



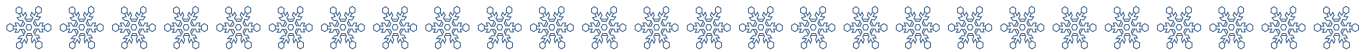
ALDLIFE

helping to cope - helping to hope

A charity to promote awareness, research and prevention of adrenoleukodystrophy

NEWSLETTER

DECEMBER 2010



CHECK THIS ISSUE FOR NEW MERCHANDISE, INFORMATION DAY & WEEKEND GET TOGETHER 2010 & 2011, LOTS OF FUNDRAISING NEWS AND NEW INNOVATIONS

Dear all,

Well, nearly another year has passed since the last newsletter and I certainly hope to be doing these a little more regularly for you in the future. I don't think I had quite realised just how much Ayden's bone marrow transplant shortly followed by Alex's spinal surgery had taken out of me until this year. Now that we are back to "normal" again my body has decided to catch every bug going and I fear the beginning symptoms of AMN are creeping up on me. However, on the very good side, Ayden has been given the all clear after his transplant which has been a huge relief, and Alex is now able to be up and about most of the day after so long confined to bed. Now he is over the spinal surgery, he is also eating orally again which is hugely enjoyable for all of us and we have been able to have our first holiday as a family in three years—see www.tyglyndavistrust.co.uk.

The first ever combined Information Day and Weekend Get Together was a huge success and our thanks go out to all who made it possible and run so smoothly, particularly those who fundraise for us, those who came along, the Hilton Hotel and staff, our volunteers and the researchers and health professionals who took part. More on this inside and the dates and booking form for 2011.

We have some changes in staffing at the charity shops and say goodbye to Elle, manager of our Sydenham store. We have welcomed in her stead Maria Colak who has previously managed our accounts voluntarily for us. She is now manager of our Sydenham shop and also deals with the charity accounts (another job off my hands thankfully!). We have also started an apprenticeship scheme with a local agency and have employed an apprentice manager who works alongside Maria, Belinda Potter. She is being trained up with a view to her managing our third shop which we hope to open next year. We also welcome on board Helen Oram, who has replaced Lorraine Stewart as voluntary fundraiser. Helen will be working for us on a part time basis from January as administrator for the charity and will be responsible for keeping the website updated, fundraising, admin and anything else we can get her involved in! She will make a welcome addition to the workforce and this will free up my time to concentrate on moving the charity forward in other ways. It also means the office can move from the back of my kitchen to the back of the Penge shop which my boys will be very grateful for!

Over the year we have welcomed many new families and individuals to ALD Life and, sadly but inevitably, lost some dear friends. We hope that between us we can continue to support each other through the hardships of living with ALD and AMN.

We wish you all a very merry Xmas and a hopeful New Year, SARA, ALEX & AYDEN xx



**THIS NEWSLETTER IS DEDICATED TO THE FOLLOWING
WHO HAVE SADLY PASSED AWAY FROM ALD**
BRENTON TSU 5 FEBRUARY 2010 AGED 26
MARC ELLIOTT 14 AUGUST 2010 AGED 6



AND TO OUR DEAR FRIENDS
HRATCH OGALI 16 JULY 2010
FRED FORRESTAL 17 NOVEMBER 2010

FUNDRAISING

CHRISTMAS RAFFLE TICKETS

Our Christmas raffles are becoming very popular and this year we have a great selection of prizes yet again. Many thanks go to the Hilton Tower Bridge, Orange and Mark Bostock for donating the prizes.

As an added incentive we are giving away a mystery prize to the person who sells the most! To start you off we've enclosed four books with the newsletter, so sell, sell, sell!!!! Draw date is Monday 20th December.

To be in with a chance of winning, send your ticket stubs back asap in the enclosed envelope. If you'd like more books to sell let us know and we'll send them out by return.

First prize is a brand new iPhone 3GS 16 GB, second prize a weekend for two at the Tower Bridge Hilton Hotel and third prize is your choice of any three Wii, X-Box or PS3 games.

CHRISTMAS CARDS

We have some new design Christmas cards this year, details enclosed. To order just phone, email or send a note to the usual contact and we'll get them off to you along with a note of the cost plus postage.

We also have some of our old ones left—see right. We're now selling the last of these off at the bargain price of £1 per pack.



ALD LIFE MERCHANDISE & PROMOTIONAL PRODUCTS

Our lines of merchandise are growing and are ever popular, especially our new key ring torches. If there is a specific piece of merchandise that we do not do and you'd like us to include in our range please do let us know. To order please contact us as usual.



WRISTBANDS



KEYRING TORCH £1.50



KEY FOBS 50p



TROLLEY COIN £1.50



PENS 75p

If you are organising a fundraising event we can provide leaflets, sashes for volunteers to wear advertising the charity, merchandise to sell and A3 posters explaining the disorder. We can also lend you a banner for display purposes to return after the event. If you need any further assistance organising a fundraising event we will do our best to help so do please get in touch.

ALD LIFE CONTACT INFORMATION:

ADVICE LINE/OFFICE - 020 8473 7493

PENGE SHOP - 020 8778 1144

SYDENHAM SHOP - 020 8659 7171

EMAIL - INFO@ALDLIFE.ORG

PO BOX 43642, LONDON SE22 0XR

Please note the advice line is at Sara's home so there may not always be an answer, but leave a message and she will always get back to you. The shops are open 9.30 to 5.30 Monday to Saturday and 10 to 4 Sunday.

FUNDRAISING



SPONSORED EVENTS 2010

2010 has been a great year for sponsored events. We filled all fifteen of our places in the Great North Run in record time, so if you are interested in doing it for 2011 do get in touch with us asap. Our thanks go to Jacqueline Birrell, John Murray, Donna Laidler, Diane Dunlop, Helen Little, Helen McLeod, Andrew Knox, Mark McBarron, Deborah Nixon, Christina Ellwood, Tracy Rutherford, Lisa Hudspith,



Jane Turner, Julie Fisher and Chris Jones. We also had a great turn out for the Great South Run and thanks go to Brendan Phelan, Anna Faulder and Chloe Knott from our new sponsors, Exodus Travels (pictured above), Vicki Macpherson-Lees, Steve Burt, Claire Thornton and finally Lee Smith who designed our website.



Hope thanks also go to Suzanne Clegg who climbed Mt Kenya back in January and raised a whopping £1,200 for us. Suzanne's nephew, James was diagnosed with ALD just before she decided on her climb.

Our Geordie runners with Donna who has two sons with ALD third from right—think the lads should be wearing tutus too though!

HUGE THANKS TO ALL OUR PARTICIPANTS IN SPONSORED EVENTS THIS YEAR AND VERY WELL DONE!



MACBETH FUNDRAISER

Many thanks go to Prudhoe's Really Youthful Theatre Company who decided to support ALD Life with their charity performance of 'Macbeth' on the evening of April 30th, 2010. They first heard about ALD Life through an article for their school newspaper written by student Jonny Hall, focusing on a local little boy with the condition, Alfie Rowell. It was a great evening supported by friends and family of the cast and Alfie, with a raffle and other 'antics' during the interval, as well as ALD Life merchandise being on sale. In the week leading up to the performance, Jonny Hall and Jonny McGuigan presented an assembly to each year group to raise awareness and many students took away leaflets. On the night, they raised £430 and they've already decided to fundraise for ALD Life next year too, with their production of 'The Fifteen Streets'.



LEEDS FUNDRAISER

Four year old Lennon from Grimsby had a bone marrow transplant last October to halt the symptoms of ALD. The transplant has so far been successful and Lennon was given the all



clear to attend his first Leeds match in April this year. He was also chosen to be the match-day mascot for the day.

Upon hearing of his illness and his special day, a group of



Swindon fans clubbed together to make his day even more memorable. The group, from internet forum www.thetownend.com presented Lennon with a signed Swindon shirt as a memento of his day, as well as raising £200 for ALD Life.

ANYONE WISHING TO PARTICIPATE IN THE GREAT SOUTH RUN, GREAT NORTH RUN OR GREAT MANCHESTER RUN FOR 2011 PLEASE DO GET IN TOUCH RE PLACES. WE HAVE SPECIAL RUNNERS PACKS AVAILABLE WHICH INCLUDE SPONSOR FORMS, T SHIRT AND LEAFLETS. PLACES ARE FREE OF CHARGE AND WE ASK THAT PARTICIPANTS CAN RAISE AT LEAST £300 FOR US.

FUNDRAISING

UPDATE ON ANGUS

Many of you will know that Angus Nicol, a great inspiration to us all in his fight against the symptoms of AMN and known by many in the UK, has unfortunately now succumbed to adult ALD.



His close friend, Karl McIntyre is running the Grand Union Canal Ultra-Marathon which is 145 miles non-stop from Birmingham to London. He aims to finish in under 45 hours and we just have to admire his stamina and courage in even attempting this one! The event is on 28th May 2011 and anyone wishing to sponsor him can



go to www.justgiving.com/karl-mcintyre1. I would really encourage you to support Karl on this one as I know that raising as much money as possible for ALD Life on behalf of Angus is very close to his heart. On his Just Giving page Karl states "A very intelligent, funny, generous and thoughtful friend of mine, Angus Nicol, was diagnosed with this debilitating disorder, and the profound impact it has had upon his life and that of his family, has driven me to do something practical to help raise money and awareness".

We would also like to take this opportunity to congratulate Angus and his girlfriend Gemma who took the plunge and got married earlier this year!



NEW DIAGNOSIS SPURS BIG PUSH TO RAISE MONEY

Shea Givin, six, from Walton, Merseyside was diagnosed with symptomatic ALD on September 16th this year with no hope of treatment. The diagnosis has inspired his family and friends to make an immense effort to raise funds for ALD charities including ALD Life as well as funds to give Shea some memorable days while he can still enjoy them.

We all know the devastation this family are going through and can only admire and congratulate them on their positivity during this horrendously difficult time. We wish them all immense success with their efforts and hope they are able to give Shea some wonderful memories.



There has been a huge drive to raise funds for the family and events have included a seven and a half mile



sponsored walk in Kent from Sittingbourne to Faversham as well as various other charity nights in Liverpool. Shea's best friend, Amelia Whitehead, (pictured with Shea) did the walk and raised a fantastic £655 for us.

For further details of any events or to give your support you can email Shea's grandparents, Nick and Jenny Cuddihy at ncuddihy@supanet.com.

FUNDRAISING



BOWLS CLUB FUNDRAISER

Our gratitude goes to the Chingsford/Ainslie Wood Bowling Club for having a fundraising day for ALD Life in May this year. Members donated money to come dressed in red, white and blue or Hawaiian and there were a series of games and events all day! As you can see everyone had a lovely time and many thanks go to Brian, a friend of Kim Apps' father, for organising the whole thing. They raised an amazing £500 for us and Kim Apps (right centre) was presented with her ALD Life fundraiser of the year award for a second time!



ALD LIFE CHARITY BALL

New trustee, Mark Bostock, has arranged our first ever ALD Life charity ball. The venue is the Aztec Hotel and Spa in Bristol, www.aztechotelbristol.com, on Friday 24th June 2011. Tickets are £45 each and include three course dinner including coffee, disco and bar til late, auction/raffle with excellent prizes including an iphone and a signed football from Manchester United, champagne reception, reduced bar prices and reduced hotel accommodation rates if you need to stay over. The hotel is absolutely stunning and myself and Alex will definitely be attending so look forward to seeing you there! Anyone interested in buying tickets can contact Mark directly at mark.bostock@everythingeverywhere.com or call him on 07973 891177. Alternatively you can contact ALD Life and we will pass any messages on to Mark.

ADVENTUROUS FUNDRAISING!

The charity is often asked how to go about organising something like a parachute jump, abseiling or zip wiring event to raise money. There are several websites out there that make doing this sort of thing very easy and we have listed a few below:

To book a zip wire go to www.ziplidesuk.co.uk. They have several events across the country and all you have to do is book a place, go along and get some sponsorship!

To book an abseiling event, find a suitable tall building or structure and go to www.charityabseils.co.uk!

To book a parachute jump go to www.skylineparachuting.co.uk who have locations around the country.

To book a bungee jump go to www.ukbungee.co.uk and click on Charity Jumps.

To book a holiday experience of a lifetime go to www.exodus.co.uk or www.acrossthedivide.com



FUNDRAISING THANKS

We have an awful lot of people to thank for their donations this year. If I have left anyone out then please accept my apologies and do let me know so we can make sure it's put in the next issue. Your donations make possible all the work that we do and on behalf of all affected by ALD and AMN, thank you so very much.

The Phillips & Rubens Charitable Trust	£250	Anna Robson and family for Wine & Wisdom Night	£1602
The Lady Eileen Joseph Foundation	£500	Muriel Coverdale	£150
Amanda McAndrew for the Nottingham Half Marathon	£3150	Sir Jules Thorn Charitable Trust	£600
Banner Contracts	£100	Speaking Out Small Grants Programme	£1000
Glenbar Groundworks & Civils Ltd	£50	Society for Endocrinology	£2000
The Walter Guinness Charitable Trust	£500	Lilley Benevolent Trust	£1000
Barbara A Shuttleworth Memorial Trust	£480	The Coutts Charitable Trust	£500
Lynn Foundation	£500	Gordon Fraser Charitable Trust	£400
Children in Need	£4500	Montague Pub, New Cross, fundraiser by Elwell	£260
Caterpillar Music	£300	The Rank Foundation	£1000
Stourfield Junior School	£75	The Vintners' Company	£1000
Paradise 9	£100	Reigate Grammar School pram race	£764
		Saz Denny	£500

ALD LIFE INFORMATION DAY &

This year's event was our first combined Information Day (formerly AMN Day) and Weekend Get Together and was, according to your feedback, an incredibly successful event. Once again, esteemed favourite, the Hilton Hotel at Tower Bridge in London was our venue. We were especially pleased to see increased numbers at this event and attendance by friends from abroad, Travis, Bjarne and their families.

We kicked off with accommodation on the Thursday night for those that could not travel to the Information Day on the Friday morning. The Information Day was again organised by Chris Ogden who arranged for many esteemed researchers and scientists in the fields of AMN and ALD to come and discuss with us and amongst themselves new innovations in the field of research. We also held discussions amongst patients giving their hints and tips on how to deal with AMN including some very inspiring talks by Peter Steadman and Wesley Brooks. Dr Robin Lachmann also hosted a question and answer session, expertly fielded by Mark Bostock. We also held a session involving bereaved parents and those with boys with the ALD gene which was hosted by child psychologist Kathryn Bond who has experience of boys with ALD. This was a very welcome addition to the weekend and we will be exploring doing something similar next year. Many thanks go to Geoff Mahy who expertly recorded the day's events for us which are enclosed.

Friday evening was fantastic with a performance by the Sing for Joy group including our very own Chris Ogden, who had us all singing along merrily! This was followed by the meal and our ice breaker quiz which was won by a team who we suspect had prolific use of advanced technology! The children's quiz was won this year by Ayden Hunt (no fix, honest!) and I must say I was so happy to see our children mixing so well together during the whole event and hearing of how superbly they support each other. They really are an inspiration and we should all be incredibly proud of them.

Saturday saw us entertain the kids with an animal roadshow of which the high point seems to have been choosing whether or not the python ate a mouse or a chick. Three guesses what our lovely boys and girls chose! Alongside this we had a gentle taster yoga session especially designed for those with AMN symptoms which was a huge success and has hopefully turned some of you on to this highly beneficial, in both mental and physical terms, form of exercise. While the children and some of their parents and carers enjoyed a tour of HMS Belfast, others were put hard at work looking at the first drafts of our practical information leaflets and giving incredibly useful feedback on what they wanted to see and first opinions. In the evening the children enjoyed a bouncy castle, face painting and balloon modelling whilst the adults eagerly awaited news of whether they'd won a prize in Kim App's now famous raffle. ALD Life is delighted to report that Kim also won our fundraiser of the year award for her constant support and inspiration to all who know her.

Due to the success of last year, Sunday morning gave our members a chance to see our two charity shops and see first hand what we are doing to raise awareness and funds not to mention boosting Sunday business! This was followed by our farewell lunch and we look forward to seeing you all again next year.

This year we also filmed the event and this will be available for viewing shortly on our website. Although there has been a long delay in this, the wait will definitely be worthwhile and our thanks go to Jerry Moody for his voluntary services.

Below and opposite are a selection of photos from the event for you to enjoy.



WEEKEND GET TOGETHER 2010



NEWS FROM ALD LIFE



INSPIRING WORDS FROM OUR NEWEST TRUSTEE, MARK BOSTOCK



'There are only around 200 people in the UK who have ALD or AMN and there isn't really a cure on the horizon. So, what I have been doing about it? Frankly not much I am ashamed to say. I have knowingly had AMN for about 10 years and have been involved with ALD Life for about 6 years. Apart from jumping out of a plane and helping to facilitate some recent ALD/AMN Get Togethers I have not done anything to help the charity. If a "sufferer" can't be bothered to help then what hope is there?

That is until recently when I became a Trustee of ALD Life and I "saw the light". The penny has really dropped for me and my efforts to help the charity in any way I can have completely consumed me. I just can't stop thinking of new ideas. If Sara didn't run the charity she would have changed her mobile number by now as I call her so often but I have never felt so motivated in doing something that will make a tangible difference in helping me through research into making me or us better or just by helping us help each other. It is the most rewarding thing I think I have ever done.

So far I have been to one meeting and set myself a target of raising £10,000. The message we have in terms of the devastating effect the disease has on us all and the lack of treatment is very powerful and I have used this in the umpteen letters I have sent recently to friends, football clubs, superstores etc. We are all busy but we should try and find time to raise money. There are many things that can be done easily and without involving you giving up weekends or having to go round with a begging bowl. These are some of the things I am doing:

Your local Superstore will probably be happy for you and your friends to pack bags at the tills for 2 hours on a Saturday afternoon. I believe (from friends who have done this) it is likely to make around £1000. If you don't think you have enough people who can help then I contacted by local Cubs and they said they can provide the helpers if I organise the buckets etc and we go halves on the money taken. If this works I am going to do it at my other local superstores so I just need to arrange the date and time and let the cubs do the rest. Other useful local resources are your local volunteer centres who will do the work for free and all monies raised are for us alone—they may even be able to provide someone to co ordinate the day if you cannot do it yourself.

I have written to all my friends and colleagues to ask that if they know someone who is doing a marathon or other charity event then they nominate our charity. ALD Life hold places on several marathons and running for ALD Life may be the only way they can get a place.

I spoke to my company about supporting me and within a day they had ordered phones for me to give away at various events—one of which is first prize in the ALD Life Xmas raffle.

I have booked a stall at next years local village fair. I will hopefully use the iphone and any other prizes (eg store vouchers) I can nab from the superstores to generate some funds.

I thought about all the people I know and who might be able to help. My Mum works for M&S, my mate's wife is an M&S Store Manager, I have friends in the Freemasons and a colleague's sister is the charity/celebrity co-ordinator for the Fire Service so I am hoping we can get her celebrity cast offs.

There are lots more things too, so if you want some ideas or advice on how to raise money without having to become a full time fundraiser then give me a call please. I am happy to share any letters I have written too if it helps.'

OUR TRUSTEES

We always welcome new trustees to help us run the charity to the best of our ability. Currently we have the following on our committee:

Sara Hunt (chair)	Mum of two boys with ALD, one symptomatic and one who has had bone marrow transplant
Chris Ogden	AMN sufferer and organiser of the Information Day
Frank Smith	Retired special needs school teacher also on the committee of other charities
Katharine Tipper	Carrier of ALD
Marie Risolino	Mum of two boys with asymptomatic ALD
Mark Bostock	AMN sufferer
Mike & Pat Hensby	Pat has AMN
Barbara Pennington	Retired NHS director of nursing and Mark Bostock's aunt
Dr Robin Lachmann	Medical advisor and AMN and adult ALD specialist

IF YOU ARE INSPIRED BY MARK'S EFFORTS OR WISH TO ENQUIRE ABOUT BECOMING A TRUSTEE PLEASE DROP US A LINE AT THE USUAL CONTACT. TO CONTACT MARK DIRECTLY YOU CAN EMAIL HIM AT MARK.BOSTOCK@EVERYTHINGEVERYWHERE.COM.

NEWS FROM ALD LIFE



PRACTICAL INFORMATION LEAFLETS

We have been working with writer, Mike Ridley, who came along to our weekend get together, and many of our members on producing practical information leaflets for newly diagnosed and existing families and individuals. We are now in the final stages of production and hope to have the finished leaflets early in the New Year. Although this has been a very lengthy process, we needed to make sure we got it right. We have also managed to secure some government funding to pay for them.

There will be five leaflets in all covering symptomatic ALD, asymptomatic ALD, AMN in males, AMN in females and being a carrier. Many thanks to all of you who have attended our workshops and agreed to be interviewed by Mike for these leaflets. Anyone wishing to view and comment on what we've done already please do get in touch as we welcome all opinions on this essential piece of literature.

ROUTE MAPS FOR RARE CONDITIONS

We have also been working with the Genetic Alliance on a pilot project for a series of route maps designed to guide new diagnoses of rare disorders through their treatment and management options, both health and social. We were chosen as one of ten organisations for this project and have been given funding by the Genetic Alliance to help us produce these route maps, within which our practical information leaflets will provide an excellent starting point.

The Route Maps for Rare Conditions project is a new, creative approach to improving the health and well being of people with rare conditions at a national level. The project will develop a practical and cost-effective framework for improving information, access and coordination of health and social care services for individuals and families with a wide range of rare conditions.

This Route Map will provide a comprehensive resource to be used by patients, families and health and social care professionals and will have the potential to play a key role in personalised care planning for people with these conditions. At the completion of this project, organisations who have taken part will have a Route Map developed by the charity themselves, with support from Genetic Alliance UK, that can be used, updated and modified over time. Each group will also have contributed to wider outcomes which will hopefully demonstrate the benefits of working with patient support groups to develop information and guidance to the services and support that are important.

THE NEED FOR ROUTE MAPS

An estimated 2.9 million people in England are likely to develop a rare condition at some point in their life and service provision for people with rare conditions is unsatisfactory. The lack of information about rare conditions means that it is extremely difficult for patients and families to play an active role in their care, make informed choices about their treatment options or plan for their future.

Although there are activities taking place to improve information, access and coordination of care for individual rare conditions, there is no other initiative that seeks to address this issue in the long term sense. This project aims to develop a methodology to address this issue in the long term across a wide range of conditions, systematically harnessing the unique expertise of user led support groups and developing their role in information provision and self directed care.



HEALTH UNLOCKED

If you have been following mine and Chris Ogden's emails you will know that ALD Life is now part of the Health Unlocked forum which aims to bridge the gap between medical professionals and patients. We are currently looking at replacing the fora on the website with this and would welcome your opinions on this. To have a look at Health Unlocked for ALD go to www.aldlife.healthunlocked.com and for AMN go to www.amneasier.healthunlocked.com. You can see news and developments via a group blog, an online helpline, local hospitals (UK only) and answer the "Big Question" to help influence change.

This is an excellent innovation and we would really appreciate your participation and give you the opportunity to enrich ALD and AMN communities.

ALD/AMN COMMUNITIES ONLINE

There are now abundant opportunities to share your experiences of ALD and AMN online which is all good for raising awareness. Listed below are some of them:

www.caringbridge.org/visit/jackmccall

www.hifa2015.org/

www.facebook.com/home.php?sk=group_163743340319439&id=178236505536789

PROJECT DETAILS

This pilot project has been funded for three years by the Department of Health. The first two years of this project will be developing the Route Maps and methodology. The final year there will be an evaluation undertaken by the Project Manager to assess the success of the Route Maps, the methodology and the toolkit as well as the process undertaken. Each group will be required to commit to the full three year duration.

NEWS FROM ALD LIFE



ALD LIFE INFORMATION DAY & WEEKEND GET TOGETHER 2011

Enclosed with this newsletter you will find your booking form for next year's event which will again be held at the Hilton Hotel, Tower Bridge on June 3rd to June 5th 2011. We very much welcome your feedback as to what we do at this event so if there is anything you really want us to include or if you have any suggestions as to how we can improve the event please do let us know—although the dates are confirmed we are still working on the itinerary and what you tell us **will** have a huge impact on proceedings.

This year we do plan to have a discussion on what you want to see ALD Life doing for you in the future so your views really will count.

MEMBER'S TIPS

Deirdre Corr would like to share a useful walking aid for those with AMN which can be found at www.musmate.co.uk along with a useful massage aid which she has found incredibly useful for her muscle spasm at www.cyclo-ssage.com.

Faye Cooper has started an incredibly detailed and comprehensive blog about her experiences with the low fat diet accompanying Lorenzo's Oil at www.lorenzoboys.blogspot.com/2009/11/introduction.html

STEVEN SIMS'S EXPERIENCE

Steven Sims was diagnosed with AMN in late 2009 and uses two sticks when walking. He wanted to share with you all his experience on going on holiday to Cyprus this year where he found that, after just three days, he no longer needed his sticks. He walked as he used to and one day even jogged and then, on his return to the UK found he needed his sticks again within a day.

Steven would be very interested to know if anyone else has experienced such profound differences whilst in a different climate and can be contacted at steven.sims@tiscali.co.uk

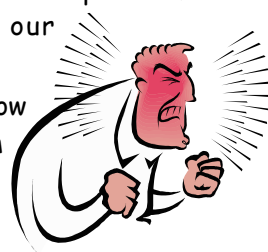


BRISTOL GETS ACTIVE

Sara is often in contact with Pete Taylor from Bristol commiserating on difficulties with social services and the community health service and our sons' care packages, which I am sure a lot of you will empathise with.

After various recent difficult experiences Pete would love to hear from anyone who is experiencing problems during the cuts resulting from our new government and the current recession. Along with his partner he plans to collate this information in an attempt to influence future decisions for our children's care.

Anyone with any stories of how the cuts are affecting them should get in touch with Pete directly at petetaylor09@hotmail.co.uk.



ALD LIFE LINKS

Further to Mark Bostock's appointment as trustee, ALD Life is very pleased to announce that Mark has taken on the role of fostering our links with the other UK ALD charities. He has set up meetings with Mark Lilley, founder of Oliver's Army www.oliversarmy.org who purely fund research. As ALD Life has grown we have more funds available for this crucial work and are strongly committed to doing more in this field. Mark is also working on establishing links with the newly reformed ALD Family Support Trust www.aldfst.org.uk. We realise that having more than one UK based charity for a rare disorder is not an ideal situation and so will be working hard to draw our resources together for our mutual benefit.

NEWS FROM ALD LIFE

NON-INVASIVE PRENATAL DIAGNOSIS



You will all be aware of the problems involved with having children when you know you carry the ALD gene. As you will read below, developments are progressing in the realms of safer testing for those not wishing to go for the traumatic option of PGD (pre-implantation genetic diagnosis). Sara attended a recent conference on progress in this field and the article provided below by Celine Lewis of the Genetic Alliance's RAPID project gives more details.

"Scientists are currently working on a new test to be offered during pregnancy called non-invasive prenatal diagnosis (NIPD) that will revolutionise the way that prenatal tests are performed. This article will explain exactly what NIPD is, how it is currently being used, and how the test will be used in the future.

HOW IS PRENATAL DIAGNOSIS CURRENTLY DONE?

Currently, couples who know they are at risk of having a child affected by a genetic condition can opt to take a diagnostic test such as an amniocentesis or CVS during pregnancy, to collect a sample of the baby's genetic material. These invasive tests carry a small but significant risk of miscarriage (up to 1%) and can only be performed after 11 weeks into pregnancy.

HOW IS PRENATAL DIAGNOSIS CHANGING?

It has been known for some time that DNA from the baby can be detected in the mother's blood early on during pregnancy. A new test called non-invasive prenatal diagnosis (NIPD) has recently been developed which can take the baby's DNA directly from the mother's blood (taken from the mother's arm as a routine blood test), instead of having to take it from inside the womb. This is a much safer way of testing because there is no risk to the baby and can be done early during the pregnancy. The DNA can then be examined in a laboratory.

At the moment, we are currently able to perform NIPD to find out the sex of the baby at around 9 weeks. This can be useful for conditions that mainly affect boys, such as ALD. Women who know they are having a boy may then want to go on to have an invasive test to see if the baby has the condition. There are, however, a team of researchers (some based at Great Ormond Street Hospital and others in other parts of the country), who are trying to develop NIPD so that it can tell us whether the baby has the condition.

HOW CAN YOU HELP?

Before we can offer NIPD to diagnose ALD during pregnancy, we need to do more work in the laboratory to make sure that the test is accurate. In order to do this development work, we need blood samples from a large number of pregnant women who are at risk of having a baby with ALD.

If you are pregnant and know you are at increased risk of having a baby with ALD you could either:

- contact us on the email at the end of this article OR
- talk to your genetic or obstetric doctor and ask them to contact us

We would then arrange a blood test for you. You will not receive any information about the results of the blood test, however we would need you to let us know what happens during your pregnancy and whether the baby has the condition. We would discuss how this could be done and any other questions you have when you contact us.

We are also interested in hearing what people think about this new test, and prenatal care in general, so that we can make sure we offer prenatal care that meets the needs of the people who will use it. By completing a questionnaire you will help us to understand what types of prenatal tests people want and what factors are most important in deciding which test to have. We would like to have the thoughts and opinions of people who are carriers of ALD, however you don't have to be pregnant, or ever have been pregnant, and we would like to hear from both men and women.

If you are interested in participating in our questionnaire study please let us know by emailing us at the address below and we will get back to you.

FURTHER INFORMATION

Our research project is called RAPID (Reliable, Accurate Prenatal non-Invasive Diagnosis), and is funded by the UK National Institute for Health Research (NIHR). If you are interested in participating or have any questions about NIPD please email us at rapid@ich.ucl.ac.uk. There is also a website with more information at www.rapid.nhs.uk.

HANDY HINT OF 2010!

Confounded by the difficulty of cleaning out the ridiculously tiny and awkwardly placed filter on my constantly in use washing machine, I was at my wit's end and unable to face waiting for an engineer. The Hoover just wasn't helping and then, I had a brainwave! Alex's suction machine saves the day!! Got any other alternative uses for medical equipment? —let us know!

AND FINALLY...

- Christmas gift suggestions:
- To your enemy, forgiveness.
- To an opponent, tolerance.
- To a friend, your heart.
- To a customer, service.
- To all, charity.
- To every child, a good example.
- To yourself, respect



REMEMBERING DEPARTED FRIENDS AND FAMILY

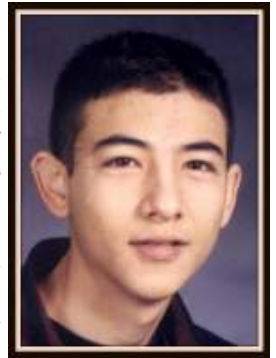
Marc Elliott fell asleep on 14/08/2010 aged 6 years

"You showed us that love and happiness can conquer all that brings you down. We know you fought long and hard to stay as long as you did and although it hurts us so much that God thought you were too special to stay with us, your smile and hearty laugh gives us hope that we will be reunited someday. You are watching over us now and we will always be thinking of you." Our love for you is eternal.
Adel and Marc Elliott



Brenton Tsu, September 16 1983 to February 5 2010

Brenton, 26 years old of Yonkers, was called to God on February 5, 2010. Cherished son of Elaine Guzy Tsu. Beloved brother of Benjamin and Jacqueline. Brenton attended PEARLS, Rye Country Day, graduating in the first class of the International Baccalaureate—Yonkers HS in 2001. His family nearly lost him at 9 years old in an Addison's Disease adrenal crisis. Then, when he was soon to begin studies at SUNY Albany he was the victim of a car crash which caused him traumatic brain injury. Recovery began dramatically and continued until yet another catastrophic event caused the onset of ALD. Brenton loved to play basketball, listen to music and be with his friends, who would turn to him for insight. His family is blessed to have had Brenton in their lives.



Fred Forrestal who sadly left us on 7 November 2010.

A sad farewell to Jamie Forrestal's dad, Fred. He is always in our hearts and so sadly missed. Fred is father to adult ALD victim, Jamie Forrestal, and donations of £310 were given at the funeral for ALD Life in place of flowers. Our thoughts are with Charlotte, Jamie and all of Fred's family

I would like to add to this part the sad and sudden demise of our dear friend, Hratch Ogali, on 16 July 2010. Hratch had been instrumental in helping us come to terms with Alex's illness and helping him to achieve more than we could have ever dreamed of. We are eternally grateful to his teachings and our sincere condolences go out to his family.



NEVER FORGOTTEN

Billy George Apps, age 7

Daniel Bray, age 6

James Cowpland

Devin Dreher, age 13

Ronald Edwards, age 68

Jonathan Mark Ellerby, age 41

Marc Elliott, age 6

Timmy Fox, age 13

Sudhir Garg, age 42

Mike Garrett, age 55

Alexander Harrison, age 8

Nora Hemestretch, age 89

Aaron Robert Hultman, age 9

James P Kane sr, age 53

Christopher Andrew Keenan, age 10

Jesse Carljames Lightfoot, age 17

Oliver Liley, age 14

George Ross Martin, age 8

Ruben Daniel Miramontes, age 12

Nathan Kurtis Morganroth, age 6

Donald Morrison, age 45

Lorenzo Odone, age 30

Jonathan Lee Padgett, age 28

Vivek Palanisamy, age 11

Joseph Payne, age 6

Sebastian Pecorini, age 10

Lawrence Prifti, age 8

Bailey Robinson, age 7

Joshua Ronquillo, age 7

Stephen Scanlon, age 36

Michael Strangwood, age 13

David John Suppan, age 10

Brenton Tsu, age 26

John Michael Vasquez, age 14

