

International



Trisomy Alliance

Trisomy 13 and 18 For Younger Children



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For Parents	Page 2
A Special Baby	Page 3
Memories	Page 8
Your Page	Page 9
Babies and Children	Page 10
Thank You	Page 11

For Parents

International Trisomy Alliance offers support groups, physicians and other professionals the latest information about trisomy 13 and trisomy 18. Our goal is to help parents make informed decisions after the diagnosis, birth, or loss of a baby with one of these conditions.

ITA has written two booklets, one for younger and one for older children, to explain the facts about trisomy 13 and 18 sensitively and in an age appropriate way. Parents can read and discuss the booklets with their children and encourage them to ask questions.

We thank Phillip Martin for permission to use his beautiful illustrations,

Jenny Robbins and Siri Fuglem Berg MD Ph.D.



www.internationaltrisomyalliance.com





A Special Baby

This is a story about a family who are going to have a baby.



Everyone in the family is very happy and they make plans for when the baby is born.





The family has lots of fun choosing names for the baby.

Sometimes mom lets them feel when the baby kicks and hiccups. They sing and play music to the baby in her tummy.





One day there is sad news.
The baby has problems
and may not be with the
family for long.



Everyone is upset.
There are times they cry.
No one is to blame, and
these sad things can
happen to anybody.





The doctor says that some babies come home from hospital and live with their families.



If a baby grows older they will need help to do things like eating, sitting and walking.





The family thinks about
their baby all the time.



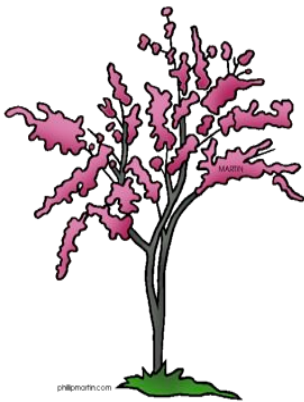
On special days
their children
release brightly
colored balloons
that float up in the
sky.





Memories

Sometimes there is a service to celebrate the life of the baby.



Families can make a Memories Box, and plant a tree or flowers.

Everyone can plan a surprise for the baby's birthday.



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Your Page

You can put your baby's name here, and draw and color some pictures.



Babies and Children

Here are some babies and children who were born with trisomy 13 or 18.





Thank You to

Phillip Martin at phillipmartin.com for his kind permission to use the illustrations.

Jenny Robbins' daughter Beth had trisomy 13 and lived for three months. Jenny co founded and was a trustee of SOFT UK for over twenty years, and she wrote several publications for families affected by trisomy 13 and 18.

Siri Fuglem Berg MD Ph.D. is an anesthesiologist who was given a prenatal diagnosis of trisomy 18, and Evy Kristine lived for three days. Siri established a Norwegian website (www.trisomi18.com) to support families in similar situations

Barb Farlow MBA Barb's daughter Annie had trisomy 13 and lived for 80 days. Barb's driving goal has been to improve communication with parents and professionals about the experience of having a child with trisomy.

Debbie Bruns Ph.D. Debbie is the Principal Investigator of the Tracking Rare Incidence Syndromes (TRIS) Project. She worked with three preschool aged children with trisomy 18 when she was a classroom teacher.

The families for sharing pictures of their precious children.

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