The development of Childrens Palliative Care (CPC) in Norway.

From idea to action.
ICPCN Conference in Mumbai, India
Natasha Pedersen
Highlights in this presentation.

• The idea.
• Action.
• Now and the future?

Yes to palliative units and care for children - JLOB www.barnepalliasjon.no
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Facts on Norway

- **Official name:** The Kingdom of Norway
- **Capital:** Oslo
- **Population:** 5,051,275 inhabitants as of 1 January 2013
- **Area (sq. km):** 385,186 km²
- **National day:** May 17th (Constitution day)
- **Religion:** Protestant Christianity
- **Government:** Constitutional monarchy and parliamentary Democracy.
- **Health:** Public Health

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• Live births, total pr 2012: 60 255
• Male 30 933
• Female 29 322
• Death estimated including fetal deaths 600

Estimated number of children in need of CPC services 3800 in Norway each year.
The IDEA.
It started with the question - WHY?

ANDREA’S LEGACY
1992- 2010

Mentor, teacher and daughter

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Key Questions:

- WHY – the kitchen idea
- WHERE - research
- WHO - research
- WHAT - knowledge
- HOW - plan
- WHEN - future

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• 2009 Research
Collecting knowledge - Internationally and Nationally, overview, the practice.
• Building a foundation and organization
• November 3. – Founding of “Yes to palliative units and care for children - starting the organization.
Action

• 2010- Collaboration – national and international, Germany, ICPCN, Together for short life.
• 2010- International Conferences- CHI 21th World Congress.
• Working for national guidelines
• Norwegian conference
• Visit to childrens hospice's in Germany and Sweden.
• 2011- ICPCN ADVOCACY

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Historical conference in 2012

In collaboration with the childrens nurse association.

Bent Høie receives a copy of ‘Touching rainbows’ at the first conference in Kristiansand on children’s palliative care in April 2012.
• Continuous dialogue with politicians and authorities
• Continuous network
• Advocasey in all levels, health, teaching, parents
• Founding and finance
• Courses in CPC with accreditations
• Working 24/7
SOME OF THE CPC FAMILY

Sharing is caring and one of the success criteria's

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Political

• The news – sharing knowledge.
• Jon J. Gåsvatn, Erna Solberg (C) now prime minister) Laila Dåvøy(The Christian Democrats), Bent Høie(c) m.m
• From 2010 - Statements to several public hearings to Parliament and White Papers.
• Hearings at the health and social committee at Parliament.
• February 2011, the Norwegian Ministry of Health and Care Services Anne-Grete Hjelle Strøm-Erichsen (labour) gave the Norwegian Directorate of Health the mission to make national guidelines for CPC – work in progress.

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• December 2013: State budget 2. million Norwegian kroner to non-profit org, too strengthen knowledge about palliative care and end of life care for children and young people

• 2014 - Assignment from the Health Minister to put down a research group. Mapping.
Tools

• Social media
• Media
• Public attention
• Journals of pediatric, nurse
• Networking
• Launch of the Norwegian translation of "The Purple Balloon” 2013
Prime Minister Erna Solberg
(Conservative Party)

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Minister of Health and Care Services
2013 - 2017 - Bent Høie

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NOW AND THE FUTURE

• New Government 2013 – ‘Sundvolden-plattformen’
• Organization development – Strategy and policy
• Journal on CPC
• Challenges
• Results and Achievements

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Thank you so much for your attention

The children are always our greatest teachers!

Yes to palliative units and care for children.

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