

# SOFT Touches...



trisomy 18



trisomy 13



related disorder

...and you

[www.trisomy.org](http://www.trisomy.org)

## SOFT INFORMATION REQUEST FORM

Mail this form to the address below if you would like information by mail. **All information is available on the SOFT website, 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](http://www.trisomy.org)



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

2982 South Union St. Rochester, NY 14624  
800-716-7638 [barbsoft@rochester.rr.com](mailto:barbsoft@rochester.rr.com)

[29<sup>th</sup> Annual Conference,](#)  
[Salt Lake City, UT, July 9-12, 2015](#)

## **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.



## **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**

◊ **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**
- **Trisomy 13, a Handbook**

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 [www.trisomy.org](http://www.trisomy.org) at little cost.

◊ **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.

◊ **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 28<sup>th</sup> Annual International SOFT Conference, Norfolk, VA, July 9-13, 2014**, 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.



### **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](http://www.trisomy.org), and **renew your registration annually**. Upon registering, the website Newsletter Library password will automatically be sent to you. Families are encouraged to submit their family stories and photos for inclusion in the Family Story section of the website.

## About Printing the SOFT Brochure – an Adobe .pdf file.



IMPORTANT! The tri-fold brochure should be printed as a single-page, three-panel document, *printed on the front & back*, then folded. To do so, follow these instructions:

***Be sure you have selected “landscape” (or auto-select) mode in the print dialog box.***

Print only the FIRST page, then put the printed page back in the printer and print the SECOND page. For most laser-jet printers, place the printed first page back in the paper holder in exactly the same orientation as it printed out. This will produce a two-sided tri-fold brochure.

**Do a test print** to be sure the printer’s paper transport path is understood. Fold the brochure so that the mail request form becomes the back of the brochure and the large photo of Kari Holladay becomes the front.

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 paper.

After printing the second side, allow the ink to dry before attempting to fold the brochure.

***You can print the brochures on ordinary paper*** but we suggest purchasing a package of brochure paper for this purpose. 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 health care provider’s office, with their permission.