



SOFT'S MISSION STATEMENT

SOFT is a network of families and professionals dedicated to providing support and understanding to families involved in the issues and decisions surrounding trisomy 18, 13 and related chromosomal disorders. Support can be provided during prenatal diagnosis, the child's life and after the child's passing. SOFT is committed to respect a family's personal decision and to the notion of a parent-professional relationship.

SOFT is well known for hosting an annual Medical/Family conference that benefits the whole family!

SOFT is a non-profit 501(c)(3) support organization. Your donations can be directed to operations, research, or conference expenses. A receipt will be provided for your records. Thank You!

Donations can be made electronically on the www.trisomy.org website using a credit card or PayPal. Donations by check should be mailed to: SOFT, 2982 South Union St., Rochester, NY, 14624.



**Support
Organization for
Trisomy 18, 13, and
Related Disorders**



www.trisomy.org

Trisomy 18 and trisomy 13 are two trisomy conditions which occur in over 2,000 births per year in the United States. Trisomy refers to the presence of 3 chromosomes rather than the usual 2, in the designated chromosome pair. Thus, children with trisomy 18 or 13 have 47 chromosomes, rather than the usual 46, with an extra number 18 or 13 being present. The extra chromosome results in birth defects, significant developmental and motor delays, and early mortality.

Kari
(1977 - 1988)
Trisomy 18
Beloved
daughter of
Kris and Hal
Holladay



Kari's mother
is the parent
founder of
SOFT!

Connect with other SOFT families!

Meet other parents and children at SOFT's annual medical/family conference.

Select the website menu's "Events" tab for information about this year's SOFT CONFERENCE

Find your **SOFT state contact**/chapter chair using the website's "About SOFT" menu tab.

Join the **SOFT Facebook Group** – a private group for parents of a child with a Trisomy or related condition to share with other parents who understand. Click the website's Facebook icon or go to:

<https://www.facebook.com/groups/TrisomySOFT/>

Check out the **SOFT Facebook Page** - a public page of SOFT news/events, plus parent and visitor posts. Click the website's Facebook icon or go to:
<https://www.facebook.com/Trisomy18.Trisomy13.Awareness.SOFTrelatedDisorders/>



Support Organization For Trisomy

www.trisomy.org

Meet Our Medical Advisor

Dr John C. Carey, Professor of Pediatrics, University of Utah, is the professional founder and medical advisor of SOFT. SOFT has a Board of Directors, elected from member parents, and a Medical and Scientific Board of medical professionals. No salaries are paid.

Welcome parents

If your expected baby or newborn was recently diagnosed with trisomy 18, trisomy 13 or a similar disorder, you are probably already experiencing an array of emotions. This will be a very difficult time in your life as you face decisions about your pregnancy and about the care of a baby with a poor prognosis. You are not alone, and we would like to help.

The Support Organization for Trisomy 18, 13 and Related Disorders (SOFT) has welcomed families of children with any chromosome disorder for over three decades. Most SOFT members had or have a child with trisomy 18 or 13. A number of varied and rare related chromosome disorder families are also members. SOFT families consist of expectant parents, those parenting infants to adults, and those who have lost a child with trisomy. Physicians, other health care providers, and supporters are welcome to join SOFT.

How to become a SOFT Member

Registration is **FREE** and personal information is not shared with any other organization. Register using the "Membership" tab on the SOFT website menu at www.trisomy.org



Stacy is 36 years
old and living with
Trisomy 18



Natalia is 17 years
old and living with
Trisomy 13



Phillip is 10 years
old and living with a
related disorder

SOFT Literature

Some publications are available in Spanish. The SOFT website includes an on-line translation capability.

The **SOFT Times** newsletter is available in the website's library of current and past newsletters.

Care of the Infant and Child with Trisomy 18 or 13 (a free e-Book, English or Spanish), also called the "**Care book**". Read about prenatal diagnosis, issues of care and daily living, medical problems and treatments.

Trisomy 18, a Handbook (free pdf, English or Spanish)
Trisomy 13, a Handbook (free pdf, English or Spanish)
Learn about the specific disorder in the title, chromosomes, and characteristics of the syndrome.

Professional Literature: Links to a large quantity of peer-reviewed articles concerning trisomy 18 and 13 are found on the website's "Professional" menu tab.

Printing the SOFT Brochure – an Adobe .pdf file.



IMPORTANT! This brochure is normally printed on both sides, although you can print it as a two-page document, if desired. To print a front & back, single page brochure, print only the FIRST page. Then, put the printed page back in the printer and print the SECOND page. For most laser-jet printers, put the printed first page back in the paper holder in exactly the same orientation as how it printed out. This will produce a two-sided tri-fold brochure.

Do a test print to be sure the paper transport path used by your printer is understood. Fold the brochure so that the large photo of Kari Holliday becomes the back of the brochure and the group photo with logo becomes the front.

Be sure you have selected “landscape” (or auto-select) mode in the print dialog box, since this document is oriented in landscape.

After printing the first side, and *before printing the second side*, give the ink a few seconds to dry, and avoid rubbing the printed surfaces, to prevent smearing. Ink sometimes takes a little longer to dry when using a semi-glossy, or glossy paper.

After printing the second side, allow the ink to dry before rubbing the pages together or attempting to fold the brochures. When folding, avoid running your fingers over the inked areas, to prevent smearing.

It is recommended that you do not print brochures on ordinary copy paper as copy paper is not glossy and the resulting printed product will not be as good as it should be. Rather, we suggest purchasing a package of a semi-glossy paper for printing brochures. Purchase the lightest weight brochure paper you can find...the store's print shop can help you in this regard. Possible papers include:

For Inkjet Printers:

HP Professional Inkjet Brochure Paper, 150 sheets/pkg, Staples #511657, Office Depot #716501

HP Professional Brochure/Flyer Paper, 50 sheets/pkg, Staples #C6817A, Office Depot #204821

For LaserJet Printers:

Avery Trifold Brochure Paper, 50 sheets/pkg, Staples #5884, Office Depot #186118

HP Premium Presentation Laser Paper, 250 sheets/pkg, Staples #863054, Office Depot #547719

HP Color Laser Brochure Paper, 100 sheets/pkg, Staples #604580, Office Depot #353080

SOFT recommends that you provide copies of this brochure to your physician offices, with their permission