

Welcome to Issue Nine Alex Hulme Foundation Newsletter

May we send you all our best wishes for a healthy and prosperous 2014.

As we enter the Foundation's third year another year, spurred on by your generous and continued support, we continue to work tirelessly to ensure Alex's legacy meets its aims and we reach our target of finding a cure for this horrendous disease and also develop kinder treatments in the process.

Each year brings a mixture of trepidation as we hope the success the **Alex Hulme Foundation** has achieved to date continues but also with great excitement. As you will read over the next few pages, we have a lot to be excited about as we have many new developments to share with you. So much so, we have had to expand this issue to six pages from our original four so as to fit it all in!

Thank you to each and every one of you for your help, love and support.

EQUIPMENT UPDATE

We are delighted to announce that due to the continued generosity of so many people we have now reached our second equipment target and have raised the £15,111 to purchase a **Bioruptor Sonication Device** which uses sound waves to break apart cells. The value of this equipment exceeds the amount other grant providers will fund so your donations have proved invaluable.

As was the case with the flow cytometer we presented Dr. Turner with at last year's Star Ball, Suzanne and her team previously had to book and pay for the use of a machine in another lab which had an impact on the progression of the project. Dr Turner took delivery of the machine just before Christmas and, as can be seen from the picture on page two, it is already working hard to provide vital results and information.

ALEX HULME FOUNDATION PhD

Having provided Dr. Turner with another vital piece of equipment we asked her for our next target. Suzanne suggested we consider an Alex Hulme Foundation PhD Studentship Award. Being able to provide such an award is considered to be a very prestigious step forward in the world of scientific research so would attract the very highest calibre of student. The PhD student would be tasked with



OUR SPECIAL ALEX

providing significant results for B-Cell NHL and it's pathogenesis with those results feeding back into future trials and directly into clinic to treat patients. The student would pick up from Jackie's work when she leaves in October so having someone dedicated full time to the project for three to four years would be great advantage for continuity. The student would be registered at the University of Cambridge and we would pay for the student's fees and stipend for a three year PhD studentship. An additional fourth year can be awarded, generally in year three. The other requirement of us would be to meet consumable costs for three years as the student would be writing up their thesis in the fourth year of the PhD.

As Trustees we considered the costs of approximately £157,000 by October 2017 fit with our fundraising targets. This along with the benefit of funding a full time researcher in the name of the Foundation and knowing the definitive cost of producing results made our decision a very easy one to make. The adverts have now gone to press so we hope to be able to report further developments in the next issue.

We currently have £57,000 available so we hope we can count on your support in raising the additional £100,000 in just under four years!

(For a detailed breakdown of our donations & costs to date, please see page two)



UNIVERSITY OF CAMBRIDGE
DEPARTMENT OF PATHOLOGY
DIVISION OF MOLECULAR
HISTOPATHOLOGY

Wow! What a great way start to the year – a new piece of essential equipment and an agreement from the Alex Hulme Foundation to fund a PhD studentship award commencing in October 2014.

The piece of equipment is a Biorupter – a machine that breaks down DNA into smaller pieces so that they are easier to work with. The Biorupter arrived just before Christmas and is now in the lab and up and running. This will really help us to work faster in order that we can keep the work flowing without having to borrow a decrepit old machine in another department. Thanks once again for your fantastic fundraising efforts.

One of the biggest costs in a science research programme is the funding of staff salaries – this often takes up a large part of any project grant. Of course without the staff we cannot carry out the research and so I am delighted that the Alex Hulme Foundation will be supporting a PhD student in the lab from October 2014 for a period of three years. This student will pick up from where Jackie leaves off in the summer (if you remember, Jackie is the student you are currently supporting with a small stipend) and therefore will provide continuity to our research programme into paediatric B-NHL. PhD students generally spend 3 to 4 years carrying out research into a defined research project, spending their days (nights, weekends.....) in the lab. Naturally, there is an initial settling in and training period but very soon, good students are able to work independently with some guidance from their supervisor(s). We hope to recruit an excellent student who will be jointly supervised by myself and Dr Amos Burke, a paediatric oncologist at Addenbrooke's Hospital in Cambridge. The combination of a clinical supervisor and a scientist really gives the student many advantages and enables them to experience the clinical issues as well as discovering ways to research for answers to clinical problems. We are very excited at this prospect and welcome the opportunity to bring together the lab and the clinic to work towards finding better treatments for children with B-NHL.



**JACKIE &
THE BIORUPTOR**

This just leaves me to wish you all a prosperous and happy New Year and once again to thank you all for your wonderful fundraising efforts – you really are all making such a big difference to our research.

Kind Regards
Suzanne

Dr Suzanne D. Turner PhD

Leukaemia and Lymphoma Research Bennett Fellow

FINANCIAL POSITION

To provide full transparency we wish to evidence a breakdown of donations and costs for the Foundation since it was formed in October 2011.

To date the Foundation has received £132,156.07. From this, deduction's stand at £12989.87. This consists of £5392.57 and £5160.20 for the two *Star* Balls along with £2437.10 to purchase wristbands, t-shirts, calendars, wriststraps and keyrings, thus leaving £119,166.20. We have paid Dr Turner £15,000 for project costs and £5,000 for the ten month stipend for Jackie, her assistant. We have spent £42,111 on two machines for the lab which leaves £57,055.20. We pledge that money will only be spent when the expense can be recouped and a profit on that expenditure made. If you have any queries, please don't hesitate to contact us.

SAMMY T JOINS AHF

We are delighted and honoured to announce that, Sale Sharks and New Zealand Inside Centre, **Sam Tuitupou**, has accepted an invitation to become an Ambassador for the Alex Hulme Foundation. Sam's standing within the International Rugby Union arena along with his popular and warm nature will be a massive asset to the Foundation in its efforts to enhance research into B-Cell Non Hodgkin Lymphoma in Children.

During his junior career Sam captained the New Zealand Under-19 and Under-21 sides to world titles before stepping up to senior level; where Sam won two Air New Zealand Cup titles and a Super 14 championship with Auckland Blues. Sam also won acclaim on the international stage with his first All Blacks call-up for the clash with England at Dunedin in 2004. He played for the All Blacks between 2004 and 2006, earning nine caps. In 2007 Sam left New Zealand rugby to join Worcester Warriors in the English Premiership where he stayed until June 2010. Sam moved to Munster for the 2010/2011 season before moving to Sale Sharks in 2011 for whom he has since played over fifty games.

We met Sam and his lovely family when Matt started playing rugby for Sale Scorpions in the same age group as Sam's stepson Mitch and were saddened to realize that Sam and his family have also been affected by cancer having lost his brother Simote to the disease on 11th January 2012

Anybody who knows him will agree that Sam is a fantastic guy and will always make time for those who wish to ask advice or just have a chat. Sam has been more than happy to get involved and do anything he can for the Foundation which is really appreciated.

Everyone at the Alex Hulme Foundation is extremely grateful to Sam for accepting our invitation and also to the Sale Sharks for contributing to this support. We look forward to working with Sam to raise awareness of the Foundation and the aims we hope to achieve at future events and fundraising activities.

Together we are making a difference



SAM & MATT

JUST TEXT GIVING

To enhance our fundraising capabilities and to provide alternative methods for supporters to make donations to the Foundation we have now signed up to Just Text Giving. As a consequence, donations can now be made by texting **ALEX29** to **70070** along with the amount you wish to donate. For example, if you wish to donate £5 you would write a text message reading **ALEX29 £5** and send it to **70070**. Donations can be made to the value of £1, £2, £3, £4, £5 or £10.

Once the message has been sent you will receive a text message receipt, and the chance to add Gift Aid (by filling in a web form or by text message).

If you don't add Gift Aid straight away, you will receive a reminder text 24 hours later so the Foundation don't miss out on an extra 20% on top of your donation at no extra cost to you.

Unlike the main Just Giving site there isn't a charge to the Foundation for this service. It costs nothing to set up, there are no running costs and no commission is taken from the donations we receive. So every penny goes to our charity, where it's needed most.

The Foundation will receive the donations in the month after they were made, and Gift Aid the month after that. If you have any queries about this service, please do not hesitate to get in touch.

BAXTER'S BLOG

Hi Everybody, I hope everyone had a Happy Christmas and great New Year?

Are you impressed? I have heard Mum, Dad and Matt say that so many times lately; I thought I would say it too!

Quite a few things have happened to me since I last 'pawed' to you. Some were great but some not so good. Have you seen the Volkswagen advert with the dogs in? In one picture you see a car with Cocker Spaniels in it. All of those doggies came from Dreamfields Cocker Spaniels in Dronfield where I came from and even better is the chocolate and tan one was Chocs, my Mum! It was great to see her but even though I sniffed her picture on the box in the corner of the room I couldn't smell her? Not so good

was that I have had another haircut! The lady went a bit mad this time and there was more hair on the floor than was left on me. I think I had less hair than my Grandad! I have also been to see that weird man again. You know the one who keeps giving me biscuits and then feels me all over and I mean all over! Then he sticks sharp things in my neck and even worse squirted some stuff up my nose which made me sneeze. I don't think Dad was too happy either as I am sure there was a tear in his eye when he passed a piece of plastic to the lady behind the counter!

I have been into Dad's work again and had lots of cuddles. Auntie Katie and Auntie Sue were there as always and I met some new people too who said nice things to me and took my picture. Sausages!

One strange thing did happen though. A bit ago the front door opened in the middle of the night a big bloke with a white beard and wearing a red suit came in with a big sack on his shoulder. He left parcels under our tree and some of them were for me! I got a new jumper, a hat and scarf and lots of things to eat. I can't wait for him to visit again. I don't think he coming for a while though as they have taken the tree down which is a blow as I loved to pinch the things that were hanging off it and chew them up!

I am really looking forward to seeing you, perhaps just for a cuddle or to see you raising money for Alex. Until then, look out for me on Facebook where I am listed as **Baxter Hulme**. or please e-mail at **baxter@alexhulmefoundation.co.uk**

I'm off to chase Matt now and then for a snooze but I hope to see you all very soon,

Baxter xx



BAXTER

THE GIVING MACHINE

Following the e-mail flyer sent out in December, the Foundation now has over fifty people who have subscribed to **TheGivingMachine** and are using the site when shopping online. As a consequence, for the sake of a couple of extra clicks, those wonderful people have raised almost £500 pounds for the Foundation during 2013. If you haven't already joined, please **visit www.thegivingmachine.co.uk** to find out how you can raise money for the Foundation at no extra cost to yourself. Thank you.

FOREIGN COINS?

Have you been abroad on holiday or on business and have returned with currency from the country you have visited? If so, you may have found it difficult to exchange the coins back to sterling so they end up left lying around?

In conjunction with **leftovercurrency.com** we are now able to exchange foreign coins, as well as notes, even those that are no longer in circulation. The added bonus is that leftovercurrency.com will add an additional 5% to the exchange rate value as a charity donation. If you have any currency you wish to donate, please get in touch as this would be gratefully received.

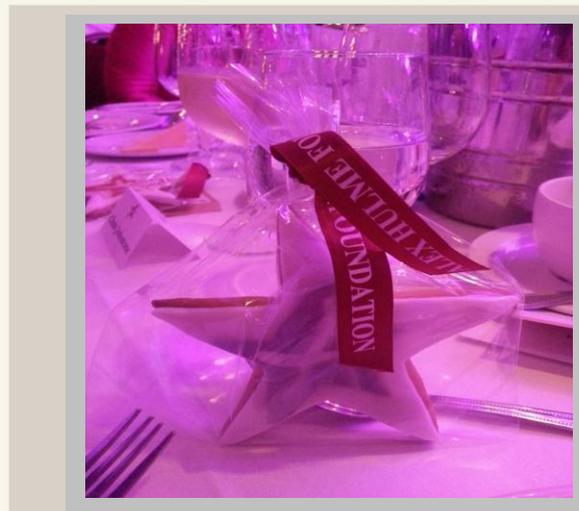
ARE YOU A SOCIAL MEDIA EXPERT?

As part of our plan for growing the charity, particularly the awareness, one important area that we do not consider has been fully developed is social media. Although we have a Facebook page along with Twitter and LinkedIn accounts we are not gaining the full benefit the rapid growth in this form of media. Facebook is just about within our capabilities but we don't use it to the extent we should. We are grateful to Alex's cousin Amy for gaining over five hundred followers for the Twitter account but again, we don't feel we use it to the maximum. LinkedIn is new to us but the account is up and running so just needs development. There may be other methods we can use or develop but this is purely down to a lack of time and of course, expertise.

This is where our plea for help comes in. Are you or do you know someone who is a Social Media expert and would like to volunteer your services and time to help us develop and maintain these forms of media? If you feel you are in a position to help, then please drop us a line at info@alexhulmefoundation or call us on 07811 510311 or 0161 973 1343 and we can discuss how we can move this forward. Thank you.

CHARITY GIVING UPDATE!

As advised in earlier issues, having been investigated by the Charities Commission, The Dove Trust which ran Charity Giving, who in turn collected our online donations and sponsorship money, have now been closed down owing the Foundation approximately £5,000. It is estimated that around £2.2M is owed to charities and that approximately £500,000 is available for an initial distribution to over 1,800 charities and good causes. The Charity Commission want to make a distribution as soon as possible, but they have been advised that, given the complexity of the charity and trust law issues involved, only the court can decide on the fairest and most equitable approach to distributing currently available funds. The Commission has made an application to ask the court and it hopes a directions hearing will take place in early January 2014, with a full hearing following early in 2014. The Commission will fund the court application to ensure as much money as possible can go to the charities. How much is ultimately available to charities will depend on the success of the recovery of funds on behalf of the charity. All available options for recovery are being



***STAR* BALL**

pursued including from debtors and trustees. Ultimately, the trustees are responsible and liable for making good any losses.

All future donations and sponsorship for the Foundation is being collected through BT's MyDonate website along with the facility for those who wish to create a fundraising page for an event.

Please visit www.mydonatebt.com and search for the **Alex Hulme Foundation**.

DATE FOR YOUR DIARY?

3rd ANNUAL *STAR* BALL

Worsley Park Marriott on Saturday July 5th 2014

Planning is well underway for our third Charity Ball with the date and venue now confirmed so we hope you can join us.

We have frozen the price of a ticket at **£35** each which will include a three course meal, entertainment, raffle and auction. Tickets will go on sale on **1st February 2014** and can be obtained via the website or by sending us a text or e-mail.

In the meantime, if you feel you are able to help or know someone who would be willing to contribute to the evening, please don't hesitate to contact us.

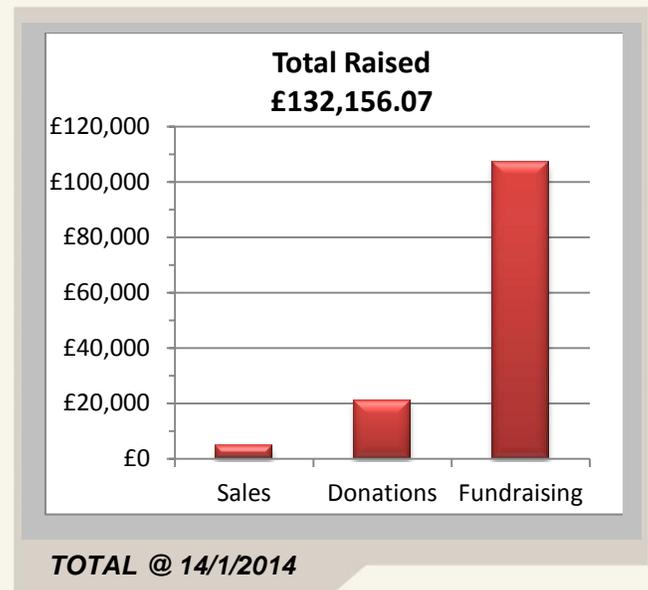
Thank you.

FUNDRAISING UPDATE

Since the last newsletter many people have undertaken various types of events or made generous donations. Please see the website for more information on some of these events.

Josh Barrett
Councillor Jane Baugh
Jonathan & Louise Brownlow
Diane Dyer
Helen & George Floros
Barrow & Lesley Gaskarth
Marion Gilchrist
Dawn Goddard (via eBay)
Heather Harrisson
Margaret Harrop
Hazel Grove United Reformed Church
Lisa & Stuart Heathcote, family & friends
Ian Hughes
Brian Hulme – OSCAR Pet Foods
Simon, Helen, Ellie & Fay Jackson
Garth & Gill Jones
S.B. Kay
Arthur Kershaws
Alison McCullen
Len Major
Margaret Neville-Cooper
Sandra, Brian & Angharad Pearce
Ceri & Darren Pickford
Councillor Brian Rigby
Lindsey & Mike Robinson
Mark Rowe - ROWES GARDENING
Sale Festival Committee
Sale Waterside
Penny Sankey
Sharon & Chris Saunders
Farrah & Naeem Shahid
Debbie Shaw, family & friends
SIG Trading
Sally Sweeney
Corporate Office, Tameside & Glossop CCG
Admin Staff, Tameside & Glossop Community Healthcare
Susan Taylor
Carolyn Waywell
Woodheys Primary School Staff, Parents and Pupils
Hujun & Tong Yin

Thank you to everyone for their efforts and support



FUTURE EVENTS

1st to 31st January 2014 - Dryathlon – Karen & Ian Sykes, Lisa & Jay Payne

Monday 10th & Tuesday 11th February 2014 - Boden Party – Carole Coram

Sunday 2nd March 2014 - Phil Sephton – Cambridge Marathon & Sunday 9th March 2014 - St Helens 10K

STAR BALL 2014

Saturday July 5th 2014 at Worsley Park Marriott

For further details of these events, please visit the website: www.alexhulmefoundation.co.uk

ITEMS FOR SALE

- * 2014 Wall & Desktop Calendars* - £8
 - * White T-Shirts* S (36"), M (40"), L (44"), XL (46") - £10
 - * Wrist Straps* - AHF - Alex Hulme Foundation - £2
 - * Wristbands* - Adult & Ladies/Youth Sizes - £2
 - * Keyrings* - AHF - Alex Hulme Foundation - £2
 - * Cross Stitch Cards * - Made to order £1.50 to £2
- *****
Simply Trafford COOKBOOK - £4

Thank you for your continued support.

Dave, Nic, *Alex*, Matt & Baxter xxx