

**TRISOMY 18: REFERRALS TO A CHILDREN'S PALLIATIVE CARE SERVICE**

**B. Hannon**<sup>1</sup>, V. Jennings<sup>2</sup>, E.J. Nolloy<sup>3,4</sup>, M. Twomey<sup>2</sup>, M. O'Reilly<sup>2</sup>

<sup>1</sup>*Department of Palliative Medicine, St Vincent's University Hospital,* <sup>2</sup>*Department of Palliative Medicine, Our Lady's Childrens Hospital, Crumlin, Dublin 12,* <sup>3</sup>*Department of Neonatology, Our Lady's Childrens Hospital, Crumlin,* <sup>4</sup>*Department of Neonatology, National Maternity Hospital, Dublin, Ireland*

**Background:** Trisomy 18 is the second most common autosomal trisomy in liveborn infants, characterised by severe psychomotor and growth retardation.

The median survival is 19 days, with only 5-8% surviving their first year of life. Despite recognising that trisomy 18 is almost invariably associated with death in infancy or early childhood, there is a dearth of published data regarding the palliative care needs of these patients.

It is estimated that there are 20 -25 new cases of trisomy 18 in Ireland annually, although the lack of a national database makes it difficult to confirm incidence rates.

**Aims:** To assess the referral rate of trisomy 18 to a Palliative Care service, review symptom burden and outcomes in terms of life expectancy & place of death.

**Methods:** A retrospective chart review of all cases referred over a ten-year period (2001-2010).

**Results:** 20 referrals were made. All had classical physical characteristics of trisomy 18. The most common reasons for referral were feeding & breathing difficulties, irritability and assistance with discharge planning. Mean age at death was 64 days.

**Discussion:** This is the first study to review the specific palliative care needs of infants born with trisomy 18, to show that successful home discharge is possible & to comment on place of death.

A national database is needed to identify infants diagnosed with trisomy 18, & to ensure correct resource allocation.

Neonatal pathways for babies with trisomy 18 could provide a framework for decision making & care planning, from diagnosis to bereavement support.