Professional Literature: Care Management and Social Issues

In addition to the information listed here, some useful books are available from the SOFT publications page: *Trisomy 18: A Handbook for Families* and *Trisomy 13: A Handbook for Families*. These touch on legal and educational aspects as well as the diagnosis itself. Also available there is *Care of the Infant and Child with Trisomy 18 or Trisomy 13* which provides a great deal of care information for families. These are available in both English and Spanish.


♦ *Stanford Medicine News Center, 2017*  Infants with the genetic disorders trisomy 13 or 18 are more likely to survive if they undergo heart surgery, a study from researchers at Stanford and the University of Arkansas has found.

♦ *Kosho T, et al, 2016.* Does medical intervention


♦ Video, McCaffrey, 2016: EVERY CASE IS UNIQUE: Delivering optimal medical care to babies born with Trisomy 13 and Trisomy 18. Dr. Martin McCaffrey speaking at the Perinatal Conference in Dublin, 2016


♦ Bruns, DA, 2016 The TRIS Project: Tracking Rare Incidence Syndromes. An on-going project managed by D.A. Bruns, PhD, at Southern Illinois University. A number of care, family experience and support articles are listed on this link. A link to updated information is here.


Lorenz, et al, 2013  *Evolving Medical and Surgical Management of Infants with Trisomy 18*

Wu, et al 2013  *Survival Rates, Times Noted for Live Births With Trisomy 13 and 18* It is suggested that detailed and accurate information about the survival of children with trisomies 13 and 18 should be provided to parents, genetic counselors, and
health professionals caring for affected families.

♦ Kosho, T et al 2013 Natural history and parental experience of children with trisomy 18 ... Natural history and parental experience of children with trisomy 18 based on a questionnaire given to a Japanese Parental Support Group.


♦ Janvier A et al 2012. The Experience of Families
**With Children With Trisomy 13 and 18 in Social Networks**

Am Academy of Pediatrics, doi:10.1542/peds.2012-0151


♦ **Bruns D, Foerster K** 2011. ‘We’ve been through it all together’: Support for parents with children with rare trisomy conditions. Journal of Intellectual Disability Research, 55(4), 361–369 abstract


♦ **Romesberg TL** 2008 *Building a Case for Neonatal Palliative Care*. Neonatal Network: The Journal of
Neonatal Nursing


18 and Trisomy 13: II. Psychomotor Development