

# International Trisomy Alliance



## Trisomy 13 and 18 For Older Children





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## 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.



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## Chromosomes

Our body is made from cells that continue to divide as a person grows. Every cell has two pairs of chromosomes numbered 1 to 22, and each pair is different.

Here are a few chromosomes. They are numbered in order of size, with number 1 being the longest.

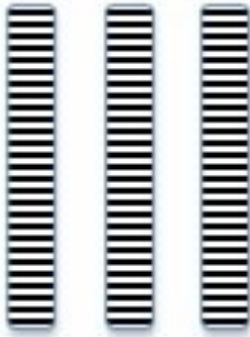


Girls also have a pair of X chromosomes, and boys have one X and one Y chromosome. This makes a total of 46 chromosomes in each human cell.



## Trisomy

Tri means three, and trisomy means three chromosomes, not the usual pair.



Trisomy 13 can be called Patau's syndrome, and there are three number 13 chromosomes in every cell.

Trisomy 18 can be called Edwards' syndrome, and there are three number 18 chromosomes in every cell.



The most common trisomy is trisomy 21 or Down's syndrome. Trisomy 13 and 18 are quite rare and it is only by chance that this condition affects some families and not others.



## Before A Baby Is Born

Doctors may know if a baby has trisomy 13 or 18 some time before the baby is born.

When mom has a scan, the children can see their baby brother or sister in her tummy.



Children can put their hands on mom's tummy to feel the baby kick. They can talk to the baby, and draw pictures for the baby, and have photographs taken with mom.



Sometimes a baby will die before or during the birth, and a family will be sad and grieve for the baby they love. The times they shared with the baby are very precious.



## A Baby With Trisomy

Every baby is unique.

Babies with trisomy 13 or trisomy 18 are individuals too, and like healthy babies, they will all be different.



Evy Kristine



Annie

These families knew their baby had trisomy 13 or 18 before the baby was born, and that their baby might not live.

Parents may be told after the birth that their baby has one of these conditions, and it is a sad and difficult time for the family.

Some babies with trisomy 13 or 18 can be cared for at home.



Beth



## A Baby At Home



Babies with trisomy 13 or 18 will grow and develop more slowly than a healthy baby, and they may need to be fed via a tube.

Nalah

A baby can have a heart condition or other problems, and some babies have a gap in their top lip called a cleft lip.



Hope



Natalia



Ole

Babies can learn to do some things, but more slowly than other babies.

The first smiles are always amazing.





## A Child With Trisomy

There are many reasons why between 10 and 40 babies in every 100 with trisomy 13 or 18 live past their first birthday.

They include fewer medical problems, less infections and more access to treatments and surgeries.

*Emeli pictured above walking has trisomy 18 and is 14 years old.*

It is rare for babies with full trisomy 13 or 18 to grow up, but a few do and they usually need a lot of special care.

*Saskia pictured right, has trisomy 18 and she celebrated her 21<sup>st</sup> birthday in 2013.*





## Mosaic trisomy and translocation

Sometimes not all the cells in the baby's body are affected. This is called a mosaic trisomy. Some cells are normal, and some of these babies grow up.

The problem is we do not always know how well a child with mosaic trisomy will be until they grow older.



Lily aged 7 and Brandon aged 15 have mosaic trisomy 18

Sometimes a baby does not have three 13 or 18 chromosomes, but one extra piece is attached to one of the chromosomes, and this condition is called a translocation.

Until the baby is older, it is hard to tell how the child will be affected.

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## Memories

When a member of our family or someone close to us dies, it is a very sad time and difficult to talk about it. Find someone you trust or a good friend, and share how you feel.



Finding ways to remember helps a family to accept their loss. Here are a few ideas:

Plant a tree or flowers in a memorial garden.

Set up a website page.

Make a memory book.

Saying goodbye to Evy Kristine

A faith leader can hold a service, and you may be able to take part by arranging flowers or reading a poem.



## Rainbows

Memories are very special, and as time passes it may become easier to think and talk about them. Some mothers have another baby who is healthy, and the family never forgets the child that died. They will love them forever.



Elliot February 2013

After such a sad loss, another baby is like a rainbow after a storm, and some families call their new baby

## A Rainbow Baby

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Your Page



Liam trisomy 18  
17.10.09 - 9.11.09

# Thank You

**Phillip Martin** at [phillipmartin.com](http://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](http://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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