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Extending the **Hand of Hope** to Children **Around the World**

**International Outreach Program Partner Sites**

Non-partner Site Collaborators: Russia, Nicaragua, Dominican Republic and Panama

St. Jude has 16 partner countries around the world and four non-partner collaborations.

St. Jude International Outreach Program is described in the British Journal of Hematology as an “exemplary model for the rest of the world.”
The St. Jude Children’s Research Hospital International Outreach Program (IOP) entered its 15th year of activities in 2007. This year once again was a tremendous year of activities at IOP and at our partner sites around the globe. In concert with St. Jude, IOP implemented a 5-year strategic plan to carry out our mission of improving survival rates for children with cancer and other catastrophic illnesses worldwide through the sharing of knowledge, technology, and organizational skills. This year’s report provides a summary of our international partners’ hard work, measurable outcomes and challenges. However, despite continued advances in therapy that have dramatically increased the survival rates of children with cancer in developed countries, fewer than 30% of the world’s children have access to modern treatment. IOP is committed to developing partnerships with medical institutions and fundraising organizations in partner countries; IOP recruits other agencies and organizations to support key programs and the education of local personnel. Regionally, we use advanced telecommunications to link programs and professionals who learn from and assist each other. The cost-efficiency of shared resources also promotes local and regional self-sufficiency, which in turn enhances local capacity to treat children with cancer.

One of our main accomplishments in 2007 was the achievement of a significant milestone for the www.Cure4Kids.org web site: access of 1 million educational items in the first 5 years of operations by 14,000 users from more than 160 countries. The Cure4Kids web site brings the latest medical knowledge on the treatment of pediatric catastrophic diseases to healthcare providers in countries with limited resources. The web site offers a digital library, on-demand seminars with slides and audio in several languages, and online meeting rooms for international collaborations. These educational materials and Web-based conferencing tools are provided free of charge to all registered users of the site. Cure4Kids has definitely evolved to become a hallmark of St. Jude’s international outreach efforts to freely share and disseminate the expertise and body of knowledge of St. Jude Children’s Research Hospital’s discoveries and experiences with our world community.

The future holds great promise for our international outreach efforts as we remain committed with our international partners to continue on our never-ending quest to find cures and save the lives of children with cancer and other catastrophic illnesses.

Raul C. Ribeiro, MD
II. International Outreach Program 5-Year Strategic Plan

In June 2006, the St. Jude Children’s Research Hospital Executive Committee and Board of Governors published the institution’s 5-year strategic plan. Similar to St. Jude, IOP faces a future of opportunities and challenges. The IOP Strategic Plan was approved by the hospital leadership and the International Committee of the Board of Governors in January 2007. In concert with the St. Jude 5-Year Strategic Plan, the IOP Strategic Plan identifies three major areas to be developed further: Deliver Broad-Based Education & Training, Build Local Capacity, and Support Targeted Research. These three overarching areas will result in and facilitate partner site sustainability in the years to follow. From these three strategic areas, four objectives have been constructed: Increase the survival rate of children with cancer and other catastrophic diseases to international levels at IOP Partner Sites, share knowledge and expertise worldwide, provide high-quality nursing care to all patients and families at IOP Partner Sites, and integrate St. Jude research into IOP. From these four objectives and from recommendations from the 2006 External Advisory Committee Report, 11 goals have been developed that are consistent and congruent with the IOP programmatic mission and vision as well as aligned with the St. Jude Strategic Plan.

**International Outreach Strategic Plan Objectives and Goals 2007-2011**

**Objective I – Increase the survival rates of children with cancer and other catastrophic diseases**
1. To provide country-specific assessment of the incidence, treatment, and survival rate at Level I/II IOP partner sites for all childhood cancers and selected catastrophic illnesses.
2. Increase the survival rates for the five most common pediatric cancers at Level I/II IOP partner sites in 5 years.
3. Improve diagnosis, treatment, and prevention of infectious diseases.

**Objective II – Share knowledge and expertise worldwide**
4. To enhance the education of healthcare professionals and the public by providing the highest quality educational content, as evaluated by international users, subject matter experts, and peer review.
5. To provide online tools to support collaborations and enhance interaction among pediatric healthcare professionals.
6. To enhance twinning between institutions in high-income countries with centers in low-income countries with which St. Jude does not currently have partnerships.

**Objective III – Provide high-quality nursing to all patients and families at IOP partner sites**
7. Establish an improvement process for nursing care quality in Level I/II IOP partner sites.
8. To work with each Level I/II partner site to create a full-time nurse liaison position.
9. Integrate and enhance infection control prevention, surveillance, and management training into nursing curricula at partner sites.

**Objective IV – Integrate St. Jude research into IOP**
10. To participate in frontline treatment protocols with select IOP partner sites.
11. To develop and facilitate research studies involving St. Jude departments and international sites.

**Figure 1. IOP Strategic Plan Objectives and Goals**

IOP will continue to collaborate with partner sites to improve survival rates in childhood cancer and other catastrophic illnesses, to promote educational initiatives via Cure4Kids, to develop clinical and epidemiologic research at select international partner sites, and to implement nursing training and educational initiatives. Achieving these goals will require the collaborative efforts of IOP staff members, St. Jude academic departments and divisions, and our international partner sites.
III. Main Accomplishments and Highlights

2007 International Retinoblastoma Conference:

International Outreach hosted the 2007 International Retinoblastoma Conference at St. Jude on January 25-26, 2007. The conference was jointly sponsored by St. Jude and The University of Tennessee Hamilton Eye Institute under the leadership of Dr. Barrett Haik and Dr. Judy Wilimas. The international symposium and roundtable discussion brought together experts from around the world to discuss the treatment and research in retinoblastoma and provided opportunities for collaboration in the development of programs to treat children with this disease worldwide. The symposium was of interest to pediatric oncologists, pediatric ophthalmologists, basic scientists, residents, and fellows. The objectives of the conference were:

- To provide educational opportunities regarding the biology and treatment of retinoblastoma.
- To provide a forum for knowledge exchange among researchers from different disciplines and different countries.
- To discuss collaborative research opportunities.

The conference was attended by 160 participants representing 35 countries, 90 institutions, and 20 different languages. A total of 13.5 CME units were awarded for those in attendance. The retinoblastoma conference was transmitted via ISDN video conferencing and Cure4Kids Web conferencing to 15 countries. The ISDN video conference was transmitted to more than 60 participants in Chile, Guatemala, Morocco, Jordan, and Brazil. The Cure4Kids Web conference was attended by many online participants from Colombia, Costa Rica, Honduras, Mexico, Ecuador, and the Philippines.

St. Jude Pediatric Oncology Nursing Workshop, National University Hospital, Singapore:

IOP with support of 10 St. Jude pediatric oncology expert nurses conducted a 2-week Pediatric Oncology Nursing workshop January 15-26, 2007, at the National University Hospital (NUH) of Singapore. Ayda G. Nambayan, RN, DSN, IOP Curriculum and Distance Learning Developer, acted as the workshop coordinator and primary lecturer in Singapore. The primary goal of this workshop was to provide participants opportunities to further develop their knowledge and skills in pediatric oncology. The workshop included 26 face-to-face didactic lectures dealing with various aspects of pediatric oncology nursing practice, 10 Web conference lectures on various pediatric malignancies, delivered via Web conferencing on the Cure4Kids Web site, and 10 hours of supervised practice and cooperative learning strategies and case scenarios to apply the theoretical components of the workshop. Participants came from the two hospitals in Singapore, the NUH and the Kerang Kandau (KK) Women’s and Children’s Hospital. The workshop was partly supported by the Health Manpower Development Program of the Singapore Ministry of Health, IOP, and the NUH Pediatric Oncology Nursing Program. The on-site activities were primarily conducted by Dr. Nambayan and Linda Ewing, RN, MEd, nurse manager at Mater Children’s Hospital, Queensland, Australia. Lectures that required localization to the area such as nutrition and social work were given by local experts. The lectures on pediatric cancers delivered through the Web conference were given by St. Jude nursing experts.
One Million Items Accessed on www.Cure4Kids.org:

In March 2007, the Cure4Kids Web site reached 1 million educational items accessed in the first 5 years of operation with 10,000 users from 155 countries. As of April 2007, Cure4Kids had 14,000 users from more than 160 countries with 1.7 million items accessed.

Established as a part of the International Outreach Program, the Cure4Kids Web site brings the latest medical knowledge on the treatment of pediatric catastrophic diseases to healthcare providers in countries with limited resources. The Web site offers a digital library, on-demand seminars with slides and audio in several languages, and online meeting rooms for international collaborations.

After launching with 5 seminars in 2002, Cure4Kids, as of April 2007, contained 1,062 online seminars, 28 online self-paced courses, recorded sessions from 30 international conferences, and 190 international groups that meet online for education and project collaborations.

Oncopedia – Successful Launch:

Oncopedia is a new, freely accessible interactive educational resource on Cure4Kids.org designed for pediatric hematologists/oncologists, physicians, and other healthcare professionals who provide care to children with cancer worldwide. Oncopedia’s content is compiled using online submissions from Cure4Kids users. The content includes complex hematology/oncology cases and images with specific questions about patient management, controversial topics, and interesting presenting features, including illustrations of patient’s clinical characteristics and imaging and pathology findings. An international editorial board reviews all the contributions. The cases that are chosen are posted on Oncopedia with expert commentary from our editorial board and then opened for online moderated discussion. Registered Cure4Kids users can interact online with other users and the editorial board by posting opinions and questions about the content. There is also peer-reviewed, disease-specific information that is practical and up to date. All material may be freely used and downloaded for reference and educational purposes.
2007 St. Jude-Asia Forum-Singapore:

The Viva Foundation for Children with Cancer, National University Hospital (NUH) and National University of Singapore (NUS), and St. Jude hosted a world forum comprising 14 world leaders in acute lymphoblastic leukemia (ALL) March 9-11, 2007, in Singapore. The forum served as a platform for sharing knowledge in the management of childhood ALL as well as the latest advances in the treatment of childhood cancers by these experts. The Forum also presented an opportunity for pediatric oncologists and healthcare professionals to review and discuss the results of the major cooperative groups on childhood ALL from around the world. Drs. Ching-Hon Pui, Dario Campana, and Sima Jeha represented St. Jude during the Forum. Dr. Pui provided the opening lecture on The Biology and Treatment Outcomes of Childhood ALL: Lessons from St. Jude Total Therapy Studies, and Dr. Campana presented Detection and Elimination of Residual Disease in ALL.

2007 AHOPCA Meeting – Santo Domingo, Dominican Republic:

Several members of the St. Jude Children’s Research Hospital IOP traveled to the Dominican Republic February 14-17, 2007, to attend and participate in a 4-day meeting of the Association of Central American Pediatric Hematology-Oncology (AHOPCA) healthcare professionals and fundraising foundations. One highlight of this year’s AHOPCA meeting was the first fundraising workshop sponsored by the American Lebanese Syrian Associated Charities (ALSAC). The Latin American foundations in attendance represented the following countries:

- Costa Rica
- Ecuador
- El Salvador
- Guatemala
- Honduras
- Mexico
- Nicaragua
- Panama
- Venezuela

The overall feedback from the participants was nothing less than outstanding. Several core concepts and initial results for these workshops were as follows:
1. Live discussion of fundraising strategies and best practices.
2. Commitment of the foundations to begin formal collaborations and networking.
3. Agreement of the foundations to begin work on selecting a fundraising event that will be launched simultaneously by all the foundations in each respective Latin American country.
4. Agreement of the foundations, ALSAC, and IOP to begin monthly meetings in March 2007 to launch the study and development of a fundraising project via the Cure4Kids Web conferencing platform.
5. Commitment to meet again in 2008 to study the results of the fundraising activities and formalize the processes.
The IOP partner site in Quito, Ecuador, inaugurated a new pediatric oncology unit at the Baca Ortiz Hospital on March 26, 2007. This is a new 16-bed unit with two of the beds arranged as isolation beds. With the opening of this new unit, the Ecuadorian government has provided salaries for seven new nurses. IOP will be assisting the partner site in training these new nurses in the months to follow. Below are some “before” and “after” photos of the unit.
**Honduras Partner Site RETCAM Donation:**

IOP and The University of Tennessee (UT) Hamilton Eye Institute donated a Retinal Laser Camera (RETCAM) to our partner site at the Hospital Escuela in Tegucigalpa, Honduras, valued at approximately $80,000 (U.S.). Drs. Barrett Haik and Judy Willimas and Mrs. Blanca Philips attended a nationally broadcast ceremony of the official donation of the RETCAM to our Honduran partners on behalf of St. Jude and the UT Hamilton Eye Institute. Following the donation ceremony, the local press conducted an interview with staff from both St. Jude and Hospital Escuela. Dr. Haik provided information about St. Jude, IOP, our global mission, childhood eye cancer, and the improvements in survival of this form of cancer when detected and treated early.

This is the second RETCAM strategically placed in Central America; the first camera was given to Guatemala in 2004. This new RETCAM in Honduras will alleviate referrals to Guatemala, which will promote easier and more cost-effective access to diagnosis, care, and treatment. Retinal images will be posted on the ORBIS Web site to facilitate diagnosis as well as treatments recommended by experts in this field. The new Honduran RETCAM site will provide a much-needed service to children in Honduras. Dr. Haik also examined several patients with the donated RETCAM during his visit.

**Live Webcast – International Dengue Fever Meeting:**

St. Jude IOP via Cure4Kids hosted an international live meeting on dengue fever with experts from St. Jude, El Salvador, and Paraguay presenting important facts regarding the diagnosis and management of dengue in children and answering questions from participants. There were 65 participants from 11 countries including Colombia (2), Costa Rica (1), El Salvador (33), Guatemala (4), Honduras (4), Nicaragua (3), Paraguay (3), Panama (4), Peru (1), Venezuela (3), and the United States (7).
IV. New Twinning Model and Partner Site

Singapore:

A new twinning model with Singapore and the Philippines was formally established in 2006, and 2007 was the first full year of collaborative efforts. In this new twinning initiative, Singapore is the lead mentoring partner in assisting the Philippines in developing a Pediatric Hematology-Oncology program. The National University Hospital (NUH) and the Viva Foundation for Children with Cancer are our collaborative partners in Singapore. This Singaporean twinning initiative has four aims: 1) improving the survival of children with cancer and hematologic disorders; 2) implementing techniques of minimal residual disease; 3) establishing collaborative research between St. Jude and Singaporean investigators; and 4) developing a Pediatric Hematology-Oncology unit in Davao, Philippines. In this collaborative relationship, IOP provides mentoring and scientific collaboration to the NUH pediatric oncology program with emphasis on enhancing the bone marrow transplant program. This twinning initiative will also introduce techniques for treating complex hematologic/oncologic diseases and detecting minimal residual disease that might have substantial impact on patient outcome. In addition, there are significant opportunities for collaborative research between this region in Asia and St. Jude Children’s Research Hospital.

The first year of NUH-Viva Foundation for Children as a collaborative site of St. Jude was a productive one. The Inaugural St. Jude-Asia forum was held March 9-11, 2007, in Singapore. The forum brought 14 of the leading experts in ALL from around the world and was well attended by participants from all over the region, including Malaysia, Indonesia, the Philippines, Thailand, Vietnam, Taiwan, Hong Kong, the People’s Republic of China, Myanmar, Australia, and Sri Lanka. The forum served as a venue for working groups to present the results of their protocols and was the first of its kind in Asia. This event was followed by a 3-day workshop on techniques of minimal residual disease detection by flow cytometry pioneered at St. Jude, as conducted by Ms. Elaine Coustan-Smith and Dr. Dario Campana. The response to the workshop was very positive among the selected participants. Participants in both events are looking forward to next year’s meeting.

Training initiatives to reach out to the region were also initiated, beginning with the IOP partner site in Davao, Philippines. The first of these is the development of Pediatrics Oncology Nursing as a critical aspect to support any Pediatric Oncology Program in the Philippines. The NUH sent a senior Clinical Nurse to Davao for a site visit and needs assessment. Based on this visit, an appropriate schema of training was outlined. A regular and constant interaction through emails and Cure4Kids Horizon Live meetings subsequently were undertaken upon the return of the nurses to Davao. Training of doctors and allied health specialties were also given attention. Under the auspices of St. Jude, several Singaporean clinicians visited St. Jude and trained with St. Jude investigators and faculty in several areas, including Cellular Therapy, Flow Cytometry, and clinical viewing rotations at the Bone Marrow Transplant service.
Davao, Mindanao, Republic of the Philippines:

Davao is on the island of Mindanao in the southern part of the Philippines. The island has a population of 25 million and reports about 150 new cases of childhood malignancies per year. The geographic location of Davao makes it strategic to serve as a referral center for nearby areas of Visayas Island and other Southeast Asian countries such as Borneo and Malaysia. The Davao Medical Center (DMC) is the largest tertiary public hospital in Mindanao. The Hematology-Oncology Pediatric Unit at DMC sees approximately 100 new cases of children with cancer every year, a proverbial tip of the iceberg, because many children in Mindanao never have an opportunity to see a doctor, their disease remains undiagnosed, and they die in their homes.

The Philippine Society of Pediatric Oncology in 2006 reported a 10–20% cure rate for childhood malignancies in the country. Some of the reasons for this dismal cure rate include socioeconomic and cultural factors such as abject poverty, use of unconventional healthcare providers such as faith healers, a healthcare system with priorities other than childhood cancers, and a lack of governmental support for health care and education. Combined, these factors lead to late diagnosis and high rates of treatment abandonment, resulting in a survival rate of 10–20%. Every day in the Philippines, approximately 300 children die of a malignancy that is curable in developed countries. It is under these austere and difficult conditions that our collaborators in Singapore and the St. Jude IOP partnered together. Thus began the twinning initiative to assist the medical professionals at the DMC in the task of improving local conditions and therapies to improve the current survival rates to at least 50% by 2011.
diagnosis and have opted to cross the border for care in the United States. Patients usually arrive through RCH's emergency room, uninsured and with no medical records. RCH has been treating these patients at no cost and discharging them for outpatient follow-up care in collaboration with the Centro Oncológico Pediátrico (COP) in Tijuana. The COP was established by the Fundación Castro Limón in 2006 with the sole purpose of providing care to children with cancer who have no insurance. COP accepts patients regardless of their ability to pay and strives to provide the best quality of care available. Through the recently created alliance between RCH and St. Jude, the opportunity exists to strengthen the availability of quality care for children with cancer in Tijuana and eventually limit the need for these patients to travel to the United States for treatment.

The COP, however, currently does not have the dedicated personnel or a supportive care infrastructure to manage complex and acute-care inpatients. Enter the third partner in the Tijuana twinning project, the Hospital General. This is a fairly new facility for pediatric and adult disorders. Mother and child diseases account for most of the medical problems treated in this hospital. However, there is a pediatric oncology program led by a group of experienced pediatric oncologists and surgeons. A local foundation called the Patronato Hospital General, which is a private, nongovernmental organization, provides support to medical projects within Hospital General and has renovated a section of the general pediatric unit to be used exclusively for children with cancer. A newly refurbished five-room unit is very well designed; however, it has not been activated because of a lack of funds to finish equipping it and hiring the necessary staff. Another local grassroots foundation, the Asociación de Cáncer Infantil de Baja California, is actively fundraising in the community for children with cancer and closely collaborating with the physicians from Hospital General. The foundation’s primary mission is to support all children with cancer in the Tijuana area. The main expenses of the foundation’s efforts have been related to purchasing anticancer medications. With the advent of the Mexican government’s Seguro Popular, a national insurance program that guarantees medication for children with cancer in Mexico at no cost, the foundation’s main efforts can potentially be redirected toward other community efforts such as equipping the pediatric cancer ward and creating patient/parent housing to reduce abandonment of treatment.

**V. New Initiatives**

**Mexico Program Expansion:**

IOP currently has two established formal partnerships in Mexico: one in Culiacán, Sinaloa, and one in Guadalajara, Jalisco. The year 2007 marked the initial phase of exploring the possibilities for twinning expansion of our Mexico program with new partnerships in Tijuana and Los Cabos, both in the state of Baja California. The four primary objectives of the expansion of the Mexico program are: 1. Establish a pediatric oncology unit in both Tijuana and Baja California; 2. Provide local access to pediatric oncology care in Tijuana that will contribute to diminishing the need for parents and children to travel to the United States (particularly San Diego, California) to seek treatment; 3. Consolidate St. Jude IOP efforts to the four main western regions of Mexico; and 4. Develop strategies to decrease abandonment of treatment in these regions of influence.

![Map of Mexico with partner and expansion sites.](image)

**Figure 5.** Map of Mexico with partner and expansion sites.

**Tijuana**

In 2007, St. Jude entered into a clinical and basic science research alliance with Rady Children’s Hospital (RCH) in San Diego, California. For several years, RCH has been receiving approximately 30 immigrant pediatric cancer patients from the Tijuana area annually. The location of RCH, just 15 minutes from the United States-Mexico border, makes it an easily accessible option for patients who have received a cancer diagnosis and have opted to cross the border for care in the United States. Patients usually arrive through RCH’s emergency room, uninsured and with no medical records. RCH has been treating these patients at no cost and discharging them for outpatient follow-up care in collaboration with the Centro Oncológico Pediátrico (COP) in Tijuana. The COP was established by the Fundación Castro Limón in 2006 with the sole purpose of providing care to children with cancer who have no insurance. COP accepts patients regardless of their ability to pay and strives to provide the best quality of care available. Through the recently created alliance between RCH and St. Jude, the opportunity exists to strengthen the availability of quality care for children with cancer in Tijuana and eventually limit the need for these patients to travel to the United States for treatment.
In summary, the COP and Hospital General contain the main elements necessary to establish a successful twinning program. Pediatric oncologists are dedicated to and excited about the possibility of further improving local conditions. The leadership at both Tijuana centers supporting this twinning initiative and the existence of a grassroots foundation with the mission to assist all children with cancer regardless of their ability to pay for treatment are critical strengths for the success of this project.

**International Atomic Energy Agency Latin American Radiation Oncology Initiative**

The International Atomic Energy Agency (IAEA) is an independent, intergovernmental, science- and technology-based organization in the United Nations family that serves as the global focal point for nuclear cooperation. The agency is known for development of nuclear safety standards and verification through its inspection system that member states comply with their commitments to use nuclear material and facilities only for peaceful purposes under the Non-Proliferation Treaty and other agreements. However, many are unaware that the IAEA also assists its member states, in the context of social and economic goals, in planning for and in the use of nuclear science and technology for various peaceful purposes. This includes the transfer of such technology and knowledge in a sustainable manner to developing radiation oncology programs in member states.

In 2004, the IAEA established the Programme of Action for Cancer Therapy (PACT) initiative with a global vision of establishing partnerships for assisting member states in cancer prevention, treatment, and control programs. St. Jude IOP was given an extraordinary opportunity to facilitate the application of an IAEA-PACT grant for the development of a pediatric radiation oncology education initiative in Latin America. Pediatric radiation oncology remains a severely neglected area in most developing countries. The main constraint is a lack of trained individuals in this discipline. Moreover, there are no opportunities for formal training in pediatric radiation oncology in member states. Over the last decade, St. Jude IOP has partnered with several pediatric oncology units in Latin American member states, leading to the creation of adequate infrastructure and human capacity to treat most pediatric malignancies. This partnership model has now extended to many other countries of the world. However, further progress will require the integration of radiotherapy into the existent multidisciplinary framework. The “twinning” model, rooted in an alliance between a local government and a grassroots foundation solely dedicated to pediatric cancer and St. Jude IOP, has been successful in improving survival of children with cancer in member states.

El Salvador was the first of such twinning programs and represents a model of positive interaction between local public and private sectors with international institutions. Hence, El Salvador is well positioned to initiate and actively participate in this IAEA radiation oncology project. Institutions in other member states, including Chile, Honduras, Brazil, and Argentina, have committed their support to this initiative. This project consists of three educational initiatives:

**IAEA Radiation Oncology Educational Initiatives**

1. Conduct two workshops in pediatric radiation oncology (one in Central America and another in South America) over the next 3 years. Member states’ radiotherapists, the IAEA, and St. Jude would collaborate to prepare these workshops.

2. Establish a pediatric radiation oncology training center in a member state in Latin America (to be determined). This would be a joint venture among the IAEA, local government, and St. Jude IOP. St. Jude IOP would provide salary supplementation for a radiation oncologist to oversee and support this training center initiative. A board composed of representatives from Latin American member states would oversee the fellowship training program.
3. Create a pediatric radiation oncology fellowship training program in this center for interested candidates in Latin America. The oversight of this center and evaluation of the training program would be done in conjunction (IAEA, local government, and St. Jude). This program can serve as a model for the development of training of pediatric radiation oncology in other parts of the developing world.

St. Jude IOP with support from IAEA can promote the effective and integrated application of radiation therapy in pediatric oncology by initially providing and hosting two regional seminars, providing fellowship opportunities, and creating a Latin American training center in a member state. This project will truly be a collaborative venture among member states, St. Jude, and other interested parties under the auspices of IAEA. St. Jude IOP would provide funding for key staffing requirements at the proposed training center in the designated member state. In addition, Dr. Thomas E. Merchant, Division Chief of Radiation Oncology at St. Jude, has agreed to personally commit time to oversee this project by establishing the workshop curriculum and coordinating all aspects for the establishment of the training center. These three projects will provide a cost-effective strategy for establishment of pediatric oncology radiation therapy throughout Latin America and other parts of the world.

**China Program Supportive Care Initiative:**

An integral part of any treatment protocol is the supportive care accessible to patients and families. As the China ALL protocol matures, we are now poised to enter into a second phase of improving and enhancing care at the Shanghai Children's Medical Center (SCMC) and Beijing Children's Hospital (BCH). The Partner in Hope Foundation has graciously provided funding to IOP to promote a comprehensive support care initiative at our partner sites in Beijing and Shanghai. The following are five new programs that will not only enhance current practices and the quality of care and life of the patients, but also serve as an example of care excellence in each respective hospital:

**Temporary Housing**

Many of the children treated in both Beijing and Shanghai come from poor families who travel long distances to receive maintenance chemotherapy for extended periods of time. This places a huge strains—financial, time, and family—on the parents of these patients. These factors many times lead to abandonment of treatment, even when treatment is provided free of cost to the child. One of the most successful programs not only at St. Jude, but also at our international partner sites in El Salvador, Brazil, and Morocco, is the provision of temporary housing for patients and families. This vital resource is a major contributing factor in reducing treatment abandonment rates. IOP is piloting a temporary housing program at both sites. In year 1, IOP is providing accommodations at two furnished apartments within walking distance of the Shanghai Children's Medical Center. After studying utilization of these apartments in Shanghai, the program will be extended to Beijing, where two additional furnished apartments will be acquired for use of patients and family members. After completion of year 3, IOP will conduct a comprehensive survey and analysis of the results and effects that this program has had on the treatment of ALL at both centers. It is anticipated that these apartments will curtail the effect of treatment abandonment as well as serve as an initial study for the development of a permanent housing program at both centers (e.g., Ronald McDonald House).
Palliative Care

Contemporary medical knowledge and access to resources is sufficient to control the suffering of most of the millions of terminally ill patients in the world if applied appropriately. However, palliative care is still unavailable to most patients in developing countries. Currently, there are no palliative care programs established at the BCH and SCMC. Three central issues arise from this situation: 1. Effective and tailored pain management is not available for children undergoing ALL treatment at BCH and SCMC; 2. Children unable to enter to the current ALL protocol due to their classification as “high risk” and having advanced terminal disease do not have palliative care available; and 3. Access to controlled pain medicines and mechanical delivery equipment is limited. There is a need for demonstrations of good care and effective symptom control for these children. IOP is piloting the implementation of palliative care programs at each center to include full-time nurses, part-time physicians, access to controlled analgesics and delivery equipment (e.g., medication pumps), and palliative care training. This palliative care demonstration project will also promote local educational programs that take account of local realities and promote attitudes, knowledge, and skills capable of gradually introducing a greater professional concern and a better prospect of effective care for dying children.

Infection Control

Among immunocompromised children treated in hospitals, such as children undergoing intense chemotherapy, the main cause of mortality is infections, most of which are nosocomially (hospital-borne disease) acquired. IOP is piloting an initial two-phase approach to locally developing enhanced infection control surveillance activities and interventions. Phase 1 consists of providing infection control training to key nursing staff, who in turn will develop local infection control programs at each hospital. This “train the trainer” instruction will take place in Hong Kong, Taiwan, or Singapore at a children’s hospital with which IOP has a longstanding relationship. Phase 2 consists of access to hand hygiene supplies. Because hand hygiene has been recognized as the single most important method of preventing infections acquired in healthcare settings, major efforts have been directed at maintaining a high rate of compliance with hand hygiene. The World Health Organization (WHO) has developed universal guidelines on hand hygiene for healthcare workers in the developing world with emphasis on the use of gel products. The use of waterless hand hygiene products such as gels containing at least 60% alcohol reduces the carriage of microorganisms on the hands of healthcare providers and effectively decreases the incidence of infections acquired in healthcare settings. IOP is supporting a pilot implementation of the WHO guidelines at both centers for the next 3 years. A similar project is currently under way at our partner site in El Salvador. If this program is successful and current infection rates can be reduced, this model easily can be replicated throughout Asia. These findings can also be published in a peer-reviewed journal by the lead Chinese infection control managers at both centers, thereby contributing to the overall body of knowledge in infection control.

Data Management

Once a functional and successful pediatric cancer treatment program is established, such as the programs at the BCH and SCMC, multiple advances are needed to develop these programs into centers of excellence. Quality improvement depends on implementation of rational, cost-effective interventions based on rigorous measurement of treatment results, complications, and obstacles to delivery of optimal protocol-based care. A data management program is essential to determine the most important areas that require improvement and to assess the effect of specific interventions on the treatment outcomes and quality of care. Many clinical programs in countries such as China lack functional data management systems even when funds are available due to lack of personnel with data managerial qualifications. St. Jude IOP has developed and implemented a computerized data collection system and a low-cost training program for data management in the pediatric oncology programs at all of our partner sites. This data management program is Pediatric Oncology Networked Database (POND). POND provides:

- A safe and secure place to store clinical data
- Easy to use Web-based technology
- Multilingual ability
- Flexible data sharing among authorized and consented users (e.g., between BMC and SCMC)
- Global access via the Internet.
POND, however, is just a tool, and without people to actually track and safeguard data, the tool is useless. IOP has provided funding to hire a full-time data manager at each center to work with each medical director to begin comprehensive tracking of data, improving the quality of care via evidence-based data reporting, and building an infrastructure for future research.

**Nursing Education Program Enhancement**

Nursing is the “foundation of health care” around the world. This is especially true in China, where the development of and access to advanced medical care and interventions is changing the face of medicine. IOP is implementing a strategy to enhance the quality of pediatric oncology nursing care at both the BCH and SCMC by: 1. Conducting and evaluating the quality of nursing care, providing recommendations based on the results, and developing a proposal for the implementation of these recommendations; and 2. Hiring a full-time Pediatric Oncology Nurse Educator for each hospital.

Baseline Nursing Evaluation: A baseline assessment is required to determine the current quality of nursing care at both the BCH and SCMC. This assessment will serve as the basis from which to appraise future efforts to improve nursing care. A comprehensive nursing quality report using nationally recognized standards would provide credible support for nursing needs. This report would be beneficial to policy-setting leaders, educators, foundation members, and others influential in health care in Beijing and Shanghai. The nursing assessment is organized into the following broad categories:

- Access to care and continuity of care
- Assessment of patients
- Care of patients
- Patient and family education
- Prevention and control of infections
- Staff qualifications and education.

Upon completion of the assessment, recommendations to support the provision of quality of nursing care will be provided. Recommendations will be guided by International Joint Commission Guidelines related to nursing care, Association of Pediatric Hematology/Oncology Nursing (APHON) guidelines, and nursing research results.

Full-Time Pediatric Oncology Nurse Educators: Currently, at both the BCH and SCMC, there are no designated nursing education staffs to ensure new nurses receive adequate training. The burden of orientation falls on whomever is available at the time, and most often, a staff nurse assumes the responsibility. There is no organized, written program for ongoing education or process to ensure that all nursing staff members receive education. Adequate orientation and continuing education programs have been shown to improve nursing retention and decrease mortality and morbidity. The nurse educator position is a new role at both the BCH and SCMC. The Nurse Educator is dedicated full-time to educating and mentoring pediatric oncology nurses.
IOP Nursing Program Expansion

The IOP Nursing Program's mission is to provide the highest quality of nursing care to patients and families at IOP partner sites. Four broad program goals were designed to create a synergy that supports the program's expansion and development. These four strategic goals are: 1. Develop and implement a process for assessing and improving the quality of nursing care; 2. Provide comprehensive pediatric oncology education and training to nursing staff by hiring partner site nurse educators and creating regional training centers; 3. Develop strong partnerships with nursing leaders and educators affiliated with international nursing; and 4. Contribute to the international nursing body of knowledge through research.

Goal 1: Develop and implement a process for assessing and improving the quality of nursing care.

A nursing quality assessment instrument was developed using universally recognized Joint Commission International standards relevant to nursing practice. Instrument development was a collaborative effort with Paula Dycus, the St. Jude Standards & Practice Coordinator and a University of Tennessee doctoral candidate. The nursing quality assessment process provides an objective and credible evaluation that serves as the baseline from which nursing needs and recommendations are determined. The assessment also provides an organizational framework for implementing change and gauging success in improving the quality of nursing care.

Goal 2: Provide comprehensive pediatric oncology education and training to nursing staff by hiring partner site nurse educators and creating regional training centers.

The nursing quality assessment reports confirmed that education and training were priority needs. Although partner sites often had a nurse designated to provide nursing education, this person was also a full-time staff nurse and thus could not realistically fulfill additional education responsibilities. To address this need, we created a partner site nurse educator position. The person filling this position will be dedicated full-time to educating and mentoring nurses and is responsible for:

- Implementing a comprehensive nursing orientation program
- Evaluating the educational needs of staff and providing continuing education activities
- Ensuring nurses demonstrate appropriate job performance skills
- Providing ongoing assessment of the quality of nursing care and facilitating quality improvement projects
- Serving as the primary contact with the IOP Nursing Director
- Completing monthly reports summarizing nursing activities.

Three nurse educators have been hired in Guatemala, Chile, and El Salvador. A summary of their combined accomplishments includes:

- Completed a comprehensive assessment and analysis of educational needs of staff, including nurses and auxiliaries
- Developed nursing educational plans for 2007
- Organized a team of nurses to review and revise policy manual and have begun revision of policies using evidence-based practice guidelines
- Provided training for nursing competencies
- Developed an educational booklet, Basic Introduction to Nursing Care of the Transplant Patient
- Presented multiple lectures and developed PowerPoint presentations
- Developed questionnaires for assessing knowledge gained from nursing presentations
- Oriented more than 30 new staff nurses and auxiliaries
- Assessed educational needs of parents using focus groups
- Organized parent education classes and created a parent education booklet.
Latin American Center of Nursing Excellence and Training

In 2007, IOP established the Latin America Center of Nursing Excellence and Training at Luis Calvo MacKenna Hospital in Santiago, Chile. The purpose of this center is to provide education, resources, and mentoring to the nurse educators. Nurse educators will visit the center annually and will receive education and witness exemplary nursing care, an organized nursing structure, and positive nurse-physician relationships. The center serves as the hub for nursing policy and protocol development and thus helps to standardize nursing care in our Latin American partner sites.

Educational Conferences

Horizon Live conferences occur monthly with nursing participants from partner sites in Morocco, Jordan, Lebanon, Honduras, Guatemala, and El Salvador. Topics presented during the past year include pain management, line care, nursing education, resources for patients and families, delivering bad news, nutritional assessment, and cancer genetics.

Goal 3: Develop strong partnerships with nursing leaders and educators affiliated with international nursing.

In 2007, IOP worked closely with nursing advisors at St. Jude and elsewhere in the United States, as well as internationally. IOP Nursing has collaborated on international nursing projects with nursing professors and students from the University of Tennessee Health Science Center. In addition, IOP is actively involved with the International Society of Pediatric Oncology (SIOP) Nursing Group, Sigma Theta Tau International Nursing Association, the Oncology Nursing Society (ONS), and the Association of Pediatric Hematology/Oncology Nursing (APHON) International Task Force. The IOP Nursing Program is aggressively pursuing and finalizing a proposal for affiliation with the University of Alabama School of Nursing World Health Organization Collaborating Center.

Goal 4: Contribute to the international nursing body of knowledge through research.

During 2007, two abstracts were accepted for oral presentations, and two manuscripts were accepted for publication.

Day S, Dycus P, Chismark E, Nambayan A: Process for Measuring the Quality of Nursing Care in Developing Countries Sigma Theta Tau International Honor Society of Nursing, 18th Nursing Research Congress, July 2007.


United Nations International Medical Assembly Meeting:

Dr. Elaine Valdov, the Secretary General, Medical Assembly at the United Nations, invited Dr. Ribeiro to speak and participate in the 1st Annual International Medical Assembly (IMA) at the United Nations, April 3-5, 2007. The IMA working together with UN agencies, UN missions, international non-governmental organizations, Civil Society International, and the private sector are dedicated to work toward strategies to facilitate the following:

- To stop the predicted worldwide cancer epidemic
- To examine ways and means to prevent cancer
- To promote early detection of cancer
- To provide knowledge of effective/accessible treatments to cancer
- To create a world environment that promotes healing and health.

Dr. Ribeiro presented the St. Jude Children’s Research Hospital International Outreach Program experience, including our twinning strategy to promote international partnerships with emphasis on sharing of knowledge, collaborative mentoring, evaluation, consultation, education, and research; a demonstration of satellite pediatric oncology clinics in Honduras; and the impact and success of Cure4Kids.

Dr. Downing Visits Chilean Partner Site:

Dr. James R. Downing, St. Jude Scientific Director, visited our Chilean partner site in Santiago April 14-18, 2007. Visiting Chile with Dr. Downing were George Vélez, Administrative Director of the St. Jude International Outreach Program; Gastón K. Rivera, MD, Medical Director of the St. Jude – Chilean Partner Site Program, and Carlos Rodríguez-Galindo, MD, Medical Director of the St. Jude – Mexico Partner Site Program.

Dr. Downing toured the facilities of the pediatric Luis Calvo MacKenna Hospital with emphasis on the Bone Marrow Transplant program. He also toured facilities at the School of Medicine of the University of Chile. The dean of the School of Medicine awarded Dr. Downing the University of Chile Academic Excellence Award. Dr. Downing is the first foreign recipient of this prestigious award.

During this visit, Dr. Downing and the St. Jude officials also met with the country’s president, Michelle Bachelet, MD. Dr. Downing discussed the planned expansion of the successful bone marrow transplantation program established by St. Jude in Santiago and potential future collaborations in basic science research between St. Jude and the University of Chile. President Bachelet is also a pediatrician committed to child healthcare issues and was pleased to learn that the St. Jude program is exploring additional collaborations in Chile.
High-Definition Telemedicine:

International Outreach supported the implementation of high-definition video equipment at St. Jude. The Polycom Corporation has donated its latest teleconference equipment model UltimateHD, named Polycom High Definition, to both Medical Missions for Children (MMC) at St. Joseph’s Children Hospital, New Jersey, and to St. Jude Children’s Research Hospital. For many years, MMC and St. Jude IOP have collaborated to broadcast medical information worldwide. From Polycom’s perspective, this is a significant opportunity for implementing their equipment for telemedicine. This is the first installation of high-definition equipment in any hospital. For St. Jude and MMC, it represents an opportunity to expand and improve our communication for patient care and research (domestic affiliates and national collaborative sites). We can imagine projects (collaborative protocols) in diagnostic imaging and pathology, retinoblastoma, osteosarcoma, and perhaps brain tumors. The dedication ceremony on March 22, 2007, was attended by Mr. Frank Brady, Chairman of MMC; Mr. Robert C. Hagerty, Chairman of Polycom; Dr. Joseph Mirro, Chief Medical Officer for St. Jude; Dr. Ching-Hon Pui, Chair of the St. Jude Department of Oncology; and Dr. Raul Ribeiro, Director of St. Jude IOP. “The new technology represents a wonderful step forward for the St. Jude International Outreach Program,” Dr. Ribeiro said. “It will also enable us to disseminate high-quality educational content to our international partner sites.” Dr. Mirro stated that, “We’re on the forefront not only of medicine but of medical education.”

Mexican Pediatric Oncology Meeting for the Design of a National Childhood ALL Trial

On August 25, 2007, 100 pediatric oncologists from throughout the Republic of Mexico met in Mexico City to discuss the final aspects on a new protocol study for children with ALL. Importantly, this will be the first national childhood leukemia study in Mexico and will be sponsored by the Mexican government. The Seguro Popular, a health agency program of the Mexican Ministry of Health, will fund all treatment-related costs for patients enrolled in the study. The protocol opens on January 1, 2008.

Dr. Gaston K. Rivera from St. Jude IOP was invited to participate as an external expert to moderate the discussion, to suggest the best treatment options, and to advise on the overall experience with management and therapy for children with leukemia in other IOP Latin American countries. Dr. Roberto Rivera Luna, Director of the Hematology Oncology Department at the Instituto de Pediatría, the head coordinator of the project, chaired the meeting.

The objective of the meeting was to attain consensus from the various group members on how best to define risk groups and design therapy for different ALL subgroups over the next 5 years, taking into consideration the present circumstances and available technology in the country. Dr. Rivera presented the St. Jude historical background, new diagnostic technologies, and the state-of-the-art for the treatment of childhood ALL as of 2007, including published results from all major childhood ALL American and European groups. In addition to the clinical results attained in worldwide trials, other aspects were also emphasized as follows:

- How to conduct the trial
- How to capture the information
- How to analyze the data, and
- How to report it.

Dr. Rivera recommended a uniform, protocol-based treatment for all children, the naming of the principal investigators in each participating institution, the definition of the roles of the principal investigators, the maintenance of good communications at all times, and the encouragement of teamwork.


**VII. Current Partner Site Trends**

*Multidisciplinary Team Composition*

The St. Jude holistic model of pediatric cancer treatment is the hallmark of our institutional focus on patient, treatment, and research. Our partner sites have embraced this model and have incorporated it into their healthcare team and delivery. Today, all of our partner sites have acquired and hired 12 healthcare specialists to promote and deliver pediatric oncology and hematology treatment. The future challenge for our partner sites is to recruit and retain the right mix and quantity of multidisciplinary healthcare professionals. This challenge is made more formidable by the lack of a nationally sponsored pediatric cancer treatment program, poor economy, competition for healthcare professionals by developed countries (e.g., physicians leaving countries to practice in developed countries), and other resource availability issues. With this in mind, it is a true testament to the dedication of our partner sites that they are able to sustain at least a limited multidisciplinary team. The chart at right provides the average number of each of the 12 healthcare specialties represented at our partner sites.

---

**Distribution of Diseases:**

Our partners are seeing a wide range of childhood cancers each year. Our partners report that ALL continues to constitute more than one third of all incidence of childhood cancers, followed in frequency of diagnosis by lymphomas and acute myelogenous leukemia (AML). Below is a graphical depiction of the distribution of 11 of the most common childhood cancers as reported from our international partner sites.

![Distribution of Diseases](Figure 7)

Figure 7. Distribution of disease at IOP partner sites: 2006-2007

**Multidisciplinary Team Composition**

The St. Jude holistic model of pediatric cancer treatment is the hallmark of our institutional focus on patient, treatment, and research. Our partner sites have embraced this model and have incorporated it into their healthcare team and delivery. Today, all of our partner sites have acquired and hired 12 healthcare specialists to promote and deliver pediatric oncology and hematology treatment. The future challenge for our partner sites is to recruit and retain the right mix and quantity of multidisciplinary healthcare professionals. This challenge is made more formidable by the lack of a nationally sponsored pediatric cancer treatment program, poor economy, competition for healthcare professionals by developed countries (e.g., physicians leaving countries to practice in developed countries), and other resource availability issues. With this in mind, it is a true testament to the dedication of our partner sites that they are able to sustain at least a limited multidisciplinary team. The chart at right provides the average number of each of the 12 healthcare specialties represented at our partner sites.

---

**Specialty** | **Average**
--- | ---
Pediatric Oncologist/Hematologist | 4
General Pediatrician | 6
Surgeon | 2
Radiation Oncologist | 1
Intensivist | 3
Fellow/Resident | 5
Nurses | 24
Infection Control Professional | 2
Pharmacist | 2
Dietician/Nutritionist | 2
Social Worker | 5
Psychologist/Psychiatrist | 4

Figure 8. Healthcare specialties at IOP partner sites.
**2007 IOP Partner Site Medical Director Survey:**

IOP conducted a survey of all of the international partner site medical directors in 2007 to gauge current trends relating to difficulties experienced at each center. The following is a summary analysis of the responses of 22 directors.

### 2007 Medical Directors Survey

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes (%)</th>
<th>No (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>In 2007, centers reporting patients having all of the medications necessary for their treatment.</td>
<td>35%</td>
<td>65%</td>
</tr>
<tr>
<td>Centers reporting government/hospital providing all medications for children with cancer.</td>
<td>41%</td>
<td>59%</td>
</tr>
<tr>
<td>In the last year, patients experiencing alterations in treatment for more than 2 weeks because of a lack of medications.</td>
<td>41%</td>
<td>59%</td>
</tr>
<tr>
<td>Centers reporting medications available for treatment ONLY if the patient’s family has the money to purchase them or our local supporting foundation provides these medications to the patient.</td>
<td>35%</td>
<td>65%</td>
</tr>
<tr>
<td>Top five medications centers report difficulty obtaining.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Actinomycin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- All-trans retinoic acid (ATRA)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- L-asparaginase</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Methotrexate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Mercaptopurine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Percentage of effort healthcare personnel dedicate to the pediatric oncology service.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Full-time</td>
<td>53%</td>
<td></td>
</tr>
<tr>
<td>- Part-Time</td>
<td>29%</td>
<td></td>
</tr>
<tr>
<td>- Contract Services</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>- Service provided by hospital</td>
<td>6%</td>
<td></td>
</tr>
</tbody>
</table>

*Figure 9. 2007 Medical Director Survey*
Cure4Kids:

Cure4Kids continues to grow at an exponential rate and has become an international gateway for pediatric oncology and hematology education, communication, and a research library. Established as a part of the International Outreach Program, the Cure4Kids Web site brings the latest medical knowledge on the treatment of pediatric catastrophic diseases to healthcare providers in countries with limited resources. The Web site offers a digital library, on-demand seminars with slides and audio in several languages, and online meeting rooms for international collaborations. Cure4Kids was launched on October 1, 2002, with 35 users and five online seminars. In 2007, the number of Cure4Kids users grew from 9,013 to 12,710. Cure4Kids has over 1,000 online educational seminars. The online content on Cure4Kids has been accessed more than 1 million times in 2007.

Online Continuing Education

In 2007, Cure4Kids contained and provided more than 1,000 online seminars, 28 online self-paced courses, and recorded sessions from 30 international conferences. The online educational content includes:

- Cure4Kids has online 1,019 on-demand seminars with slides and audio in several Languages, including English, Spanish, Portuguese, Chinese, Arabic, French and Russian.
- The Cure4Kids Pediatric Nursing Oncology course has been accessed 12,337 times by 8,625 users.
- The End-of-Life Nursing Education Consortium palliative care course on Cure4Kids has been accessed 33,393 times.
- Since 2004, Cure4Kids has recorded the keynote seminars from the annual conference of the International Society of Pediatric Oncology (SIOP). The 62 SIOP keynote seminars on Cure4Kids have been accessed 123,702 times by 2,621 users.
- Cure4Kids has 70 Grand Rounds seminars from Le Bonheur Children’s Medical Center.

Figure 10. Cure4Kids world map of access locations.

Figure 11. Growth of the number of Cure4Kids users from September 2002 to December 2007.
Cure4Kids Podcast

In 2007, Cure4Kids made available selected seminars in podcast format. These seminars can be viewed in portable multimedia players such as Apple’s iPod, Apple iPhone, Microsoft Windows Zune, and other handheld devices. Seminars may be downloaded from the Cure4Kids Web site or from the Apple’s iTunes Web site. Due to the popularity of handheld portable devices today, the Cure4Kids podcast format will allow busy professionals to have access to the Cure4Kids content anytime, anywhere.

New Content Initiatives

Several local and international conferences were recorded in 2007 and made available on Cure4Kids. These include:
- SIOP Congress – International Society of Paediatric Oncology (Held in Mumbai, India)
- 2007 Pediatrics in the 21st Century (in collaboration with Le Bonheur Children’s Medical Center and The University of Tennessee Health Science Center)
- Retinoblastoma Conference – One World, One Vision (in collaboration with The Hamilton Eye Institute, The University of Tennessee Health Science Center)
- St. Jude-PIDS Pediatric Infectious Diseases Research Conference (in collaboration with Pediatric Infectious Diseases Society)
- Nursing Genomics Conference (in collaboration with Nursing Education, St. Jude Children’s Research Hospital)
- St. Jude Domestic Affiliate Annual RN/CRA Conference (in collaboration with St. Jude Domestic Affiliate program)
- St. Jude Biomedical Symposium
- St. Jude Hodgkin Lymphoma Symposium.

Pediatric Nursing Oncology Course

The Cure4Kids Pediatric Nursing Oncology Course was released fully online in 2007. This comprehensive course has more than 14 modules, totaling more than 1,000 pages of educational nursing content, and related Cure4Kids nursing seminars. It was designed specifically for international nurses. In 2007, the course was accessed 12,455 times by 8,697 users. In 2007, this course was translated into Spanish. The Spanish version of the course was accessed 2,881 times by 1,780 users in 2007. New nurse oncology courses were also added to Cure4Kids that allow users to take the course at their own pace.
- Oncology Nursing Review Sessions (in collaboration with Oncology Nursing Society – Memphis Area Chapter)
- Curso Corto de Ética en la Investigación del St. Jude Children’s Research Hospital (in Spanish)
- Curso de Control de Infecciones del St. Jude Children’s Research Hospital (in Spanish)
- Cure4Kids Curso de Enfermería Oncológica Pediátrica (in Spanish).
Pediatric Oncology Networked Database (POND)

POND is an online, multilingual clinical database developed by the St. Jude International Outreach Program for supporting international pediatric hematology/oncology treatment protocols. This tool allows uniform data collection so treatment protocols and outcomes can be meaningfully compared between treatment centers. POND is available free to St. Jude partner sites. Currently in use in Costa Rica, Dominican Republic, El Salvador, Guatemala, Honduras, Nicaragua, Mexico, Morocco, and Paraguay, this tool has been used to analyze clinical data on thousands of patients and provide advice to partner sites to improve the delivery of treatments. This initiative also supports the salary of data managers at international partner sites who enter data in POND. Weekly online conferences are held on Cure4Kids with data managers at international partner sites for education and analysis of data. POND is the only pediatric oncology database focused on supporting countries with limited resources by the exchange of information and experience between oncologists in diverse geographic regions who practice in a similar medical environment. More than 30 countries are currently using POND for analysis. In the first 3 years of operation (2004-2007), more than 10,000 records have been added to POND. Records by disease type are being shared with experts on that disease for research analysis.

External Collaborators

Cure4Kids has ongoing collaborations for educational initiatives with the following organizations:
- International Society of Paediatric Oncology (SIOP)
- International Union Against Cancer (UICC)
- Pediatric Infectious Diseases Society (PIDS)
- Oncology Nursing Society
- End-of-Life Nursing Education Consortium (ELNEC)
- Le Bonheur Children’s Medical Center
- The University of Tennessee Health Science Center (UT)
- Medical Missions for Children.

Awards

The St. Jude Clinical Care Improvement award was given to the Cure4Kids team in 2007 for significantly improving the clinical care infrastructure to support the mission of St. Jude Children's Research Hospital.

Cure4Kids.org also received the Distinction Award in the Best Overall Internet Site Category from the 2007 e-Healthcare Leadership Awards. There were more than 1,000 entries from 200 organizations.

International Visitors Program:

The purpose of the International Visitors Program (IVP) is to provide specific training at St. Jude Children’s Research Hospital to selected visiting international healthcare professionals and fulfill a stated need of their home institution. The IVP provides the opportunity for our visitors to observe the St. Jude model of holistic medicine, which is based on the delivery by a multidisciplinary team of care for children with cancer and other catastrophic diseases. The following healthcare specialties are represented by our international visitors:
- Physician oncologists/hematologists
- Nurses
- Nutritionists
- Pathologists
- Infectious disease physicians
- Social workers
- Pharmacists
- Laboratory technologists
- Surgeons
- Psychologists/psychiatrists
- Dentists
- Physical therapists.

In 2007, faculty and staff at St. Jude sponsored 88 international visitors from around the world with an average of seven visitors per month. These visitors came from 31 countries, which are listed below:
- South America: Brazil, Ecuador, Peru, Chile, Colombia, Grenada
- Central America: Guatemala, Honduras, El Salvador, Nicaragua
- North America: Mexico
Infectious Disease:

Many of the infectious complications that occur in children with cancer at international partner institutions are nosocomial and could be prevented with appropriate infection control measures. In Latin American hospitals that have pediatric oncology partnerships with St. Jude, infection control programs are often deficient or completely lacking. Poorly trained infection control practitioners (ICPs) and a lack of dedicated personnel to act as ICPs are among the deficiencies of these hospitals’ infection control programs. IOP conducted a survey of all of the international partner site medical directors in 2007 to gauge current trends relating to nosocomial (hospital–borne) infections and infection control processes. The following is a summary analysis of the responses of 22 IOP international partner site medical directors. As part of our strategy in addressing the limitations experienced at the international partner sites, the following educational courses and training were conducted:

4-Week Infection Control Training Course

To address a critical need for trained infection control providers at our partner institutions, a 4-week intensive course was developed and implemented in collaboration with the University of El Salvador and Hospital Bloom in San Salvador, El Salvador. IOP trained 22 healthcare professionals from 11 Latin American countries to be infection control professionals. Several of these professionals are staff members of our partner hospitals. A second 4-week course was also conducted in Paraguay during 2007.

Training of infection control providers is the cornerstone of effective prevention and control efforts. IOP developed and validated simple, economical educational materials (e.g., flipcharts) to facilitate training in key prevention practices. IOP also created PowerPoint lectures and compiled reading lists in 24 selected topics in the prevention and treatment of infection in children with cancer. These resources are available via Cure4Kids.

Building Research Capacity at St. Jude Collaborative International Sites

Collaborative clinical protocols are needed to appropriately evaluate the outcomes of our interventions at international sites, and a basic infrastructure for human research subject protection is essential. Last year, with the experience gained establishing Research Ethics Committees in El Salvador, IOP trained committee members of a newly established Research Ethics Committee in a St. Jude collaborating pediatric hospital in Paraguay.
Services/Support Provided:

Our partner site foundations truly symbolize their titles. They are the supportive foundation for all pediatric cancer treatment at our partner sites. The availability of pediatric oncology resources are scarce or often nonexistent in many of our partner sites. Without the support from the foundations, our partner site healthcare teams could not perform their mission and provide care and treatment to thousands of children around the world. Last year, our partner foundations cared for more than 22,000 children and their parents or guardians, providing services as noted in the chart below. Of these services and support, purchase and delivery of medications to the pediatric cancer units constituted 96% of their total costs for the past year. Without this support, many of the children would not have had access to the most basic pharmaceutical interventions needed to treat their diseases.

![Patient Support - Partner Site](image)

Figure 16. Support provided by foundations

Fundraising:

Taking into consideration that the average person from the IOP partner countries lives on less than $2.00 (U.S.) per day, it is inspiring to report that our partner site foundations collectively raised a total of $21.8 million in 2007. Throughout the years, they have had much success developing and cultivating grassroots support for the children they serve, with 68% of their annual funds coming from corporate sponsors, individual monthly pledges, and local fundraising activities; 31% from government subsidies; and 1% from St. Jude IOP support. With guidance from ALSAC through annual workshops and monthly Web-based meetings, the foundations have begun to diversify their fundraising strategies to include an inventory of event-based activities including:

• Dinners/galas
• Concerts
• Product sales
• Pin-up campaigns
• Auctions
• Walks/marathons
• Raffles
• Radiothons.
2007 IOP Partner Site Foundations Survey:

IOP conducted a survey of all of the international partner site foundation directors in 2007 to gauge current trends relating to difficulties experienced at each foundation. The following is a summary analysis of the responses of 14 directors.

<table>
<thead>
<tr>
<th>2007 Foundations Survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the average amount of paid employees employed by your foundation?</td>
</tr>
<tr>
<td>What is the average amount of volunteers who provide services to your foundation?</td>
</tr>
<tr>
<td>Average annual funds raised by the foundations worldwide.</td>
</tr>
<tr>
<td>Amount of the average annual individual donation.</td>
</tr>
<tr>
<td>Healthcare professionals for whom the foundations provide some or all salary support.</td>
</tr>
<tr>
<td>Average annual expenses incurred by the foundations in 2007.</td>
</tr>
</tbody>
</table>

International Outreach Program Partner Site Listing

- **Brazil**
  - Foundation: Núcleo de Apoio às Crianças com Câncer (NACC).
  - Medical Facility: Unidad de Oncologia Pediatrica – (IMIP) Instituto Materno Infantil do Pernambuco (inpatient); Centro de Hematologia e Oncologia Pediátrica (outpatient) in Recife.
  - Program Medical Director: Dr. Francisco Pedrosa. Year Program Initiated: 1993

- **Chile**
  - Medical Facility: Hospital Luis Calvo MacKenna in Santiago.
  - Program Medical Director: Dr. Hector Olguín. Year Program Initiated: 1997.

- **China**
  - Foundation: The Partner in Hope Foundation (Hong Kong), Ltd. The Partner in Hope Foundation was initiated in 2002 with the goal to improve the cure rate of children with cancer in China, particularly those whose families do not have economic capabilities. The initial project was aimed toward children with low-risk ALL from low-income families. This program has four components: 1) develop a joint leukemia protocol for Beijing Children's Hospital and Shanghai Children's Medical Center specifically for the genetic profile of Chinese children and with built-in cost efficiencies; 2) improve the nursing care for the pediatric oncology patients at Beijing Children's Hospital by initiating a subspecialty training program similar to that at the Shanghai Children's Medical Center; 3) provide treatment to leukemia patients who would otherwise not be treated as part of a proof of concept; and 4) use telemedicine, electronic linking of healthcare professionals for knowledge transfer, to link BCH and SCMC to each other and to smaller centers in their region. In addition to the Partner in Hope Foundation, SCMC also receives support for the Project Hope Foundation, [http://www.projecthope.org/](http://www.projecthope.org/).
  - Medical Facility: Beijing Children’s Hospital Affiliated with Capital University of Medical Sciences in Beijing. Program Medical Director: Dr. Minyuan Wu. Year Program Initiated: 2005.

- **Costa Rica**
  - Foundation: Asociación Lucha Contra el Cáncer Infantil.
  - Medical Facility: Hospital Nacional de Niños in San José.
  - Program Medical Director: Dr. Juan Manuel Carillo. Year Program Initiated: 2002
<table>
<thead>
<tr>
<th>Country</th>
<th>Foundation/Medical Facility</th>
<th>Program Medical Director</th>
<th>Year Program Initiated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ecuador</td>
<td>Foundation/Medical Facility: Hospital de la Sociedad de Lucha Contra el Cáncer Núcleo de Quito</td>
<td>Program Medical Director: Dr. José Eguiguren</td>
<td>2002</td>
</tr>
<tr>
<td></td>
<td>Foundation: Fundación Por Una Vida. Medical Facility: Hospital de Niños Baca Ortiz in Quito</td>
<td>Program Medical Director: Dra. María Barba</td>
<td>2005</td>
</tr>
<tr>
<td>El Salvador</td>
<td>Foundation: Fundación Ayúdame a Vivir. Medical Facility: Hospital Benjamin Bloom in San Salvador</td>
<td>Program Medical Director: Dr. Miguel Bonilla</td>
<td>1993</td>
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<td>Guatemala</td>
<td>Foundation: Fundación Ayúdame a Vivir. Medical Facility: Unidad Nacional de Oncología Pediátrica in Guatemala City</td>
<td>Program Medical Director: Dr. Federico Antillón-Klussman</td>
<td>1997</td>
</tr>
<tr>
<td>Honduras</td>
<td>Medical Facility: Hospital Escuela Materno Infantil in Tegucigalpa. Program Medical Director: Dr. Ligia Fu Carrasco</td>
<td>Year Program Initiated: 2000</td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td>Foundation: The Children’s Medical and Research Foundation. Medical Facility: Our Lady’s Hospital for Sick Children in Dublin. Program Medical Director: Dr. Owen Smith</td>
<td>Year Program Initiated: 2004</td>
<td></td>
</tr>
<tr>
<td>Jordan</td>
<td>Foundation: King Hussein Cancer Center Foundation. Medical Facility: King Hussein Cancer Center in Amman. Program Medical Director: Dr. Mahmoud Sartan</td>
<td>Year Program Initiated: 1996</td>
<td></td>
</tr>
<tr>
<td>Lebanon</td>
<td>Foundation/Medical Facility: American University of Beirut/Children's Cancer Center of Lebanon in Beirut. Program Medical Director: Dr. Miguel Abboud</td>
<td>Year Program Initiated: 2000</td>
<td></td>
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<tr>
<td>Mexico</td>
<td>Foundation: Grupo Amigos de Niños Afectados con Cáncer (GANAC). Medical Facility: Hospital Pediátrico de Sinaloa in Culiacán, Sinaloa. Program Medical Director: Dr. Eduardo Altamirano Álvarez</td>
<td>Year Program Initiated: 2000</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Foundation: Fundación Mi Gran Esperanza Medical Facility: Hospital Civil de Guadalajara in Guadalajara. Program Medical Director: Dr. Óscar González Ramella</td>
<td>Year Program Initiated: 2003</td>
<td></td>
</tr>
<tr>
<td>Morocco</td>
<td>Foundation: L’Avenir, Association des Parents et Amis de Enfants. Medical Facility: Hospital d’Enfants in Rabat. Program Medical Director: Dr. Fouzia Msefer Alaoui</td>
<td>Year Program Initiated: 2000</td>
<td></td>
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<tr>
<td>Philippines</td>
<td>Foundation: Davao Children’s Cancer Fund, Inc. Medical Facility: Davao Medical Center. Program Medical Director: Dr. Mae Dolendo</td>
<td>Year Program Initiated: 2006</td>
<td></td>
</tr>
<tr>
<td>Venezuela</td>
<td>Foundation: Asociación Venezolana de Padres de Niños Con Cáncer (ASOVEPANICA). Medical Facility: Hospital de Niños J.M. de los Ríos in Caracas. Program Medical Director: Dr. Augusto Pereira</td>
<td>Year Program Initiated: 1998</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Foundation: Fundación Amigos del Niño con Cáncer Zulia. Medical Facility: Hospital de Especialidades Pediátricas in Maracaibo. Program Medical Director: Dr. Rosario Montilla</td>
<td>Year Program Initiated: 2000</td>
<td></td>
</tr>
</tbody>
</table>

**Non-Partner Sites – Collaborating with POGO Grant POND Project**

<table>
<thead>
<tr>
<th>Country</th>
<th>Foundation</th>
<th>Medical Facility</th>
<th>Program Medical Director</th>
<th>Year Program Initiated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dominican Republic</td>
<td>Foundation: Fundación Amigos Contra el Cáncer Infantil. Medical Facility: Hospital Infantil Dr. Robert Reid Cabral in Santo Domingo.</td>
<td>Program Medical Director: Dr. Rosa Nieves de Paulino.</td>
<td>Year Program Initiated: 2004</td>
<td></td>
</tr>
<tr>
<td>Nicaragua</td>
<td>Foundation: Comisión Nicaragüense de Ayuda al Niño con Cáncer (CONANCA). Medical Facility: Hospital Infantil Manuel de Jesús Rivera “La Mascota” in Managua.</td>
<td>Program Medical Director: Dr. Fulgencio Báez.</td>
<td>Year Program Initiated: 2003</td>
<td></td>
</tr>
<tr>
<td>Panama</td>
<td>Foundation: Fundación Amigos del Niño con Leucemia y Cáncer (FANLYC). Medical Facility: Panama’s Children Hospital in Panama City.</td>
<td>Program Medical Director: Dr. Béllica Moreno.</td>
<td>Year Program Initiated: 2004</td>
<td></td>
</tr>
</tbody>
</table>
X. Challenges

Abandonment of Treatment:

One of the major causes of treatment failure in childhood cancers in resource-poor countries continues to be abandonment of treatment. Our partner site foundations have done much to decrease abandonment rates by providing services and interventions such as funding for transportation, satellite clinics, support groups, and access to medications, and facilitating early treatment of infection. Calendar year 2007 marked a significant milestone, as 15 of our partner sites achieved a reduction in abandonment rates to 5% or less. Two centers in particular in El Salvador and Honduras were able to reduce their abandonment rate to half the previous rate! This striking fall in the frequency of abandonment reflects the continuing improvement in the ability of families to understand the disease, develop greater hope of cure and increased trust in the medical staff, recognize the importance of early intervention, and appreciate the support and interventions of local foundations. However, the struggle continues at all our partner sites, with greater urgency as three of the partner sites continue to report abandonment rates greater than 15%. This disparity is mainly the result of myriad interconnecting issues, such as lack of education, low income, limited access to tertiary medical centers, geographic location of parents' residence and work in relation to the pediatric cancer treatment units, and sociocultural variables. Universally, at all the international partner sites, there are five basic strategies being implemented by the supporting foundations and pediatric oncology centers to prevent and decrease the incidence of abandonment. These are identified in Figure 19 below. There is still much work to be done in this area. IOP will work closely with partner sites and foundations and continue our joint efforts to find solutions and access to local resources to combat this serious problem. Our ultimate goal is a rate of 0% abandonment of treatment.

Top Five Challenges:

Challenges are an inherent part of any organization. However, challenges also produce opportunities when effective management and leadership oversights are in place. This is truly the case for our partner sites. Most of our partner sites are experiencing “growing pains” as they decrease rates of treatment abandonment, increase cure rates, provide treatment access to more children, achieve early diagnosis, begin early treatment, and develop local and national reputations as centers of excellence. The following are a list of the top five challenges as reported by our partner sites’ medical and foundation directors in ranking order. These challenges are being aggressively addressed by IOP and our partner sites and incorporated into the strategic plan of each partner. While these challenges might at first look formidable, we are confident that our partner sites, with both the guidance and the support of IOP, will find real solutions to these challenges.

<table>
<thead>
<tr>
<th>Rank</th>
<th>Pediatric Oncology Unit</th>
<th>Foundation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Lack of space (capacity)</td>
<td>Increase in number of patients seeking treatment</td>
</tr>
<tr>
<td>2</td>
<td>Lack of physicians</td>
<td>Achieving fundraising goals</td>
</tr>
<tr>
<td>3</td>
<td>Lack of nurses</td>
<td>Limited funding support from government</td>
</tr>
<tr>
<td>4</td>
<td>Access to medications</td>
<td>Cost of medications</td>
</tr>
<tr>
<td>5</td>
<td>Nosocomial (hospital-borne) infections</td>
<td>Lack of space (capacity)</td>
</tr>
</tbody>
</table>

Figure 18. Five universal strategies for the prevention and decrease of Abandonment of Treatment

Figure 19. Top five challenges as reported by partner sites.