



WORKSHOP
*DEFINING THE ESSENCE
OF PALLIATIVE CARE FOR CHILDREN:
RELIGIONS TOGETHER*

ROME, 10th NOVEMBER 2015
PONTIFICAL ACADEMY FOR LIFE

L'Evento è stato reso possibile anche grazie al sostegno di



Banca Patrimoni
Sella & C.

FONDAZIONE MARUZZA LEFEBVRE D'OVIDIO ONLUS

Via del Nuoto, 11 - 00135 Roma

Telefono +39 06 3290609 | +39 06 36306482 | Fax +39 06 36292743

info@maruzza.org | www.maruzza.org

BUIO

Circondato dal buio: timore.
Accendo la luce, ma è tutto nero,
il buio dentro di me.
Denso,
mi fa sudare, mi fa gridare.
un grido liberatorio,
il coraggio di cambiare,
di ripartire.
Nessun ladro rubi la mia dignità.

DARKNESS

Surrounded by darkness: fear.
I turn on the light, but everything is black,
the darkness inside me.
Dense,
it makes me sweat, it makes me shout out,
a liberating cry,
the courage to change,
to start over.
No thief will steal my dignity.

Francesco Ostellari

VISIONE

Nel mondo, ogni bambino colpito da malattia cronica e inguaribile ha diritto di accedere alle cure palliative pediatriche.

OBIETTIVO

La responsabilità delle religioni nella cura dei sofferenti, degli esclusi, dei vulnerabili non è solo un obbligo universale. È l'espressione più alta dell'obbligo morale di ogni uomo e donna di creare una società più umana possibile. Una società che rifletta le qualità della compassione, del rispetto e della giustizia.

Per questo chiediamo l'impegno delle principali religioni perché sia riconosciuta l'importanza delle cure palliative pediatriche come le più adeguate per aiutare i bambini a vivere con la migliore qualità di vita, a prescindere dalla loro malattia, salvaguardando la dignità loro e dell'intera famiglia.

WORKSHOP

L'incontro "Le Cure Palliative Pediatriche e la Voce delle Religioni" riunisce i massimi esperti di cure palliative pediatriche, i teologi appartenenti a diversi credi religiosi, i comunicatori, gli esperti in diritti umani e i pazienti e le famiglie di diverse culture, esperienze e fedi religiose.

LA CARTA

L'obiettivo è la stesura della Carta: "Carta delle Religioni per le Cure Palliative Pediatriche" condivisa da tutti i partecipanti, per rafforzare il consenso globale sulla tutela della vita dei bambini con malattia cronica e inguaribile.

Un'iniziativa ideata e organizzata dalla Fondazione Maruzza Lefebvre D'Ovidio Onlus in collaborazione con la Pontificia Accademia per la Vita.

THE VISION

Every child living with a life-threatening and life-limiting illness should have the right to access children's palliative care.

THE GOAL

Sharing the responsibility of caring for those suffering, isolated and vulnerable is not only an universal obligation of all religions, but the expression of a moral duty in actively creating a caring society that reflects the fundamental qualities of compassion, respect and equality.

For this reason, we are calling upon the global faiths to reaffirm that children's palliative care safeguards the dignity and best quality of life possible for children affected by life-threatening and life-limiting illnesses and their families.

THE WORKSHOP

The international workshop will bring together some of the most prominent paediatric palliative care specialists, theologians of different faiths, human rights experts, global communicators and thought leaders, as well as patients and families from diverse cultures, faiths and walks of life.

THE CHARTER

The overall goal of the workshop is the formulation of the Charter: "**Religions of the World Charter for Children's Palliative Care**" aimed at strengthening the universal consensus on global access to paediatric palliative care for all children living with life-threatening illnesses.

An initiative conceived and supported by the Fondazione Maruzza Lefebvre D'Ovidio Onlus (Maruzza Foundation) in collaboration with the Pontifical Academy for Life.

PROGRAMME

TUESDAY 10th NOVEMBER 2015

08:30 - 09:00 Greetings

H.E. Msgr. Ignacio Carrasco De Paula,
President of the Pontifical Academy for Life

Silvia Lefebvre D'Ovidio,
Maruzza Foundation

09:00 - 13:00 4 simultaneous technical roundtables

13:00 - 14:30 Light Lunch

14:30 - 18:00 Unified meeting to formulate and endorse the Joint Statement (Charter)

18:15 - 18:30 Charter Signing Ceremony

MEETING VENUE

Pontifical Academy for Life
1 Via della Conciliazione | 00193 – Rome

CONGRESS SECRETARIAT AND ORGANIZERS

Fondazione Maruzza Lefebvre D'Ovidio Onlus
11 Via del Nuoto | 00135 – Rome

TECHNICAL ASPECTS ROUNDTABLE

Prof. Joanne Wolfe (Group Leader)

CHILDREN'S RIGHTS ROUNDTABLE

Prof. Kathleen Foley (Group Leader)

THE PATIENTS' AND FAMILIES' PERSPECTIVE ROUNDTABLE

Prof. Myra Bluebond-Langner (Group Leader)

SPIRITUALITY AND RELIGION ROUNDTABLE

Dr. Richard Hain (Group Leader)

PARTICIPANTS

TECHNICAL ASPECTS ROUNDTABLE

Prof. Joanne Wolfe (Group Leader), Director, Paediatric Palliative Care, Boston Children's Hospital - Associate Professor of Paediatrics, Harvard Medical School, USA

Mrs. Margaret Al-Sayer, Founding Director, Bayt Abdullah Children's Hospice (BACCH), Kuwait Association for the Care of Children in Hospital (KACCH), Kuwait

Dr. Franca Benini, Pediatrician, Head of the Veneto Regional Reference Centre for Paediatric Palliative Care and Pain Management and the "Casa del Bambino" Children's Hospice – Department of Paediatrics, Padua, Italy

Dr. John Collins, Head of Department Pain Medicine & Palliative Care the Children's Hospital at Westmead, Australia

Dr. Ann Goldman, Paediatrician, Editor Oxford Textbook of Palliative Care for Children, (retired) Consultant in Paediatric Palliative Care, Great Ormond Street Hospital for Children, London, UK

Prof. Rut J. Kiman, Head Paediatric Palliative Care Team, Hospital Nacional "Prof. A. Posadas", ICPCN Board member representing Latin America, Buenos Aires, Argentina

Mrs. Joan Marston, Chair International Children's Palliative Care Network (ICPCN), South Africa

Prof. Mary Ann Muckaden, Head of the Palliative Department at Tata Memorial Hospital in Mumbai, India

Prof. Marcello Orzalesi, Director of Training School in CPC – Maruzza Foundation, Italy

Dr. Carlo Peruselli, President of the Italian Society of Palliative Care (SICP), Director of Scientific Committee of Maruzza Foundation, Italy

Prof. Lukas Radbruch, Chair of Palliative Medicine, Director of Department of Palliative Medicine, University Clinic of Rheinische Friedrich-Wilhelms-University, Germany

CHILDREN'S RIGHTS ROUNDTABLE

Prof. Kathleen Foley (Group Leader), Neurologist at Memorial Sloan-Kettering Cancer Center in New York City, Chair of the Society of Sloan Kettering in Pain Research, Board Member of Physicians for Human Rights, USA

Prof. Jane Adolphe, Associate Professor at Ave Maria School of Law, USA and Italy

Dr. Stefano Bellon, Physician Co-Founder and President of Scientific Committee of the "City of Hope", Padua, Italy

Mr. Carlo D'Asaro Biondo, Europe President of Strategic Relationships at Google, France

Dr. Mounir Farag, Regional Adviser Hospital Care Management & Regional GHI/ Health System Strengthening - WHO/EMRO (former), Founder and Director St Joseph Institute for the Family, Bioethics and Pro Life, Egypt, Ordinary and Board Member Pontifical Academy For Life, Vatican City

Mr. Bruno Giussani, Director of TED Europe, Switzerland

Mrs. Silvia Lefebvre D'Ovidio, Maruzza Foundation, Italy

Dr. Diederick Lohman, Associate Director, Health and Human Rights Division, Human Rights Watch, USA

Dr. M.R. Rajagopal, Founder and Chairman of Pallium India, Trivandrum, Kerala, India

Prof. Stefano Semplici, Past President of International Bioethics Committee UNESCO, Chairman of the Bioethics Committee of the Italian Society of Paediatrics, Professor of Social Ethics, Tor Vergata University, Rome, Italy

Mr. Marco Spizzichino, Head of Office XI – Directorate General of Healthcare Planning, Italian Ministry of Health, Italy

THE PATIENTS' AND FAMILIES' PERSPECTIVE ROUNDTABLE

Prof. Myra Bluebond-Langner (Group Leader), Professor and True Colours Chair in Palliative Care for Children and Young People, Louis Dundas Centre for Children's Palliative Care, UCL-Institute for Child Health, London and Board of Governors Professor Anthropology, Rutgers University, Camden NJ, UK

Mr. Zaid and *Mrs. Zeenath Ayoob*, Lameez's father and mother (deceased from leukemia), South Africa

Mr. Omar Leone, Edoardo's father (deceased from brain tumor), Italy

Master Francesco Ostellari, patient, affected by muscular dystrophy, accompanied by his mother Stefania, Italy

Miss Sara Pavan, patient, affected by SMA1, accompanied by her mother Patrizia, Italy

Mrs. Natasha (Kjærstad) Pedersen, Mother of Andrea (deceased from cancer), Board member at Elisabeth Kübler Ross Foundation, Editor in Chief at JA Til Lindrende Enhet Og Omsorg For Barn and Advocacy Advisory Group at International Children's Palliative Care Network Lives in Kristiansand, Norway

Dr. Chakrapani Vasudevan, Consultant Neonatologist at Bradford Teaching Hospitals NHS Foundation Trust, UK

Mr. Giovanni Vena, Carlo's father (deceased from brain tumor), Italy

Mrs. Valentina Vittadello, nurse, Giacomo's aunt (deceased from Trisomy 13), Italy

Mr. Matteo Vittadello and *Mrs. Maddalena Bano*, Giacomo's father and mother (deceased from Trisomy 13), Italy

Mrs. Antonella Zamboni, Matteo's mother (affected by Ondine Syndrome), Italy

SPIRITUALITY AND RELIGION ROUNDTABLE

Dr. Richard Hain (Group Leader), LATCH Senior Lecturer in Paediatric Palliative Medicine, Lead Clinician Welsh Managed Clinical Network for Paediatric Palliative Medicine, Cardiff, Wales, UK

H.E. Prof. Abdussalam Al-Abbadi, Secretary General of the International Islamic Fiqh Academy, Saudi Arabia and Jordan

Rev. P. Armando Auffero, President of CVS Confederation International, Vatican City

Imam Izzedin Elzir, Imam of Florence, Italy

Rev. Mia Hilborn, Hospitalier, Head of Spiritual Health Care and Chaplaincy Team Leader, Guy's and St Thomas' NHS Foundation Trust, UK

Dr. Jyh-Gang Hsieh, Physician, Heart Lotus Hospice, Family Medicine, Hualien Tzu Chi Hospital, Buddhist Tzu Chi Medical Foundation, Taiwan

Dr. Anne Merriman, Founder Hospice Africa Uganda – Nobel Peace Prize Nominee 2014, Uganda

Dr. Kshama Metre, Pediatrician, National Director of COD, Chinmaya Organization for Rural Development, India

Rev. Mons. Renzo Pegoraro, Chancellor of the Pontifical Academy of Life, Vatican City

Dr. Christina Puchalski, Depts of Medicine and Health Sciences The George Washington Institute for Spirituality and Health (GWish), USA

Prof. Dr. Traugott Roser, Professor for Practical Theology at the University of Muenster, Germany

Rabbi Avraham Steinberg, Paediatric Neurologist, Shaare Zedek Medical Center, co-Chair of Israel's National Bioethics Council, Israel

Father Alexander Tkachenko, Russian Orthodox Archpriest, Founder of St. Petersburg Children's Hospice, Russia

Ufficio Stampa e Media Relations

ALETEIA
COMMUNICATION