

S.O.F.T. IRELAND

Support Organisation for Trisomy 13/18.

Letterkenny,
Co. Donegal.

21st June 1992

Hello Everyone,

This newsletter is quite a lot more substantial than our first, and includes all the happenings of a very busy S.O.F.T. organisation here in Ireland. What with parachute jump, wine tasting, coffee mornings and a table quiz there's just no stopping now.

FUNDRAISING

First up the parachute jump. This was the brain-child of Miriam O' Connor, Ardcarne, Boyle, Co. Roscommon and what a success it proved. Miriam has known Aine since she was born and when she learned of

pending parachute jump. Eleven people finally jumped each having to raise a minimum of £200.00. Sponsorship cards were printed, and issued among the jumpers and members of S.O.F.T. The jump was scheduled for the 1st February at Punchstown Racecourse in Kildare. There was an intensive six hour training session and at about 4.30pm the first three jumpers were ready to take to the skies. Unfortunately only the 1st three had jumped when the jump was called off due to poor visibility. We all retired for hot drinks and champagne and arranged to meet back early on Sunday morning. Sunday however was too windy and the jump was postponed to a later date. On the 16th February Miriam did the Tandem from 1100 feet!! The jumpers were;

Miriam O Connor

Joey O'Connor

Ronan O'Conghaile

Denise Kelly

Fiona Neil

Ben Conlon

Ken O'Connor

Gerry King

Pat King

Mark Shields

Liam Kelly

The parachute jump realised in excess of £6,000. I am sure you'll all agree that it was quite a considerable amount. Well done Miriam and Thanks from all of us in S.O.F.T. Ireland.

Both Marie O'Conghaile and Noel and Sheila Mc Manaly organised coffee mornings. Marie raised £140 from her coffee morning and Noel and Sheila raised £170 from theirs. Ronan O'Conghaile had a wine tasting

evening and it raised £170. What a nice way of raising money!!

Here in Letterkenny I organised a Table Quiz. It involved quite a lot of work but the results were worth it. I wrote to most of the large business in the town and explained about S.O.F.T. Ireland when I rang them back needless to say none of them even heard of Trimsomy 13 and 18 but were still willing to offer support in return for my personnel story. The Table Quiz was a great success, in all 33 tables of 4 participated and it realised in excess of £750.

Details of all funds raised for S.O.F.T. Ireland are as follows:

	£
1. Coffee Morning	140.00
2. Card Game & Raffle.	360.00
3. Wine Tasting	170.00
4. Donation from Patricia Kelly and friend	100.00
5. Collection at Christmas in Mary Mount College for the mentally handicapped. (£160 - £100 to Cregg House and to S.O.F.T. Ireland)	60.00
6. Grainne O'Hara collected from Table Quiz	500.00
7. Ben Conlon - Parachutist	650.00
8. Table Quiz and Raffle organised in association with Parachute Jump	200.00
9. Parachute June	6,000.00
10. Noel & Sheila School Coffee Morning	200.00

At this stage S.O.F.T. Ireland are financially self sufficient and have sent a small donation to S.O.F.T. U.K. in recognition of their support and encouragement in the beginning.

A radio interview before the Table Quiz on the local station made

contact with Geraldine McBrearty from Strabane. Geraldine is the mother of Killian who has both Trisomy 13 and 18, we all look forward to meeting Geraldine and Killian in the future.

J O H N O ' D O N O H O E B R E A V E M E N T

Our last meeting in May was attend by John O'Dohohoe who was our guest speaker. I am sure by now that everyone has received a copy of his talk. For myself there was one paragraph which summed it up.

"The only way to bring about change in your grief is through expression. Hence express yourself in any way you feel you can. Whether by talking, or writing it all down, or painting, or through meditating your feelings in sport, or gardening or whatever."

Some of the talk is pretty heavy going but believe me if you can get a quiet hour with no fear of interruption it's well worth the read. On behalf of all who attended the last meeting, Thank You John. I think I speak for everyone when I say it was very interesting!

I should say at this stage that John O'Donohue is available at (0905) 42117 (Ballinsloe) if anyone wants a chat.

S.O.F.T. U.K. C O N F E R E N C E

This year the conference was held in Brimingham on the 13th June in the Grand Hotel. Marie, Bernadette and myself attended. I must say

that having attended the conference for the first time that I can understand how Marie felt the determination to form the Irish branch. Needless to say some of the speakers had a greater impact than others but as Bernadette said our own stories were told in different ways so many times.

After Jenny Robbins and Christine Rose opened the meeting, members of S.O.F.T. U.K. spoke of their personal experiences and their subsequent involvement with S.O.F.T. Sylvia Hanley spoke of her son Alistar, while he enjoyed himself in the creche in the next room now aged 14 (T.13). Lorna Forrest spoke of her daughter Hannah aged 5 (Partial T.13) while she ran around entertaining everyone. I thought it good taste to start the day in such a hopeful way. After tea break the parent who spoke had experienced the loss of their children, I could identify with most of the speakers here as my feelings at the time of Shane's birth and subsequent death seemed to be the topic here.

After lunch Barbara Cooke Bereavement Counsellor spoke and she was followed by Dr Ian Young Consultant Clinical Geneticist, spoke on why it happens and the possibility of the reoccurrence. He explained in lay terms the division of the chromosomes and how the extra chromosome may arise during this division. I found his talk extremely interesting and could have listened to him for longer. The conference was most enjoyable it was extremely well organised and chaired. We were made feel very welcome and Marie enjoyed meeting some of the people she met last year. I gather from Marie that Jenny is willing to come to Ireland so maybe we could coincide her visit with a meeting. It's just an idea.

There were a few point from the conference that I feel might be of

interest to us here in Ireland Stamp collection and the idea of getting Christmas Cards printed. I enclose a handout from the Edmonds about the kind of stamps to send, And on the subject of Christmas Cards, I know its only June but it might be a topic for our next meeting I would suggest that we all contact larger firms in our area and look for sponsorship to get some cards printed and the profits of which would go to S.O.F.T. Ireland funds.

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Since writing the first newsletter two of our families have been bereaved. Nicola Fenlon (T.18) daughter of Larry and Cathleen and Ian Kelly (T.13 son of Kieran and Jacinta both died. We hope that the joy they brought to their families during their short lives will help them cope with their loss and sadness.

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At this stage I would like to thank Marie for her submission for the newsletter. Where she finds time to do all the things she does I have no idea. I would also ask any one who is good at putting pen to paper to write articles for the newsletter.

Apologies for the delay in getting this posted. My next newsletter will be scheduled for mid-September and hopefully there will be no postal strike at that time.

Look foward to seeing you all soon.

Kind Regards,

Anne

Anne & Noel.

From:

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STAMPS FOR SOFT UK

WHAT TO SEND:-

ALL FOREIGN STAMPS

ALL CHANNEL ISLAND STAMPS

ALL OLD PRE-DECIMAL STAMPS

ALL STAMPS 50P AND ABOVE

WHAT NOT TO SEND:-

*ANY 1ST OR 2ND CLASS BRITISH STAMPS

MANY THANKS FOR YOUR CONTRIBUTIONS SO FAR AND IN
THE FUTURE!!

(*The reason being that so many are needed to make it worthwhile
- dustbin bags full to be precise! - that it is not economical
or practical to keep sending them.)

CHARITY STATUS

It is time to decide if **S.O.F.T. (Ireland)** should register as a charity. The English charity number does not apply to Ireland. If we register as a charity donations by deed of covenant are tax deductible and we would not have to pay tax. At the moment we have to pay Deposit Interest Retention Tax (D.I.R.T.). This is approximately 27% of interest earned. Our capital remains untouched.

To register as a charity is costly. It cost S.O.F.T. U.K. approximately £600 and this was a cheap rate. I am writing to the solicitors who registered the Irish Sudden Infant Death Association (I.S.I.D.A.) as a charity - Patrick MacNamee & Co., Dublin. I hope they will give me some indication of cost. If we decide to register we will have to draft a constitution and forward it to the tax office. We would also have to furnish an audited set of accounts every year.

I would like to form a sub-committee to work on this. Anyone interested please let me know.

FUNDRAISING

Traditional Irish Night - Carlow.

S.O.F.T. (Ireland) continues to inspire others to fundraise on our behalf. A friend of Marie O'Conghaile's from Carlow - Sheila Smyth - decided to host a Traditional Irish Night during St. Patrick's weekend. Sheila informs me that it was a very enjoyable evening and they raised a total of £125. To advertise the event Sheila contacted Carlow Radio and inserted an article in the local newspaper "The Nationalist". This article gave details of S.O.F.T. (Ireland). Our thanks to Sheila and her friends for organising the event.

Oriental Night Out - Boyle

This was certainly an original occasion. Mr. Wang Tang gave a demonstration of Cantonese Cuisine using an oriental stir-fry pan. The venue was Cleo's Night Club in Boyle. Surrounded by images from Cleopatra's Egypt with wafts of delicious Chinese cooking, the ambiance had a decidedly oriental flair. This was further enhanced by an opportunity to sample the Chinese delicacies and free flowing wine.

Supervalu sponsored the occasion as they wished to publicise their new promotion - a stir-fry pan. Paul Kelly, owner of Supervalu, Boyle, contacted Miriam O'Connor. Miriam, as you all know by now, is a tireless fund-raiser on behalf of S.O.F.T. (Ireland). Paul very kindly offered to donate the proceeds of the evening to S.O.F.T. (Ireland). Admission was optional. There were no overheads or expenses. Total raised £425.

As a gesture of goodwill to the people of Boyle who have been so supportive of S.O.F.T. (Ireland), (many people have attended events 3 - 4 times on our behalf) we decided to donate half the proceeds to the new school to be built in Boyle this year by the Brothers of Charity for the Mentally Handicapped. Aine O'Conghaile attends the present school.

S.O.F.T. and the Mental Handicap Association gained a lot of publicity on the occasion with local newspaper coverage.

On both fund-raising occasions, we used the posters prepared by Jasper and Della McKinney. They were invaluable - promoting and giving details of S.O.F.T.

Woman's Way

The article outlining S.O.F.T. (Ireland) and giving Aine O'Conghaile's story is scheduled to appear at the end of May. Nora Pat Stewart - the journalist who wrote the article and Woman's Way have kindly agreed to let me use the article for "Frontline" Magazine. This is a magazine for parents and workers involved in Mental Handicap. I will contact Frontline with a view to publication after May.

Media Advertising

To date, articles on S.O.F.T. (Ireland) have appeared in the "Leitrim Observer", "Roscommon Herald", "Carlow Nationalist" and "Donegal News

and Derry People". We have had radio coverage on Carlow Radio, North West Radio and Shannonside. Shannonside has a listenership greater than R.T.E. 2. The newspapers and radio have been very useful in advertising fund-raising events. As a result of this exposure one person has contacted S.O.F.T. (Ireland).

We have to decide whether to broaden the media exposure on a nationwide level. Joy Nairn (Sligo) was the first person to suggest the idea and has a particular interest in promoting our group through the local newspapers. Bernadette has obtained a list of local papers. If anyone is interested in embarking on this as a project please let me know. Likewise for national and local radio. John Donohue (Consultant Thantalogist) suggested we contact 98 F.M. so here is your opportunity to become a household name!

BOOKLETS AND LEAFLETS

Now that we have funds I think we should print our own booklets and leaflets. Knowing the generous nature of Jenny Robbins and Christine Rose, there should be no problem if we substitute S.O.F.T. (Ireland) for S.O.F.T. (U.K.)

The leaflets in question are:

The Effect of Bereavement on Brothers and Sisters.

Reflux Vomiting.

Tube Feeding a Baby at Home.

Weaning.

Eye Defects in Children with Trisomy 13/18.

Heart Defects in Infants with Trisomy 13/18.

We need to draft a leaflet giving details of the origin of S.O.F.T. (Ireland) and the services we provide. Would anyone or group like to undertake this project? Does anyone have any ideas for a leaflet that we might print in Ireland?

Sponsorship

To minimise expense, John Donohue has suggested that we apply for sponsorship from companies such as Milupa and from hospitals. Perhaps we can consider this for our new leaflets.

Telethon are sending an application form shortly.

PEN FRIENDS

Can I remind families that it is possible to organise pen friends for children in the U.K. and U.S.A. - see leaflet on "The Effect of Bereavement on Brothers and Sisters". Our children might like to share their experiences, grief and sorrow with someone their own age.

OUR SPECIAL TRISOMY CHILDREN

We would like to wish Aine O'Conghaile (5½), Megan Doherty (4½), Maire Catherine Faulkener (4¼), Killian McBrarty (3½) and Tara Rooney (7 mths) a happy and healthy summer.

Next Meeting

Rather than depend on meetings as a means of communication, Anne has very kindly agreed to develop the newsletter. Please keep articles flowing in - your personal experiences, events, etc. We will be free to use our S.O.F.T. gathering of members - to have a speaker, informal get-together etc.