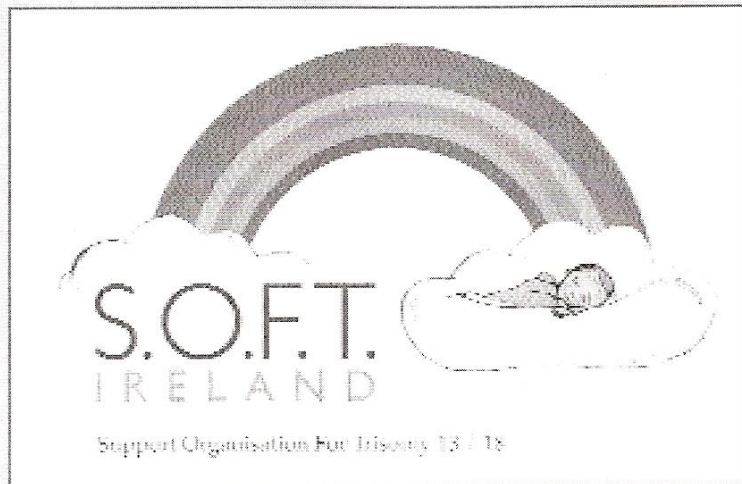


# Why Our Baby?

A support booklet for the families of  
babies with Trisomy 13, Patau's Syndrome,  
and Trisomy 18, Edward's Syndrome



**“Why Our Baby”** has been written by parents who had a baby with either Patau’s Syndrome or Edwards Syndrome. It succeeds **“Why My Baby”** which was published in 1996.

This booklet contains a significant amount of information on Patau's Syndrome and Edwards' Syndrome. Some parents may find it upsetting to read it all at once. For this reason we suggest that you use the **Contents** page of the booklet to decide on what you would like to read and at what pace.

If you are a single parent, a separated parent or your partner has died, we hope that there is nothing in the booklet that indicates that the only acceptable family unit is a father, mother and children, as this is not the intention.

We will refer to Patau's Syndrome and Edwards' Syndrome babies as "she" and "her", because of the higher incidence of the syndromes in female babies.

**Patau's Syndrome** (Trisomy 13) and **Edwards' Syndrome** (Trisomy 18) are chromosomal disorders. Babies born with these syndromes often have serious life-threatening conditions, with developmental delay and a limited life expectancy.

### **Contact S.O.F.T. Ireland**

**National Freefone Number 1800 213 218**

**Email: [info@softireland.com](mailto:info@softireland.com)**

**Website: [www.softireland.com](http://www.softireland.com)**

## Rainbows

*Rainbows would never be rainbows  
If sunshine had never met rain.  
No one would ever need comfort  
If there were no sadness and pain.*

*But life holds both sunshine and showers  
The days aren't all bright and fair.  
So look through the showers for the rainbows  
You'll always find hope shining there.*

Anonymous



Antoinette Dove

**This booklet is dedicated to all babies born with Patau's Syndrome and Edwards' Syndrome.**

## CONTENTS

### **Chairperson's Address**

### **Aims**

#### **Chapter 1: History**

#### **Chapter 2: Why Trisomy 13 or Trisomy 18?**

#### **Chapter 3: Chromosomes**

Trisomy - How it Occurs  
Related Disorders  
Genetic Counselling

#### **Chapter 4: The Heart**

How the Normal Heart Functions  
Heart Defects

#### **Chapter 5: Pre – Natal Diagnosis**

Diagnostic Tests

#### **Chapter 6: When Your Baby is Born**

Your Feelings at this Time  
Seeing Your Baby  
Your Baby's Needs  
Spiritual Support

#### **Chapter 7: How Long Will My Baby Live?**

Surgery for Congenital Abnormalities

#### **Chapter 8: Special Care Baby Unit**

#### **Chapter 9: Feeding and Digestion**

#### **Chapter 10: A Double Sorrow**

A Father's Grief  
Grandparents' Grief  
Physical Signs of Grief  
Recovery from Grief

#### **Chapter 11: When Your Baby Dies**

Keepsakes  
Little Children  
Post Mortem

Funeral Arrangements

**Chapter 12: Children and Bereavement**

Suggestions for Dealing with Bereaved Children

**Chapter 13: Having Another Baby**

**Chapter 14: When Your Baby Lives**

Bringing Your Baby Home

Caring For Your Baby

Activities For You and Your Baby

Development of Your Baby

Cleft Lip and/or Palate

Respite Care

Entitlements

Heaven's Special Child

**Chapter 15: Family Stories**

Denise	T18
Leah	T18
Louise	T18
Megan	T13
Shauna	T13
Ellen	T18
Patrick & Niall	T18
Kate	T18
Christina	T13
Darren	T18
Karl	T18
David	T18

**Chapter 16: Tribute Book**

**Glossary of Medical Terms**

**Acknowledgements**

**Useful Contacts**

## Chairperson's Address

Firstly, it is a great honour and privilege to be Chairperson of S.O.F.T. Ireland.

S.O.F.T. Ireland is a great organisation providing support of many different kinds, you can get first hand advice, you can see how much love is being shared with Dad, Mam and all the siblings, you can see real people dealing with real children in real family situations and in my opinion become better people in dealing with almost any other situation. Pauline and I got involved in 2003 after our son Patrick Gerard passed away. S.O.F.T. was a wonderful support to us in many ways and if it hadn't been for our son we would not have met all the wonderful families that we know all over Ireland today. We have no doubt that our children Leona, Michael, Yvonne and Rebecca have made friends for life and share similar experiences with people their own age.

I would like to pay tribute to the late Hugh Lambert. During my time in S.O.F.T. my memory is of Hugh turning up at every event, taking pictures, talking to everyone and before you knew it, your picture would be in the Newsletter. To Hugh we owe a huge debt. The Newsletter would not be of such a high standard but for all the hard work put in by Hugh and his family. We will always remember you "Hugh".

"Why My Baby", the first edition, I want to pay a very special tribute to all the people who put this book together and for having the foresight to produce such a fine publication. This book has been like a Bible to people who found themselves in the situation that we have all been through.

I remember first talking about a new edition of the book at a committee meeting about 4 years ago and once again Hugh Lambert was to the fore. Hugh suggested that we change the title to "Why Our Baby", he asked Professor Greene to write the Preface and he began collecting new stories. Due to Hugh's untimely death the book was put on hold for quite a while as everybody was in shock. Martina O'Reilly was chairperson at that time and after such a knock she did very well to get the book back on track.

At this point I want to pay tribute to the committee of this new book. It is a very fine edition. There has been so much research involved –updating and adding new chapters, compiling history, collecting stories, photographs and illustrations etc. It would only be at meetings in the Ardboyne Hotel, when we would all meet up that you would appreciate all the hard work that was being done and all the hard work that lay ahead. It was an honour to work with such a dedicated team as Martina O'Reilly, Geraldine Matthews, John & Jacqui McNally and Paula Doyle. To be fair, Paula would have had the hardest job taking over from Hugh Lambert. Paula and Alex made many trips to the printers to make sure

everything was being done to the highest standard. To all of you I want to say a very big "Thank You".

At the moment we are very busy trying to meet people's needs. The introduction of the Freephone Number is giving more people the chance to get in touch with our fine organisation. I hope S.O.F.T. continues the good work it is doing, like being there for new families to talk to, providing support to families of living children and hopefully making life a little easier for our special children. I would like to see this new book available in every maternity hospital in Ireland for the people who need it and that they get the strength and courage to make that call. Our aim is to increase the awareness of S.O.F.T. among the medical professionals and maybe put S.O.F.T. in touch with families sooner to offer support in many different ways. Our Newsletter is a great source of information and contact for all the members of S.O.F.T. and gives people the chance to write articles for inclusion in future issues.

As you know no organisation can operate without funds and we are very lucky to have some great families within S.O.F.T. who raise large amounts of money every year, without these people S.O.F.T. would not be able to function. For this I thank you all for the great work and hopefully we will see some more people helping out with fund raising in the near future.

The one person I haven't thanked is my own wife Pauline, I wouldn't be able to do as much for S.O.F.T. without Pauline's support and help. When I am away at meetings I know the home fires are still burning, so thank you Pauline.

The only advice I can give for the future, and what I have tried to do in the past, is know when to get into positions in organisations, but more important is to know when to get out and let new blood in. This keeps an organisation sharp and in touch with what is going on.

I'm going to sign off now and wish S.O.F.T. every success in the future.

Patrick Farrelly

August 2008

## ***The Aims of S.O.F.T. Ireland***

**The SUPPORT ORGANISATION FOR TRISOMY (S.O.F.T.)** was founded in Ireland in 1991 as a voluntary group dedicated to providing support for families of children born with the chromosomal disorders - Patau's Syndrome or Trisomy 13 and Edwards' Syndrome or Trisomy 18.

### **S.O.F T. Ireland provides support by:**

- Putting families in contact with one another
- Providing information
- Funding bereavement counselling
- Funding respite assistance
- Publishing regular newsletters
- Organising conferences and arranging professional speakers
- Raising funds through various events
- Linking with **S.O.F.T.** organisations worldwide

### **S.O.F T. Ireland provides support, assistance and information for:**

- Families with newly diagnosed babies
- Families caring for babies and children with these disorders
- Families experiencing bereavement

### **Contact S.O.F.T. Ireland**

**National Freefone Number 1800 213 218**

**Email: [info@softireland.com](mailto:info@softireland.com)**

**Website: [www.softireland.com](http://www.softireland.com)**



## CHAPTER 1

### The History of S.O.F.T. Ireland

The following is the history of S.O.F.T, Ireland as recorded in some newsletter articles and in accounts by former chairpersons.

## S.O.F.T. Ireland Winter Newsletter 2001

### A TIME TO LOOK BACK

#### The 10<sup>th</sup> Anniversary of S.O.F.T. Ireland

Reflections by  
Marie O'Conghaile, founder  
member and first chairperson



Geraldine Dodd and Marie O'Conghaile, Marie O' Conghaile and Dessie Boylan

**“Most people who have been in contact with S.O.F.T. have given back in some way and it is this energy that has made it a very special group”**

#### **THIS is a time for looking back: The 10th Anniversary of S.O.F.T.**

September 1991 was the first get together of families who had the experience of having a baby with Patau's syndrome or Edwards' syndrome. A small group of nervous, hurting, apprehensive people gathered in the Prince of Wales Hotel, Athlone, quite unsure of the future - Anne Boyle, Margaret Doherty, Edward and Bernadette Doyle, Noel and Sheila McManamly, Marie and Ronan O'Conghaile and Siena Ravensberg. All were united in a common experience of having had a baby with a trisomy, and all had a common goal to set up a support group to help other families experiencing the birth of a baby with Patau's or Edwards' syndrome.

On October 17<sup>th</sup> 1986 my daughter Aine was born in Portiuncula Hospital, Ballinasloe. The sad news that Aine had Patau's syndrome and was severely handicapped both mentally and physically, was given very sympathetically to myself and Ronan by Dr. K. Connolly, Consultant Pediatrician. The future seemed grim and sadly there seemed to be no future for Aine, as babies born with Patau's syndrome rarely survived beyond the first year. Our hearts heavy, we brought Aine home to die.

One year later Aine was still with us and doing very well, so we decided to take a more positive attitude and to deal with a child with serious problems who was part of the family. Our oldest child Niamh was eight, Conor was six and Donal was born when Aine was eighteen months old. They were difficult years, especially for Aine, with many a crisis to be overcome, permanent exhaustion and some joyful moments. We felt so alone. Why had this happened to us? This was a baby we welcomed and could give so much to.

Why Aine? The only information we had was clinical medical literature, with distressing illustrations and a list of medical terminology that necessitated a medical dictionary to comprehend. The loneliness and the isolation were all encompassing.

Who could we turn to? Who could guide us?

In October 1988 we met Noel and Sheila McManamly in Portiuncula Hospital, Ballinasloe. Their daughter Dara was newly born with Patau's syndrome. Although respecting the sorrow of Noel and Sheila, I was selfishly glad they had a baby with the same syndrome as Aine. I wasn't the only person. For me this was the first human contact with a family in our own circumstances. Sadly, Dara lost the fight to live after three weeks.

Life went on. Would I ever meet anyone caring for a baby with Patau's syndrome?

Later in 1988 I heard that Anne Boyle, my past pupil that I had known since she was 12 had given birth to Shane who had Patau's syndrome. Anne cared for Shane for six months until he also parted this world. Anne and myself shared our concerns and worries. Some time later I met Margaret Doherty and of course Megan who had partial trisomy. Megan was very like Aine, in age and appearance and presented some similar problems in caring. At last I could talk to someone who understood.

These were the emotional beginnings of S.O.F.T. The more practical beginnings originated in 1988 when Laurette Kiernan, a social worker in Temple Street Hospital through a family member gave me the address of "In Touch," an umbrella organisation of support groups in the UK founded by Anne Worthington, MBE.

**AFTER** about three years when Aine was four and a half I felt strong enough to contact "In Touch." Imagine my surprise to discover that Jenny Robbins and Christine Rose had just founded a support group in 1990. Jenny is the mother of Beth with Patau's syndrome who lived for three months. Christine is the mother of Jonathan with partial trisomy 18. I attended the first conference of S.O.F.T. UK in Birmingham June 1991. Noel McMamamly also attended the conference. I was delighted to meet Fiona and Duncan Kerr caring for John with Patau's syndrome. John was aged three. I also met Phil and Sylvia Hanly caring for Alastair aged thirteen who also had Patau's syndrome. There were other children like Aine in the world. I returned home happy.

The seeds of an idea were sown to extend the marvellous work of S.O.F.T. UK to Ireland: putting families in contact, supporting each other and giving information. I knew I would have the support of S.O.F.T. UK as Jenny had very generously pledged financial help, and the use of their newly published booklet, "*Why My Baby*". Three months later after many phone calls and letters our group met in Athlone. S.O.F.T. had its growing pains. We resisted pressure from the "Foundation for the Prevention of Childhood Handicaps" (FPCH) to become part of their group. We felt S.O.F.T. was strong enough to go it alone. We had no money and we had no experience of running a group. We just had a belief that we had something to give to others. S.O.F.T. had as its ethos that if we could help one family not to have to endure the loneliness, isolation and lack of information that we experienced, then it was worthwhile.

I would like especially to remember the first officers of S.O.F.T: Bernadette Doyle our first Secretary; Sheila McManamly our first Treasurer; Anne Boyle, the first newsletter editor; Joy Nairn, S.O.F.T.'s first contact person for Patau's Syndrome; Larry and Kathleen Fenlon, the first contact persons for Edwards's Syndrome and Margaret Doherty S.O.F.T.'s first contact person for Northern Ireland. These people had no precedent, they could not ask, "How did you do things last year?"

**SPEAKING** on behalf of S.O.F.T I would like to acknowledge and thank these people for their belief in me and for their vision and hard work in setting up S.O.F.T.

I remember from the meetings of 1991- 1992 Jasper and Della McKinney who designed our first posters, Geraldine O'Reilly, Fred and Michelle Faulkner, Mary and Derry O'Brien, Rosemary McCumiskey, Dessie and Joan Boylan, nurses Evelyn Higgins and Catherine McHale who gave a professional touch.

There were many more that were in contact. I recall some milestones in the development of S.O.F.T. In November 1991 S.O.F.T. received a cheque of £100 from Dr J Houghton, geneticist at University College Galway. I do not believe any Lotto winner could have been more excited -we had a professional who believed in us and we had money. Dr Houghton spoke subsequently at S.O.F.T.'s first conference and I know he holds a very special place in the hearts of the founder members of S.O.F.T.

Next milestone I recall was a major funding drive by Miriam O'Connor from Boyle in 1992. This fundraising was a parachute jump, involving friends and family of S.O.F.T. members and indeed anyone we could persuade to be adventurous and courageous and jump out of an aeroplane to help us. Again we had many who believed in us and thanks to the determination and hard work of Miriam, who, fuelled by her love of Aine, raised in excess of £6,000 for S.O.F.T. This money enabled S.O.F.T. to move forward and develop and implement plans and projects to help families.

Our next milestone was a commitment from the Department of Health to fund a booklet as yet not started. The booklet was a major undertaking over a period of over two years. Groups held meetings all around the country deciding on content and format, culminating in the launch of "*Why My Baby*" in November 1996 by the Secretary of State at the Department of Health, Mr Brian O'Shea. The book was written by families and from the heart of our experiences.

**OUR** first Conference in Athlone May 1994 was a joyful and sad experience. It was sad that Aine had died three weeks previously aged seven and a half. It was joyful in that her birth had brought about a forum where people came together from all parts of Ireland to meet, share, laugh and weep. We remember our speakers on that day, Dr. Jim Houghton, Dr. D. Brown, Consultant Paediatrician at Atnagelvin Hospital, Derry, and Ms Nuala Harmey, Social Worker at Temple St Hospital, Dublin.

Thinking about the past 10 years of S.O.F.T., there have been so many people that have helped its development. Indeed I believe that most people that have been in contact with S.O.F.T. have given back in some way and it is this energy that has made S.O.F.T. a very special group. Looking back and reflecting on the people who began with S.O.F.T. in 1991-1992, some are still present in an official capacity:

Mary and Derry O'Brien, Margaret Doherty, Dermot Keenan and I know Mary is in the background, and of course Dessie Boylan supported by Joan.

It is fitting that Dessie leads S.O.F.T. into the second decade. He knows the difficulties of caring for Emma for seven years and the pain of

bereavement. I know he will continue to implement the ethos and ideals of S.O.F.T: to provide information, to put families in contact and to support each other through our common experience of having a baby with Patau's Syndrome or Edwards' Syndrome.

## CHAPTER 2

### Why Trisomy 13 or 18?

Babies have been born with trisomy 13 and trisomy 18 since the beginning of time, but it was only in 1960 that Dr. Patau and Dr. Edwards identified the respective features of these syndromes. Both syndromes are the result of an extra 13th or 18th chromosome, respectively, being present in each cell.

We know what happens, but in the majority of cases nobody knows why a baby is conceived with trisomy 13 or 18. Parents should not feel that anything they did or failed to do was responsible for their baby's chromosomal disorder.

One in four of all pregnancies ends in miscarriage and a high proportion are thought to be caused by a chromosomal disorder. A high proportion of trisomy 13 and trisomy 18 pregnancies end in miscarriage within twelve weeks of conception. It is therefore quite rare for such a pregnancy to continue to full term. The incidence of trisomy 13 is about 1 in 5,000 of total births while that of trisomy 18 is about 1 in 2,500 of total births. As the female X chromosome is more viable, there are more girls born than boys.

The risk of conceiving a baby with a chromosomal disorder increases with age. The average age of a mother giving birth to a baby with trisomy 13 or trisomy 18 is 32 years. However, as most babies are born to mothers in their twenties and early thirties, many babies with trisomies 13 and 18 are born to women of this age.

Unless there is a genetic problem, it is extremely rare to have a second baby with the same disorder. However, if you are considering having another baby it is worthwhile to seek the advice of a genetic counsellor.

## CHAPTER 3

### TRISOMY 13/18 CHROMOSOMES

Chromosomes are minute thread-like structures found inside the cells of our bodies. Each chromosome consists of two parts: the short arm “p” and the long arm “q”. On the chromosomes there are between 50,000 and 100,000 genes. These genes determine the individual hereditary characteristics of each person i.e. height, eye colour, blood group. See Fig 1



A human cell contains 46 chromosomes and these are arranged into 23 pairs. A human egg or sperm contains only one chromosome from each pair. Therefore, there should be 23 of the mother’s chromosomes in each egg and 23 of the father’s chromosomes in each sperm, the resultant fertilised egg will contain 46 chromosomes (23 pairs); one chromosome of each pair came from the mother and the other chromosome from the father. This is the unique “blueprint” for the individual baby. See Fig 2

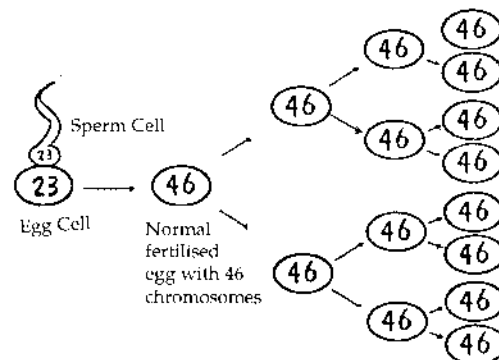


Figure 2. The fertilised egg divides repeatedly to become first a ball of cells and then an embryo.

### Karyotypes

A karyotype or picture of chromosomes is prepared from a sample of blood. The blood cultures are grown for three days and the thread-like chromosomes in the cell are released on to a slide and stained with special dyes before being photographed, cut out and arranged in order of size to make study possible. See Fig 3

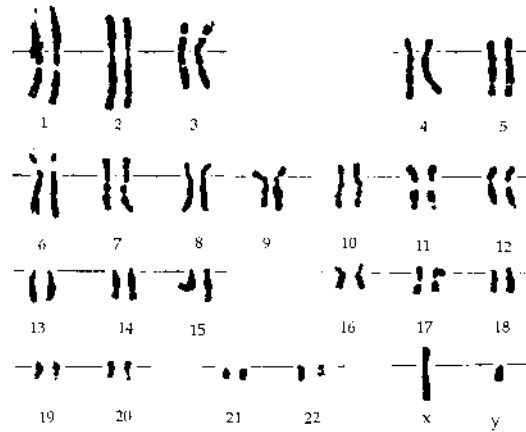


Figure 3. This is a karyotype of a male with the correct number of chromosomes.

### Trisomy - How it occurs

The word trisomy is from the Greek **word tri** (three) and means that there are three identical chromosomes present in each cell instead of the usual pair. In trisomy 13 (Patau's syndrome) an extra chromosome number 13 is present in each cell. [See Fig 4](#)

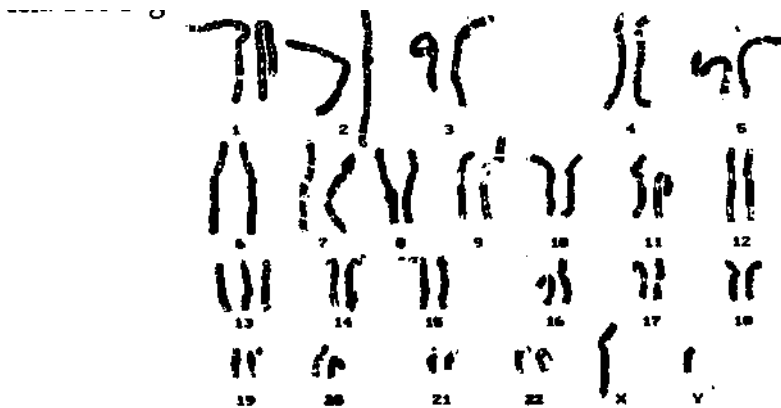


Figure 4. The karyotype of a male with Trisomy 13.

In trisomy 18 (Edwards' syndrome) an extra chromosome number 18 is present in each cell. [See Fig 5](#)



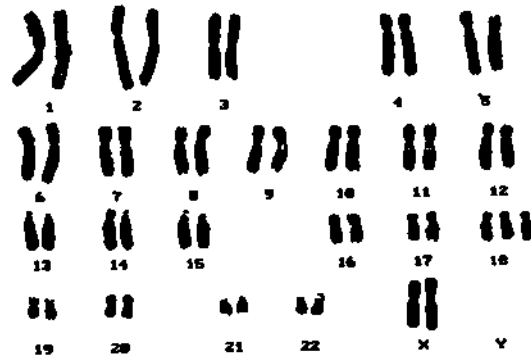


Figure 5. The karyotype of a female with Trisomy 18.

The extra chromosome may come from either the mother's egg or from the father's sperm during cell formation, or when the cells of the fertilised egg do not divide correctly during cell division. See Fig 6

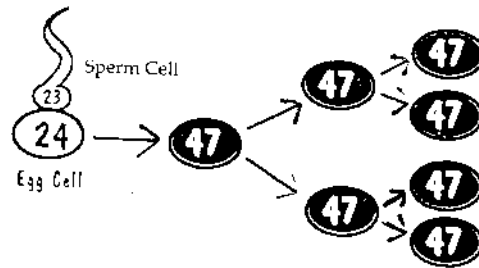


Figure 6. Here you can see that the chromosomes did not divide correctly. The result is an extra chromosome or trisomy. Trisomy may occur in either the mother's egg or the father's sperm.

Although the genes in the three chromosomes are normal, too much or too little genetic material in a cell affects every stage of the development of the baby. Therefore the blueprint for development is altered from the moment of conception.

### Related Disorders

In addition to trisomy 13 and trisomy 18, there are a number of related disorders as follows:

## Partial Trisomy

A very small percentage of babies are born, not with a complete trisomy but with a partial trisomy. This means that an extra piece of a chromosome is present. Babies with a partial trisomy may show some or all of the characteristics of the particular trisomy. This depends on the precise amount and nature of the additional chromosomal material.

## Balanced Translocation

In a balanced translocation, the normal number (46) of chromosomes are present in each cell but some or all of the material from one chromosome may be located on to a different chromosome. There is no loss of chromosomal material. Babies with balanced translocations are completely normal and their chromosomal rearrangement should have no implications regarding health or physical appearance. However, their children would be at risk of inheriting an unbalanced translocation.

## Unbalanced Translocation

This means that either

- (a) an extra piece of chromosomal material is present in each cell, usually attached to another chromosome
- (b) that a piece of chromosomal material is missing.

Balanced or unbalanced translocations can arise spontaneously where both parents have normal chromosomes.

However, if a parent has a balanced chromosome re-arrangement then there can be a higher chance of that person having a pregnancy which may be miscarried or also going on to have a pregnancy which is affected with an unbalanced chromosome translocation. The chance of these happening depends on the nature of the translocation and what has previously happened in the family.

In addition, where one person in the family carries a balanced translocation it is also possible that other members of the family, who are otherwise healthy, may also carry that translocation which may have implications in turn for them if they are thinking about children.

## Deletion

A deletion is a condition where some chromosomal material is missing from the normal chromosome. In the case of a condition denoted by 13q-, the long arm "q" of chromosome 13 is missing. In the case of 18p- the short arm "p" of chromosome 18 is missing.

## Mosaicism

This condition is a less common form of trisomy. It results from an incorrect separation of chromosomes after the first normal division of the fertilised egg. Therefore, some cells have an extra chromosome (47), while other cells have the normal number of chromosomes (46). The number of cells having the

extra chromosome varies from baby to baby and therefore each baby with mosaicism is unique. These babies are often less severely affected compared to those with an extra chromosome in every cell.

### Ring Formation

Here the two ends of a chromosome have broken off. Rejoining of the broken ends results in the formation of a ring chromosome and the loss of two chromosome fragments from each end. Ring chromosomes are rare.



Antoinette Dove

## GENETIC COUNSELLING

A genetic counselling service is available to all parents. Your GP, Obstetrician, or Paediatrician can refer you for counselling. Your GP may refer you for genetic counselling, if appropriate, to the National Centre for Medical Genetics, Our Lady's Hospital for Sick Children, Crumlin, Dublin 12.

The genetic counsellor will:

- Discuss the results of your baby's chromosome study
- Explain all aspects of the disorder
- Discuss the variable and less common forms of trisomy with the family
- Assess the risk of having a second baby with a chromosomal disorder
- Discuss the implications of the genetic diagnosis for any children or any other family members which the couple may have
- Answer any questions you may have.

In most cases, the genetic counsellor will be able to reassure you that Patau's or Edwards' syndrome is unlikely to reoccur.

## CHAPTER 4

### THE HEART

#### HOW THE NORMAL HEART FUNCTIONS

The heart is like a pump which pumps blood around the body. Described below is one complete cycle of blood flow through the heart.

Fig 1. shows a diagram of the heart. The blood flows into the heart from the lungs and enters the left upper chamber (left atrium) through a vein (pulmonary vein). The blood here is oxygen rich, having obtained its oxygen through the lungs and it passes down into the left lower chamber (left ventricle), through a valve (mitral valve). From this chamber it is pumped through to the main artery (aorta). The main artery branches off into many arteries and the blood flows off to the head, arms, stomach, liver, intestines, kidneys, legs and every other part of the body. As the blood flows, it passes from the arteries, through capillaries, where the oxygen goes into the cells and is used up. Blood is brought back to the heart through the veins and into the main vein (vena cava), or the heart.

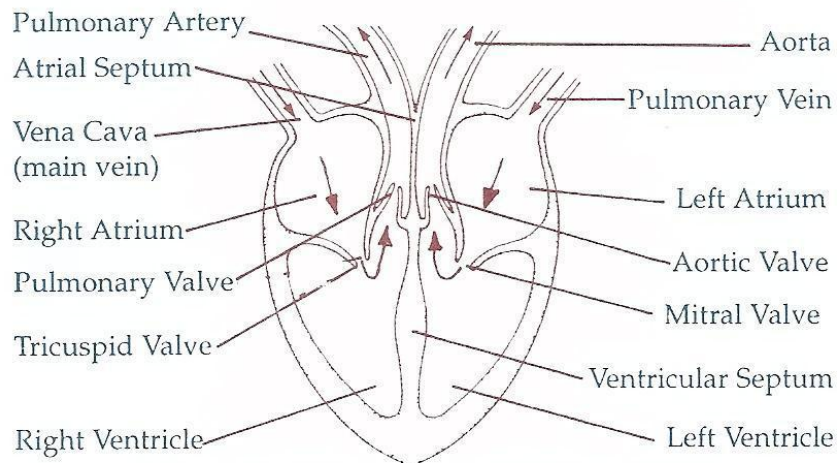
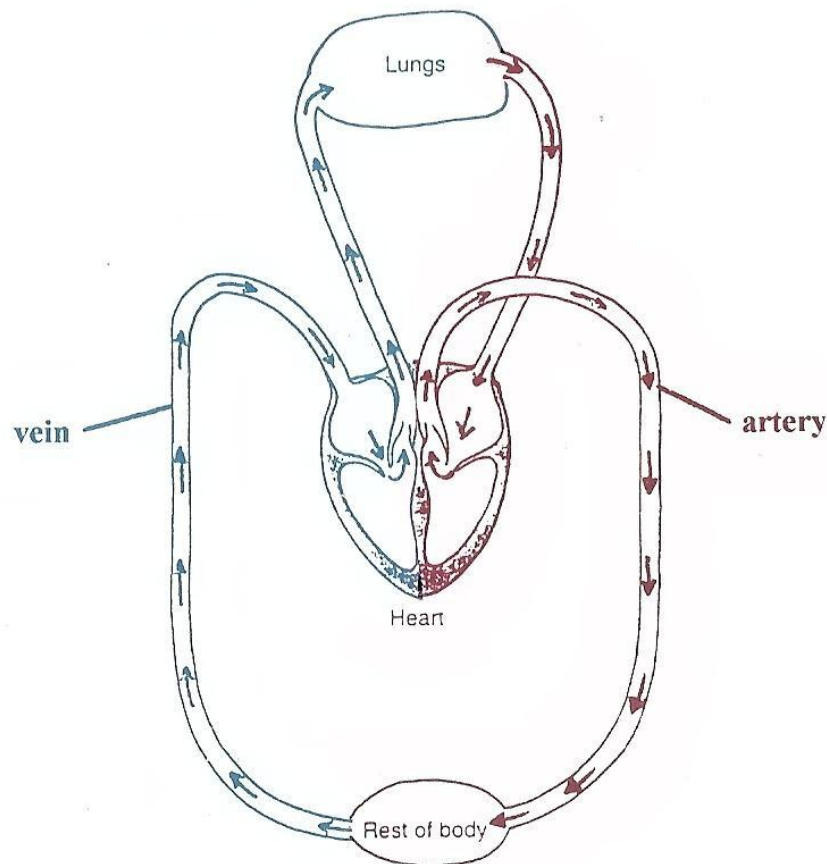


Fig 1. DIAGRAM OF A NORMAL HEART

Fig 2. shows a diagram of the blood flow around the body. From the main vein (vena cava) blood comes into the right upper chamber (right atrium) of the heart. At the bottom of the right atrium is a valve (tricuspid valve). This valve is like a trapdoor allowing the blood down and it cannot return through the valve. The blood has been right around the body, so its oxygen has been used up. When the blood drops into the right lower chamber (right ventricle); it is pumped to the lungs to get more oxygen. It flows out through an artery (pulmonary artery), where it goes into the tiny capillaries of the lungs and picks up oxygen. The capillaries deliver the blood into the pulmonary vein, which carries it back to the heart and into the left upper chamber (left atrium) and the cycle starts again.



**Fig 2. DIAGRAM OF THE BLOOD FLOW AROUND THE BODY**

**RED** := BLOOD WITH OXYGEN  
**BLUE** = BLOOD WITHOUT OXYGEN

## **HEART DEFECTS**

The heart is the one organ which is most affected by Patau's and Edwards' syndromes. Eight out of ten babies with Patau's and nine out of ten babies with Edwards' syndrome are affected with a heart defect. The effects may be mild or life-threatening.

### **The most common defects are:**

#### **Ventricular Septal Defect (V.S.D.)**

This is a hole between the lower chambers or ventricles of the heart. It means that the heart has to work harder and may become enlarged. A small opening does not strain the heart and the only abnormal finding is a murmur. However a large opening can cause serious complications or even heart failure. If your baby has a V.S.D. she may need regular treatment to clear congestion from her lungs to make breathing easier.

#### **Atrial Septal Defect (A.S.D.)**

This is a hole between the two upper chambers or atria of the heart, making it difficult for sufficient oxygen-rich blood to be pumped to the body's tissues. A soft heart murmur is heard.

#### **Tetralogy of Fallot**

This refers to a large hole between the two ventricles; and a narrowing at or just beneath the pulmonary valve. This allows oxygen-poor blood to flow directly to the body, without first passing through the lungs to get oxygen. The result is blueness (Cyanosis) .

#### **Patent Ductus Arteriosus (P.D.A.)**

Every baby is born with an open passageway between the aorta and the pulmonary artery (Ductus Arteriosus). This normally closes within a few days of birth and failure to close is quite common in premature babies. When a baby has a chromosomal abnormality this process may take several weeks. If this fails to happen some of the blood that should have gone through the aorta and on to nourish the body is returned to the lungs.

## TESTS

There are a number of tests which can be carried out to determine the extent of a heart defect, and these include a physical examination, chest X-Ray, electrocardiogram, echocardiogram and, possibly, blood and urine tests. After reviewing the examinations and tests, the heart specialist (Cardiologist) will make recommendations about possible treatment.

### Chest X-Ray

Provides information about size and shape of the heart and the blood vessels in the lungs.

### Electrocardiogram (E.C.G.)

Electrical pulses generated by the heart beat are recorded on a graph.

### Echocardiogram

An image of the heart is created by high frequency sound waves. A clear definition of the heart can be seen.

### Cardiac Catheterisation

A catheter is inserted into a vein or artery, and the Cardiologist watches by a special X-ray technique as the catheter is slowly advanced until it reaches the heart. The Cardiologist can learn about the nature of the heart defect by taking blood samples and measuring blood pressure through the catheter.



## CHAPTER 5

### PRE – NATAL DIAGNOSIS

Whilst most women give birth to healthy babies, about 3% have a major birth defect. These result from a genetic or chromosomal disorder. When an abnormality is diagnosed, this information with expert counselling and support, can help parents to make decisions about the pregnancy.

The initial effect of hearing during pregnancy that your baby is not the perfect baby you anticipated is traumatic. During the days, weeks and, indeed, months that follow, there will be many additional concerns. You may worry about what the baby will look like, about the baby dying in the womb or at birth, or about the labour starting early. There will be concerns about the actual birth, about the baby actually surviving and the responsibility of caring for a baby with problems. There can be a feeling of helplessness and of a lack of control of your life. You may doubt the diagnosis and try to convince yourself that it is all a mistake. It is hard to accept that your baby may not live.

#### Pre-Natal Diagnosis

- Provides counselling, screening and diagnostic testing
- Follow-up care and monitoring is jointly provided for those women who require it from a multi-disciplinary team

#### Information and decision making in ante-natal screening

- Some women are offered a form of screening in pregnancy to determine if they are at a sufficiently high risk of a particular disorder to warrant a diagnostic procedure such as Chorionic Villus Sampling (CVS) or Amniocentesis.
- No test should be presented as routine.

All women should make an informed decision to opt into ante-natal testing. As part of the pre-test “counselling” process, it is therefore understood that the purpose of ante-natal testing is to detect foetal abnormality. Issues such as language and terminology can then be explained and some of the confusion and distress can be avoided.

#### Approach

- A multi-disciplinary team approach is essential. The team will comprise of midwives, obstetricians, sonographers, social workers, paediatricians, geneticists and surgeons.
- There will be support from disability organisations.

- Counselling before a test is done will help couples decide which test, if any, is right for them and their baby.
- If a baby is found to have an increased risk for a chromosomal problem following screening, or an abnormality following a diagnostic test, counselling provides an opportunity to discuss the following:
  - What the result means for couples and their families
  - The options available at this time
  - Whether they wish to have further testing that is available
  - What course of action to take
  - Support will be offered to couples no matter what they decide to do

### **Why should Pre-natal Diagnosis be considered?**

- Family history of a person with a serious disorder
- Being a “carrier” for mutation
- Having a previous child affected by a serious problem in growth, development or health
- Maternal age related anxiety
- Where ultrasound findings suggest an abnormality in the pregnancy

After a prenatal diagnosis of a chromosomal disorder, take each day at a time and do not anticipate the future too much. It is best to focus on your child as a baby and not as a combination of problems and symptoms. This is a new life you are going to deliver which you have carried and nurtured for months. Even if your baby's lifetime is limited to a few months in the womb, or a matter of hours, days or months in this world, her life can be a positive experience.

## **PRE-NATAL DIAGNOSTIC TESTS**

### **First Trimester Screening (FTS)**

This is a non -invasive screening test.

By combining history, scan details and a maternal blood test, an individual's personalized risk for Down Syndrome, Edward's Syndrome and Patau's Syndrome can be calculated.

- Gestation: 11 – 13 weeks
- Result available in 1 – 2 days

## **Chorionic Villus Sampling (CVS)**

This is an invasive diagnostic test.

This is a procedure where a sample of the placenta tissue is obtained for testing.

Tests can be done on the sample to check for disorders such as Down Syndrome, Cystic Fibrosis and to determine gender.

- Gestation: 10.5 – 14 weeks
- Results: 3 weeks (Rapid test – 3 days)

## **Amniocentesis**

This is an invasive diagnostic test.

This is a procedure where a sample of amniotic fluid is obtained for testing for similar disorders as CVS.

- -Gestation: 15-20 Weeks
- Results: 3 Weeks (Rapid test - 3 days)

## **In Summary**

- It is important to discuss concerns openly. It may be useful to weigh up pros and cons of testing.
- There is no right or wrong answer to any of these questions. Each woman must decide what she feels comfortable doing. Some will chose to have testing, while others will decide against it.
- It is important to remember that the majority of women who opt for tests receive normal results and have no complications after testing.
- When a foetal abnormality is diagnosed parents and their families may, if they so wish, continue to avail of the Prenatal Diagnosis Clinic (PND) multi-disciplinary team.
- If parents have been referred for specific tests from another hospital to a tertiary centre they will be offered the choice to remain in their locality or deliver in the tertiary centre.

## CHAPTER 6

### WHEN YOUR BABY IS BORN

#### YOUR FEELINGS AT THIS TIME

Parents are understandably upset when a chromosomal disorder is diagnosed. You were looking forward to experiencing the joys of motherhood or fatherhood, and now there are multiple problems to face, along with the threat of your baby's death hanging over you.

Sometimes, a parent finds it difficult to **accept** a baby born with a chromosomal disorder. You may feel confused and disappointed and experience a sense of **rejection** of your new baby. If your baby has obvious abnormalities, your disappointment may be intensified.

It can be difficult to **bond** with your new son or daughter who seems to bring so many problems and who may not be with you for very long. Parents may also feel **guilty** for having such feelings and for not welcoming wholeheartedly their son or daughter. Indeed, many mothers of a baby born with a chromosomal disorder say that they feel **jealous** of mothers of normal babies born at the same time.

You **worry** how you will cope if your baby dies. It does not seem right to have to think of death so soon after giving birth. You **worry** how you will cope if your baby lives. You may **fear** for her future and wonder what quality of life she will have. You may **hope** that your baby will die, both for her sake, your own sake, and maybe for the sake of your other children and then feel **guilty** for having such thoughts.

You may feel **apprehensive** about your **family's and friends' reaction to** your baby. You may not want them to see her. Your family and friends themselves can often find it difficult to deal with the situation. They will wonder whether to send cards or flowers, buy presents, congratulate you or express their sorrow. It may be difficult to face meeting people for the first time. Some people may not know what has happened and may say the wrong thing. Others may try to avoid you or may pretend nothing has happened for fear of upsetting you.

On the other hand, you may feel **joy** and **hope** and **delight in** this new life. There may be total **acceptance** of whatever the future may bring for yourself and your baby.

But it is okay to feel **sad, angry, disappointed** etc. It may take time to mourn the loss of the healthy baby of your hopes and dreams and accept your new son or daughter. These are normal feelings. Don't hesitate to express them to a member of your family, a friend, a mother or father who has experienced the same situation, or to a professional.

**It may be useful to read the section "A Double Sorrow".**

## SEEING YOUR BABY

You may wish to allow some time to pass before you see your baby. If you do not feel ready, ask a member of the hospital staff to describe her and to take a Polaroid photograph, if possible. You may like to see the photograph before you see your baby.

However, consider seeing and holding your baby and getting to know her as soon as possible. If you have been told that your son or daughter may not live very long, try to spend as much time as possible with her. Hold her, talk to her, touch her, get to know her and share the time you have together. Take lots of photographs. Some parents like to capture these precious moments on video.

If you have older children, ask them if they would like to see the baby too. They may like to hold her and have their photograph taken with their brother or sister. Other family members may also wish to get involved and support you at this difficult time.

## YOUR BABY'S NEEDS

Think of your baby as a baby and not as a syndrome. She is first and foremost your daughter with her own personality, likes and dislikes. Your baby has all the needs of a newborn. She needs food, warmth, a dry nappy etc. Your baby needs \_ you and will be comforted by your visits. She may be able to focus on your face, hear your voice, feel your touch. Be positive and become aware of her good points: maybe she has beautiful fingers or toes, lovely hair etc. If you have other children, she may become aware of their presence. If possible, get involved with your baby by feeding and caring for her.

## SPIRITUAL SUPPORT

When your baby is born with either Patau's Syndrome or Edwards' Syndrome, the overriding message that comes across from the medical profession is that her condition is

***"incompatible with life"*** and that there is ***"no hope."***

No matter what your religious beliefs are, the hospital chaplain or your local cleric can provide valuable support. Remember, he/she probably knows even less than you do about your baby's condition, and sees your baby as a new life.

Your baby's birth may bring on feelings of rejection of God and of your religion. This is a very natural reaction and can be discussed with the chaplain or cleric. He/she should be able to offer you support in journeying with you to a deeper understanding of what has happened. He/she will help you to accept your child for the person she is, and through this acceptance, help you see light and God at the end of the tunnel.

## CHAPTER 7

### HOW LONG WILL MY BABY LIVE ?

Nine out of every ten babies born with Patau's Syndrome or Edwards' Syndrome do not survive beyond their first year. About three out of every ten babies with these conditions will die within the first month. Half will die before they are two months old. But of the one child in ten who celebrates her first birthday, some will survive into childhood. Occasionally, a child with trisomy 18 will live into her teens and beyond. Usually, girls live longer than boys.

If your baby has an immediate life-threatening condition, such as a major heart defect, or a defect of the forebrain, your paediatrician may be able to give some indication of how long your baby may live. You may be consulted about life-saving decisions involving corrective surgery or resuscitation.

Parents need accurate information about their baby's condition. One way parents can learn about their child is to take part in the doctor's examination of their baby. ***Parents should not be afraid to ask for straightforward answers in language they can understand.***

The uncertainty of knowing how long a baby with this condition will live is painful for parents and family. The parents are grieving because their baby is seriously ill and at the same time are trying to deal with the cruel reality that she may die. If you have other children, explain the situation clearly and simply to them.

Sometimes, family, friends or professionals may encourage parents not to become "too involved" with their baby. This is not necessarily a good decision. Parents who have withdrawn affection and contact from their baby in order to shield themselves from later sorrow may feel more intense grief and guilt when she dies. On the other hand, if a baby outlives her predicted lifespan and the parents have prepared themselves for her death, they often find that it is difficult to readjust, to become reinvolved with their baby, and to accept the responsibilities of caring for her.

If your baby has no immediate life-threatening condition it is difficult to make an accurate prediction of life expectancy. If your baby does quite well initially you should try to get back to some sort of normality. The thought of the possible death of your baby will hang over you all the time, but try to establish a routine and take each day as it comes.

## **SURGERY FOR CONGENITAL ABNORMALITIES**

Many Patau's and Edwards' Syndrome babies undergo successful surgery for **eye defects, cleft lip/palate, kidney defects and even heart defects.**

Some problems at birth can be life-threatening, such as a major heart defect, and your baby's problem would need to be carefully considered with the paediatrician to evaluate the risk of surgery. Other abnormalities may not affect the baby's health and surgery would be performed purely for aesthetic reasons. In the latter instance treatment would be optional.

**Each baby with a trisomy is unique and what is right for one baby is not necessarily right for another.** Surgery may prolong your baby's life, or make her more comfortable. On the other hand, treatment or surgery may mean putting your baby through an ordeal which may or may not prolong her life.

**The decision not to use intensive treatment or surgery does not mean that loving care is withdrawn.** Your baby can be comfortable and contented during her time in this world, despite her condition. Corrective surgery may not necessarily improve the quality of her life.

It can be helpful to talk to a parent whose baby has undergone surgery, or who decided against intensive treatment or surgery. **S.O.F.T.** may be able to put you in contact with a parent whose baby's medical problem resembles your baby's.

## **CHAPTER 8**

### **SPECIAL CARE BABY UNIT**

Babies are cared for in the Special Care Baby Unit (S.C.B.U.) when they need extra nursing and attention. The S.C.B.U. or Neonatal Unit, can be a frightening place. Your tiny baby may be in an incubator, attached to tubes, wires and monitors. This equipment is a support for your baby and it helps the nurses to monitor her more closely. Emotionally, this time can be very draining for parents. You are trying to come to terms with your baby's condition and are awaiting news hour by hour. Spend as much time as possible with your baby, talk to her, touch her and she will become aware of your presence.



The following are brief descriptions of some of the equipment in the S.C.B.U.

### **APNOEA MONITOR**

A lead with a sensor is attached to your baby's tummy to register her breathing. If she stops breathing an alarm will sound.

### **CARDIAC MONITOR**

There are two leads attached to your baby's chest and one to her tummy in order to record her heart rate and breathing.

### **INCUBATOR**

This is a transparent container for keeping premature or sick babies in controlled conditions and protecting them from infection. If your baby can breathe on her own; she will be put in a closed incubator and oxygen administered if necessary.

### **INTRAVENOUS (I.V.) PUMP**

If your baby is unable to feed, the nurses will attach an intravenous pump, consisting of a bag of fluid hanging on a stand. The fluid passes through a tube into your baby's vein and supplies her with sufficient fluids.

### **PHOTOTHERAPY UNIT**

This unit uses fluorescent light to treat jaundice in the new - born baby. Eye shields are placed over your baby's eyes for protection.

### **PULSE OXIMETER**

A tiny probe usually attached to the baby's foot, links to a machine which displays her heart rate and the amount of oxygen circulating in her blood. The pulse oximeter can also be used instead of the cardiac monitor.

### **RADIANT WARMER**

If your baby has difficulty breathing and needs to be ventilated, she may be placed on a radiant warmer. This is an open incubator that keeps her warm and gives the doctors and nurses easy access to put up drips etc.

### **VENTILATOR**

A Ventilator provides artificial breathing for your baby if she is unable to breathe on her own. If your baby needs to be ventilated, ie. needs a life support machine, she will probably be nursed on an open incubator.

## CHAPTER 9

### FEEDING AND DIGESTION

If you want to breast-feed but your baby is unable to, you can express milk which can be fed to your baby by bottle or tube.

If you are *bottle feeding* your baby keep her head up in good body alignment.

If your baby is unable to breast-feed or bottle feed she may be *tube fed* by passing a tube through the mouth (*Oral-Gastric*) or nose (*Nasal-Gastric*) into the stomach. Tube feeding provides baby with all the necessary fluid and nutrients. Many babies will go on to bottle feeding or spoon feeding but tube feeding may be continued for as long as necessary. Parents with no special medical experience can learn the correct procedure to tube feed their baby.

*Trisomy babies may need small and frequent feeds. Some babies may not tolerate certain formulae and you should consider changing to a different brand or a soya-based formula. If your baby is not gaining weight the dietician at your hospital may be able to assist you. A high-calorie infant food may be recommended.*

#### Reflux Vomiting

Reflux vomiting is when food is regurgitated through the mouth and sometimes down the nose. Many babies have a problem with this.

*Reflux vomiting may be helped by:*

Placing the baby on a level surface with the head raised slightly at an angle of about 30°

Giving smaller and more frequent feeds

Thickening the feeds

Medication.

If the reflux vomiting is severe your paediatrician may recommend surgery.

## Aspiration of Food

Aspiration is when some of the baby's feed trickles into the lungs. This can occur due to poor muscle co-ordination and can be the cause of chest infections.

## Colic

Many babies have colic which is a severe pain in the tummy causing baby to scream and draw up her knees. Some parents find that a change of infant milk formula, a soya formula or a different type of bottle or teat helps. If your baby is uncomfortable with colic your doctor may prescribe medication.

## Constipation

Your baby may be uncomfortable with constipation. Relief of this discomfort can be helped by:

Diet to encourage the formation of a soft stool

Extra fluids

Medication such as laxatives, suppositories, or a stool softener

Exercises to encourage your baby to have a bowel motion and to improve the tone of the muscles involved.

## CHAPTER 10

### A DOUBLE SORROW

For parents who give birth to a baby with severe disabilities the grieving process may need to be completed twice.

The **first** period of grieving begins when your baby is born and you mourn the baby you expected but did not have. Grieving at the death of your baby or child is accepted as a natural reaction but what those around you may not realise is that it is normal to grieve the birth of a baby with a problem.

The **second** period of grieving occurs if your baby or child dies.

The grief process involves moving through different stages. The sequence and the duration of each stage can vary from one individual to another. Some emotions you **may** or **may not** experience include:

**Shock** can result in a feeling of numbness and it can take some time before the news sinks in. You may find yourself in denial and emotionally removed from the events which are taking place around you. This is nature's way of protecting you from the trauma and your system will adapt over a period of time.

**Anger** is a normal and acceptable reaction and can be directed at God, the doctor, nurses, yourself (especially if you had not planned the pregnancy), or even the baby. Other parents may feel a profound sense of injustice and ask "**Why me?**" or "**What did I do to deserve this?**"

**Guilt** feelings may be very strong after the birth or death of a baby with a chromosomal disorder. There is a strong need to find someone or something to blame. You ask yourself: "**Did I do something wrong?**"; or "**Could I have prevented this?**"; or "**Why do I feel negative towards my baby?**" or you say to yourself: "**If only....**" or "**God is punishing me**" etc. By talking about this to the doctor, your partner, family, another parent, friend or cleric you can come to understand that you should not feel guilty.

*Loss and loneliness* and a yearning for your baby, or for what might have been, can be very intense, even if your baby is alive. These feelings can be compounded by the fact that those around you are unsure of how to approach you.

*Depression* is a natural reaction to loss and the symptoms can vary in intensity. You may feel: dejected in spirits, withdrawn, unresponsive, with poor self-esteem or that life is not worth living.

The birth of a baby with serious disabilities may put **a strain on a marriage, or family unit** and **siblings**. Now, more than ever the family and other children and grandparents need to be there for one another. All family members should talk about what it means to them - their grief, their needs, their fears etc.

Even though you may **love** and feel very maternal or paternal towards your new son or daughter, there can be a sense of *sadness, loss* and *emptiness*, similar to a bereavement. You will need to mourn the loss of the healthy baby of your dreams and **accept** this new baby for herself.

## **A FATHER'S GRIEF**

Society in the past did not encourage men to express their emotions. This attitude is now changing. As a father, you may experience the same feelings of *shock, anger, guilt, loss, loneliness* and *depression* as your partner. You may want to cry but feel you must be strong for your partner or family. People tend to forget that it is your baby too. You may experience a sense of non-involvement and isolation if you are asked "*How is your wife/partner?*" and they do not ask how **you** are. You will need to grieve and express your emotions in order to move forward. Share your grief with your partner, a friend, or a father who has gone through a similar experience.

**S.O.F.T** can help you make a contact.

## **GRANDPARENTS' GRIEF**

You will probably be as shocked and confused as your children when you know what is happening and there is a problem.

There are conditions in pregnancy where the outcome is certain, others where the prognosis is uncertain and again others where it is known that the baby will die before or soon after the birth. Ante-natal care may need to be arranged in a special pre-natal diagnosis unit where extra care for the mother and baby will be organised, including access to a special care baby care unit..

Grandparents, whose children have gone through this experience often say they feel helpless. Although you can offer support and advice, you cannot take the pain away. Watching your child suffer is perhaps the hardest thing of all. You may feel lack of power and control over the situation. These feelings are very common, and do not mean that there is anything wrong with you. You may find it will help you if you can acknowledge your feelings, be yourself and talk to someone else about them.

If the baby dies it is important to recognise that you too have suffered a loss and you may need time to grieve. The loss of your expected grandchild may hit you very hard, and this may even be more difficult if you are trying to support your children through their own hurt.

The need for an explanation as to why there is a problem with the baby is natural. The parents should receive as much information as is available about what is wrong with the baby, and what caused the abnormality, together with advice about the future.

The baby's parents often have feelings of guilt about what has happened, grandparents too sometimes feel that they are somehow to blame, or at fault. This feeling can be even stronger with inherited genetic disorders, and is entirely understandable.

Support and counselling for grandparents may be arranged through the Pre-natal Diagnosis Clinic or through the Medical Social Work Department and is available in most maternity hospitals.

**S.O.F.T.** can put you in contact with other grandparents who have gone through a similar experience.

## **PHYSICAL SIGNS OF GRIEF**

The depth of sorrow you have experienced may affect your body in a physical way. You may notice:

- Crying: this will vary with the individual
- Sleep can be disturbed, often accompanied by bad dreams or nightmares
- A constant need for sighing to catch your breath
- A feeling of heaviness in your chest like a heartache
- Palpitations
- A change in your appetite
- Shaking, shivering or feeling cold
- Exhaustion, no energy The smallest task can seem a major effort
- Difficulty in concentrating and a feeling of disorganisation
- Restlessness and irritability

*If these physical symptoms of grief become a burden and persist, check with your family doctor in order to verify that there is no underlying medical problem.*

## **RECOVERY FROM GRIEF**

It is important that you go through the grieving process in your own way and at your own pace. Sometimes, a father or mother appear to accept the situation initially, but at a later date find that they are not coping very well. The opposite is equally true. This can have its advantages as one partner may be able to support the other at different times.. Everyone experiences grief in their own way, and if two people do not show grief in the same way, this does not mean that they are not grieving. However, if you are a single parent you may feel doubly alone in your grief.

A sorrowing person should not try to suppress their emotions: to show grief is a normal and necessary part of the grieving process. It helps us to accept what has happened. Communication at this distressing time is important for all the family. Share your feelings and emotions and tell your story time and time again. This will help you to cope. Talk to your partner, your children, family or close friends. **S.O.F.T** parents who have gone through the same feelings themselves may be helpful to talk to at this stage.

### *Points to remember in recovery:*

- You can only do your best, one day at a time
- Be realistic about what you can expect from yourself
- Understand and accept the loss of energy, both emotional and physical
- If you are caring for, or helping care for your baby, be aware that you may experience conflicting thoughts and emotions
- You may need time to yourself: this is a healthy selfishness
- Comfort yourself with small pleasures
- If you have a bad day put it behind you and approach the next day with a fresh frame of mind.

The symptoms of the grieving process should ease with time. If you are finding it particularly difficult seek the help of a friend, family member, another parent, family doctor, a sympathetic counsellor or **S.O.F T**.

## CHAPTER 11

### WHEN YOUR BABY DIES

#### If your baby dies before birth

You may find out from a scan, an examination or you may know yourself, that your baby has died within. But no matter how you find out, nothing can prepare you for the shock and the total disbelief of what is happening to you. The medical term applied to a situation when a baby dies while still in its mother's womb is called **Inter Uterine Death (I.U.D.)**.

Initially, a common reaction is to believe there has been some mistake, that the monitors aren't working properly, that the hospital staff aren't reading them right, or that your baby is only holding its breath and is asleep. You are now in the difficult situation of having to begin the grieving process for a baby you have not yet seen.

It is very natural to feel a degree of fear once your baby has died as to how she will look when delivered. Your baby is no longer the familiar, living, breathing bundle you had anticipated. A lot of mothers, on hearing that their baby has died within them, are afraid to carry it for any length of time for fear that doing so, may harm them. Providing the membranes have not ruptured and there is no suspicion of infection, a dead baby in the uterus is of virtually no risk to the mother for several weeks. Your doctor will give you the option to go full-term and wait for natural labour to commence, or to attempt to be induced. It will be pointed out that occasionally induction will not work the first time, and they may have to try again. Discuss the options with the doctor and your partner and decide how you would like the remainder of the pregnancy and birth to be managed. You may like to find out the sex of your baby and give her a name. This will help you bond with your baby before delivery.

If your baby has died before birth you may like to obtain a **Stillbirth Certificate**. Any parent of a baby born who weighs 500 grams (1lb 1.60ozs) or more, or having a gestational age of 24 weeks or more, is entitled to register the birth. Contact the local Registrar of births, deaths and marriages, who is also the Registrar of stillbirths.

#### If your baby dies at birth

If you didn't know the extent of your baby's condition prior to delivery, your feelings on being told of your baby's death will be shock and disbelief. If you were aware of her condition, you will feel disappointed that she has not survived the delivery. You will probably have had plans for her to spend time with the family.

#### If your baby dies shortly after birth

If your baby dies within hours or days of life, the hospital is the only home she will have known. However, you may have had the privilege of being with her



at the time of her death. You may have built up a relationship with the medical and nursing staff. They will have become quite involved with you and your baby and will experience their own grief and disappointment when she dies. They may welcome a signal from you that you wish to talk.

**Even when your baby dies your body will experience the normal post natal symptoms such as your breasts starting to produce milk. If you find the symptoms particularly difficult discuss the situation with your obstetrician and he/she may be able to alleviate them.**

### **If your baby dies at home**

In deciding to take your baby home, you are aware that she may die at home. Despite the fact that the possibility is there, it is difficult to predict how and when your baby will die and how you and your family will react. Some parents may feel helpless because of the lack of professional help around. In this case, perhaps a doctor, cleric or public health nurse could be called for support. Some parents may feel contented and happy that their baby died in their home environment and they may wish to remain alone with their child for a while before calling anyone. It may be the last time they can be alone with their baby, as the next couple of days are likely to be spent surrounded by family and friends. At some point however, it will be necessary to call a doctor. He or she needs to certify the death of your baby.

### **If your baby lives for some time**

If you have been caring for, or helping care for your baby for some time, the final end may be a relief, especially if she has been ill for some time. But nothing can really prepare you for the death. The grief that is experienced is often different and deeper than was anticipated.

**You may like to read Chapter 10 "A Double Sorrow".**

## **KEEPSAKES**

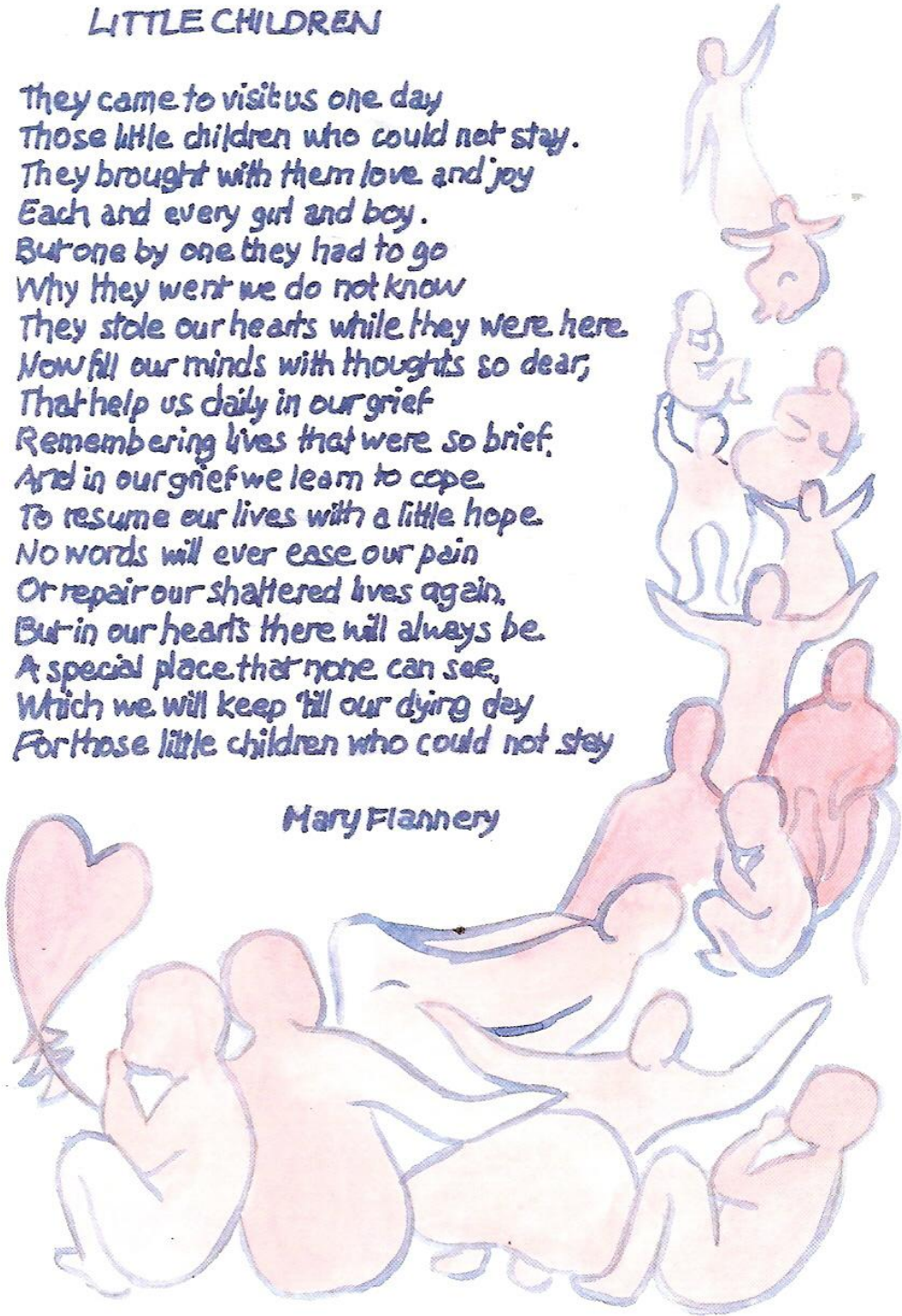
**Do keep some of the following as reminders of your baby:**

- Photographs of your baby by herself and with family members. This is important even if your baby has died before birth
- Your baby's hospital identification bracelet
- A copy of any scan photographs
- The weight and other measurements of your baby
- A stillbirth certificate, birth certificate, baptismal certificate if applicable, death certificate
- Cot card
- A lock of hair
- A hand print and/ or foot print
- A blanket or special outfit
- You may like to use a camcorder

## LITTLE CHILDREN

They came to visit us one day  
Those little children who could not stay.  
They brought with them love and joy  
Each and every girl and boy.  
But one by one they had to go  
Why they went we do not know  
They stole our hearts while they were here.  
Now fill our minds with thoughts so dear,  
That help us daily in our grief  
Remembering lives that were so brief.  
And in our grief we learn to cope  
To resume our lives with a little hope.  
No words will ever ease our pain  
Or repair our shattered lives again.  
But in our hearts there will always be  
A special place that none can see,  
Which we will keep 'til our dying day  
For those little children who could not stay

Mary Flannery



Antoinette Dove

## **POSTMORTEM**

A post mortem is a careful examination of the internal tissue and organs of the baby. This procedure is carried out at the hospital by a pathologist. You will need to sign a form granting your permission but you have the right to say no to a post mortem. If the hospital personnel do not suggest a post mortem, you also have the right to request one. The thought of a post mortem often evokes fear and distress in parents, but it has been found to be a source of reassurance to them in the future. Most parents feel better if they know where the baby is being taken for the post mortem, so don't be afraid to ask.

Also on the day of the post mortem you may not be able to visit your baby. If this concerns you, be sure to come to an agreeable arrangement with the hospital.

### **The usual reported causes of death are:**

- Cardiac failure
- Respiratory failure
- Failure to recover from an apnoeic spell or seizure
- Pneumonia.

The preliminary results of the post mortem will be available within a day or two. The final report may take up to six weeks. Many parents find it helpful to discuss the post mortem findings with their own family doctor or paediatrician. Many hospitals make an appointment for you to come back to discuss the findings.

## **FUNERAL ARRANGEMENTS**

If your baby has died in hospital, support and advice will be available from the chaplain and the hospital staff. However, if your baby dies at home, this advice can be sought from your doctor or cleric. It is important at this stage not to rush the arrangements. Consider involving your children, extended family, friends and neighbours, in the service.

### **Some details you will need to consider:**

- Burial or cremation (Note that there are no ashes from a baby's cremation)
- Using existing family grave (Note that sometimes parents who have buried their baby with their grandparents or other relatives later regret this decision)
- Purchasing a new grave
- Undertaker services to open a grave
- Church service or private home service
- Newspaper notices (You may like to write something more unusual than the standard type entry)
- Mum and Dad could put whatever they like in the coffin e.g. a photo, a toy, write a letter or card etc.
- Use the family car – ask a family member to drive Mum, Dad and Baby. Dad takes the baby to the car and from the car to the church and/ or grave.
- Flowers
- Music
- Family meal afterwards

## CHAPTER 12

### CHILDREN AND BEREAVEMENT

Children are always affected by a death in the family. Each child will grieve differently, depending on their age, maturity, personality, and experience. Even very young children will realise that something is happening in their family.

Various problems may emerge with your children. For example some children may develop vague physical symptoms of feeling unwell. Others may develop stomach aches, headaches, or have episodes of bed-wetting, tantrums or tearfulness. At school a child may not progress as normal, be disruptive in class or have difficulty concentrating. Other children can become sullen, withdrawn, and do not communicate well with their parents. On the other hand, your son or daughter may adopt the role of being perfect and cause no problems.

Like adults, children and adolescents can experience the different stages of grief - denial, shock, anger, guilt, sadness and feelings of loss and loneliness. In the beginning the child may not accept that their baby brother or sister has died. In time the child will come to accept that he/she will not return. Finally, comes the acceptance of the loss and a letting go of the deceased. At this point children will reinvest more in their lives, although there may be upsets relating to the death.

Older children and adolescents tend to mask their feelings and their grief can become an unhealthy burden. They may worry about death in general, their own death and that of their parents. Like adults, they search for a meaning for death. Adolescents may find it difficult to communicate the grief they are feeling with their parents but may do so with a friend. If the older child or adolescent has been a caregiver the sense of separation will be greater.

#### **Bereaved children have four basic needs:**

- **Information**
- **Reassurance**
- **Involvement**
- **Expression of feelings.**

Although you may fear for the psychological well-being of your child, research has shown that children are not necessarily damaged by the experience of death, provided they have correct information, support and understanding shown to them. It is important for children to be involved in all that is happening when their brother or sister dies. They will gain comfort in the future from knowing that they were important enough to be involved. In fact, children who do not have the opportunity to be involved or discuss what is happening may later have regrets.

## SUGGESTIONS FOR DEALING WITH BEREAVED CHILDREN

It is often easy to misinterpret the signs and think your child is not grieving and does not need special consideration. For example children will often resume play and other activities in a seemingly heartless manner. Keep the following points in mind when dealing with bereaved children whether they appear to need your help or not:

- Talk to your children openly about the death of their brother or sister and use the baby's name.
- Speak openly about your own grief and do not be afraid to cry in front of your children.
- Use proper terminology when speaking to children. For example, do not say "**your sister has gone to sleep**", instead say that she has "**died**". Otherwise your child may become fearful of sleeping.
- Do not confuse religious and medical reasons. Do not say, for example, that "**God wanted a little angel**". Your child may be afraid that God will want him or other family members.
- Involve your children in the funeral service even at a young age. Explain the procedure clearly to them and the importance of their role. They too need to say "**Goodbye**" to their brother or sister.
- Children often feel insecure after a bereavement. They need love, support and companionship. Provide a sense of security by having the same routine and rules as existed previously. A little special time with each child or a family day out will help.
- Allow your children to cry and express their emotions. They can be encouraged to express their feelings by drawing or writing.
- Inform the teacher at school and check from time to time if there are any problems.

Parents may be so preoccupied with their own grief that they may not be aware of the unhappiness of their children.

Sometimes, because their own grief is so intense, it may be appropriate to ask someone close to the child, i.e. close friend or relative to take on a supportive role. Your family doctor, health visitor, or public health nurse will understand what you are going through as a family and can offer support and advice.

Do not feel guilty because you cannot meet all the needs of your child. Remember a child has his or her own resources and eventually you can all be strengthened by the experience.

## GUIDELINES

- Share your grief with your children
- Encourage them to share their feelings with you
- Express your love to your family
- Make time to listen and talk
- Answer questions with honesty

## CHAPTER 13

### HAVING ANOTHER BABY

Although the risk of it happening again is very low, the fear of having another baby with Patau's Syndrome or Edwards' Syndrome is great among parents. To ease your fears **it** is helpful to seek the advice of a genetic counsellor on the risk of recurrence. (See **Genetic Counselling** in Chapter 3 )

The decision to have another baby is a personal one. If you are caring for a baby or child with Patau's or Edwards' Syndrome you will have to take into consideration the extra work that a new baby will bring. However, many parents in this situation successfully embark on another pregnancy while caring for their baby or child who has a trisomy.

If your baby has died, it is important to give yourself time to mourn your baby and to come to terms with what has happened. A new baby will not necessarily ease the feelings of pain and loss that you are experiencing. It is important to welcome a new baby as a new life for his or her own sake.

Doctors often recommend that you wait about three months before trying to conceive again. There are many things to consider before making the decision to try for another baby. Some parents are desperate to try again as soon as possible, while others need more time. For others, trying again is a healing process in itself.

If there is a genetic factor that puts you at increased risk of conceiving a baby with a particular condition, this may also play an important part in your decision. Your Doctor may refer you for genetic counselling if appropriate to the National Centre for Medical Genetics, Our Lady's Hospital for Sick Children, Crumlin, Dublin 12. The Prenatal Diagnosis Clinic at the Rotunda Hospital, Dublin 1 provides Antenatal screening and diagnostic testing services in conjunction with the Genetics Centre and will see patients from around the country by referral by a Doctor.

A subsequent pregnancy is always a stressful and worrying time for both parents as they are more aware of all the things that can go wrong. The father may be suffering from his own anxieties, worrying about his partner and the stress she is under and he may also have doubts about the successful outcome of another pregnancy. Even when another pregnancy progresses normally, it may be difficult to be positive. The prospect of another pregnancy is often very frightening, it may bring back painful

memories. Support and counselling can be arranged through the Pre-Natal Diagnosis Clinic and is available in most hospitals.

Once you have decided to try for another baby, you might like to start taking special care of yourself. This is sometimes called preconceptual care. Your general health before and around conception is important, both for yourself during the pregnancy, and for your baby's development.

## **Pregnant again**

Contact your Doctor as soon as you think or know you are pregnant. This will help you to have the best possible care for you and your baby.

This pregnancy is likely to be emotionally difficult for you. You may be full of fear, relief and hope all at the same time. Your GP, Midwife and Social Worker will be able to help with these emotional difficulties.

Some parents value being cared for at the same hospitals and clinics, and perhaps even by the same staff as during their previous pregnancy. You might want to think about whether this is important to you, and ask for the care that you want.

In another pregnancy you may like to avail of an early reassurance scan. This can be arranged in the Pre- Natal Diagnosis Clinic and will allow you an opportunity to discuss any testing you wish to avail of at an early opportunity. You may be offered specific tests depending on what was found to be wrong with your baby before.

You may find it helpful to speak to parents who have had a subsequent successful pregnancy.

**S.O.F.T.** will be able to put you in contact with others who have experienced a similar situation.

Parents say that a new baby restores their sense of confidence in themselves and their future.

## CHAPTER 14

# When your Baby Lives

### **BRINGING YOUR BABY HOME**

You may wish to consider bringing your baby home. At home, your baby will be in a family situation where the process of getting to know and care for her will be less clinical and more private. The constant visiting and the burden of travelling may be leaving you emotionally drained. The decision to bring your baby home is one you should make in consultation with the medical staff at the hospital, **but whatever decision you make, it will be the right decision for you and your baby.**

There will be a number of factors for consideration:

#### **A Gradual Transition**

Perhaps you could take your baby home for a few hours per day, then maybe an overnight stay, a weekend and, gradually, work up to taking your baby home permanently, if you wish.

#### **Family Circumstances**

You are the best judge of the situation. You may have other children, difficult living conditions or other family problems to deal with.

#### **Medical Equipment**

Some hospitals will provide or arrange medical equipment, such as oxygen, an apnoea monitor, or a suction machine for home use.

#### **Readmission to Hospital**

Check with your baby's paediatrician what the hospital's policy is on readmission. Most hospitals have open admission for such babies.

#### **Caring for your Baby**

If there are any aspects of caring for your baby at home that you feel unsure of, your paediatrician, nurses in the S.C.B.U., family doctor or public health nurse will advise you on how to deal with situations that may arise.



### **Telephone Contact**

Have 'phone numbers near at hand that you can ring if you are worried about your baby, need advice, or in an emergency:

- The S.C.B.U.
- Public health nurse
- Your family doctor
- Useful contacts at the back of this book

### **Tube Feeding**

Many parents of babies with Patau's or Edwards' Syndrome tube feed their babies. If you do not feel confident about inserting a tube, you may be able to arrange for a nurse in your locality to assist you .

### **Possibility of Baby Dying at Home**

Parents whose baby died at home report that it was a peaceful experience.

You may like to read the information on “Caring for your Baby”, “Respite Care”, and “Entitlements”.

## **CARING FOR YOUR BABY**

The following information is for parents who are caring for their baby or child at home or helping to care for her in hospital or another environment. The following are common problems of babies and children with trisomy 13 or 18. Your baby may have none or very few of these problems or she may experience more difficulties.

### **APNOEA (BREATH HOLDING)**

Apnoea is most common in infancy. The baby stops breathing without warning and becomes limp and blue. If you notice your baby having an apnoeic spell move and stimulate her to encourage her to remember to breathe. In rare instances resuscitation may be needed. However your baby will usually begin to breathe again without any assistance.

### **EYE CARE**

If your baby has a tendency to eye infections, careful attention to bathing the eyelids can help. Clean the lid edges using a sterile saline solution wiping away from the direction of the nose.

If your baby suffers from sensitivity to bright light avoid placing her in direct sunlight or facing strong light. Shade her eyes if necessary.

### **HEART CARE**

If your baby's heart defect is relatively mild then it is best to treat her as normally as possible. However, if her heart condition is serious or terminal, it is advisable to:

- Give small feeds on a frequent basis
- Consider having oxygen in the house in the form of an oxygen cylinder and a special mask, available through your health board.

### **IMMUNISATIONS**

Studies in the U.S.A. conclude that there is no evidence for an increase in adverse reactions to immunisations in babies and children with Patau's syndrome and Edwards' syndrome.

## **INFECTION**

Babies with chromosomal abnormalities tend to get infections more easily than other children. They are more susceptible to:

- Upper respiratory infections such as colds and bronchitis
- Pneumonia
- Ear infections
- Urinary tract (kidney) infections

## **IRRITABILITY**

Irritability is a common feature of babies born with Patau's syndrome. Poor feeding, colic, reflux of food, constipation, or an underlying medical problem associated with the eyes, heart or kidney could all be contributory causes. One area which could be explored in consultation with your paediatrician is irritation of the brain due to the abnormal electrical activity. All suspect causes should be thoroughly investigated in order to keep your baby - and yourself contented.

## **SEIZURES / CONVULSIONS**

Seizures are caused by extra electrical activity in the brain. They may be mild and take the form of jitteriness or small jumps lasting seconds, and may do little more than startle the baby. They tend to happen more often when a baby is going into or coming out of sleep. Sometimes these mild seizures interfere with a baby's feeding or sleeping.

During a more serious seizure your baby's body becomes rigid and there will be jerky movements of her arms and legs. Seizures can be accompanied by apnoea. You will be taught the best way to look after your baby during a seizure. Your paediatrician may prescribe medication to control these jumps or seizures.

## **SLEEPLESSNESS**

Frequently, babies with Patau's Syndrome or Edwards' Syndrome do not sleep well at night. Contributory causes could be: feeding problems, brain irritation, medical problems etc. Even if you have been told that your baby will not live very long it is worthwhile to seek medical advice to solve the problem. A good night's sleep will help you give better quality care to your baby, and your baby will be more contented.

**Never hesitate to seek medical advice should you become concerned about any aspect of your baby's health. Advice may be sought from the Special Care Baby Unit at the hospital, your paediatrician, G.P., public health nurse or appropriate professional.**

## **ACTIVITIES FOR YOU AND YOUR BABY**

Babies with Patau's Syndrome and Edwards' Syndrome will not make the same mental or physical progress as a normal baby. Each baby is an individual and as parents you will feel happy and proud when your baby expresses her personality and makes small achievements.

As your baby develops, the hospital or community physiotherapist will advise you on appropriate exercises and activities to stimulate your baby. However, to begin with these simple activities may be enjoyable and beneficial for your baby:

- When carrying your baby, check that her head is not buried in your chest or shoulder
- Gentle manipulation will help loosen the baby's clenched fists or thumbs
- Gentle leg exercises will encourage her to have a bowel motion
- Arm and leg exercises can improve the tone of the muscles
- Your baby may enjoy kicking without a nappy on, or may move her arms or legs in the bath
- As she gets older, she may like to sit up in a bouncer or special chair with her back well supported
  
- Even if your baby has problems with sight, hearing etc., try to develop her five senses as much as possible. Concentrate on your baby's own strengths so that she may experience life to the full
  
- Smile at your baby and encourage eye contact

- Hang mobiles or brightly coloured objects over your baby's cot or in a position where she might see them
- Talk to your baby and encourage other family members to do so
- Your baby may enjoy nursery rhymes, songs or musical toys .
- In Summer, weather permitting, take your baby out for a walk or into the garden. She may enjoy a gentle breeze, the sight of the flowers, the washing blowing, the singing of the birds or the smell of newly cut grass. Don't forget the cat-net if you leave your baby in the pram.

## DEVELOPMENT OF YOUR BABY

Many professionals tell parents that a diagnosis of Patau's or Edward's Syndrome means that their baby/child will never interact with their environment or that the condition is incompatible with life. While this is true in the majority of cases, it is not always the case and many surviving children do develop and make progress - albeit at slower rates than a normal child. According to a survey carried out in the United States in 1994, many babies with Patau's and Edward's Syndrome do the following before their first birthday:

- Smile responsively
- Hold up their head
- Watch a toy or face
- Reach for an object
- Laugh out loud.

### Before their second birthday many children:

- Sit up with help
- Sit up alone

- Say consonant sounds
- Roll over

In later years a few children cruise around the furniture or manage to walk with a walker. Although these children are severely developmentally delayed, they can achieve some of the skills of childhood and they can continue to learn.

## **CLEFT LIP AND/OR PALATE**

A cleft lip is a gap in the lip where the tissue has failed to grow together.

A cleft palate is a gap in the roof of the mouth and is often combined with a cleft lip.

### **Feeding your baby**

Babies with a cleft lip and/ or palate find it difficult to create a seal between their mouth and nipple or bottle teat, and cannot suck properly. Sometimes liquids also come down through the nose. Special teats are available to help baby to suck more effectively. The nurses will advise you on the correct way to feed your baby and maintain oral hygiene.

### **Surgery**

Some babies with Patau's Syndrome or Edward's Syndrome have undergone successful surgery for cleft lip and/or palate.

The situation should be evaluated carefully with the appropriate professionals. You may like to talk to a parent of a baby who made a decision to repair the cleft lip and/or palate.

The Cleft Lip and Palate Association can provide more information. See Useful Contacts.

## **RESPIRE CARE**

The role of taking care of your baby full time can be very demanding, both physically and emotionally. It is important therefore to take a break. Respite care gives you time to spend with your family and friends, time to rest and get a good night's sleep. Following a break, you will welcome your baby back and feel refreshed and enthusiastic about caring for her again.

Do not feel guilty about leaving your baby for a few hours, overnight, a weekend or longer. Others will enjoy the opportunity to care for her, and she will have professional care both day and night.

Even if your baby is given a limited life expectancy or you do not feel the need to avail of any of these services, it is worthwhile to become aware of the respite care facilities in your area. Family events, holiday, time with your other children, or just simply time for yourself, make respite care very desirable. Having your baby admitted to residential care does not take away your rights as parents and you will be free to visit, phone, take your baby out etc. at any time.

Respite care may involve providing alternative family or institutional care for a person with a disability in order to enable the carer to take a short break, a holiday or a rest. It can cover very short-term respite, for example, a “babysitter” for an evening, or a much longer arrangement for a holiday.

Respite care or temporary care in Ireland may be based in the community or in an institution. In practice, respite care is provided to a varying degree at a number of locations around the country – in some cases by your Local Health Office and in others by voluntary organisations. To find out what is available in your area contact the Disability Services Manager in your Local Health office.

### **Respite Care Grant**

The Respite Care Grant is an annual payment for carers who look after certain people in need of full-time care and attention. The payment is made regardless of the carer's means but is subject to certain conditions. You do not need to apply for the Respite Care Grant as it will be paid automatically if you are getting Carer's Allowance, Carer's Benefit or Domiciliary Care Allowance.

You can apply for the Respite Care Grant by completing the application form RCG1 and sending it to : Respite Care Grant Section, P.O Box 10085, Dublin 2.

See Website <http://www.welfare.ie/publications/sw113.html>

## **ENTITLEMENTS**

### *Republic of Ireland*

#### **Infant Care Services**

The GP who attends the mother also provides care for the new-born baby. This entails two developmental exams during the first 6 weeks following the birth, that are free of charge. The baby's entitlement to free GP services depends on whether the parents have a medical card. This means that visits to the GP for any conditions related to the baby's health during this six week period or afterwards are not covered by the scheme unless the parents have a medical card.

The public health nurse visits the mother and baby at home during the first 6 weeks.

#### **Charges in public hospitals**

If you are in a public ward under the care of a consultant for treatment and you remain overnight, you are receiving in-patient services.

If you are admitted to the hospital under the care of a consultant where you do not require the use of a bed overnight and your discharge from hospital is planned, you are receiving day services.

The charge does not apply to the following groups:

medical card holders, children up to six weeks of age, children suffering from prescribed diseases and disabilities

In cases of excessive hardship, a health board may provide the service free of charge.

#### **Community Health Services**

Following the birth, your public health nurse will visit you and your child at home, usually within 48 hours of discharge from hospital and make other visits as necessary. Public health nurses provide both general health and specific developmental advice to parents and monitor the development of the child.

A developmental examination is offered to every child by the Area Medical Officer at approximately 9 months, by appointment, in the local health centre. This examination covers all aspects of the child's development, including hearing, sight, language development, physical development, etc, and is offered to infants irrespective of the family's income.

Problems that are identified at this examination may be treated free of charge at out-patient hospital departments and any subsequent treatment is free as a public patient. Most health boards offer additional doctor and public health nurse appointment clinics for those parents who have concerns about their child's development.

<http://www.citizensinformation.ie/categories/health/children-s-health>



## Medical Cards in Ireland

Persons are entitled to a medical card where they are unable, without undue hardship, to arrange for the provision of medical services for themselves or their dependents. In determining eligibility, the local health board will have regard to the financial circumstances, and medical needs of the applicant. In this regard, income guidelines have been drawn up for health boards to assist in deciding a person's eligibility. However, even in circumstances when your income exceeds the guidelines, you may be still eligible for a medical card if your baby requires excessive amount of medical services. In all cases, the decision is a matter for the Chief Executive Officer of the relevant health board. You should apply for this card as soon as possible after the baby's birth.

### **Persons who qualify for a medical card are entitled to:**

Prescribed drugs and medicines free of charge

Free general medical practitioner services, with a choice of doctor.

Hospital in-patient and out-patient services.

Free consultancy services.

The services of a social worker.

Dental, Optical and Oral services.

Aids and appliances for home use (oxygen, feeding tubes, suction machine etc).

These can usually be arranged through the hospital or your local Public Health Nurse.

Free Travel vouchers may be available to visit children with intellectual disability who are in residential centres or in hospital for comparatively long periods. Application should be made to your local health board.

<http://www.citizensinformation.ie/categories/health/entitlement-to-health-services>

## Community Drugs Scheme

Non-medical card holders and people with conditions not covered by the Long Term Illness Scheme can use the Drugs Payment Scheme. Under the scheme, no individual or family unit pays more than XX euro per calendar month towards the cost of approved prescribed medicines.

<http://www.citizensinformation.ie/categories/health/entitlement-to-health-services>

## Domiciliary Care Allowance

The Domiciliary Care Allowance is a monthly means tested payment made to the carer of a child with a severe disability who lives at home.

The child must need substantially more constant care and attention than a child of the same age who does not have a disability.

Eligibility for the allowance is determined primarily by the degree of additional care and attention needed by the child rather than the type of disability involved, subject to the means test. Medical assessment is carried out by the Senior Area Medical Officer in the relevant health board.

### **Pro rata payment**

Children who are being cared for on a full time basis in residential homes or other institutions are not eligible for the allowance. However, children in residential care who go home at weekends or holidays may receive a pro rata payment based on a per nightly rate (nightly rate is equal to the monthly rate multiplied by 12 and divided by

365). The allowance is continued in cases where children who normally live at home are absent for a period or periods of not more than 8 continuous weeks.

#### **The means test**

The means test applies only to the means of the child and not the means of the carer or carers. If the child has means above the level of the allowance, then no allowance is payable. If the child receives a compensation payment as a result of an accident or injury, this will be taken into account. Entitlement to child benefit is not affected and a person may also qualify for Carer's Benefit or Carer's Allowance if he/she meets the other conditions.

The person is also eligible for a Respite Care Grant, which is paid automatically each year during the month of June.

Your child may be entitled to free nappies at discretion of the health office.

Apply to your local health office.

<http://www.citizensinformation.ie/categories/health/health-related-benefits-and-entitlements>

### **Long-Term Illness Scheme**

If you are suffering from one of a list of prescribed diseases or disabilities, including mental handicap, you are entitled to the drugs, medicines and medical and surgical aids and appliances prescribed for that disease free of charge.

If your doctor certifies that you are suffering from one of these designated long-term illnesses or disabilities, you are given a prescription booklet that contains details of the type and quantity of drugs prescribed for you. The booklet also contains a number of detachable prescriptions. You may present this booklet to any pharmacist, who will supply the prescribed items. You do not have to use the same pharmacist all the time.

<http://www.citizensinformation.ie/categories/health/health-related-benefits-and-entitlements>

### **Bereavement Grant**

A Bereavement Grant is a payment based on PRSI contributions which is payable on the death of a child under age 18. The Bereavement Grant is a once off payment.

The scheme replaces the former Death Grant Scheme.

Apply to Department of Social and Family Affairs (DFSCA or Social Welfare)

<http://www.welfare.ie/schemes/bereaved/bereav.html>

### **Supplementary Welfare Allowance**

A weekly supplement may be paid towards special dietary or heating needs.

Apply to Department of Social and Family Affairs (DFSCA or Social Welfare)

<http://www.welfare.ie/schemes/families/swa.html>

### **Private Medical Insurance**

If you have private medical insurance such as VHI, QUINN, VIVAS – your baby is automatically included in your policy. However inform them within a reasonable time of baby's birth. If you choose private treatment, you will be liable for consultant and hospital fees.

<http://www.vhi.ie>

<http://www.quinn-healthcare.com>

<http://www.vivashealth.ie>

## **Incapacitated Child Tax Credit**

Details of this special tax free allowance is available from your tax office or the inspector of taxes who deals with your tax affairs.

<http://www.revenue.ie/>

## **Medical Expenses**

A tax refund is available for money spent on additional medical expenses not covered by long term illness scheme. Expenses include doctor's bills, drugs, supply and repair of medical and surgical appliances used on medical advice and nursing home expenses. You should complete the special claim form MED 1 at the end of the tax year.

<http://www.revenue.ie/>

## **Home Improvement Grants**

A grant may be given where an extra room or other structural changes are necessary for the accommodation of a child with disabilities.

Apply to your local health board

<http://www.citizensinformation.ie/categories/housing/housing-grants-and-schemes>

## **Payment for Disabled Passengers**

Parents caring for a severely and permanently disabled child who buy or adapt a car for their use may be entitled to claim

Exemption from motor tax and vehicle registration tax

Refund of VAT

Refund of duty paid on petrol / diesel (subject to a maximum of 600 gallons per year).

Further information from

Disabled Drivers Section

Central Repayments Office

Office of the Revenue Commissioners

Coolshannagh

Co. Monaghan

Tel: 047 82800

[http://www.citizensinformation.ie/categories/travel-and-recreation/transport-and-disability/tax\\_relief\\_for\\_disabled\\_drivers\\_and\\_disabled\\_passengers](http://www.citizensinformation.ie/categories/travel-and-recreation/transport-and-disability/tax_relief_for_disabled_drivers_and_disabled_passengers)

The Disabled Drivers Association provides advise on aids and adaptation of cars.

Disabled Drivers Association

<http://www.ddai.ie>

## **Northern Ireland**

Every baby/child gets complete free medical care until age of 16 years or after (depending on circumstances).

Everybody is allocated a Health Visitor after registering with a General Practitioner. The Health Visitor introduces a Social Worker and gradually all other experts and professionals get involved e.g. Department of Education, Occupational Therapist, Physiotherapist.

Aids and equipment are supplied as needed.

For further information on your entitlements contact the Disability Living Allowance Branch and The Family Fund (U.K.)

<http://www.dsdni.gov.uk/>

## **For more information on “Entitlements” telephone**

Department of Social & Family Affairs on

LoCall 1890 662244

Citizen’s Information Service on

LoCall 1890 777121

Contact your nearest

Social Welfare Local Office or

Citizen’s Information Centre

## **Useful Website Links**

<http://www.welfare.ie/>

<http://www.citizensinformation.ie>

<http://www.revenue.ie/>

<http://www.irlgov.ie/>

<http://www.disability.ie/>

<http://www.dsdni.gov.uk/>

<http://www.ddai.ie>

<http://www.vhi.ie>

<http://www.quinn-healthcare.com/home.htm>

<http://www.vivashealth.ie>

This information on entitlements is intended as a guide only and does not purport to be a legal interpretation.

## Heaven's Special Child

A meeting was held quite far from earth,  
It's time again for another birth  
Said the angels to the Lord above,  
This special child will need much love.  
Her progress may seem very slow,  
Accomplishments she may not know  
And she'll require extra care  
From the folks she'll meet down there.  
She may not run , nor laugh, nor play,  
Her thoughts may seem far away,  
In many ways she'll not adapt  
And she'll be known as handicapped.  
So let's be careful where she's sent,  
We want her life to be content.  
Please Lord, find the parents who  
Will do this job for you,  
They may not realise right away  
The leading role they are asked to play.  
But with this child sent from above,  
Comes stronger faith and richer love,  
And soon they'll know the privilege given  
In caring for this gift from heaven.  
This precious girl (boy) so meek and mild,  
Is heaven's very special child.

## CHAPTER 15

### FAMILY STORIES

*DENISE*

**Mary & Derry O' Brien  
Denise 02/07/86 – 31/01/08  
Edward's Syndrome**



**Denise celebrating her 21<sup>st</sup> birthday**

#### **Living with Dolly**

At the AGM in Portlaoise, 2003 I spoke of life with my sister Dolly who had Edward's Syndrome and whose being had changed our lives forever, this is a shortened version of that story.....

I've always loved Christmas, but 1985 was extra special, I was 9 and my sister Eunice was 11. Mam and Dad (Mary and Derry) had a big surprise for us.....We would have a new brother or sister joining the family next July. We were ecstatic.

From the early stages Mam suspected something was wrong and doctors were quick to confirm this. We never thought anything of the very frequent check ups.....not that we minded, it meant another trip to Drogheda for us and maybe a trip to Bettystown. On 2<sup>nd</sup> July 1986 Denise Mary O' Brien entered the world by Caesarian Section weighing just 4 lbs 5 ounces. We raced round the roads telling everyone about our new sister. After a few days we were allowed to visit this little scrap of life lying in a glass box, with a tube in her nose. So this was her!!.....Then we were told that she was different, she would never walk, go to school.....Why????

Whilst walking on the beach Daddy had to be blunt and told us the truth – Denise might not live very long.....She might never see home, Teddy the dog.....we were devastated. After 5 months, Denise or Dolly as she was christened by Uncle Jack was allowed home on 2<sup>nd</sup> December. Home would never be the same again.

Mam and Dad took turns to sleep on the couch beside Dolly's cot in case she budged. And she did!!!. Mam and Dad were constantly exhausted. As her first Christmas approached I prayed for God to keep her alive so Santy could come to her at least once. It was a Christmas I still cherish. In February 1987 Dolly got her first bout of pneumonia and was gravely ill for 3 weeks. She was confirmed on admission to Hospital but miraculously survived. Against all the odds Dolly came home again and "normal home life resumed".

By her first birthday she had bloomed into an adorable living porcelain doll. Her first birthday was a huge celebration. All my friends treated Dolly like a real person and they talked to her as if she could understand them. She made us a very close group of friends. Every time we met they would always ask "how is Dolly?". Some close family friends firmly believe that Dolly brought the best out in all the lads and kept us out of harm's way in our teenage years. Dolly's health was always foremost in our minds. As she grew bigger the main problems were persistent kidney problems etc. She had been in Lourdes three or four times which was wonderful for Mammy and Daddy to visit this special place with their special daughter. The first time to Lourdes was Daddy's first time to fly. That wouldn't have happened without Dolly.

***One hot summer's day a friend, Roy, and I landed home for lunch. A woman from Limerick was in Mam's and she had a child like Dolly but a little older. The likeness was uncanny and I definitely reckon they were communicating through touch and noises. This woman was Kay Fagan***

***with her daughter Elaine. Kay and her husband Michael introduced Mammy and Daddy to S.O.F.T. Ireland. Soon families like the Fagans, Boylans and Matthews and many more became household names. It was fantastic for Mam and Dad. Dolly was my mascot and I carried her holy medals and her picture with me through the hardest days of school and college exams. I often wondered what would she be like as a regular seventeen year old but without Dolly as she was life would never have been the same. I never wished she was a regular teenager despite all her sickness and complications through the years.***

When I met Jackie five years ago we found we had a common bond. Both of us had sisters with special needs. Jackie's sister Olivia has Spina Bifida and is in a wheelchair. From the minute Jackie met Dolly I knew she had accepted her for the little person she was. She had the same caring side to her personality that Dolly had given me, a caring side that can only be fully recognised by a person with the less fortunate sibling. I used to get mad if I saw someone staring at Dolly but I know that some people without the experience of someone with special needs are going to stare and it can actually be quite amusing to see the look on their faces. I was so proud of Dolly. She had to fight for her life and had the heart of a lion. She helped me through last summers' marathon cycle from Malin head to Mizen head. When every sinew in my body ached she inspired me to fight the pain as she had done so many times.

I feel that Dolly has made saints out of Mammy and Daddy. They have such strength and courage. I am very proud of how my family adopted to life with Dolly. It was an ongoing challenge which I was privileged to be part of. I believe the strength we drew from Dolly will get us through anything that life will throw at us.

Dolly is Dolly, always was, always will be. She has changed our lives for the better.

It is an honour to be her brother.

Dolly celebrated her 21<sup>st</sup> on 14<sup>th</sup> July 2007. Celebrations kicked off with a Mass in the home of Mary and Derry O' Brien. It was celebrated by Fr. Richard Goode and was attended by over 140 people. There was a meal in Dunderry Lodge and it was a fantastic and fitting tribute to such a special lady. The party continued back at the house until the wee small hours of the morning. Jackie and I composed a song for Dolly's 21<sup>st</sup> entitled "Dolly", which was performed during her Mass. This song sums up Dolly's life and what she meant to us.



**Thank you Dolly, you are our queen, our ray of sun**



*Verse 1*

*Twenty-one years have come to pass,  
My doesn't life go by so fast.  
And on the very day that you were born,  
We were told you might never see the morn.*



*Chorus*

*Thank you Dolly you are the one,  
You are our queen, our ray of sun.  
And the love you bestow, you speak with your eyes,  
Deeper than the oceans, bluer than the skies.*



*Verse 2*

*But the morn did come and many more,  
You defied the odds and many so sure.  
And now as we celebrate your twenty-first,  
We remember the better days not the worst.*

Verse 3

*And we marvel at your journey through life,  
Despite all the hurdles, hardship and strife.  
And the virtual mountain everyday that you climb,  
Has shown us your courage time after time.*



Verse 4

*You've a heart of gold it's plain as can be,  
And you're an inspiration for all who see.  
You're one of life's miracles that is so true,  
You've enriched all our lives by being you.*

Lots of love,  
Ian & Jackie  
02/07/2007

In January 2008 Dolly was admitted to the Lourdes Hospital, Drogheda with a chest infection. Her condition deteriorated over 12 days and she slipped away on Thursday 31 January with Mam and I beside her. It was just so so upsetting to stand and feel the warmth drain from her little body.

Dolly reposed at home for 4 days and the amount of people who called to our house to see her was unreal.

Dolly's funeral Mass was simply "perfect" if that's possible. The readings, songs and poems were all specially chosen and written for Dolly. The church was overflowing with well wishers. Dolly even got a "guard of honour" to her place of rest.

We released two white doves at the graveside and watched them disappear into the great beyond.....I imagined them to be Dolly's spirit.

"Goodbye Dolly", I thought and I blew her a kiss. "Safe Journey Home"

Life without Dolly has been very hard. For such a little person to make such an impact on people's lives it's unbelievable. People have been fantastic and this has eased the burden. Thanks to one and all, your caring words and kind gestures have not gone unnoticed. We will be forever in your debt.

We miss you so much Dolly and you will be forever in our thoughts.

Ian O' Brien

## **LEAH**

**Fiona & John Hennessy**  
**Leah 25/9/05 - 5/11/05**  
**Edward's Syndrome**



Leah was born on the 25th September, 2005 she weighted 4lbs 2 ozs by selective c section, as I had an emergency section with my other child Cian and I didn't want to go through that again. I had no problem with the pregnancy I was just a bit tired, but my obstetrician scanned me every time I went to him but didn't seem to think there was any problem. I still can't understand why he didn't see that her weight was quite small for 39 weeks. He told me I was having a fine baby.

When I went to the hospital on the Sunday night for the section the nurses checked the heartbeat and the machine was showing it was low. They performed a section straight away, unfortunately my husband John had gone home so I was quite nervous. Leah was born at 7.10 pm and the obstetrician told me there were a couple of problems - number one she had a cleft lip and one of her hands was slightly twisted. It was all such a shock, she was so small when we saw her and her breathing seemed quite laboured, the next day they told us that she also had a heart problem, they thought she had a syndrome called TAR. We looked it up on the Internet and that told us that she may live a normal life.

The doctors decided to send her to Our Lady's Hospital in Crumlin for more tests. John went with her and I followed that weekend. They told us

that they were going to perform a heart operation on her. When they were preparing her for the operation all I could think of was I will never see her again alive, but she came through it, she was such a little fighter. They led us to believe it was going to be a long road and she would have to have further heart operations.

Then two weeks later they informed us that a result had come back from England and that Leah had Edward's Syndrome. I had never heard of this syndrome before, they told us it was incompatible with life, they were the hardest words I had ever heard.

Our little girl was going to die. It hit us like a ton of bricks we had such hope. I couldn't cry as I felt this really wasn't happening to us. They said she didn't have the look of an Edward's baby.

We decided to bring her back to the Bons Hospital in Cork the next day to be nearer to our families as her grand parents had not yet met her. We wanted to spend what time we had left with her. We didn't know if it would be days, weeks or months. We went to visit her everyday and two weeks later I decided to bring her home. We feel now we should have brought her home sooner.

It took us a further 3 days to organise the medication etc to come with her. Leah came home on the Friday. It all seemed quite normal as this was what was meant to happen and Cian her brother was delighted to have her home. He had spider man waiting in her cot for her. There were so many people to greet her when she arrived. But little did we think that the next night she would die. I feel she held out to come home, to see the sea, to be with her family, to say her goodbyes.

Fiona Hennessy

## **LOUISE**

**Martina and Frank O'Reilly  
Louise 31/08/89 (D)  
Edward's Syndrome**



In 1989, our only daughter, Louise died. In many ways it seems like only yesterday and in other ways it all seems more like a nightmare we dreamt - many years ago.

Frank and I were living in London - we had our first home together, jobs we both loved, lots of new friends and the most important thing in the world to us - we were expecting our first baby. The pregnancy had its little ups and downs - nothing major - but I must admit I was concerned that I had a very small 'bump' - I never really needed to wear maternity clothes. Everybody (including doctors) assured me things were progressing well - and there was nothing to worry about.

However at 33 weeks during a routine ante-natal check up, a Doctor casually mentioned the baby was small for dates! From that moment on the alarm bells rang. I was scanned and rescanned - I just knew from the faces around me, the half nods and whispers that something was terribly wrong. They picked up a 'heart problem' - which was confirmed the next day by a more precise foetal heart scan at Guys Hospital. I was given the news every mother dreads - my baby's heart had a large septal wall defect and one side of the heart had not developed. She was unlikely to survive a labour with such problems - let alone live independently for any length of time. My baby was going to die.

The next few days were a blur - I cried for hours on end. We were devastated. For the first time in our lives we were heartbroken. A Genetic Counsellor confirmed later that week that Louise also had Edward's Syndrome. As I had worked for a time as a student nurse with 'special needs' children - I knew the prognosis was poor. It was agreed I would be induced at

37 weeks - this would give me the best possible chance of seeing my baby alive, but I was warned it was quite likely Louise would be stillborn.

I had 4 weeks left with Louise: 4 weeks to steer our lives down a new path, to pack away her pram, her tiny clothes and her cuddly toys, to arrange her funeral and to somehow muster up the courage to face what lay ahead.

On August 31st - as I walked from my room down the cold silent corridors to the labour ward I never felt so totally afraid and alone in my life - it must be a similar feeling walking to your execution, knowing the end is so near and totally out of your control.

Louise was born later that day - and I could not believe how beautiful she looked. She weighed 3lb 10oz and she had a head of black hair. Myself and Frank held her and took photographs - we laughed when she yawned and stretched her arms out in front of herself. I suppose we heard so much about her abnormalities we were delighted with any normal thing she did. Sadly, Louise died in my arms two and a half hours later.

I went home that night and I was amazed that the world was still carrying on as normal - because for us our world had stopped revolving. We felt our future had died, she was part of so many hopes and dreams and now they would never be. We found it hard to believe we would ever be happy again. I physically ached to hold her. I could not bear to look at a baby girl - I often ran hysterically from shops if I saw a pram that even looked like Louise's. The worse thing was when somebody asked if we had any children - what do you say.....?

The years since Louise's death have been tinged with the sadness of her birthdays, the day she should have started school, made her First Communion, started Secondary School. We worried during my subsequent pregnancies and were incredibly happy and relieved at the birth of our sons Andrew and Robert.

A day does not pass when I do not think of Louise and what she would be like now. Andrew and Robert talk about her as though she is just somewhere else - which gives me hope that some day we will meet Louise again.

Her life may have been short - but her impact was immense.

Martina O Reilly

## MEGAN

**Margaret and Seamus Doherty**  
**Megan 12/09/87 – 17/04/00**  
**Patau's Syndrome - Translocation**



It's now eight years since our only daughter and fifth child died. Our lives have entered a new phase, a more lonesome one as we no longer have a baby in the house and our sons have grown up and are moving on. Megan was born on the 12/9/87 two weeks early with no pre-warning that there were going to be problems. She was rushed from Enniskillen to the neonatal unit in Derry and then on to the Royal Hospital for sick children in Belfast within 24 hours. She was diagnosed with a heart condition and needed careful monitoring for a few days. Although her heart problem wasn't a major one, her other problems were becoming evident to the staff, but Seamus and I were blissfully unaware of these as all we could see was this beautiful baby girl.

When she was discharged on her sixth day the cardiologist said, out of the blue to me, that Megan had a chromosomal disorder and that it was life threatening and we'd need to see a geneticist very soon to find out all the details.

We took Megan home and very soon realised all her problems. She had her tightly closed fists, with her thumb across her palm, small cysts on the back of her head, glaucoma and cataracts on her eyes, high palate which left feeding a major problem, vomiting a few times everyday. She cried a lot due to cerebral irritation and soon started taking apnoea attacks. We met Professor Nevine a geneticist in Belfast when she was two weeks old.

He said he had never seen Megan's pattern of chromosomes before in his life. She had two normal 13 with  $\frac{3}{4}$  of a third 13 on top. She certainly had a lot of features of Patau's syndrome but he didn't know what the future held for Megan as he hadn't seen her pattern before then. Seamus and I were tested and our chromosomes patterns were normal so there were no reasons to suggest the boys had anything abnormal in their pattern. The fact relieved us but it didn't help us with Megan's condition.

Her first year of life was very hard for her and for us. Megan had four eye operations for glaucoma and to remove her cataracts which revealed these gorgeous keyhole shaped brown pupils. Her "blue" attacks got worst developing into true epilepsy. On two occasions I give her mouth-to-mouth resuscitation. Her feeding was a major problem with a lot of vomiting and a constant battle to keep her nourished. She couldn't cope with a spoon-feed. She rarely slept more than two hours and cried a lot. During this time she was under the care of Dr. Des Brown a paediatrician in Derry who was an enormous help and support to us. With a lot of trial and error we eventually got a combination of medications that helped to control Megan's fits and irritability, Megan's quality of life improved with better sleeping and eating.

There began a pattern which we kept for 12 years. Our first waking thought was Megan and our last act at night was to bring her to her bed in our bedroom. She moved on to tube feeding when she was four years old. Mentally her development was extremely slow though she smiled at about a year old and learned a "clicking" noise with her tongue. She sat for short spells in a specially adapted chair but her favourite position was to be nursed on your knee.

Despite her many admissions to hospital (approx 40) for treatment for chest and kidney infections, she had spells of good health and when Megan was happy and well life was very good. She taught us that good health is all that matters to be happy. There was never going to be the right time to let Megan go and when it came it was very hard. We are grateful we had her for 12  $\frac{1}{2}$  years and were able to look after her with a lot of help at home. We believe now that she helps look after us!.

Margaret Doherty



## SHAUNA

**Jacqui and John McNally  
Shauna 26/05/05 (D)  
Patau's Syndrome**



**Early in spring 2005 listeners to Marian Finucane's RTE radio programme heard the moving story of a couple who had just been told the baby they were expecting had Trisomy 13. This is their story:**

**SHAUNA . . .**

*Dawn of Light sent to us*

*Within colours wildly*

*Dancing...Fondly*

*Our life and life of life Everlasting*

*Send forth flower'd rainbows*

*for a child, our child to follow rainbows*

*To show all we feel and breathe and hope*

*For you and you and you.*

*- Your Daddy*

## DADDY'S STORY

Dublin City: A busy bank holiday crowd formed a vague and translucent tapestry hurrying past two aimlessly lost souls trying to come to terms with the news they had heard but could not comprehend. A cold breeze shot up from nowhere. They held on to each other as tightly as they dared. The breeze harder now, as cold as the love of God. They were only 93 million miles from the sun.

Life for little Shauna Imelia compressed more into 19 weeks what others could not squeeze into generations. Our little girl was a Patau's baby. We were advised to form a deep relationship with her. We had already done that. From that day high up on an Austrian hill when we found that we were expecting Shauna, she was the most loved child in the world. For two people for whom life turned from a living hell into a new hope.

We were given the option of undergoing a nuchal-fold scan at the Rotunda. This scan measures the fold at the back of the baby's neck. A larger fold indicates possible problems, usually a Trisomy. After a silence from the consultant, news was given to us that, yes, the fold was very large.

We were advised to return in two weeks for an amniocentesis. Those were two weeks that we would not wish on anyone, not anyone. We researched all the Trisomies for all we were worth. What we did decide was that our baby was going to be the most loved child ever sent. We wanted her so badly.

Two weeks dragged past, and then back to Dublin. Another scan, another horror. Both consultants agreed that our baby had Patau's Syndrome, Trisomy 13, and that her brain was badly affected. We were warned that these babies just don't survive. They tried to do an amniocentesis but that didn't work - Shauna was too feisty to be disturbed from her play. So they did a CVS and we were told the results would be back on Friday. Another trip up to Dublin. We were almost spent at this stage, but not Shauna. She was such a playful child. She never heard of Trisomy anything. She just wanted to play and play.

## MAMMY'S STORY

It's now May 26 and back to Dublin. This time we are going to get some counselling.

I'm not looking forward to going back to the hospital - it always ends up in tears. But not this time - we both come out feeling great.

A good start to our last week with Shauna. By this time Shauna is moving around quite a lot. I know she is still with us every time I feel her gentle moves.

As the week goes on John feels our angel for the first time. He is thrilled. It gives him some hope that he will see his daughter.

We try not to think of the day it will end but to enjoy what time we have with her. At this stage I'm so sure that we will make it well into 20 to 30 weeks that we start to settle down - but deep down it's still in our mind that we could lose her.

I've started to cut my hours at work. The hours I do now is just enough to get me out of the house and take my mind off what we are going through.

Friday comes. Nothing unusual.

Saturday. My mother comes to stay.

Everybody is relaxed, not too worried about Shauna not moving. She was active for most of the week, so I just put it down to her quiet moment.

Sunday. A bad morning. Got up and things settled by that night. I could not remember her moving.

Monday morning. I don't want to upset John. I can't bring myself to tell him I felt nothing. So many times we went to doctors just to be told everything was all right. I met John for lunch. We're both in low form.

Deep down we know Shauna has gone.

Tuesday. In hospital. So many doctors came, but I didn't want to talk to anybody.

By Thursday we are drained - will it ever be over?

My mother has come to Dublin just to be with us. She rings to see if it's all right to come over. We are all in the room when we get more visitors. The mood is relaxed mood. By lunch time it's just John and I. Mum is back in the hotel resting.

At one o'clock things start to happen. At two o'clock it's all over. Our angel has been delivered.

Calmness has now come over us. At last we get to see a beautiful angel. My mother comes over and we spend three lovely hours with her.

Friday. We lay Shauna to rest. The sun comes out. It's so peaceful.

Nobody can ever explain how you feel when you lose somebody you love so much, especially your unborn child. We had six weeks to get to know our daughter, to name her and to enjoy every movement she made. It was hard not knowing what she looked like, but a wonderful feeling getting to know her inner self. We made a bond with her and that will be with us till we meet again.

We will always be grateful to my mother, John's parents, family and friends who gave us a lot of love and support.

## **BIG SISTER'S STORY**

### **ANNA-MARIA'S DIARY**

**March 6th, 2005:** Mother's Day today. Told I was going to have a new brother or sister. Secretly hoped it would be a girl. I have wanted a sister ever since I could talk. So glad to hear that it could be happening now after 25 years.

**April 9th 2005:** Told that there could be something wrong with the baby. Don't know how I feel. Hoping against hope that the doctors could have it wrong. Will have to wait for two weeks before we can relax and get on with enjoying the preparation for the baby.

**April 29th 2005:** Two weeks have come and gone. Have been on edge all day. This is the day we will find out if there is anything wrong with the baby. Waited all day for a phone call to tell me that the doctors were wrong. With every phone I hear ring I jump. I'm a nervous wreck. Eventually found the courage to ring Mammy at 8.30 in the evening. John answered: said he would ring me back in a few minutes. Had a funny feeling that something was wrong by the tone of his voice. Phone rings. I'm afraid to answer, don't want to hear the news. If I don't answer then I won't have to hear what the doctors said. The doctors were right in what they had predicted; cried for mammy and John, cried for the baby, then I was told that the baby was a girl; she will be called Shauna. My own sister after all the waiting, was "happy sad", happy that I had my sister, sad that she was so ill. Felt that everything around me was spinning and wanted to curl up in a ball and not live anymore, until I heard my own little angel ask

"what's wrong mammy, why are you crying?"

Put on a brave face had to be strong. Modern technology can get it wrong, it has happened before.

**May 14th 2005:** Weeks have passed. Had an angry and frightening feeling in the pit of my stomach that I could not move.

**May 26th 2005:** Cried my eyes out today, Shauna has left us, to go to a better place.

Don't know what I can do to make this gloomy and terrifying feeling leave my body

**May 27th 2005:** Feeling strong I can do this, have to do it for Mammy and John. Still standing don't want to do this. Feel so proud of Darren, he is so strong to be taking Shauna on her last journey. Broke down when I realised that Darren could not let go of Shauna's "princess bed". My heart is breaking; I feel that part of it has gone with Shauna. Hoping that she

is looking down on us all laughing and playing like all little girls should be.

**May 29th 2005:** My birthday is a week away; mammy had a little party today for me. Got a card from Shauna, with sister on it. That “Happy Sad” feeling has risen from deep inside my body. It is more happy now as I believe that Shauna was meant for God and He had a special reason for giving her to us for a short period of time. Shauna will be with us and helping me, her Big Sister and two nieces through the hard times we may have to face in the future. She will always be remembered and loved until we meet face to face in the future, which I believe we will and then we can do all the things that sisters do together.

### MAMMY & DADDY

If every person in this country got even a taste of the quality professional service the staff of the Rotunda rendered to us, what a wonderful health service we would have. It would be inappropriate to single out anyone in particular. The prenatal team and all the staff of the Rotunda Hospital, we thank you, you were wonderful and God willing, we will see you again. To all our new friends in S.O.F.T. Ireland, to Marian Finucane, to Joe Finnegan of Northern Sound Radio, to all our friends, we thank you.

*To come at swallow-time how wise!  
When every bird has built a nest;  
Now you may fold your wings and rest  
And watch this new world with surprise;  
A guest  
For whom the earth has donned its best.*

- **To A May Baby** by Winifred Letts

## **ELLEN**

**Geraldine and Terry Matthews  
Ellen 19/08/96  
Edward's Syndrome**



Our daughter Ellen was born in August 1996 weighing 3lb 10ozs. We were sad and shocked to find out that our new baby had Edwards Syndrome and to hear of all the physical and mental disabilities she would have. But all of this was put into perspective when we were told that she was not expected to live and that we would not be taking her home with us. Ellen's progress surprised us all and once I was comfortable with passing her feeding tube down, we got her home a month later.

Looking back now this was a very bleak time, we were afraid to love her because we knew we could lose her at any stage. Our lives changed drastically, I now became the full time carer of a sick child, surviving on very little sleep and living in fear of something happening.

Our first year consisted of endless visits to doctors, consultants and specialists.

Although we were lucky that Ellen's heart condition was not life threatening, she suffered from a very weak chest. Her low immune system left her prone to recurring chest infections, where she needed constant suction, physiotherapy and antibiotics. Our whole lives revolved around Ellen, we didn't know how long we had with her so we relied heavily on family and friends to care for the boys.

Although Ellen's development was very slow every little milestone, first smile, giggle, her eyes following us around the room, was a major achievement. We had a big party for Ellen's first birthday a day we thought we would never see. At this stage we started to watch Ellen live rather than waiting for her to die.

Over the next few years Ellen started to get stronger but she still suffered from chest infections. Because of her high muscle tone, scoliosis and poor head control, she needed to be put in her stander and on her wedge at regular intervals throughout the day. She also needed a lot of one to one attention to help develop her interactive skills.

We were very protective of Ellen and we wouldn't go anywhere without her as we thought she couldn't function without us. Our friend worked in the local day care centre and had always encouraged us to send Ellen. We were very reluctant to let her go but when she was five and I was pregnant with Niamh we decided to send her. This was one of the best decisions we ever made; Ellen loved all the attention from the nurses and benefitted greatly from all the sensory work in the classroom. Going to day-care gives Ellen independence and a chance to learn new skills and meet new friends. It taught us that children like Ellen are made to be shared.

Another milestone in Ellen's life was the birth of her sister Niamh. She was no longer the only baby and missed being the centre of attention. We were shocked to see she had a jealous streak by developing a pretend cry, but this was short lived and soon Niamh became her entertainment and playmate.

Initially we felt that Ellen's capabilities would be very limited, but she has proved us so wrong. She has achieved more than we could have ever dreamt. She can sit up balancing herself on one arm. She can roll around the floor to get to something she wants. She just loves company especially the company of other children. She loves to be in the middle when Luke, Adam and Niamh are playing a game. She always manages to get hold of the TV remote and change the station when she is sitting beside me. We need eyes in the back of our heads when we are feeding her, she always manages to get the dish and turn it upside down. When

we give out she giggles and laughs. She may not be able to talk but you can see the devilment in her eyes. For all the heartache we initially felt the happiness that Ellen has brought us could never be measured. We are very proud and honoured that God has given us a special little girl.

Geraldine Matthews



## **PATRICK AND NIALL**

**Patrick**  
**Pauline & Patrick Farrelly**  
**Patrick 17/01/03 – 14/10/03**  
**Edward's Syndrome**

**Niall**  
**Mary & Danny Rispin**  
**Niall 06/09/02 - 03 /06/03**  
**Edward's Syndrome**

**Maria Moynihan of the *Irish Farmers Journal* met 2 S.O.F.T. families.**

**This is her report on her interviews with the Farrellys and the Rispins.**

### **The Rainbow Children**



**Baby Patrick with his parents Pauline and Patrick, brother Michael and sisters Leona, Yvonne and Rebecca**

Tragedy has a way of bringing people together and the Farrelly and Rispin families are a perfect example. Although these Co Meath farmers were just a few miles apart, they really weren't aware of each other's existence until they both suffered identical loss. Their stories are both heartbreaking and inspiring. They are stories of loss, despair and hope and above all of families pulling together.

When Patrick and Pauline Farrelly, from Carnaross, north of Kells, were told that their unborn baby had Edward's Syndrome and wouldn't survive more than a few hours, little did they know that only a few miles away the Rispins were going through the same ordeal.

"He was born and he was handed to me - all I could really do at that stage was cry."

Patrick Farrelly looked at the little boy in his big, strong arms and knew he would never grow up. Doctors had said the best they could hope for was three hours. If he survived that, he would not live a year. On January 17, 2003, baby Patrick Gerard had come into this world already

condemned by Edward's Syndrome. The chromosomal disorder, also known as Trisomy 18, had been diagnosed four and a half months before he was born. Confirmation was cold and blunt. A major heart fault, incompatible with life, too many internal problems. Words like shrapnel to his parents.

Their gynaecologist was more gentle.

"He told us that all we could do is hope for the best," recalls Patrick. "He couldn't guarantee that we weren't going to have an angel. He said maybe God would give us an angel, but from here on his duty was to make sure the baby was delivered OK and it was our duty to make sure that we stayed sane enough for that to happen in five months."

It was an impossible demand. The rest of the pregnancy seemed a lifetime. The Farrellys struggled on, aware of the inevitable but not of the when or the how.

"All we thought about was dying, rather than living," says Pauline.

Then one evening the phone rang. It was a local teacher to say that another family in the area, the Rispins, recently had a baby with Edward's Syndrome - did they want to get in touch?

That phone call sparked a relationship that was to buoy both families through the toughest of times.



**Niall Rispin**

Mary and Danny Rispin from Navan had baby Niall on September 6, 2002. It had been a normal pregnancy, no indication of any problem. When Mary was admitted to Our Lady of Lourdes Hospital, Drogheda, for a routine section she was expecting an 8lb baby. Niall was only 5lb.

"Straight away all the bells started," she says. "The theatre was full - they knew something was wrong as soon as he was born. Then he was taken to special care."

Edward's Syndrome was diagnosed. There were major heart complications and breathing problems. Niall would have to be tube fed because he couldn't

swallow. He probably would not survive a week, the experts said. It was all too much.

“When you have two healthy kids and then you’re told there’s something wrong,” says Mary, “you kind of wonder whether it would be better if he died or if he lived. But when he did live we didn’t want him to die. You do bond. Sure it’s your baby. He was part of the family, and you kind of wish them on I suppose.”

Although the nurses advised the Rispins to keep Niall in hospital, they were adamant that they were bringing him home as soon as he was fit. Time was short and he needed to be with his family. After three weeks in hospital, Niall was home in Navan. The responsibility of looking after such a sick baby was overwhelming at first. Because Niall had to be tube fed every three hours, Danny and Mary took turns giving him the 20ml of feed that his little body could handle; a rota was regulated by alarm clock through the night. Then there were the oxygen and suction machines to deal with. As Niall grew bigger, it put more pressure on his heart and fluid started to build up in his lungs. He had pneumonia every eight to 10 weeks, and was in and out of hospital regularly. Every morning, the Rispins had to face the reality that Niall might not be alive at the end of the day. While they were trying to cope, they got the news that the Farrellys had been told they were expecting a baby with Edwards' Syndrome. It took Mary almost a week to get up the courage to call. Once she did, she says it was like they had known each other all their lives. For the remainder of the pregnancy, Patrick and Pauline Farrelly would visit the Rispins. Seeing Niall progress through the months, despite the odds, was a great source of comfort to the couple.

“It definitely kept us going,” says Pauline. “I kept saying I want what they have.”

And when they finally had baby Patrick, the Rispins were on hand once again for support and guidance when they brought their son home from hospital just a week after he was born.

Like Niall, Patrick was tube fed and needed an oxygen machine. He suffered attacks where he would stop breathing, turn grey and then go very pale. At first, Patrick and Pauline would rush to hospital, but later they were advised just to gather the family around, hold him and rub his hands to let him know that they were there. Each attack could mean the end. But, despite the trauma and constant fear, the Farrellys cherished every second they had with their little boy. Like any new baby, Patrick was fussed over by his siblings as he held court on a foot poof in the middle of the floor. Photographs were taken, videos recorded. He was enveloped by the family.

“You know you’re not going to have them for that long,” explains Pauline. “I suppose you try to think you’re going to have them, but you’re not.”

But, as both families already knew, good wishes were never going to be enough. Even though the boys had survived far beyond what was expected, their little bodies were coming under increasing strain. One Saturday, Niall seemed to be in great form. That night, however, he was agitated. Sunday, he was unconscious. He slipped away, nine months old. That week, the Rispin family had a funeral, a Communion and a birthday. Mary and Danny will never forget it.

“We buried him on Thursday, David made his First Communion on Saturday and Niamh’s birthday was on the following Tuesday,” Mary says. “Do you know, to have three big days, one for each of the three kids in the one week. It was very hard and to get dressed up for the First Communion, which is a great day, and to have to go over and have everybody looking at you. They were feeling sorry. They did say to me afterwards: ‘I don’t know how you did it.’ And the choir that sang for the funeral sang for the First Communion. All the same hymns.”

In a most extraordinary coincidence, baby Patrick passed away at nine months too, only living one hour longer than Niall. Knowing that he just wasn’t well, the Farrellys had taken him to hospital. After Pauline had stayed with him through the night, Patrick arrived and insisted that she go home to get some sleep. As he sat with him, he noticed that his chest was going “up and down like mad”. The doctor’s response was immediate.

“She took one look at him and just said to me: ‘Where’s your wife?’” recalls Patrick. “I said she’d gone home to get some sleep and the doctor said to get her back to the hospital as fast as possible. She said all this baby wants now is plenty of TLC.”

“They took off all the monitors, all the cables, everything. Then she sat me on a chair and said: ‘Nurse him now.’ So she put a pillow on my lap and spread him out. I was nursing him, waiting for Pauline to come over, and just before 12 o’clock he opened his eyes and he took in a big deep breath.

“Then he just puffed it out, looked up at me and just closed his eyes. And that was it.”

Life goes on. It has to. Patrick and Pauline had to hold it together for the sake of their four other children Leona (10), Michael (7), Yvonne (4) and Rebecca (2). Mary and Danny had David (8) and Niamh (5) to think about. They have since gone on to have Aoife. But Patrick and Niall are still part of their families, in memory and everyday actions. The Farrelly living room is covered in pictures charting Patrick’s few months. If a stranger asks Mary how many children she has and she says three, her kids will always contradict her and say there’s four, to include Niall.

The Rispins and the Farrellys have had each other through the cruelest of times. But they also had external support. The staff of Our Lady of Lourdes Hospital in Drogheda, particularly paediatrician Dr Siobhán Gormally, did everything they could for Patrick and Niall. The Jack and Jill Foundation supplied a home nurse, Cathy Keighery, whose help was invaluable. But S.O.F.T. Ireland was a godsend. The voluntary organisation, which works with families of children born with Edward's Syndrome (Trisomy 18) and Patau's Syndrome (Trisomy 13), provides support at prenatal diagnosis, during the child's life and after its passing. For example, the group will pay for a nurse to come to the house one night a week to give the parents a good night's sleep. Families get to share experiences and advice; siblings meet other kids their age who have lost brothers and sisters. Both the Farrellys and the Rispins would encourage any parent of a child with Edward's or Patau's Syndrome to get in touch with the organisation.

"I'd urge anybody who finds themselves in the same situation as either of us to contact SOFT and get talking to people," says Patrick. "It's just a great organization to be involved with and everybody is so much into worrying about the babies that are alive and feeling for them and thinking of ways to make things easier for them."

For any parents who find themselves in that situation, Patrick Farrelly has only one piece of advice: just make the most of every single second you have with your baby. They did and don't regret one moment of it.

"It was a brilliant time for us," he says. "The hardest time was before he was born. That was the hardest time in my life and I suppose after he was born, then there was no bother. He took a lot of pressure off. You actually could see him. You knew what he looked like and he'd be in great form. You'd come in and he'd smile up at you - he had a great smile. "Every morning when you'd come in there'd be a rainbow in the room and it'd be shining on his forehead, just where he was. Nearly every day the rainbow would be somewhere in the room once he was there. I suppose since he died now, the rainbow has appeared several times, and when the kids come in and see a rainbow now, automatically it's Patrick's rainbow. It's a great memory for them to have."

## KATE

Allison and Kevin Donohue

Kate 08/04/99 – 09/04/99

Edward's Syndrome



The 29<sup>th</sup> March 1999 is a day I will always remember, I was having a deep scan done by the scan specialist in the Rotunda. At a previous scan they had told us that the baby's abdomen had stopped growing.

We had an appointment at 12. We were brought into a cubicle and from then on our lives were to change forever. The first thing the Doctor said was that our baby had hydrocephalus. This possibility had never been mentioned to us so we were shocked. She then proceeded to say that there was calcification of the bladder wall, she could not locate one kidney and the heart did not look right. She was talking about our baby but not directing any of this information to us. At this stage I had gone into shock, I was sobbing.

We spoke to our gynaecologist. He explained that a baby with one problem is serious enough but a baby with numerous problems - we had to look at the possibility of its compatibility with life. He could not be talking about my baby who had been growing inside me for the last 7 months.

We went home and Kevin explained to Robert and Megan who were 8 and 6 at the time that the baby in mum's tummy may not live. They were heart broken. Our family and friends were of great support to us. At our

next visit we decided that our baby would be induced at 38 weeks. It was of no benefit to either our baby or me to prolong it any further.

For the next week we just muddled through each day. I found it hard to go out, I was afraid of meeting people. I kept feeling my baby kick and I used to think that where there is life there is hope.

On the 8<sup>th</sup> April 1999 we went into the Rotunda at 8am. The induction began at 10am. I felt guilty because as long as our baby was inside me it would stay alive but as soon as it was born it could die. I wanted to hold on to it forever. The nursing staff were brilliant, always on hand if you needed to talk or just to comfort us when crying. At 7.10pm our little girl Kate was born weighing just over 4lbs. She was flat born but they resuscitated her. She gave a strange high-pitched cry. I held her and both Kevin and myself looked at our little girl, so small and so helpless. She was brought to the neonatal unit. We were told that Kate had either Edward's Syndrome or Patau's Syndrome. Edward's Syndrome was confirmed at a later stage. We were brought to the neonatal unit to see our little girl. She had a lot of wires attached to her. Her little fingers were crossed over on each hand. One of her legs was turned in and she was missing three toes on each foot. She had only one ear. Her breathing was laborious, but she was still our little girl and we loved her.

The next morning she was on nearly 80% oxygen and still having difficulty breathing. I phoned Kevin to come with the children. They arrived at 11am and they each held her. I was holding her, she gave a little sigh and she slipped away at just after 12 noon. The grief was unbearable, our little girl was gone. She had only lived for over 17 hours.

Kate was buried with my Dad in Sutton. Both our families were present and they saw our beautiful little girl. Looking back, we felt we were lucky that she lived for those 17hours. It meant we had time with her and her brother and sister got to see and hold her.

We have since had another little boy Sam on 29<sup>th</sup> June 2000.

Allison Donohue

## CHRISTINA

**Moira and Jim Martin**

Christina 01/02/99 – 10/05/99

Patau's Syndrome



**Easter Sunday 1999: Baby Christina with her parents Moira and Jim Martin and sisters Laura 9 and Sarah 3 and brother Stephen 6**

Three weeks premature, baby Christina Martin entered the world at 1.13pm on 1st February 1999 weighing 7lb 13oz. A beautiful chubby baby girl. Her eyes tightly closed and fists tightly clenched, I held and admired her. It was then I noticed the extra digit on both hands. The nurse picked her up and ran her finger around the inside of Christina's mouth. At that point, neither my husband or I, knew why she did this! The nurse had discovered a cleft palate! Although we were not aware, this was the second abnormality. Christina was within those first few minutes taken away to be 'checked out'. It all sounded routine. The nurse did not alarm us - and so we just continued to be the proud parents of a baby girl. We telephoned our parents and passed on our good news.

About 10 minutes later, the Paediatrician returned with our daughter. We were told that our baby had an extra digit on each hand, a cleft palate, under developed eyes, low set ears and a heart murmur. More tests would have to be carried out and Christina needed to go to the Special Baby



Unit to be monitored. Having asked what under developed eyes meant , they said she was definitely blind in one eye and possibly in the other. This was the case - Christina was in fact blind. Some weeks later in Our Ladys Hospital for Sick Children, having undergone intense hearing tests, it was discovered Christina was also profoundly deaf. Jim and I were numb, in complete shock. Our happiness crumbled and our world was falling apart.

A little later, Jim went to see Christina - she was in an incubator with many wires and tubes. He became distressed and had to leave. It was later in the evening before I got to see and hold our daughter again. That afternoon was spent in tears....it was all a blur. That evening the paediatrician discussed Christina's problems. It could be a chromosomal problem, but we needed to await blood test results.

The following evening at 7pm the paediatrician broke the devastating news. Christina had Patau's syndrome or Trisomy 13, a syndrome we had never heard of and knew nothing about. She explained that babies with this condition did not live - it was a condition "incompatible with life".

We then went to visit Christina in the baby unit. The nurses gave us a small room where we could hold our tiny baby, cuddle her, kiss her, cradle her and photograph her. In the privacy of this room we wept for our little girl - she was not going to be with us long.

The next day our children, Laura age 9, Stephen age 6 and Sarah age 3, along with other family members came to visit. Many photographs were taken. There was a great sense of urgency for everyone to get to know her.

I left hospital on 5th February without our daughter. Her christening was held on 6th February in the chapel of Holles St. Hospital. The service was beautiful filled with sadness and joy.

Christina stayed in hospital until February 18th. During this time we visited twice daily, learned to tube feed and change her tubes.

On February 18th we brought our daughter home. It was an amazing feeling. She was now ours. Baby Christina Martin gave us 14 special weeks during which time we nursed her 24 hours a day. Christina did suffer pain. She began having apnoea attacks and on 10th May 1999 died peacefully in my arms. I was not prepared for this - I was devastated.

A beautiful funeral for a beautiful little girl. All our hearts were broken. Her time of suffering and pain was over. Ours was just beginning. Our 14 precious weeks came to an end.

We are privileged to have been her parents. We have three other wonderful children and one very special angel. Christina will remain in our hearts forever.

Moira Martin

## **DARREN**

**Ellen and Brian Mulvihill**  
**Darren 13/05/01 – 25/08/01**  
**Edward's Syndrome**



It's difficult to confine Darren's little life to this short story even more difficult to imagine life before Darren. He is never more than a thought away and is spoken of every day. His little face with those beautiful blue eyes and those blow bubble lips is on the walls and mantles of all our homes.

Darren Michael Mulvihill was born at 8.50pm on Sunday May 13th 2001 to parents Brian & Ellen and brothers Donal, Timmy, Brian and Mikey his birth was awaited with great excitement and anticipation by all but especially by Mikey who looked forward to being the big brother and teaching Darren all those things only a big brother can.

Immediately at birth it was evident that Darren was not well, the diagnosis came piecemeal. Those first few days I think were the most difficult when the family had to come to terms with on the one hand welcoming baby Darren and on the other preparing to say goodbye. The diagnosis was Edward's Syndrome- Trisomy 18, the bottom line those awful words, his condition was incompatible with life.

Darren came home from hospital after two weeks to the immense joy of all the family.

Mikey decorated the house with balloons and banners and we had fifteen wonderful weeks with Darren. His parents were brilliant; they didn't hide him away and keep him all to themselves. They opened their door to everyone and we were all allowed to share in Darren's life and death. I cannot describe how difficult this time was but we got through it with the help of family, friends and neighbours.

Darren passed away peacefully in his mother's arms on Saturday 25th August 2001 surrounded by his family. So many people came to the house to offer words of comfort and support, the majority of whom had come to visit Darren in the previous weeks.

Because he died on the weekend of the Fleadh Cheoil he wasn't buried until Monday which gave the family lots of time to say their goodbyes.

During his time with us he went to football matches, his cousin's christening, to restaurants, to the beach and to visit the relics of St. Therese. His life was short but very full. Darren's love has touched all our lives. It's astonishing how one so tiny and helpless can exude so much love and inspire so many people to do good. To date in his name in the region of £30,000 has been raised for charities and two African families' lives have been changed through sponsorship.

I have no doubt that the world is a better place because Darren Michael Mulvihill lived - That life is not about quantity or quality- it's about Love.

The Mulvihill family has since been blessed with the gift of a precious daughter Molly.

She is a beautiful bubbly happy and healthy little girl who is loved and cherished by all those around her and is the life and soul of the household.

Life is full of surprises, no one knows what the future holds so we embrace life and enjoy our precious little girl and continue to keep Darren in that special corner of our hearts.

Mary O' Sullivan – Collin  
Darren's Auntie

## **KARL**

**Helen and Pat Lawlor**  
**Karl 05/01/01 – 04/03/01**  
**Edward's Syndrome**



Our beautiful Karl was born on January 5th, 2001, at 1.53 pm at the Rotunda Hospital, Dublin. He was born when I was 37 weeks pregnant and weighed 3lbs 14 oz. We got a shock at first and both thought he was just small for 37 weeks. But then the nurses noticed he had club feet. From then on our worst nightmare began. Karl was taken away to be examined by a paediatrician and after about 10 minutes he came to see us in the labour ward. Nothing could have prepared us for what we were about to hear. He told us he suspected that Karl had Edward's Syndrome (Trisomy 18), although not all his features were typical. We had never heard of the syndrome and were in total shock. What should have been a happy occasion turned into a nightmare.

We asked the paediatrician about Edward's Syndrome? He told us that Karl's organs were incompatible with life and that he would not live very long. It was all too much to take in. We couldn't even cry, our bodies were in total shock.

I was taken to a private room where we could be on our own. We couldn't understand why this had happened and it was all unreal. Later that evening we visited Karl in the neo-natal unit. He was so small but so beautiful. I felt such an overwhelming love for him that I didn't want to leave him. The next day the paediatrician visited us again, he said they had sent off blood tests and that we would have the results in a few days. Those tests would confirm that Karl had Edward's Syndrome. On January 6<sup>th</sup> I left the hospital without Karl. He stayed in the Special Care Unit but it was so strange and sad leaving the hospital without my baby. On the

Sunday morning we had arranged to have Karl christened in the hospital. We brought our other two boys, Darren and Craig, and my mother. It was a beautiful christening but it was tinged with sadness. We cried for this beautiful baby that we knew we couldn't keep. Karl stayed in the Special Care Unit until 9th January. He was then moved to the Paediatric Unit where he had his own little room and we could spend more time with him.

Twice a day we visited Karl, once in the morning and then at night. It broke my heart to leave him there. On the Saturday we decided we would bring him home for the day. We collected him at 10am. The boys were so excited that their baby brother was coming home. I felt a bit nervous at first but after a while we just treated him like any other baby because he was our baby. We brought him back to the hospital at 6pm. It killed me to bring him back so we asked if we could bring him home permanently. They said there was no reason why we couldn't.

On Monday, January 15th, Karl came home. He was tube fed every three hours. We soon got used to it. He slept between Pat and myself. Some nights he didn't settle very well so Pat stayed up nursing him while we went to sleep.

As the weeks went on we increased his feeds and he began to gain weight. We were happy about this. He was thriving for one so small. So many people came to our house to see Karl. Everyone loved him. He was so special. Karl had 24-hour care. It was very tiring but we did it. He was our baby and we loved him so much. Karl started having apnoea attacks. He would have three attacks a week. This was very frightening but we got used to it. Once he was patted on the back he would start breathing again. At about six weeks these attacks stopped. We were quite relieved. He was still gaining weight and was about 5 lb 7 oz. We began to think that maybe he would live for a few months. But during the last ten days of his life he seemed to be uncomfortable, crying a lot between feeds. He only seemed to be comfortable when he could sit up and then fall asleep. We felt so helpless. But we did everything we possibly could to make him as comfortable as possible.

On Saturday, March 4th, we took Karl and his brothers to the park for a walk. Little did we know that this was to be our last outing together as a family. We brought Karl to bed that night as usual. Pat fed him at 3am.

I woke up at 7am on Sunday, March 5th, to find that our beautiful Karl had slipped away during the night. We were granted all we had hoped for. That he wouldn't suffer any pain and that we would both be with him when he died. His life was short and he changed our lives forever. We will always love and miss him. Our precious angel. He will look after us and his two brothers who will love and remember him always.

Helen Lawlor

## DAVID

**Helen Doherty & John Shine**

**David 12/10/00 – 14/10/00**

**Edward's Syndrome**



Our story began on 11<sup>th</sup> October 2000. I was almost full term in an uneventful pregnancy, due in 11 days and counting every minute. We already had a little girl, Meabh, age 2 years and 2 months. I went in for a routine scan and expressed my concern about how small I was. I was scanned and told to come back the next day, Thursday, for a more detailed scan (Doppler study). After the scan, the obstetrician decided to keep me in and induce me. She said that it was either a small baby or possibly a chromosomal problem (the first mention of a possible problem).

To cut a long story short, on the second contraction, our baby became distressed and I was rushed to theatre for an emergency caesarean section. As the obstetrician made the incision, she said "Helen, I don't have a good feeling". That was when my heart sank and the nightmare began. David was born at 1.33 pm on Thursday 12 Oct weighing 3 lbs 90zs. The doctors told me they were 100% sure that he had Edwards Syndrome. I was by myself as my husband John was not in theatre during delivery. He was also told the news and told that our baby's condition was "incompatible with life". Those 3 words just kept ringing in my ears. They said so much - no false hopes.

I was able to hold David almost immediately. I will always remember lying there with an oxygen mask on and tears running down and pooling in my ears. The next 2 1/2 days were like a complete dream – they were such traumatic and sad days. Even now, 6 years later, when I delve back into those dark days, the hurt and pain come right back. We spent as much time as we could with David over the next 2 ½ days.

The staff in the Rotunda were great, letting me do the tube feed and allowing us to change his nappies and hold him. Distraught grandparents came from Limerick to see him. Frantic phone calls from family at home and abroad trying to make sense of it all.

On Saturday morning, the paediatrician told us that David has developed a serious heart murmur and time was probably running out. We asked him about bringing our daughter to see David. I will always be grateful to him for suggesting that we bring her in straightaway. We cherish the afternoon we spent as a family with both Meabh and David. The staff kindly allowed us to bring David from ICU into a private room, where we had him in a little crib connected to a portable oxygen cylinder.

We were able to take him out and let Meabh hold him and got some treasured video clips and photos. It was a lovely few hours but so so sad, knowing that poor Meabh would soon no longer have her little brother. In fact it was to be her last time seeing him. It was so hard to play happy families while all the time our hearts were breaking.

David died that night at 11.45 - in our arms. We brought him back to my room overnight which was lovely and John stayed. The next few days were cruel, leaving the hospital with no baby, the funeral, meeting people. Just getting out of bed every morning was an effort but Meabh kept us going and we survived. 18 months later I gave birth to a little girl, Alice and we have had another girl, Sarah, since.

There will always be a huge absence in our lives. The girls regularly discuss their brother and those 2 1/2 days we had with David will always be treasured.

Helen Doherty



## CHAPTER 16

### The Tribute Book



S.O.F.T. Ireland decided to dedicate a page to each child in a well bound and presented book. This was to be known as the Tribute Book. It was made in Dublin at the request of Noreen and Michael Mulhall. It is not restricted to deceased children but also dedicated to living children. Hence the name “Tribute Book”.

The pages in the book are of excellent quality and are quite large between A4 and A3 in size. The only drawback is that the pages cannot conveniently be posted. A special effort is made to have the book available at Spring Break and AGM weekends for viewing and especially updates. All the information on the page from baby’s name to brothers’/sisters’ names is written in using a calligraphy set.

The personal message is written in by a parent(s) with a memento attached. The personal message contains sentiments about the child. This includes a poem or sample phrases like....

“ A child is like a butterfly in the wind... Our only beloved daughter and sister....Our precious gift from God... You will always be loved...Always in our memories... Thinking of you... You passed away peacefully in our arms... Sweet dreams little one... A tiny flower... Life will never be the same without you... We love and miss you so very much... Our little bud that never bloomed.....etc”

The memento is anything that fits flat on the page and is small in size. A passport size photo, a photocopy of a photograph, a fingerprint or a footprint etc.

The first Tribute Book Officers were Noreen and Michael Mulhall, followed by Alex Doyle, Brian and Ellen Mulvihill and Mary Kinsella.

This is the “Tribute Book Sample Page” which is brought along to the Spring Break or AGM.

**Tribute Book Sample Page**  
To be transcribed into Tribute Book

Baby's Name: \_\_\_\_\_

Parent '(s) Name (s): \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Date of Birth: \_\_\_\_\_ Date of Death: \_\_\_\_\_ Birth Weight: \_\_\_\_\_

Disorder: \_\_\_\_\_ Hospital: \_\_\_\_\_

Brother'(s) / Sister'(s) Name(s): \_\_\_\_\_

*The information above will be transcribed by a Calligrapher onto the page in the Tribute Book.*

*The Personal Message below should be written by the actual parent (s) ideally with a black felt pen onto the page in the Tribute Book. It would include sentiments about the child and, if desired, a memento of the child ( or a copy of it ).*

*Only use below for practice and to have it ready for transcribing into the actual Tribute Book.*

**Personal Message:**



Copy of Memento

## GLOSSARY OF MEDICAL TERMS

*This glossary has been compiled as an aid to understanding the complex medical terminology associated with Patau's Syndrome and Edward's Syndrome. The Glossary should only be used for the clarification of information already provided by a doctor. If any item raises questions in the mind of parents, they should seek further discussion with their medical advisers.*

**ABDOMEN** The area between the diaphragm and the pelvis enclosing the stomach, spleen, pancreas, liver, gall bladder, kidneys, intestines, urethras and bladder.

**APNOEA** Periods of interrupted breathing or breath holding.

**AURAL** Pertaining to hearing.

**AUDITORY BRAINSTEMEVOKED RESPONSE** Determines if hearing system can transmit information about sounds to the brain.

**AUTOSOME** The term used to denote any of the paired chromosomes - excepting the sex chromosomes.

**CAMPTODACTYLY** Permanent bending of a finger or fingers.

**CARDIAC** Pertaining to the heart.

**CELLS** "Building blocks" of body tissue.

**CEREBELLUM** The part of the brain which is concerned with movement and muscle tone.

**CHORION** The outer of the three tissue membranes which enclose the foetus during pregnancy.

**CLINODACTYLY** Curving round of a finger or fingers, most commonly in the fifth finger.

**COLOBOMA** A congenital gap in one of the structures of the eye - usually applied to the lens, retina, iris or lid.

**CONGENITAL** Present at birth.

**CRYPTOCHIDISM** The testes have not descended to the scrotum.

**CYANOSIS** A blueness of the skin, commonly occurring on the lips, tips of the ears; fingers and toes. It is a sign that the blood is not receiving sufficient oxygen in the lungs or that the circulation of the blood is impaired.

**CYCLOPIA** Fusion of the eyes.

**CYTOGENETICS** The science of chromosome analysis.

**DERMATOGLYPHICS** Ridged patterns of the fingers, palms, toes and soles of the feet. Unusual patterns may suggest a chromosomal abnormality.

**DEXTROCARDIA** The heart is on the right side of the chest.

**DIGIT** A finger or toe.

**DIAPHRAGM** The dome shaped muscular partition which separates the cavity of the abdomen from that of the chest.

**D.N.A.** The abbreviation for deoxyribonucleic acid, the essential "building blocks" for all genetic material.

**E.C.G.** (Electrocardiogram) An electrical recording of the action of the heart.

**E.E.G.** (Electroencephalogram) A system of recording the rhythmic waves of electric energy discharged by the nerve cells in the brain.

**EMBRYO** The term used to describe the foetus in the womb, prior to the end of the eighth week.

**EPILEPSY** A sudden discharge of energy from the brain, resulting in convulsions and mild to severe changes in the level of consciousness.

**FERTILISATION** The process in which the female sex cell (egg) is impregnated by the male sex cell (sperm).

**FLEXION CREASES** Creases upon the palm of the hand, sole of the foot and digits.

**FOETUS** The unborn baby after the eighth week of pregnancy.

**GAMETE** A sex cell - an egg or sperm. When two gametes unite the result is termed a “zygote”.

**GASTRO-OESOPHAGEAL REFLUX** Splashing or rising of food and stomach acids from the stomach to the oesophagus.

**GASTROSTOMY** A method of feeding through a tube permanently inserted through the abdomen.

**GENE** One of the 50,000 to 100,000 codes which direct development and function. Different genes govern different features.

**GENETICS** The study of heredity, characteristics and development.

**GESTATION** The period of pregnancy.

**GRAND MAL** A convulsive epileptic attack of the more severe type.

**HAEMANGIOMATA** A swelling consisting of abnormal blood vessels.

**HAEMOGLOBIN** The colouring matter of the red blood cells, which gives blood its colour.

**HEREDITY** Transmission of characteristics from parents to their offspring.

**HERNIA** Protrusion of an organ or part of an organ into, or through, the wall of the cavity in which it is situated.

**HOLOPROSENCEPHALY** Failure of the forebrain to divide properly.

**HYPERCONVEX** Excessively curved outwards or spoon shaped.

**HYPERTONIA** An increased degree of tone or tension, usually applied to muscle.

**HYPOTONIA** Lack of muscle tone: floppiness.

**HYDROCEPHALUS** Faulty distribution of cerebral-spinal fluid, usually resulting in a large head because of fluid accumulation.

**HYPARRYTHMIA** A type of infantile spasm, characterised by a high-voltage wave pattern on an electroencephalogram.

**INTRAUTERINE** Within the uterus.

**KARYOTYPE** The photograph of a set of chromosomes arranged in order.

**LONG ARM** (“q” arm) Lower long arm of chromosome.

**MICROCEPHALY** A small head.

**MICROGNATHIA** An abnormally small jaw.

**MICROPTHALMIA** Abnormal smallness of one or both eyes.

**MONOSOMY** Absence of a whole chromosome or arm of a chromosome.

**MYELOMENINGOCELE** A hernial protrusion of the spinal cord and its meninges through a defect in the vertebral canal.

**NEONATAL** Newborn.

**NISSSEN FUNDOPLYCATION** A surgical procedure which creates a functioning valve at the bottom of the oesophagus. This prevents the stomach contents from splashing into and up the oesophagus.

**NON-DISJUNCTION** The failure of chromosome pairs to separate correctly during division, resulting in an abnormal number of chromosomes in the cells.

**OCULAR** Pertaining to the eye.

**OEDEMA** Swelling due to an accumulation of fluid in the tissues.

**OESOPHAGUS** The canal down which food and drink is conveyed from the mouth to the stomach via the throat.

**OMPHALOCELE** Protrusion of the intestines through the abdomen of the infant at the umbilical cord, usually covered by a thin membrane.

**OPTIC** Pertaining to the eye.

**PAEDIATRICS** The branch of medicine concerned with childhood illness.

**PALATE** The roof of the mouth. The hard palate is at the front of the mouth and is composed of bone. The soft palate is at the back of the mouth and is composed of muscle.

**PALMAR** Pertaining to the palm of the hand.

**PERINATAL** Around the time of birth, immediately before, during or after birth.

**PETIT MAL** A convulsive epileptic attack of a minor nature.

**POLYCYSTIC KIDNEYS** The substance of both kidneys is largely replaced by numerous cysts.

**POLYDACTYLY** One or more extra fingers or toes.

**PRENATAL** Before birth.

**REFLUX** A backward flow or regurgitation.

**RENAL** Of the kidneys.

**ROCKER BOTTOM FEET** An abnormality of the feet in which the soles curve outwards, rather than inwards - giving them a rocker appearance.

**SCOLIOSIS** Curvature of the spine.

**SEX CHROMOSOMES** The “X” and “Y” chromosomes which determine the sex of an individual.  
XX = Female, XY = Male.

**SHORT ARM** (“p” arm) Upper short arm of chromosome.

**SIBLINGS** Children of the same parents i.e. brothers and sisters.



**SIMIAN CREASE** An abnormal palm crease found in about five per cent of the normal population, but also found in Down's syndrome and other chromosomal disorders.

**SPINA BIFIDA** A defect in the development of the spinal column, and in some cases the spinal cord.

**STENOSIS** The narrowing of an opening e.g. heart valve.

**STERNUM** The breast bone.

**STRICTURE** Narrowing of a natural passage or channel of the body, such as the oesophagus, bowel or urethra.

**SYNDROME** The term applied to a group of symptoms or features, occurring together regularly enough to constitute a disorder to which a particular name is given.

**TALIPES** Club foot.

**TRACHEA** The wind pipe.

**URETERS** The long tubes, one leading from each kidney which convey the urine to the bladder.

**UPPER RESPIRATORY TRACT** The part of the respiratory system which constitutes the nose and mouth, down to the trachea.

**ZYGOTE** The fertilised "egg"- the product of the fusion of the two sex cells (gametes) i.e. the sperm and the egg.

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## USEFUL CONTACTS

<p><b>1. Accord</b>  <u>Catholic Marriage Care Service</u>          Central Office          Columbia Centre          Maynooth          Co Kildare          TEL: (01) 505 3112          FAX: (01) 601 6410          EMAIL: <a href="mailto:admin@accord.ie">admin@accord.ie</a>          WEB: <a href="http://www.accord.ie">www.accord.ie</a></p>	<p><b>6. The Cleft Lip &amp; Palate Association of Ireland</b>          c/o          36 Woodlands Ave.,          Dun Laoghaire          Co. Dublin          TEL: 087 131 9803          EMAIL: <a href="mailto:info@cleft.ie">info@cleft.ie</a>          WEB: <a href="http://www.cleft.ie">www.cleft.ie</a></p>
<p><b>2. Barnardos</b>  <u>National Office and General Enquiries</u>          Christchurch Square          Dublin 8          CALL SAVE 1850 222 300          TEL: (01) 453 0355          FAX: (01) 453 0300          EMAIL: <a href="mailto:info@barnardos.ie">info@barnardos.ie</a>          WEB: <a href="http://www.barnardos.ie">www.barnardos.ie</a>          Have a Bereavement Counselling Service for children called Solas</p>	<p><b>7. The Disabled Drivers' Association of Ireland</b>          Head Office          Disabled Drivers Association          Ballindine          Claremorris          Co. Mayo          TEL: (094) 936 4054          (094) 936 4266          FAX: (094) 936 4330          EMAIL: <a href="mailto:abilty@iol.ie">abilty@iol.ie</a>          WEB: <a href="http://www.iol.ie/~ability">www.iol.ie/~ability</a></p>
<p><b>3. Brainwave</b>  <u>Irish Epilepsy Association</u>          249 Crumlin Road          Crumlin          Dublin 12          TEL: (01) 455 7500          Nurses' Helpline (01) 4554133          FAX: (01) 455 7013          EMAIL: <a href="mailto:info@epilepsy.ie">info@epilepsy.ie</a>          WEB: <a href="http://www.epilepsy.ie">www.epilepsy.ie</a></p>	<p><b>8. Fannin MedCare</b>  <u>Medical &amp; Rehabilitation Products</u>          Unit 3          The Square Industrial Complex          Tallaght          Dublin 24          TEL: (01) 466 4130          FAX: (01) 466 4138          EMAIL: <a href="mailto:rehab@fanninmedcare.com">rehab@fanninmedcare.com</a>          WEB: <a href="http://www.fanninmedcare.com">www.fanninmedcare.com</a></p>
<p><b>4 The Carer's Association</b>          Unit 3, Dolcan Mall          Tower Rd..          Dublin 22          TEL: (01) 4670795          Freefone 1800 240724</p>	<p><b>9. Professor James Houghton</b>          Cytogenetics Unit          University College Galway          Tel: (091) 750 384          FAX: (091) 525 700          EMAIL: <a href="mailto:jim.houghton@ucg.ie">jim.houghton@ucg.ie</a></p>

<p><b>5 Hospitals</b></p> <p><b>The Adelaide &amp; Meath Hospitals incorporating The National Children's Hospital</b>  Tallaght,  Dublin 24  TEL: (01) 4142000  EMAIL: <a href="mailto:info@amnch.ie">info@amnch.ie</a>  WEB: <a href="http://www.amnch.ie">www.amnch.ie</a></p> <p><b>Our Lady's Hospital for Sick Children</b>  Crumlin  Dublin 12  TEL: (01) 409 6100  FAX: (01) 455 8873  EMAIL: <a href="mailto:info@olhsc.ie">info@olhsc.ie</a>  WEB: <a href="http://www.olhsc.ie">www.olhsc.ie</a></p> <p><b>The Children's University Hospital</b>  Temple Street  Dublin 1  TEL: (01) 878 4200  FAX: (01) 874 8355  EMAIL: <a href="mailto:info@cuh.ie">info@cuh.ie</a>  WEB: <a href="http://www.cuh.ie">www.cuh.ie</a></p>	<p><b>10. Irish Association for Spina Bifida &amp; Hydrocephalus</b>  National Resource Centre  Old Nangor Road  Clondalkin  Dublin 22  TEL: (01) 457 2329  FAX: 01 457 2328  LO CALL: 1890 20 22 60  WEB: <a href="http://www.iasbah.ie">www.iasbah.ie</a></p>
<p><b>11. I.S.A.N.D.S  <u>Irish Still Birth &amp; Neonatal Death Society</u></b>  Carmichael House  North Brunswick Street  Dublin 7  TEL: (01) 872 6966  EMAIL: <a href="mailto:info@isands.ie">info@isands.ie</a>  WEB: <a href="http://www.isands.ie">www.isands.ie</a></p>	<p><b>13. The Miscarriage Association of Ireland</b>  Carmichael Centre  North Brunswick Street  Dublin 7  TEL: (01) 8735702  (01) 872 5550  (01) 872 2914  FAX: (01) 873 5737  EMAIL: <a href="mailto:info@miscarriage.ie">info@miscarriage.ie</a>  WEB: <a href="http://www.miscarriage.ie">www.miscarriage.ie</a></p>
<p><b>12. The Jack &amp; Jill Children's Foundation</b>  Johnstown Manor,  Johnstown,  Naas,  Co. Kildare  TEL: (045) 894538/660  FAX: (045) 894558  EMAIL: <a href="mailto:info@jackandjill.ie">info@jackandjill.ie</a>  WEB: <a href="http://www.jackandjill.ie">www.jackandjill.ie</a></p>	<p><b>14. Treoir  <u>Federation of Services for Unmarried Parents &amp; Their Children</u></b>  14 Gandon House  Custom House Square  IFSC  Dublin 1  LO CALL: 1890 252 084  TEL: (01) 670 0120  FAX: (01) 670 0199  EMAIL: <a href="mailto:info@treoir.ie">info@treoir.ie</a>  WEB: <a href="http://www.treoir.ie">www.treoir.ie</a></p>

## **Health Service Executive**

**Dublin Mid-Leinster:** Dublin City South of the River Liffey, South Dublin County, Wicklow, Kildare, Longford, Westmeath, Laois, Offally  
Dun Laoghaire Local Health Office, Tivoli Road, Dun Laoghaire, Co. Dublin  
**Tel 01 2843579.**

Dublin South East Local Health Office, Vergemount Hall, Clonskeagh, Dublin 6  
**Tel 01 2680300**

Dublin South City Local Health Office, Carnegie Centre, 21-25 Lord Edward Street, Dublin 2  
**Tel 01 648 6500**

Dublin South West Local Health Office, Old County Road, Crumlin, Dublin 12  
**Tel 01 415 4700**

Dublin West Local Health Office, Cherry Orchard Hospital, Ballyfermot, Dublin 10  
**Tel: 01 6206300**

Kildare / West Wicklow Local Health Office, Poplar House, Poplar Square, Naas, Co Kildare  
**Tel 045 876 001**

Wicklow Local Health Office, Glenside Road, Co. Wicklow  
**Tel 0404 68400**

Laois/Offaly Local Health Office  
Laois: Health Centre, Dublin Road, Portlaoise  
**Tel 057 86 21135.**  
Offaly: Health Centre, Arden Road, Tullamore  
**Tel 057 93 41301**

Longford/ Westmeath Local Health Office  
Longford: Health Centre, Dublin Road, Longford  
**Tel 043 50169.**  
Westmeath: Health Centre, Longford Road, Mullingar  
**Tel 044 93 40221**

Dublin North East: Dublin City North of the River Liffey, the community of Fingal County, Louth, Meath, Cavan, Monaghan

**Dublin North East Local Health Offices**

North West Dublin Local Health Office, Rathdown Road, Dublin 7

**Tel 01 8825000**

North Central Dublin Local Health Office , 193 Richmond Road, Dublin 3

**Tel 01 857 5400**

North Dublin Local Health Office, Cromcastle Road, Coolock, Dublin 5

**Tel 01 8164200**

Cavan: Community Care Offices, Lisdaran, Cavan

**Tel: 049 4361822.**

Monaghan: Community Care Offices, Rooskey, Monaghan

**Tel: 047 30400.**

Louth Local Health Office, Community Care Offices, Dublin Road, Dundalk

**Tel: 042 9331194.**

Meath Local Health Office, Community Care Offices, Co. Clinic, Navan

**Tel: 046 9021595**

West: Limerick, Clare, Tipperary (North Riding), Galway, Mayo, Roscommon, Donegal, Sligo, Leitrim

**West Local Health Offices**

Donegal Local Health Office, Ballybofey, Co. Donegal

**Tel : 074 9131391**

Sligo/Leitrim/West Cavan Local Health Office Community Services, Markievicz House, Sligo

**Tel: 071-9155100**

Roscommon Local Health Office, Community Services, Roscommon, Co Roscommon

**Tel 0903 375 00**

Mayo Local Health Office, County Clinic, Castlebar, Co. Mayo  
**Tel 094 223 33**

Galway Local Health Office, Community Services, 25 Newcastle Road,  
Galway  
**Tel 091 523 122**

Clare Local Health Office, 16 Carmody Street Business Park, Ennis Co.  
Clare  
**Tel 065 6863483**

North Tipperary / East Limerick Local Health Office, Civic Office,  
Limerick Road, Nenagh  
**Tel 067 46600**

Limerick Local Health Office, St Joseph's Hospital, Mulgrave Street,  
Limerick  
**Tel 061 461140**

**South:** Carlow, Kilkenny, Tipperary (South Riding) Waterford,  
Wexford, Cork, Kerry

### **South Local Health Offices**

Cork / South Lee Local Health Office, Abbeycourt House, George's  
Quay, Cork  
**Tel: 021- 4965511**

Cork / North Lee Local Health Office, Abbeycourt House, George's  
Quay, Cork  
**Tel: 021- 4965511**

West Cork Local Health Office, Coolnagarrane, Skibbereen, Co. Cork  
**Tel: 028- 21722**

North Cork Local Health Office, Gouldshill House, Mallow, Co. Cork  
**Tel: 022- 22220**

Carlow/Kilkenny Local Health Office  
Carlow Community Care, Athy Road, Carlow. Tel: 0503-30053  
Kilkenny Community Care Headquarters, James' Green, Kilkenny.  
**Tel: 056-52208**



South Tipperary Local Health Office, Western Road, Clonmel  
**Tel: 052-22011**

Waterford Local Health Office, Cork Road, Waterford\  
**Tel: 051-842800**

Wexford Local Health Office, Grogan's Road, Wexford  
**Tel: 053-23522**

Kerry Local Health Office, 18-20 Denny Street, Tralee, Co. Kerry  
**Tel: 066- 7121566**

## **Northern Ireland**

### **Eastern Health and Social Services Board**

Champion House  
12-22 Linenhall Street  
Belfast BT2 8 BS

**Telephone:** (028) 9032 1313

**Fax:** (028) 9055 3681

**Text Phone** for people who are deaf: (028) 9032 4980

**E-mail:** [pr@ehssb.n-i.nhs.uk](mailto:pr@ehssb.n-i.nhs.uk)

### **Northern Health & Social Services Board**

County Hall  
182 Galgorm Road, Ballymena  
BT42 1QB

**Website Address:** [www.nhssb.n-i.nhs.uk](http://www.nhssb.n-i.nhs.uk)

**Telephone Number:**

(028) 2531 1000

**Fax Number:**

(028) 2531 1100

**Email Address:**

[webinfo@nhssb.n-i.nhs.uk](mailto:webinfo@nhssb.n-i.nhs.uk)

### **Southern Health & Social Services Board**

Tower Hill  
Armagh  
BT61 9DR

**Telephone**

(028) 3741 0041

**Fax**

(028) 3741 4550

**Textphone**

(028) 3741 4530

**Email**

[info@shssb.n-i.nhs.uk](mailto:info@shssb.n-i.nhs.uk)

Health Information Helpline  
Freephone 0800 665544

**Western Health & Social Services Board**

15 Gransha Park  
Clooney Road  
Londonderry  
BT47 6FN

**Fax Number**

(028) 7186 0311

**Email Address**

[info@whssb.n-i.nhs.uk](mailto:info@whssb.n-i.nhs.uk)

<p><b>1. Disability Living Allowance Branch</b> Castle Court Royal Avenue Belfast BT1 1SL TEL: (028) 9090 6182 <i>Have details of financial allowances and entitlements</i></p>	<p><b>3. Relate (Northern Ireland Marriage Guidance)</b> 74-76 Dublin Road Belfast BT2 7HP TEL: (Helpline) (028) 9032 3454 TEL: (Admin) (028) 9032 3454 FAX: (028) 9031 5298 WEB: <a href="http://www.relatene.org">www.relatene.org</a></p>
<p><b>2. Regional Genetics Service</b> Belfast City Hospital Lisburn Road Belfast BT9 7AB TEL: (028) 9026 3873 FAX: (028) 9026 3691</p>	<p><b>4. Remember Our Child</b> 50 University Street Belfast BT7 1 HB TEL: (028) 9033 3315 <i>Offers support to parents who have suffered the death of a child. The Stillbirth &amp; Neonatal Death Society, the Sudden Infant Death Syndrome, The Miscarriage Association and Support After Termination for Abnormality can also be contacted through Remember Our Child</i></p>

## Useful Websites

S.O.F.T. Ireland

[www.softireland.com](http://www.softireland.com)

S.O.F.T. (UK)

<http://www.soft.org.uk/>

S.O.F.T. (USA)

<http://www.trisomy.org/>

Rainbows Down Under

<http://members.optushome.com.au/karens>

Trisomy On-Line

<http://www.trisomyonline.org>

Jack and Jill Foundation

<http://www.jackandjill.ie>

Baby to Angels

<http://www.geocities.com/baby2angels2000>

Chromosome 18 Registry and Research Society

[http:// www.chromosome18.org/](http://www.chromosome18.org/)

Inclusion Ireland

<http://www.inclusionireland.ie/about.html>

Enable Ireland

<http://www.enableireland.ie>

UNIQUE The Rare Chromosome Disorder Support Group

<http://www.rarechromo.org/html/ChromosomesAndDisorders.asp>