

## Syndrome Support Group

**Providing support, information and friendship for families, carers and professionals**

When I joined the Group, back in 1994, modern technology was still in its infancy, even the internet was at its earliest stages. Families like ours formed groups because of the real need, given the rareness of the syndromes, to find support and to encourage further research.

Research still forms a major part of our work with, of course, your involvement a necessity in achieving success. However with the former, despite the estimated 1 Cri Du Chat birth in 50,000, it seems that the majority of younger families may no longer feel the need for that communal support. We are trying to find reasons why this is and it is of course possible that they gain everything they initially feel they need from the information available from our website and therefore don't feel the need to contribute to the Group?

However any successful support group requires a turnover of its membership to prevent staleness and new members provide a freshness and updated views. Consequently your committee is considering ways and means of encouraging new families to register with the Group and this may include the introduction of varying levels of membership. For instance at this time any surfer on the internet has access to all our information obtained with the help of our family base when the majority will only be looking for a brief description of the Syndrome.

We would welcome any of your views or suggestions.

Established small groups like ours are finding a voice through involvement with other charities, as shown in the current Lottery backed Three Syndrome research project, to influence outside agencies with which families have to deal. Perhaps you are having a problem where a supporting letter from the Cri Du Chat Group may prove of assistance.

Please do feel free to get in touch. Your input would be most valuable.

We look forward to hearing from you



Ray Clarke, Chairman



### **CONFERENCE 2008** **June 20/22<sup>nd</sup> at Stratford upon Avon.**

Have you forwarded your completed booking form? Don't forget closing date is 20<sup>th</sup> May, and if you will be requiring the crèche ideally we should receive your application as soon as possible. If you've mislaid the original booking form you can telephone us on 0845 094 2725 or download another from <http://www.criduchat.co.uk/conference2008/Booking%20Form.pdf>

Application forms were forwarded early March, and all our registered members should by now have received their pack. The schedule includes an update on the Lottery funded research project and Professor Chris Oliver and his team will also be conducting workshops and personal clinics. Where else do you get the opportunity to chat with professionals who have knowledge of the Cri Du Chat Syndrome? As always there is a full weekend schedule and we will also be holding the AGM.

Why don't you experience it for yourself, if only to meet in a social setting with other families involved with the Syndrome and who may also be able to offer some practical advice. The price is only £95 per delegate for the WHOLE WEEKEND, with children under 13 free.

## WHY SIGNING?

Debbie is aged 33, and back in 1975 there was little advise as to communication possibilities. Some parents were reluctant to concede that their child may not develop speech and many were slow to introduce new aids including signing.

Debbie did not get on with voice boxes and only started to learn Makaton at the age of 19 when she moved on to adult education at her new centre. Thankfully there she had an excellent teacher and within a few years it was estimated that she had learned over 500 signs. Don't get me wrong, because of her excitable nature many of the signs are not produced correctly but she certainly now has a voice.

Whilst we, her parents, have attended courses and should have a greater knowledge of Makaton regrettably we rarely sign to her because of course Debbie does understand everything we say. Isn't that what all CDC parents advocate? However the lazy lack of our use means that we have forgotten many of the signs and conversations with Debbie are often a case of "Give us a clue"

This weekend we were reminded of what Makaton means to Debbie outside of the home. She is gregarious, loves shopping trips and will always insist on a cappuccino or drinking chocolate. At Starbucks she provided her order and then we went to find a table whilst dad collected the drinks.

By the time her dad returned Debbie was deep in a signing conversation with a wheelchair-bound young man who was also severely disabled with limited speech. He was with his parents a few tables down. Throughout our short stay the two laughed and joked with each other, clearly understanding their communication. Both sets of parents were mesmerised by the interaction and grateful that the two were able to entertain themselves.

We just wish that Debbie had attained her voice much earlier, unfortunately the incidence of people with Cri Du Chat producing understandable speech is rare. Hopefully parents of all children and adults will make every effort to encourage communication, whatever form that may take, at as early a stage as possible. **Effective communication does reduce frustration and, in turn, challenging behaviour.**

At this year's conference we will be providing workshops on Makaton, in three age groups. Yet another reason for you to come along.  
**Have you booked your family's place?**

**Mandy Clarke**



*Debbie and her feathered friends*

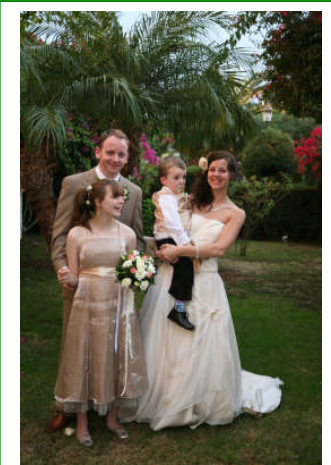
## **We love receiving light-hearted updates from our families and the following should bring a smile to all your faces**

Hi, It's Louise, Janice's mum here in dreary old Dublin. Just received your newsletter and we're all very excited about the change of venue for the conference this year, so far we're pretty sure we're going and we're contemplating driving but we'll see. Have to find Stratford-upon-Avon on a map first.

Jan made her Holy Confirmation last May, (a rather un-holy event to be honest, lots of burping, too loud singing in the church tee hee) but she was a princess for a day so she was happy, lovely day that was. She's in senior school now, as she's 14, so she's in 1<sup>st</sup> year and all that entails, namely shopping, boys, clothes and discos!! Janice goes bowling every week with her friends at school and she's actually quite good at it, she'd beat me any day! And she just loves the Wii, dab hand at that too ☺ Her little brother Sean is 4 and adores his big sis, he's well able to handle her "adorations" that's the diplomatic term for strangling the bejaysis out of him while trying to kiss/lick/eat him, you know what I mean LOL.

Myself and Anthony were married in October '06 in lovely Cyprus, we "eloped" with 40 guests ☺ had a great time. Janice was my bridesmaid, she was beautiful. Even though she wailed the entire way through the ceremony, wonder was she trying to warn us??? ☺

Jan loves Billy Connolly, always has since she was tiny, (think it's the loud over active character) We have tickets for his show here in July (over 18's but we'll try get by that little detail hahhaa) and also that the "Share a Dream Foundation" are currently doing their level best to arrange for Janice to meet Billy!!!!!!!!!!!! (it's all a surprise though as Jan would drive us mental if she knew with the whole repetitive thing. I can hear it now... "Billy coming? Billy coming? Billy coming? ... .."and so on, 100 times a minute forever and ever...



*Louise, Anthony, Janice & Sean*

We get that all day with normal mundane things like "Out in car?, Out in car? Out in car?.....".then as soon as her butt hits the car seat to go anywhere we get "home now? Home now? Home now?....."  
AAAAAAAAAAAAAAAAAGGGGGGGGGGGHHHHHHHHH!!

Ok I'm waffling away here again and it's past my bedtime. Looking forward to the conference,

**Louise Keelan**

# Letters, questions & fundraising activities

Thank you to all our members and supporters who have donated or organized events on our behalf.

Cheryl Burrige	£310	Ceilidh night
Mary Sheridan	£30	Donation
B J Stone	£110	Donation
Gemma Thornily	£50	Donation
Melksham Young Wives	£20	Donation
James Pearson	£300	Donation
Mark Rowley	£100	Donation

Don't forget that UK tax payers can now Gift Aid their donations. Please contact the office for a Gift Aid declaration form.

After our last edition we have had a good response from people **using the Amazon link from our website**, [www.easyfundraising](http://www.easyfundraising) and [www.easysearch](http://www.easysearch) but we are always looking for more. Remember this is the ideal way to raise funds for us – at no extra cost to yourself!

Easyfundraising & Easysearch	£138.58
Amazon	£87.89



JustGiving is a wonderful website where those who want to do some sponsorship can register and create their own fundraising page on behalf of the CDC Support Group. Registration is easy (and free!) [www.justgiving.com/criduchat](http://www.justgiving.com/criduchat)

Or check out the progress of our marathon runners. [www.justgiving.com/criduchat/raisemoney](http://www.justgiving.com/criduchat/raisemoney)

#### TOP JUSTGIVING FUNDRAISERS

Kevin Ayres London Marathon April 2008  
£413.89 already received, £1500 pledged

The date:- 13<sup>th</sup> April 2008.

The venue:- The London Marathon.

The weather:- Typically British. It's raining, cold and windy.

The transport:- Trains are cancelled so we are having to drive into London and the traffic is awful.

Despite all these difficulties we managed to get to the start in Greenwich on time. The atmosphere was electric as thousands of hopefuls lined up to begin. All shapes and sizes were there, even a brave soul on stilts and a whole troop of Masai warriors.

Kevin was very nervous at this point, but had no reason to be as he eventually made the 26 miles in 4 hours 4 minutes. We all thought this was a pretty good effort for a first try but Kevin was disappointed. He blamed the lady on the stilts for holding him up at the start.

We didn't manage to spot him going around but met up at the finish in a nearby pub for a well earned pint (or two). The training had obviously paid off as Kevin didn't appear tired out at all. He never "hit the wall" and said he even sprinted the last bit. Fit as a butcher's dog my brother.

We are all very proud of Kevin, and so far he has raised over £1500 for the Cri Du Chat support group, and the money is still rolling in. If anyone fancies joining up for the 2009 marathon don't bother asking me, it was exhausting enough just watching them go round!!

Darren Ayres  
Dad to Evie Bowden-Ayres 3.5yrs.

We are especially pleased for Kevin who should be very pleased with his timing – this puts him in the top third of the race, a wonderful effort.

Ray Clarke

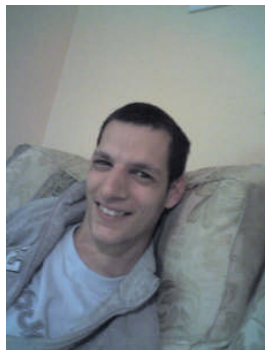
Every month the CDC office receives questions from families and professionals about Cri Du Chat Syndrome. Each question is answered quickly to ensure that we achieve our stated aim of ensuring that everyone who requests information is provided with the most up to date and accurate answer available.

Recent correspondents have been from as far afield as Chile and Switzerland and cover many different areas relating to the Syndrome.

We have also been in correspondence with the office of the Prince of Wales Trust that had received a request for help from an elderly mother coping on her own with the effects of the aging process on her Cri Du Chat daughter. The mum had no idea of the existence of the support group and was pleased to receive the subsequent telephone contact.

We are a support group and would hope that you do not hesitate to contact us if you are in need of advice or would like to make contact with other families in your area.

# Shared advice, experience & observations



Ashley Watts

After Ashley left school he spent four years at college, the first two years on a Personal Achievement Course (PAC). He found it difficult to settle in at first, as the college is very large, but soon made many friends and by the time he had finished his first two years he was able to take himself from the college bus into the lifts to the third floor where he studied, and also from the canteen. During the next two years he did a work experience course, which was college based throughout, as there was a lack of one to one support and insurance to enable Ashley to work in the community. After college there was a gap of seven months with him at home, I was hoping to employ someone through the Direct Payments Scheme, to do activities with him but couldn't find anyone suitably qualified – he needs someone kind and good humoured but “firm” or he will run rings around them. I did manage to find him a job one afternoon a week through an organization called “People First” where he worked with one to one help in our local social services office, taking round tea and sandwiches for the student/workers lunches. He also had to take a food and hygiene course, which was specially adapted for Ashley, which he passed and now has a certificate which he is very proud of! Now for three and a half days a week he attends a local day center. At first Ashley didn't want to go but after a few weeks he couldn't wait to get there. He has done car maintenance, gardening (they have their own allotment) and he has made some lovely things in pottery. For the social skills they go every week to play ten pin bowling and then have lunch out at a pub. Ashley is a very happy, sociable, and caring man who gets on with everyone. We take him once or twice a week to our local pub where he is accepted and thought highly of, He has made lots of young friends there and never sits with us – we don't see him until he wants another drink or some crisps!

Gill Watts

The lovely Mrs Mary Smith has been an avid supporter of the Group over many years, you may recall her articles during 2006 when the family took the extremely difficult decision to allow son Ian, at the age of 35, to move into a supported living situation. Mary now advises;

“My husband, Ray, and I plodding along here, with our aches and pains!

Ian is doing well and we are so fortunate to have him settled so well. He looks good and the staff seem like part of our family now. We visit 3 times a week and have trips out to the pub or have fish and chips at the coast which we all enjoy very much. Ian visits us fortnightly for lunch and he is happy to be here but always happy to go back to **his** house which makes Ray and I content. We have no regrets, it was a very very difficult decision but the right one.”

Is there ever a right time for our Cri du chat child/adult to leave home? Every parent will have their own view, emotions will run high and we will always be seeking the best ever environment. One thing that is certain is that parents themselves do get older and often find that their physical capability to continue the same level of care does diminish with age. Over the years I have taken several calls from emergency residential placings where suddenly the Cri du chat adult finds him/herself totally unprepared for the new situation and whose subsequent behaviour is difficult to contain.

Personally I would much rather know that my child is settled into a new environment that will continue after my death and applaud Mary and Ray on taking that step.

Ray Clarke

Darren Waldron writes: Our son Oliver won an award from school in Spring 2007 for effort in swimming and a 'Special Award' in Autumn 2007 term for doing well with his workboxes on a new training programme. Although the school awarded him trophies we had to give them back at the end of term so as we were so proud we had replicas made for us to keep.

**Disclaimer: The view, ideas and comments contained in this newsletter are those of the individual writers and do not necessarily represent the views of the Group**

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