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.


♦ 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.


Natural History and Parental Experience of Children with Trisomy 18 Based on a Questionnaire Given to a Japanese Trisomy 18 Parental Support Group, Am Jnl Medical Genetics, March 2013

Evolving Medical and Surgical Management of Infants with Trisomy 18

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


18 and Trisomy 13: II. Psychomotor Development