network news

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LETTER FROM THE CHAIR

Dear Friends,

As the world goes into a time of recession and financial uncertainty, our children's hospices and palliative care services will be amongst those charities looking at new ways to sustain their services and continue to provide quality care to children with life-limiting conditions. We know that some children's hospices are now in a very precarious financial position as donors are unable to provide the level of funding that was given in the past, and we are challenged to raise the profile of children's palliative care so that all governments will accept this as an essential part of a country's health care service, and all donors will consider children's palliative care in their priority focus areas.

The strength of a Network is that we are all equal partners, and each contributes what they are and what they know to the world-wide movement to improve care for life-limited children. We can share successful interventions and sustainability projects with each other and we encourage you to send information and success stories that we can circulate through the ICPCN.

Despite the challenges we are facing, there have also been many reasons to celebrate as children's palliative care continues to develop internationally. We were delighted to hear of the first children's hospice and palliative care service in China – ChinaKidz - and wish them every success as they go forward with this important programme and develop their facility.

We also send congratulations to Julia's House in Dorset, on being selected as number 14 in the Top 100 Companies to work for in the UK. A wonderful achievement for Mark Edwards and his staff , who also achieved 3 star Best Companies Accreditation. As all good things come in threes, Mark Edwards received the Wessex Charity Award as Chief Executive of the Year.

The success of one children's hospice raises the profile of all children's hospices and highlights the importance of the work that you all do so well.

In South Africa, we are looking forward to hosting the Children's Hospice International (CHI) 20th World Congress in Cape Town. CHI is working in partnership with the ICPCN, the Hospice Palliative Care Association of South Africa, and the Tutu Institute of Prayer and Pilgrimage to bring this very first congress dedicated solely to issues around children's palliative care to the continent of Africa and we are hoping that it will be well supported by ICPCN members both in South Africa and abroad. We are delighted that Sr Frances Dominica has graciously agreed to be our Keynote speaker.

I would also like to extend a very warm welcome to the newest member of our Steering Group, Dr Ross Drake. Apart from being a much needed representative of the male gender on the steering group, Dr Drake will represent Australia and New Zealand and we look forward to his input in our official activities.

Last week I visited a children's hospice where I held a 10 month-old orphaned baby girl who weighed 3.5 kg; had advanced AIDS and TB – but who still managed a sweet smile and was beautifully cared for by the hospice staff. It re-enforced the need for each one of us to be advocates for these children, through raising our voices, but more importantly through our works which highlight the value of children's palliative care.

Blessings as you continue to provide your skilled care and compassion for so many children.

Joan

Voices for Hospices is a wave of simultaneous concerts around the globe which takes place on World Hospice and Palliative Care Day every two years.
Any event that uses the voice to raise funds and awareness for World Hospice and Palliative Care Day is classed as a Voices for Hospices event. These events could be concerts from any musical genre, poetry events, drama evenings or spoken word. The theme for World Hospice and Palliative Care Day and Voices for Hospices 2009 is "Discovering your voice".

EVENTS CALENDAR: APRIL, MAY, JUNE 2009

More information and contact details for all these conferences, courses and events can be found on our website. Go to www.icpcn.org.uk

April		
5 - 7	IAPAC 4th International Conference on HIV Treatment Adherence	Miami, Florida, USA
23-24	Children and Young People in a Changing World	Queen's University, Belfast, Ireland
25	4th Children's Complementary Therapy Network Conference	Birmingham Children's Hospital, UK
May		
1	Creative ways of helping bereaved children and their families	YMCA, High Wycombe, UK
5 - 6	4th Worldwide Summit for National Associations of Hospice and Palliative Care Service Providers	Austria, Vienna
7 - 8	13th Annual Palliative Care Forum Conference hosted by the London Children's Hospice Alliance	Marriot Hotel, London, UK
7 - 10	11th Congress of the European Association of Palliative Care	Austria, Vienna
8	Understanding Trauma - with particular reference to the impact on grieving children	West Wycombe, Buckinghamshire, UK
18 - 27	World Health Assembly 2009	Geneva, Switzerland
26 - 30	36th Annual International Conference on Global Health	Omni Shoreham Hotel, Washington DC, USA
June		
8 - 12	8th International Symposium on Pediatric Pain	Acapulco, Mexico
21 - 25	IPOS 11th World Congress on Psycho-Oncology	Austria, Vienna
21 - 26	Pediatric Pain Master Class - Children's Institute for Pain and Palliative Care	Marquette Hotel, Minneapolis, USA
24	Teenagers and Bereavement	West Wycombe, Buckinghamshire, UK
26 - 28	Supporting you, the professional carer	Lane End Conference Centre, UK
27 - 4 July	ICN 24th Quadrenniel Congress: Leading Change - Building Healthier Nations	ICC, Durban, South Africa

Report from Bueonos Aries

TWELVE YEARS OF HISTORY AND DEVELOPMENT OF PEDIATRIC PALLIATIVE CARE IN SOUTH AMERICA: 1996 - 2008

Eulalia Lascar, M.D., Palliative Care Group Coordinator

The "Dr. Ricardo Gutiérrez" Hospital, is the oldest pediatric hospital in Buenos Aires city (1875), and pioneered the creation of a Pediatric Palliative Care Team.
At the beginning in 1990, patient care was given in the Oncology Unit, and later on, after my personal training in United Kingdom, and a very important growth demand from different hospital areas, a Project of Pediatric Palliative Care was approved in 1996, to cover the needs of little patients with life-limited conditions and their families.
The Unit receives patients from the whole country and Argentina's neighbouring countries, such as Paraguay, Bolivia and Perú.
In an integrative way with other disciplines, our group developed the following activities:
"Responding to Holistic Needs from Diagnosis through to Terminal Care and Bereavement"

- Assessment of Needs and application of different Models of Care
- Evaluation, Measurement, and Treatment (pharmacological and non pharmacological) of chronic and acute pain
- Evaluation, Measurement and Treatment (pharmacological and non pharmacological) of distressing symptoms in patients with life threatening conditions
- Emotional Support of children and families (including siblings and grandparents), across the disease, the terminal phase and bereavement
- Periodic emotional support and reflection meetings for the team
- Continuous education programme for hospital staff, Residents in pediatrics, nurses, pharmacists, and other public and private health and academic centres.
- Postgraduate and Interdisciplinary annual Pediatric Palliative Care Course.
- Small clinical research projects at a very early stage.

Our team consists of three pediatricians, certified in palliative care, two volunteers especially dedicated to complementary treatment, an anthropologist, psychologist, pharmacist, psychometrist, art therapist and an anaesthesiologist.

Plans for the future include:
The development of a distance learning course by Internet to reach more countries in Latin America.
To recruit more human resources, especially nurses and psychologists.
To receive more recognition from the government.

A warm welcome to Dr Ross Drake, the newest member of the ICPCN Steering Group

Dr Ross Drake has gained fellowships in Paediatrics (2000) and Palliative Medicine (2003) from the Royal Australasian College of Physicians and currently holds the position of Clinical Director of the Paediatric Palliative Care (PPC) and Complex Pain Services at Starship Children's Hospital in Auckland, New Zealand. The service consists of a small, interdisciplinary team that provides care to children/young people and their families/ whanau with life-limiting conditions at home in the greater Auckland region and for children/ young people who are in-patients at Starship hospital. He is also available for advice nationally. The service exists on limited funding and has a working philosophy of integrated, collaborative and culturally-appropriate care across tertiary, secondary and primary healthcare settings.

Ross's interests include neuropathic and central pain syndromes and the decision-making process for children/young people with life-limiting conditions. He is a member of the International Association for the Study of Pain, Australia and NZ Society of Palliative Medicine, NZ Palliative Care Working Group, Paediatric Society of NZ and chairs the PPC Special Interest Group and The Australian and NZ Paediatric Palliative Care Reference Group for which he is the International Children's Palliative Care Network representative for the Australia and New Zealand region.

United States

The National Standards for Pediatric Hospice and Palliative Care are being dispersed to all members of NHPCO, and discussion is underway on how to make these available to members outside of NHPCO. An article on Standards development was published in NHPCO's newsline and NHPCO is launching a new online curriculum for Pediatric Palliative Care, to be completed by the end of August.
A compendium of tools will be available with the online curriculum.
NHPCO Clinical team conference is hosting a pediatric intensive in Denver, Colorado this September. The call for abstracts is out.
Children's Hospice International is hosting their PACC technical conference in April as a webinar.
Lobbying efforts continue to support efforts in the US congress and senate to pass new legislation, allowing states to offer palliative care programs and modify hospice benefits for children.

CAPC : Center to Advance Palliative Care named two pediatric training sites. Akron, Ohio and Minneapolis, Minnesota.

Ongoing projects include
Efforts to establish community Pediatric palliative care program with local Hospices in the state of Maryland and DC.
Continuation of Hospice Agency training in pediatrics. However major funding for a program at Johns Hopkins was lost due to the poor economy.

Sue Huff

Belarus

By Anna Garchakova

We have opened one more Children's Hospice so there are 8 Children's Hospices now in Belarus. Besides this a palliative care department was opened in a local 'Home for Special Children'.
The first statute of pediatric palliative care was passed by the Ministry of Health after two years of scientific research showed how much children need palliative care and correct diagnoses. According to this research, plans were worked out and a proposal submitted by palliative care organizaitions, which were sent to the Ministry of Health.
We organized the 4th International Conference on palliative care in Minsk.
We have taught specialists and initiated the opening of a new Adult Hospice in Belarus. All specialists from this Adult Hospice studied in the Children's Hospices.
We have achieved the passing of a new law which describes and approves three stages of anesthetization, which was accepted on a national level.

United Kingdom

In England, our work continues to focus on the implementation of Better Care Better Lives, England Government's direction setting document to improve the delivery of children's palliative care at a local level. Much of the work has focused on the development of the role of networks at the level of England's 10 regional strategic health authorities, on the basis that the networks will drive the local implementation of the strategy. It is hoped that that the recent announcement for funding will facilitate the rolling out of monies to provide to children's hospices and other providers of children's palliative care in England.

ACT and Children's Hospices UK have produced a guide for services in England to work with those commissioning children's palliative care services and it is hoped that this will facilitate the engagement of all providers of children's palliative care with those who hold the purse strings so that there is better funding for the overall sector.

England's government Minister in charge of children's palliative care holds a ministerial oversight meeting where senior people from various national bodies meet on a regular basis to ensure that Better Care Better Lives is being implemented. The government had threatened to withdraw this group and they have recently confirmed that this will not be the case, a direct result of our lobbying.

In England, lobbying work relating to children's palliative care links in well with the lobby for disabled children and there is a powerful campaign called The Every Disabled Child Matters Campaign who have been willing to include issues for children's palliative care within their advocacy. This has been tremendously advantageous to us in securing a higher profile for children's palliative care.

In the public affairs arena, our key challenges are as follows:

- Equip our members at a local level to engage with their commissioners and the overall agenda for children's palliative care
- Secure government funding in England for the continuation of our project to map the number and needs of children who are life limited.
- Secure government funding in England for continued development of networks which bring together commissioners and service providers.
- Work with the networks in Wales, Scotland and Northern Ireland to build on their national policy documents and ensure implementation

Barbara Gelb
Children's Hospices UK

Lizzie Chambers
ACT

The True Colours Trust

ICPCN acknowledges with gratitude the funding received from The True Colours Trust for the furtherance of its work in developing paediatric palliative care worldwide

THE CHI 20TH WORLD CONGRESS

REGISTRATION IS NOW OPEN FOR THE CHILDREN'S HOSPICE INTERNATIONAL'S 20TH WORLD CONGRESS

icpcn
international children's palliative care network

CHI
14 - 16 September 2009
Cape Town
South Africa
20th World Congress
·Nurturing the Spirit·

icpcn
international children's palliative care network

THE TUTU INSTITUTE FOR PRAYER & PILGRIMAGE

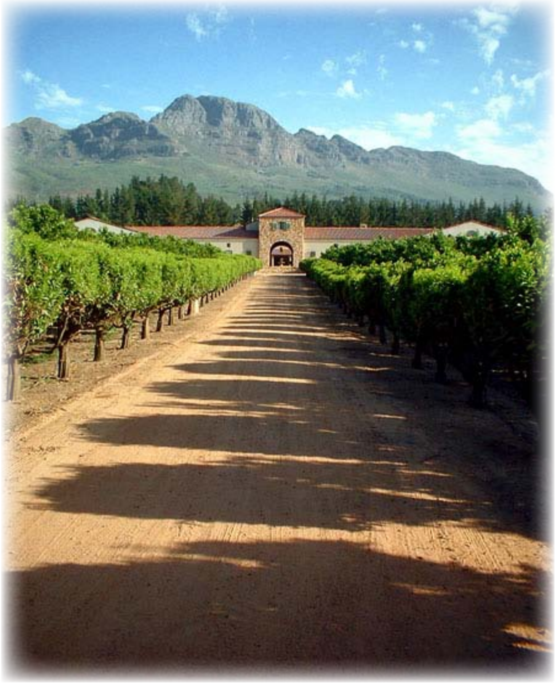
Hospice Palliative Care Association of South Africa
no end to caring

14 - 16 September 2009

Cape Town International Convention Centre

Cape Town, South Africa

Abstract submission deadline has been extended to:
Friday 20 March



Children's Hospice International, in partnership with the International Children's Palliative Care Network (ICPCN), the Hospice Palliative Care Association of South Africa (HPCA) and with logistical support from The Tutu Institute of Prayer and Pilgrimage are proud to bring the very first world congress dedicated to issues surrounding hospice and palliative care for children to the continent of Africa.

Key Note Speaker: Sister Frances Dominica, founder of Helen House, the very first hospice for children.

The location for this congress is the beautiful city of Cape Town, known as the 'Mother City', nestled below the legendary Table Mountain - a spiritual touchstone for the people of South Africa. The Congress will take place in the African springtime and will be held at the Cape Town International Convention Centre, a world class events venue.

The Congress theme is "Nurturing the Spirit"

Motivated by the beauty of its location, the theme "Nurturing the Spirit" which will run as a thread throughout the talks and presentations, is especially fitting. Through three broad tracks focusing on *Care, Policy and Development,* the congress will look at ways to nurture the spirit of compassion, and the quest for knowledge and understanding. It will do this by sharing insights and innovations to overcome challenges faced in providing quality palliative care to children around the globe, including the many millions in Africa affected by AIDS. It also aims to spotlight the importance of providing adequate care and nurturing for the spirit of the caregivers themselves as more than most, those who work in this field tend to give a great deal extra than just their time and their skills.

For information on tourism, hotel and other accommodation visit
www.icpcn.org.uk

Who should attend the CHI 20th World Congress?

The CHI World Congress aims to enrich and inform those who care for children with life-limiting and life-threatening conditions and their families, about the latest international developments and innovations in the field of hospice and palliative care for children. It offers delegates the opportunity to network and learn from one another as they share valuable experiences and insights acquired from the day-to-day application of their chosen professions. Delegates will include administrators, clinical leaders, physicians, nurses, child life specialists, social workers, chaplains, counselors, volunteers, coalition leaders, educators, researchers, advocates, parents and any individuals interested in hospice and palliative care for children. Registration form will be available from the ICPCN website from 24 March.

FOCUS ON INDIA

By Dr Geeta Govindaraj

Paediatric Palliative Care Clinic Inaugurated in Calicut, India

Dr Geeta Govindaraj cuts the ribbon at the inauguration ceremony.

The Pediatric Palliative Care Clinic at the Institute of Maternal and Child Health, Calicut was inaugurated on February 18th 2009.

The clinic is a joint venture of the Department of Pediatrics, Medical College Calicut and the Institute of Palliative Medicine Calicut. It will cater to children with cancer and other life limiting and life threatening illnesses. Medicines for pain and other symptoms will be provided free of cost at the clinic.

This clinic is the first of its kind in this part of the country and services will be provided by pediatricians trained in Palliative care.

A HELPING HAND FOR CHILDHOOD CANCER

Our dedicated volunteers visited several colleges and schools in the city and distributed leaflets about childhood cancer. A few classes were arranged by doctors working in this field.

The children were provided with necessary stationery and their hand prints were collected.The hand prints of our children on treatment for leukemia were also collected. All the hand prints were displayed on a long canvas. The childrens response was enthusiastic and spontaneous. Members of the public came forward to lend their hands to the effort by having their hand prints taken and also by giving donations.Every one was given a gold ribbon to wear.

PLEDGE

The event concluded with a pledge read out by the Zamorin, the erstwhile ruler of Calicut. It was a promise to spread the message that childhood cancer is curable and that eveyone would work unitedly to ensure that all children with cancer would receive the best possible treatment and support.

HIV/AIDS in India

The HIV epidemic in India is creating a new class of children who need care and support; these are children orphaned and made vulnerable by HIV and AIDS. Usually when we talk of this epidemic we do not look at children separately. The number of children who are positive and affected by HIV and AIDS, including those who have to head households, care for infected parents and siblings and lose their education and childhood, is rapidly increasing.

In India, as per latest National AIDS Control Organisation (2007) estimates there are 70,000 children under the age of 15 living with HIV/AIDS and a rapidly increasing number of children orphaned or affected by AIDS.

More information can be found on the Save the Children website

Over 35% of AIDS cases reported in India are children and young people below 25 years of age and 50% of new infections are between 15 and 24 years old.

The current HIV/AIDS programmes are reaching only 15% of young people.

Less than one quarter of young people have accurate information on how to protect themselves from HIV which, coupled with profound gender inequalities, make change in sexual attitudes and practices very difficult.

It is estimated that there are 200 million young people in high prevalence and vulnerable districts who need access to information, skills and services to reduce their vulnerability to HIV infection.

More information can be found on the Unicef website

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21 - 26 June 2009

Pediatric Pain Master Class

Marquette Hotel, Minneapolis, MN

Presented by
Children's Institute for Pain and Palliative Care (CIPPC)
Children's Hospitals and Clinics of Minnesota
Pain Medicine and Palliative Care Program

Course Director
Stefan J. Friedrichsdorf, MD
Medical Director, Pain and Palliative Care Program, Children's Hospitals and Clinics of Minnesota

CIPPC Planning Committee

Stacy Remke, MSW, LICSW	Children's Institute for Pain and Palliative Care (CIPPC), Children's Hospitals and Clinics of Minnesota
Jody R. Chrastek, MSN, CHPN	Children's Institute for Pain and Palliative Care (CIPPC), Children's Hospitals and Clinics of Minnesota

This seminar offers state of the art education in pain management for the pediatric patient from a holistic and multidisciplinary perspective. The program features a faculty of internationally recognized experts, who will cover pharmacological, medical, psychosocial, and integrative therapies in the management of children's acute and complex / chronic pain. Pain assessment and management of somatic, visceral, neuropathic, and psychosocial/spiritual pain as well as end-of-life management of pain and distressing symptoms will be discussed in depth using lectures, workshops and small-group approach.

The Master class is primarily designed for physicians and advanced practice nurses to develop their expertise in the field of pain management and/or palliative care in a highly interactive seminar format. Space is limited.

For more information, or to request a registration packet, please contact Children's Institute for Pain and Palliative Care (CIPPC) at 612-220-5400, or via e-mail at cippc@childrensmn.org.

For more information about our program, visit our website at www.childrensmn.org/painandpalliativecare

The CIPPC is offering two competitive scholarships for physicians or advanced practice nurses from developing countries currently working in the field of pediatric pain and/or palliative care.

UP IN ARMS ABOUT CHILDHOOD CANCER IN KENYA

icpcn
international children's palliative care network

by James Nyaga Ngari

Hope for Cancer Kids

CURE FOR EVERY CHILD, CARE FOR EVERY FAMILY

The health minister's wife Mrs Dorothy Nyongo assisted by Dr. Zipporah Ali of KEHPCA during the launching of Hope for Cancer Kids.

Mrs Nyongo consoles a young child with cancer as SNO Seruta Otiti, Dr Esther Munyoro and popular gospel Singer Esther Wahome look on. The child asked to see his friends and family. HCK wanted to raise some money to take him home over Christmas but unfortunately he passed on before they could start the process.

Kenya is set to have its first Paediatric Palliative Care Centre soon, thanks to a local Non Governmental Organization, Hope for Cancer kids (HCK).

The organization has prepared a five year plan that will be undertaken in three phases. The first phase is already in progress and aims at creating awareness about the unique needs of children suffering from cancer, strengthen childhood cancer support groups and empower parents with basic palliative skills. This will lay the foundation for the much needed social support system for Cancer kids.

To accomplish this, HCK holds educational workshops and counseling sessions for parents and relatives of children diagnosed with cancer. HCK also plans to start family support days in the 2nd quarter of 2009. This aims at reuniting children who have been hospitalized for long stretches of time with their siblings and family members. Funds for this activity are expected to come from well-wishers.

HCK believes that those who have experienced the pain of spending all the family's resources and have watched their children die after staying with them in hospital can become better counselors/social workers if given the right skills. This ambitious plan is difficult given the poverty levels in Kenya but nevertheless, it is not impossible.

HCK has blessings from the Health Minister who terms it as a 'big step to give real hope the children'. Indeed, it was his wife, Mrs. Dorothy Nyong'o who launched the organization on October 31 ,2008.

The launch was made possible with kind donations and support from Kenya Hospice and palliative Care Association (KEHPCA) and Kenyatta Hospital's Palliative Care unit.

Our motto is: Cure for Every Child, Care for Every Family

HCK was formed by parents and relatives of children suffering from cancer and has been running as a support group with minimal activities. The major challenge has been 'why us and not professionals.' However, as a means of diversifying and sustainability, we have added the other activities. At first, members used to meet in hired halls, but through the good work of Dr. Esther Munyoro (head of palliative care unit Kenyatta National Hospital) we have started using the hospital's facilities from February 2009. Our Long term goal is to open a Childhood Cancer Speciality Hospital offering palliative care from the moment a child has been diagnosed all the way to cure or bereavement.

The childhood death rate from cancer is alarming - 70% die within one year of diagnosis and little attention is given to oncology in Kenya. Parents live with fear of loosing their children and rarely are they prepared at all to face the reality. This has been made by lack of drugs at the main referral hospital and the high cost of treatment in this country where more than 70 % live for less than a dollar per day.

HCK welcomes any information, technical or otherwise on the best way to fulfill its mission. As of now, we are yet to identify a donor to fund our project.

James Nyaga is the founder of HCK and freelance journalist with the Daily Nation. He has written extensively on health matters especially cancer. His son was diagnosed with cancer at the age of 3 years. The child's determination to live gives him the motivation to not just make noise about it but to take action in order to help others.

ICPCN Chair Participates in talks on 'Decent Care Values' as the representative for Children's Palliative Care

A recent World Health Organization (WHO) and Ford Foundation-sponsored Global Consultation on Decent Care Values in Palliative Care Services brought together people living with HIV/AIDS, palliative care experts and specialists, and global health leaders to explore the conceptual alignment between the concepts of decent care and the practice of palliative care.

The Consultation aimed to document how the values of decent care resonated with people worldwide and whether those values might influence new approaches to primary care and palliative care.

"Decent care" offers a new approach to health care that seeks to acknowledge and apply universal human values of decency. Just as the concept of "decent work" sought to name and redefine the conditions of work in the industrial age, decent care seeks no less than to redefine and describe values that are essential to primary health worldwide.

Decent care begins with three questions that patients should ask of themselves and that providers should bear in mind as they work with patients, families, and communities to develop treatment plans:

- What do I/we need now?
- How do I/we live in the face of disease?
- How might I/we flourish?

A WHO white paper on decent care explains, "Decent care … posits an approach to health services which is holistic, inclusive, and responsive to the community and which enrolls the community in the problem-solving and support for care." With this first Global Consultation on decent care, WHO focused on palliative care because it is an area of medical practice that already embraces and promotes decent care values, particularly in terms of agency and dignity. Palliative care presented a clear medical discipline in which WHO could begin to talk about and describe real-world, on-the-ground applications of decent care. As a result of the Consultation, several WHO regions are now looking at ways to develop regional consultations of their own and create strategies that will include decent care values as a way to conceptualize the framework needed to develop palliative care services in places where none now exist. Decent care values suggest that health care services are best planned and developed with the collaboration not only of care providers, but with the people who are affected by that system. This values proposition should be a powerful warning to policymakers when considering sweeping health care reforms. Where too often debates on health care reform seem to be driven largely by large special interests, we cannot forget that the true end of health care is to serve the needs of the people who must live within that system.

Full article can be found at Altarum Institute Health Policy Forum

Berman Institute Faculty to explore ethical challenges health professionals face while caring for children affected by life-threatening Neuromuscular diseases

Press Release from the Berman Institute of Bioethics

(Baltimore) The Greenwall Foundation recently awarded two core faculty members of the Johns Hopkins Berman Institute of Bioethics a grant that will allow Drs. Gail Geller and Cynda Hylton Rushton to explore the ethical challenges health professionals face while caring for children and families affected by life-threatening neuromuscular diseases (LTNMD).

The concept for this latest LTNMD study grew out of the work of the international HeartSongs Project funded by the Stavros Niarchos Foundation. The goal of the HeartSongs Project is to develop a worldwide network of professionals from a range of disciplines, parents and affected children who share a common vision of comprehensive care for children with LTNMD.

In addition to the United States, countries involved in the Heartsongs project include the United Kingdom, Canada, Australia, France, Denmark and Greece. The Project aims to integrate the principles of pediatric palliative care (PPC) into the care of individuals living with LTNMDs. PPC can be described as a holistic, interdisciplinary model of care that incorporates emotional, spiritual, developmental, and physical dimensions. The Heartsongs' International Consortium will develop recommendations regarding promising practices in comprehensive and integrated care. The two-year project, co-directed by Geller and Rushton, opened with a summit in England this past April and will culminate in a second summit to be held in Greece in March 2009.

Hopes for a Heartsongs II call for expanding the project to include more European countries as well as countries in South America, Africa, Asia and the Middle East.

The HeartSongs Project is named in honor of the young American poet Mattie J.T. Stepanek who lived with a rare form of muscular dystrophy.

Mattie's messages of love, hope and peace have stirred the hearts and souls of millions worldwide. The author of 7 books, Mattie shared hope through his 'Heartsongs' poetry, and collaborated with Former President Jimmy Carter on an essay book, Just Peace.
(http://www.mattieonline.com/)

Mattie died in 2004 just before his fourteenth birthday. According to Dr. Rushton,

> *"Mattie's legacy for a better world for all children has inspired our work to improve the lives of children, like Mattie, who live with LTNMDs."*

Geller and Rushton's earlier research, also funded by the Stavros Niarchos Foundation, revealed that many parents of children living with LTNMD often do not take advantage of Advanced Care Planning (ACP) as early as experts recommend. "Because the life expectancy of LTNMDs is uncertain and unpredictable," Drs. Geller and Rushton claim that "ACP, and palliative care more broadly, should not be restricted solely to children who are considered close to death."

Geller and Rushton's newest Greenwall Foundation funded study will focus on the attitudes and behaviors of health professionals who care for patients living with Duchnne Muscular Dystrophy (DMD) and Spinal Muscular Atrophy (SMA Type 1), the two most common pediatric LTNMDs worldwide. "Although both diseases are life threatening," says Dr. Geller, "each has a unique life expectancy and disease trajectory thereby creating distinct ethical challenges for the children, their families and the health care team." Dr. Rushton says, "based on a review of the literature and our own prior work, there is a need to more fully understand the nature, prevalence, and consequences of ethical challenges experienced by Neuromuscular Disease specialists who care for these children, adolescents and their families."

These findings will fill an important gap that will inform the development of targeted interventions to support patient/family centered care of children with LTNMD's and their families.

Rushton and Geller say results of the national survey of health care practitioners will be presented to a focus group of regional Muscular Dystrophy Association-clinic directors and pediatric palliative care specialists to develop clinical and policy recommendations for enhancing ethically appropriate care for children with LTNMD.

Most of Drs. Rushton and Geller's research and work is motivated by their commitment to improving the quality of life for patients and families, involving patients and families in communication and decision-making, and improving communication and well-being among interdisciplinary health professionals. In addition to her work at the Berman Institute, Gail Geller, ScD, MHS is a professor at the School of Medicine with joint appointments in the Department of Pediatrics and the Bloomberg School of Public Health's departments of Health, Behavior & Society and Health Policy & Management. In addition to her affiliation with the Berman Institute, Cynda Hylton Rushton, PhD, RN is the program Director of the Harriet Lane Compassionate Care Program at The Johns Hopkins Children's Center, and an associate professor at the School of Nursing. She is a Robert Wood Johnson Executive Nurse Fellow.

About the Johns Hopkins Berman Institute of Bioethics

One of the largest centres of its kind in the world, the Johns Hopkins Berman Institute of Bioethics is the home for collaborative scholarship and teaching on the ethics of clinical practice, public health, and biomedical science at Johns Hopkins University. Since 1995, the Institute has worked with governmental agencies, non-governmental organizations, and private sector organizations to address and resolve ethical issues. Institute faculty represent such disciplines as medicine, nursing, law, philosophy, public health, and the social sciences. Their works helps anticipate and inform debates on complex moral challenges; discerns ethically acceptable alternatives in medical, scientific, and public health policy; and helps to prepare the next generation of bioethicists. More information is available at www.bioethicsinstitute.org.

Mattie Stepanek wrote that a "'Heartsong' is a person's special gift to be shared with others... or a person's 'reason for being.'"

The ICPCN is part of the Worldwide Palliative Care Alliance

Membership of the ICPCN is free and open to all who work in the field of palliative care for children. To join go to www.icpcn.org.uk

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