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.


♦ 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


