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**ICPCN POSITION PAPER ON PALLIATIVE CARE FOR CHILDREN WITH DRUG-RESISTANT TB**

<b>Purpose</b>	To advocate for palliative care for children with drug-resistant TB
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**Introduction**

The International Children’s Palliative Care Network (ICPCN) was established in 2005 and is the only international organization bringing together individuals and organizations involved in the development and provision of palliative care for babies, children and young people. Present membership is from 81 countries. The vision of the ICPCN is a world where all children with a life-limiting illness or life threatening illness have access to palliative care services. The objectives of the ICPCN are Networking; Advocacy; Research and Education and Information- sharing.

**Summary of Recommendations**

The ICPCN recommends that all governments

- integrate children’s palliative care into all health care services for children;
- include children’s palliative care in relevant health, welfare and educational policies;
- ensure training for health care workers in children’s palliative care;
- ensure equitable access to pain-relieving and other palliative medicines, including opioids;
- make available adequate funding for children’s palliative care.

**Value Statement**

The goal of palliative care is the relief of suffering and the improvement of quality of life. It is a holistic and professional approach to caring that includes pain and symptom management. Its provision is applicable from the peri-natal and neo-natal period until the child either dies or becomes a young adult.

Children with drug resistant TB face long periods of suffering from a debilitating illness as well as side effects of the treatment they have to take. The treatment includes multiple tablets and daily injections for close on two years. They also experience psychosocial pain due to the stigma attached to the illness and accompanying socio-economic conditions brought about by such an illness.

## Definitions

Drug resistant TB (DR-TB) refers to TB resistant to any of the first line anti-TB drugs. Multi-drug resistant TB (MDR-TB) refers to TB resistant to rifampicin and isoniazid which are the most effective anti-TB drugs. Extensively drug resistant TB (XDR-TB) is resistant to rifampicin and isoniazid as well as the fluoroquinolones and injectable second line agents. The source of DR-TB children is often a close contact whilst past treatment for TB is also an important factor. These forms of TB do not respond to the standard six-month treatment with first-line anti-TB drugs and can take up to two years or more to treat with drugs that are less potent, more toxic and much more expensive, from 50 to 200 times higher.<sup>i</sup> Extensively drug-resistant TB has a high mortality rate, especially among children and those infected with HIV.<sup>ii</sup>

## Legislative Background

The UN Convention on the Rights of the Child

Article 24

1. States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of the illness and rehabilitation of health. States parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.
2. States Parties shall pursue full implementation of this right and, in particular, shall take appropriate measures:...
  - (a) To diminish infant and child mortality
  - (b) To ensure the provision of necessary medical assistance and health care to children...
  - (e) To ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition...
4. States Parties undertake to promote and encourage international co-operation with a view to achieving progressively the full realization of the right recognized in the present article. In this regard, particular account shall be taken of the needs of developing countries<sup>iii</sup>.

## Statistics

In 2010 there were 8.8 million incident cases of TB, 1.1 million deaths from TB among HIV negative people and an additional 0.35 million deaths from HIV associated TB. One of the important findings cited by this report is that almost 10 million children were orphaned as a result parental deaths caused by TB.

Drug Resistant TB is an increasing health problem worldwide, particularly in areas with a high TB and HIV burden. In 2008, an estimated 440 000 cases of Multi Drug Resistant (MDR) TB emerged globally. In the same year, MDR TB accounted for 3.6% of the global TB incidence and an estimated 150 000 deaths worldwide<sup>iv</sup>.

Due to the difficulty in diagnosing TB in children, global statistics of children with drug resistant TB is sparse and is in the form of case series and observational studies. It is estimated that TB represents 10%-20% of the total cases of in areas with poor epidemic control, and this translates into 40,000 children with MDR TB per year.<sup>v</sup>

## Qualitative evidence

The Sentinel Project has published 15 stories of children with drug-resistant TB. This collection documents the devastating impact of drug-resistant TB on children. Common factors emerging from these stories include:

- Diagnosis is often made too late
- Sometimes the wait for appropriate therapy is too long
- Children are required to receive daily injections, which is a very painful experience for them
- They have to take multiple tablets for 18-24 months, which makes adherence difficult
- They suffer from the illness itself as well as the side effects of the treatment e.g. peripheral neuropathy
- Sometimes they have to undergo surgical procedures to treat some of the complications
- They suffer emotionally and socially due to the stigma attached to the illness

### ***The story of Fetene from Addis Ababa, Ethiopia***

When a faith-based charity in Addis Ababa found 17 year-old Fetene, he weighed just 66 lbs (approx. 30 kg). Fetene had been sick with TB since he was 13, and had already cycled through three gruelling, ineffective TB treatment regimens. His parents had abandoned him, leaving him severely malnourished and isolated.

Given his dire clinical status and the long course of his TB, Fetene was enrolled in a collaborative TB treatment programme sponsored by the government in partnership with a non-governmental organisation. There, doctors found that TB had ravaged not only Fetene's lungs but also his peritoneum, the membrane lining the abdominal cavity. Given these clinical symptoms and his previous, multiple treatment regimens, Fetene's doctors presumed that he had MDR-TB and enrolled him in appropriate treatment.

But by the time of Fetene's diagnosis and treatment, his lung disease was already so advanced and progressive that he developed pneumonia. After less than two months of his MDR-TB treatment, the pneumonia led to respiratory failure, and Fetene passed away.

Fetene's untimely death illustrates many of the tragedies and injustices of paediatric drug-resistant TB. It took four years for Fetene to receive an appropriate diagnosis and treatment for his MDR-TB. During this time, he lost not only his health, but also his family and any other form of social support. By the time Fetene did receive a proper diagnosis and adequate care, it was too late<sup>vi</sup>.

### **Palliative care for children**

The World Health Organization (WHO) defines palliative care for children as a special, albeit closely related field to adult palliative care which includes:

- The active, total care of the child's body, mind and spirit and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health care providers must evaluate the child's physical, psychological and social distress.
- Effective Palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's own homes<sup>vii</sup>.

### **Call to action**

Diagnosis of drug-resistant TB in children is difficult and it often takes a long time before it is made. Due to lack of paediatric formulae in almost all the necessary medications, it is often difficult to administer treatment, compounding the challenges facing children and their caregivers. "Almost all

children will need these pills broken into bits, sometimes half, sometimes quarter; sometimes medication needs to be ground and most formulations don't dissolve in water" said James Seddon a researcher at the Desmond Tutu TB Centre in Cape Town. This may lead to underdosing or overdosing in children. Side effects and the pill burden can lead to adherence problems. One of the children in the 15 stories is quoted saying "I wish I didn't have to take so many medications, they make me feel nauseas and weak" Noting that there is a new Global Plan To Stop TB 2011 – 2015, it is also important to realise that families of and children with drug-resistant TB continue to suffer from the devastating effects of this illness. Urgent intervention is necessary to mitigate these effects to ensure quality of life for children and their families. The Resolution Sixty Second World Health Assembly 62.15 1(a) Urges all member states to develop comprehensive frameworks for management and care of multidrug-resistant and extensively drug-resistant tuberculosis, that include directly-observed treatment, community based and patient centred care. It is therefore highly recommended that palliative care be incorporated into all care programmes for children with DR-TB.

#### **Recommendations for all governments to:**

1. Integrate children's palliative care into all health care services for children.
2. Include children's palliative care in relevant health, welfare and educational policies.
3. Ensure training for health care workers in children's palliative care and development of mentor programmes to support these professionals in their work settings.
4. Ensure equitable access to pain-relieving and other palliative medicines, including opioids. This may necessitate a review of the Essential Drug Lists to include palliative medicines.
5. Make available adequate funding for children's palliative care

#### **Conclusion**

Palliative care is a human right. Children with drug-resistant TB suffer from physical and psychosocial symptoms that can be mitigated by the provision of palliative care. Palliative care improves the quality of life of children and their families who face life threatening illnesses, by providing pain and symptom relief, spiritual and psycho-social support from diagnosis to end of life and bereavement.

#### **References**

1. Multidrug and extensively drug-resistant TB (M/XDR-TB) 2010 Global Report Surveillance and Response published by the WHO
2. Global Tuberculosis Control. WHO Report 2011
3. Being Brave: Stories of children with drug-resistant tuberculosis. The Sentinel Project on Pediatric Drug-Resistant Tuberculosis, March 2012
4. United Nations: Convention on the Rights of the Child
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9. The Global Plan to Stop TB 2011 – 2015 published by the WHO
10. Pharmacology of second-line anti-tuberculosis drugs and potential for interactions with antiretroviral agents. [Journals.lww.com/aidsonline/Fulltext/.../Pharmacology\\_of\\_second\\_line\\_antituberculosis\\_drugs.1.as...](http://www.aidsonline.com/Fulltext/.../Pharmacology_of_second_line_antituberculosis_drugs.1.as...)

11. Children with drug-resistant TB make up the most neglected patient population. Treatment Action Group. <http://www.tbonline.info/posts/2012/3/24/children-drug-resistant-tb-make-most-negle...>
12. International Child Health Review Collaboration. *What are the indicators of multi-drug resistant tuberculosis in children?*
13. HEALTH: MDR-TB remains a difficult diagnosis in children. LILLE, 8 November 2011 (PlusNews)
14. Multidrug-resistant Tuberculosis in Children: The Pediatric Infectious Disease Journal. Volume 31, Number 9, September 2012
15. Centers for Disease Control and Prevention. *Treatment of Drug-Resistant Tuberculosis* <http://www.cdc.gov/tb/publications/factsheets/treatment/drugresistanttreatment.htm>

### **Resources for Children's Palliative Care**

#### **Organizations and their websites**

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| 1. International Children's Palliative Care Network  | <a href="http://www.icpcn.org.uk">www.icpcn.org.uk</a>                                 |
| 2. African Palliative Care association   | <a href="http://www.africanpalliativecare.org">www.africanpalliativecare.org</a>       |
| 3. Hospice Palliative Care of South Africa   | <a href="http://www.hpca.co.za">www.hpca.co.za</a>                                     |
| 4. European Association for Palliative Care  | <a href="http://www.eapcnet.org">www.eapcnet.org</a>                                   |
| 5. Asociacion Latinoamericano de Cuidados Paliativos   | <a href="http://www.cuidadospaliativos.org">www.cuidadospaliativos.org</a>             |
| 6. Together for Short Lives  | <a href="http://www.togetherforshortlives.org.uk">www.togetherforshortlives.org.uk</a> |
| 7. The Bigshoes Foundation   | <a href="http://www.bigshoes.org.za">www.bigshoes.org.za</a>                           |
| 8. Children's Hospice International  | <a href="http://www.chionline.org">www.chionline.org</a>                               |
| 9. Help the Hospices UK  | <a href="http://www.helpthehospices.org.uk">www.helpthehospices.org.uk</a>             |
| 10. National Hospice and Palliative Care Organization  | <a href="http://www.nhpco.org">www.nhpco.org</a>                                       |
| 11. International Association for the Study of Pain (IASP) Special Interest Group on Pain in Childhood | <a href="http://www.childpain.org">www.childpain.org</a>                               |

#### **Text Books on Children's Palliative Care**

1. Children's Palliative Care in Africa  
*Edited by Dr Justin Amery (available as a download from [www.icpcn.org.uk](http://www.icpcn.org.uk))*
2. Oxford Textbook of Palliative Care for Children  
*Ann Goldman; Richard Hain; Stephen Liben*
3. Hospice Care for Children  
*Anne Armstrong-Dailey, Sarah Zarbock*
4. Textbook for Interdisciplinary Pediatric Palliative Care  
*Joanne Wolfe; Pamela Hinds; Barbara Sourkes*

5. Palliative Care for Infants, Children and Adolescents: A Practical Handbook 2<sup>nd</sup> edition  
*Edited by: Brian S. Carter, Marcia Levetown, and Sarah E. Friebert*

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<sup>i</sup> ESPID Reports and Reviews. Multidrug-resistant Tuberculosis in Children: The Pediatric Infectious Disease Journal. Volume 31, Number 9, September 2012.

<sup>ii</sup> World Health Organization. Multidrug and Extensively Drug-resistant TB (M/XDR-TB): 2010 Global Report on Surveillance and Response. Geneva, Switzerland

<sup>iii</sup> Convention on the Rights of the Child. United Nations, 1989: Geneva, Switzerland.

<sup>iv</sup> Multidrug and extensively drug-resistant TB (M/XDR-TB): 2010 Global Report on Surveillance and Response

<sup>v</sup> ESPID Reports and Reviews. Multidrug-resistant Tuberculosis in Children: The Pediatric Infectious Disease Journal. Volume 31, Number 9, September 2012.

<sup>vi</sup> Being brave: Stories of children with drug-resistant tuberculosis. The Sentinel Project on Pediatric Drug-Resistant Tuberculosis, March 2012.

<sup>vii</sup> World Health Organization: 2002