



## Alton Towers Weekend Words by Chris Anderson from Newcastle upon Tyne (the main man in this adventure!!)

The adventure started with families from both ends of the country converging in Derbyshire. Us (the Anderson's) from Newcastle Upon Tyne and the Cardew's from Salcombe. Cars packed full and kids asking "Are we there yet?". (bless 'em!) Tents duly pitched and conversations in full flow... then the rain started. The children were all excited to meet one another and enjoyed ball games on the large open camp field when (??!!) the sun shone.

On Saturday those who wanted to go to Alton Towers only to come back to the camp site shattered; others went roof-box banging in multi-storey car parks in Derby (new sport.. wonder if it will catch on), and others went swimming at the local leisure centre. We were honoured by the Murphy family's attendance, that is gate crashing the camp site from a nice warm dry hotel to see how the toughies were managing. It was an ideal excuse to go to the village pub on the campsite.

Sunday morning saw the weather, which had been damp on Saturday, turn truly miserable. So tents were brought down and the journeys home began. All too little time to talk.

"It's a small world" the Mitchell's turned out to know the Cardew's home town (and almost everyone in it) having frequented the Cardew's cafe. The Pitcairn posse live near Stockton (more Northerners).

The weekend served its purpose with information being passed around and shared: such as keeping hydrated to stave-off leg pains and possible salt build up in the muscles. The possibility of children with heart conditions passing out on spinning, centrifugal rides, and a better understanding of different conditions with a common cause; 22Q11 deletion. Lots of new friends were made.

One of the best things for a healthy heart is the fresh air and exercise which camping can offer. Rain helps growth and adds character... no really, it does.

Thought is already going into next year's weekend.

*The Mitchell family writes:*

Huge excitement at the prospect of camping and our first visit to Alton Towers turned to thoughts of "we must be mad" when we saw the weather forecast, confirmed on the Friday night with a deluge which made us think of those already under canvas. We



made our way to Alton Towers on the Saturday morning, fully equipped with waterproofs, put to good use on several of the "wet" rides as well as with the inclement weather!

Having met up with other members of the group at the picnic spot suggested - some who are old friends and others who we were meeting for the first time - we

> continued overleaf...



### Anthony Head - Patron of Max Appeal!!

We are delighted to announce that Anthony Head has generously agreed to become our patron! (or "Tony" to us, seeing as he's a mate now! - soo cheeky!) Almost everyone will know him through his acting career in Buffy the Vampire, Little Britain and, of course, lately as the Alien Headmaster in the fantastic new Dr Who series.

Watch this space to see how he can help out Max Appeal. Well done to Mike Hennessey for this initiative!

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set off round the park. The Alton Towers staff had been excellent in advising us what rides would be suitable for those with various medical conditions and there were plenty of rides suitable for all - as well as some that you just had to be crazy to contemplate! It was quite enough just to watch "Oblivion" - the name says it all!

Although the weather was awful, everybody had a great time even though some of the Dad's regretted having been egged on to go on some of the rides, the kids all had a lot of laughs and fun. Everybody agreed it was well worth the effort and, in particular enjoyed the opportunity of exchanging experiences later in the evening in a more relaxed environment at the excellent campsite. Thank you Chris for organising it all.

Max's final comment on it all as we left the campsite: "It was lush. This place really rocks!"



Sophie Cardew with Jonathon Anderson and Max Mitchell

similar experiences. We met Rob and Suzie, Max and Helena who as it turns out often visits Salcombe where we live. Once again, many thanks to Chris

*"It was really good. I enjoyed seeing people I'd never met and also spending time with*

*James and Jonathan (Evans, who Max has known for several years). I enjoyed the rides I was able to go on at Alton Towers. The camping was good, but very wet, but overall I really enjoyed the weekend" Max (age 14)*



*"It was better than good, it was superb. Really, really good. I liked all the wet rides and the Alton Towers people were really nice and gave us advice and told us where to go and what it would be like. The roller coaster rides were my favourite and the Skytrain was very relaxing. It was lovely to see the gardens from above. I'd like to go again. The camping was more than superb. It was really nice to see friends we knew and meeting new people. I liked Max and me having the tent to ourselves and it was funny seeing Mum and Dad squashed in the car! Even though it was rainy, there wasn't a moment when we were miserable or wanting to go home" Helena (age 11)*

*Dear all at Max Appeal*

I am just writing to express our thanks to Chris Anderson and his family for the recent camping trip to Ashborne in Derbyshire that we attended. Much fun was had by us all even though the weather wasn't very good. We felt that as a family it was very beneficial to be able to meet other families and talk about

for organising the weekend.

*From, Philip, Sarah, Sophie, Emma and Adam Cardew, Salcombe in South Devon*

*Dear all at Max Appeal*

I would like to say thank-you very much to the trustees who have agreed this and tell you that the weekend was excellent. It is lovely to meet up again with old friends and the children now have no problems enjoying each others company due to the fact that they can enjoy experiences like these together. It is really appreciated and it was extremely generous of Max Appeal to organise and help with these costs. Once again, on behalf of our family, thank-you.

*Kind regards, Lesley, Steve, Jonathan and James Evans. Bristol*

## A couple of places left for Great North Run 1st October 2006

### Events Thanks...



Many thanks to Sara Vestey in Gloucester for her donation of £160.00, Sarah organised a 'Virgin Vie' party and also gave a talk to her mother's Church Wives Group on 22q11.2 deletion.

Helena Mitchell and Lechlade Guides for their donation of £21.61 from their Mothers Day 'Pamper Evening'. Photo pamper evening

Peace Lodge, in the Provence of Bristol held their annual Treasure Hunt and raised £230 for Max Appeal, thank-you to all those who took part.

Trek Cuba, undertaken by Mike & Claire Hennessey, is still bringing in sponsorship money. £5,000 including Gift Aid was raised through this. A big thank you to all our sponsors.

Thank-you to the Wrington Luncheon Club, for their continued support; their Easter Raffles raised £33.00.

Also to Alicia Hennessey who donated some of her toys in a car boot sale and raised £24.70. Well Done Alicia!

### Dragon Boat Festival

1st October 2006 at Bristol Docks will see fun and sogginess! Would your work colleagues be up for the challenge???? We have one entrant already!! Join us!!



Crews of 16 paddlers (plus a drummer) will race in Chinese-style Dragon Boats over a 250 metre course. Crews do not need to be super fit or skilled to be successful - all that's required is teamwork and a good sense of fun!

Dragon Boat racing is steeped in mythology and has been around for many thousands of years in China. Popular legend has it that through the racing, Chinese dragons would bring rain. We hope that this will not be the case on 1st October!

The racing will be run by leading events company The Organisation who provide the boats, helms, safety equipment, life-jackets and rescue boats.

More info from Max Appeal [claire@maxappeal.org.uk](mailto:claire@maxappeal.org.uk) or

[www.funraisers.org.uk/general\\_mainlayout.asp?PageID=82&EventID=7](http://www.funraisers.org.uk/general_mainlayout.asp?PageID=82&EventID=7)

### Wills & Bequests

The Homeowners Will and Trust Services in Wolverhampton wrote to us:

"On the matter of bequests to your charity, we would be happy to collaborate with you, offering a postal will drafting service to your charity members at £50 per single will, enduring power of attorney and living will, or £90 per pair of wills, provided within the will there is a bequest to your charity, with 20% per will from those charges being donated to your charity. This will provide extra day by day revenues. The bequests will obviously bring long term benefits."

Please contact Bob Evans on 01902 850461 for more information or get in touch with Max Appeal.

### World Cup!!

By the time you read this we will probably know the BIG result! But at the time of writing England had just won their first game in what can only be described as an uninspiring manner...

But Max Appeal says: "Come on England" - pronounced "Eng-er-land, of course!! Send us your world cup piccies!



# Caitlan's Story



Caitlan and Jude

Caitlan was born on 1st August 1999, five weeks early. I was carrying extra fluid whilst pregnant and this can be an indication that something may be wrong with the baby. Nothing was detected from my regular scans.

When Caitlan was delivered by caesarean section I could hear the doctors discussing the vast amounts of additional fluid and questioning as to whether the cause of this was known. The paediatrician checked Caitlan's mouth to see why she had not been swallowing some of the fluid when I had been carrying her; this is when he found that she had a cleft palate.

I was told about the cleft when I was in the recovery room; Caitlan had been taken to the special care baby unit to see how her first feed would go. I had only held her briefly and didn't see anything wrong with her. Caitlan's cleft was on the soft palate; it looked as if the roof of her mouth had not fully developed.

Once Caitlan came back to me on the ward the doctor came to explain that on listening to her heart they had detected a murmur. We were taken to Great Ormond Street Hospital five days later where Caitlan was diagnosed with Tetralogy of Fallots.

## Shellshocked we came home.

Three weeks went by with us watching her constantly, waiting for the next "blue" spell, which wasn't even blue!! Caitlan went grey, bright red, light purple but not blue!! If you tilted her body to a different angle she would return to a semi-healthy colour!!

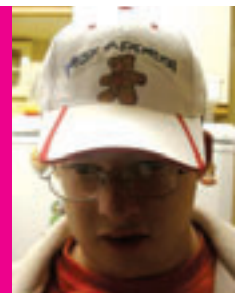
She was admitted to Frimley Park Hospital who managed to get her oxygen levels up before discharging her. Great Ormond Street phoned us a few days later with an admission date for her to have a BT shunt fitted. A week later, on the day Caitlan was supposed to be born, 4th September she was in theatre having a right BT shunt fitted.



## Hinkley Carnival

Craig Adams and family do it again!!! This time in the blistering heat!!! Second place was awarded to them (Craig's Mum says they're fed up coming first all the time anyway!!) for their outfits as pantomime ostriches... very convincing they were too... it took Archie until the evening to work out where the legs went!!

As usual the attention to detail was excellent...



Craig is wearing a hand crafted Max Appeal baseball cap!!

Weighing nearly six pounds, she was so small we were convinced she was going to die, but she came through fighting. Whilst in hospital the nurses gave her a dummy to drag out feeds and to comfort her. They explained that she shouldn't be left to cry as she would still have "blue" spells. Because of her cleft and being unable to suck Caitlan learned to sleep holding the dummy in!! In hospital Caitlan had tests to see if the heart condition and cleft palate were linked. In December we were sent to the Chelsea and Westminster Hospital to see the cleft specialist. The nurse who was giving us advice on feeding bottles let slip that Caitlan had VCFS. We told her that we hadn't been told this and she quickly backtracked on what she had said.

It was the following year that we were told that Cait had DiGeorge syndrome and she went on various tests on her kidney's etc to see how else she was affected.

We trawled through the internet terrifying ourselves with all the different defects of the syndrome. It was then that I found Max Appeal and began harassing Julie for information, guidance and support.

At our first encounter of the VCFS clinic at Chelsea and Westminster we decided that Cait had a bad heart and a cleft palate and until anything else was diagnosed we would deal with what we knew about and not keep looking for defects which she could have. From that day we decided that we would expect no less from her than we would any other child and treated her no differently to our other daughter, Jude.

At 10 months Caitlan had a repair of the Fallots, which isn't really a repair as she still needs a valve replacement. After this operation Caitlan had a lung infection and we were told that she was walking on a tight rope and that they were taking it hour by hour. This wasn't what we expected; she wasn't supposed to die now. Caitlan is a fighter and she pulled through.

## Home again until the next time.

At 19 months Caitlan had her cleft palate repaired which, again, she came through.

Caitlan is six now and over the years she has been in hospital fourteen times. Each year until she was three she was admitted because of various coughs and colds. At these times she needed oxygen support as too much strain was being put on her heart. The worst of these times was when she had pneumonia.

Touch wood, Caitlan hasn't been in hospital since 2002, she still needs her valve replaced; this will be

done when she needs it. Caitlan is always busy!! She enjoys her karate, gymnastics, swimming, Badgers and beating up her sister!!

Caitlan is in her second year of mainstream school which, at times, she finds difficult. The other children mother her as she is very small for her age (still in age 3 clothes!!), this frustrates Cait no end!!

Each visit to the hospital or GP is like a trip to the park for Cait, she doesn't know any different so she goes straight in and takes off her top, gives them her arms and fingers for blood pressure and SATS tests.

Obviously this is a shortened version of the past 6 years. We had our ups and downs; in the early years mainly downs.



There is a light at the end of the tunnel and it is possible to live a nearly normal life!! Different people deal with things in different ways, but I'm glad that we made a conscious decision to mother her or to treat her

as if she was wrapped in cotton wool. Caitlan is growing (sort of!) up showing determination, independence and real carefree attitude.

Friends say that they don't know how we cope and they couldn't do it, but when it's your child you have no option, there is no choice. It's Caitlan's life that VCFS affects now and will do forever, and if she can cope with it the way she does, then so can we. We are very proud of her and she is an inspiration to all that know her.

## Max Appeal Golf Day!



We know how you golfers are creatures of habit, so the venue remains at the ever popular Abbey Hotel Golf and Country Club in Redditch, where Gary Hawkesford gains us a member's privilege rate. Put the date in your diary: Tuesday 19th September. By the way can someone tell The Croydon boys that it's not fancy dress this year?(look at those knees!!)

## More family events:



### Spring Centre, Gloucester, Meetings

**T**HE NEXT MEETING will be on 23rd September from 1 ~ 4 p.m. PROFESSOR PETER HAMMOND has kindly agreed to talk to us about the results of his important worldwide facial imaging study into 22q11.2 deletion. Professor Hammond's study is fascinating and very visual: something that really has to be seen! He is also presenting his information at the international meetings in Strasbourg and Marseilles in July.



As usual, there will also be entertainment for the children and this time we have a Circus Skills workshop with local performer, Andy Clay, to keep everyone (adults included!) occupied! Come along and learn to juggle, spin plates (don't do this at home!), ride a unicycle and much more. If you don't think you are up to this, prepare to be amazed - Andy can teach these skills to all abilities! At the last meeting in March, all the children had loads of fun with all the new equipment bought with the generous

grant from the Rowland's Trust. This includes a brand new PlayStation 2 and TV with games (dual controls, so you can play against each other), PS2 dance mats and karaoke machine, football and more. To say nothing of all the great facilities (air hockey, table football, pool, ball pit and sensory rooms to name but a few) that the Spring Centre already has to offer.

Tea, coffee and squash are provided, but please bring something along to share for lunch (something your child will like!). Please phone Susie on 01285 712821 if you need to know more and she will also give you directions if you've not been along before.

AT THE LAST MEETING on 11th March 2006, Di Caesar, Lead Advisory Teacher for disabilities at the Special Educational Needs Support Services, Gloucestershire LEA (in other words the teacher who teaches the teachers and support staff!) kindly came to talk to us about Fine Motor Skills and 22q11.2 deletion. Di takes a broad view on Fine Motor Skills: it's not all just about threading beads and finger work (although that comes into it) and she gave an utterly fascinating talk which we all felt very privileged to hear. What she has to say applies just as much to teens and adults as to tiniest and affects everything from handwriting to concentration levels and fitness, and there is probably a rush of parents going into there children's schools as a result. If you were not able to come along, but would like notes from the meeting, please contact Susie. Thanks, too, to the Magic Alfredo who so ably entertained the children while Di was

## Reminds me of a joke... Mechanics and Surgeons

A mechanic is removing a head gasket from the engine of a Harley Davidson motorbike when he spots a well-known heart surgeon in the garage waiting for someone to look at his bike. The mechanic shouts across the garage, "Oi! Guv, can I have a word in your shell-like?" (NB we know all mechanics aren't Cockney's, but it sets the scene)

The surgeon, a bit surprised, walks over to where the bloke is working on the machine. The mechanic straightens up, wipes his hands on the proverbial oily rag and asks, "So, Doc, look at this engine. I open its heart, take out valves, repair any damage then put them back in and when I've finished it works as good as new. So how come I get peanuts and you get a big, fat wad every month when you and I are doing basically the same work?"

The surgeon pauses, then leans over and whispers to the mechanic ...

..."Try doing it with the engine running."

*ed. of course, this isn't technically correct, but the general point stands... ALSO, no reference here to Payment By Results or the new consultant contracts!*



## Pony Riding

Sunday 1st October is the date of our next Horse riding courtesy of The Camp Riding School, near Stroud, Gloucestershire meeting at 12.15 p.m. for 12.30 riding.

If you would like to come along, please contact Susie (01285 712821 or [susie@rjmitch.globalnet.co.uk](mailto:susie@rjmitch.globalnet.co.uk)) to book a place. It's very important to book via a call/message to Susie as the Riding School need to know numbers, ages, weights, etc. prior to the day. Riding is free for those with 22q11.2 deletion and siblings can also ride for a nominal fee - please see the website for more information or phone Susie.



**CONGRATULATIONS** to Joshua Pitcairns (age 14) on achieving his Black Belt in ju-jitsu.



## British Grand Prix



**NO PUBLICITY PLEASE!!!** Harrison the next driver to occupy pole position on the grid with his wheels!!!!

**H**arrison Stedman took his Dad, Bernard, to the F1 in Silverstone. The organisers upgraded Harrison to Gold tickets when Bernard pointed out that Harrison had a steel pillar in front of his reserved spot which held up the fence, as well as a horizontal rail at eye height, and on top of this the crash barriers on the circuit in front of him were above the head height for adults in wheelchairs. Just shows that it pays to speak up!!! Bernard gave them his address and mentioned that Max Appeal could offer advice as a charity!!!

The pre-race material showed that Silverstone and Bernie Ecclestone tied up with GOSH and brought a bunch of kids to the circuit. They showed how F1 arranged for GOSH's cardiac clinical intensivist to take a team to Ferrari's base at Maranello to learn about how they manage changeovers in the context of pit stops, and how the co-ordination of all the team members is made. Apparently this has all been of use to help GOSH with how they transition kids from theatre back to PICU...





*Writes Dave (Matthew's dad):*  
 "Matthew was born on 18th March 1997 in Blackburn. On the 5th day just before coming home from hospital he went into Heart failure, he was transferred to Alder Hay and at 10 days old had 6 hrs of open heart surgery to correct an interrupted aortic arch, VSD's & have Pulmonary artery banding. Tests for 22q11 deletion returned positive. At 18 months old he had 5 hrs open heart surgery to remove the pulmonary banding. Then at 4 yrs there was more surgery to repair sub-mucous cleft palate with a second cleft palate operation at 6 yrs old.

Matthew is now 9 and is a lovely placid boy (except sometimes with his 5 year old sister Holly Ha! Ha!). He loves his Golf and he goes to James Webster every Saturday morning for his lesson, he now has a really lovely swing and really enjoys the game. He also has professional drum lessons every week and is now reading music. He recently played 4 nights for the stage version of Bugsy Malone and he only had 6 weeks to learn all 8 numbers, his Mum and I are so proud of him, especially after all he has been through."

James Webster is a 27 year old Burnley born golf pro and Head Teaching Professional at Lee Golf Academy in Rishton. He was a schoolboy footballer with Queens Park Rangers and went

on to play professionally for Burnley Football Club. His sporting pedigree includes being grandson of DIV 1 Champions 1959/60 Burnley FC Manger, Harry Potts!!

**For further details contact 01254 884222.  
 E-mail [james@pjgolf.co.uk](mailto:james@pjgolf.co.uk).  
 Website [www.pjgolf.co.uk](http://www.pjgolf.co.uk)**

James says " I am delighted to be doing this sponsored day for such a great cause. Matthew is a special boy with a lot of talent and it has been a pleasure to coach him over the past 2 years. His enthusiasm for life and personality rubs off on everyone around him".

*With a tribute like that how can you not dig deep in your pockets??? You can call Max Appeal on 01384 821227.*



## Matthew Densfield - Sponsored Golf Day

Professional golfer, James Webster, will conduct a sponsored day with Matthew at Great Harwood Golf Club near Blackburn in August, playing as many holes as he can in a day starting at 7am in the morning. Sponsorship can be pledged per hole or a fixed amount.

## Sky Dive!!!



Max Appeal's first Skydiving Challenge took place on 7th June. It was a fantastically sunny day and all eight of our participants completed their challenge. A big thank-you to all our skydivers; Tina Smith, Julia Jones, Hayley and Natalie Cross, Daryl Jacobs, Chris Bailey, Tom Hemmings and Martin Oxenham.

Overall we are expecting to raise £2,500. Again, a big thank-you to all who have sponsored them. Chris and Tom's work mates from

Soundwell Service and Repair and Auto Mobile at Warmley near Bristol closed the garages for the day and came and supported them.

Thanks also to everyone who came to support our jumpers and to Hinton Skydiving Centre for ensuring they safely touched the ground.



*The nutters... sorry brave jumpers.... simulating landing... I'll bet they weren't smiling when they leapt into thin air... gulp!*

We had two additional skydivers, Maxi Bear must now hold a record for freefalling from 12,000 ft.

He landed safely with Tina, and Alicia's Hennessey's school bear, Barnaby, also completed the challenge tightly strapped to her instructor, Martin.

So if anyone would like to sponsor their efforts please send in your donations. Everyone said the experience was "out of this world" and Chris is already looking into taking a further course of lessons. If anyone else would like to fulfil a dream challenge in skydiving and raise some money for Max Appeal, please get in touch with [claire@maxappeal.org.uk](mailto:claire@maxappeal.org.uk)



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## Fundraising

Write Mike and Claire Hennessey (Max Appeal's very own comic relief!!!)

## The money keeps on rolling in!!

### The Fantastic Thurlows

We featured the Thurlow family in our last newsletter and the overwhelming and inspirational support from the whole family over the last year in memory of Blayne. Well they just can't stop! The Tot Stop Nursery in Driffield, where Blayne's mother, Beth now works, held a sale of chocolate teddies and heart shaped biscuits during Heart Awareness Week on 14th February and raised £122 and gained headlines in the local newspaper!

Blayne's brother, Lars, was ably assisted by all the staff and pupils at Driffield School, when they held a non-uniform day in memory Blayne and raised the staggering sum of £746.15. Congratulations to all involved.



### Runners

Our intrepid runner Gary Chamberlain who was featured in our last newsletter has donned a new Max Appeal vest and completed the London Marathon in an impressive time of 3 hours and 54 minutes



raising £1,100 pounds in the process and enjoying a well earned post race massage courtesy of Leukaemia Care. Many thanks to Gary and all his sponsors including staff at Fuller Peiser. Time for a rest Gary!!

Also taking part in the London Marathon for Max Appeal were Rachel Davis, Annette Whitchurch and Jacqui Perriman (Jacqui's time was 4hrs 5mins, one to beat for next year!), congratulations to all three who successfully completed the course. Their sponsorship money is still being collected in, but in total we are expecting to have raised £3,000. Well done for your efforts and a big thanks to everyone who has sponsored our runners. Extra special thanks to Jackie Rogers of Brown Bums Tanning Salon, Kingswood, Bristol!!!!

### Donation Thanks

Tony and Christine Mitchell, Stockbridge, Hants, for £60 from collections at their pop in coffee mornings.



Hannah Bostock's estate agency business based in Warrington continues to go from strength to strength, a further £400 donated, representing £ 50 for every completed sale since May last year, many thanks Hannah!

Many thanks to the Pearlgood family for their continued support and stunning donation of £150, together with the Grant family for their generous donation of £75

Thanks to Sue Burgoyne, £10 donation from the sale of birthday cards.

Thanks also to 'The 89 Circle', a group of Bristol Freemasons for their donation of £50.00, to help support the continued best practice care work for heart children.



We were successful in our application to the Children's Heart Federation for a £3,000 grant to update and improve our data base. The work on the improvements will start soon. A big thank-you to CHF for supporting this much needed work.

## Travel Tips

Bus Passes are actually for OAP's and the disabled. Get a form from your local council office, fill in your part and get your GP to do their bit!

Disabled Persons Railcard, costs £14 and gives 30% off...  
[www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk) if you have the mobility part of DLA you are probably eligible.

Out and about and need the loo? National Key Systems (or RADAR keys) can be obtained from your local council or RADAR, 12 City Forum, 250 City Road, London EC1V 8AF Tel: 020 7250 4119. The key works on all disabled toilets, so you wont have to find an attendant anymore! (source: GUCH newsletter)

## VCFSEF UK Representatives.



If you want to find out what's going on in Europe then ask the reps!

Ahmad Al-Khattat email:  
[ahmad@footpaths.fsnet.co.uk](mailto:ahmad@footpaths.fsnet.co.uk)

Julie Wootton email:  
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