

S.O.F.T. Ireland First Newsletter



Hello Everyone,

This is our first newsletter and I hope you all enjoy it. I am rushed for time, so this edition will be short - hopefully subsequent editions will be better planned and contain more news.

Our son Shane was born on the 13th July 1988. He was diagnosed Patau's Syndrome and at the time of the birth both Noel and I thought nobody experienced Patau's Syndrome before us. The doctor told us it was a very rare chromosomal disorder and that they did not expect Shane to live more than 3 months. Shane lived for exactly 5 months. He died on the 13th January 1989. We were very frustrated at the time of Shane's birth about the lack of information on Patau's Syndrome and it was only through the grapevine that I learned of Marie's baby Aina (Marie had taught me at school but as I had moved away from home, I was not aware of Aina's birth). Noel and I went to visit Marie and Ronan to see Aina. It helped a lot and it was good to talk to someone who knew the problems we were going through.

When Marie contacted me about S.O.F.T., I was delighted to get involved - I feel if we can help families of newly diagnosed Patau's Syndrome babies it will be great.

Our first meeting was on the 13th September 1991 and our second on the 9th November 1991. All of us involved are very enthusiastic about the future of S.O.F.T. Ireland.

Our meeting on the 9th November was a great success and we elected our officers:

Chairperson -	Marie O'Conghaile
Secretary -	Bernadette Doyle
Treasurer -	Sheila McManisly

Sheila's husband Noel is going to organise the trip to the S.O.F.T. conference in 1992. He attended the conference in 1991 and really enjoyed it.

Della McKloney is going to look after the P.R.O. side of things. We decided to display posters in the nursery units of the Irish hospitals and Della agreed to design and print these posters. It is our ambition to let people know of S.O.F.T. Ireland and that from now on the families of Patau's and Edward's Syndrome babies will know they are not on their own.

We discussed ways of fundraising and everyone hopes to have some money raised before our next meeting in February.

Our good news this month is that Joy and Peter Nairn, Sligo have been blessed with twins - a boy and a girl - both babies and Mother are doing well. Joy and Peter's first baby Arleen died at birth. Arleen was diagnosed Patau's Syndrome. Joy and Peter both hope to get involved in S.O.F.T. but at the moment have their hands full.

By the way, I should have mentioned that since Shane's death Noel and I have two kids, Gareth was born on the 14th February 1990 and Lisa was born on the 13th February 1991.

Now with nothing else to write, I'll get this in the post. I look forward to being in touch for the next newsletters.

Best wishes,

Anne & Noel

Publication Notes

6th April 1992

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Enclosed is our first newsletter. The second one will be posted before our next meeting of the 16 May, and will include minutes of the last meeting in Dublin. Marie will take it that everyone has read these, and hopes the formal part of the meeting on 16th will be kept to a minimum.

At this stage I would like if people submitted articles for inclusion in the next newsletter.

This first issue is very small in comparison to the English newsletter but as you will appreciate there is full of letters from members. Please send me details of your thoughts on S.O.F.T. Ireland, details of the fundraising etc. and all will be gratefully accepted and published.

To make a real success of this newsletter I need everyone's help.

Look forward to hearing from you.

Regards Anne Boyle

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