



Net News

Capturing a Short Life [A DOCUMENTARY]

Capturing A Short Life is a beautiful and life-affirming documentary about families dealing with infant loss.

Combining verité and interview footage with still photography, this poignant documentary details the stories of families who are dealing, in an immediate sense, with the loss of a newborn baby. **Capturing A Short Life** portrays in

a sensitive, intimate and cinematic manner, the emotional, medical and ethical choices that parents are often faced with when they are told that their baby is incompatible with life. Although this subject matter is impossibly sad, the lives and relationships that evolve, even in this context, are not.

This film follows the stories of four families as

they live through, and detail, their baby's lives. Although the circumstances surrounding the births, lives and deaths of their children vary significantly, at the core of their stories there is a similar emotional resonance.

Lydia is born full term, but during labour, suffered massive brain damage due to a lack of
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Special points of interest:

- Capturing A Short Life—Documentary
- ICPCN Launches Its Charter
- IPPC Retreat in Vancouver in

INITIATIVE FOR PEDIATRIC PALLIATIVE CARE (IPPC) RETREAT MARCH 5-7, 2009 VANCOUVER, B.C.

Canuck Place Children's Hospice and B.C. Children's Hospital (and supported by Bayshore Health Services) is working in partnership to host the Initiative for Pediatric Palliative Care (IPPC) Retreat in Vancouver, B.C. on

March 5-7, 2009. We are inviting staff that work with children who live with life-threatening illnesses to come as a team from their local community and learn together. It is a very unique and exciting program that includes

families as participants on the teams and is focused on staff returning to their local communities with enhanced skills in pediatric palliative care and working team relationships. Several
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Capturing a Short Life

[A DOCUMENTARY]

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oxygen. Her family is told that she will never evolve beyond a non-responsive state. Her parents are forced to make difficult decisions about whether or not to withdraw life support and, ultimately, whether to take her off nutrition.

Emerson was born four months early, weighing less than two pounds. With each ounce he gains his parents hope that he will be able to beat the odds and survive.

Twins, Kayla and April were born healthy but, at one month old, Kayla contracted meningitis and her parents have been told she will likely become non-responsive within 48 hours.

Hailey was born with Type Two Gauchers disease, a rare genetic illness that causes extensive and progressive brain damage. The outcome of Hailey's life is inevitable, but her parents are determined to enjoy every second they have with her.

Few people are aware that, in North America every year, tens of thousands of families are having to say goodbye to children they've only just met, and millions more lose babies to miscarriage or stillbirth.

When a baby dies, it is not only an infant that is lost, but a toddler,

a child, a teenager and an adult. An entire life, an entire future, disappears. There will be no first birthdays, no first steps, no first report cards, no first loves...instead there is an intense, impossible, few moments to say hello and goodbye.

Capturing A Short Life is not a film about death, it is a film about how critical it is to remember and celebrate the beautiful babies who are only with us for a moment, and how impossible it is to forget them.

If you are interested in purchasing the film please go to:

www.capturingashortlife.com

Submitted by:

Sheona McDonald

Capturing A Short Life

will broadcast on CBC
Newsworld's series
"The Lens" on
Tuesday,
December 9th, 2008
at 10pm

Congratulations

Capturing A Short Life won a jury award at the Yorkton Film Festival earlier this year.

IPPC RETREAT

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staff with many years of experience in pediatric palliative care from Canuck Place and BCCH have participated and highly recommend this advanced and progressive learning experience. It's the first time that IPPC has come to Canada!

IPPC is an education and quality improvement project and is entering its 11th year as a national leader in pediatric palliative care. IPPC's Faculty is an interdisciplinary team representing physicians, social workers, and nurses. The curriculum consists of 5 modules: engaging with children and families, relieving pain and other symptoms, analyzing ethical challenges in end-of-life decision making, responding to suffering and bereavement and improving communication and strengthening relationships. More information about IPPC can be found on their website:

www.ippcweb.org

Although our priority is for teams within BC we are inviting teams to come from other provinces and locations. It is open up to 70 participants.

Please go to the Canuck Place website, www.canuckplace.org for further details on how to register.

Also see pages *and * of the newsletter for more info.

*Submitted by: Canuck Place
Children's Hospice Staff*

The ICPCN Launches Its Charter

www.icpcn.org.uk

Palliative care is the right of all life limited and life threatened children and their families from the time of diagnosis and should continue alongside any curative treatment aimed at the disease, through death and into bereavement. Its main purpose is to relieve suffering, whether physical, spiritual or emotional, and to promote quality of life. This and other tenets are embodied within the new International Children's Palliative Care Charter launched to coincide with World Hospice and Palliative Care Day on 11 October 2008.

The Charter also calls for palliative care to be provided within the child's home or within an environment that is child-friendly and that this care should be offered by professionals and caregivers who



have undergone training in palliative care specific to the needs of children.

With acknowledgement to the ACT Charter, the ICPCN Charter sets out the *international* standard of support that is the right of all children living with life limiting and life

threatening illnesses worldwide, and their families.

The Steering Group of the ICPCN expects that the Charter will prove to be a useful instrument for all of its members and for those who campaign for the development of or for improved hospice and palliative care services for children around the world.

The ICPCN Charter has been translated into a number of African and European languages and any person who would be willing to translate it into an additional language/s is asked to make contact with the ICPCN Information Officer at sue@icpcn.co.za

The Charter may be downloaded at www.icpcn.org.uk

Submitted by: Sue Boucher

THE ICPCN CHARTER OF RIGHTS FOR LIFE LIMITED AND LIFE THREATENED CHILDREN

1. Every child should expect individualized, culturally and age appropriate palliative care as defined by the World Health Organization (WHO). The specific needs of adolescents and young people shall be addressed and planned for.

2. Palliative care for the child and family shall begin at the time of diagnosis and continue alongside any curative treatments throughout the child's illness, during death and in bereavement. The aim of palliative care shall be to relieve suffering and promote quality of life.

3. The child's parents or legal guardians shall be acknowledged as the primary care givers and recognized as full partners in all care and decisions involving their child.

4. Every child shall be encouraged to participate in decisions affecting his

or her care, according to age and understanding.

5. A sensitive but honest approach will be the basis of all communication with the child and the child's family. They shall be treated with dignity and given privacy irrespective of physical or intellectual capacity.

6. Every child or young person shall have access to education and wherever possible be provided with opportunities to play, access leisure opportunities, interact with siblings and friends and participate in normal childhood activities.

7. The child and the family shall be given the opportunity to consult with a pediatric specialist with particular knowledge of the child's condition where possible, and shall remain under the care of a pediatrician or doctor with pediatric knowledge and experience.

8. The child and the family shall be entitled to a named and accessible key-worker whose task it is to build, coordinate and maintain appropriate support systems which should include a multi-disciplinary care team and appropriate community resources.

9. The child's home shall remain the center of care whenever possible. Treatment outside of this home shall be in a child-centered environment by staff and volunteers, trained in palliative care of children.

10. Every child and family member, including siblings, shall receive culturally appropriate, clinical, emotional, psychosocial and spiritual support in order to meet their particular needs. Bereavement support for the child's family shall be available for as long as it is required.

Adapted from the ACT Charter



First Annual Interprofessional Practice Award in Paediatric Hospice Palliative Care *An initiative at SickKids Hospital*

The Palliative & Bereavement Care Service at SickKids Hospital is proud to announce the first annual **Interprofessional Practice Award in Paediatric Hospice Palliative Care**.

This award is meant to recognize a team at SickKids Hospital that embodies the principles of family centred care and interprofessional practice within their daily care of children and their families.

Some of the award criteria includes:

- Demonstrate an understanding of the principle of paediatric palliative care and the consistent application of these principles in their dealings with children with a life limiting illness and their families.
- Demonstrate the development and support of communication and trust amongst their group, with their patients and families and between their patients and

families.

- Model mutual respect (personal & professional expertise) and shared responsibility designed to promote active participation of each profession in patient-care planning and delivery while remaining focused on child and family-centred goals and values.
- Seek out opportunities to enhance their practise of paediatric palliative care through education, consultation or debriefing of cases.
- Acknowledge the need for team support in the area of professional self-care.
- Demonstrate to the child and family and others with the hospital and in the paediatric community: a clear purpose, good communication (cooperation, coordination, and collaboration), and a mechanism for conflict resolution

This award was announced at SickKids during Interprofessional Practice week, and will be presented annually during Palliative Care Week in May. The winning team will receive resources for each team member and their team libraries, as well as a 'Care for the Caregiver' team session at a local spa.

This award is made possible thanks to the generous donations of the Sasha Bella fund for Family Centred Care. The Sasha Bella Fund For Family Centred Care is a family tribute fund at Sickkids Foundation set up by Sasha's parents Pamela Stein and Jonathan Blumberg just before their first daughter's death on June 20, 2006. The Fund celebrates Sasha and supports family-centred care initiatives at Sickkids Hospital. To learn more about the Sasha Bella Fund, visit

<http://www.sashabella.com/>

For more information about the award contact Sabrina Menezes at Sabrina.Menezes@sickkids.ca

Canadian Hospice Palliative Care Conference

Congrès canadien de soins palliatifs

October 18-21, 2009 in Winnipeg, Manitoba

For more information: <http://www.chpca.net>

Email your suggestions for pediatric palliative care resources to include in the next newsletter!

newsletter@cnpsc.ca

Infants, children,
and adolescents
with life
threatening
illnesses deserve
the very best care
possible.

Interdisciplinary
teams of
healthcare
providers, family
members and those
whose professions
bring them into
contact with such
children and their
families are invited
to join us in this
interactive
educational
retreat.



www.ippcweb.org



Initiative for Pediatric Palliative Care Educational Retreat

March 5-7, 2009

The Chan Centre for Family Health
Education at Child and Family Research
Institute

BC Children's Hospital Site

950 West 28th Avenue Vancouver, BC, Canada

For more information, contact Camara van Breemen
at: cvanbreemen@canuckplace.org

Sponsored by BC Children's Hospital and Canuck Place Children's
Hospice in partnership with Bayshore Home Health



Canuck Place
CHILDREN'S HOSPICE
embracing life

Bayshore
Home Health

What is IPPC?

Spearheaded by the Education Development Center, The Initiative for Pediatric Palliative Care (IPPC) is a national consortium in the United States aimed at enhancing culturally respectful, family-centered care of children with life-threatening illnesses. The IPPC curriculum reflects five years of research and development and includes more than 25 hours of peer-reviewed curriculum and an award winning video series. Using a retreat format to intensify the learning experience for participants, IPPC addresses key domains of pediatric palliative care through:

- An interactive, interdisciplinary team approach
- Plenary sessions interspersed with small group "train-the-trainer" sessions
- Collaborative learning in a practitioner-family member partnership

How best can we help children and families?

The IPPC approach addresses compelling challenges in pediatric palliative care, including how best to honor the knowledge and insight of parents in the medical world when their children are seriously ill, and how best to address the anguish of patients, family members, and practitioners alike.

Who Should Attend?

IPPC's educational program is designed for interdisciplinary teams from:

- Children's hospitals
- Pediatric services of general hospitals
- Hospice/home care services
- Other organizations serving gravely ill children

Teams will be prepared to return to their own institutions equipped with knowledge, skills and quality improvement tools to implement educational programming and organizational change in pediatric palliative care.

What makes this retreat special?

- Experiencing the unique IPPC learning approach
- Opportunities for family members and clinicians to learn together
- Care provider teams build enthusiasm and develop plans to take back to their home institutions.

Want to Find Out More About IPPC?

- Visit IPPC on the web at www.ippcweb.org
- Hear about IPPC on National Public Radio. Go to <http://www.here-now.org/shows/2004/08/20040823.asp>
Scroll down to "Palliative Care for Children" and click "Listen"
- Read about IPPC in the Baltimore Sun's four part series "If I Die" by Pulitzer Prize winning reporter Diana Sugg at <http://www.baltimoresun.com/angels>

Teams attending this training who wish to purchase the IPPC video series for their institution will receive a 50% discount