Helpful Information

Providing sources of information does not constitute SOFT’s endorsement of the sources, the products or the information they provide. Please report broken links or other comments here.

**Accessibility**

- [Ramps.org](http://Ramps.org) has created a national directory of community service organizations that provide free or low cost ramp building services for members of their community who cannot obtain them on their own for financial reasons. It is a free resource providing information on home accessibility and ramping systems.

- [AMSVANS](http://AMSVANS) has a new airline seat for disabled children. See it at the blue AMSVANS link.
Medical Devices and Equipment

This information, submitted by SOFT members, might be of assistance. If your child is using equipment that you would be comfortable recommending to others please let us know and we will add it to this page.

♦ Hearing Bands:
  • The Cochlear™ Baha® system is a Softband device for older children. See the NIH PubMed abstract about this device here.


♦ Footware – Hatchbacks provides shoes to fit over AFO’s

♦ Beds – Here is a selection of beds for special needs children:
  • The Courtney Bed https://www.cyrdesigns.com
  • Posey Bed https://www.posey.com/Posey/Posey%20StaySafe%20Bed.aspx
  • The Safety Sleeper https://www.thesafetysleeper.com

♦ eSpecial Needs, an equipment company suggested by another mom, retails strollers, wheelchairs, ramps, strollers, pushchairs, stroller-style pushchairs, and other equipment.
♦ **Rifton Activity Chair 870:** Lynne Stockman, mother to Lyndsay who has trisomy 18, says the Rifton Activity Chair 870 is a really neat chair to feed in and do activities. The Rifton Activity Chair is a positioning chair that provides versatile and adaptable seating for clients. Click here to read about it: **Rifton Activity Chair, a revolution in active seating.**

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**Medical or Surgical Information** (also, go to the SOFT publications library to find similar literature)

♦ **Apnea:**
  • **Pediatric Apnea – a Medscape overview.**

♦ **Cardiac:**
  • **Congenital Heart Defects:** – Explanations of many defects are provided here.
  • **Hypoplastic Left Heart Syndrome:** From Nationwide Children’s Hospital
  • **Pulmonary Hypertension in Children** From the Cincinnati Children’s Hospital.

♦ **Cleft Lip Palate Repair: A University of Michigan booklet**

♦ **Dandy-Walker Malformation (DWM) –** the exact cause is not known but a few SOFT families mention DWM as a part of their child’s medical findings. DWM is
GI Problems:

- **Constipation:** A 40 minute video presentation is on the trisomytalk.com website, and here is a transcript of the video presentation’s text.

- **Information about Meckel’s Diverticulum:** from Cleveland Clinic Children’s Hospital

- **Omphalocele or Gastroschisis anomalies and treatment:** Excellent explanation and must-see video from Children’s Hospital of Philadelphia.

- **Scoliosis – what is scoliosis?** by Dr. S. Shah of Nemours Alfred I. DuPont Children’s Hospital.

- **Information regarding scoliosis surgery,** from the Scoliosis Research Society.

- **Tips on taking a special needs child to the ER:** Taking your child to the ER: Tips for Making It Less Traumatic, By Douglas J. Segan, MD. Permission to link provided by Joe Graedon of People’s Pharmacy.

- **Tracking Rare Incidence Syndromes:** The TRIS project provides a means to change perceptions about children with rare trisomy conditions. Through data from TRIS Surveys, new information is available about long-term survival, positive surgical outcomes and achievement of developmental milestones such as using gestures and vocalizations to communicate, walking (with or without assistance) and interacting with
family members. A combined total of 860 surveys representing children and adults with rare incidence conditions such as trisomy 18, trisomy 13 and trisomy 9 mosaic were completed as of 10/31/16. 58.3% of children were at least 2 months of age or greater. A total of 1007 children and adults are enrolled in the project; many are SOFT members. Your participation is welcomed and encouraged. Contact Debbie Bruns, Ph.D., Southern Illinois University, Carbondale, IL at dabruns@siu.edu or go to the project enrollment page located at https://tris.siu.edu/survey/form/PreEnroll.php.

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Nutrition and Feeding Aids

♦ Probiotics to Ward Off Colds – The People’s Pharmacy® Probiotics may help children as well as grownups fight off colds and other respiratory infections. Permission to link provided by Joe Graedon of People’s Pharmacy.
Other information

- **American Bar Association, Division for Legal Services:** Consumer’s guide to Legal Help and to FREE legal help for special populations

- **National Disability Rights Network (NDRN)** is the non-profit membership organization for the federally mandated Protection and Advocacy (P&A) Systems and Client Assistance Programs (CAP). There is a P&A/CAP agency in every state and U.S. territory as well as one serving the Native American population in the four corners region. Collectively, the P&A/CAP network is the largest
provider of legally based advocacy services to people with disabilities in the United States.

- Medicaid Waivers and general information about them can be found on this linked page.
Perfectly Preemie: Clothing for Preemies and a shopping app for international families. Australian SOFT mom Bron recommends an app called tunnelbear that puts your browser into “local mode” so American shopping sites can be browsed more easily by non-USA members.
She was looking for Preemie clothing and found it at Perfectly Preemie.

- **“Hello My Name is Simon”** by Sheryl Crosier and as told by Samuel and Sean Crosier. This book is about a very special relationship among three brothers. Even though Simon, their baby brother has died, his older brothers continue to have conversations with him.

- **“I Am Not a Syndrome – My Name is Simon”**
  This book by SOFT parent Sheryl Crosier is now available from publisher All Star Press – Books that Change Lives. It is offered in .pdf and all online e-book formats and in paperback from the publisher’s website. A portion of the proceeds from every sale of this book goes to SOFT.

- **Exceptional Parent (EP)**
  This monthly magazine is helpful for parents of a child or young adult with special needs. It provides family stories, an annual resource guide of organizations for all disorders, and discusses products, and services.

- **The Complex Child**
  The Complex Child is a monthly e-magazine. Each issue contains subjects of interest to SOFT families and the magazine’s website article archives are extensive.