

SOFT Touches...



trisomy 18



trisomy 13



related disorder

...and you

www.trisomy.org

SOFT INFORMATION REQUEST FORM

Mail this form to the address below if you would like information by mail. Even more information is available here, on the SOFT website, (http://trisomy.org/?page_id=23979) for instant download & printing.

(Mr, Mrs, Ms) first last

street address

city state zip

Phone () _____

Email _____

Child's Name _____

birth date death date (if appropriate)

Child's Diagnosis: Trisomy 18 _____

Trisomy 13 _____ Other _____

I am enclosing a donation to SOFT in honor or in memory of: _____

My relationship to the child is: _____

Amount: _____

VISA/MC #: _____

Expiration: _____ Security Code: _____

date signature

Mail to: SOFT, 2982 South Union St.,
Rochester, NY, 14624.

Get instant information at:

www.trisomy.org



www.trisomy.org



**Support Organization For
Trisomy 18, 13 and Related
Disorders (SOFT)**

2982 South Union St. Rochester, NY 14624
800-716-7638 barbsoft@rochester.rr.com

[31st Annual Conference, Madison, WI, July 19-23, 2017](#)

INTRODUCTION

Trisomy 18 and trisomy 13 are two trisomy conditions which occur in over 2,000 births per year in the United States. The term "trisomy" refers to the presence of 3 chromosomes rather than the usual 2 in the particular chromosome pair designated. Thus, children with trisomy 18 or 13 have 47 chromosomes, rather than the usual 46, with an extra number 18 or 13 being present.

If your child has recently been 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 and trying time in your life as you face decisions regarding your child's care. You are not alone, and we would like to help.

SOFT is the Support Organization for Trisomy 18, 13 and Related Disorders. SOFT welcomes families having children with any chromosome complication; all are welcome, regardless of diagnosis. SOFT has been helping families since its incorporation in 1980.

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 the diagnosis and care in trisomy 18, 13 and related chromosomal disorders. Support is 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.

SURGERY AND GROWTH INFORMATION

SOFT maintains a registry of surgeries, provided by member families. This is sometimes helpful for medical studies and informing a family of a nearby hospital or surgeon who has given our children the benefit of his or her skills. Growth charts are available, for sharing with your child's physician.

MEMBERSHIP

There is no cost to register with SOFT and your personal information is not shared with any other organization. Register or contact SOFT through the SOFT website at www.trisomy.org, and **renew your registration annually**. Families are encouraged to submit their family stories and photos for inclusion in the Family Story section of the website.



HOW CAN SOFT HELP?

The special needs associated with the care of children with trisomy can span several years, and differ from year to year, child to child and family to family. However, most of what we experience, we hold in common. From the shock of the initial diagnosis, through difficult medical decisions and crises, to the fear and grief surrounding the potential loss of a child, we extend our help to each other. SOFT offers help in several ways:

PUBLICATIONS: http://trisomy.org/?page_id=23979

♦ **Newsletters** – the SOFT Times is published four times per year. It is free to registered members and a library of current and past newsletters resides in the SOFT website.

♦ **Books -**

- **Trisomy 18, a Handbook** (print or pdf, English or Spanish)
 - **Trisomy 13, a Handbook** (print or pdf, English or Spanish)
- Each book has information about the specific disorder, explaining chromosomes, diagnosis and characteristics of the syndrome.
- **Care of the Infant and Child with Trisomy 18 or 13** (in both print and e-book form). This book discusses issues of care and daily living and includes medical problems, reported treatments, milestones, growth charts & more.
 - **Order books** from link above (most are free).

♦ **Professional Literature** The "professionals" section of the SOFT website contains many peer-reviewed articles concerning trisomy 18 and 13. Many of these will also be of interest to parents: http://trisomy.org/?page_id=23979

♦ **Website** – there is a wealth of free information, family stories, photos, links, professional information and more,

available on the website and we invite you to tour it. Some publications are available in Spanish and the website includes an on-line translation capability.

MEETINGS, CONTACT AND CONFERENCES

♦ **Contact with local chapters** and families who have "been there," with whom you can share.

♦ **SOFT's Facebook page** provides a forum for parent-to-parent exchange of news, ideas and discussion.

♦ **SOFT's 31st Annual International SOFT Conference, Madison, WI, July 19-23, 2017**, will provide:

- Speakers and workshops that focus on emotional, practical and medical aspects of chromosome disorders.
- Free medical specialty clinic sessions for the children.
- Sibling outings, activities and workshops.
- Special sessions for families grieving a child's loss.
- Designed to benefit the entire family.



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 mail request form becomes the back of the brochure and the large photo of Kari Holliday 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.