



Welcome and update from Karen & Kevin

A warm welcome to our summer newsletter. We hope that you've been able to enjoy the recent blue skies and warm weather. It's great that we are including summer in this year's seasons!

We have had a busy few months since we last wrote to you with positive updates from our researchers which we'll share with you in our Science Update section.

In May we participated in a CCLG (Children with Cancer and Leukaemia Group) Conference in London. It was a great opportunity to meet face to face and chat to other similar organisations with whom we have often spoken but never previously met. The agenda was varied and allowed interesting discussion and as is often the case where children and cancer are concerned, there were also frustrations at the slow pace of progress in a number of areas.

On 16th June we set off to Brussels to present on the panel at a European Parliament Health Meeting entitled "Paediatric Regulation: Are children still missing out on potentially life-saving treatments?" co-hosted by MEPs Glenis Willmott (UK) and Alojz Peterle (Slovenia). We spoke about our experiences of Christopher's illness and the need for a change to the implementation of article 11(b) within the EU Paediatric Regulation. The panel of speakers comprised European Commission representative Olga Solomon, European Federation of Pharmaceutical Industry Associations (EFPIA) representative Magda Chelbus and Clinical Expert from Milan, Professor Andrea Biondi. We are grateful to Glenis Willmott for ensuring our action points were taken forward for further discussion in the early autumn and we will continue our fight for change. We remain realistic and optimistic although we anticipate a certain amount of opposition. If we are successful, it would mean a massive step forward in terms of early access to new potential life saving drugs across Europe for children with cancer. Fingers crossed!

We continue to focus on raising awareness through the media in general as well as through social media. Our Christopher's Smile facebook page following is slowly but surely growing. Please check it out and "Like" and "Share" with your friends. You'll be helping to raise the profile of the charity and the work we fund. You can also follow us on Twitter @cozkids.

As well as finding out what our supporters have been up to recently with various events and activities, we have updates from Sam Exworth and Jack Daly on the last six months of life following their earlier cancer treatments. We think you'll find their accounts insightful. On another note, if you would like a home collection box or one of our car stickers, please get in touch. We still have some and we would love them to be put to good use!

We hope as always you enjoy the newsletter....Karen & Kevin



ABOVE: ENVI Health Meeting Panel, Altiero Spinelli building at the European Parliament; the audience and Kevin and Karen Capel with Glenis Willmott MEP

Our main fundraising event this year is our Autumn Ball at Wentworth. We will be celebrating 7 years of Christopher's Smile and we will be offering a great night out for everyone.

The evening will commence with a drinks reception followed by a specially selected 3 course dinner including wine. We will have fundraising activities including live and silent auctions and musical entertainment for you to dance the night away. If you would like to reserve a table or if you wish to attend with a smaller group of friends or colleagues please get in touch with us. We hope you'll join us.

CRAFT & GIFT FAIR

Sunday 8th November 2015
12 - 4pm

The Briars Centre
Briar Avenue
Lightwater
Surrey GU18 5YY

in aid of

Christopher's
Smile
coz kids get cancer too

Stained Glass • Handmade bath and body products
Speciality cakes, chilli products and fudge
Face painting • Bottle Tombola
Personalised Plaques & Bags • Floristry
Cards • Jewellery
Handmade cushions, bags and bunting

For more information contact

Klaudia Gibson 07876 506749 or Caroline Atkins 07961 986917

CHRISTOPHER'S SMILE BALL



SATURDAY 17 TH OCTOBER 2015 7PM TO 1AM

WENTWORTH GOLF CLUB

TICKETS £85

TABLES UP TO 12 PERSONS

For tickets visit www.christopherssmile.org.uk
or email info@christopherssmile.org.uk



REGISTERED CHARITY 112906



**Fashion Show by Amanda
at Ashted Peace Memorial Hall
Wednesday 16th September
Doors open 7.30 for 8.00 start**

Tickets £12.50 to include a glass of wine and nibbles

Email:

**rosemary@christopherssmile.org.uk
for more details and tickets**

Camphill Family Fun Day West Byfleet

From 12.00 on Monday 31st August.

Games, BBQ, bouncy castle, raffle and cake stall.

Sainsbury's

We'll be bag packing at Sainsbury's Camberley on 5th and 6th September and 2nd October. More dates will be added. If you can help at all, please let us know.

Waitrose Sunningdale Collection

Saturday 19th September

**Please let us know if you can help us at
all during the day!**

**Please get in touch with us at
info@christopherssmile.org.uk**

www.christopherssmile.org.uk



Our two ongoing funded researchers Elisa Izquierdo and Dr Sally George at The Institute of Cancer Research (ICR) have been taking important steps towards the validation and clinical implementation of a new genetic test (the first of its kind for children in the UK) to help improve outcomes for children.

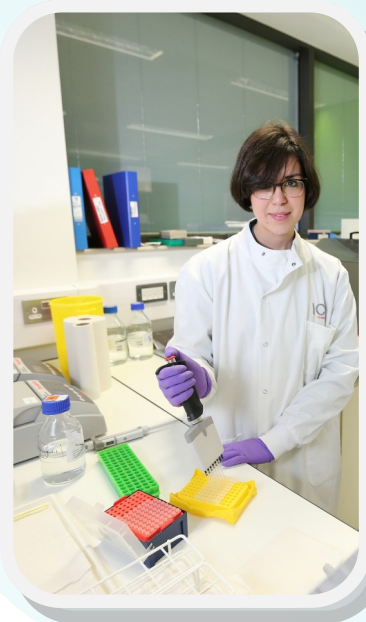
The genetic test, developed at the ICR last year and funded by Christopher's Smile has the potential to improve diagnosis and inform treatment strategies for children – not only on clinical trials at the partner hospital, The Royal Marsden but across the UK.

The aim is for every child with a solid tumour to have the molecular make up of their tumour analysed using the test at diagnosis and relapse, offering children a truly precision approach to their treatment. More targeted therapies have the potential to improve outcomes with fewer side-effects than current standard treatments.

Elisa Izquierdo Delgado has been performing a detailed validation of the test, which uses next generation sequencing (NGS) to analyse patient samples for the genetic faults that drive childhood cancers, providing a valuable tool in clinical decision making.

Elisa has sequenced over 90 tumour samples, including cell lines and clinical samples. Her comprehensive study showed that around half of the clinical samples had a genetic alteration for which a trial targeting those alterations in adults already exists. This provides strong evidence that personalised precision medicine can be adopted for treating childhood cancers as well as adult cancers.

The validation of the paediatric gene panel has been very successful so far: to the point where this test is being implemented in all paediatric patients from The Royal Marsden with solid cancers.



Dr Sally George, the second of our funded scientists, has made great progress in facilitating the incorporation of the NGS panel test into clinical trials for children. The ICR and Royal Marsden recently received ethical approval for a study called 'Tumour profiling for Biomarker Development'. Excitingly, this means that every child with a solid tumour treated at the Royal Marsden, from this month (July 2015), is eligible to enrol in this study. Each child will be offered NGS panel testing on their tumour with results being made available to their clinical team.

LHS : Elisa Izquierdo, Christopher's Smile funded paediatric molecular pathologist demonstrating work with a multi channel pipette

However, not content with piloting the NGS panel locally at The Royal Marsden Hospital, the ICR is also putting in place the infra-structure to enable the NGS panel test to be made available for all children in the UK. Sally has been involved in setting up a steering committee with the Children's Cancer and Leukaemia Group (CCLG) tumour bank and has identified a network of pathologists to develop a centralised system for pathological validation and processing of samples and distribution for NGS panel testing. This national initiative for integration of NGS panel testing across the UK, known as 'METEOR', will feed directly into 'COMET' – a national trial where patients are offered biopsy at the time of relapse for a comprehensive molecular profiling of their tumours (including NGS panel testing) in order to identify 'targetable' genetic alterations in individuals. We are proud to have initiated the funding for this panel work and we believe that this could see the introduction of a huge step change in the way in which children will be treated for cancer.

Elisa will be using the gene panel to analyse patient samples retrospectively from multiple paediatric tumour types. This successful pilot study has the potential to provide key information for implementing a precision medicine approach for children with cancer. It is providing new information for further research, but crucially will suggest which genetic alterations are relevant in childhood cancers. Data from this work was presented by us recently in our call for change in the implementation of certain clauses in the Paediatric Regulation at the European Parliament, It is crucial that such data is obtained to enable the changes in frontline treatment so critically needed.

In March 2015 the ICR hosted a SIOPEN genomics conference focusing on integration of NGS panel testing in to the next clinical trial for patients with high-risk neuroblastoma. This meeting was very successful, achieving a consensus approach for NGS panel testing across Europe. The ICR are hosting a second more focused meeting this month to finalise the design and strategy for clinical implementation of this panel.

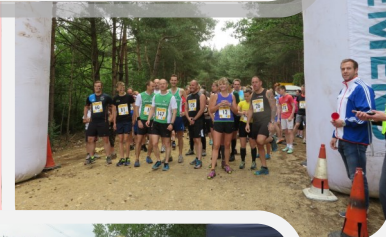
RHS FROM L TO R: Dr Sally George, Elisa Izquierdo, Karen and Kevin Capel in the labs at the Institute of Cancer Research, Sutton



We were delighted with the turn out and great crowd of enthusiastic participants who began to arrive at the Bagshot MOD test track site from 8.30 on Sunday morning 21st June in anticipation of our second **Feat for Feet** event. There were teams wearing fancy dress, sporting teams and walking teams, individuals and keen runners as well as equally keen walkers. Face painting was available for those who wanted to "camouflage" their faces or just look muddy! A great warm up was hosted by Della Warrener and this helped to raise heart rates ready to start the race at 10 o'clock sharp. Tim Benjamin, former British 400m Olympian was in charge of the starter horn and at 10a.m. precisely everyone was "off" to encounter the ups and downs of the 4 or 8k course. Prizes were awarded to fastest male and female and fastest Junior over 8k and we also had prizes for Juniors of over 12 and under 12 years who successfully completed 4k.

Camberley fire station and a number of firefighters provided added interest for both spectators and participants with one of their fire engines and refreshments and cakes were available to hungry runners and walkers as well as spectators. We are grateful to all the helpers on the day and to those who helped prepare and organise the event over the past months. Without this help it wouldn't have been possible to run the event which will help fund more vital research into finding safe and effective treatments for children with cancer.

FEAT FOR FEET 2015



ABOVE : Warm up; under starters orders with Tim Benjamin; Della's demons; Frimley running team; Ollie and Bettina; BeFit Team ladies walkers; runners at the finish line



On Saturday 2nd May we headed north to Newark Showground where the **Autosleepers Owners Caravan Club 2015 Rally** was underway. Christopher's Smile was the Club's chosen charity for this year and we were invited to participate in their weekend of activities. On Sunday morning before proceedings drew to a close for this year, we were presented with a cheque for £2,292 by the Chairman with additional donations to follow. We are grateful for the support and it was an honour to meet new people and introduce the charity to them.

ABOVE : Cheque presentation at Autosleepers by the Lady Chairman for 2015

Sainsbury's

In June we were invited to present to Sainsbury's Camberley and were shortlisted as one of three local charities. Thanks to those of you who voted for us both online and in store, we secured the most votes and have been chosen as the store's Local Charity for this year.

On Wednesday 6th May **Emma Cannon** from **Lightwater Leisure Centre** organised a Bake a Smile coffee morning and shopping event. As well as cakes and coffee, a spa type "treatment" was offered and raffled by local ladies Kim Pritchard and Erika Laycock and the event helped to raise over £200 for the charity. Thank you everyone who took part and came along to support.

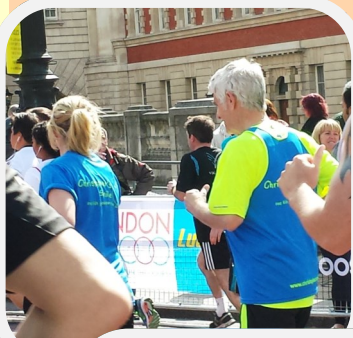
RHS: Stallholders with Anita Lorenc (second from right) from the coffee shop who supported the event and Emma Cannon (on right hand side) from Lightwater Leisure Centre



LHS: Summer Karate Camp organised by Bob Davis.

Participants in "civvies" and "ready for action".

Our thanks to **Robert Davis** who ran a **Summer Karate Camp** at **Maple Cross School** in Hertfordshire on 2nd—4th May. We were delighted to be supported by the Karate Camp for a second time this year. A donation of £380 from the proceeds of the activities was made following the Camp weekend which was great fun for all who took part.



Three special people had been training hard on behalf of Christopher's Smile ready to take part in the BUPA London 10k on 25th May. **Frances Ruthven**, **Denis Conroy** and **Gail Tudor** all did us proud completing the course and finishing in great times whilst raising funds for the charity. It was great to cheer you on and also see smiling faces (albeit near to the start!)



The brilliant **TASIS** England students and staff (thanks to **Sharon Hudgens**) based in Thorpe Surrey organised a Senior Night Basketball Games fundraiser evening along with a number of linked activities — a sale of t-shirts, "rags and tags day" for the whole school and a bake sale. They successfully raised in excess of £2,000 for the charity which is a fantastic achievement. Thank you for such fantastic support.



LHS: TOP PHOTO: Frances Ruthven and Denis Conroy speeding past by Admiralty Arch, London at the start of their 10k run and BOTTOM PHOTO: Gail Tudor clearly enjoying the first few kilometres of her 10k challenge!



On 17th June the **3 Counties Business Club** extended an invitation to us to speak at their morning meeting about work in which the charity has recently been engaged. We were delighted to also be presented with a cheque donation from the group for £500 in support our research.

LHS: John Fairley, Chair of 3 Counties Business Club presents cheque to Karen Capel at Pennyhill Park Hotel, Bagshot

LVS Ascot

A Co-educational Day & Boarding School
for young people aged 4 - 18

The Christopher Capel Cup, in memory of Christopher has now been placed at **Licensed Victualler's School** in Ascot for 6 years and each year it is presented to the most deserving pupil who has notably demonstrated qualities such as care and consideration for others. The school has supported the charity on a number of occasions in the past and we were privileged to receive a donation in the early summer of £4,000.

Heather Ridge Infant School in Camberley hosted a successful Bake A Smile after school on 7th July. Within approximately 20 minutes all cakes were sold and more than £130 had been raised! Thanks to all who contributed by making cakes, selling and eating them.



Christopher's
Smile

coz kids get cancer too



Bake A Smile

Registered Charity No. 1220966

We are grateful for the continued support from **The Lodge of Industry 6068** who made a recent donation of £150.



The Windlesham Picnic organised by The Windlesham Picnic Committee has become a local tradition over the years.

Around 250-300 local residents from Windlesham, Bagshot and Lightwater bring their own picnics and drinks and enjoy the ambiance of a summer's evening whilst listening and dancing to the music by the live band. All monies raised are donated to local charities and we were chosen as one of this year's recipients. We had a great evening and enjoyed meeting new people as well as having a chance to relax in good company.



TOP LHS: Preparations and pitch set up underway; BOTTOM LEFT: Karen and Kevin by the raffle table; TOP RIGHT: Introducing the charity BOTTOM LEFT: Dancing to The Fat Cats live band

We remain grateful to everyone who supports or has supported our charity in the many and varied ways you do so. Please stay in touch with us and be part of making a difference for children with cancer.

We continue our updates on our friends and supporters Sam and Jack who struggle to deal with challenges post-treatment. This is what they've been doing and how they've been getting along over the past few months....

Jack's mum writes: I am pleased to say that we have hit the 5 year mark since the end of Jack's chemotherapy and radiotherapy treatments.

However, although this is a fantastic achievement, it still doesn't give us any guarantees that the beast won't return! With this type of tumour, you can't be too optimistic and the fear of symptoms returning is always there.

We are now having yearly scans and regular blood tests together with 6 monthly appointments to Oxford for Jack's endocrine appointments to make sure everything is still ok and to ensure his hormones are behaving. The blood tests sound simple but they are far from it! Chemotherapy and endless needles, have damaged Jack's veins to the point where it is extremely difficult to find one at all. This creates a lot of anxiety for Jack and that alone makes it even more difficult because the veins hide even more! Every blood test has to be planned with distracting devices like a game on Jack's phone. Blankets and hot water bottles are needed to keep warm along with hot chocolate and "emla" cream to numb the area along with ice-cold spray. We usually have a few people on board to help Jack with his anxiety during the test. As for a simple MRI scan, Jack needs gas and air because a cannula has to be inserted. As always, Jack's energy levels are still very low as his hormones have been affected from treatment. That and being a typical teenager now mean that he spends most of his time at weekends chilling in his bedroom or actually sleeping!

There is always a silver lining to every cloud though and Jack was up flying a plane at Blackbushe airfields recently, thanks to O.S.C.A.R. (offering support for children and relatives) He had a fantastic day out with his friend Lauren. Jack is still enjoying his street dance classes when he has the energy and he performed in an amazing show recently at the weekend!

BELOW LEFT: Jack with mum Helen; "in flight" with friend Lauren and Jack with his drama group



Sam writes: This year has flown and it's hard to believe that I have completed my first year at University. It has been a challenging time due to my health complications but it has also been very enjoyable and I feel a sense of achievement. In March I began to feel a lot of pain in my knee. I had the usual scans and investigations which culminated in a trip to The Royal National Orthopaedic Hospital. It seems that I have developed avascular necrosis in the lower femur above my knee and the upper tibia below my knee. I have been told to rest my leg as much as possible and to use crutches. Thankfully my Mum got me a mobility scooter to help me get around University until the end of term which made completing my studies possible, as due to my shoulder problems I can't crutch for long. We are hoping that given time it will heal and most importantly, not get any worse. My consultant is now looking into the possibility of a scan to access all of my bones as I seem to go from one problem to another. I am still having physio and I have recently had a few sessions in the hydro pool. I am enjoying been off for the summer break and I have been keeping myself busy with voluntary work at The Royal Surrey Hospital and for the University of Surrey.

ABOVE RHS: Sam with Rosemary Conroy at Wisley and Pyford Fete in July

Regular Giving

You can help Christopher's Smile by setting up a standing order to give on a regular basis. Any amount helps, a few pounds a month makes a huge difference and 100% of your donation will go to childhood cancer research.

STANDING ORDER INSTRUCTION

(Please complete in block capitals)

To: THE MANAGER

.....BANK LTD

.....

.....

Please pay to the account of:

Christopher's Smile
HSBC Bank plc
29 High Street
Camberley
GU15 3RE
(bank sort code **40-16-05**; Payee's account number **81847120**)

Please tick the 'Gift Aid' box below if you are a UK taxpayer* so that Christopher's Smile can reclaim the tax you will have paid on your donation. For every £1 you give us we can claim 25p more. To qualify for Gift Aid, it is vital you give your FULL NAME, HOME ADDRESS, POSTCODE,

the sum of £:.....

giftaid it

☐

on the.....day of the month
and then monthly thereafter until further notice

Signed:.....

Sort code:.....-.....-.....Account number:

Name:.....

Address:.....

.....

.....

Postcode:.....

Date

Registered Charity No. 1129906

**You can claim Gift Aid if you are a UK taxpayer and have paid income or Capital Gains Tax at least equal to the amount we reclaim*

Print this form, complete your details and return to Christopher's Smile, PO Box , 1363 Lightwater, GU18 5ZS. We will then forward the information to your bank.

Please continue your support—it is important to us. We look forward to seeing you soon. Karen & Kevin.

www.christopherssmile.org.uk