

The aim of this leaflet is to inform and support parents and families who have received a diagnosis of Patau's or Edwards' syndrome during their pregnancy.

Bearing in mind that each family's situation is unique to them, the following suggestions are taken from the experiences of parents whose babies were diagnosed with Patau's or Edwards' Syndrome. We hope that it will help you start to cope with the devastating news you have received. Even if it is only to know you are not alone and that others have shared the same pain. Although it may seem that you no longer have any control over the situation you find yourself in, there are in fact many things you can do that will bring control, comfort and strength to you.

Listed briefly are some of the recommendations and suggestions from families. Please refer to our website if you require more details about any of the points. You can read the personal experiences of a number of parents and download the S.O.F.T. Ireland booklet "Why Our Baby".

### ***When you receive the diagnosis.***

- The first and most important thing to remember is that your baby is still your baby. Try to identify with him or her rather than the syndrome - naming your baby helps in this regard.
- Remember, everyone responds differently and both parents may not experience the same emotions at the same time.
- When due to meet with any health professional, write out a list of questions you would like to ask. It is a good idea to write down the responses as well.
- You will need to think about telling family and friends your devastating news. Their support can make a huge difference at this difficult time. You may also wish to consider telling work colleagues some of the details of your situation or you may prefer to keep it private until you feel ready to talk about it.

- It is perfectly normal to feel a range of emotions such as numbness, shock and feeling detached from the situation. You may be grieving for your baby even though he or she is still alive. You may doubt the diagnosis and try to convince yourself it is a mistake. All of these feelings are perfectly normal.

*See Chapter 5 "Pre-Natal Diagnosis" in "Why Our Baby".*

### ***Coping with the remainder of your pregnancy.***

- Try to enjoy the time you have with your baby rather than focusing on the predicted outcome.
- Remember you are still pregnant and need to take care of yourself. Think about how you would like your pre-natal carers to manage the rest of your pregnancy. You may wish to meet with the same doctor or midwife at each visit.
- Your baby may spend time in a high dependency unit, so you might like to arrange a visit to the intensive/special care baby unit beforehand.
- Your pregnancy will be an emotionally challenging time for you. Be aware that you need to look after your emotional as well as your physical health. Some hospitals provide counselling services. You may wish to seek professional help if you feel it appropriate.
- Keep a pregnancy diary.
- Organise "Days Out" to ensure you have good and happy memories of your time with your baby.
- Take plenty of photographs of family and friends with your bump so there are many precious moments recorded for the family album.
- Try to remove fears - always remember no question is foolish or unimportant if it matters to you.
- Often parents worry about what their baby will look like - enquire about additional scans. Some parents have had private 3D scans where they have seen their baby's face and have found these very helpful. Others have found reading the stories and looking at the photos on our website comforting.

- Be prepared for the reactions of others. Unfortunately some people will not know how to react or respond on hearing the news. Well intentioned comments can sometimes upset and hurt. Some people will disappoint you, while others will surprise you with their empathy and support.
- You may wish to speak with or meet other parents who have gone through a similar experience. S.O.F.T. Ireland can help in this regard.
- Many parents have found great comfort in doing the usual things to prepare for their baby's arrival such as buying clothes for them. As the likelihood is that your baby will be very small you may wish to purchase clothes more appropriate to his or her size. Most baby shops stock a range of clothing for smaller babies. Alternatively the hospital may be able to supply them directly.
- Start a Memory Box for keepsakes.
- You may need to reconsider the timing of your maternity leave after the diagnosis.

### ***The birth of your baby.***

- Think about the care and treatment you would like for your baby after birth. Consider meeting with the paediatric team beforehand to discuss their care plan for your baby.
- Consider who you would like to have at the hospital - grandparents, siblings, close friends. Some families have gained great comfort from these precious family memories and photographs.
- Have a camera/video to have plenty of photographs and footage recorded.
- Try hard to treasure the moments through your grief.
- Think of things to do to make these moments special - having a family blanket to wrap your baby in, a present for your baby (maybe a cuddly *toy*).
- Depending on your religious beliefs you might like to arrange for pastoral care for your baby. Try to find ways to make the occasion special for you and your family - for example by using the family christening gown.
- Take handprints, footprints and lock of hair.

### ***If your baby lives.***

- Be involved as much as possible in the care of your baby in Hospital.
- Consider bringing your baby home as soon as it is suitable. Although tube feeding and other medical needs may seem daunting, they will be explained and any anxieties are usually far outweighed by the joy of bringing your baby home.

The Jack and Jill Children's Foundation provides nursing support and respite to families. S.O.F.T. Ireland also provides funding support for families caring for a baby with Patau's or Edwards' Syndrome.

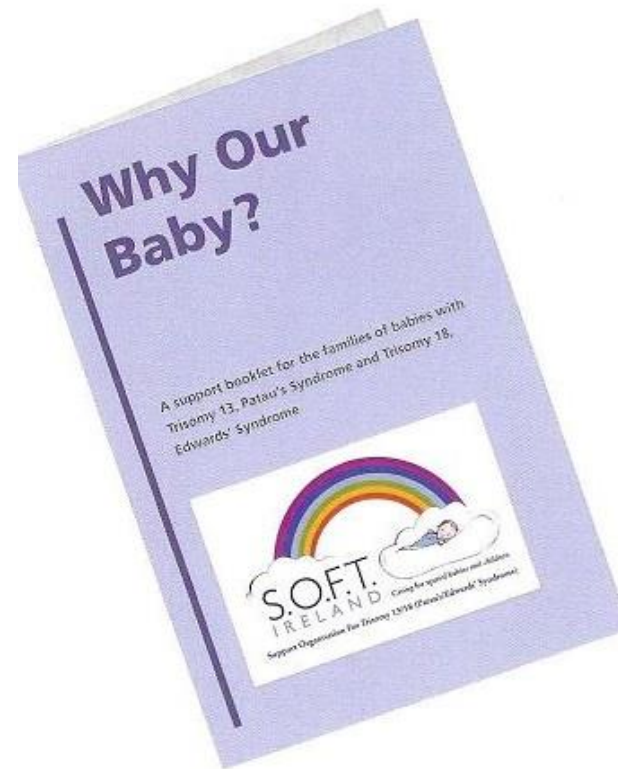
See Chapter 14 "When Your Baby Lives" in "Why Our Baby".

### ***Preparing for the possibility of your baby's death.***

- Deciding where to lay your baby to rest is a very heartbreaking and difficult thing for any parent to do. Yet it is important to give it careful consideration as some parents later regretted a rushed decision or a decision made for them by family members.
- Give thought to the type and location of service, religious or otherwise, you and your family would want for your baby ;
- Most parents who we have talked to have commented that the time they spent holding and cuddling their baby who has died was a precious and beautiful experience.
- Consider bringing your baby home if your baby dies in hospital. Some parents have found this additional time spent with their baby hugely comforting.
- Think of things you can do - shared experiences that will bring comforting memories later.

See Chapter 11 "When Your Baby Dies" in "Why Our Baby"

You can refer to our website for more detailed explanations of the content of this leaflet and other information, some of which may be of benefit to grandparents, family and friends. There are various stories in "Why Our Baby" hardcopy and these plus new stories of Fionn and Preya May are on the website. Most are the experiences of families who received a pre-natal diagnosis.



**S.O.F.T. Ireland** The Support Organisation For Trisomy 13/18 in Ireland is a voluntary group dedicated to providing support, assistance and information for families of children born with Patau's Syndrome (Trisomy 13) and Edwards' Syndrome (Trisomy 18). Support is provided during prenatal diagnosis, during the child's life and after the child's passing. It was formed in 1991. S.O.F.T. Ireland is run by parents affected by Trisomy 13/18 and related disorders.



Caring for special babies and children  
Support Organisation For Trisomy  
13/18 (Patau's/Edwards' Syndrome)

## **Trisomy 13/18 Pre-Natal Diagnosis Support and Information Leaflet**

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