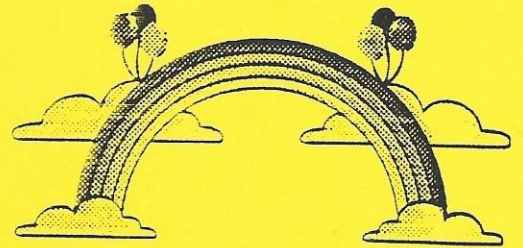
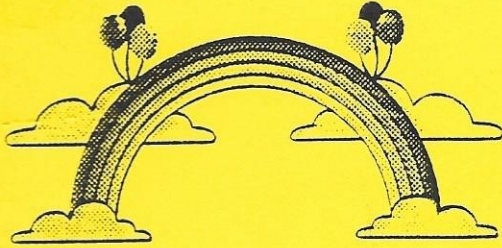
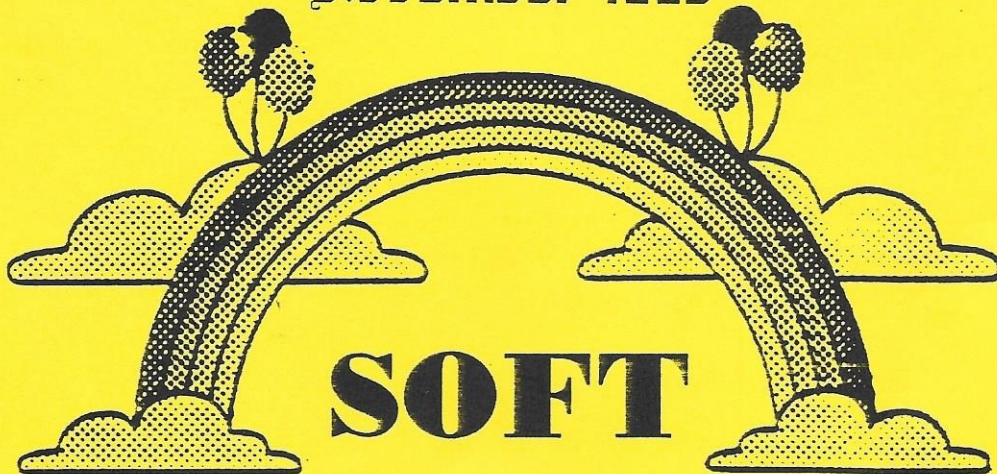


Marie



Newsletter No. 3

November 1993



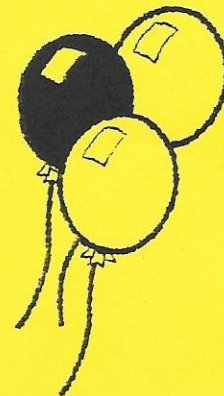
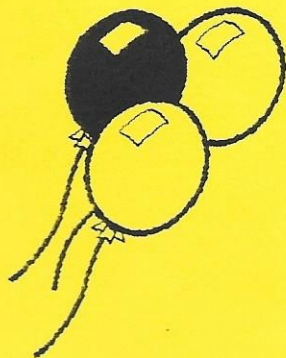
SOFT

Support Organisation

for

Families Affected By:

Trisomy 13 (Patau's Syndrome) Trisomy 18
(Edwards' Syndrome)
And Other Related Disorders



NEW BOOKLET

Work has begun on the preparation for publication of an Irish edition of the S.O.F.T. booklet. A decision has been taken on the general format and the themes to be dealt with. We welcome contributions from families involved with S.O.F.T. Everyone's experiences, thoughts and advice are essential, in order to create a booklet that truly reflects the families that have/had a baby/child with Trisomy 13/18 or a related disorder. If you feel you can contribute - no matter how little, please contact Bernadette Doyle or any of the co-ordinators.

Dermot Keenan has undertaken to be the co-ordinator for the new S.O.F.T. booklet.

The Department of Health has agreed to fund the publication of approximately 3,000 new booklets.

New posters and leaflets have been printed. They are on their way to the hospitals. Jacinta Kelly has kindly agreed to send them out. Aine Boyle will give one to Letterkenny Hospital and Michelle Faulkener to Temple Street and Baldoyle. The cost of these is £120. The Department of Health is funding these.

We have also printed notepaper and compliment slips with the S.O.F.T. logo.

SADLY

Reece McChrystal died this summer. We hope Reece's short life has brought joy to his parents and that the future will not be too difficult without his presence in his family.

Gemma Healy and **Teresa Gallagher** died peacefully in the loving care of their families. We wish their families strength to come to terms with their loss.

ALL IRELAND CHILDREN'S HOSPICE

This hospice offers respite and terminal care for children suffering from life-threatening and life-limiting conditions. There is no charge to families. At present there are two new regional centres, one in Limerick for the Mid-West, and one in Kilkenny for the South-East. There is also a domiciliary support service in these two regions. This involves a qualified paediatric nurse visiting the family giving the parents a deserved break - allowing them to go shopping, have a night out, or just a night's rest free from interruption, secure in the knowledge that their child is being cared for adequately.

Near future plans include extending to the South-West and the Midlands. Long-term plans are to extend up the North-East and the North-West regions.

If you would like more information on this service, or feel you could avail of the facilities of the hospice contact:-

John Henchion,
National Director,
A.I.C.H.,
Ballinderry,
Mullingar,
Co. Westmeath.
Tel: 044 41500 or Marie O'Conghaile.

S.O.F.T. UK CONFERENCE

Della McKinney and Martin and Valerie Farrelly attended the S.O.F.T. UK Conference in Birmingham. Della enjoyed the conference very much and found the smaller informal discussions groups most beneficial. According to Della "it was well worth going to". There is a full report of the S.O.F.T. '93 Conference in the next UK newsletter.

Professional Speaker

On February 13th 1993 in the Ashling Hotel we were delighted to have Dr. Desmond Duff, Paediatric Cardiac Specialist, Our Lady's Hospital for Sick Children, Crumlin, as our guest speaker. He spoke on the heart conditions affecting Trisomy 13 and 18 babies. His talk was very enlightening and he spoke to us in very clear language after which we had a brief question and answer session with him.

S.O.F.T. UK - 2nd Annual Conference Video

On loan - To whom? Please return.

S.O.F.T. UK - 3rd Annual Conference Video

This video is now available for loan. I would recommend especially the talk given by Dr. Ian Young - Geneticist. If you wish to borrow the video please contact Marie O'Conghaile.

FAMILY TREE SCHEME

If you would like to commemorate an important family event such as the birth of a baby, a marriage, graduation, or sadly, the death of a member of the family, The Family Tree Scheme may be the solution for you. You can contribute £20.00 to the cost of planting trees at various sites around Ireland - Phoenix Park, Dublin; Muckross Gardens, Killarney; Glenveagh, Co. Donegal; Kilkenny Castle, Co. Kilkenny; Connemara National Park, Co. Galway; Birr Castle, Co. Offaly and Strokestown House, Co. Roscommon. Your family tree will grow with the years and span many human generations, giving pleasure to many, while enriching Ireland's environment. For every tree sponsored, you receive a certificate with an inscription of your choice and the number and location of your own tree.

If you wish to know more about this Family Tree Scheme, you can contact:-

The Tree Council of Ireland,
33, Botanic Road,
Glasnevin,
Dublin 9.

BIRTH CONGRATULATIONS

Seamus and Rosemary McCumiskey are happy to announce the safe arrival of baby Nicola.

AGM OF S.O.F.T. (IRELAND)

The first A.G.M. of S.O.F.T. (Ireland) was held on September 25th 1993 in the Hotel Nuremore, Carrickmacross, Co. Monaghan.

The first part of the day was devoted to a talk by Matt Flynn, Director of Nursing at Cregg House, Sligo. Matt spoke movingly on his experiences of dealing with handicapped children and adults; he has worked and cared for these special people in U.S., Korea, Romania and here in Ireland. A full account of Matt's talk will appear in the next edition of the newsletter.

Officers elected are:

Secretary:	Bernadette Doyle
Treasurer:	Shiela McManamly
Newsletter:	Anne Boyle
Co-ordinator for Booklet:	Dermot Keenan
Trisomy 13 Co-ordinator for South:	Joy Nairn
Trisomy 18 Co-ordinator for South:	Larry & Cathleen Fenlon
N. Ireland Co-ordinator:	Margaret Doherty
Fundraising Co-ordinator:	Dessie Boylan
National Co-ordinator:	Marie O'Conghaile

A representative from two areas were co-opted to serve on the committee - these were Jacinta Kelly representing the North West and Geraldine O'Reilly representing the North East.

REPORT ON THE FIRST NATIONAL CONFERENCE ON CHILDHOOD AND DEATH

I wish to thank ISIDA for their kind permission to use their report on the **"First National Conference on Childhood and Death"**. The report was published in the June 1993 edition of their newsletter.

Those of us who were privileged to attend the First National Conference on CHILDHOOD AND DEATH last April found it a most profound experience, albeit emotionally draining and physically exhausting. The Conference was held at Garbally College, Ballinasloe, from Friday 16th to Sunday 18th April and was organised by Eimear Berry, Dr. Kevin Connolly, John O'Donohue and Nuala Harmeay.

Many support groups including ISIDA, SOFT, ISANDS, Miscarriage Assoc., Bereavement Counselling Service, Samaritans, Victim Support Group and SOLACE were represented at the Conference. Each group had a stand in the registration area where we provided literature and information to delegates, most of whom were professionals in the medical and nursing fields. Slides showing general information and the aims of each organisation were provided by us and shown during the Conference interspersed between speakers.

S.O.F.T. was represented by Marie O'Conghaile, on Friday 16th and Saturday 17th, Dermot Keenan and Mary Flannery were present on Friday 16th and Eveleen Higgins and Catherine McHale gave us their support on Saturday 17th.

The opening address was given by Sen. Gordon Wilson, who gave a simple, dignified and very moving account of his daughter Marie's life and tragic death. He recalled his early life in Co. Leitrim and secondary school in Dublin, unmarred by religious bigotry. As an adult, he moved to Enniskillen and became aware of an intolerance in the community, divided half and half along religious grounds, which he felt unworthy of a people who individually were good and caring. Marie was the third child of Sen. Wilson and his wife, Joan - the pet. Of the awful events of 7th Nov. 1987, when lying together under the bomb-created rubble, her last words to him were "Daddy, I love you very much". He described how he felt emptied of all but love, and that Marie's dying message to him was what somehow enabled him to get through the following days, weeks and months when he was unexpectedly catapulted into a blaze of publicity following his statement of having no bitterness or hatred for the perpetrators of the bombing. Gordon Wilson finished by saying that while we all have to find our own way through grief, love is the bottom line. It is through love that the answer lies for "this lovely land of ours, the land of Saints and Scholars".

Friday 16th.

Dr. Anthony O'Flaherty was the first speaker, his subject:-

Impact of Death on the Family - Normal and Abnormal Grief

Death is inevitable, but in our culture, it's discussion is such a major taboo that there are great difficulties for the dying and the bereaved, which would be lessened if only we could be more open. Our first task in supporting the bereaved is to allow them to mourn. Dr. O'Flaherty defined grief as the physical and emotional response to any loss of consequence, and went on to describe the normal reactions of a bereaved person. There are no set rules - no set period of time, but roughly three stages:- 1 /

Numbness, 2 / Stages of Suffering, 3 / Recovery. Abnormal grief is most unusual. In ascertaining how a grieving person is coping, one could ask if they are thinking less negatively and destructively, going out socially, thinking of the dead person in the past or present tense, dreaming of the deceased, and if they can smile and laugh without guilt.

Nuala Harmey, Medical Social Worker at Temple Street Hospital was the next speaker on **Childrens' Reactions to Death**.

She gave a most enlightening account of her work with bereaved children. In the event of the death of a child, and the devastation of the parents, it often happens that the siblings are ignored. Children feel sad, lonely, angry, confused, and guilty, but lack the ability to communicate those feelings verbally and will go to great lengths to avoid upsetting their parents. They need an opportunity to express their feelings in their body in a colour-coded drawing representing different emotions, and this can give a good indication of "where they're at". Headings such as "Sometimes I get angry because..." "I worry a lot about..." "If only..." "I feel frightened when..." (drawing makes it less powerful) can be revealing and expressive. Children are greatly helped by being enabled to share grief feelings. While parents (especially those of cot death babies) are overwhelmed at the time, it is essential that both parents and children are given the help that they need. Adults' perceptions of a child's worry may be way off the mark. Misconceptions are also a huge issue, and it is important to update information for a child as s/he gets older.

The final speaker on Friday morning was Rita O'Shea, Matron at Temple Street who spoke on **Death in the Special Care Baby Unit**.

There is no death so sad as that of a loved baby. As well as losing their child, parents experience the loss of all their dreams and aspirations for that baby. Most parents are scared by all the equipment in the Unit. They need reassurance that all that can be done is being done, truthful information and practical facilities. Most importantly, they need positive memories of their baby. Thus parents and family are encouraged to hold their dead baby for as long as they feel the need to. Also time to talk and ask questions, clear information about funeral arrangements and an opportunity to see their baby again are all vital. Mementoes such as photos, a lock of hair, foot or hand print, and the baby's I.D. bracelet are given to the parents.

Rita O'Shea also expressed a great need for a support network for professional working in this very difficult area.

After lunch at Portiuncula Hospital, which was a welcome break, we heard Fr. Maurice Reidy speaking on **The Right to Die**.

He quoted Seamus Heaney's poem "Mid-term Break".

Death is about time. There is a sense of being summoned or called out, also a feeling of marking time. It is a transition period graduating to permanent separation which if not viewed in the religious sense, at its least it is a transition to dissolution and the unknown. Where modern technology has made timing an issue, in relation to a child's death, we must look to the well-being and comfort of that child. Fr. Reidy's thesis:- There is a Right to Die belongs, he feels, where basic human rights belong. We must be allowed to accept death, and in saying that, he was not implying any concept of Euthanasia. There are differences of culture between professionals, and hospital staff should have a **humane view** of death that is shared.

Dr. Bartley Sheehan G.P. and Coroner spoke on the subject of **Children and Suicide**.

In Ireland "troublesome" things are not addressed in our Constitution, and this includes suicide. Figures show an increase in suicides by 31% between '81 and '90/ There are 400 every year in Ireland, which is the same number as deaths from road traffic accidents. Because suicide is still legally a crime here (the only country in E.C. where this is the case), it is difficult to know how accurate the figures are. There is an aura of sin or madness in peoples perception of this tragedy which promotes secrecy and prevents people seeking help. Dr. Sheehan went on to outline risk factors and how to recognise people at risk. He has come to feel that there is a "flavour" of suicide. There may be references made in school work, letters or diaries as to a person's state of mind. If a young person's diary is left conspicuously around, it could be their effort at communicating a hint or inviting further discussion. If we are privileged to be taken into someone's confidence, it is well to pick it up. Listening is the most helpful thing, but we must provide a listening environment free of interruptions. We should give time, not judge, deny or diminish. We must encourage and commend their courage in telling us. We must put heart into them. The focus on success is unhealthy, as it is in failing we have to make an effort to get out of situations. We must be sensitive to those touched by suicide, who may be carrying a great burden of guilt, as well as all of the other aspects of bereavement. We must decriminalise suicide.

Dr. Kevin Connolly whose subject was **Death Before Birth** also opened by quoting Seamus Heaney - "Elegy for a Still-born Child".

Death before birth is significantly different from death at any other time. ISANDS (Irish Stillbirth and Neonatal Death Society) was founded 10 years ago, and the Miscarriage Association 5 years ago. Early on in pregnancy, a mother can experience miscarriage like an amputation. There is no opportunity for a funeral, no memory of the baby, no ritual. There are 300 stillbirths p.a. in Ireland, and no one can say that the deaths of such babies doesn't have an impact. People experience a feeling of emptiness, poor self-esteem, helplessness. Mostly, grief proceeds normally, but it's process may be hampered by various factors such as the attitude of hospital staff, the giving of drugs etc. The use of the term "abortion" can be most hurtful because of it's other connotations. Important helping strategies are encouraging parents and siblings to meet the dead baby when possible. Professionals have to be educated, doctors must be taught how to empathise, and if someone is unable to, then the public should be protected from them.

There is no registration of stillbirths in this country - a scandal when the protection of the unborn child is written into our Constitution. This anomaly must not be allowed to continue and a petition was signed by delegates to be presented to the Minister for Health.

Saturday 17th.

Dr. Brendan McCormack opened proceedings with his talk on **Grief and Mental Handicap**.

The special difficulties (cognitive, verbal, visual or auditory) of the bereaved mentally handicapped child makes their grieving more complicated for them. However, there is no reason to suppose that they do not experience grief as the rest of us do. Others don't include the mentally handicapped in talking about loss, or in making arrangements as "they might

get too upset". The death of a parent provokes a series of losses. Often the bereaved child may be put into temporary care thus losing their home and social network as well as the parent who was the care giver. Dr. McCormack went on to describe other aspects of the difficulties which are experienced in the whole area of mental handicap both for the person themselves and their families.

Anne Ferguson, Social Worker of the Northern Ireland Hospice gave her talk on **Working with Children whose Parents have Died.**

The death of a parent is an overwhelming experience for a child, and in the midst of grieving adults, it is very important that the child will have the security of another caring adult. Children process information differently from adults. Infants and toddlers have no understanding of the permanence of death but will experience separation anxiety. 3 - 5 year olds see themselves as the centre of the universe and believe that their thoughts and actions cause events, and can suffer accordingly. 5 - 11 year age group have a growing awareness of death and great care must be taken to be honest and avoid euphemism. From 11 through adolescence, there is an ability to accept death on a near adult level. We must encourage all of them to ask questions. Sometimes young children have fantasies which may be more damaging than the actual truth. Anne Ferguson went on to describe their work at the Hospice with bereaved children. Life-cycle stories, books and exercises all aim to ease a sense of isolation and promote normal grief.

After a short break we heard Dr. Dora Black, Child Psychiatrist of the Royal Free Hospital, London on **Childhood Traumatic Bereavement.** This subject made absolutely harrowing listening, and as Dr. Black herself said, is probably the most sad and damaging experience of bereavement a child could have.

If a child witnesses the violent death of a parent, or takes part in or witnesses awful events, the effect on the child will be traumatic. Images of violence, horror etc., cannot be processed by a brain and will reverberate round and round in the child's mind. If intervention occurs before these images enter the longterm memory, it may prevent Post Traumatic Stress Disorder. It is essential for all who have witnessed extreme violence to have psychological "first-aid". We heard stories of children who have witnessed one parent kill the other and of her work with them through art and other means to enable them to express and therefore come to some terms with the awful events. Other causes of PTSD are abduction, witnessing other murder, mass disaster such as Zebrugge Ferry or Hillsborough, and in all cases immediate intervention is vital to try to minimise the damage. We again had lunch at Portiuncula Hospital feeling devastated by what we had just heard.

Dr. Fin Breathnach, Child Oncologist at Our Lady's Hospital for Sick Children, Crumlin, gave his paper on **Childhood Cancer - Breaking the Bad News.**

There are 100 cases of childhood cancer diagnosed in Ireland each year, but it is important to be optimistic as there is 70% cure rate. Parents will experience grief first at the diagnosis, secondly at relapse and thirdly when active treatment is no longer justifiable. We were shown slides of the new wing at Crumlin where young patients are treated and of Dr. Breathnach's office where the sad task of telling parents that their child has cancer usually occurs. There is always a nurse present, to let him know how well or badly he did, and to be with parents afterwards. His

chair is on wheels so that he may be in physical contact with the parents - there is no barrier such as a desk between them. He spoke of the difficulties that arise when treatment fails - should parents be made aware of a very minimal chance of success if treatment is resumed? Most will grasp at any glimmer of hope given. In working with children, honesty is required above all. A child may not fear what adults fear, and vice versa. It is important to encourage children to talk about their worries. They are always more aware of what is going on than is perceived and will scan the parents' faces when they enter their room and "know" how things are with themselves. Dr. Breathnach went on to talk of the special needs of children and parents when the terminal phase of the child's life is entered into. There is a policy at Crumlin of keeping in contact with the parents after the death of a child.

Sue Potter, Matron at the Childrens Hospice for the East of England spoke on **The Children's Hospice and the Family.**

Children die from many different causes. The Hospice is there for parents and children to choose. 70% of children have degenerative diseases, and the Hospice can offer much that would not be possible in a hospital setting e.g. meals where and whenever the child wishes. There is a hydrotherapy pool which children can enjoy with their families. The Hospice is there for the whole and extended family, including grandparents, teachers, neighbours and friends. The child can live at whatever pace is comfortable for him or her. They are encouraged to express themselves through play and art. The worries of siblings are recognised and addressed including the sibling who didn't know the lost child. The Hospice is a home from home and there for families from the time of diagnosis for as long as they need. It is for all children who have a life-limiting illness and endeavours to make their time as fruitful and fulfilling as possible, while supporting their families.

John Donohue, Psychologist, was the final speaker on Saturday with his talk on **Coping Skills.**

It is not valid to compare griefs: all dimensions are multi-factorial. We are bereaved for life, John O'Donoghue believes, we do not get over it. However, we learn to be bereaved, and we can learn how to cope. He recognises that his view of grief and bereavement differs from some of the earlier speakers, but thinks that this is healthy. He spoke about how normal and human grief is, and in helping people who are grieving, we must tell them how normal their experience is. Listen with people. While no one has all the answers, there are some essentials in coping with grief. Express yourself verbally, in writing, through activity. Talk as much as possible - never mind if you feel you are being a bore. Anger is a common response and is difficult because nobody welcomes it. There are strategies to express anger in a harmless way. Beating a pile of folded up newspapers as hard as we can, smashing a couple of eggs on which we've written the cause of our anger were two such strategies. You should legitimise yourself (NO, I'm not over it yet). Legitimise your child. It is the impact of the life of your child which you are grieving. Planting a tree in your child's name is very helpful. How do you cope? By allowing yourself to be totally human.

Sunday 18th.

Sunday morning's lecture was attended by fewer delegates. Dr. Bartley

Sheehan's talk on **Legal Aspects and Sudden Death** was very informative. For example I don't think many people are aware that the State owns your body when you die. A doctor is the only person who can pronounce death and it is the place where death is pronounced which is considered the place of death.

In the case of unexpected or unnatural death, it is the legal duty of all to inform the Coroner (usually by means of telling a Garda Sergeant). Dr. Sheehan went on to describe the role of the Coroner which is a quasi-judicial office, incorporating medical and legal aspects. There are five main functions:- **Investigative** (through police) **Judicial** (making judgements in the Coroners Court) **Recording** (in recording facts which have been judged in the Coroner's Court) **Administrative** and **Educational**. The latter affording an opportunity to "make noise" about situations which are a cause for concern.

There are some difficulties attached to a Coroner's work which Dr. Sheehan outlined. Those pertinent to SIDS are the fact that a post-mortem is always a cause for distress. However, he reminded us that Pathologists are experienced people, and would take due care and have a degree of reverence when performing such examinations. There can be investigative insensitivity, having gardai around can be accusatory and distressing. Only one reported SIDS case in his 20 years experience turned out not to be so.

There were several workshops after Dr. Sheehan's talk on helping bereaved children. These workshops were chaired by Nuala Harmey, John Donohue, Dr. Kevin Connolly, Dr. Fin Breathnach and Eimear Berry.

The conference came to a close with a Remembrance Service at Portiuncula Hospital Chapel with hymns and readings, followed by a tree planting ceremony in the grounds of the Hospital. Eimear Berry planted a tree to commemorate all our children. It was a moving and fitting end to such a conference.

RADIO PUBLICITY FOR S.O.F.T.

"First National Conference on Childhood and Death"

Arising from the conference I (Marie O'Conghaile) was requested by the organisers of the conference to take part in a radio programme. The programme was "This Week" at 1.00 p.m. on RTE 1 on Sunday.

I discussed the format of the interview with Eoin Ronayne, the presenter, and he was very agreeable to giving publicity to S.O.F.T. During the interview I spoke about my daughter Aine, the development of S.O.F.T. and at the end there was an announcement giving details of S.O.F.T. and where we could be contacted. The other support group represented on the radio programme was I.S.I.D.A.

"Cycle Race"

Dessie and Joan Boylan plus relatives and friends organised a cycle race for S.O.F.T. and Dessie gave a very informative interview. He spoke about Emma who was born in February 1992. Emma had Edwards' Syndrome. He spoke of the effect she has had on their lives, their involvement with S.O.F.T. and the cycle race. By all accounts it was a very professional and moving interview.

FUNDRAISING FOR S.O.F.T.

"Gardening Through The Seasons"

Terry Murray, Gardening Correspondent to the Evening Herald gave a slide show and talk at the Bush Hotel, Carrick-on-Shannon on the 30th March 1993. Terry's talk was informative, interesting and entertaining. It was a special treat for the gardening enthusiasts of the area and encouraged the less than eager to take up their spades. A total of £375 was raised.

During the course of his work Ronan O'Conghaile gives lectures on Landscaping and Gardening. Ronan does not charge a fee but asks for a donation to a charity. This year he raised a total of £140 for S.O.F.T. Our special thanks to Terry and Ronan.

Cycle Races

As previously mentioned, Dessie and Joan Boylan with the help of their relatives and friends organised two cycle races in the North-east. These cycle races have turned out to be marvellous family days. The co-operation and enthusiasm of the locals knows no bounds. Dessie and Joan have the support and good-will of their community. We thank them for making public their story with Emma. Their generosity has supported and will support the families of babies born with Patau's Syndrome, Edwards' Syndrome and related disorders. The organisation, planning and efficiency of the races were second to none. Dessie has achieved such a level of expertise that we have nominated him unanimously "Fundraising Co-ordinator". Last year's race achieved the amazing total of £3,240. - donated to S.O.F.T.

Congratulations to Dessie and Joan on their achievement and sincere thanks from S.O.F.T.

T-Shirts

Yellow T-Shirts with the S.O.F.T. logo - front and back - plus a cute little teddy are available from Dessie and Joan Boylan.

S.O.F.T. FAMILY FORM

A S.O.F.T. Family Form is enclosed with the Newsletter. If you have not already signed a form please do so and return to Marie O'Conghaile as soon as possible.

S.O.F.T. must have forms signed for permission to hold and circulate names and addresses - Data Protection Act.

If there are any errors on the S.O.F.T. Family List please inform Marie O'Conghaile.



S.O.F.T.

**Support Organisation For Trisomy 13/18
And Related Disorders**

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