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.

♦ Pyle, A.K., et al, 2018  *Management Options and Parental Voice in the Treatment of trisomy 13 and 18*  *Journal of Perinatology*  A summary of current data and an ethical analysis of whether medical and surgical interventions should be offered to parents of newborns with trisomy 13 or 18.

♦ 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.
Fukasawa, T. et al. 2015  

Tsukada, et al. 2015  

Picoraro, JA, et al. 2014  

Wilkinson, DJ et al. 2014  

Kosho, et al. 2013  
*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

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.


♦ 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


