

Family Fun Day

At Thames Valley Adventure Playground

The last Family Day of the outgoing millennium was held at the Thames Valley Adventure Playground in Maidenhead, Berkshire.

The event was well attended, and all those who went said that they thought it was worthwhile. You can judge for yourself what the children thought of it from the photos.

The Thames Valley Adventure Playground was a little difficult to find, and the Sunday morning car boot sale traffic only added to the difficulties, but once we arrived it was down to the business of enjoying ourselves.

The centre offers massive indoor and outdoor safe play environments, and thankfully the weather meant that the children were able to get out and enjoy it. I know my son Thomas enjoyed playing the drum set on the stage which was thoughtfully positioned well away from the main building.

Indoors there was a huge array of; play equipment, craft materials, and a PC with various interactive programs (and a variety of input devices).

Also indoors was the soft play room. This went down well with most of the kids who seemed only too willing to get on and mix. I noted that throughout the whole day there had been an absence of any antagonism between the children.

It was also a good place to get to know some of the people that you've only spoken to on the phone before, and of course, for seeing other children with Worster-Drought Syndrome.

Dolphin Human Therapy

On Friday 28th of May we set off on a journey that we hoped would not only change Rebecca's life for the better but ours as well. A very long and hard year of fundraising finally paid off. We had booked the therapy, flights, car and accommodation ourselves so things crossed it would all fall into place.

Virgin airline were very generous and helped us financially with our flight expenses, they were an excellent company to fly with, very helpful and friendly. We arrived at Miami airport after a very long flight {where to now} we thought. We had heard so many stories about Miami airport but it all fell into place, we picked the car up and off we went down and down to the keys, Key Largo to be precise.

When you are working on a budget you try to shop around, some people stayed in hotels but we opted for a condominium with two bedrooms two bathrooms and use of a pool and surrounding facilities, this gave us the freedom we were looking for, no time limits or rules just a relaxing time. We soon adjusted to the American way of life, the shops the roads and the people who were all very friendly.

Monday came very quickly and it was time to begin the therapy. We were greeted by Deena and had a discussion about all the forms and records on Rebecca. She put on her flotation belt and then we were taken down to the dock to meet our therapist – Janet. Each child is assessed and placed with a therapist to meet their individual needs. Next came the dolphin - Alphonsel and the trainer - Rudolph. There were two

sessions a day, and we had the 10:30 session. Each session had four docks with children of all nationalities and disabilities working on them, {one to a dock}. Dr David Nathanson, the man behind Dolphin Human Therapy, introduces himself to Rebecca and us and stands close by to observe the session. On the actual dock there were four people, Rebecca, Janet, Rudolph and all the time Rebecca is working on the dock every word, gesture, movement is carefully wrote down for a detailed report at the end of the therapy by an internee.

We didn't realise just how hard Rebecca would find the therapy until the first session. Janet worked her facial muscles and you could see that Rebecca could not physically do as she asked. The idea behind the therapy is to kick start the child to continue progressing. The child (Rebecca) performs the tasks and if they complete them their reward is to swim with the dolphin. It is a very strict and disciplined therapy. Rebecca had no hesitation at getting in with Alphonse. He greeted her by rubbing his nose against her foot, that greeting is known as a foot kiss, she swam round several times doing various touches and swims with Alphonse. She was very happy and very curious. As the first few days went on Rebecca relaxed and cooperated fully with Janet's every request knowing there would be a swim with Alphonse at the end of each correct task. In order to get in the water Rebecca had to attempt to say "I want in please". Well she could get "I" sort of and "please" with the help of a sign and a verbal prompt but "want in" was a lot harder, but bless her she did try so hard and as Dr Dave said "it's a start, it doesn't have to be perfect but it's there, in you go Rebecca". Each day proved beneficial. She attempted different sounds she had never said before; she laughed at Alphonse and Rudolph the trainer as she asked if Alphonse could jump over the pole (Rebecca's favourite part was to see Alphonse jump out of the water). Everyone's emotions were in full swing as each day brought a new facial expression it was fantastic. Although the rain came down several times it did not affect the therapy because the water was very warm and the air was hot, but all in all the weather was excellent, sunny and hot. Janet worked very hard trying to move Rebecca's facial muscles with the "f" sound and "b", "p", "h" all of which were nearly impossible for her, but gentle persuasion and dedication paid off. They are not perfect now but they are there.

We had several progress meetings during the therapy and Janet visited us on several occasions to play and see how Rebecca was getting on. Rebecca was working very well by the end of the second week so three weeks was beneficial as it pushed her forward that little bit more. Although the therapy is only forty minutes a day it is very intense and hard work for every one involved. We watched and videoed every session to look back on the slightest improvement and the fun that Rebecca had with her new friends. At the end of the therapy as well as a report you get a video with a back up programme to continue when you return home.

When all the therapy is over the Keys is a fantastic place to relax and enjoy some of the most beautiful scenery in the world. It has a lot to offer, you can relax in the John Pennecamp state, swim, snorkel, scuba dive and go on glass bottom boat trips to see the barrier reefs. There is Key West, which must be seen to be believed. The shopping is fantastic but the most wonderful thing is the fact that Dolphin Human Therapy is situated there.

When the three weeks therapy was over we were given a video for follow up exercises and a daily programme to work on at home also shortly afterwards we received the detailed report on Rebecca which showed everything right down to the last detail.

For further information or just to talk to somebody at Dolphin Human Therapy contact:

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Message From the Chairperson

Within the committee we have been thinking of ways to help everyone in the group find out what the best ways to help our WDS children. It certainly became very clear at the family day this year that within the group right now, there is a huge amount of experience on things, from communication aids, alternative therapies, LEA statementing to swimming with dolphins and on and on.

What we do lack as a group is a way of pooling this knowledge for others in the group to use and benefit from. Lots of ideas have been put forward as to how we could spread our knowledge, and the most obvious and simple solution is here already, the newsletter! All we need to do is to write in to the editor and say we have used a particular therapy or aid and we found it worked or didn't, our phone number or email address is If you didn't want to worry about phone calls then write a little more of your experiences or may be just talk it through with the newsletter editor and let him write it up for you. Go-on, write some thing for the newsletter right now and send it in.

The group is growing.

Just out of interest, the group has just over 70 families registered. That number has grown from less than 30 families four years ago and new families are registering almost even month. Even so Worster-Drought Syndrome is still a rare condition with most of the diagnosis carried out at Great Ormond Street Hospital in London with so far only two children diagnosed by Birmingham Children's Hospital. This of course means that the majority of known WDS children are in the south east of the country with just ones and twos in other parts of the country.

News from the National Contact

For the last six months I have been filling in for Jane who has ongoing back trouble, unfortunately she is unable to carry on, so I hope you will all join me in wishing her well, as this group would not exist without all the hard work that she has put in

The group continues to grow we have around Seventy families in touch with the group. We have also had enquiries from professionals seeking more information. I am still finding that professionals have not heard of the condition, you can help by giving our information sheets to all the agencies that are involved with your child, feel free to photocopy our leaflets but if you need further copies then please contact Karen or myself.

I also have had parents wanting information on certain issues about the syndrome these have included behaviour, signing and symbols and feeding I would like to say thanks to Simone who has helped me with answering parent's questions about tube feeding.

The WEB site is very successful and we have had e-mails from America, Pakistan and more recently from Canada. We are also getting more parents getting in touch with us through e-mail.

If you look us up on the Internet you will find we have links with Contact a Family and the Genetic Interest group. In the next month we hope to have our information on the Edinburgh Genetics Dept Web Site. Which I hope will be helpful, as we have no families in Scotland at present

In my role as National Contact I attended the GIG conference in October this was a useful meeting and I have passed on our information sheets to Geneticists in Cardiff and Edinburgh.

Andrew & Karen Hinks

Our eight year old son Thomas has mild symptoms of Worster-Drought Syndrome, we also have two other children Alex aged five and Clare, two. Thomas has quite good speech, which really developed when he started mainstream school, his understanding of concepts and organising tasks is a delayed but with the help of a support assistant in class he is coping well with lessons. For Thomas mainstream school has produced steady improvements but we were lucky that the situation has fitted with Thomas. It's a small village school (210 pupils) where his support assistant, teachers and head teacher have been very keen to help, although this is probably helped by Thomas's friendly personality.

His tip-toe walking which is a symptom of the cerebral palsy has been treated with "Botulinum toxin injections" and three weeks in plaster have had some short term results.

We noticed things were not quite right with Thomas's speech when was about a year old and at his eighteen-month check his was referred to a speech and language clinic. Two years of observation at a special needs nursery lead to him being referred to Birmingham Children's Hospital where Professor Green diagnosed him.

A stroke of luck is that we have a private boarding school only twelve miles away which specialises in children with dyslexia OK it's not the same problem but they do have specialists who are able to help with complex development delay. The Samonas sound therapy and exercises designed for Nero-development therapy do appear to have an effect.

Karen and I found getting information on Worster-Drought difficult, probably because there's so little of it available. The opportunity to talk with other families and read about their experiences has helped so we now don't feel alone with the problem.

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After 16, Whats New?

This has been recently published by the Family Fund, if you have a child who is approaching 16 this is a very useful book and it has a wealth of information on the choices and challenges that face our young people.

As a parent of a disabled child you can obtain this book free if you send an A4 stamped address envelope to;

**The Family Fund Trust
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