



Maxi Bear Travels to Basrah

Dear all, just a little note from me and Maxi Bear. We have now been in Basrah for a couple of weeks and Maxi Bear has been doing a grand job of guarding my room whilst I'm at work. As a reward, I took Maxi Bear out this week, he came into work so that he could see what I do. Unfortunately, Maxi Bear fell asleep in a box and ended up going through the x-ray scanner but I think he is OK, he said he felt a bit worn out but he is alright now. So as a treat and also to keep an eye on him, I sat him beside me

whilst I did some scanning. Maxi Bear sends his love and will be home for Easter but he is also looking forward to spending Christmas in Baghdad. I have promised him that if he is good he might even get to see Saddam's Palace. I am not sure how the Americans are going to take to him but we will have to wait and see.

PS - A Christmas update on Maxi Bear: he is doing fine sitting beside my bed with a Christmas Hat on and a friend. As I had promised, he

even went to Saddam's Palace and sat in his special chair. Thanks for all the Christmas wishes. We have now done more than a third of our tour!

*Lots of love
Simon and Maxi Bear*



Royal Presentation at RDA's 50th Anniversary Celebrations



rising trot without bouncing once, for which he earned a round of applause from the crowd of 140 invited guests including Jane Holderness-Roddam, Chair of the RDA and former Olympic rider! HRH Princess Anne watched the displays intently and talked to Joy Munden and Sylvia Barron. Joy and Sylvia were founder members of the Kitty Barron RDA Group together with Sylvia's late husband Jo and sister-in-law Kitty after whom the Group is named. Following the dedication of a plaque commemorating the event and the blessing of a banner by the Reverend John Jessop, The Princess Royal then presented rosettes to Max as well as the other riders, she also spoke to Max and helped him attach his rosette. He was a little overcome and said afterwards that he had been quite nervous but felt very proud.

Princess Anne went on to present various awards to people involved with the RDA and Susie Mitchell (Max's Mum and Max Appeal trustee) was asked to go out with a small group to represent the groups who use the school. Being right at the end of the line, Susie thought she would merely get a handshake as it had been made clear that the Princess was on a tight schedule. You would never have known this, however, as the Princess was relaxed and unhurried, taking time with everyone, stopped and asked Susie whether Max Appeal was all about Max? This was particularly impressive as Max had been the first rider she met and the Princess could be forgiven had she not made the connection considering the number of people there! Susie had been worried that there might be confusion between Max and Max Appeal, but this turned out to give her the opportunity to tell the Princess about baby Max Wootton, the syndrome, what it was, how common it was, why she had not heard of it and what Max Appeal does and is aiming to do in the future. The Princess was very interested and asked a number of

questions before having to move on to cut a magnificent celebration cake. However, the Princess didn't get to enjoy the cake as she had to fly to Leeds that afternoon. We, though, tucked into the cake as well as a buffet lunch, a fitting finale to a great and memorable occasion. Our congratulations and thanks, as always, go to Chris and the team at The Camp for all that they do, and have done for us and others over the years.

The Camp sessions have become extremely popular and Chris has kindly agreed to making this a more regular event. We have therefore organised our next Max Appeal RDA horse riding at The Camp Riding Stables, Gloucestershire, Sunday 29th March 2009. Meet 12.15 for riding at 12.30 pm as usual. For more information and if you have not been before contact Susie on 01285 712821 or susie@maxappeal.org.uk. Riding is free, but booking is essential.

If you are interested in riding, but Gloucestershire is too far for you to travel, please also contact Susie. Max Appeal are trying to set up similar riding events in other areas of the country - Cambridgeshire is quite well advanced and there will be more news of that shortly!



Post script

Just to let you know that Maxi Bear will be back from his Tour of Duty in March, and he is now looking forward to a year of Toddles. This is set to start in April and the idea is to encourage members to raise funds and awareness by organising local toddles, walks, runs etc. You could contact your local nursery group, school, Brownie or Cub Pack, grandparents or any local community group. We can help with forms etc. and naturally Maxi Bear could join you too. You will need to get in touch and reserve him for the date you have in mind. So if you would like Maxi Bear to join you on a Toddle event, please contact claire@maxappeal.org.uk for more information.

Contact Details...

General enquiries: Julie Wootton

Email: Julie@maxappeal.org.uk

Tel/Fax: 01384 821227

Fundraising: Mike and Claire Hennessey:

Email: Claire@maxappeal.org.uk

Mike@maxappeal.org.uk

Tel: 01934 863401

Family Support: Susie Mitchell

Email: Susie@maxappeal.org.uk

Tel: 01285 713262

In writing: 15 Meriden Avenue,

Stourbridge, West Midlands, DY8 4QN

Newsletter Editor: Tina Elven

Email: editor@maxappeal.org.uk

Tel: 07932008541

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bee3 communications

Bee3 Communications Limited, Harris Business Park,
Stoke Prior, Bromsgrove, Worcestershire B60 4DJ.
t: 01527 871747 www.bee3.biz

HRH The Princess Royal, Princess Anne, came to The Camp Riding Stables on a sunny day on 14th July as part of the 50th Anniversary celebrations of the founding of the Kitty Barron Riding for the Disabled Association Group. Max Appeal have been very fortunate to benefit from regular sessions through the Group at the Stables for the past 6 of those 50 years, thanks to Helen Mansfield who first suggested Max Appeal to Chris Barron, his wife Vicky and mother Sylvia who run and organise it all.

We were very honoured to be invited to be part of these momentous celebrations and Max Mitchell (who is 16 and has been riding at every Max Appeal session) was chosen by Chris to ride on "Mouse" who is rather large and anything but a mouse!

Max did really well - with representatives from other groups who use the Kitty Barron RDA Group sessions, he did a display with Chris instructing and did a

New Issue!

Welcome to a new issue of the Max Appeal newsletter and welcome to 2009 which is full of exciting Max Appeal events. Also, a big hello from us, the Elven family, we have been landed with the huge challenge of becoming editors for this and future newsletters.

First things first, a little bit of background about us as a family and our 'interest' in 22q11. My name is Tina, my hubby is Simon and we have two children. Our daughter Kia, who is turning 10 in April, was born with a cleft palate and she was diagnosed with 22q11 at 12 months old. The hospital recommended that Simon and I were tested and it turned out that Kia's chromosome deletion was a fluke! Well, fair enough, we had our son Jayden, now 6 years, and he was indeed born without complications or the 22q11 deletion. Jayden attends year 1 in the same school as his older sister and takes part in all activities and games initiated by his idolised sister.

To summarise Kia's medical history; her palate was repaired at 4 months old and then again at 6 years as her speech was very nasal, the second repair made a tremendous impact on her clarity as she was now able to be understood by everyone. Through her first two years of life she underwent, what felt like millions,

of tests and anything else they could think of that would involve a hospital appointment. When Kia was around 2.5 years we moved to High Wycombe in Bucks and life finally became more 'normal' as all our appointments were centralised and we were allocated one paediatrician (instead of 5 different consultants). Kia has never had any heart problems, calcium deficiency, kidney issues or other conditions that would affect her health. Her issues are centred around her moderate learning difficulties, her delayed speech and comprehension as well as her social skills. Kia wore hearing aids for several years due to severe glue ear and she has been wearing glasses since she was 2.5 years. Her stature is petite and she does have the classic long tapered fingers. Kia's early diagnosis, and her assignment to a canny paediatrician in High Wycombe, led to an early application for a statement of special educational needs and Kia was able to start nursery school with 20 hours LSA support. Today Kia is in year 5 in a mainstream school and she is now supported through a full time statement (25 hours). More recently she has been diagnosed with ADHD and severe dyslexia. We are now in the process of considering where Kia should attend school when she moves into secondary education and we are currently hopeful of finding her a place in a special school as

we feel this will benefit her social and life skills among others.

As a family we lead a very active life, and the kids are attending various clubs such as gym class, swimming, football, judo and cubs (for Kia). One of the big events of the year is coming up soon, the family skiing holiday! This is something that everyone looks forward to - Kia is a real star as she has really taken to the slopes, she has in fact been found singing all the way down a mountain! Last year she and her brother insisted on going down a black diamond mogul run which they managed to do with considerably less fear than I did!

But back to the newsletter; we are hoping to bring new ideas to the table and will endeavour to make the newsletter an interesting and informative piece of reading, however, this is only possible with your regular input. We would really welcome your contribution, however big or small, to upcoming issues. Please e-mail Tina at editor@maxappeal.org.uk or call 07932 008541 if you have any ideas.

Enjoy the newsletter, Tina and Simon



Personal Story of Todd and his Success with a Guitar

We wanted to share this personal story which we came across on an American discussion forum on 22q11. It is very inspiring and it links nicely into the article about antenatal screening for congenital heart disease later in the newsletter.

"I have been coming to this site for quite a while now, I sit and read the post and my mind goes back 20 years to where many of you are now. You are overwhelmed with the diagnosis of DiGeorge, you are confused having to learn about medical terms and procedures that just months ago you never thought you would need to know. As I read I cry, I understand and yes I laugh, because my story is so like many of yours and it takes me back down memory lane. As parents we love our children unconditionally, we realize even in our fog that we are blessed to have a child, and we will do anything for them but, this does not change the fact that we are sad, that we are exhausted and at times we are literally coping minute by minute because tomorrow seems an eternity away. Our hearts break every time a new medical procedure is done, we cannot catch our breath because our hearts are racing while our precious child is

again having surgery. Yes, the days are long and brutal but so rewarding when our little one survives another day. Your post reminds me of how far my son has come and I feel driven to share his story with you, so you can dare to see a future in a way that is hard to imagine when in the midst of the battle. This is Todd's story, his past and the life he is living today. I pray it inspires you to believe that so much is possible for your child and realize that these children are unique and special, sometimes so much so that it is beyond what we, as parents, can even dream. Todd was our third child, he was expected to be pre-mature due to my past history with carrying our other two children who were both pre-mature. Todd was born 6 weeks early but weighed 6lb 12 oz. Shortly after birth Todd had breathing difficulties and was not rosy pink but more navy blue. We all assumed it was due to premature lungs, later that night we found out it was a heart defect, Pulmonary Atresia requiring immediate surgery. Todd was transferred to a hospital that could give him the care he was going to require over the next several months, only it was not several months instead it was over 700 days later that

Todd would join his siblings at home. Todd's heart defect was just one of many issues he would face. Todd could not feed, at the time contributed to his heart defect. His swallowing was so poor that at one point Todd was scheduled to have his oesophagus removed and relocated to form a fistula coming out the side of his neck to allow draining, since he choked so violently due to the dismotility. Todd was in the operating room when he started running a fever causing them to cancel the surgery. A week later Todd had a second open heart surgery, during which they found a nerve pinched and it had contributed to his swallowing issues. Thank God he still had his oesophagus. At 18 months Todd's nutrition was so poor in spite of the feeding tube that he weighed barely 9 pounds. During these first two years all we wanted to do was hear one positive thing but day after day we faced poor prognoses without really knowing why Todd had these hosts of health problems. After 2 open heart surgeries, weekly oesophageal dilations and numerous stomach surgeries we brought Todd home shortly after his third birthday. Todd came home still on a feeding tube with obvious developmental delays but to

us it was a miracle, we as a family had weathered a storm that we could never have imagined and we were still working together, my husband and I were still in love and our other two children were thriving and they loved their little brother fiercely which to this day has not changed. When Todd was nine, after numerous life threatening infections and viruses that wrecked havoc on him, he was maybe 50 lbs and so frail and in so much pain due to inflammation in his joints that he told me he felt like he was an old man, he asked what would he feel like when he was an old man....I think he said a forty year old man....LOL. We had all been so busy keeping Todd alive that we had stopped searching for the cause. Well, you know us Moms we go on a mission and go out of the way...after internet research and a Paediatrician that was as curious as we were about what Todd's actual diagnoses was, we knew it had to be a syndrome due to the host of problems and to make a long story short we came upon the DiGeorge Syndrome and the rest is history. It was discovered that Todd had a combined immune deficiency associated with DiGeorge, at the age of twelve he started IVIG which literally was the answer to our prayers. He gained weight, grew tall and the inflammation in his joints lessened greatly. This is the point where Todd will tell you he really started living. School was a struggle due to his learning disabilities and speech impediment. My husband was the high school football coach always having successful years yet Todd could only watch because sports were not an option for Todd. His brother was the quarterback and went on to play college baseball. My husband Wes always found ways to include Todd. Wes had played guitar since college so he introduced Todd to music, it was any type and any

instrument, it didn't matter. When Todd was nine he found a harmonica in the toy box and hearing my husband and a friend in another room playing some blues songs he started to play along. His eyes were shut and we knew he was in a place he had never been before. Song after song he would play that night, weak lungs and all, it just did not matter because as he told us, he could feel the music. Two days later my husband took him to a musical festival to let him see some live blues, his little harmonica in his pocket, while getting a great blues legends autograph he was asked to play it... to make a long story short he played later that day on stage for 55 minutes with this blues icon and we knew at that instant that Todd had found himself through music. We could not have had any idea at the time of what was in store for Todd and just what a gift he had been given. High school was not always easy for Todd, he says he spent a lot of time on the outside looking in but he did have some friends whom he is still close to today. Due to Todd's severe dyslexia he watched a lot of videos, a great learning tool for a child with DiGeorge. When he was 17 and a junior in high school he watched a Jimi Hendrix DVD and once again he was instantly playing the guitar. For you who are familiar with Jimi Hendrix know that when I say playing I mean playing the guitar as in upside down, right side up, left handed, right handed, and behind your back. Well, shortly after my husband put a band together and found a small gig for them. Less than three years later, Todd fronts the same band and not only is he the lead guitarist, he is the singer as well, funny that his speech impediment goes away while singing. Todd has recently opened for the Allman Brothers, Marshall Tucker Band, City Stages, he

has won the Blues Challenge for Alabama and went on to be in the top five in the world. He plays 4 to 5 shows a week all over the country, recently recorded an album with the legendary Johnny Sandlin. Todd has done fundraisers for The Children's Hospital of Alabama. Also, he has been featured in numerous local and national magazines and has a diverse and loyal fan base that he loves dearly. His dad retired at the age of 50 when Todd graduated High School and is now helping Todd live his dream, Todd has just turned twenty years old. Todd has inspired his brother to teach in the field of special education, just as he has inspired his doctors to believe in miracles. I tell you Todd's story, yes as a proud mom but more importantly as proof that children with DiGeorge can lead wonderfully full and creative lives all the while by educating millions of people about those with disabilities. You can visit Todd's my space music site, Todd Simpson and Mojo Child. Todd is and will continue to be an advocate for those with DiGeorge Syndrome so they too can live their dreams. As parents of a child with DiGeorge, I ask you to offer creative avenues for your child, these children have special abilities that, if tapped into, can open the pages to a wonderful journey for your child, always believe!! I have started a photo album of Todd under photos so be sure to check them out.

Much love to you all,
Ina Simpson and family"

If you would like to visit the above forum site please go to:
http://health.dir.groups.yahoo.com/group/22q_Exchange



The Amazing Muschamps by Julie Wootton

Many people reading this newsletter will have been drawn to it because someone in their family has a 22q11 deletion. In the majority of cases families have only one member with the condition but in the Muschamp family there are three!

Charlotte Muschamp is 19 years old and has been through many operations for her palate and other things. On one occasion she and her sister Katie both underwent palate surgery on the same day at Great Ormond Street! Charlotte's next challenge is to undergo more surgery to remove an extra womb, which is a very rare condition. A successful outcome of this operation will mean that Charlotte will not have to have a full hysterectomy and would retain the chance of having her own family in future. Charlotte is a bright friendly girl who has lots of friends.

Katie, her little sister, is featured here looking fabulous with her friends at prom night. Katie has a different set of problems than her big sister but last year Katie was in hospital at the same time as Charlotte again. She had to have

an MRI scan and a discussion with the surgeon about what should happen next for her uncomfortable scoliosis (an abnormal lateral curvature of the spine). Katie, also has a Chiari Malformation, which is essentially a hindbrain hernia where part of the brain at the back of the head protrudes and so is not protected by bone. This is also very rare. Katie won the Blue Peter Child of Achievement award in 1999 where she met Konnie Huq and won a trip to Lapland in the same year. Katie had her broken elbow in plaster signed by the Blue Peter team. Katie is a lively, bubbly girl with a hectic social life!

Tracey is Charlotte and Katie's mum, she also has 22q11 deletion and has had problems of her own to overcome but she still has the time to raise lots of money for a hydrotherapy pool in her home town of Scarborough. Both Charlotte and Katie have gold Blue Peter Badges for their part in the hydrotherapy pool fundraising. Tracey also does voluntary work in the local community and supports Charlotte and Katie through school, college and the

many rounds of appointments in various hospitals and clinics. Tracey is re-launching the new arthritis care branch in Scarborough and if anyone wants to get in touch please contact Max Appeal as she is happy to speak to parents, Tracey is always cheerful and despite currently going through the last stages of an unhappy divorce she manages to be the best of mums to her girls, as well keeping up a healthy social life singing on stage and taking the money at her darts club! She is truly an inspiration to us all.



Teenage Weekend, Goblin Combe Environmental Centre

Ideas for our first teenage weekend were gathered at our last Max Appeal conference in Bristol. A group of young people put forward their suggestions for an outdoor activity weekend. Tutors from the Goblin Combe Environment Centre were on hand to listen to what they would like to achieve and explain what could be offered.

After some careful planning the weekend began to take shape. It would be an opportunity to try out some new things in an outdoor environment, a chance to get together with their peers and have some fun, but at the same time have Mum or Dad on hand. The centre put together a packed weekend using the outdoors to develop new skills, work as a team, building confidence and self-esteem.

The "Centre" is set in woodlands, on the edge of the Mendip Hills. It has a new "eco friendly" residential centre, so there was plenty of room for twelve young people and their carers. Susie Mitchell warned me, teenagers eat loads so to make sure we have a well stocked larder! Everyone arrived on a Friday evening in April, from as far as Newcastle, Yorkshire, Berkshire and around the South West. There was a chance to explore the centre, have an evening meal and find out more about what was in store for the weekend. It wasn't long before everyone started to relax and various sounds from musical instruments and laughter were jamming out of the common room.

It was an early start on Saturday. Parents had breakfast in hand and soon everyone was ready for the first five hour session. After a quick ice breaker everyone was off into the woods for a morning of woodland skills, fire lighting and cooking. It was a beautiful spring morning and parents took the opportunity to walk into the nearest village, collect the morning paper and find a cafe to enjoy a coffee and 'catch up' with experiences.



After lunch we were taken by mini bus to the off road centre to try our hand at off roading in some very muddy old Land Rovers and Range Rovers. Everyone enjoyed the experience and there were plenty of screams heard as they plugged their way over rough terrain. There were a few instances of getting stuck and having to be pulled out of a ditch. After all the excitement of the off roading there was even the chance to feed some baby lambs before heading back to the centre for the evening activities.

Our young people were organising the evening meal. They worked together to light the camp fire and get the barbeque going and then they cooked an array of food for everyone. It was quite a task, but everyone helped out and soon we were enjoying some fabulous burgers, salads and cooked bananas with melted chocolate, not forgetting toasted marshmallows.

The last activity of the day was to go on a night hike through the woods just using the light of the moon. Everyone stepped up to the challenge and soon there was a long line of us feeling our way along some well trodden paths. There was still some energy left for more music and chatting before getting some sleep before the next day's tasks.

Not quite as early a start on Sunday, but there was another five hour session planned of walking and cooking in the woods. Each time the tutors increased the challenge and by the end of the weekend everyone could clearly see when they set their goal they really could achieve lots of things and certainly more than they imagined.

Everyone took away some very important lessons and great relationships were built and renewed. Everyone agreed they'd had a fantastic time and would love to do it again.

Thanks to all those who helped make the weekend happen. We are very grateful to Berkshire Community Foundation for their support and donation.

By Claire Hennessey

Katie Muschamp shares her experiences at the Teenagers Weekend Trip

Max Appeal had a teenagers weekend camping trip it started the Friday 25th April till the Sunday 27th April. It was totally amazing we had a chance to meet new friends who have the same 22q11 syndrome as you. There was about 7 or 8 of us it was a good weekend there was a night walk into the woods both adults and teenagers when together and there very 123 Steep Steps to walk down and back up to the cabin which was called The Goblincombe. We also went to 4x4 (rally driving, ed) now that was really cool. The weather was good the Saturday 26th we had an BQQ for tea. We also celebrated somebody birthday. While the teenagres was in the woods they build a shelters on the trees by using long branches and using some string we got split up into 3 teams. Also in the woods everybody had to pick up some small pieces of wood to build a fire. While the teenages was in the woods the alults was doing something different to the teenagers. Also with the teenagers they had to help out with their dinner. We had toasted marshmallow. The cabin which we stayed in was lovely.

By Katie Muschamp



Max Appeal's Second Young People's Weekend

Following on from the success of our get together in Somerset, which was so much fun last year, we are organising a second weekend as promised. The dates are 3rd - 5th July 2009 at the South Cerney Outdoor Education Centre (www.southcerneyoutdoor.co.uk) in Gloucestershire's Cotswold Water Park. Based on water sports (but not entirely!) the weekend promises to be lots of fun and will be free to Max Appeal members, with a £25 deposit refunded at the event. More information will be sent to you shortly, but if you are interested in coming along and are aged between secondary school year 7 and your early 20's, please phone Susie on 01285 712821 or email susie@maxappeal.org.uk to provisionally reserve a place. Places will need to be booked by the end of April.

By the way!

Congratulations from all of us at Max Appeal to Katie Muschamp on her GCSE successes in Design and Technology, Food Technology, Child Development, English, Mathematics, Religious Studies, Science and Additional Science Grade.

Attendance at the Annual BCCA Meeting

On November 19th and 20th Max Appeal had a stand, manned by Julie (Chairperson of Max Appeal) and myself (Hilary a Trustee) at the British Congenital Cardiac Association meeting.

The charity stands were given places within the main hall which not only gave us the chance to listen to all the talks but also to spread the word about Max Appeal to newcomers as well as to greet old friends. The official delegates were mainly surgeons and cardiac nurses and speakers came from the UK and the USA.

The program covered the treatment of some of the major neonatal and infant surgery but also discussed issues about the quality of life after surgery and the organisation of services for adult patients. The latter are usually know as GUCHes from the abbreviation Grown Up Congenital Heart.

As the 22q11 children are growing to adulthood the provision of services for the GUCHes will be very important and the chairman of the GUCH Patient support group, Michael Cumper, gave a presentation outlining what the patients would like to see. Recently he had talked to representatives from the House of Commons making the case for improvements.

Over the last 30 years the number of children born with congenital heart failure has remained

constant but the survival has improved dramatically. As more children reach adolescence and ultimately adulthood other difficulties are emerging such as cognitive and behavioural problems. Young people are often happy to discuss problems about their heart with the consultant but do not see lifestyle issues as being part of cardiac specialist's remit. Many surveys have been carried out concerning the quality of life experienced by teenagers but only one out of seventy actually asked the opinion of patients instead of parents, health care professionals and teachers.

It was evident that the patients perceived more problems than those not actually living with the condition and it is clear that support is needed for young people as they perceive life style problems unsuspected by others. An annual check on both the heart and general health is recommended throughout life for GUCHes.

The skill of the surgeons in carrying out surgery on newborn children was impressive. Several of the presentations discussed the best timing for carrying out a complete repair of major defects rather than carrying out a temporary procedure until the child is a few months old. However further surgery may be needed several years later as the child could outgrow even a 'complete' repair.

Opinion seems to be favouring the former option as corrective cardiac surgery can be carried out successfully even on very underweight babies. Achieving good circulation as soon as possible prevents some pre-operative complications from developing and makes other problems easier to combat if and when they occur.

It is clear that the national database needs a complete rethink as at present the data records only the procedures carried out without taking into account other complicating factors such as 22q11 deletion. It is hoped that the full diagnosis will be the key factor in a new database.

Severe cardiac problems may be detected before birth and if routine scans pick up abnormalities further tests may be carried out but a clear cut diagnosis with well known risk factors is not always possible. Please note that these so-called 'grey areas' are not necessarily in the surgeon's brain! Research is being carried out on the feasibility of operating on the unborn child but much more work needs to be done before such procedures will be feasible.

Bryony Hannam tells us about the Teenager's Weekend

Day 1 When we got to the Goblin Coombe we were greeted by the organisers of the trip and various other people. It felt a bit awkward at first, because you didn't know anyone, but the organisers got us to do some team building activities on a log. We had great fun because when we tried to get in order, we did it with great difficulty and kept falling off the log. When we got everything sorted we went down into the woods. Whilst we were walking we learned a bit more about the woodland and we did some more team building activities e.g. making a tepee, making a campfire, cooking food on it and having fun contests.

Day 2 We went down to the valley, walked until we got to the stop. We heard an ancient story and then we did loads more other activities. When it was getting dark we turned on the torches and went for a night walk. It was really fun because we kept falling over.

I had a great time and made new friends. I'd like to thank all the staff and organisers that took part on this trip. I'd love to do it again!!



Sherwood Forest Weekend by the Anderson Family

Back in June we had a fantastic weekend in the Sherwood Forest with 17 people participating. Luckily the weather held until we were walking back to the cars on the Sunday and it was pleasantly warm, in fact our son Jonathon had to have after-sun cream on the back of his neck on Sunday night. Maybe this could have been avoided if he had not sulked with his head down "you always want to go walking and then add a bit on!" while we were walking around Rufford Park. Well, to be truthful he was right! On Saturday we walked from the campsite to the Major Oak ('Robin Hoods Tree'). Here, by chance, we came across a magnificent folly - a house built as an archway overlooking the once central boulevard and the Centre Tree in Sherwood forest (before the forest overtook the view). We stopped for lunch before a game of tag-ball en route. The DiGeorge children needed encouragement and a distraction during the walk, but the parents all knew their traits. I felt sorry for Bradley who did not complain but by the end of the day his leg pains were making him limp slightly - but not enough to stop him playing football etc that evening! - brave lad. It became apparent that most children had exhibited the same need to remove their shoes and socks immediately they get home or indeed more often! Walking is an effort, a discomfort and is boring for them but at the visitor centre spirits were lifted by Coke, ice cream, bows and arrows - and the fact that they could take the bus for a large part of the way back!

It was nice to find that Caroline and Simon's son Daniel, who held everyone's hand on the walks, was diagnosed pre-birth. The detection of a heart defect led to the results of an earlier Amniocentesis being checked and helped the

diagnosis. Early diagnosis helps prepare families and assists the professionals resolve issues more effectively. It certainly pigeonholed Jonathon's problems.



Bradley's grandma, Clare, who does not drive, managed to get down from Whitby and spent the weekend in a tiny two-person tent with Bradley. She has helped start a local support group for children with no visible conditions such as DiGeorge, autism, general learning difficulties etc. Clearly, this is a wide spectrum and it sounds as though a lot of cross pollination of ideas and methods will evolve. We wish them every success. If you are interested in speaking to Clare, you are welcome to contact her on 01947 600 938 or send her a mail at plev17@hotmail.com.

One of the great benefits of going along to this type of event is the informal chats that you have with other parents who can pass on their experience. For instance, we knew that DiGeorge children are not the most creative, struggle with comprehension and prefer things that have only one specific answer (as you would get in Maths) with problem solving being a common difficulty. We learnt from Andrew and Helen, however, that Algebra presents a problem because they cannot relate to the concept of $2x + 2y$. So whilst we thought

maths would be a little more straight-forward we now know to expect problems. I only hope trigonometry is more comprehensible. Doubt it, what will Jonathon make of Sin, Tan & Cos in the coming years? (Immortality, brown skin and be'cause.)

I enjoy these weekends which are healthy, friendly and informative. We are planning another camping weekend at Poole Bridge, Ullswater, Lake District for the weekend starting Friday 26th June 2009. Please check out www.parkfootullswater.co.uk. Families will have to book their pitches individually and you should BOOK EARLY. The Shop Field has electric hook ups and a triangular area in the middle without hook ups for tents only. It is relatively easy to get to it from the M6 at the North East side of the Lake District. You can also check out Park Foot website for local activities and other accommodation. We would like to do a little walk and have a picnic on the Saturday. Please contact me, Chris Anderson, if you want to attend or if you have any queries on either phone 01661 854264, mobile 07909 553 924 or you can e-mail on andersonheddon@btinternet.com.

What characters the kids are, how similar they all are.

Regards, Chris, Lynne, Jonathon and Amy



Alton Towers as told by Tracey Hennighan

Wow we had a fantastic time. We arrived at 2.00pm and had a late lunch at the Splash hotel bar. We were watching the people in the water park and then decided to join them, it is the best water park we have ever been to! We went to the hotel to book in and meet everyone at 4pm and we then visited the reindeer and Santa in his grotto. The children loved the decorations as well as the pond and the stepping stones. They all got a gift from Santa and we had a lovely photo taken. We went to our room to get ready for dinner which was at 6'o' clock. We meet Hannah and An Durrant, unfortunately, The Picters were poorly so we did not actually meet them. At the end of dinner, the children were all given gift bags and we set off to explore the two hotels. Unfortunately, Cerys walked into a post, too busy looking at the pool, so we had to get a medic and some ice..... Ryan saw a bit of the magic show and the carol singers. After a busy day, we went to our room and settled for the night as everyone was tired. We woke up and had breakfast at 8.30 although Cerys didn't eat until 10.30 because she was still tired! We packed the car and went to explore the hotels and garden, and also went swimming again. We had a snack and played crazy golf which was fun. At the end, we had a drink and left for home but both children wished they could have stayed longer. We had a late lunch at Frankie and Bennys in the nearby town and then went home, both kids fell asleep in the car!

Thank you Max Appeal, we had a lovely time.



Staffordshire Meet Up - Saturday 12th July 2008 by Sharon Hunt

As you are all aware Max Appeal have held a conference in the winter each year. We therefore decided to take advantage of the stunning surroundings we are lucky enough to live in, and to offer a summer alternative to families, where parents could have the opportunity to just meet and chat while the children were suitably entertained outdoors, weather permitting.

Set in rural Staffordshire (half an hour from the M1 and M6) Blithfield Reservoir provides a stunning visual aspect in a particularly picturesque landscape. The reservoir has become a haven for wildlife, particularly birds, a fact that was recognised in 1988 when the reservoir and most of its surrounding woodland was designated as a Site of Special Scientific Interest (SSSI). Situated in this charming, broadleaved woodland Blithfield Education Centre offers opportunities to learn all about water and the environment and children can take part in a range of activities including pond dipping, hunting for mini-beasts, nature trails and bird watching.

Although not warm, the weather did stay dry and the children had a good time riding bikes, playing football and walking in the woods and by the reservoir. Hopefully for those families that made the journey the day was a chance to meet other families, chat and discuss all the issues that so many of our families face, in a relaxed and informal atmosphere.

For more information on the area please look at the following links
<http://www.south-staffs-water.co.uk/community/blithfield.asp> and
www.blithfieldeducationcentre.co.uk



GUCH Patients Association Conference

As this year's conference was held in Bristol I decided to go along to see what useful tips I could pick up.

GUCH is a charity supporting adults with congenital heart disease. There were a number of speakers from the Bristol Congenital Heart Unit, who were specialists in treating children and adults born with a heart defect. Dr Graham Stuart talked about living happy and healthy lives, he will reproduce the key points of his talk

for us which we are hoping to put in a later newsletter. Dr Mike Turner discussed interventional techniques, as alternatives to open heart surgery and Dr Stephanie Curtis discussed pregnancy and contraception for GUCH's.

GUCH organise lots of social activities for adults with CHD, as well as providing a wealth of information. Check out their website www.guch.org.uk for example anyone thinking

about specific careers may find the 'Into Series' a useful source of information. These are guides for disabled people thinking about specific careers. They include information about qualifications, entry routes and fitness to practice regulations, as well as profiles written by disabled people already training or working in these professions. Also, it may be worth checking out www.skill.org.uk/shop/shop.asp for the online bookshop.

Claire Hennessey

Antenatal Screening for Congenital Heart Disease

I'm sure that aspects of **Todd's Personal Story and his Success with a Guitar** earlier in this newsletter will be familiar to many of you. One of the things that stands out, however, is the time that it took for a diagnosis of both Todd's congenital heart disease and his underlying 22q11 deletion. Early diagnosis in both of these areas is key in getting swift and effective intervention. Todd's story starts 20 years ago and naturally we would all hope that experience and protocol would make the chances of early diagnosis much better today.

A recent study promoted by Tiny Tickers (the charity for infants born with congenital heart defects), however, shows that this is not always the case. The study, by the Royal College of Obstetricians and Gynaecologists highlights the fact that the current UK-wide screening for congenital heart disease misses around 70% of all babies born with CHD and, worryingly, there is

widespread postcode inequality. The study further showed that serious and life-threatening defects were missed as often as less serious ones. More effective antenatal screening would result in earlier diagnosis and this would bring significant benefits including:-

- Allowing parents to be informed and supported by relevant agencies
- Permitting the birth to be planned with a view to availability of appropriate services for the baby
- Allowing early intervention giving improved quality of life and a reduction in the time spent in hospital

The study advocates six recommendations for improvement in antenatal screening:-

1. Standardised Training and Accreditation for all health professionals, using a systematic approach to screening and diagnosis.
2. Hospital screening protocols and practice should reflect this standardised training and

support sonographers to screen the fetal heart to a higher standard.

3. Standard referral protocols need to be developed for referral of suspected cases of CHD to know how and when to refer and give screeners a sense of ownership.
4. Local 'gatekeepers': Sonographers may refer to local obstetric/radiology 'gatekeepers' to identify false positives.
5. Diagnostic Specialists: Referral on to a centre for diagnosis should be timely and effective, with accredited specialists.
6. Closing the audit loop. Continual improvement through on-going analysis of reports and audits.

If you are interested in knowing more, the full article from Tiny Tickers has been posted under 'news' on the Max Appeal website.



Dyslexia – Is this finally the right program for you!

If your child has delayed literacy skills or indeed been diagnosed with dyslexia this method may be able to offer a helping hand. I have been involved in teaching this computer program to a number of children, including my own daughter, since the beginning of the summer. I have also been running a pilot project in our school teaching 9 children on a weekly basis for the past 6 months. The changes I have seen in the children are quite drastic both with regard to literacy skills but more importantly in respect of increased confidence. Some of 'my' children have increased their 'spelling age' by over a year in just 26 private lessons. My own daughter, who has severe dyslexia and moderate learning difficulties, has increased her spelling age by 10 months in 25 lessons (2 lessons per week). The best result I have seen is with a child in the school pilot project who has had one lesson at school as well as one lesson privately. Her spelling ability in the span of 30 lessons has increased by 1 year and 4 months. I worked with this child all last year

for two hours per week on programmes recommended by the school and she never progressed beyond 3 letter words. Wow, what a success!

Please find a short summary about the IDL program below but I urge you to look at IDL System's website for more detailed information. Should you be interested, please contact CENTRA (IDL System) directly to find a tutor in your area as this program is only available through private tuition. However, there are now options for schools to purchase the license so if you can convince your school to invest in a great product, this may just be the one. Naturally, as with any structured programme there are no guarantees but I have been pleasantly surprised and feel very encouraged that I am finally able to help a range of children who have exhausted various avenues in the past with no success.

The Search for the Gold Standard Test is Underway!

Ideally a test for 22q11 deletion will be non-invasive, 100% accurate and suitable for use as soon as a pregnancy has been confirmed. Taking a sample of blood from the mother would be so easy but life is not always that straightforward.

New technology for non-invasive pre-natal testing for genetic diseases is advancing rapidly but not all tests are suitable for a chromosome deletion as opposed to someone passing on a 'bad' gene.

Non-invasive testing has been around for years. Many people going for an ultra sound scan forget that the main purpose is to check for abnormalities and not simply provide a peek at the baby and a picture to show friends and relations.

However the scans do have limitations and when a genetic problem is a real possibility then more accurate non-invasive testing would be much appreciated.

In order to carry out a FISH test a whole cell has to be used. The invasive methods currently used to obtain cells for testing carries a 1:100 risk of causing a miscarriage and every couple has to make a decision by weighing up the risk of losing a healthy child versus bringing a disabled child into the world. Although maternal blood does carry some foetal cells these can persist for years after birth isolating these will not be helpful.

Tests can be run for some diseases by sampling the mother's blood and examining the tiny amount of free foetal DNA (ffDNA) that can be isolated. Unfortunately this method cannot be used for testing for deletion syndromes.

What option is available for couples with a known 22q11 deletion?

Pre-implantation testing is suitable for checking for chromosome deletions but the procedures involved are not simple.

First the mother has her ovaries 'turned off' with a hormone injection and then kick started by a dose of follicle stimulating hormone (FSH). This aims to ripen a clutch of eggs at the same time to allow collection of about 12 eggs. These are then fertilized by the father's sperm and incubated. By the

third day the cells have increased to an 8 cell embryo and a single cell can be removed for a FISH test from each embryo. Only embryos without the deletion will be used for implantation or freezing for a future pregnancy. Thankfully if implantation of the embryo is successful ante-natal care can usually proceed as usual. This is a rare instance of where life is easier for those with 22q11 as there is no 'carrier' state and future inheritance of a defective gene to be considered.

What options may be available in the future?

Hopefully with the huge advances in genetics a test using ffDNA can be developed by searching for a gene that should normally be present on both chromosomes. Trisomies can be detected by finding increased signals so it would be good to speculate that deletion syndromes could be confirmed by a decreased signal.

The IDL Concept

"The IDL System was devised some 20 years ago by a group of software engineers working with the Starcross Educational Research Association. The company is dedicated to combating the problems associated with dyslexia in both children and adults and has significantly invested in the technology that supports the IDL system.

It is important to emphasise that our role in helping people with reading and spelling difficulties is not in the diagnosis of dyslexia. However, we do carry out an initial assessment, using standard tests to, among others, establish a student's reading and spelling ability, indicating a suitable starting point within the IDL system.

IDL stands for Indirect Dyslexia Learning and

is a simple enjoyable and highly successful method of alleviating the symptoms associated with dyslexia. The IDL system contains nearly 1000 lessons and has helped thousands of students with great success.

The IDL system is a specialised computer program that is based on the principle known as connectionism and incorporates a multi-sensory approach involving sight, hearing, touch and speech. Although the rate of learning for each individual student can vary, the improvement they achieve using the IDL system will be permanent.

The IDL system is based on students learning, very quickly, how to use the talking computers, and then working their way through a series of gently graded touch-typing

lessons that involve reading and spelling. In this way, students strengthen the relevant connections within their brain, helping them overcome their difficulties.

Emphasis of the IDL system is very much on a student learning from the computer, rather than the computer teaching them. In this way a student always feels in control of the situation and is able to progress at a comfortable rate, without being under any form of pressure. While the programme is primarily computer based, there is always a tutor on hand and the tutor reinforces the learning through white board work and various exercises towards the end of the one-hour lesson.

The Benefits of the IDL Program:

- 1 It is computer based—no books are required
- 1 It is suitable for both children and adults.
- 1 It is a simple, yet effective, program to follow.
- 1 It is a learning system, not a teaching one.
- 1 It is tailored to each individual student.
- 1 It allows students to work at their own pace, without any pressure.
- 1 It gives only positive encouragement to students.
- 1 It requires no extra work to be done in between lessons.
- 1 It monitors and assesses progress regularly".

Please check out their website: www.idlssystem.co.uk or www.centra.org.uk for school solutions. Recommended, tested and proven by Tina Elven ©

Fundraising Events

A huge thank you to everyone who has supported Max Appeal with fundraising during the last year, all of your efforts make a big difference and they all help to generate much needed funds. We are lucky to have so many enthusiastic supporters.

You can help in so many ways big or small and you can contact us for advice and support, we will make every effort to help. Check out fundraising on our website for ideas and remember to use the online tools available to let your supporters know about your efforts and it also makes the collection of monies so much easier.

There is a range of challenges available both UK based or abroad. Did you read about Louis Stafford's experience of climbing Kilimanjaro? Each of these trips offers a truly unforgettable experience and a challenge of a lifetime whilst giving you the opportunity to support Max Appeal. We have partnered with some organisations that have a lot of experience in delivering successful events. They offer a vast array of challenges, but if you can't find the one for you just contact claire@maxappeal.org.uk and she will see if she can put you in touch with the right organisation.



Kilimanjaro Trek as written by Louis Stafford

The first couple of days of the trek were very enjoyable, one day trekking through the dense jungle and the second through forest and moor land and I didn't suffer any hardship regarding physical fitness or mental. It was around day three when we climbed the 'Barranco Wall' at 6am. This is a steep wall about 200 metres high which requires scrambling using hands and feet. Again, physically I was fine but as we approached 4000 mtr I was suffering from headaches and I began popping the pills. Lunch was spent head down and very unsociable by most people!

We then negotiated a steep incline and a large valley over scree to arrive at camp (4600 mtr) at 5pm, almost as high as Mont Blanc. I was feeling pretty weak and had a thumping headache so went straight to bed and missed any opportunity to eat, not that I had much of an appetite! I slept in all my clothes including boots and gaiters. Wake up call at 12 midnight and most people were up ready to give the summit a try. About 3 people didn't attempt due to altitude sickness.



We would walk the 7 km in single file with a porter between every other person. They would make sure you were OK and fit so that you could carry on. The first couple of hours went OK, I was singing in my head most of the time until I hit a point where I thought to myself 'don't kid yourself into thinking everything is fine!' All I could do was think about how hard it was to put one foot in front of the other and how my headache would not stop thumping. I would often fall asleep walking to wake up a few seconds later pleased I hadn't fallen over!

I had pretty much walked 5 hours without talking to anyone, my water had frozen in my camelback and I was searching for excuses to quit in my head. I am still walking behind my friend Joe, he stopped and noticed the red sunrise behind us. The sunrise gave us the energy to go on another half an hour to reach 'Stella Point', the top of the mountain but not technically the peak. We scrambled up, what seemed like a massive sand dune, and finally made up a small gradient. We had walked 7 km in 7 hours, how lame does that sound! But we had also climbed over 1km in altitude.

I think 19 people made the summit out of our group of 30. The remainder was all downhill.....in a good way! And it's true, I do have 'the bug', I now have the 7 Summits in my sight, that is the highest 7 summits in 7 continents. I have done 1 out of 6 so far - so watch this space!

Offa's Dyke from Mold to Chirk

One afternoon after returning from a long journey I nodded off in an armchair to be woken by the telephone. A voice said "your search is over we can help, this is Peter from the Max Appeal, you recently registered your son with us". This was the start of a happy association where I found real help for my son of 21 years who has been suffering mental illness for the last three years, complicated by having learning difficulties. His self-esteem was always delicate but now it was heart breaking to see him suffer yet again. The heart specialist had asked the psychiatrist to do a genetics test as all the symptoms might be connected, this is the first time we had ever heard of the DiGeorge syndrome. The test was conclusive and explained to Rhys and us why all these things were happening to him. I asked the voice on the phone if he was an angel from heaven. Before dropping off to sleep, my last thought had been that Rhys needed my help but I didn't know how to make him better, what could I do to change things for him and get the best help? The voice on the phone said "Professor Kerian Murphy is visiting tomorrow, he is working on a paper on the DiGeorge

Syndrome and I will ask him about your son" you must be an angel I replied. Professor Murphy was able to consult with Rhys' psychiatrist and confirm that he too had had good results with Clozaril!

A little time after this, my niece and I were going on a walk over a couple of days, something we had planned since last year but had only recently confirmed the location. We tried to persuade other family members to come along but 'maybe next time' they promised. One evening I had a brain wave perhaps we could invite our family to sponsor us and donate the money to Max Appeal. I wanted to give something back because Max Appeal had given me hope and some real help. Once the idea was agreed there was no stopping us, we happily asked family, colleagues and friends as well as anyone else we came across for donations. The outcome far exceeded my expectations, I had hoped to raise at least £100 but £544 was just great.

As for the walk, that was also a reward in itself, my niece and I loved the scenery and the

adventure, we didn't run out of conversation and our accommodation in Llandegla was magnificent and very welcoming, they even packed us off the next day with a scrumptious picnic. We completed the 26 miles and we were so happy as it was a gratifying and fulfilling adventure. At the end, we were very fit and pleased that in some small way, maybe, some of the Max Appeal children will benefit from our sponsored walk.

Thanks, Mair



Abseiling in Bristol

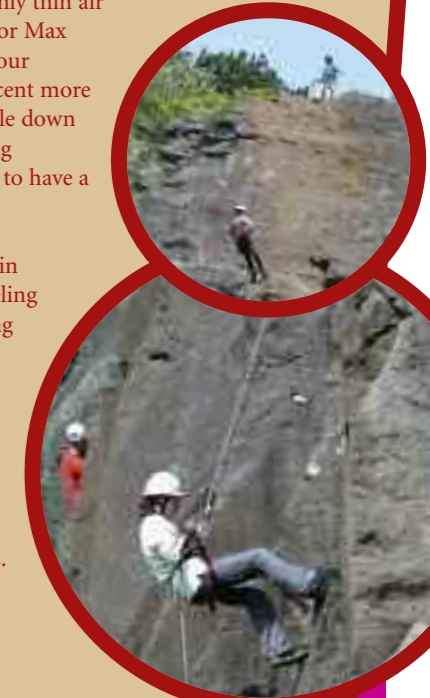
There are many ways to help raise money for Max Appeal and Claire Hennessey, who coordinates and organises fundraising for Max Appeal, is a keen advocate of all of them. It is interesting, therefore, to hear which activity Claire chose for one of her personal fundraising activities in 2008 as it is one that would turn many of us white at the thought. Claire's report is below and luckily she had some solid support from other 'adrenaline junkies' including the entire Mitchell family who have also sent their own comments on the success of the day.

"My challenge for 2008 was abseiling down the Avon Gorge. I'm not sure how I got talked into that one!!! When the instructor was telling me 'just lie back as if you are going to sink into an arm chair', knowing full well there was only thin air behind me it wasn't very comforting!! Well done to everyone who took part and raised lots of money for Max Appeal. Special mention to Max Mitchell who led the way, Helena Mitchell – what a way to celebrate your birthday and Mum and Dad who took part too! Some leapt down the Gorge while others took the descent more gingerly! Billy Thomas raised £1,000, an excellent effort. So if you can find a few cliffs or a tower to scale down near you, how about setting up your own abseiling challenge. We can help you find a specialist climbing organisation to arrange the abseil. All you need to do is find some willing volunteers. If you would like to have a go contact claire@maxappeal.org.uk"

"Thank you very much for your kind and generous sponsorship of our abseil event on 13th May 2008 in Bristol. Your generosity really did make a difference – particularly as we stood at the top of the cliff, feeling very nervous and thinking of many other things we would rather be doing than contemplating abseiling down an 80 foot cliff. Max showed tremendous courage by going first and although he found it quite difficult, he did manage to get down eventually. Helena equally showed great bravery, as by the time it was her turn, a few people had found it to be quite nerve racking and so she had naturally quite a few reservations about doing it, but she completed the task very well. Susie, however, almost seemed to be enjoying the experience!"

You have helped to raise an amount in excess of £2000 for Max Appeal, which is an incredible figure and this will be immensely valuable in directly supporting those with 22q11 deletion and their families.

So a huge thank you from us all at Max Appeal and from a very relieved Mitchell family"



Spanish Run by Danny Gowan

In the Summer, I ventured to Spain to partake in an organised running event. The course was 22 km from Roncesvalles to Zubiri being the first part of the pilgrims route known as the Camino de Santiago de Campostela. The entire route is about 700kms and runs right across the north of Spain. The weather was great, it was about 20c and sunny which was helpful as the course was really little more than a track that

was very rough and stony. The underfoot conditions combined with the steepness made it a pretty challenging run both when going up and coming down. I finally finished in 2hr and 25mins which I thought wasn't a bad effort for a 57 year old! I didn't see anyone who looked older than me on the run and I came in about the middle of the field so all in all it was quite pleasing.

The most satisfying feature, however, has been the generosity of the response of friends and acquaintances to my raising money for Max Appeal. As a result of this Max Appeal will benefit to the tune of more than £6000 which really delights me and I hope it will help you continue to do good work for children who face the same challenges as my 23 year old daughter Harriet.



Youth Group Wake-Over Fundraising Effort by Sue Mitchell

A group of youngsters in Gloucestershire came up with one of the most unusual ways to raise money for Max Appeal. The St. Lawrence Church Youth Group from Lechlade-on-Thames challenged each other to a "sleepover" in the church on the night of 12th July (the same day that Sharon Hunt was organising the Max Appeal get together in Staffordshire – which you can read more about elsewhere in this newsletter).

However, the Sleep Over turned into a "Wake Over" as none of them went to sleep at all! It started out with a Youth Group Church service in a farm barn featuring a rock band and it was suitably cold just like a festival! Afterwards, 11 youngsters – Sam, Fiona, Hannah, Joanna, Alicia, Sally Ann, Laura, Matt, Josh, Ben and Danielle - and 3 valiant adults (Simon Paul, Sandi Gear and Di Kitchens) went to St. Lawrence Church in Lechlade complete with sleeping bags, blankets and emergency rations. Simon Paul, the principal organiser, had set up a screen and was able to show the Max Appeal DVD and those taking part were given Max Appeal balloons, badges and wrist bands. The Church was very beautiful and peaceful at that time of night - and they had turned the heating on specially! A "before" photo of them all was taken and they were all very bleary eyed for the "after" photo at 7.30 a.m.! Amazingly, everyone managed to stay up for the 10 o'clock family service, though several of them actually went to sleep during the service - one even whilst trying to play the flute!

Over the next few weeks, the Youth Group raised an amazing sum of over £350 for Max Appeal and the money is still coming in as I write. Thank you to everyone in the Youth Group for choosing Max Appeal as their charity, for a great effort and to the people of Lechlade for their generosity.



Fundraising Achievements Since May 2008

Our sincerest thanks for fundraising achievements:

To team Max Appeal who took part in great numbers again on 5th October 2008 in the Great North Run, a total of 22 runners completed the course and helped achieve our target of £10,000 which is a tremendous effort. The runners were able to take advantage of our modest marquee at the finish to replace those calories and fluids lost on the way round the 13.1 mile course. A number of impressive times were recorded the quickest of 1hr 38 minutes going to Graham Armstrong appropriately from Newcastle. If you fancy taking part this year we have secured 25 places again for the event to be held on Sunday 20th September please call Paul Wootton on 07917 664929.

To our patron Anthony Head and his partner Sarah Fisher took part on ITV's Saturday night entertainment show Mr and Mrs. We were delighted to be chosen by Tony and Sarah as their charity for the show and were extremely pleased to receive a cheque for £5,000 as a result. Plenty of embarrassing questions were asked of them both as to their knowledge of each other's habits!!

To Rebecca Dimond, one of the contributors to our Consensus Document, took part in the Abseil down Bristol Gorge and raised £120. Young Dominic Humber who also took part raised £170.

To Halesowen and Rowley Regis Rotary Club donated £450 from their Santa Sleigh event.

To Natalie Martin, a friend of members Amanda and Craig George, has raised around £500 for taking part in the Vale of Belvoir half marathon back in June. Natalie completed the marathon in just 2 hours and 7 minutes making this her personal best time. Well done!

A big thank you to Ian Hopwood and his company Caitlin Underwriting who matched pound for pound the monies Ian raised from not one but two triathlons and a 10k run. A serious athlete and a glutton for punishment and Max Appeal benefited to the tune of £1000.

To all the children and staff at Wellfields Junior School in Sale who took part in a Fun Run raising £1293.

To the family and friends of the late Norah Kirk who donated £293. To the family and friends of Caroline Sawdon who celebrated her 80th birthday and asked for donations in lieu of presents with £400 being donated.

To the Adams family again who took part in the Nuneaton and Hinckley Carnivals raising £350.

To our intrepid skydivers took to the sky again. Heather Topping and Kelly Smith raised £750 between them.

To Mair Jones who decided to do a sponsored walk along Offa's Dyke raising £544 (read her story elsewhere in the newsletter).

To Mabel Mitchell who once again generously donated a further £100 to our cause. Barbara Lester for her donation of £100.

To the pupils of Haybridge High School in Hagley Worcs for their donation of £105.

To the staff at the Sunflower Nursery School from Lochgelly in Fife whose sponsored walk raised £281.

Grateful thanks to the Saddlers Company who approved a grant of £1600 toward the cost of our 2009 Conference to be held in April at the Imperial College in London.

To the parents and staff at Icknield Walk First School in Royston Herts who donated £397 following their end of term play.

To the family and friends of the late Mrs Irene Prince who donated £297.

To those attending Wollaston Methodist Church in Stourbridge who donated £200.

To the Surrey Community Trust for their donation of £500 also toward our April Conference.

To BP who matched Smiths fundraising in the Devises to Westminster Canoe Race, which appeared in our last newsletter to the tune of £1250.

To David Lees a regular supporter for a further £100. To the staff at Smith and Williamson who nominated Max Appeal to the tune of £250.

To Marie Hamilton who took part in a 10K run raising £150.

A massive thank you to Danny Gowan and all his supporters. Danny who works for Davies Arnold Cooper in London was persuaded by the younger members of staff at their Madrid office to complete 22km of the Pilgrims Way in the Pyrenees (see story elsewhere in the newsletter). Danny's supporters did him proud with over £6,000 being raised - a phenomenal effort by all.

To Beth Holman, Martha and Lizzie Gayten, who along with their school friends took part in the Great South Run as well as selling cakes at school raising £450.

To the Pollitt family who raised £987 from a sponsored walk and cycle. Kevin Boyle who took part in the Birmingham Half Marathon raising £300.

To Emma Richardson, friend of founder trustees Gary and Sam Hawkesford, who completed a half marathon raising £722 and James Donnelly who had a full body wax raising £325.

And finally to all those players and companies including Acushnet Europe Ltd, Srixon and Mizuno for their support at our Annual Golf Day last year. The event held again at Stourbridge Golf Club raised the fantastic sum of £2500 and will take place again at Stourbridge on Tuesday 30th June. If you wish to take part or wish to support this event in anyway please call Paul on 07917 664929.



The Davies Family

Jason and Shelley's son Jay turned 3 last April. Jay was diagnosed at 12 weeks after his Tetralogy of Fallots diagnosis. He had his correction in February 2007 when he was aged 10 months with a few complications as he needed pacing for 24 hrs after and a blood transfusion a week later. The NG tube was removed 1.5 years ago after having been tube fed from 14 weeks. However, Jay still doesn't eat much but he manages on Paediasure Plus. Jay was also diagnosed with Epilepsy in March this year (mostly absence epilepsy with a bit of myoclonic and febrile). He has just learned to say a few words - Mama, Yeah and Uh-Oh, though he still gets his point across very firmly despite the lack of more advanced speech. Jay makes people fall in love with him wherever we go - apart from when we eat out when he can clear a restaurant within minutes once he starts screaming, having tantrums and throwing things! Our beautiful boy, wakes up every morning with a smile, regardless of how much harder he has to work than other children his age - he truly is an inspiration, as are all of our special 22q babes!



Devon Holiday Apartment Offer

Jason and Shelly Davies, who are parents to Jay, have very generously offered their holiday home in Devon to Max Appeal families at a discounted rate. Visit their web site www.shaldon.net. It is a very small fishing village and has the benefit that the residents and local GP is familiar with the 22q11 condition! Shelly writes:

The 2-bedroom apartment, Fisherman's House, is located in the lovely Georgian Fishing Village of Shaldon, South Devon. It is just a few moments walk to the beach, if you walk a little further you can visit the Ness Beach through a 'Smugglers Tunnel'. When you've finished sunbathing on the beach, visit Shaldon Zoo which is the smallest Zoo in Europe featuring some of the world's most endangered species. The flat is available to families all year round. Charges for July/August and Christmas/New Year are £400 per week. (cheaper than a caravan up the road from us) The rest of the year we would be delighted to offer the flat to Max Appeal members for the cost of £175 per week (normal cost £250 in 2008). Just mention Max Appeal when booking! We live just up the road so are on hand to help should you need us.



Dates for Your Diary

March 2009 - Maxi Bear is back from his trip to Basrah so he will be available for bookings! Why not organise a Toddlers event in your local area with either your school or sports club. Anyone can partake in a Toddle event, from our little ones to our grandparents - Get Toddling! Please contact Claire for more information at claire@maxappeal.org.uk.

29th March 2009 - Max Appeal RDA horse riding at The Camp Riding Stables, Gloucestershire, meet at 12.15 for riding at 12.30 pm. For more information and if you have not been before contact Susie on 01285 712821 or susie@maxappeal.org.uk Riding is free, but booking essential.

18th April 2009 - Max Appeal's yearly conference will take place at the Imperial College London on Saturday the 18th April. The conference will be packed with presentations from a range of professionals. The day will also present a great opportunity for you to meet other families and share your experiences and naturally it is a chance for your child/ren to have a fun-filled day.

April 2009 - We have some places in the London Marathon. Please contact Paul if you are interested in running! Maybe you just fancy supporting our runners, one of which is Lisa Cunningham, in either case please call Paul Wootton on 07917 664929 for more information.

9-17 May 2009 - Children's Heart Week. CHF (Children's Heart Federation, ed) is having its main campaigning week in May, to coincide with European Children's Heart Week. They will be taking up themes around the re-organisation of paediatric cardiac services in the UK and the inclusion of heart children in sporting activities. For more information, please check out www.chfed.org.uk or contact Max Appeal for more information.

25th May 2009 - Max Appeal member Beverley Spence in Northern Ireland has organised a meeting at the Comfort Hotel in Antrim from 7 - 9 pm. If anyone is interested in going along, please contact Beverley on Tel: 07725366859 or email: bevspoospence@fsmail.net.

26-28th June 2009 - Camping Weekend at Poole Bridge, Ullswater, Lake District, please see article earlier for details and links to websites. Please contact Chris Anderson, if you want to attend or if you have any queries on either phone 01661 854264, mobile 07909 553 924 or you can e-mail on andersonheddon@btinternet.com.

30th June 2009 - Max Appeal's Golf Day at Stourbridge Golf Club (M5, junction 3/4). If you wish to take part or wish to support this event in anyway please call Paul on 07917 664929.

3-5th July 2009 - Max Appeal's Young People's Weekend in Gloucestershire's Cotswold Water Park. The weekend will be free to Max Appeal members, with a £25 deposit refunded. You need to be aged between secondary school year 7 and your early 20's (see article in newsletter), please phone Susie on 01285 712821 or email susie@maxappeal.org.uk to provisionally reserve a place. Places will need to be booked by the end of April.

20th September 2009 - Great North Run is on the Sunday. We have secured 25 places so if you fancy taking part please call Paul Wootton on 07917 664929.

Did we miss you out? If you have organised an event on behalf of Max Appeal and you want to spread the word, please contact Tina at editor@maxappeal.org.uk and we will include it in the next newsletter. Thank You.



A Few Helpful Pointers!!

Cinema - If you are a recipient of Disability Living Allowance you could be eligible for a Cinema Exhibitor Association Card. This is a national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema. The card is valid for 3 years from the date of issue. Application forms are available from cinemas across the UK or you can download an application form at www.ceacard.co.uk. A processing fee of £5.50 is chargeable per card which is to be sent along with the completed form to CEA Card, PO Box 199, Deeside, CH5 9BW

Swimming - Some local authorities issue swimming passes for those in receipt of DLA: ask at your local leisure centre to see if this applies to your area.

Dogs for the Disabled - they are a national charity who provide specially trained assistance dogs to disabled children and adults to help them lead independent and fulfilling lives. Apart from practical help, the dogs are able to give confidence that can make all the difference. For more information go to www.dogsforthedisabled.org or phone 01295 252600.

Have you come across any helpful hints, please share them with our Max Appeal members, you can forward your advice to Tina at editor@maxappeal.org.uk.

Raffles

We will be running our annual raffle, to be drawn at the April Conference in London. Please do your best to sell as many raffle tickets as possible as it all helps to cover some of the costs associated with the day. Tickets will be sent out to members shortly. If you can sell some additional tickets please let us know and we can send you some additional books.

If you would like to organise a raffle at a local event it's good fun and people like them, so have a go! For more advice on how to run a raffle and lottery regulations contact claire@maxappeal.org.uk. You may even like to organise a street collection. Licences from your local authority are required. Contact your local Licensing Department for advice.

Special Birthday or Anniversary?

Instead of receiving lots of unwanted gifts why not ask family and friends to contribute to a special Max Appeal Celebration Fund set up in your name. The donations will be used to support the day-to-day work of Max Appeal. We will send you some special donation envelopes which will help us make the most of donations by allowing us claim Gift Aid on all eligible donations.

Please contact claire@maxappeal.org.uk for further details.

Some Ideas for Fundraising

Max Appeal PowerPoint Fundraising Presentation

If you are interested in raising money for Max Appeal and would like to give a short talk to your group, friends or organisation but don't know what to say, help is at hand! Hilary Joyce, Max Appeal trustee, has put together a brief and informative presentation that can be personalised if required. If you would like to use this presentation, please contact any one at Max Appeal.

Recycling

Don't forget to keep recycling your old inkjet cartridges and mobile phones, just pop them into one of the Greensource Solution bags or Donor Toner bags (if you still have some) and make sure they are clearly marked for Max Appeal and return to the Bristol address. For each one Max Appeal will receive a donation. If you need any extra bags please contact claire@maxappeal.org.uk

eBay for Charity

Are you intending to dispose of all those unwanted things that clutter up your home in 2009? Max Appeal now has its own online charity shop through eBay for charity and receives donations from eBay sellers. Visit our website and via our fundraising pages you can go directly to our entry on eBay. Anyone can give to our charity when they sell on eBay. Sellers can donate 10-100% of each item's sale price to our charity and claim Gift Aid (if eligible) and pass the money to us. Missionfish takes a small deduction from each donation to cover its processing and administration costs. Start Spring Cleaning now!

Payroll Giving

Does your employer run a payroll giving scheme? Get in touch with your HR Department and ask if you can give a regular amount to your nominated charity directly through your salary (monthly or weekly). It's an effective way to give to charity as the donation is a pre-tax deduction, reducing the amount of income tax taken from your pay. It provides charities with a regular, reliable source of income stream, helping us to plan ahead.

Max Appeal Helpline Rota

We are organising a rota to man the Max Appeal helpline. If you are interested in volunteering to help with this (training can be given), please contact Susie on 01285 712821 or susie@maxappeal.org.uk. If you have volunteered previously, Susie will be contacting you again very shortly. Thank you for your help.