care Course

### PALLIATIVE CARE FOR CHILDREN WITH CANCER

Through the concerted effort and support of the medical oncologist and the department team we have started a unique pain relief and palliative care program for children. Almost every child with cancer in the hospital is enrolled in the program from day one. In 2009 we cared for 1532 children, of whom 365 were new patients. 66 gms of morphine were consumed during the last six months.



**Nurse assistants at MNJ undergo training in palliative care.**



**Support group meetings help families and patients cope with childhood cancer.**

The palliative care team offers pain relief to children during interventions for diagnosis and treatment, regular support-group meetings for families and children, active supportive and end-of-life care, and psychosocial and bereavement care. Two social workers, funded by NATCO Pharma Trust, work exclusively with the children. The early intervention has helped in improving compliance and reducing the treatment drop-out rate. There is now a smoother transition to end-of-life care and improvement in the overall quality of care for children and their families.

### SUCCESSFUL INTERACTIONS WITH THE GOVERNMENT OF ANDHRA PRADESH

Andhra Pradesh became the 14th state in India to amend and simplify its narcotic regulations. This was the result of about 10 years of continued effort by the palliative care team at MNJ and Pallium India. The amendment simplifies the procurement process and

ensures that all palliative care centers in Andhra Pradesh can obtain the morphine they need without becoming entangled in the complicated licensing process. The Drugs Controller is now the only agency involved in the process.

Palliative care for cancer patients has also been made more accessible by its inclusion in the state-sponsored health insurance scheme for people living below the poverty line. The NTR University for Health Sciences, Hyderabad, will start a post-doctoral fellowship program in palliative medicine at MNJ in the coming academic year. Preliminary discussions have taken place with the Andhra Pradesh State AIDS Control (APSAC) Program to have palliative care training and services included in their program to help people living with HIV and AIDS.

## **PARTNERSHIPS WITH NON-GOVERNMENTAL ORGANIZATIONS**

The department is exploring how it can extend services to people with other life-limiting illnesses by partnering with organizations like Alzheimer's and Related Disorders of India, ImPACT (a NGO for children with cancer in Hyderabad), M Venkatarangaiya (MV) Foundation and the Catholic Health Association of India. One example of this is the community-based palliative care program for the chronically ill that we are providing in partnership with the MV Foundation.

Limited health infrastructure severely restricts access to healthcare, particularly when it comes to chronic illness. In keeping with its commitment to the concept of "total care," MNJ began a community-based program in two villages on the outskirts of Hyderabad. Since the MV Foundation already has an established network of volunteers in these villages, we identified a few

<b>Total number of patients seen in department of palliative care from 2006 to 2009</b>				
YEAR	NEW CASES	REVIEW CASES	CHILDREN	TOTAL
2006	-	-	-	1851
2007	2160	5669	130	6021
2008	2255	5639	223	8117
2009	2236	5096	1532	8864

<b>Total morphine consumption in department from 2006 to 2009</b>	
YEAR	MORPHINE CONSUMED
2006	-
2007	Kg 4.532 grms
2008	Kg 5.216 grms
2009	Kg 3.957 grms

<b>Partner institutions with other institutions</b>
<ol style="list-style-type: none"> <li>1. Mamidipudi Venkatarangaya Foundation (M.V. Foundation)</li> <li>2. Catholic Health Association of India (CHAI)</li> <li>3. Dr. Reddy's Foundation (DRL, LAYDS)</li> <li>4. Alzheimer's and Related Disorders Society of India (ARDSI)</li> <li>5. Roda Mystry College of Social Work (RMCSW)</li> <li>6. International Collaboration with INCTR and BCCA</li> </ol>

<b>Members trained in Certificate Course</b>				
YEAR	DOCTORS	NURSES	VOLUNTEERS	SOCIAL WORKERS
2006	2	2		
2007	6	8	2	
2008	3	14	4	6
2009	3	6	1	2

<b>Sensitization Programs from 2006 to 2009</b>	
YEAR	NUMBER OF PROGRAMS
2006	-
2007	5
2008	10
2009	24

who were open to the concept and approach of palliative care. They were then trained and are now able to look after the chronically ill people in the villages themselves.

## **NATIONAL**

The department has also been involved with several national projects. The team worked with the WHO-India office

and the Ministry of Health to develop guidelines on setting up palliative care services and procuring oral morphine. MNJ has been approved by The Indian Association of Palliative Care as one of the regional centers that can offer classes for the "Essentials of Palliative Care" course. Members of our team participated in a capacity-building workshop in Delhi on pediatric pallia-

# NETWORK

tive care, jointly organized by Cankids, INCTR and Pallium India. MNJ has taken on a consultative and advisory role, guiding centers in other states, for example Maharashtra, as they develop nodal palliative care centers similar to ours. Lastly, the team has raised its profile by presenting posters and abstracts at many national conferences.

## INTERNATIONAL

MNJ was one of the centers used to prepare the Human Rights Watch report "Unbearable Pain: India's Obligation to Ensure Palliative Care." It was based on qualitative research conducted in different parts of India. A quantitative research project will soon be starting to provide further evidence. The whole report (including a three-minute video) can be accessed at: <http://www.hrw.org/en/reports/2009/10/28/unbearable-pain-0>

MNJ gave certificate training in palliative nursing and medicine to nurses and doctors from various parts of Nepal. It has also been recognized by the International Association for Hospices and Palliative Care (IAHPC) as one of the centers providing bursary for students undergoing certificate courses in palliative care.

The MNJ program has grown steadily over the last few years. Every step that we take reveals how much more needs to be achieved. The future agenda will be to reinforce and strengthen what has already been built while working towards sustainability of the whole program. ■

*Gayatri Palat*  
*INCTR PAX Program*  
*MNJ Institute of Oncology and RCC*  
*Hyderabad, India*  
*Padmini Menon (volunteer)*  
*Hyderabad, India*

## PALLIATIVE CARE PROGRAM AT MNJ: REFLECTIONS FROM A VISITING CANADIAN PHYSICIAN

I am a recent family medicine graduate from Canada and am currently enrolled in a palliative care fellowship in Toronto. One of my goals for the fellowship year was to explore challenges facing palliative care in the developing world. I am of Indian heritage and as such had a particular interest in palliative care in the Indian subcontinent. Under the advice of a Canadian colleague, Dr. Fraser Black (Co-Director of the INCTR PAX), I approached Drs. Gorijavolu Durga Prasad and Gayatri Palat about an elective month in their palliative care department at the MNJ Regional Cancer Center, which is part of the INCTR Palliative Care Network. I was thrilled when they accepted my application. What a wonderful opportunity!

Prior to arriving in Hyderabad, I read an article on MNJ Institute of Oncology's Palliative Care Program in the INCTR newsletter (Volume 7, number 4). This served as a great introduction to MNJ's palliative care program. I also read a few articles on general issues facing palliative care in India. From my readings I understood that some of the key issues included the large burden of advanced cancer, which cannot be adequately addressed because of the paucity of regional and local palliative care centers, the need for education of health professionals, and restricted access to opioids. I thought this was reasonable preparation but I don't think anything could have prepared me for the reality I was about to face.

In November 2009, I spent three and a half weeks working with Drs. Palat and Durga Prasad's team in Hyderabad.

During my first few days at MNJ I was most impressed by the staggering volume of patients. On an average day, the team would see between 40-60 outpatients and 15-20 inpatients. The department also sees on average 8-10 pediatric outpatients and 4 pediatric inpatients. It's not just about case volume, but also unique psychosocial case complexity. MNJ is a government hospital, and the majority of the patients who are seen live below the poverty line. Patients travel long distances - taking up to 12 hours to attend their appointments. In addition to geographic isolation, patients are often isolated from family and friends because of the stigmatization of cancer (e.g., fear of contagion). Unlike in Canada, the community supports are very few. As such, there is very little support for end-of-life care at home.

By the second week of my elective, these realities had all made me a bit weary. A consistent buoy to my spirits was the commitment to quality palliative care demonstrated by the team at MNJ. In addition to Drs. Palat and Durga Prasad, the team consists of a physician locum, three full-time nurses, two social workers, several volunteers, and an administrative assistant. The nurses are well trained in the management of lymphedema, wound care, pain and symptom management, and supportive counseling. The skilled social workers help support patients and families facing the pressures of poverty, illness, and social stigmatization associated with cancer.

The palliative care program at MNJ was established in 2003. Over the last seven years, the group has made tremendous gains with respect to building palliative care capacity within the region. This has been accomplished through educating health professionals, advocacy for improved opioid availability and government funding for palliative care, development of community outreach programs, and partnerships with non-governmental organizations. These efforts are a result of the dedicated leadership of Drs. Palat and Durga Prasad. Their mentorship was the most valuable part of my experience at MNJ.

Research is a key area of growth in palliative care. The same holds true for palliative care in India and at MNJ. The group at MNJ hosts several workshops throughout the year aimed at building palliative care capacity through health professional education. The main courses are funded through the INCTR PAX program. Future research grants along with training in research methods will be a key part of the growth of the program. The team at MNJ has taught me the importance of advocacy and public awareness in improving healthcare. I am currently developing a working knowledge of research methods in palliative care. It is in the capacity of a colleague with an interest in collaborative palliative care that I hope to contribute to the success of palliative care in India. ■

*Shiraz Malik  
Palliative Care Fellow  
University of Toronto  
Toronto, Canada*

## **BPKMCH BHARATPUR, NEPAL/VICTORIA HOSPICE, CANADA TWINNING PROJECT**

As part of its overall palliative care initiative in Nepal, the INCTR PAX team first began visiting B.P. Koirala Memorial Cancer Hospital (BPKMCH), in Bharatpur, Chitwan, Nepal in 2005. The palliative care service at BPKMCH started in 2004 with a hospice/palliative care unit, and the INCTR PAX Program had been asked to provide support for the activities already underway.

For the next couple of years INCTR PAX continued to help the program through expert visits, education, training and mentorship. In 2007 the team at BPKMCH expressed their wish to develop a twinning link with another hospice. They wanted to expand patient care, education and research and introduce a home/community-based service in the future.

Following the lead of Nanaimo Hospice, which is twinned with

Bhaktapur Cancer Hospital, and building on the work already conducted by INCTR PAX at BPKMCH, Dr. Fraser Black, Associate Director of INCTR PAX and Medical Director of Victoria Hospice, Victoria, British Columbia, Canada, met with a group of his Canadian colleagues to discuss the idea of twinning with BPKMCH. A steering committee was formed and, as the saying goes ... the rest is history!

Today, the project provides mutual benefits through the transfer and exchange of knowledge and expertise in palliative care between Victoria Hospice and the BPKMCH Palliative Care Program. Funds have been found to help support patient care and to make further education available for healthcare professionals at BPKMCH.

The project adheres to Victoria Hospice's vision: "Quality End of Life Care for All." It is further reflected in its mission statement: "To enhance the quality of life for those facing advancing illness, death, and bereave-



**Sr. Usha, Dr. Sushil, Dympna Devlin (Canadian nurse) and BPKMCH palliative care nursing team with a patient and family member.**

# NETWORK

ment through skilled and compassionate care, education, research and advocacy.”

There are no national boundaries to these guiding principles. The skills to meet the needs of local communities that have been developed within Victoria Hospice over the last 30 years can also help meet similar needs in palliative care centers in other parts of the world. At the same time there are mutual benefits through the opportunity to exchange information and methodologies on ways to deal with the physical, psychological and spiritual issues surrounding palliative end-of-life care.

Numerous Victoria Hospice staff and volunteers have visited BPKMCH since the beginning of the twinning project. Nurses, physicians and psycho-social counselors have participated in both formal and informal education sessions, and have worked at the bedside providing patient care together with their Nepalese colleagues.

Through the dedication, compassion and vision of the palliative care team and administration, the palliative care services at BPKMCH continue to grow. They now include a 12-bed inpatient unit as well as an outpatient clinic and inpatient consultation service to other parts of the hospital. There is a dedicated palliative care team with a physician and six nurses. Over the last five years there have been close to 1200 outpatient and inpatient consultations and almost 800 admissions. And plans remain to develop a home/community-based program.

At present BPKMCH is offering a six-week training program for health-care professionals wanting to learn more about palliative care. Victoria Hospice staff and volunteers with the twinning project have participated in this program, helping to further

palliative care knowledge not only at BPKMCH but also among participants from other areas of Nepal. To learn more about the twinning project between BPKMCH, MCH and Victoria Hospice, visit our website at <http://sites.google.com/site/nepalhospice-twin>.

With the help of INCTR PAX, a national palliative care association, NAPCare, was formed in 2009 to increase communication and collaboration between the various programs and individuals leading the way in Nepal. Through its members combined efforts, NAPCare is providing the support, education and networking opportunities that are needed to move palliative care forward in Nepal. The association is also working with the government to develop a national palliative care policy.

Thanks to the contribution of many committed individuals – including those working with INCTR PAX/NNCTR, B.P. Koirala Memorial Cancer Hospital, Hospice Nepal, Kanti Children’s Hospital, Nepal Institute of Health Sciences, Bhaktapur Cancer Hospital, Shechan Hospice, Scheer Memorial Hospital, Patan Hospital and the twinning programs with Victoria Hospice and Nanaimo Hospice – palliative care in Nepal continues to grow. More programs are providing palliative care to more people, both adults and children. The improvement in access to opioids and other essential medications is bringing many people relief from their suffering. The future indeed looks promising for palliative care in Nepal. ■

*Fraser Black  
INCTR PAX Program  
Victoria Hospice  
Victoria, Canada*

## BHAKTAPUR TWINNING PROJECT BUILDS ON THE WORK OF INCTR

INCTR has been supporting the development of palliative care in Nepal since 2002. In 2007, my husband, Dr. Robin Love, and I travelled to Nepal with a group from INCTR PAX to teach palliative care skills to the doctors and nurses there. One of the centers we visited was the Bhaktapur Cancer Care Hospital (BCCH) in the city of Bhaktapur, just outside Kathmandu. At that time, oral morphine had been in use for about six months and doctors told us how grateful they were to have the means to relieve the suffering of their dying patients.

Other medicines were also available, but still out of reach financially for many families. One patient whom Robin visited was experiencing terrible nausea and vomiting. When he asked if they had Haldol to treat this, he was told that the family could not afford it. “How much does it cost?” he asked. “Five cents” was the answer. When I heard this story, I reached into my pocket and took out a two-dollar coin. Just that small sum of money was able to relieve the patient’s suffering and allow him a peaceful death. How could we get a few Canadian coins from our pockets to the hands of those who are suffering on the other side of the globe? The Nepali medical staff were eager to learn and implement palliative care at BCCH, but without financial support their success would be limited.

When we returned home to Canada, we spoke with others in the Nanaimo palliative care community. So many asked how they could help that we decided to arrange a twinning partnership between Nanaimo’s Mid Island Hospice and BCCH based on our

mutual commitment to care for the dying. Our idea was that by providing long-term support for a center where INCTR PAX had helped introduce palliative care, the team would be able to move on to new projects.

Now called "Partners in Compassion," our twinning partnership has been developing for three years. It is based on this mission statement: "The hospice palliative care communities of Nanaimo and Bhaktapur have come together, in friendship, to share resources and learn from each other's experiences and cultures, in order to enhance compassionate care and comfort to the dying and their families."

The Nanaimo community made a commitment to provide modest and reliable financial support for the BCCH palliative care program. Initially this paid to hire two nurses and a ward aide. Later, additional funding supported the opening of a new ward dedicated exclusively to palliative care. We have also been able to send enough money to buy morphine for patients who cannot afford it. Our financial support has been instrumental in enabling palliative care to continue at BCCH, especially with so many demands on the hospital's limited resources.

Our yearly site visits have breathed life into this partnership, making those personal connections and demonstrating caring that simple financial support cannot achieve. Nurses and doctors from Nanaimo have travelled each fall to BCCH where they are received like family. The focus of these visits has been to teach practical skills such as patient transfers, the use of pain assessment tools, and effective charting. Teaching and working at the bedside with their Nepali partners, our Canadian colleagues have learned humility and gratitude. Friendships have been built and perspectives broadened.

Partners in Compassion has been able to provide funding for several BCCH nurses and a physician to travel to India for further palliative care training. BCCH now has a committed and knowledgeable palliative care leadership team that is passionate about continuing to train others in this important aspect of cancer care.

Partners in Compassion has committed to another three years' partnership between Nanaimo and Bhaktapur. We feel that our twinning project has built on and supported the important work of INCTR PAX and is increasing the independence and sustainability of palliative care in Nepal. ■

*Deirdre Love*

*Partners in Compassion Project Leader  
Nanaimo Community Hospice Volunteer  
Nanaimo B.C. Canada*

## PALLIATIVE CARE PROGRAM AT SANTA MARCELINA HOSPITAL SYSTEM

A very exciting PAX initiative is underway setting up the first Brazilian PAX collaborating center at Santa Marcelina Hospital. Santa Marcelina is the main tertiary cancer hospital and primary healthcare provider in the eastern and poorest area of the city of São Paulo. The 67 primary healthcare centers affiliated with the hospital serve about six million people, providing a highly integrated health service system that carries out excellent work.

The INCTR PAX team first met with Sister Monique Marie Marthe Bourget, the hospital director, in March 2007 and plans were made to introduce a palliative care service at the hospital. Initially a physician and nurse ran an internal consultation service that pro-

vided palliative care advice to doctors and other health professionals working in the Santa Marcelina Complex.



**Multidisciplinary health professionals working with children and teenagers.**

In 2008 a six-bed ward was opened and a more extensive palliative care team was brought together. During the first year they treated more than 600 inpatients and many more outpatients. Twenty resident physicians spent 30-day periods with the team learning the principles and practice of palliative care. A second physician was appointed in 2009 so that there are now two doctors, a nurse, social worker, psychologist, pharmacist, physiotherapist and nutritionist. Although the members of the team are highly qualified in their own fields, they have had little formal training in palliative care.

The team is very active. It looks after patients in the palliative care ward and emergency room, and also provides ambulatory and internal consultation services in other areas of the hospital. They hold an outpatient clinic every week and see an average of eight patients every time. They interact at an individual level on a day-to-day basis, and once a week hold a team meet-

# NETWORK

ing to discuss difficult cases in more depth. "Group therapy" is offered every month, providing an opportunity for team members to share their



**TUCCA Ambulatory aims to provide both our patients and their parents with the assurance that their specialized medical needs will be met.**

experiences and receive support. Although very rewarding, caring for palliative patients is also extremely distressing.

Other activities the team has organized are fortnightly training courses for any Santa Marcelina staff members who wish to learn more about palliative care, and monthly meetings for bereaved families. Palliative care has been integrated into the pediatric oncology service and work is underway on developing an extensive community-based program through the associated primary healthcare centers.

The INCTR Palliative Care Handbook is being used on a daily basis and they have found it very useful, particularly the sections on pediatric and psychosocial care. A Portuguese translation is being prepared and will be ready for printing later this year.

Some education has been provided during two international workshops at the hospital that were organized together with INCTR. The first was an

introduction to basic palliative care principles, both pediatric and adult. Approximately 200 people attended, mostly doctors and nurses. But there were quite a few social workers, pharmacists, physiotherapists and volunteers who came as well.

The second workshop built on the concept of using a "palliative approach" across settings. Participants explored the many aspects of palliative care provision including ethical considerations and the nature of suffering. They learned in more depth how to manage patients' pain and other symptoms which can be difficult and complex.

After the second workshop the INCTR PAX faculty also contributed to a two-day workshop for the "Medicine Paulista Association" that provided palliative care training and sensitization to additional physicians working in other care settings.

The National Cancer Institute (INCA) is based in Rio de Janeiro and advises on palliative care at the national level as part of its wider cancer control program. INCA has in place an exemplary and world-class palliative care program with a large inpatient unit (60 beds) and a busy outpatient clinic. Care in the favelas (slum areas) is a huge challenge but the program meets this need with a very strong home-based service. INCTR PAX is delighted to have the opportunity to work with INCTR Brazil, TUCCA, Santa Marcelina Hospital, INCA and the Brazilian palliative care community to expand access to palliative care countrywide. ■

*Claudia Lancman Epelman*

*Sidnei Epelman*

*INCTR Brazil, Santa Marcelina Hospital*

*São Paulo, Brazil*

*Stuart Brown*

*INCTR PAX Program*

## **BUILDING CAPACITY FOR PALLIATIVE CARE SERVICES IN TANZANIA**

Tanzania, like other sub-Saharan African countries, faces great challenges in meeting the health needs of its people in general as well as its palliative care needs. The HIV/AIDS pandemic has caused much physical, social, economic, emotional and psychological suffering for many patients and families. This was highlighted in a 2002 World Health Organization situation analysis and needs assessment study.

In addition to HIV/AIDS, the number of cancer cases has been increasing year after year with HIV-related malignancies such as Kaposi's sarcoma the leading cause of hospital cancer admissions and mortality. Furthermore, the adoption of a more "westernized" lifestyle by many Tanzanians has resulted in an alarming increase in people with diseases such as diabetes, hypertension and arthritis, most of whom will require palliative care at some point during their lifetime. There is, thus, an enormous and growing unmet need for palliative care.

In response to this health crisis, INCTR PAX and the Ocean Road Cancer Institute (ORCI) in Dar es Salaam drew up a proposal for a collaborative project to expand Tanzania's capacity to provide palliative care. We requested funding from the International Atomic Energy Agency Program of Action for Cancer Therapy (IAEA/PACT) which is assisting the Tanzanian authorities to build a comprehensive national cancer control program. The proposal was accepted and financial support offered from the Organization of the Petroleum Exporting Countries Fund for International Development.

In 2006, we secured a grant from the Open Society Institute (OSI). This was used to buy furniture, a laptop com-

puter and LCD projector for the palliative care office at ORCI. It also helped meet the office operating costs, and allowances for the program director and secretary for a year. In addition it paid for a sensitization workshop for



**Graduates receive PC certificates.**



**Graduates sing for their guests.**

Eastern and Southern Zones' heads of government health facilities, and training for 30 healthcare workers from Kinondoni municipality. These initiatives generated a lot of enthusiasm among our palliative care team members who continued with the work even after the grant was exhausted.

A course was held for healthcare workers in Llala municipality. This led to the formation of palliative care teams in the municipal hospital and a strengthened referral process to step-down facilities, for example, health centers and dispensaries. As a result patients now continue to receive treatment after going home.

Other workshops were given for regional medical officers to encourage them to integrate palliative care

into the existing health care system. Training was provided for physicians, pharmacists and nurses working at some of the main zonal/referral hospitals in Tanzania, namely Muhimbili, Bugando, Mbeya and Kilimanjaro Christian Medical Centre (KCMC). Following on from this, a palliative care service was launched at KCMC.

Two more ORCI staff, a doctor and a nurse, completed a distance learning diploma program managed from Uganda so we now have a total of ten fully trained personnel on our team. In addition, we have written a palliative care training manual for Tanzanian healthcare professionals and volunteers.

So although substantial progress has been made since 2006, as always, the challenge remains to secure sufficient money to continue with our work. Most of the funders in Tanzania are only interested in supporting palliative care for HIV/AIDS patients. ORCI, therefore, continues to face problems because of its cancer "brand" despite the fact that the training offered here is for the care of all patients whatever their disease.

ORCI, being the sole government palliative care provider and the epicenter for palliative care in Tanzania, enjoys a unique strategic position which if utilized effectively will help scale up services throughout the country. In addition, ORCI works very closely with the Tanzania Palliative Care Association, Africa Palliative Care Association and other internal stakeholders. ORCI and INCTR PAX remain committed to pushing forward with the project and we are now waiting for the grant from the OPEC Fund for International Development (which is dedicated to cancer patients) in order to continue our work. ■

*Msemo Diwani  
Ocean Road Cancer Institute,  
Dar-es-Salaam, Tanzania*

## PAX COLLABORATION WITH BCCA

It seemed like a perfect match when, in late 2007, the previous CEO of the British Columbia Cancer Agency (BCCA), Dr. Simon Sutcliffe, and Ian Magrath, the President of INCTR, met in Vancouver, Canada and invited members of the BCCA Pain and Symptom Management/Palliative Care (PSMPC) Program to work collaboratively with the INCTR Palliative Access Program (PAX). We leapt at the chance to explore areas of common interest in palliative care development in low-resource countries.

The BCCA provides a province-wide population-based cancer control system for the residents of British Columbia and the Yukon, a combined population of approximately 4.5 million and has five Regional Cancer Centers, each having a Pain and Symptom Management/Palliative Care multidisciplinary team. Some team members had previously worked in low-resource countries and wanted to put their palliative expertise to good use. Others were just plain keen. The Indian Palliative Care Network was selected as the first area of collaboration between the BCCA and INCTR PAX and since 2007 several BCCA PSMPC staff, both physicians and nurses, have visited the Mehdi Nawaz Jung Institute of Oncology and Regional Cancer Centre (MNJ) in Hyderabad, India. The MNJ Pain Relief and Palliative Care Program is led by Drs. Gayatri Palat and G. Durga Prasad and, in addition to treating patients, engages in research and provides training to health professionals sharing their expertise and creating a network of well-trained care providers. They have also developed a Pediatric Palliative Care Program, a home-based program, and are working with local HIV/AIDS agencies.

The BCCA collaboration was designed

# NETWORK



**Drs. Palat and Durga Prasad work with Ann Syme of British Columbia.**

to a) provide external faculty for on-site teaching in the one-month Certificate Course in Pain and Palliative Medicine that occurs at MNJ six times a year; b) facilitate program development in India by meeting with local hospital and government leaders; c) assist with policy development particularly in the pediatric palliative care realm; d) enhance support for nursing education; and e) develop a targeted fundraising program.

Ann Syme, Director of the BCCA PSMPC Program, and Gillian Fyles, Medical Lead for the PSMPC team at the Centre for the Southern Interior, travelled to Hyderabad in February 2008 and again in September of 2009, spending two weeks each time at MNJ with the team. It has been a humbling and very meaningful experience working with the incredibly dedicated professionals and volunteers. Returning in 2009 to see the changes since our last visit was really wonderful as much progress had been made, particularly in caring for children with cancer. At our first visit it took us a while to get oriented and up to speed with how things were done, what was available, and how we could be useful. The majority of our time, however, was spent teaching in the course and mentoring the students.

Our second trip in September allowed us to contribute more fully not only in teaching and mentoring the students, but also in assisting with selection and development of symptom assessment tools, program development and nursing resources. In order that our cadre of oriented and trained external faculty grows, the team members plan to return separately next year, each taking with us another health professional.

On a broader scale, the BCCA/INCTR PAX Collaboration has resulted in heightened awareness at the BCCA of palliative care needs in India and enhanced understanding of the Indian Palliative Care Network. In addition we have been able to help with palliative care training for multi-disciplinary students in India, provide protected time for MNJ staff to treat their patients and demonstrate international support.

The future holds more external faculty visits, including expansion of the external faculty pool and increased fundraising efforts. ■

*Gillian Fyles and Ann Syme  
Pain & Symptom Management/  
Palliative Care Program, BCCA  
Center for the Southern Interior  
Kelowna, Canada*

## A CASE STUDY FROM BRAZIL

In October 2009 I had the opportunity to be part of the INCTR PAX team visiting Santa Marcelina Hospital in São Paulo, Brazil. I spent some time on the palliative care ward and it was here that I heard Julieta's story from her doctor.

Julieta was a 55-year-old woman who had first come to the hospital in 2009 as an emergency because of seizures. She had an urgent scan of her brain that revealed several lesions. From the appearance on the scan the lesions looked as if they had spread from another primary source. After further investigations Julieta was found to have breast cancer which had metastasized to her brain. When she was given her diagnosis, Julieta said that she had known she had a breast lump which had been increasing in size for the last two years. She was afraid it was cancer as her own mother had died of breast cancer at a similar age. This fear had stopped her from seeing a doctor and she kept herself busy by looking after her two-year-old grandson and working in a local supermarket. Julieta was not surprised at the diagnosis and said that she had expected the bad news. However, when asked whether she wanted to know more about what was going to happen next, she said no, all she wanted was that the doctors treat her condition.

At diagnosis Julieta already had advanced breast cancer which in addition to spreading to the brain was also invading other parts of her body, including her chest muscles, and forming ulcers on the surface of the tumor. She had radiotherapy to her brain followed by a course of

## REPORTS / CASE REPORTS

chemotherapy the following month. During her treatment she recovered well. Her seizures stopped and the ulcers on the surface of the tumor reduced in size. Her daughter, Ana, visited her daily while she was in hospital. Ana was very shocked by the diagnosis of cancer. She asked the doctor whether this cancer was curable and was very distressed when told that there were ways of controlling the tumor and even slowing down its growth but, unfortunately, it was not possible to cure such an advanced tumor. It was extremely hard for Ana to accept this and she reacted by being angry and argumentative with the doctors on the ward.

Julieta was discharged home after completing chemotherapy. However, she came to the Emergency Department four weeks later with severe pain in and around the breast tumor which had been gradually getting worse since leaving hospital. The tumor had grown and the ulceration over the tumor increased. In addition, she had swelling of her arm where the tumor had blocked the lymphatic drainage. Her swollen arm had signs of infection and was almost as painful as the tumor. Due to the severe pain, which was worsened by the slightest movement, she had taken to her bed. She had also lost her appetite because of the pain. She became withdrawn and spoke little, which made her daughter worried and upset. All the wards in the hospital were full and she had to remain in the Emergency Department for three days to receive painkillers and antibiotics for her arm.

When she was finally moved to the palliative care ward she was given oral morphine and an anti-inflammatory drug. The oral morphine was then

switched to an infusion. However, she developed side effects (drowsiness, confusion and constipation) from the morphine and continued to have pain. Clearly, the morphine infusion at the dose being given was not helping and the doctors switched her to a related opioid painkiller called Fentanyl which was applied as a patch on her skin. In conjunction with this she was also started on a drug called Gabapentin which is useful for pain caused by nerve irritation. This combination of drugs gave her great relief. Unfortunately, the Fentanyl patches, which are expensive, were samples donated by a drug company and the ward had only a one-month supply. The doctors now needed to find more patches or think of another way to manage her pain once the supply ran out.

As her pain was better controlled she found that she could now move her painful arm with greater ease. Her tumor was also less painful and she managed to get out of bed to walk around the ward. She also regained her appetite and started to eat more. She was started on different chemotherapy which resulted in an improvement in her breast cancer, decreasing the size of the tumor and ulcers.

As her pain improved so did her mood and she began to talk to her daughter and interact with her grandson again. Her daughter had coped with her mother's deterioration as before, by being angry with ward staff. However, as her mother improved Ana began to trust the staff and confided in one of the physicians that she had found a breast lump herself six months ago but did not want to see a doctor for fear that it would be cancer. She also told staff on the ward that her father,

who was separated from her mother, was a religious minister. He had been pressuring both her and her mother to join his church, and telling them that Julieta would be cured if she converted to his religion. They were thinking about doing this but did not feel entirely comfortable about it yet. Finally, after a few weeks of listening and gentle encouragement, Ana gained enough courage to see a doctor and is now waiting for the results of investigations.

This was where Julieta's journey has taken her so far. During this journey she had experienced different thoughts and emotions. One can imagine the depths of fear, questioning and anxiety she must have endured in addition to physical suffering. Her daughter Ana had to face her own feelings and worries, for her mother's as well as for her own health. Palliative care aims to provide a team of caring professionals who will walk alongside the patient and their families during this difficult journey and help improve their quality of life in a holistic manner. The team understands that a patient is not just a person with a physical ailment but a person with emotional, social and spiritual needs, and generally surrounded by loved ones who struggle to cope with the condition as well. Unfortunately, as illustrated by the other case histories, misinformation can sometimes result in the loss of family and community support. This is a much greater problem in uneducated societies. ■

*All patients' names have been changed to protect their identity.*

*Ruth Ting  
Marie Curie Hospice  
Newcastle-upon-Tyne, UK*

# NETWORK

## A SELECTION OF CASE STUDIES FROM INDIA

### 1. HE HAS POLIO - NOT CANCER!

Raj is 11 years old and hails from Nagaupally in East Godavari. He was diagnosed with neuroblastoma approximately two years ago. After doing the usual rounds of the private hospitals in the region, he

cer, he was referred to the Palliative Care Department at the MNJ Hospital prior to the initiation of therapy. To start with, the counselor simply explained the ailment to the child. The child, they told the family, was developing progressive paraplegia. Raj took it all in his stride. It seemed that little could affect his sunny disposition.

questioning why she was spending all that money and taking the child to Hyderabad for treatment. "He is suffering from polio and not cancer and we cannot spend that much money for treatment and traveling charges!" she would say. For her, the long periods of absence when the mother took her son for treatment meant that there was no one to do the housework!

For Raj and his mother, even their stay at hospital was unpleasant as caretakers of other sick children often humiliated Raj's mother. Her single status made her vulnerable to others' criticisms; they questioned her morality and accused her of having affairs with every man who spoke to her. She faced ostracism through no fault of her own, and was further pushed into isolation.

At home, Raj found it difficult to stomach his grandmother's outbursts and insults and expressed the desire to return to the hospital. Fortunately for him, the MNJ team had partnered with an organization that worked in the district where the family lived - CHAI (Catholic Health Association of India). CHAI has a care and support center, Sneha Kiran, which offers a home for patients suffering from HIV/AIDS. They welcomed the child and his mother with open arms, giving them a room to stay in. Raj could now surrender himself to the make-believe world of television for as long as he wanted. No one would criticize or nag him anymore. His mother's cooking skills came in handy in the kitchen and she was employed as a cook by CHAI. Finally, they had managed to find some peace. ■

*Padmini Menon (volunteer)  
Hyderabad, India*



**Doug Ennals, a psychosocial consultant with INCTR's PAX team, and Raj meets at the MNJ Institute.**

came to the MNJ Hospital, accompanied by his widowed mother who is the sole caregiver. They lived with many relatives and, after his father's death, depended on the charity of the rest of the family to pull through. His mother did all the housework.

When Raj was diagnosed with can-

cer, he was referred to the Palliative Care Department at the MNJ Hospital prior to the initiation of therapy. To start with, the counselor simply explained the ailment to the child. The child, they told the family, was developing progressive paraplegia. Raj took it all in his stride. It seemed that little could affect his sunny disposition.

## 2. HOW LONG SHOULD I TAKE TREATMENT? WILL I EVER BE ABLE TO GO TO SCHOOL?

Thirteen-year-old Minnal, a native of Huzoornagar, Nalgonda district, was diagnosed with acute myeloid leukemia in January 2009. Initially her response to treatment was poor, but subsequently she responded to the medication and seems to be doing well now as the disease is in remission – although her oncologist cannot be sure that the disease will not come back.

As a patient in the ward, Minnal was a real asset. She would play with the other children and read them stories and news articles. Her desire to know more about the disease prompted her to regularly scan the newspapers for information on cancer. However, once back in the village after the treatment, she had to face social isolation. The other children in the village refused to play with her. At school, her teachers made her sit separately in a corner in the class, and at home her extended family members avoided her as they were scared that their children would contract the disease.

As for Minnal, she constantly worried about her studies. She felt terribly disheartened when she could not go to school. In the ward, her constant query was: “Am I going to get well or am I going to die like the other children in the ward? For how long should I take the treatment? Will I be able to go to school and lead a normal life?” Her parents were equally worried.

At MNJ, the palliative care team is well aware of the anxieties that plague the children and their parents. To answer their questions and help them cope with their anxieties, the team conducts regular support group meetings. It was at one such meeting that Minnal’s full story came out into the open. Many other families also shared similar stories of the

social stigma that they were facing.

To help Minnal reintegrate with her friends and be re-admitted in school, the team’s volunteers went to her village to speak to the principal of the school and the teachers and to network with the local support groups. They coordinated with a partner, MV Foundation, whose workers were well-known in the area and had considerable influence in the community. Their efforts bore fruit and Minnal was taken back into the school; she found acceptance among her classmates. There was greater sensitivity now to her problems, thus reducing the added burden she had been forced to bear in addition to her cancer. ■

*Priya Kumari  
Pain Relief and Palliative Care Society  
Hyderabad, India*

## 3. NO, I DON’T WANT TO TAKE OFF MY COAT!

When five-year-old Indivar came to the Palliative Care Department of MNJ in January 2010, it was a warm bright day. But the little boy clung to his mother. In spite of the heat, he wore a coat with a hood that hid most of his face. He was shy and withdrawn and talked only in whispers or looked to his mother to answer the questions that the doctor posed.

Ewing’s sarcoma had been diagnosed and chemotherapy begun. As expected, this resulted in hair loss. The little boy could not accept the way he looked and did not want others to see his baldness. The cloak that he drew tight around him was his way of avoiding unwanted glances and unwarranted questions. The physical discomfort was a small price to pay as long as he did not have to reveal his appearance. Obviously, the small child had anxieties

about his body image—anxieties that he could not express or share. In addition to the pain of the disease and the treatment, this was one more burden.

Indivar had also been ostracised by his cousins and neighbors. Viewing the disease as contagious, his uncle and aunt passed a strict injunction that none of his cousins should play with him. In fact, they even advised his mother to keep away from him. The parents found themselves increasingly isolated and bereft of social interaction.



**The little patient at his first visit.**

The palliative care team was quick to note the problems that Indivar and his family faced. Through regular counseling of the immediate family, and dialogue and interactions with the child, they succeeded in reducing his sense of isolation. In the meantime, the pain medication helped reduce the pain while the side effects of chemotherapy wore off. Indivar slowly regained his confidence. In fact, recently, he even posed for a picture, and was last heard asking his mother to enquire with the doctor if he could have a copy of the photograph! And, incidentally, he does not need to hide behind his cloak anymore! ■

*All patients' names have been changed to protect their identity.*

*R. Vineela  
MNJ Institute of Oncology and RCC  
Hyderabad, India*

# NETWORK

## INCTR PALLIATIVE CARE HANDBOOK

The next edition of the INCTR Palliative Care Handbook is now available in both print and online versions. The original impetus behind this project came in 2004 after requests from healthcare professionals providing palliative care within resource-constrained systems for a quick and practical reference book.

Approximately 1455 copies of this latest edition have been distributed to countries with which PAX is associated, including Nepal, India, Tanzania, Egypt, Pakistan and Brazil, as well as to institutions, groups and individuals in other parts of the world. The handbook has been translated and printed in Turkish; Portuguese, Spanish and French translations are underway.

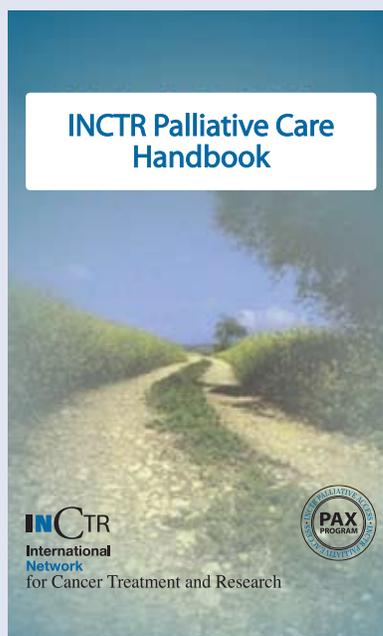
The handbook covers 18 different distressing symptoms commonly seen in palliative care. For each symptom there are sections on key points, assessment, management, pitfalls/concerns, palliative tips and useful references. Information pertaining specifically to the care of children is highlighted within the text making it easy to find when needed.

In addition to symptom management there are a number of new sections in the fourth edition: a chapter on psychosocial care, an equianalgesic opioid table, the Palliative Performance Scale (PPSv2), signs and symptoms at the end of life and other useful appendices. A formulary is also included that gives information on pharmacology, adult and pediatric dosing, unwanted effects and pitfalls/concerns for drugs commonly used in palliative care.

As mentioned, the handbook is freely accessible via a "wiki" website

<http://inctr-palliative-care-handbook.wikidot.com>. Hard copies can be purchased directly from INCTR (contact [bene@inctr.be](mailto:bene@inctr.be)) or from Amazon ([www.amazon.co.uk](http://www.amazon.co.uk)).

There are already plans for the next edition. It will cover additional topics and provide updated material for the existing sections. It is hoped that this and future editions of the INCTR Palliative Care Handbook will continue to help improve the quality of palliative care provided to patients and families wherever they live.



All of the work, past, present and future, would not be possible without considerable help from colleagues around the world, the INCTR staff in Brussels and Alison Brown, who helped create the online Wiki version. We would also like to thank the many endorsing agencies listed in the handbook, as well as Lilly Oncology and the Office of International Affairs, United States National Cancer Institute, for their generous financial support.

### TABLE OF CONTENTS :

#### Symptom Management

- Anorexia and Cachexia
- Ascites
- Bleeding
- Constipation
- Cough
- Delirium
- Dyspnea
- Hiccups
- Malignant Bowel Obstruction
- Malignant Spinal Cord Compression
- Malignant Ulcers or Wounds
- Nausea and Vomiting
- Pain
- Pleural Effusion
- Pruritus
- Respiratory Secretions at the End of Life
- Seizures
- Superior Vena Cava Syndrome

#### Psychosocial Care

- Introduction
- Communication
- Breaking Bad News
- Psychosocial Assessment
- Distress
- Anxiety
- Depression
- Hope
- Loss, Grief and Bereavement
- Self Care
- Therapeutic Interventions

#### Appendix

- Breakthrough or Rescue Doses of Morphine
- WHO Pain Ladder
- Equianalgesic Tables
- Naloxone in Respiratory Depression due to Opioid Overdose
- An Approach to Neuropathic Pain
- Transfusion of Blood Products in Palliative Care
- Palliative Performance Scale
- Signs and Symptoms at the End of Life
- Abbreviations

#### Medications

- IAHPCL List of Essential Drugs for Palliative Care
- Formulary

## EDITORS :

Dr. Fraser Black  
Dr. Stuart Brown

## Contributing Authors:

Doug Ennals, MSW  
Dr. Juan Diego Harris  
Virginia LeBaron, RN  
Dr. Robin Love

## ACKNOWLEDGMENTS :

Dr. Alison Brown  
Anne Callegari (Pharmacist)  
Dr. Gayatri Palat  
Dr. MR Rajagopal  
Dr. Aziza Shad  
Dr. Sudip Shrestha  
Dr. Geoff Spry

We would also like to thank our Nepali, Indian and Tanzanian colleagues as well as Dr. Ian Magrath, Benedicte Chaidron and Sophie Lebedoff for all their efforts and support.

Endorsed by the African Organisation for Research and Treatment in Cancer (AORTIC), African Palliative Care Association (APCA), British Columbia Cancer Agency, Latin American and Caribbean Society of Medical Oncology, Middle East Cancer Consortium (MEC), Nepal Network for Cancer Treatment and Research, Pallium India, and Victoria Hospice, British Columbia, Canada. ■

*Fraser Black*  
*INCTR PAX Program*  
*Victoria Hospice*  
*Victoria, Canada*

## VISIT BY DRs. TRISH SCANLAN AND UDO BODE

A meeting was held at INCTR with Drs. Scanlan (who is in charge of pediatric chemotherapy at Ocean Road Cancer Institute; ORCI) and Dr. Bode (former head of Pediatric Oncology at Bonn University) on 14th and 15th September following Dr. Bode's trip to Tanzania to discuss the several years of collaboration with Dr. Ngoma (Director of ORCI) and his staff and to discuss future directions. ■

## ETON COLLEGE ADDRESS

Mark Lodge, Director of INCTR UK, addressed senior students at Eton College (the alma mater of 19 British Prime Ministers) on 27th October on the topic of cancer in developing countries. The talk was partly educational but also delivered in the hope of encouraging students to become involved in INCTR's work. ■

## INTERNATIONAL SOCIETY OF PEDIATRIC ONCOLOGY MEETING (SIOP)

INCTR Brasil (Director, Dr. Sidnei Epelman) played a major role in the organization of the 2009 Annual Meeting of SIOP (5th to 9th October). Several INCTR members made presentations and Dr. Aziza Shad held further discussions with SIOP on updating the guidelines for developing countries on the establishment of Pediatric Oncology Units. ■

## VISIT BY CAMEROONIAN PATHOLOGIST

Dr. Blaise Nkegoum visited INCTR in Brussels on 15th October (his wife was undertaking training at Erasmus Hospital). This provided an opportunity to discuss participation of Cameroon in ongoing INCTR projects, particularly the treatment of Burkitt lymphoma and improvement of pathology services. ■

## WORKSHOP ON SCIENTIFIC WRITING

Between 18th and 21st October, Drs. Heseltine and Rohatiner held a workshop on scientific writing for 5 laureates selected during INCTR's meeting in Antalya. ■

## VISIT BY PAX TEAM LEADERS

Stuart Brown and Fraser Black, co-directors of INCTR's palliative care program (PAX), visited INCTR on 29th and 30th October to discuss future strategies for the evolution of PAX. ■

## VISIT TO CASABLANCA

Sabine Perrier-Bonnet of AMCC visited Morocco from 3rd to 5th November with Prof. Benider from the Val d'Aurelle cancer center to hold a course for nurses on breast cancer. ■

## WORKSHOP ON PEDIATRIC CANCER

INCTR held a workshop on pediatric cancer in developing countries at the International Cancer Control Congress held in Cernobbio, Italy, from 8-11th, 2009. ■

## MEETING OF AORTIC

INCTR members participated in the biennial meeting of the African Organization for Research and Training in Cancer held in Tanzania from 12th to 14th November, in part by helping to organize a workshop on psychosocial care. During the meeting, the President of Tanzania promised to take a leading role in emphasizing the importance of cancer as a health problem in Africa. ■

## MEETING IN PARIS RE: AMCC

A meeting was held on 9th December in Paris to discuss the appointment of new board members to the French branch of INCTR. ■

# NETWORK

## B.P. KOIRALA MEMORIAL CANCER HOSPITAL, BHARATPUR, NEPAL

Nepal is a small Himalayan country situated between India and China. It is landlocked, and stretches to 800 kilometers in length and just 241 kilome-



**B.P. Koirala Memorial Cancer Hospital.**

ters at its widest point. The country is divided into three distinct geographical regions: the extremely high mountains in the north, home to eight of the highest peaks in the world, including Mount Everest, hills and valleys in the central region, and a vast plain (known as Terai) in the southern part of the country, which is covered with dense forest. The Nepalese are traditionally very patriotic people and proud of the natural beauty of their country.

Non-communicable diseases like cancer, cardiovascular disease and diabetes are becoming more common in Nepal, as they are worldwide, and cancer has become a major public health concern. While it is the second leading cause of death in most developed countries (after cardiovascular diseases), the number of people developing cancer in resource-poor countries is growing as their populations increase and they increasingly adopt the bad habits of more developed countries, particularly smoking. Coping with this increased cancer burden in countries like Nepal is hampered by widespread poverty, illit-

eracy, social deprivation and ignorance about healthcare matters, such that mortality rates tend to be much higher than in technologically advanced countries. The government of Nepal is working actively to tackle infectious diseases but to date has given scant attention to cancer control.

To complicate matters further, there is very little information in Nepal on the incidence and prevalence of cancer. Based on data collected at some Nepalese hospitals and from other countries in the region, it has been estimated that the incidence of cancer is between 100-120 cases per 100,000. Since Nepal's population is 28 million, this means that the number of new cases each year is somewhere between 28,000 and 34,000, and that at any one time 45,000-51,000 people in the country are afflicted by cancer.

Cancers of the cervix, lung, breast

es, and contribute to the high mortality and morbidity from cancer.

B.P. Koirala Memorial Cancer Hospital (BPKMCH) is in Bharatpur, a city 150 kms south of Kathmandu, and the only government cancer hospital in Nepal. It was built in the memory of (and named after) Bishweshwar Prasad Koirala who was the first democratically elected Prime Minister of Nepal. Unfortunately, he died of throat cancer. Founded in 1992 with Chinese assistance, the hospital started offering outpatient services in 1995 and began treating inpatients in 1999. It provides diagnostic, therapeutic and supportive services for cancer patients and has specialists in medical oncology, radiation oncology, surgical oncology (including neurosurgery, and head and neck surgery), gynecological oncology, radiology, pathology, preventive oncology and hospice care. There is a



**BPKMCH Outpatient Block.**

and stomach are the most common cancers in Nepal. Unhealthy customs such as smoking, high alcohol consumption and poor hygiene continue to be a challenge in our society due to extensive illiteracy and lack of resour-

volunteer organization associated with the hospital and also a cancer welfare society that helps needy patients and relatives during hospital stays.

The hospital is affiliated with INCTR, the International Agency for Research

# PARTNER PROFILE



**Palliative care unit family lounge.**



**Palliative care unit nursing station.**

on Cancer (IARC) and the International Union Against Cancer (UICC). With the support of IARC and UICC International Cancer Technology Transfer Fellowships (ICRETT), many doctors, nurses and technicians have received training in the prevention, diagnosis, treatment and palliative care of cancer patients.

## PALLIATIVE CARE

The palliative care service at BPKMCH started in 2004 with a hospice/palliative care unit. At the moment we have six nurses and one doctor providing hospice care on the palliative care ward, at outpatient clinics and as a consultation service within the hospital. There are enough palliative care nurses to ensure that for every shift there is always one nurse on duty. The palliative care patients also have access to a dietician and physiotherapist. Family members are actively involved in patient care as this is very much expected in the Nepali culture (in part, of course, also due to the limited numbers of professional health providers).

One of the biggest challenges in palliative care at the hospital is the lack of information given to the patients regarding their diagnosis and prog-

nosis. Similarly, decisions about medical care and treatment are generally made by a family member rather than the patient. This presents a major ethical dilemma especially if the patient asks for information regarding diagnosis and prognosis. Skillful negotiation is required to deal with this and we are very thankful to Victoria hospice staff for their teaching relating to communication and psychosocial care.

BPKMCH hospice has had a twinning

arrangement with Victoria Hospice, Canada (whose Director co-directs INCTR's PAX program), since 2009. Victoria Hospice provides help with our training program, technical assistance and financial support for hospice patients. We offer six-week palliative care nursing training courses. The faculty includes Dympna Devlin, Ms. Susan Breiddal and Dr. Ryan Liebscher from Victoria Hospice, as well as doctors, nurses, a dietician, physiotherapist and spiritual advisor from BPKMCH and other Kathmandu and Bharatpur hospitals. Altogether, 11 registered nurses from several different hospitals have graduated from these courses.

We have seen some measurable improvements in cancer outcomes at BPKMCH in recent years as a result of the comprehensive management we offer, including palliative care. As the population becomes more knowledgeable about cancer, we hope that this will result in earlier diagnoses and improved survival rates. ■

*Bhaktha Man Shrestha  
B.P. Koirala Memorial Cancer Hospital  
Bharatpur, Nepal*

## INSTITUTIONAL RESOURCES

Total beds	162
Palliative care beds	12
Staff physicians	2
Nurses	130
Specialized oncology nurses	10
Pathologists	8
Medical oncologists	2
Radiation oncologists	8
Pediatric oncologists	1
Specialized surgical oncologists	7
General and specialist surgeons	6
CT scanners	1
MRI scanners	none
Cobalt radiotherapy units	1
Linear accelerator units	2
Brachytherapy	1
Simulator	1

# NETWORK

## PROFILE IN CANCER MEDICINE

### PALAT DIRECTS INCTR PALLIATIVE CARE INDIA PROGRAM

The INCTR PAX Program is fortunate to have Dr. Gayatri Palat, an energetic and skilled palliative care physician, as its Program Director in India. A diplomate of the National Board of Anesthesiology, India, Dr. Palat has focused exclusively on end-of-life care and pain management in her medical practice. She credits teachers and mentors Robert Twycross, Professor MR Rajagopal and Suresh Kumar for the inspiration to pursue this path.

As project director of PAX India, Dr. Palat launched a pilot project at Mehdi Nawaz Jung Institute of Oncology and Regional Cancer Center (MNJ) in 2006. Collaborating with Dr. Durga Prasad, she succeeded in establishing a successful nodal center for palliative care at MNJ. Supported by the American Cancer Society and Pallium India, INCTR's pilot program now includes a medical officer, four nurses and three social workers.

MNJ is the only regional cancer center and the tertiary referral site for the entire state of Andhra Pradesh, population 65 million. The hospital accepts approximately 10,000 new patients every year, most suffering from pain and other distressing symptoms. "In India, by the time most patients seek help, their cancers are at an advanced stage and curative treatment is no longer an option. That is the reality," says Dr. Palat.

Under her leadership, the INCTR Palliative Care India Program has grown rapidly. More than 10,000 patients have received palliative treatment at the hospital itself, and, working with local agencies, a community-based service is underway, caring for cancer and HIV/AIDS patients in their homes. Many



**Dr. Gayatri Palat**

healthcare providers and members of the public have attended training and sensitization courses, gaining valuable patient care skills and spreading awareness of palliative care. "The good news is," Dr. Palat explains, "that when you educate the public about terminal care pain management, they expect it. With public pressure, the politicians will take note. So we put a lot of emphasis on public awareness."

Dr. Palat recognizes that the strengths of the program include continuing support from INCTR, Pallium India and others, a committed hospital management and a strategic location. In addition, family bonds are key. "We can teach family caregivers to deal with feeding, wound care and intestinal discomfort very effectively because they approach the patient with such dedication."

There are, however, limitations, not least of which are poor community access to care, inadequate palliative care for patients living with HIV/AIDS, and concerns about long-term funding for the project. She also believes they need to expand psychosocial support services. "Palliative care goes beyond medicine. It calls for a team approach among doctors, nurses, family members and social workers."

The absence of palliative care from the medical curriculum is an additional problem. Dr. Palat is working with others to rectify this situation as an advisor and faculty member of Education in Palliative and End of Life Care (EPEC) – India, and the National Faculty in Palliative Care.

Another challenge is ensuring an adequate and reliable supply of essential drugs, particularly morphine. In 2009 she and her associates successfully advocated for more liberal laws in Andhra Pradesh, which have improved the availability of opioids for medical use.

In addition to her responsibilities at MNJ, Dr. Palat serves on the advisory committee for palliative care of the National Cancer Control Program, India, and this year joined the Board of Directors of the International Association of Hospice and Palliative Care (IAHPC). She was selected to participate in The International Palliative Care Leadership Development Initiative operated by the Institute of Palliative Medicine at San Diego Hospice, a two-year program to develop the leadership skills of palliative care physicians from resource-limited countries. Dr. Palat has worked as a consultant for WHO-India preparing guidelines for establishing palliative care programs in the hospitals and communities of India, and addressing opioid availability. She was also a member of the International Atomic Energy Agency's mission to Colombo, advising on the development of palliative care in Sri Lanka.

Huge challenges remain, but with the passion and dedication of Dr. Palat, her colleagues, and support from national and international organizations, the future for INCTR's PAX program and palliative care in India looks encouraging. ■

*Marcia Landskroener  
and Alison Brown*