International Trisomy 13/18 Alliance

TRISOMY 13 and TRISOMY 18:

Preparing for your baby's arrival

www.internationaltrisomyalliance.com

Preparing for your baby's arrival

Dear Parent,

If you have just received a diagnosis of trisomy 13 or trisomy 18 for your unborn or newborn infant, you are probably in a state of shock. You may feel anger and anguish together with moments of hope. These are natural emotions.

The purpose of this book is to give you a broad overview of trisomy 13 and trisomy 18, pregnancy, possible loss, planning and caring for a baby.

Many women are overwhelmed by negative information and grim statistics about lifespan and quality of life. It is important to realize that your baby is not a statistic or a genetic label. Seldom can a baby's journey be predicted with certainty. Each child deserves to be cared for as the unique individual they are.

TRISOMY 13 and TRISOMY 18: Preparing for your baby's arrival includes the most recent published research. We sincerely hope that this and other information provided by the International Trisomy 13 and 18 Alliance (ITA) will support you to make informed decisions on behalf of your baby.

Best wishes

Siri Fuglem Berg Jenny Robbins Barb Farlow Deborah Bruns

Founders of ITA

Trisomy 13 and Trisomy 18: Preparing for your babies arrival - September 2014

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DIAGNOSIS OF TRISOMY 13 OR TRISOMY 18

What are trisomy 13 and trisomy 18, and how rare are they?

Trisomy means three chromosomes. A baby with trisomy 13 has three number 13 chromosomes in every cell instead of the usual pair, and a baby with trisomy 18 has three number 18 chromosomes in every cell. Trisomy 18 and trisomy 13 are the second and third most common trisomy respectively after Down syndrome, which is trisomy 21. There are differences in the way trisomy 13 and trisomy 18 affect children both medically and in their appearance, but many medical issues, disability and survival rates are very similar.

A recent review of European cases revealed that there are 4 fetuses with trisomy 13 in every 20,000 pregnancies at 20 weeks gestation. However, only 1 in every 20,000 live births will have a diagnosis of trisomy 13. There are 10 fetuses with trisomy 18 in every 20,000 pregnancies at 20 weeks gestation, and only 2 in every 20,000 live births will have trisomy 18. The difference between the number of fetuses and the number of babies born is due to termination of pregnancy and stillbirths (Loane et al., 2013).

Are mosaic and partial trisomy conditions less serious?

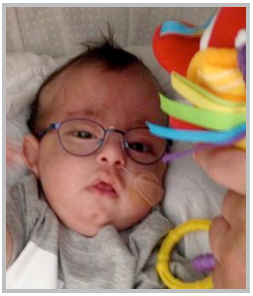
Mosaic trisomy is when only a proportion of cells in the body have three chromosomes and the remaining cells have the usual pair. Partial trisomy is when only part of the chromosome is extra (due to a translocation or other chromosome rearrangement). Children with mosaic or partial trisomy 13 or trisomy 18 often have a much larger spectrum of outcomes than those with **full** trisomy, and publications about **full** trisomy 13 and trisomy 18 may be inappropriate if applied to children with a mosaic or partial trisomy.

Lily, mosaic trisomy 1
UK

There have been instances when a baby was initially diagnosed with full trisomy 13 or full trisomy 18 by amniocentesis or blood work, but was later re-tested and found to have the mosaic form. If doctors suspect the diagnosis of full trisomy could be wrong, they might order another blood test that analyzes more cells than the original and/or a test using a tissue sample (usually the skin). These tests might reveal mosaicism (Banka, 2013).

In the absence of a serious medical condition, it is impossible to know before or at the time of birth how a child with the mosaic or partial form of trisomy 13 or trisomy 18 will develop.

Ivory, mosaic trisomy 13, before and after surgery for a cleft, UK



Jonas, partial trisomy 18, Norway

Why are clinical texts and the Internet so negative?

It is important to know the history of trisomy 13 and trisomy 18. Both conditions were initially identified in the early 1960s, and published cases were of infants with multiple deformities, and the more extreme cases became associated with these genetic labels. The early studies revealed more babies with trisomy 13 or trisomy 18 lived longer than now (Magenis et al., 1968; Weber, 1967).

The survival rates for infants with trisomy 13 and 18 that are often provided to parents reflect survival of large groups of children during a time when withholding care to newborns, or withdrawal of care after a postnatal diagnosis, was a common practice.

These studies do not describe the care that the babies received (if any), only when they died (Courtwright et al., 2011; Koogler et al,. 2003; McGraw & Perlman, 2008; Rasmussen et al., 2003).
As a result, one-year survival rates are typically reported as between 3-10% (Bos et al., 1992; Wu et al., 2013).
Further, when the diagnosis of trisomy 13 or trisomy 18 was made during pregnancy, the practice in some hospitals was to:

- question whether to resuscitate newborns in distress (i.e. not breathing; slow or no heart rate)
- not offer the level of standard or intensive care that would normally be provided for babies without a genetic diagnosis.

The result of these practices is that the 'incompatible with life' label became a self-fulfilling prophecy (McCaffrey, 2011; Morrison et al., 2010).

This misled physicians into believing that trisomy 13 and trisomy 18 are always lethal. International guidelines were developed that recommended no newborn resuscitation for babies with trisomy 13 or 18 *'due to an expected short life span and unacceptable morbidity among survivors'* (Bos et al., 1992; McCaffrey, 2011; McGraw & Perlman, 2008; Morrison et al., 2010).

Mikayla, trisomy 18, South Africa

Changes began with the formation of support groups connecting families, and when Internet support groups for parents of children with trisomy 13 or trisomy 18 came into existence. New parents now discovered that some children survived and without as many complications as they had been led to believe. Parents began asking doctors to consider medical care for their children.

Amy, trisomy 18, Germany

An article entitled 'Lethal Language, Lethal Decisions' (Koogler et al., 2003), suggested that doctors were imposing their own view of an acceptable 'quality of life' on parents: '*Although many of the congenital syndromes that used to be lethal no longer are, they are still routinely referred to as lethal anomalies. But the label is not only inaccurate, it is also dangerous: by portraying as a medical determination what is in fact a judgment about the child's quality of life, it wrests from the parents a decision that only the parents can make.*'

What is the TRIS project?

The Tracking Rare Incidence Syndromes (TRIS project) began in 2007 with the purpose of collecting information about surviving children, and offering a more realistic view of medical needs and family support.

To date, the TRIS project has published numerous papers to help doctors and clinicians understand more about survival and how to care for children with trisomy 13 and trisomy 18 (Bruns 2011, 2014; Bruns & Campbell, accepted for publication, 2014; Bruns & Springer, 2013).

Cati, trisomy 13, Rumania

For a complete list of publications and presentations see:
http://web.coehs.siu.edu/Grants/TRIS/ipublicationsandpresentations.html

When did the first research include the views of parents?

Finally, in 2012, research was published which for the very first time asked parents about their experience of having a child with trisomy 13 or trisomy 18 (Janvier et al., 2012).

Even when the baby did not live for long, the time the parents and the siblings enjoyed with baby was considered a positive event for their families. This study also revealed that treatment is beneficial in prolonging life for some children.

Sophya, trisomy 13, Bulgaria

Around the same time, Japanese studies were published which showed that medical interventions such as intensive care and surgery including heart surgery can prolong life and increase the one-year survival rate for some babies with trisomy 13 and trisomy 18 to over 40% (Kaneko et al., 2009; Kosho et al., 2006; Maeda et. al., 2011).

There is now greater awareness of the spectrum of trisomy 13 and trisomy 18, and more is known about the life and experience of children with these conditions and their families.

Outdated attitudes and definitions still exist but they are slowly changing:

'Healthcare management approaches or policies that reject out of hand the goal of prolonging the life of any infant/child with trisomy 18 are not defensible', (Lorenz & Hardart, 2014).

What is the outlook for babies with trisomy 13 or trisomy 18?

Bristol, trisomy 18, USA

Parents may be told that a baby diagnosed with trisomy 13 or trisomy 18 is incompatible with life or that the condition is 'lethal' (Koogler et al., 2003).

This is not universally true as some babies can live for months, years, and in a few cases, for decades.

Length of life is impossible to predict as the same medical issues will not affect all babies in the same way, and not all children will have similar access to medical care, treatments and surgeries (Cereda & Carey, 2012).

When babies with trisomy 13 and trisomy 18 are given the medical treatment they need, they may live longer.

PREGNANCY AND BIRTH

What types of screening tests are available?

Screening tests are non-invasive and do not cause a miscarriage. Screening tests consist of ultrasound scans and blood tests that indicate if a pregnancy is in a low or high-risk category for certain medical conditions including chromosome defects, but they do not provide a definitive diagnosis.

Parents are rarely prepared for a result indicating something may be wrong with their unborn baby, and an amniocentesis or chorionic villus sampling (CVS) currently remains the only way to confirm a chromosome problem, see: http://www.webmd.com/baby/chorionic-villus-sampling-cvs.

If an ultrasound scan shows a medical problem such as a cleft lip or cardiac defect, your obstetrician can tell you what treatments are available, and the medical team can monitor your baby closely during the pregnancy. Your physician can highlight any medical problems identified by ultrasound scanning, and you can discuss the different care options.

Should I have a diagnostic test to confirm the diagnosis?

Genetic amniocentesis and chorionic villus sampling (CVS) are the only tests that can confirm a trisomy or other chromosomal problems. The diagnostic tests have a slight risk of causing a miscarriage, and may not be advised after previous miscarriages, placental problems or an incompetent cervix. In the absence of a diagnostic test, close monitoring by ultrasound scans will assist you to discuss treatments with your physician.

If you are deciding to have a diagnostic test that will confirm whether your unborn baby has trisomy 13 or trisomy 18, ask your doctors what the consequences of a diagnosis would be, and if it is in the interests of your baby to have one.

The following are examples of questions to ask your doctors:

- would your medical team be more likely to withhold monitoring during labor even when this is your wish?
- would your obstetrician consider performing a Cesarean section (C-section) for fetal distress if requested?
- is your baby more likely to be refused treatments immediately after birth?

Why do mothers continue their pregnancy?

After receiving a diagnosis of trisomy 13 or trisomy 18 parents experience a rollercoaster of mixed emotions with good days and bad days. Many parents say they choose to continue their pregnancy because they love their child unconditionally and want to give them a chance (Guon et. al., 2013).

Others believe in destiny and that the child was meant to be. Some religions forbid pregnancy termination.

Parents who continued their pregnancy said they did so with the aim of filling their baby's life with love for as long as possible. Women described continuing their pregnancy when life was expected to be brief, as a positive experience, in spite of the sorrow and grief (Lathrop & Vandevusse, 2011).

Regardless of the length of the baby's life, moms also said their pregnancy was a time to fill their baby's life with love and create wonderful memories for their family.

Siblings could feel the kicks when the baby moved, and parents told us they enjoyed these precious moments of being able to care for and interact with their baby, and they tried not to focus on worries for the future.

Vera, trisomy 18, Singapore

When perinatal palliative care is offered as an alternative to termination, between 40-85% of women decide to continue their pregnancy (Balaguer et al,. 2012).

What are the chances of a miscarriage or stillbirth?

The chance that a fetus will miscarry or be stillborn is high in early pregnancy, and decreases as time goes on because babies with the most serious afflictions are more likely to die earlier in utero.

For trisomy 13, the risk of fetal loss before birth estimated from a recent study was 49% at 12 weeks, 42% at 18 weeks and 35% at 24 weeks gestation. For trisomy 18, the risk of fetal loss before birth was approximately 72% at 12 weeks, 65% at 18 weeks and 59% at 24 weeks gestation (Morris & Savva, 2008).

There is a higher risk for the baby during labor, and one study showed that 17% of fetuses with trisomy 18 died during this time (Yamanaka et al., 2006).

When there is no prenatal diagnosis, approximately 50% of babies with trisomy 18 and 25% of babies with trisomy 13 were delivered by C-section. These rates are higher than average, and may indicate that babies with trisomies are more vulnerable and prone to fetal distress during delivery (Baty et al,.1994; Courtwright et al., 2011).

Alessandra, trisomy 18, USA

Even when the pregnancy ends in a miscarriage or stillbirth, women report happy memories and value the time given to bond with their baby. This was also true when the baby lived only for a short time.
Women who continued their pregnancy describe the pregnancy as a positive experience (Balaguer et al., 2012 Boston USA; Walker et al., 2008; Wool, 2011).

What if my baby is stillborn or dies shortly after birth?

Sometimes a baby will not survive birth. Some parents like to prepare for this possible outcome, whereas others will want to focus on life. If you want to be prepared for a stillbirth, you may ask your midwife or obstetrician to talk through the procedure of stillborn delivery, and tell you what help and keepsakes they can offer. Many parents are glad they held their baby after a stillborn delivery. Decide what is best for you.

Some parents appreciate having photos of their stillborn baby, footprints, and a lock of hair if possible. Most families choose to name their baby, and some do not. Some like the hospital minister to perform a service. If your baby only lives for a short time and you have shared him/her with friends and family, this may be of help in the grieving process.

Parents may have the choice whether to take the baby home before a funeral while others ask the funeral home to hold the baby until burial or cremation. Some parents prefer a funeral for their baby and invite family and friends. Others prefer to be alone. There are several options: an individual or shared gravesite, a memorial site for stillborn babies, or deciding where to place the ashes after a cremation. You and your family can choose. There is no right or wrong way to collect your memories, or the type of burial, rituals and ceremonies you select.

The loss of a baby in the womb or shortly after birth is perhaps one of the more difficult losses one can experience. Ask what the hospital has to offer, whether they provide seminars for bereaved parents, or if they can help your grieving process in other ways.

Grieving takes time. Periods of grief may recur even years after your loss. It can be an emotional rollercoaster, and couples often grieve differently and at different times. Most parents appreciate the short time they spent with their baby, whether only in the womb or as a brief life. The memories you make and love for your baby will stay with you.

Should I be induced, request a C-section or aim to have a natural birth?

Numerous studies have shown that babies carried to full term and with a greater birth weight, tend to live longer (Bruns & Campbell, 2014; Wu et al., 2013).

Placental failure is a known cause of stillbirth in babies with trisomy 13 and trisomy 18 and is often identified by growth retardation during ultrasounds, and can alert physicians to closely monitor and sometimes deliver a baby before term by C-section or induction. This is a reason why some women might request to be monitored for risk of stillbirth in the final weeks of pregnancy, See: http://www.aafp.org/afp/2000/0901/p1184.html

Discuss with your neonatologist whether it might be beneficial to be given steroids to help to develop the baby's lungs before birth.

Some doctors agree to a planned C-section if this increases the possibility of a live birth. It is also important to ask whether a C- section is an option if fetal distress occurs during labor, as well as the associated present and future risks of C-section for both present and for subsequent pregnancies.

Annika, trisomy 13, Netherlands

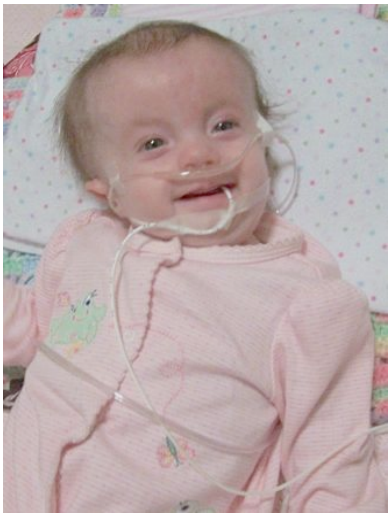
You need to discuss the options thoroughly with your physician.

Should I have a birth plan for my baby?

All birth plans are personal and include instructions for different scenarios that might unfold during or after delivery.

Most parents like to work with their medical team on a plan that takes account of their baby's particular medical issues suspected or identified by ultrasound, as well as a parent's values and choices on necessary interventions.

Seek advice on whether to choose a hospital with a higher level of neonatal intensive care (NICU) unit to give birth, and how the birth should take place.



Lilliana, trisomy 18, USA

Ask whether you will be monitored frequently for placental failure, and discuss your wishes if this happens. Tell your physician how important it is for you and your family to have time with your baby.

It is critical to check that your baby will not be denied resuscitation solely on the basis of a diagnosis of trisomy 13 or trisomy 18.

Also ask about monitors and respiratory support options: bagging, blow-by oxygen, nasal prong oxygen, CPAP (continuous positive airway pressure delivered by a mask over baby's face), and intubation (a tube placed in the airway attached to a ventilator that breathes for the baby).

You can request a room away from other new mothers if you wish.

AFTER A BABY IS BORN

How many babies with trisomy 13 or trisomy 18 survive?

Generally, the statistics quoted for one year survival are 5-10% but there are some important things to realize about survival. The major studies that reported these low survival rates do not include any information about the care that babies were offered (Burke et. al., 2013; Rasmussen et al., 2003).

- In these studies, did the babies receive nutrition?
- Did they receive oxygen for respiratory distress or was respiratory support withheld?

There appears to be a major difference between the survival of babies with a prenatal diagnosis of trisomy 13 or trisomy 18 compared with a postnatal (after birth) diagnosis. Babies that are diagnosed after birth are given the same care as other babies until a genetic diagnosis is made. For some babies, this is after life saving procedures or surgery.

Delainey, trisomy 13, Canada

After a diagnosis, recommendations are often made to withdraw or limit care.

The early care provided to babies with a postnatal diagnosis might contribute to their improved survival.

A baby with trisomy 13 or trisomy 18 that is doing well at 6-8 months has a higher probability of living for several years (Imataka et al., 2007).

What type of care plan should my baby have?

You should discuss a care plan for your baby. First ask whether the diagnosis is full trisomy 13 or full trisomy 18, or a related disorder. If the diagnosis is mosaic or partial trisomy 13 or 18, ask to speak to a geneticist for more information.

You may wish to speak with a specialist about specific medical problems your baby might have. If you do not agree with their views, you will have the option to choose another doctor who is more sympathetic to your values, hopes and wishes. Do not be afraid to ask for treatments and follow ups as you would for a baby without a diagnosed trisomy condition.

Conversely, some parents choose a care plan that keeps their baby comfortable by providing basic newborn care and no invasive treatments.

Will I be capable of feeding my baby?

Babies with trisomy 13 and trisomy 18 are often unable to suck effectively and tire quickly making them difficult to breast or bottle feed. They may need to be fed through a nasogastric tube (n-g tube), and gavage is also an option (tube to the stomach).

Oral feeding (bottle/breast/syringe) can be tried even if there is a need to supplement with an n-g tube for example, unless there is a concern about aspiration (milk in the lungs). Many children with trisomy 18 also experience reflux which can complicate oral feeding (Bruns & Springer, 2013).

Some older babies are able to eat solid or mashed food, but may need additional nutrition via feeding through an n-g tube or gastrostomy tube (or g-tube, a tube inserted directly into the stomach).

Parents can learn how to give these feedings and the supplements that may be prescribed to help a baby to gain weight.

How can I help my baby live longer?

Your child should not be denied resuscitation, medication, surgery or treatment solely because he or she has trisomy 13 or trisomy 18. There will be a number of ways to confirm prenatally suspected medical issues after the birth including blood tests, echocardiograms for the heart, abdominal (stomach) scans, and other tests according to the needs of your baby.

After discussing the results with a supportive pediatrician, parents can make informed decisions based on accurate information. A neonatal specialist will tell you if treatments are available for conditions such as omphalocele, a diaphragmatic hernia, or esophageal atresia, see:
http://www.internationaltrisomyalliance.com/ita-booklets-for-families

What is apnea?

Anaya, trisomy 18, USA

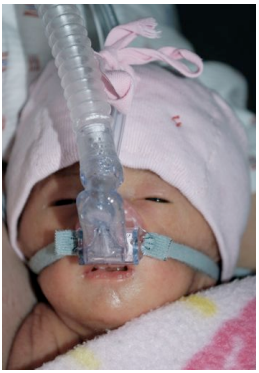
Apnea is the medical term for a pause in breathing lasting more than 20 seconds. About 50% of babies with trisomy 13 or trisomy 18 will have apnea, especially during early infancy. No research has been done on this newborn apnea in these babies despite apnea being the most common cause of early death.

Central apnea (when the brain does not signal the baby to breathe) might be overcome by delivering babies at full term if prenatal monitoring shows they need not be delivered early.

It may be helpful to start caffeine therapy after birth. This is the medication that can be given to premature babies with apnea but is contraindicated in some forms of epilepsy. You should discuss caffeine therapy with your neonatologist.

Apnea is frightening for parents as breathing stops suddenly and a baby may become limp and blue. Breathing usually restarts after a few moments and gentle stimulation of a baby, stroking their face or moving them slightly, can encourage a quick recovery unless the child is otherwise ill with pneumonia or heart failure.

Before a baby leaves the hospital, discuss with the medical team if you wish to monitor your baby's breathing with a pulse oximeter or apnea monitor. Monitoring your baby might be a wise precaution and you can request information about resuscitation techniques if your child does not breathe after stimulation. Some parents might choose to complete a CPR course before leaving the hospital.



Evy Kristine with CPAP mask, trisomy 18, Norway

Many parents have discovered that their child's apnea is not central apnea but obstructive apnea. This means there is something obstructing baby's airway such as tonsils and adenoids, or a 'floppy' trachea that makes it difficult to breathe.

Obstructive apnea due to floppy or undeveloped upper airway may be treated with surgery, CPAP, nasal trumpet, or by a tracheostomy (surgery to place a small hole in the neck to assist breathing).

Do babies with trisomy 13 or trisomy 18 survive surgery?

There is research that describes babies surviving surgery to repair cardiac defects (Graham et al., 2004; Maeda et al., 2011; Muneuchi et al., 2010). Surgeries for children with trisomy 13 or trisomy 18 may not be offered in all hospitals, and this can vary by country, state and region. Yet, it is important to stress to doctors that most children with trisomy 13 or trisomy 18 do survive and thrive because they have surgery (Bruns & Campbell, 2014; Cereda & Carey, 2012; Nelson et al., 2012).

Felicia six months after cardiac surgery, trisomy 18, Norway

Babies with trisomy 13 or trisomy 18 do tolerate anesthesia, but their airways are often narrow and/or floppy which can be problematic.

Surgery should be performed at a hospital with experienced pediatric anesthesiologists and pediatric surgeons, and preferably with staff who have experience working with children with genetic syndromes.

Each baby is unique and surgery would not be the right course of action for every baby. Some babies with cardiac defects can be supported to live longer with heart medications and oxygen.

Physicians should describe all options including benefits and risks to your baby. It is best for everyone involved to keep an open mind as options are discussed.

What developmental milestones can my baby meet?

After a diagnosis of trisomy 13 or trisomy 18, the majority of parents hear 'incompatible with life' and worse.

This section includes the milestones reached by children with trisomy 13 and trisomy 18 that have been published.

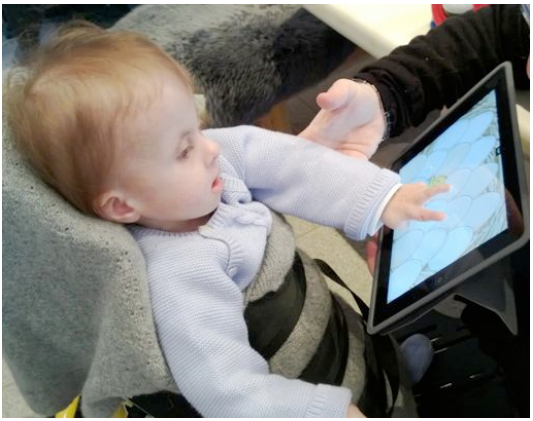
Baty and colleagues (1994) were the first to study developmental milestones.

John Paul, trisomy 13, USA

The TRIS project is reviewing data and will share the results with parents and medical professionals, see:
http://www.internationaltrisomyalliance.com/tris-project-ongoing-research.html

Although children with full trisomy 13 or trisomy 18 typically experience significant developmental delays, parents want their baby to recognize and interact with them and signal when they need something, and we know most babies with trisomy 13 and trisomy 18 do that.

They are able to show preferences and reach milestones that may include smiling, sitting, and standing, and children with full trisomy 13 or trisomy 18 sometimes learn to walk, or walk with assistance such as a gait trainer.



Ole aged 2 years, trisomy 18, Norway

Some of these milestones are reached with help, but they are achievements that delight their families.

A child may use facial expressions rather than spoken words to communicate, and this is not a baby or child communicating solely with his or her parent or carer. It is communication by the child on a wider scale, and exploring their world rather than being passive and too sickly to be aware of their surroundings.

Parents of seventy-nine older living children with full trisomy 13 or trisomy 18 were asked for their views, and 95% reported that their child could communicate needs to them, while 99% described their child as 'happy'.

There are challenges to caring for a child with trisomy 13 or trisomy 18, and many parents tell of significant financial sacrifices, but almost all parents reflect on the lives of their children as being positive and enriching (Janvier et al., 2012).

Saskia aged 22 years, trisomy 18, UK

CONTACTS AND RESOURCES

The books produced by ITA and details of research can be read and downloaded free of charge from the ITA website:

Other Resource Books produced by ITA

- **Trisomy 13 and Trisomy 18 for Younger Children**
- **Trisomy 13 and Trisomy 18 for Older Children**
- **A Family Dictionary of Medical Terms**
- **A Cherished Pregnancy**

International Trisomy Alliance (ITA) has produced the two e-books for younger and for older children to explain trisomy 13 and trisomy 18 in an age appropriate way. Parents can decide which book to read with their child.

The ITA book for younger children has topics that include 'A Special Baby' and 'Memories'. The ITA book for older children covers trisomy 13 and trisomy 18 in more depth with an explanation of chromosome types. There are translations of the books for children into Italian, Spanish, Norwegian, Indonesian, Turkish and Finnish on the ITA website.

Resource books produced by other organizations

- **Care of the Infant & Child with Trisomy 13 or Trisomy 18 SOFT USA**
- **Special Delivery - A grief support book for kids**

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We hope families preparing for the arrival of a baby with trisomy 13 or trisomy 18 will find 'Preparing for the Birth of a Baby with trisomy 13 or trisomy 18' a valuable resource.

Parent Groups and Organizations

Trisomy 13 and trisomy 18 groups and organizations can provide valuable support and information. Connecting with other families who have a similar experience can give you the confidence to advocate for your child. International Trisomy 13/18 Alliance has details of groups and organizations in the following countries, see: http://www.internationaltrisomyalliance.com/trisomy-support-groups.html

America
Australia
France
Germany
Ireland
Italy
Japan
Norway
Romania
UK

Facebook

Families often use social networks like Facebook to ask questions and share with other parents. Many SOFT and other trisomy 13 and trisomy 18 groups also have links to Facebook pages.

Hope for Trisomy
Sindrome-de-Edwards-Trisomia-18
Sindrome Patau Trissomia
SOFT Australia Support for Trisomy 13/18
Trisomia 13 habla hispana
Trisomy 18 Mommies
Trisomy Families
Trisomy 18/13 Support UK
Trisomia 18/13 (apoyo para la comunidad hispana) los estados unidos
Trisomy13 - Patau Syndrome - Living with Trisomy 13 Community
Trisomy Angel Parents
TRIS Research Project

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