

Celebrating 25 years of the Childhood Eye Cancer Trust

selection is deserved based on my current form. But selection is only one hurdle. Friends and fans right behind me too which will be invaluable when we are facing those difficult... Follow Darren on Twitter @DarrenHarris... Turn to page 3 to read about two CHECT members bestowed with a great Olympic honour.

This special commemorative edition of InFocus has been brought to you with kind thanks to



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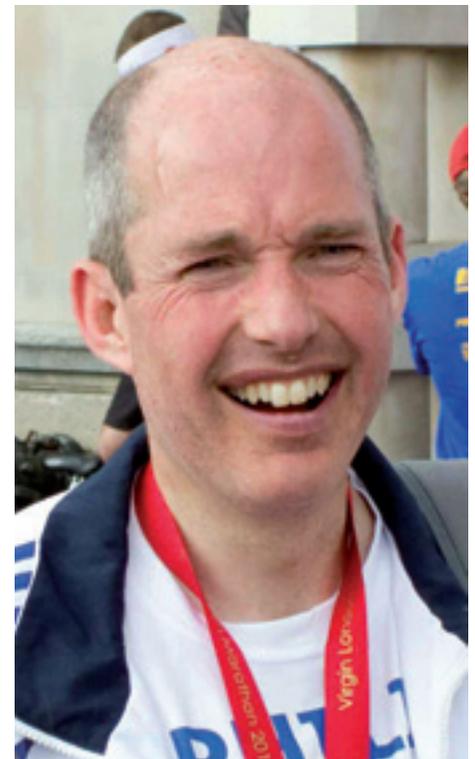
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Photo gallery and ode to CHECT

The Childhood Eye Cancer Trust has come a long way since its foundation as FISHS (Family Information and Self Help Society) in the mid 80s. However, over that time it has held to its founding objective of providing support and information to families affected by retinoblastoma (Rb).

Research was added around 10 years later when the Retinoblastoma Society, as it had officially become in 1987, merged with the David Allen Retinoblastoma Appeal, established by Pelham and Janet Allen after the death of their son from Rb. Since then awareness and influencing have been added to make CHECT's four charitable objectives. The need for awareness of the symptoms of Rb amongst parents and health professionals to enable early diagnosis is an obvious objective. In a very successful Rb awareness week we managed, amongst a lot of broadcast and print media publicity, exposure in national (and international) press.

In a recent poll of our members, the importance of influence was not rated highly; however I believe it is a crucial fourth leg to what CHECT does. Many important changes to the way the NHS Rb service is provided to patients and their families have arisen as a direct result of quiet, but forceful influencing behind the scenes. There have been many achievements and milestones in CHECT's development over the last 25 years. For me some of the most significant are:

- Raising funding to employ Jenny Coates as the first



Chairman of trustees Philip Moore

- national co-ordinator.
- The funding of Zerrin Onadim's genetics work which resulted in major breakthroughs in developing tests which could identify family links.
- The opening of a second Rb service at Birmingham Children's Hospital, which was much debated in London. The success of BCH is perhaps a good example of competition and collaboration working positively in the NHS!
- The first See Red Campaign; this put awareness raising firmly on the agenda.
- Building a specialist staff team. We now have seven, soon to be eight, dedicated team members with the necessary expertise to achieve our objectives. All very different from the days when the national co-ordinator/CEO and family support worker did everything!

We've come a long way...



Linden Smith, Libby Halford and Juliette Carter at the Big Blue Ball

- The 20th Anniversary Celebration Big Blue Ball; a wonderful evening for all attendees, but more importantly a coming together of people covering all aspects of Rb, past and present.

CHECT would not be what it is today without the dedication, support and sheer hard work of many people; there are far too many to list, but I will name just a few: Margaret Atkin (who put together the first functioning board of trustees), Audrey Allen (Chair and newsletter author for many years), Pelham and Janet Allen (who raised significant sums for research), Sandra Jeffs (chair and major fundraiser) along with husband Simon Jeffs, Sarah Hollyer (trustee for 20 years plus), Judith Kingston (London's ever present and wonderfully reassuring consultant oncologist) and Bryony Webb (who together with student Imelda Phelan and social worker Jackie Martin (nee Howe) brought

together a group of Rb-affected parents to form FISHS.

However, two individuals stand out in CHECT's history: John Hungerford and Libby Halford. John defined Rb treatment throughout our 25 years and has achieved hero status with a number of our members. John was a key part of CHECT's establishment. Libby has played virtually every role in CHECT from member/parent just after it was formed, volunteer, chair of trustees, support worker, fund raiser, lastly stepping down as CEO in 2011 after over 20 years' involvement.

Looking forward we are intending to use our 25th anniversary to celebrate our achievements, thank as many of those

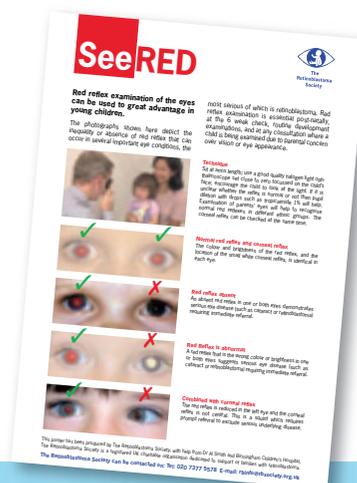
involved with CHECT as we can and raise significant funds to carry on CHECT's work. If we are successful, we would like to extend our service beyond what we currently do in three areas:

- Funding further crucial research specifically directed at the cause and treatment of Rb.
- Enhancing our awareness campaign so that every GP and health visitor is aware of the symptoms of Rb and knows what action to take. Never again should we have a child's parent told "it's nothing - come back in three months if the symptoms persist".
- Increasing our support post the treatment stage, especially to teenagers.

Longer term we would like to do more internationally other than funding some research overseas and ensuring our website is accessible worldwide; our ambitious plan to meet the needs of those affected by Rb in the UK will keep us going for quite some time to come.

Maybe our ultimate objective should be to disband CHECT as, through its work and that of the dedicated medical professionals, it is no longer required. That would be a momentous event to celebrate at our 50th anniversary!

Philip Moore
Chairman of the Board of Trustees





Margaret Atkin, Thomas Jelley, Zerrin Onadim and Jenny Coates

Early formation

The thinking of 1985 gave way to a hive of activity in 1986 when all parents attending Moorfields were invited to meetings to hear about the possible formation of a society (FISHS – aka Family Information and Self Help Society). The response was overwhelming and ideas for fundraising, support and communication via newsletter abounded.

Regional co-ordinators

A network of regional co-ordinators was quickly established of people who would befriend new parents facing retinoblastoma. They quickly formed bonds amongst themselves. The society was gifted the part-time use of a small office at Moorfields and had the backing and active support of John Hungerford, who many of you will remember as the consultant ophthalmic surgeon, and Judith Kingston, current consultant paediatric oncologist for the London Rb service.

Becoming a charity

Charitable status of the more aptly named Retinoblastoma Society was applied for and finally granted on 14th July, 1987 – the official birth date we are commemorating this year. A management

The story - how we've

What better way to start the story of the Childhood Eye Cancer Trust than with an extract from the Retinoblastoma Society's activity report 1986-1989, found buried in the archives at Barts. It reads:

"The embryonic thinking about this society started in 1985. Its concept and development were based on an American model, using a



The FISHS logo carved in a plaque

committee was set up, aims and objectives of the society agreed. The FISHS logo continued to be used alongside the Retinoblastoma Society name. A national co-ordinator was based in the office two days a week, collaborating with medical staff and supporting parents immediately after their child's diagnosis.

Family meetings

By the end of 1987 eight regional co-ordinators had been appointed across the UK. Outings were also encouraged for the families to enable siblings to join in and the first weekend gathering was held in Coventry – children went to Alton Towers while parents shared their concerns with one another.

After a promising start a few early teething troubles left the support system floundering – around this time Libby Halford's daughter Camilla was diagnosed and after treatment Libby volunteered to be a regional co-ordinator.

of CHECT e evolved

national co-ordinator to link up groups across the country. Our study was researched and written up by a final year Social Science Honours student who was based at Moorfields Hospital at the time. Her dissertation 'Mutual Support for the Families of Visually Handicapped Children' was the springboard for the subsequent growth of The Retinoblastoma Society. This student (Imelda Phelan) collaborated with Bryony Webb who helped to found the society and became the first voluntary co-ordinator."

Full support

Social workers Margaret Atkin and Jackie Martin (nee Howe), along with play specialist Mary Digby - a pioneer of childcare in hospitals - and Audrey Allen, social worker at Barts, were all on board by the early nineties, helping steer the society toward a more



Mary Digby receives a bouquet on the Retinoblastoma Society 10th anniversary



The Rb Society had an important campaigning role

stable footing and provide full support for children and parents on the ward. Audrey later went on to edit the newsletter for many years and became chair of the Rb Society management board. She and Mary Digby are still regular volunteers to this day.

Charity merger

The service at this point was run between Moorfields and Barts hospitals. 1994 brought a major milestone for the society when it merged with the David Allen Retinoblastoma Appeal (DARA), at the same time replacing the FISHS logo and name with DARA's logo - the familiar child inside the eye image which is still used today. DARA had funded Zerrin Onadim's genetics work resulting in major breakthroughs in developing tests which could identify family links.

This important merger allowed the Rb Society to adopt a more prominent role in research which it did through funding the significant Rb database project at the Childhood Cancer Research Group, under the watch of Dr Gerald Draper. This database is the source of data for the research he later undertook into second malignancies.

The Rb Society then became one of the founder members of the Genetic Interest Group (GIG) now called the Genetic Alliance UK. Dr Michaela Aldred (who had Rb as a child) was a member of the society's management committee and the representative at GIG.

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Rb awareness

Members of the board were anxious by now to increase the charity's remit towards awareness raising and after a very significant donation from one family, the Mug a GP campaign was launched in 1996.

In case you are unaware, the campaign involved sending a mug containing the Rb awareness message to every GP in the country. You can read more about this on pages 24-25.

In the late 90s the society played a major role in the campaign against the highly publicised threatened closure of Barts hospital, which after much outcry and political intervention was avoided.

Charity name change

The Rb Society decided to change its name to the Childhood Eye Cancer Trust during 2003. It was felt that the Retinoblastoma Society only meant something to people who already knew what Rb was but to reach the wider public and increase fundraising opportunities, something more accessible was needed.

The original name and strap was "Retinoblastoma Society, fighting eye cancer in children" so it was transposed to "Childhood Eye Cancer Trust, fighting retinoblastoma". The design, by This Way Up (now Fabrik), was selected and presented it in its final form to the trustees and members in late 2003 and the name, as we know it today, was then registered with the Charity Commission.

Donations and appeals

Around this time it had become clear that the management committee couldn't manage all the

25 years on, '1



From the original information leaflets to our new website, launched last year

workload and needed to employ people. Margaret Atkin had a £15,000 commitment from the Guide Dogs for the Blind and Libby Halford applied successfully to the National Lottery in the very first round of awards to charities - of which only 65 grants were made!

Personal appeals for donations towards the salary of a national co-ordinator were also made. Three-year funding was achieved enabling the trust to employ Jenny Coates. The charity also won an appeal to Children in Need to fund Mary Digby's role as Play Specialist at Barts on Wednesday clinics after her original funding ran out. These days the need for this crucial role has been recognised by the health service and we are pleased to say both Rb teams now employ their own play specialists.

Growth

A few months after the 2002 launch of the Rb service at Birmingham came a new responsibility for the charity in the form of influencing. CHECT was invited by the central funding body, at the time called NSCAG, to join the audit team responsible for ensuring the service provided in Birmingham and London met required standards. And in December 2003 Julia Morris was appointed part-time support worker for Birmingham. In 2002 Sonia Home was appointed as the charity's first chief executive -

On the Saturday morning, after we'd had a lovely breakfast, we went upstairs to meet our helpers for the day. The volunteers were from the Red Cross Society and the Womens Royal Voluntary Service. Once we all got to know each other, we boarded the coach and set off to Alton Towers.



'Setting off for Alton Towers.'

we're stronger than ever



comprehensive site produced pro bono by This Way Up (now Fabrik). This was relaunched again last year with a raft of new sections and features after months of hard work and again pro bono expertise - this time from Jigsaw (now Migcan). Did you know that we have outgrown our offices four times over the years too!

The trust has seen at least seven chairmen and some 24 members of staff who have all played a role in driving the charity ever closer to its goals. Moving forward the trust is fortunate to find itself in a stronger position than ever before – now employing eight staff – two posts of which have been introduced this year.

In recent months we have focused on future-proofing the trust, investing in a new database and IT system to enable staff to work more efficiently and subsequently deliver a better service to you.

And in our 25th year we are delighted to celebrate perhaps one of our biggest achievements to date – following our year-long campaign the signs of Rb will be included in the personal child health record of every new child born in the UK in the very near future. A very proud moment for everyone involved as we look forward to the next 25 years!

followed in 2003 by Libby Halford and in 2011 by Joy Felgate. The last 10 years has seen a transition in governance style from management committee to board of trustees, with greater emphasis being placed on the skills each member of the board can bring to the charity.

The first website was launched during 2002/3 and was replaced in 2004/5 by the more



The CHECT staff team today: (from left) Ruth McLaren, Seraye Delnissaw, Juliette Carter, Joy Felgate, Fiona Heath, Julie Firth and Julia Morris

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Congratulations
on your
25th birthday



My parents didn't get to see me for three days

Sarah Hollyer has been involved with the charity since its inception, first as a family contact before becoming trustee for 20 years. Here she talks through her extraordinary experience of Rb spanning 58 years as a patient, mother and grandmother.

I was diagnosed with bilateral Rb by a doctor family friend when I was 7 months old in spite of my mother mentioning her concerns at the baby clinic and within a day I was seen by Mr Stallard at Moorfields, admitted and had my right eye enucleated and a plaque put in my left eye.

My parents were not allowed to see me for 3 days, a concept I find unbearable - to leave your baby when they most need you - but it was common practice in those days.

When they saw me for the first time, a no doubt well meaning Mum said "if you think she looks bad now you should have seen her yesterday." When I went for EUAs I would be admitted on day 1, have the EUA on day 2 and be collected from hospital on day 3.

My abiding memory is always vomiting and my treats of a packet of Dairylea cheese



The Hollyer family, from left: William, Tomos, Helen, Clive, Sarah and Alys

triangles and sometimes Toffets neither of which I ate for days. I can't say I was traumatised by any of this, my parents would always tell me to say thank you to Mr Stallard - at the time I didn't understand why. Thanks to his pioneering treatment of Rb I am here to tell the tale.

My parents were told I should not have children - I can't imagine how difficult it must have been for them, firstly to deal with the diagnosis and treatment, then to have an uncertain future at seven months old.

Sadly by the time I had my first child 24 years later they

had both died. As we were aware of the risk of passing on the Rb gene Helen, our first child, was screened at Moorfields.

We had to leave her overnight. The next morning we were phoned to come in, but unfortunately by the time we arrived Mr Bedford had been called away which meant we had to wait a further 24 hours for the diagnosis, by which time my mind had imagined the worst scenario. So when I was eventually told she had bilateral Rb which could be treated I was a little relieved.

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She started a course of radiotherapy treatments over six weeks. We were admitted into a side room in Radcliffe ward at Barts which was an adult ward. A bed, cot and bedding were provided, so we went with the car packed with sterilisers, toys etc.

We went home on Fridays and back on Sunday. I remember once Helen and her brother Tomos were on a large ward full of old people and during the course of a few days we had to move beds 4 or 5 times. The stress got to me and I just dissolved into tears having a sick child with a chest infection on top of having treatment, being on a large ward of older sick people was not good for any of us.

I was told about my second child Tomos's diagnosis by Mr Bedford coming out of theatre calling me over, pulling down his mask and saying "he's got it". During his first course of radiotherapy we had the same side room on Radcliffe. I was able to have Helen stay with me and even more packing to do on a Sunday - this time I filled a cupboard in the room with toys and took a portable TV in.

I would go for a walk on non-treatment days to keep Helen amused. After about two weeks I decided it would be less stressful and disruptive not to go home at weekends. We would go out and go back to the hospital to sleep. This obviously had financial implications as eating out 30 years ago wasn't easy as there was very little open around Barts. Tomos had to have further

"The stress got to me and I just dissolved into tears."



Helen and her brother Tomos

'We chose to have child

radiotherapy when he was 15 months, so we repeated the whole process again.

During these years there was no support, our only contact was on clinic days with Penny the nurse. Then 25 years ago

very gradually things began to change as the Retinoblastoma Society was formed providing information,

family contact support, play specialist etc.

The children were transferred to Lucas children's ward which also provided extra support and a better environment.

EUAs were held on Radcliffe ward, we would arrive at 10.30am, nil by mouth from 6am. The list would start at 2pm, sometimes

there would be as many as 18 children being seen. At about 1pm the babies under 1 were given an anal pre-med then while they were asleep the drops were administered, sometimes it would be 4 or 5pm before they went to theatre.

After they had all been seen, parents would be invited to the treatment room to be given the results in front of a panel of consultants, fellows, social worker, sister, SHO and anyone else passing! This could be very distressing and intimidating. Sometimes it could be 7 or 8 o'clock before we left but our treat was a wonderful ice cream from an Italian deli near Goodge Street.

Not long after, I started the whole process again with William who fortunately did not inherit the Rb gene but was still screened. The EUA experience



Alys Hollyer today



Sarah's granddaughter, Cerys

I ren knowing the risks'

changed as Mary Digby the play specialist arrived. She had a wide selection of toys and activities, with a special toy up her sleeve if she noticed a child getting particularly distressed, at the same time keeping her eye on any parents who needed support and comfort. Then after the last child had gone to theatre out came the tea trolley and the atmosphere would lift, the tea and biscuits were like nectar.

As the children went home they were given a basket of knitted toys to choose one from and chocolate coins for siblings.

Nine years later when Alys was born things had moved on again although Mary was still on Radcliffe ward on EUA days. Placenta blood was analysed and Dr Judith Kingston told us when Alys was eight days old she had inherited the Rb gene. She had

her first EUA at two weeks and it was decided to treat her with chemotherapy. Her line was put in on Thursday and she started chemo on Friday.

As a parent I found this a much tougher treatment to cope with.

Alys had a course of eight treatments starting in April and finishing in November and she had her line removed the following March. She had a very rough ride for her first three treatments but after that it was much less traumatic. I appreciate that sometimes it is good to talk to other parents with similar experiences and now I am starting the journey again with my daughter and granddaughter, I remember just how much I missed my mother. I wish we had

had the opportunity to share experiences.

Helen was told by Dr Elisabeth Rosser when Cerys was three days old she had inherited the Rb gene. So when she was two weeks old we went on her first visit to the Royal London fully expecting history to repeat itself with Cerys but fortunately to date she has only needed cryo treatments.

Cerys is now 18 months old. The whole experience is less traumatic these days as there are two lists, so if you are on the morning list you can be gone by 11am and on the afternoon list the latest we have left is 5.30pm. The staff are all helpful and friendly, however I am not sure if there is so much interaction between the children and between the parents. Maybe the need is not so great as there are other mediums for people to communicate now and perhaps people prefer that, personally I still like the face to face contact.

I know there is always room for improvement but I hope this has helped illustrate where the

service has come from and how things have changed on a practical level over the last 58 years.

"We have the same joys and frustrations as any other family."

We chose to have our children knowing the risks, but I am aware there is a school of thought that would think us selfish.

In case you're wondering, we all have a good quality of life and have the same joys and frustrations as any other family with just a few more hurdles to overcome and we are very proud of them all.

Talking to founding member Judith Agyrakis about how her daughter was treated 28 years ago it became clear why there was a need for parents to form a self-help group. An EUA clinic at Barts was a very long day in cramped conditions without any distractions.

One of the most important differences the formation of the Retinoblastoma Society made in the early days was to employ Mary Digby as the first play specialist.

Mary (interviewed on page 15) stepped in where she was needed to help the children, and parents, get through the long hours of starvation prior to the EUA. Now the centres have dedicated play specialists who work with the children to distract and prepare them to lessen their anxiety.

Initially the Rb Society supported families through volunteer regional co-ordinators under the chair of the management committee. These co-ordinators kept in contact with families in their locality, linked them to others and organised social and fundraising events.

By 2000 a support worker was employed who introduced families to official family contacts - members willing to share their experiences and practical advice to help parents through treatment. This linking service is still going strong today. But with the advent of Facebook and the website forum our members are finding new ways of sharing

Listening for of a century



One of the first annual days

experiences and helping each other through darker times.

CHECT has been at the forefront of providing parents with clear information, working with Dr Judith Kingston to produce the original booklet "Understanding Retinoblastoma" and information leaflets to support all the procedures taking place at Barts and then the Royal London. Accessing information has been revolutionised by the internet and the creation of a CHECT website. In 1987 parents contacted the Institute of Ophthalmologists' library if they wanted to gather more information. Now the



Dino enjoys a cuddle from Theo

CHECT website holds a raft of information not only about the condition and treatments available but also has tailored information for children, with a catalogue of personal stories, advice and research information. The Rb teams at the treatment centres now ensure parents are given medical information at every stage of their treatment

'a quarter

by Julia Morris



When we arrived at DUDLEY ZOO, we were surprised to see that it was built on a hill, and what a climb that was. Our helpers were on hand at all times, but some of them needed our help to climb up to the top!



and CHECT factsheets complement them, ranging from practical financial advice to emotional issues at diagnosis. But practical help doesn't always take the shape of an information booklet or factsheet - several years ago Dino the dinosaur was introduced by CHECT, a cuddly creature fitted with removable eyes to comfort children after

Bringing people together

an enucleation. He was a hit with every family he has helped out along the way but sadly due to the high production costs, CHECT could not afford to replenish stocks. There are still one or two surviving Dinos around today and we always welcome the return of old Dinos to help out newly-diagnosed families!

As the service has evolved one thing that hasn't changed is the devastation and isolation most feel when they are told their child has a rare cancer. The comfort that hearing another member's experience can bring can be priceless and is never underestimated by us.

We are extremely lucky to have so many people whom we can call upon to help others when they are most in need and we are very grateful to everyone who offers to share their personal stories. We have recently been able to include some of these stories in the leaflets which are distributed on the ward.

But support spreads much further than the bedside and we help members throughout all major stages in their life, with information on linking with peers, advice on screening when planning a family and healthy lifestyle tips and advocacy for older members. We are hoping to build on the support service we can offer to our teenage members now too at the most vulnerable point of their lives. One method of support which has stood the test of time (and technological advances) has been the regional meet-up. From the start we have been bringing families together to share happy times. The first meet-up saw a bus load of children whisked away to Alton Towers and Dudley Zoo while parents chatted at their leisure about their experiences. The value of these meetings has held strong as was evident from your feedback in the members' survey last year and CHECT has pledged to increase meet-ups in the future.

CHECT continues to listen, source information and contacts and to link members, represent their views and be there for those affected by retinoblastoma throughout their lives. Much has changed over 25 years in the treatment of Rb and CHECT has been steadfast in its support.

Libby's experience

Libby Halford has been involved with CHECT almost since the beginning – after her daughter Camilla, right, was diagnosed with Rb in 1988. Here Libby reveals her memories around the time the beginnings of a support service were formed.

Camilla was diagnosed with unilateral retinoblastoma at Moorfields in September 1988 and treated with lens sparing radiotherapy at St Bartholomew's. We went through 18 months of EUAs before the treatment was deemed to have been unsuccessful and her eye was removed.

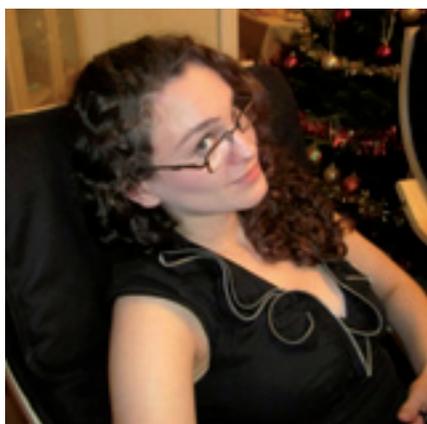
Camilla's EUAs were on Radcliffe Ward at Barts. This was an adult ophthalmology ward, where one room was given over to the children on a Wednesday. By the time we arrived, the beds had been replaced with cots but my father always went in search of the broom to sweep the clumps of dust off the floors so the children could play. Then he went in search of the small gowns which the children had to change into. There were no specialist nurses and since the ward was staffed by agency nurses there was no chance to form relationships.

There was no play specialist, or even a toy cupboard. We parents brought a few toys and shared them out. When Camilla was going through the EUA process, there were 16 children being seen by one consultant (John Hungerford) in one afternoon. I understand that

went up to 23 children before the service moved to The Royal London.

Eye drops were given in an annex at the end of the ward. Children could be heard screaming so dread was felt by all. There was no place for parents to go for a break but a tea trolley was brought onto the ward once the last of the children had been anaesthetised.

Children were given pre-med sedation in the form of rectal suppository which in itself caused quite a bit of trauma with long-term psychological impact for some. Many parents objected to this



Camilla, now 25 and marketing manager of The Leatherhead Theatre, has a determined attitude and passion for life. If asked what she recalls from the ward she will say, without hesitation, the penguins...



practice. I had a blazing row with the anaesthetist about this one day - the system was changed shortly after that!

After the EUA, all parents had to line up to receive 'the news' in a clinical room, with total strangers watching you. You then had to walk back to your child, past all the other parents waiting in dread to be given the outcome – trying not to show your own emotion, whether good or bad.

Things started to improve when Mary Digby was brought to the ward to do play and preparation. She brought in a wonderful array of toys and play dough; fought for a cupboard to put them in; and ultimately got two dedicated rooms for the children.

Every child was given a 'lucky bag' when they left. These were made by her legion of friends and contained a sweet and little knitted teddies. She made a real difference to the day and Camilla still remembers watching the penguins going up and down the slide - a treat for children after their eye drops.

It all went up from there...

Marvellous Mary's open house

Like many parents, I am grateful to hospital play specialists for their ability to keep children entertained during even the longest wait for an EUA. It was a pleasure therefore to talk to Mary Digby, who spent 30 years working as a play specialist for children with retinoblastoma, first at Moorfields and later at Barts, writes Christina Rozeik.

Mary knew from an early age that she wanted to work with children. She trained as a nursery nurse at the prestigious Norland College – although she is keen to point out that she didn't conform to the stereotype. "I wasn't a Norland nurse who wore white gloves and expected to be waited on. I was never a luxury nanny, I was not interested in that at all! I helped families and I did new babies. And then I started to travel, and I worked my way right round the world over a few years, in South Africa, Kenya, Australia and New Zealand."

In 1965, she returned to the UK and started looking for the next thing. "I knew that there must be something somewhere for me, waiting, I didn't know what it was... and then through some extraordinary coincidence I read an article in *The Lady* magazine". That article described efforts by David Morris, a consultant paediatrician, and Susan Harvey, a Save the Children Fund (SCF) adviser, to set up play schemes in hospitals to



Former play specialist Mary Digby, who still volunteers for CHECT today

care for the emotional as well as physical well-being of child patients. Fired with enthusiasm, Mary volunteered with SCF and was later employed by them as a play specialist in Moorfields Eye Hospital. Children's wards then were very different: "The children's eyes were superbly looked after, but nobody really had any idea about little people, or how parents felt. There was no open visiting, no resident mothers – I had a hard task and it took me 20 years!"

Mary was paid £6 a week (not much, even in 1969) and was so successful during her first year that she persuaded the hospital to keep her on as an employee. She stayed until her retirement in 1989, becoming known to all as Aunty Mary. She was adamant from the start that her role should include the whole family, not just the child receiving treatment. "It was always open house (in the playroom) to all the brothers

Turn to page 16

and sisters, so they didn't feel left out. Every week, every child had a little gift to take home: I had a band of wonderful ladies who knitted and sewed and gave me money, so there was always a basket of goodies at the end of the day, and they all chose what they were going to take home. But there was always something to take home for the brothers and sisters too, so they knew they had been remembered."

Mary paid particular attention to grandparents, who are often forgotten when a child is ill. She recalls inviting a couple who were very anxious about their grandson's treatment to join her in the playroom one day. "They sat with the children and I soon got them involved – the grandpa playing cards with the boys and the granny at the Play-Doh table with the mums and the children – and the reward for me was so great, the big smile I got at the end when she said, 'Thank you, we've had a wonderful time, I didn't know children could be happy in hospital'. The seed was sown in my heart: now I've got to do more for grandparents. Grandparents have treble the pain: they have the pain of the grandchild, the pain of their children, and the pain that they have themselves. It's very, very hard for grandparents."

The children at Moorfields came from all over the world and had many different conditions, including cataracts, glaucoma and accidental injuries, but Mary soon found herself worrying about the retinoblastoma patients in particular.

In the early days, an EUA meant a stay of two or three days in



Mary encouraging play with parents and children on the ward

“Mary’s affection for all her ‘chi

hospital and many children ended up losing both eyes. The genetic aspects of retinoblastoma were not well understood, and Mary saw families where the parents did not know their medical history, only realising that their own blindness was due to retinoblastoma when their children were also born with the disease:

“There are some horrific stories I’ve heard in the past and it

was very hard for me sometimes. But I had to keep going, I had to go the next day and be there for another batch of children.

“Alright, nobody wants to come, nobody wants to have drops in their eyes, and they don’t want these nasty things to happen. But that’s only part of the day. The rest of the day, in my mind, has to be good!”
In 1984, five years before she



Keeping the children busy in her first play specialist role



The lucky dip after an EUA and a cuddle from Mary



Children' was fully reciprocated"

retired from Moorfields, Mary herself was treated for cancer. She was given three months off work to recover from surgery and radiotherapy and used that time to think how best to help the retinoblastoma families. In 1987, with her friend Jackie Martin, Mary joined the group of families and professionals who founded the Retinoblastoma Society (which later became CHECT). "At the first AGM, we were lent a room at

Moorfields – but we bought the tea and the biscuits and had a raffle to make it a bit more interesting and homely and used the money for the next meeting and we went on from there."

After retiring from Moorfields in 1989, Mary began a second career as retinoblastoma play specialist at Barts, where most of the retinoblastoma cases were treated. Her Play-Doh and

colouring pencils were not initially welcomed on the ward, as it was feared that they would be messy and unhygienic. She soon won over the ward staff, and hundreds of children have since benefitted from her pioneering work.

Mary retired for good in 1998 – although at 83 she is not putting her feet up yet and can still sometimes be found in the CHECT office: "Audrey Allen, Sarah Hollyer and I go in together and we do the newsletters, stuff the envelopes and reminisce about the old days."

Feeling that she needed to "cut the cords", she recently donated all records of her time as a play specialist to Moorfields and Barts. These archives contain photographs, drawings and letters, as well as the card indexes and photograph books which carefully recorded the progress of each child on the ward. It is clear that Mary's huge affection for all her "children" (many of whom are now in their forties!) was fully reciprocated, and she still receives many Christmas cards from her retinoblastoma families.

At the end of our interview, Mary asks after my son Alexander, who is having treatment at the Royal London for bilateral retinoblastoma. Her final words to me are typical of the forthright confidence with which she has supported so many families over the years. "If anyone in this world understands what you've been through, I do, because I've been through it with so many families. And it's still very painful for me to even think about it sometimes. But you'll win, you'll be alright!"

The changing face of Rb management

When paediatric oncologist Dr Judith Kingston first started working at St Bartholomew's Hospital in 1980, retinoblastoma was considered an ophthalmological condition and therefore looked after almost entirely by the ophthalmic surgeon - the fact that children with retinoblastoma were also children with cancer with additional needs was not really considered. Dr Kingston looks at the changes in the management of retinoblastoma over the years.

The children with unilateral tumours who were treated by enucleation alone, and who did well, were looked after by an ophthalmologist and never saw a paediatrician. The majority of children with bilateral tumours were referred for a course of radiotherapy and then referred back to the ophthalmologist for follow-up examinations.

These children may possibly have seen a paediatrician once if they required admission to the ward during radiotherapy. Therefore the only children seen by a paediatric oncologist were those who developed metastatic disease or orbital recurrences, so the picture I was presented with in the early 1980s was one of children with multiple lumps on the scalp, widespread bony swellings and ill-fitting ocular prostheses due to an enlarging

mass in the orbit, who all inevitably died. Hence my initial impression of children with retinoblastoma being "hopeless" cases.

During the early 1980s Professor James Malpas at St Bartholomew's Hospital led the field in developing the separate national speciality of paediatric oncology. He also established the Kenton ward multidisciplinary meeting (MDT), which must have been the first MDT to be established in paediatric oncology and every Tuesday morning oncologists, radiotherapist, ophthalmic surgeon, radiologist, junior doctors, ward sister, social worker and pathologist would meet together to discuss all the oncology patients, including children with retinoblastoma undergoing radiotherapy. It was always a lively meeting with opportunities for cross fertilisation



Pelham and Janet Allen with Dr Judith Kingston



The introduction of orbital implants to appearance of artificial eyes

of ideas. In 1984, Mr Hungerford (ophthalmologist), Dr Plowman (radiotherapist) and I as paediatric oncologist, all newly appointed consultants with enthusiasm to change things, set up a close working relationship with the aim of improving the outcome of children with retinoblastoma.

This collaboration was to remain active and therapeutically beneficial to children with retinoblastoma for the next 20 years until the break-up of the team, first in part with the move of the paediatric oncology unit from Barts to the Royal London in 2000 and subsequently the dispersion of paediatric oncology to Great Ormond Street Hospital and University College London Hospitals.



Judith Kingston and Dr Gerald Draper at the 2011 CHECT annual day



Lens sparing radiotherapy



Orbital implants into the socket improved the

Our achievements during the 20-year collaboration were substantial and included the development of a lens sparing radiotherapy technique which dramatically improved the quality of life in children requiring radiotherapy, the introduction of chemotherapy as adjuvant therapy for children with adverse histology thereby almost abolishing the problem of metastatic disease and orbital recurrence, the introduction of chemotherapy as primary treatment for intra-ocular disease to avoid the use of radiotherapy in babies and very young children and the use of orbital implants to improve cosmetic outcomes.

Radiotherapy

Dr Nicholas Plowman worked



The UK was first to introduce chemotherapy as a primary treatment

to establish the technique of lens sparing radiotherapy at Barts whereby the front of the eye was "spared" from the devastating effects of radiotherapy in that the children no longer developed a dry painful eye because they still formed tears.

The dry-eye syndrome has devastated the quality of life for many of patients treated in the older era of whole eye radiotherapy whereas no child treated by the lens sparing technique has developed this debilitating syndrome. Lens sparing radiotherapy remains a very effective and cosmetically acceptable salvage therapy for patients who have failed chemotherapy. In addition, the children no longer suffer visual

deterioration or go blind from cataracts and they avoid the need for cataract surgery.

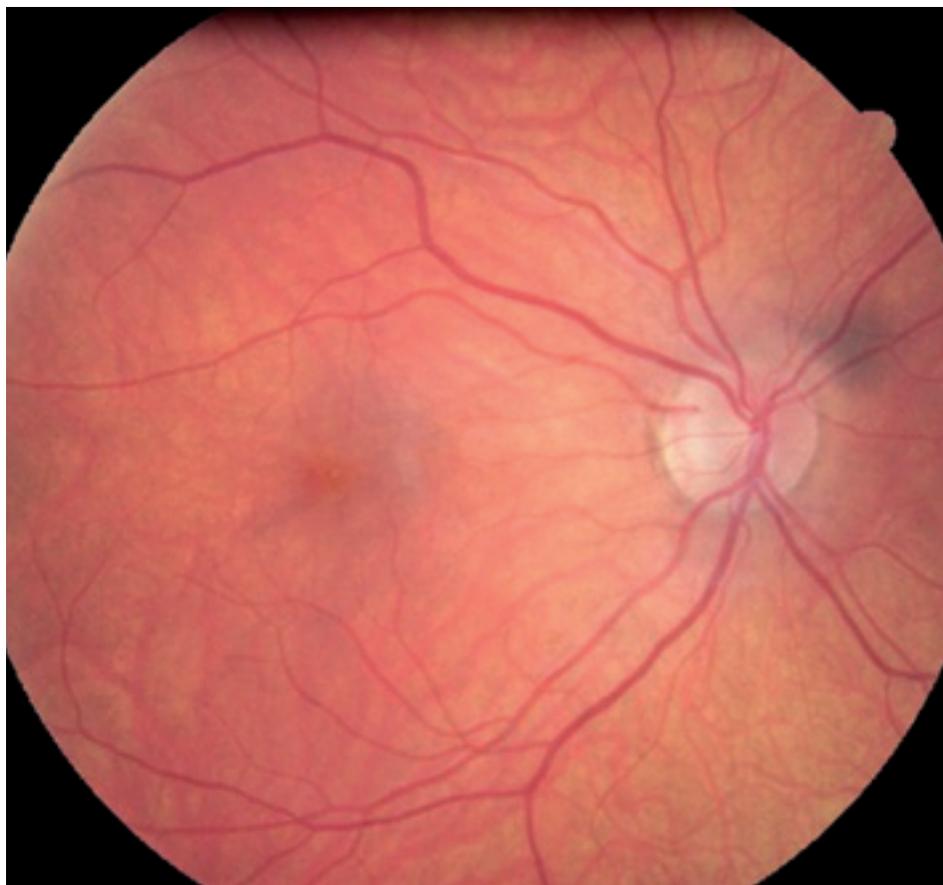
Chemotherapy

In the early 1980s, we were referred a poor child from the Middle East whose parents had refused enucleation and who had bilateral tumours growing out of both eyes. We decided to try chemotherapy before radiotherapy and were amazed by the response to chemotherapy. Prior to this, a group from Philadelphia Children's Hospital in the USA, led by Professor Anna Meadows, had concluded that chemotherapy was ineffective in retinoblastoma. They had set up a study which had randomised all children undergoing enucleation between adjuvant chemotherapy

and no adjuvant chemotherapy and they had seen no significant difference in outcome between the two groups and so they had concluded that chemotherapy was of no value in retinoblastoma. In retrospect this was a problem of small numbers and the very high overall survival rate of retinoblastoma.

At about this time we analysed the outcome of 13 children with orbital relapse and only one had survived – Professor Malpas, with great foresight, had decided to give this child chemotherapy in addition to the standard treatment with radiotherapy, and this child was the only one of the 13 children to have survived. Therefore we felt if we could select the children who needed chemotherapy and choose the appropriate chemotherapy drugs, we might see a beneficial effect and reduce the number of developing orbital recurrences and metastatic disease.

Mr Hungerford and I analysed the pathology reports of over 300 patients who had undergone enucleation during the preceding 10 years and we collated the outcome of these patients with regard to the development of metastatic disease. I remember spending many hours “burning the candle” to computerise all the information on the database. Analysis of our data which we presented at a meeting of the International Society of Genetic Eye Diseases in Essen showed quite clearly that there were two groups of patients who were at high risk of developing metastatic disease – those with retrolaminar optic nerve invasion and those with extensive choroidal (inner membrane) invasion. We



A ret cam is used to photograph inside the eye - picture by Arthaey

“Unlike the rest of the world at Barts we decided to treat Rb with chemotherapy”

then developed guidelines for adjuvant chemotherapy in children with adverse histology and since then have almost (but not quite) eradicated the problem of metastatic disease. The introduction of adjuvant chemotherapy has therefore been the most important factor in the improvement in survival of children with retinoblastoma that has been seen over the past three decades. Enthused by our success in reducing the problem of metastatic disease

we then looked to see if we could reduce the number of children requiring bilateral enucleations, which at that time was running at about 13% of the children with bilateral tumours. So in children with advanced retinoblastoma we gave two courses of chemotherapy followed by lens sparing radiotherapy. The bilateral enucleation rate has since fallen to about 5%. By the end of the 1980s there were a number of publications including a study by Dr Gerald Draper from



Plaque therapy

the world, to treat py alone.”

the Childhood Cancer Research Group with which I was involved, which showed children with the heritable form appeared to be sensitive to radiotherapy and were at increased risk of developing a second radiation-induced malignancy within the radiation field.

Therefore, in 1992 we decided to give chemotherapy to all newly diagnosed babies with bilateral retinoblastoma and not give radiotherapy unless they failed

chemotherapy. Unlike the rest of the world, at Barts we decided to treat with chemotherapy alone as we were convinced some tumours could be successfully treated this way. We reserved additional treatment with laser, cryotherapy and plaque for tumours that relapsed after chemotherapy. This reduced the burden of treatment for some children.

Surgery

Before the mid 1980s insertion of orbital prostheses (implants) was taboo as it was felt it would mask the development of an orbital recurrence and make it more difficult to diagnose. With the decline in orbital relapse secondary to the introduction of adjuvant chemotherapy and the availability of CT scans, these concerns were no longer valid and so Mr Hungerford started to insert an orbital prosthesis at the time of enucleation. Initially he used a simple acrylic ball implant and subsequently a vicryl mesh covered implant to which the muscles could be attached to give the overlying artificial eye more movement. As a result, there has been a significant improvement in the cosmetic appearance of all children undergoing enucleation.

Genetics

During the 1980s, thanks to Pelham and Janet Allen's fundraising (page 24) a retinoblastoma molecular genetics laboratory was set up as a research lab under John Cowell with Zerrin Onadim as a PhD student. Subsequently, NHS funding became available to establish a Retinoblastoma Genetic Screening Service in London and once Zerrin

had completed her research thesis, we invited her to set up a Molecular Genetics service at St Bartholomew's Hospital.

As a result we now have a superb and efficient service under the leadership of Dr Zerrin Onadim and she has more than repaid the research grant she was awarded from the David Allen Retinoblastoma appeal, by the amazing contribution she has made to our understanding of the molecular genetics of retinoblastoma.

With the help of Dr Elisabeth Rosser, our clinical geneticist, Zerrin and Dr Rosser have established a world class service which now benefits families from the UK and many parts of the world.

The future

This topic is covered on page 36 by Manoj Parulekar but we have achieved an amazing survival rate of more than 98% in retinoblastoma in the UK and we must now continue our efforts to improve visual outcome, limit side effects and improve the quality of survival in all children with retinoblastoma and reduce the incidence and impact of second malignancies in those with the heritable form of retinoblastoma. We will best achieve this by continuing to work as an expanded multidisciplinary team.

Finally I would like to extend my particular thanks to Professor James Malpas, John Hungerford, Zerrin Onadim, Nick Plowman and Gerald Draper without whom the past 30 years of my working life would not have been such a pleasure.

Give a little, help a lot

At CHECT we are extremely careful how we spend the money raised or donated to us – we make sure all donations are put to the best use possible – we know how hard many of you have worked to raise the money CHECT receives.

We keep a tight rein on the budget, always using the most competitive suppliers available and take up any pro bono offers if they are appropriate. We have become very skilled at making a little go a very long way!

But you don't have to be a marathon runner or a sky diver to help CHECT develop and grow over the next 25 years. Reliability is extremely important when planning what we do and this is why the small number of stalwart members who give a little every month make a huge difference too.

With regular giving we can forecast, much more accurately, how much income we are expecting, which helps us to plan

ahead and target the funds to the right areas where it will be most effective in achieving what we have set out to do.

As a charity we cannot stand still, our survey of members last year showed that our families are really happy with the level of support they receive from us on the ward, but there is still so much more we could be doing, particularly in awareness raising and research – regular giving can help us to achieve those goals.

By becoming a regular giver you help us widen the services we provide for families affected by Rb, but also to fund awareness campaigns and help secure the charity's work in the future. We would like to say a very big thank you to every one

of our regular givers, current and past. If this is something you have not previously done we would be delighted if you would consider becoming a regular giver too. There are three ways you can set up a monthly donation to us:

1. Through our website - (click through on the donate now button) at the top of the page and you will be able, through justgiving, to set up a regular donation .
2. Through your online banking - Account Name: Childhood Eye Cancer Trust, Account No. 00088630 Sort Code 40-52-40
3. Or through the Standing Order form on this page.

Regular Giving Form - Standing Order

To the Manager, Bank PLC

Branch.....

Sort Code:.....Account Number:

Bank Address:.....

.....Post Code

Please pay the following amount (please tick a box):

£5 £10 £20 £50 Other amount (please specify) £

To: CAF Bank Ltd, Sort Code 40-52-40
for credit to The Childhood Eye Cancer Trust, Account Number: 00088630

On (date) and on the same day of each succeeding week/month/
quarter/year (please delete as appropriate) until I give you notice in writing.

Signed:.....

Date:.....

Please return to: Childhood Eye Cancer Trust, The Royal London Hospital,
Whitechapel Road, London E1 1BB



Thank you to everyone who helped us get to where we are today. We have so many people to thank for all that has been achieved over the last 25 years. This newsletter covers only a fraction of the work that has taken place and the many people that have been involved in the journey along the way. We want to thank everyone involved, including those whose names we have not included. Thank you all!

As CHECT celebrates its 25th anniversary, Oliver Comyn and Rowan Miller, trustees and members of our research sub committee, look back on what has been achieved through CHECT-funded research.

A close look under the microscope

Back in 1997, molecular genetic techniques like PCR (polymerase chain reaction) that we now take for granted were relatively new in laboratory work.

Zerrin Onadim received a substantial grant of around £90,000 from CHECT for a project that led to increased knowledge of mutations present in the RB1 gene, raising the prospect of genetic screening for families affected by retinoblastoma. Now, just over a decade from the conclusion of this project, genetic screening is readily available and provides vital information to families affected by Rb.

Around the same time, Dr Gerald Draper from the Childhood Cancer Research Group at the University of Oxford was laying the groundwork for later epidemiological studies. A grant of £20,000 from CHECT supported the development of a comprehensive database to facilitate future research, with data from 2600 individuals entered.

This ranged from clinical data and information about families affected, to molecular



Dr Carmel McConville and Dr Gerald Draper

data documenting the mutations in RB1 that were leading to disease in UK Rb sufferers.

A second grant of £35,000 to Dr Draper from 2003-6 allowed his group to work from this database to establish essential information about the risk of second tumours for those diagnosed with Rb.

It has long been known that a diagnosis of the heritable form of Rb carries an increased

risk of sarcomas (tumours of connective tissue like bone and cartilage), but this important epidemiological work was able to provide more accurate information about risk.

While the increased risk of a second tumour is not welcome news, it is reassuring that the risk is only slightly larger than that for the population in general. This knowledge empowers Rb families to

Turn to page 24

persuade GPs and other health professionals to take seriously concerns over new symptoms and make appropriate referrals for further investigations where necessary.

Laboratory science has been important to CHECT too, as it is only by investigating a wide range of possible molecular targets in cell lines in the lab that new therapies will be developed. A great example of this pathway working in practice can be seen starting with Ashwin Reddy's project in 2005 studying HMGA 1 and 2, proteins that are expressed by Rb tumours. A grant of £5,000 helped his group study these molecules in Rb cell lines. Four years later, the CHECT RSC approved a grant for three years to Professor Krishnakumar in Chennai, India to study ways of silencing the expression of these proteins using a new class of molecule, small inhibitory RNAs (siRNA).

RNA is a messenger molecule within cells, copying information from genes, made of DNA, to enable the cell to manufacture proteins. These RNA messenger molecules can be blocked by siRNAs, in effect preventing a gene from being expressed. While it may be years more before any useful therapies are developed from this research, the CHECT trustees believe that only by funding very exploratory projects like this will progress eventually be made.

Dr Carmel McConville is another scientist studying molecular mechanisms of

disease who is producing great work funded by a CHECT grant. Studying multiple retinoblastoma tumour samples has led to her finding that different tumours express different patterns of genes and so different protein

molecules are made by the tumour cells. It might be possible to classify Rb tumours based on these differences, and this might explain why some tumours behave differently; spreading beyond the eye, for example.

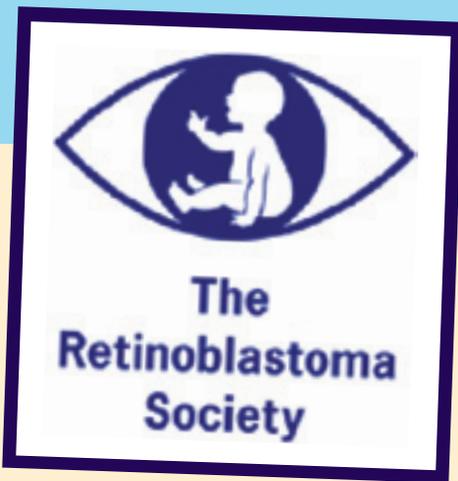
David's legacy

In 1994 The Retinoblastoma Society merged with the David Allen Retinoblastoma Appeal. Without this huge injection of funds and the commitment of the appeal's founders – David's parents Pelham and Janet Allen – CHECT would almost certainly not exist in the format it does today. Hundreds of Rb families have benefitted over the years from the research funded by the appeal. Here Janet and Pelham tell their story of David's legacy.



In June 1984 we first learned about Rb very suddenly. Friends had noticed our two-year-old son David had something wrong with his eyes. We already suspected he had a squint and had arranged for his eyes to be looked at. However our friends insisted we took David straight to Moorfields.

He was diagnosed that Sunday, and began a period of treatment and involvement with the Rb service that lasted until his death in 1988. David enjoyed singing and dancing, which he continued to do even after losing his second eye. His dancing teacher annually organised a show for her students, and asked us if she could use it to raise funds for Rb research.



At that time The Retinoblastoma Society had only just been formed and there was no charity dedicated to raising funds for Rb research. We decided to set one up, and the David Allen Retinoblastoma Appeal was born. Our artistic au-pair created the child in an eye logo, and we set ourselves the target of raising £250,000.

It seemed to be easier to raise the money than to spend it. Lots of events and thousands of Christmas cards sales steadily built up the fund. We sought advice on suitable research projects, and were introduced to Zerrin Onadim, who needed support to finance her PhD. We agreed to do this, and started her on the Rb research work she has continued ever since, to the great benefit of affected families, and the body of knowledge about the genetics of Rb. Over the years The Retinoblastoma Society grew in strength, and it became obvious the two bodies should merge. This took place in 1994,

As taking a biopsy from a retinoblastoma carries a risk of spreading the tumour outside the eye, another aspect of her project looks at whether scans can be used to examine the behaviour of tumours inside

The Retinoblastoma Society adopted the David Allen appeal logo which has stayed with the charity.

with the transfer of research funds (and the logo) from the David Allen Appeal to the Society, with both of us continuing to work for the merged charity for several years. We have continued to take an interest in Rb research. The work that identified the Rb gene was funded by the money we raised, and has enabled dramatic improvements in Rb screening and treatment. The Rb gene is also a factor in breast cancer. We believe strongly that David's short life has left a very positive legacy and are delighted research continues to be a strong interest of CHECT. Cancer is talked about much more openly now than in 1984. Much more is known about Rb. The tri-lateral variant of Rb (which affected David) has been virtually eliminated by advances in chemotherapy. However Rb will continue to challenge new families every year. The work of CHECT makes these challenges less traumatic to deal with, and we are proud to have played our part in the establishment and development of the trust.

the eye. One day, scans to detect tumour behaviour and an individual treatment plan based on the results might be a routine part of Rb care. CHECT is also conscious of the impact of having Rb on individuals and families,

so has funded research to examine the psychological aspects of living with Rb. Sarah Norgate's 2002 study, supported by a £31,000 grant from CHECT, provided detailed information about the issues that most concern parents of a child diagnosed and living with Rb, and how they want to learn about these issues. This research is hugely important to CHECT and its members. The results of Dr Norgate's study inform policy on support programmes and keep the charity informed of the issues that matter most to members.

Research supported by CHECT is flourishing, with publications expected from Dr McConville's group very soon and the results of Dr Trevor Cole's work looking into knowledge of genetic screening and providing follow up to families affected by heritable Rb to come.

The charity is also funding an ongoing study at Great Ormond Street Hospital investigating adverse reactions to intra-arterial chemotherapy, meaning that we continue to fulfil our key strategic aims of funding both laboratory science and clinical research projects to further our knowledge of the causes, treatments and outcomes of Rb as we head into CHECT's second 25 years.



My childhood memories are hazy, and I try to remember the good points of life, so having Rb at the age of one is something that I do not recollect too much about. I only remember visiting the artificial eye fitters in Euston, London when slightly older. Large metal lifts and drawers of eyes!

Things are definitely better now! I had a brother Roger who sadly died at the age of 3 before I was born. From what I have found out he had “blastoma”, which affected his eyes, but also his kidneys. I never knew him but searching paperwork has not uncovered a death certificate - something we need to rectify. My Rb was unilateral and I have no idea if I had further treatment but I am sure if I did my parents would have told me.

I enjoyed my time at primary school, finding school work easy, and gained a place at the local grammar. Secondary school became harder. I did not find socialising easy especially when my closest friend moved away and although I was not teased or bullied I was not really included in class groups.

I realised I was different to others and resented it. I hated discussions and talking in front of the class and never talked about my condition to others. I can even remember never being able to tell staff at school medical tests that I could not see out of my left eye, so I cheated. To this day I do not know if they really knew what was wrong with me!

Later, I gained a place in the school choir and orchestra which gave me something to focus on

I never told school staff I could not see

In this special edition of InFocus we are featuring stories from members who were diagnosed long before a support service was in place. Val Kewley, 60, had unilateral retinoblastoma and was diagnosed in 1953.



Val as a toddler

and I even sang solos for a local operatic society. Since school I have worked for the Metropolitan Police, as an executive officer, as a medical records officer for the local health authority and I have worked as administration manager for a local school now for over 20 years.

My mother died when I was 16, a hard age to lose someone. My sister Sue and I were typical



Val with husband of 38 years, Nigel

teenagers – often arguing, and then she went off to college which left me alone with my dad. I think from then, just like my dad, I kept things to myself with no-one else to talk to easily about how I felt.

I loved my dad, who was great, but rather quiet and serious. My parents never let my eye condition affect what I did although rarely talked about it. Check-ups finished at the local children’s



Val kept her artificial eye a secret



hospital when I was around 12 although replacing my prosthetic eye continues. I have seen many different/odd venues and many different specialists. The current one has just retired so I am not sure what will happen next!

Aged 7, I joined the local Brownies, and have been involved ever since! I have run the local Guide unit for over 30 years and now I am a member of the



Val receives her Anglia Award for outstanding service to Hertfordshire Guiding

county outdoor activities team. My main interests are camping, walking and the outdoors. I have been married to Nigel for 38 years and have two healthy children, Jo and Daniel – now grown up. Jo is getting married this month and all of my memories have been stirred whilst we have been referred to genetic specialists to check it will be okay for her to have children.

Nigel always talked with me about my problems when we first got together, and often teased me (especially about my car-parking!) He always knew when I was tired because my eyelid drops on my blind eye. Slowly I think I became more relaxed about my problems and can now talk happily about it.

In 2002 I was referred to our local hospital to check a lipoma on the back of my neck. I do not know why but the registrar checked further only to discover a lump on my breast. This turned into two and resulted in an operation, chemotherapy and radiotherapy for breast cancer.

My world went into a massive whirl but excellent treatment and follow-up from my nurses kept me focussed. Ten years

later I have been discharged! All the treatment meant I had to talk to so many people about my condition, which has helped me discuss my eye problems too. In gratitude to all who helped me I have since taken part in two Moon Walks, and several midnight walks for the local hospice. Maybe now I should think of something to do for CHECT!

I have reached that stage in my life now that I feel that I would like to support others, perhaps less fortunate than me, feeling grateful for all the excellent medical care and support I have received to date.

I have been lucky and now cherish everything I have. I am always willing to give everything a try, but there is still one thing I can't do - see in 3D, which saves me a great deal of money on a new 3D TV!

If you would like to get in touch with Val or meet other people of your own age who have been affected by retinoblastoma get in touch with a CHECT support worker for more information.

Opening people's eyes to Rb for 25 years

One of the Childhood Eye Cancer Trust's founding aims has been to increase awareness of the signs of the condition. The charity and its members have always worked in partnership to get the messages out there. The charity composes the message and publishes the material but if it was not for members' hard work the charity's reach would never have been so far, writes Juliette Carter.

Since CHECT began members have told their personal stories to the press about their experiences. These accounts, sharing the highs and lows of diagnosis and treatment, have informed millions of people about the signs of eye cancer. More people today have heard that a white reflex can be a sign of eye cancer and we now meet families on the wards who have acted fast because they, or someone they know, read about it in a magazine.

Our archives have close to 300 cuttings from papers, magazines and now websites too. CHECT members have told their story to millions upon



Your stories help others to understand the warnings signs of Rb

millions of people in the local and national press and have also appeared on regional and national TV and radio. With the internet those stories now reach a worldwide audience. A story of retinoblastoma has even appeared on an ITV medical soap. That's not bad for such a rare condition.

Talking of TV, the charity has been lucky enough to appear on the BBC Lifeline programme twice; in 2006 we reached 1.25 million people and in 2011 the number of viewers was 2.6 million.

In keeping with these large figures, over the years CHECT has printed around 200,000 leaflets. The See Red

poster, which advises health professionals how to do a red reflex eye test, is highly respected amongst ophthalmologists and those who train clinicians and midwives. It was developed in 2003 and there were several campaigns over the years which saw these leaflets sent to thousands of GPs, paediatricians and health visitors.

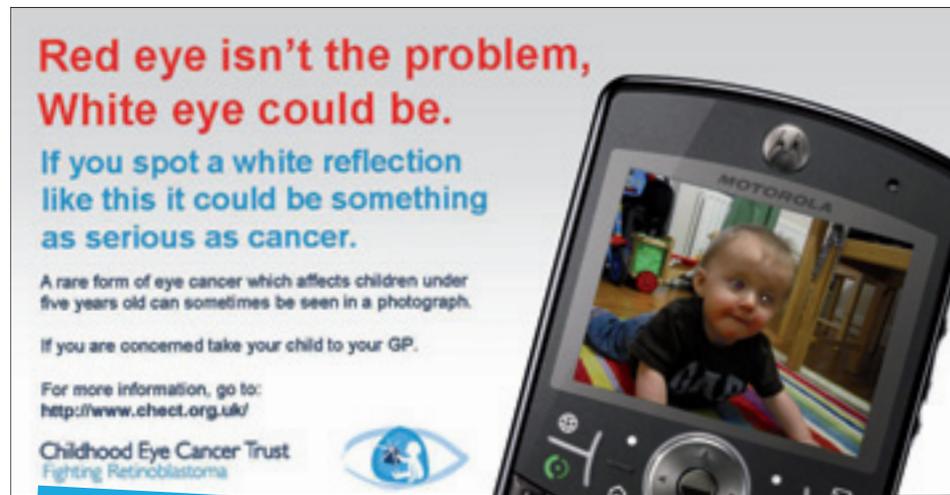
Later on awareness leaflets were designed for the general public, a vast quantity of these were distributed by our passionate members, some of whom opened the door for other awareness-raising activities and new audiences. Back in 2001 we worked with



The Mug A GP mug

Genetic Alliance UK (formerly GLG) and the Stickler Syndrome Support Group to hold medical professional training. Two years after that the Childhood Eye Cancer Trust, or Retinoblastoma Society as it was known then, was responsible for the birth of the National Retinoblastoma Awareness Week. This became World Retinoblastoma Week when CHECT joined forces with Daisy's Eye Cancer Fund and other international Rb supporters around the world in 2007.

All in all we've had many different awareness-raising activities. More people have heard of eye cancer now and we owe a lot of thanks for this to our members.



as the red book or PCHR). The Department of Health listened to our concerns about the absence of this vital information and wholly accepted the recommendations we made. We will continue to lobby for changes to the Birth to Five book and website and the NHS Direct service. If you have not already signed our petition then please do so here. <http://www.gopetition.com/petitions/publish-signs-of-childhood-eye-cancer-retinoblastoma/sign.html>.

One of the most important tasks we have undertaken is raising awareness with the GPs whom for many families are the first port of call with their concerns. We are currently working on our biggest and most ambitious plan to date and will reveal all when the details are finalised.

Our plan sits very neatly alongside our campaign to have information about the signs of Rb in all Department of Health publications available to parents. We recently celebrated a huge victory in this campaign when it was revealed that the signs of Rb would be included in the eye health section of the Personal Child Health Record (known

We have also spread our message by attending professional conferences and writing for medical journals but would like to leave you with some information on our very first awareness campaign. It was perhaps dangerously named 'Mug a GP'. We distributed mugs with the message 'Urgent referral could save sight and even lives' to all the GPs in the UK. These mugs carried a list of signs to be aware of and we hoped, back in 1987, that they would sit on the desks of GPs up and down the country and remind them to be aware of Rb. We wonder if there are any mugs still out there in the surgeries 25 years on. We are still proud of ours in the office!

It would've helped me to have met others in the same position

CHECT volunteer Bill Johnson has been helping out the trust for many years now, giving up several hours of his time most weeks of the year to help the office run smoothly. Bill reveals here how he struggled with the effects of his treatment throughout his childhood, when no support service was available for children or their parents. We like to believe things have improved for children these days as both the Rb services and CHECT strive to minimise the impact treatment for Rb has on youngsters.

I was born on Christmas day, 1945, the first baby born in that hospital (Nether Edge Hospital in Sheffield) on that day, or so I was told.

I started to become ill after a few months, and was taken to the hospital on more than one occasion, but was told that it was my ears, or something like that, but on one particular day, my mum took me back to the hospital again (Sheffield Children's Hospital), and told them that she would not take me home again until they found out what was wrong with me. I was examined, and after a while, was rushed up to the operating theatre, where my left eye was removed due to retinoblastoma.

I then had to go for regular check-ups, where I used to have my right eye examined under a general anaesthetic. At that time, it was an unpleasant procedure, and as each appointment drew near, I used to cry, knowing what



Bill Johnson pictured above, as a young baby

was coming. Also, every time my mum took me to the welfare department, to collect the orange juice and milk that was issued to young children at that time, whenever I saw anyone in a white coat I used to scream.

At this point, I must explain that I was very young at this time, and I got all this information from my parents over a period of time.

I cannot remember much about my early school days, apart from the regular hospital visits, but – even then – I knew that there was something different about me. I'd had some teasing, because I didn't wear spectacles at that time, so the difference in my appearance was quite noticeable.

It got worse once I went to secondary modern school in 1957. I lacked confidence and was



Bill lacked confidence at school

reluctant to get involved in fights or defend myself, because I had a fear that they might target my one good eye. Even now, I have a worry that one day, I might lose my sight.

I was quite naïve back then, and didn't really understand why I was the only one like that in the whole school, and outside. It would have been nice and helpful to meet people in the same position as

myself, but that didn't happen until the eighties. I was often reduced to tears at school, not because of any pain, but because of the humiliation that I felt, especially in front of people. I'm certain that this was the cause of my lack of confidence as well as the policy of some of our teachers, who tended to encourage the favourites, rather than people like myself, who needed it the most.

Despite that, I did quite well in most of the subjects, and the last year before leaving school, I came 2nd in the class, being pipped for 1st place by just a handful of marks.

As a result of this, I was asked if I was planning to stay on for a 5th year (now known as sixth form), but I turned it down, because I wanted to get away from the bullying and start working.

As I got older, I began to find out more about the 'Retinoblastoma Society' (now

known as CHECT of course). Only then did I realise that there were quite a few people involved, and I was not the only one affected.

Since then I have become involved with CHECT, attending a few annual days and I now am involved in volunteer work with them.

In the past year or so we have been contacted by several people who were diagnosed and treated long before CHECT or the Retinoblastoma Society had started.

If you would like to be put in touch with other members to share experiences with please contact our support workers on 0207 377 5578 or 0121 708 0583, who will help connect you.

10 years on for BCH



Birmingham Children's Hospital has cared for children affected by retinoblastoma for over 15 years but it was only given funding and official recognition in 2002. Clinical nurse specialist for the Birmingham Rb Service, Sister Maureen McCalla, explains how the service was officially established, 10 years ago.

A second UK Rb treatment centre was sought after the centre in Scotland had ceased to exist and another UK-based service that could serve the central and northern areas of the United Kingdom was needed alongside the already established London service.

At this point a multi disciplinary team was formed under the guidance of the National Specialist Commissioning Service. Birmingham's consultants Harry Wilshaw and John Ainsworth both had patients on their lists at this time, who were already being actively treated for retinoblastoma and, as it is a children's hospital, the other members of the team were already employed within the trust but in different areas or specialities.

More than half of the original team remains in post to this day and it is this consistency as well as stability that has ensured any new additions have enhanced the dynamics of the team. The essence of the team remains to work in partnership with the child and family in order to

ensure they are fully supported and informed throughout the treatment journey. As a small team, good communication is essential and ensures that everyone is able to support the family effectively in a co-ordinated manner.

We are a small group compared to other groups within the trust but we all respect the expertise and opinion of each other. We have learnt so much along the way but we have all developed a much greater understanding and depth of knowledge by sharing our expertise with each other.

Over the years we have been proactive in designing and promoting written information relating to the care and treatment for retinoblastoma. A number of these leaflets have won awards at a national level. The team has developed a number of joint clinics that aim to be a one-stop clinic for families. We currently have a monthly joint clinic with the National

Artificial Eye Service as well as a transition clinic for teenagers. As well as keeping abreast of new treatments, the team in Birmingham also aims to meet the psychosocial needs of the families by offering a framework of seamless support and hosting regular social events for families. Amongst these social events are the annual Christmas party and family get together days.

To ensure we maintain the level of service achieved over the last 10 years the team in Birmingham carry out regular audits as well as hosting study days. Looking to the future, we would hope to maintain our high standards of care and communication as well as continuing to raise awareness of the condition in conjunction with the team in London.

Birmingham Children's Hospital





My one regret

by Elaine Birtwistle

I don't remember much about the diagnosis other than what I've been told by my parents. Back in the sixties medicine wasn't quite as advanced as it is now and my parents initially had problems getting the local GP to accept there was even a problem.

I recall my dad telling me that he took me to Manchester Eye Hospital one Sunday teatime as my mum was worried about an orange light in my left eye. I had only been home from hospital a short while when my parents received a call from the hospital to say they had to take me back to hospital the very next morning! (Alarm bells must have started ringing for my parents!)

My dad tells me that when we left home the next morning, my mum's parting words were 'whatever you do bring her back home, do not leave her there'. However, within a short-time of getting to the hospital I was rushed into an operating theatre and my poor dad was sent home to fetch my mum with the parting words of 'we will try to save her sight but we can't promise'.

On their return they were told that my left eye had been removed, but the right eye was fine, however due to the progression of the tumour there was a chance that they may have removed it too late for me

to survive, for which I'm pleased to say they were wrong.

Life after Rb

Whilst I was oblivious to any of the above, I was only 2 years old at the time, for many years after I wasn't aware that I had even had retinoblastoma (Rb). I know how affected my parents were by the diagnosis and to this day are still affected by it. For some reason they blamed themselves for not spotting it sooner etc, but there was no need for them to blame themselves, it was just one of those things that happen.

Whilst I wasn't aware of having Rb, I quickly became aware of the limitations only having one eye brings and also

other people's perceptions of me. Mainly lack of co-ordination, limited sense of balance but strangely enough the one good thing was I had perfect vision in my 'good' eye.

My high school years were not very pleasant and the few friends that I had were the same friends as my siblings, as that way I wasn't subjected to the bullying I had to endure due to the fact that I looked different to everyone else.

High school wasn't all bad, my sister and I used to use my artificial eye to our advantage especially when we had lessons we didn't want to be in and needed an excuse to get out of it. School was under the impression that only my sister could reinsert my artificial eye whenever it came out. We never told them that I'd been looking after my artificial eye since the age of 7!

Since leaving school I can honestly say that only having the one 'good' eye hasn't really affected me. I have two beautiful daughters, who thankfully haven't been affected



Elaine with husband Robert

Turn to page 34

“Do I miss not having two eyes? I can honestly answer... no!”



Elaine as a child with her family

by Rb and two lovely nephews who also haven't been affected. I can drive just the same as everyone else, though I struggle driving anything too large as I can't judge the size of the vehicle and I still have my clumsy days as the amount of bruises on my arms and legs will testify.

The one way having Rb has affected me is in my appearance,

or rather my perception of my appearance, though in fairness that may be attributable to lack of self-confidence due to my school days. I tend to do 'back office' type work rather than be in the limelight as I don't like to be, as I describe it, 'stared at'. It has led to some interesting discussions throughout my working life but once I explain the reasoning behind this decision most people understand.

Elaine Birtwistle's story speaks of a gentleman called Mr Smith. Her writings of him were intriguing so some research was done to try to find out more about him and the programme he worked for.

His name was Jack Lindley Stewart Smith and he lived to the age of 82, passing away in 1997. The information here was taken from his obituary published in the British Journal of Ophthalmology and from information provided by Professor Jillian Birch, the director of the Cancer Research UK Paediatric and

My family and I were part of a research programme undertaken by a Mr Smith, whom I'm told was linked to a research programme at Birmingham. Mr Smith visited my entire family from 1965 until the late 1990's when he sadly passed away. His mission was to find out as much as he could about Rb, more so as my grandmother had suffered from brain tumours and he was interested to see if there

Elaine with husband Robert and daughters Louise and Katy



The intriguing Dr JLS

by Juliette Carter

Familial Cancer Research Group at the University of Manchester.

All people who have talked about him have painted a picture of quite a character. Dr Jack Lindley Smith, known to some as JLS, became a consultant ophthalmologic pathologist at Manchester Royal Eye Hospital before moving to a similar post in Liverpool. 'He developed an ocular pathology service based in the Manchester Royal Eye Hospital which attracted specimens from many other hospitals in the region. His major interest was in retinoblastoma and he collaborated closely with the Manchester Children's

Tumour Registry in a study of their natural history and inheritance.' (D R Lucas BJO)

'During the early 1950s he and Dr Jake Steward (who set up and ran the Manchester Children's Tumour Registry, MCTR) initiated a survey of Rb patients in the North West of England, tracing cases diagnosed back to 1925 and their descendants.

'He abstracted their medical records and aimed to examine everybody's eyes by indirect ophthalmoscope (which he carried with him) at venues convenient to the individual. Venues were usually their homes

but included pubs and working men's clubs.' (Prof J Birch)

He was interested in the patterns of inheritance of unilateral Rb as well as bilateral Rb. He was one of the first to observe an increase in lifetime risk of second cancers including carcinomas of lung and bladder and published on this. He was also interested in other cancers in non-Rb affected family members and also minor congenital anomalies. (Prof J Birch) The MCTR is the oldest children's cancer registry in the UK, established in the 50s, it is considered to set the standard for other registries and epidemiological studies and is internationally renowned.

was a link between the two. He helped my parents to deal with Rb and also ensured my own two daughters became part of the same research programme.

I am frequently asked do I miss not having two eyes; well I can honestly answer no. How can I say yes when I don't know any different? And apart from that my parents always instilled

into me from as far back as I can remember that nothing was ever going to change, so in the words of my dad 'she had best just get on with it'.

And finally

If you are still reading this then I'm sure you're wondering why this is called my one regret, and I'm equally sure my family will be laughing as they are reading this.

My one regret

well that's simple - I have always wanted to see what it is you see when you look through a pair of binoculars and my one regret is that I know that will never happen!

Keeping an eye on the future

One of the most regular questions we are asked at our annual members' day is what treatments lie on the horizon for retinoblastoma. Here Manoj Parulekar, consultant ophthalmic surgeon at Birmingham Children's Hospital, notes his thoughts on where current research may lead and his hopes to eradicate the need for enucleation.

There is much excitement among retinoblastoma experts as new treatment options have and continue to become available. After chemotherapy and laser treatment largely replaced radiotherapy in the late 20th century, the first decade of the 21st century has seen a major emphasis on local delivery of chemotherapy - both around the eye (peri-ocular, sub-tenon) or by intra-arterial injection. (The drug is called Melphalan.)

Although intra-arterial chemotherapy (IAC) is a major advance and has become part of mainstream management of retinoblastoma, the initial enthusiasm has been tempered by the reported side effects from Melphalan, mainly sudden and severe loss of vision in treated eyes. The drug of choice continues to be Melphalan, but work is under way to identify other suitable drugs with fewer side effects. It is becoming evident that IAC is a great advance, but not always the answer to every case. A major stumbling block in treatment of intra-ocular retinoblastoma



has been the limited success in treating vitreous disease without resorting to radiotherapy. Intra-ocular delivery of chemotherapeutic agents was considered off limits due to the risk of spreading disease out of the eye through the injection tract.

However, recent ongoing research suggests direct intra-vitreous injection of Melphalan using safer injection techniques might be safe and effective in selected cases. This very exciting development challenges

conventional wisdom of "not surgically entering an eye with active retinoblastoma".

We will no doubt learn more in the coming years, but this may well be the breakthrough we need for some resistant cases once the safety of this technique has been established.

An important and up until now unanswered question is whether local chemotherapy alone is a safe treatment for retinoblastoma. In other words, is systemic chemotherapy necessary in the treatment of retinoblastoma, or is local chemotherapy alone sufficient? Most of our colleagues believe that once retinoblastoma tumours have grown beyond a certain size within the eye, they have the potential to spread out of the eye. There is therefore the risk that a few cells that might have spread out of the eye could result in metastatic growth and considerable morbidity and mortality.

Systemic chemotherapy has the added advantage of treating such unseen cells that have spread into the rest of



the body (occult metastases), something local chemotherapy alone cannot do. It is important not to forget the abiding principle of management of eye cancer—the primary aim is to save life, followed by saving the eye, and then saving sight in that order of importance. Retinoblastoma is a cancer, and over-emphasis on local chemotherapy and abandonment of systemic chemotherapy might result in an increased risk of metastatic disease and death.

One question often posed to me by parents as well as colleagues is - where do I see retinoblastoma treatment going in the next few decades? I can see two major areas of development that could yield cost effective and safe treatment in the longer term - gene products and biologic agents.

The retinoblastoma gene controls production of a protein in each cell that protects against cancer. Of course, it is more complex than it sounds, but the essence is that if the protein production could be stimulated by an alternative process, or the product could be synthesized outside the body and delivered as a pill or injection, it might minimise the development of retinoblastoma tumours, and indeed other second cancers in heritable cases. Rapid advances

in recombinant DNA technology might make this possible in the years to come.

Another potential avenue for retinoblastoma treatment is biologic treatment. Our understanding of tumour biology has evolved over the past few years, and we are beginning to understand better how the chemical environment in the body affects tumour growth.

Tumour analysis and magnetic resonance spectroscopy (MRS) provides invaluable information about the growth factors that drive tumour proliferation. Anti vascular endothelial growth factor (VEGF) agents such as Avastin are already in use for bowel cancer, and similar treatment might become a reality for retinoblastoma in the not-too-distant future.

Tumour immunology is a rapidly growing field, and scientists have had some success with the development of the melanoma vaccine. It is possible that synthetically-manufactured antibodies to the retinoblastoma cells might, one day, permit customised treatment for individual patients. This might require a biopsy of tumour tissue to obtain cells, currently contra-indicated due to the risk of causing metastatic spread. Newer surgical techniques might permit safer

biopsy and make this utopian dream a reality in the decades to come.

Finally, do I see a role for enucleation in the management of retinoblastoma in the future? I would like to answer with an emphatic NO. However, the reality is many cases of unilateral retinoblastoma will continue to present late. This is because the other eye compensates visually, and the child functions normally.

The tumour might remain undetected until it is quite large and visible externally. While treatment options for advanced intra-ocular disease will undoubtedly improve, and the rate of enucleation will reduce with introduction of each new treatment to our armamentarium, some cases will sadly still require surgery. It is a very sobering thought, and a reminder of how much work lies ahead in the years to come.

Please note, not every treatment is suitable for every case and some 'treatments' referred to are still at the embryonic stage of development. Please consult your Rb team for information on the most appropriate treatment for your child.

Keeping CHECT

As we celebrate 25 years of the Childhood Eye Cancer Trust we are also thanking and acknowledging our members, their extended families and friends without whose financial support we wouldn't be here today, writes Fiona Heath.

The funds raised from events, businesses and individuals are the lifeblood of CHECT's annual income and we wholeheartedly thank our families, their colleagues, friends and neighbours, because without

them we would not have been able to support so many families and would certainly not have evolved from the tiny "kitchen table" charity

we were in 1987 to the small but significant organisation we are today.

There have been many firsts in our journey – the first London Marathon Gold Bond places in 2000, the first Christmas Day Swim, still going strong some 17 years later, the Devizes to Westminster Kayak Race in 1999, now an annual event and the amazing CHECT London to Paris cyclists. There have been fantastic golf days and fabulous gala balls. Our supporters have turned to their hobbies to help support us with everything from fishing competitions and clay pigeon shoots to lindy hop and Scottish dancing groups.

Families have asked local churches, community groups and schools to organise events – from sponsored silences to parachute jumps and jumble sales to auctions. All our supporters are important to us, from great aunts who hold coffee mornings, or loved ones who leave us a legacy, from little ones who do a toddle waddle to those intrepid adventurers who scale the Three Peaks or conquer Kilimanjaro.



London to Paris cyclists

Today's fast-paced environment presents us with new opportunities, with online giving sites such as JustGiving



Ellis's efforts raise £25,000

Ellis Collins has been fundraising for more than two decades after his goddaughter's son Thomas Jelley lost his left eye to retinoblastoma in 1990 when he was two years old. Here he shares his tips and advice on how to make a little go a long way for CHECT.

I started fundraising in the following year after Thomas's diagnosis, in 1991, when I asked

my employers Notcutts Nurseries of Woodbridge if their rose fields could be used as a means

of fundraising. As I was already involved with the Hacheston Rose Festival in my capacity as chargehand of rose production we were allowed to hold a craft fair as part of the festival and received a percentage of the profits. This ran for a number of years with great success but like all good things it packed up

going

and Virginmoneygiving making life much easier for our fundraisers undertaking sponsored events. The advent of text giving offers us new challenges and social networking sites such as Facebook and Twitter mean constant vigilance in the pursuit of new income streams.

Having said all that however, a cheque received in the post never fails to put a warm smile on our faces, and the sheer determination and generosity of our supporters always makes us all feel humble indeed. Not all gifts come in the form of money, we are always extremely grateful for gifts in kind, the complete redesign of our website, the printing of many

Marcella Lambert-Smith's sponsored silence



25th celebratory wristbands!

Our stocks of commemorative wristbands have now arrived in the office and are available for you to order. Can you sell to friends, family and colleagues? Get your classmates and gym buddies interested too! These high quality leather wristbands look fantastic and act as a great conversation starter for raising more awareness of the disease. They have a popper fastener and are available for a suggested donation of between £2 and £3. Call the office on **0207 377 5578** or email **info@chect.org.uk** for more details and to order your wristbands now.

thousands of leaflets, online surveys, giant awareness posters in children's play areas - if we would have had to budget for some of these items they simply would not have happened.

Without your commitment to raising funds we would not be able to progress as an organisation - we would not be able to increase awareness, or develop the GP and health

professional campaign we are currently working on. Your efforts play a pivotal role in our progress and future plans.

We are frequently told that our fundraisers are constantly amazed by the level of support they get from their colleagues, neighbours or friends. We believe this is because our members are so passionate about spreading the word and genuinely know their funds really do make a difference and have done so for 25 years.

Thank you to everyone who has helped us throughout the years - and keep up the good work!



Thomas Jelley and friends at a fundraiser

due to lack of helpers. I then joined a group called Hacheston

Events, raising money for local events by holding rallies and music festivals. In exchange for our help in loaning and erecting marquees etc we again received a percentage of the profits and got to run a CHECT information stall as well. The committee running this then tried to make it too large to run economically and profits went down making the huge effort and cost of putting on a three-day event unviable. We still have a small, dedicated

fundraising team here in Suffolk with our main efforts now selling plants and wrapping items for the Lucky Dip and then going to whatever events we can fit in. To date we must have raised in excess of £25,000.

When planning your event for CHECT - it always pays to remember the first three letters of FUNdraising!

Why working together matters to CHECT *by Joy Felgate*

Members

It is primarily because of members we exist. Most of our members have been directly affected by retinoblastoma (Rb) maybe as a child or as the parent, grandparent, aunt or uncle of a child with Rb. Many will have received support from CHECT and their ability to tell us how we are doing and what we should be doing is highly valuable. We used the information from last year's members' survey to help shape the work of CHECT going forward into the next five years.

Not only do members give feedback to CHECT but they also enable us to feed back to the clinical teams in London and Birmingham. We can also raise concerns on a member's behalf or let the teams know when something is working really well. Members also help support each other through the CHECT network and link up through our Facebook site, the Forum, the annual members' day, regional events and days out.

People sometimes ask me about our role in working with others and why these relationships are so important to an organisation like CHECT. I thought this would be a good opportunity to explain why these are of such enormous value to us.

Having a large membership gives us a voice that is heard externally, one that is listened to and can initiate change. Our recent campaign has obtained almost 4,000 signatures backing our call for the signs of Rb to be available in the Department of Health publications and websites. This volume of supporters carries weight and makes people listen and take notice, as we have seen with the Red Book success.

Nothing we do in the CHECT office is quite as powerful as a member telling the real life story of how they were affected by Rb. Our members all over the country are contacting the media, giving interviews and holding events where they can tell their story to other families.

so most of the money needed to run the organisation comes from fundraising activities. This is not just about keeping the charity going. Funds raised pay for vital awareness campaigns for GPs and healthcare professionals, critical Rb research projects and support for new families.

Volunteers

Volunteers enable us to do more. Not only because they increase our capacity but often because they bring specialised skills and knowledge we may not have in our small staff team. Sometimes all we need is some extra pairs of hands to lessen the workload as we know we can't do it all. It is great to have the energy and new ideas volunteers bring to the team. Many of our key services, such as the website and forum would not be possible without help from our wonderful volunteers.

Trustees

Trustees are needed to ensure the organisation stays on track - they have a leading and monitoring role and are responsible for the strategic direction of CHECT. They ensure we comply with all relevant laws

Finally, members raise funds. We have no government funding and

Fiona and Joy with CHECT patron Bill Roache MBE





Andy Abraham pictured with Emily King (former administrator), Juliette Carter, Libby Halford (former CEO) and Fiona Heath, in 2010.

and regulation, provide oversight and monitor the management team's performance, requesting remedial action where necessary.

Trustees meet six times a year, plus sub committee and occasional ad hoc commitments. They are elected for three-year terms at the trust's AGM. A trustee's role is voluntary and most current trustees have been directly affected by Rb so fully understand the needs and concerns of our membership.

Patrons

Our patrons and friends – currently Andy Abraham (X-Factor), Bill Roache MBE (Coronation Street) and John Hungerford (retired Consultant Ophthalmologist RLH) help us raise the profile of the organisation. They enhance the status of CHECT by their willingness to be publicly associated with the charity's mission. They can attend public events on behalf of the trust as VIPs and may be asked to participate in significant fundraising events or activities. They can also use contacts to further our work.

Health professionals

CHECT support workers work closely with the teams at both hospitals. We can provide additional support when needed and this works both ways. CHECT support workers spend time with families, listen and reinforce any

'It is great to have the energy and new ideas volunteers bring to the team.'

messages the clinical team need to get across. We learn from the Rb teams and benefit from their research and audits. We can also feedback to the Rb teams any issues concerning our members and help to resolve them. This advocacy role is extended to other healthcare services members may be in touch with such as health visitors/GPs and the National Artificial Eye Service.

Supporters

Our supporters come in all shapes and sizes from

suppliers, like our printers Fine Print (Stockport) who we work with, to fundraisers and corporate partners. Mostly our supporters become involved through a connection with one of our members.

They may help fundraise or promote the charity, sometimes by match funding what has been raised by employees. Partnerships such as Vision Express bring a number of benefits: being linked to a high profile organisation, publicity and awareness raising from store promotions and, of course, fundraising. Vision Express has raised nearly £120,000 for CHECT since our partnership started 18 months ago. We have also benefited from being linked to Cath Kidston and bmi baby through fundraising activities.

Professional partnerships

Collaborating with like-minded charities and organisations means we can share resources and work on big issues together. One example is working with Rare Disease UK on the government's recent consultation on their strategy for rare diseases. Another is working with Fight for Sight who are match-funding the places we have purchased for the Carrots Night Walk through London in September. This money will provide a grant for Rb-related research.

Without the dedication and commitment of all the people we work with CHECT would not be where it stands proudly today and to that end we say a heartfelt thank you to everyone who has offered us help and support over the past 25 years.

"We have collaborated with CHECT on a number of projects as well as participating in the annual members' day. Over the years CHECT has worked very hard to raise the profile of retinoblastoma, support families and increase the research aspect. We would like to take the opportunity to wish everyone in CHECT the very best for the next 25 years."

The Retinoblastoma team at Birmingham Children's Hospital

"My mum found the charity really useful when I was young. Less was known about Rb in those days and nobody else has this condition in my family. So she was kind of on her own. RbS (Retinoblastoma Society) as it was then, provided that information and support to her."

Darren Harris, 2012 Paralympian and CHECT member



"Many congratulations to CHECT on your 25th birthday. Having CHECT as an integral part of the Rb service ensures we understand the concerns of families when there is a reluctance to speak to the health care professionals. The support is particularly helpful when parents find it difficult to come to terms with a child with cancer."

Ashwin Reddy, Consultant Paediatric Ophthalmic Surgeon



When I was first appointed consultant at Moorfields and at Barts, the information culture had barely begun and the internet as we now know it was yet to arrive. Up to date medical information was difficult to come by. Our first attempts at information sheets aimed to fill this vacuum but it was rapidly apparent that what the medical team thought was wanted was not necessarily what was needed by the families! The break-through that inspired the formation of The Retinoblastoma Society, came when it was realised that an organisation intended for children and their families should not only belong to them but, also, that the motivation and running of any such society should be patient led. The enormous commitment of time and energy expended by the CHECT members and staff, together with their

"One of the many good and encouraging things about CHECT, and particularly its annual Members' Day, is that it is an important way of bringing together patients and their families with 'professionals'. This benefits all those involved - including the professionals - not just patients and families."

Dr Gerald Draper

"The work of the Childhood Eye Cancer Trust is invaluable. They're the only charity in the UK to dedicate themselves to supporting families affected by retinoblastoma. Through their tireless efforts, CHECT provide support to families at the time when it's needed most and on top of that they fund valuable research into the condition and run information campaigns. I'm proud to support them in their vital work."

CHECT Patron, William Roache, MBE

“CHECT has provided us with a wonderful opportunity to take part in the global synergistic effort to fight against the paediatric eye cancer. It’s marvellous to be a part of this collaborative research and enabled us to reach a significant milestone on achievement in the management of retinoblastoma.”

Dr Krishnakumar Subramanian, MBBS, MD Pathology,
Deputy Director-Research, Vision Research Foundation, India

immense drive, has made this formula extremely successful. The information now travels in both directions instead of only one. Informing families is now only a small part of the ethos of CHECT. Feed-back on all aspects of patient care is extremely valuable to the hospital teams and, thankfully, the old ‘we know best’ approach is long gone. The worldwide web contains vast amounts of valuable information but we shouldn’t believe every claim and, sometimes, there seem to be so many options for treatment that it may be difficult to be sure of what is best. Perhaps the greatest strength of an organisation like CHECT is that it channels the efforts of so many more people from all sorts of disciplines, to focus their minds on one goal than was ever possible before.”

John Hungerford, CHECT
Patron and Consultant
Ophthalmologist, Moorfields
Eye Hospital

“ I have always found Members’ Days very good for meeting other adults who, like myself, have suffered from and survived this unfortunate disease. Also, there are experts in the field always present to talk about various topics. Before we know it, it is time to say our goodbyes and go our separate ways back home.”

Bill Johnson,
Volunteer



“I became involved with the CHECT when I learned about their fantastic work in support of children and families who are suffering the effects of eye cancer. Through my involvement I’ve become more aware of their activities and I’m delighted to be part of an organisation that strives every day to battle the disease through raising awareness of Rb, pioneering research and providing support. The work of CHECT is truly inspirational.”

Andy Abraham, X- Factor finalist and CHECT Patron

“Research into Rb, to better understand why it develops and how it grows, is key to improving treatment and outcomes for children with this cancer. Our Childhood Cancer Research Group at Birmingham University and Birmingham Children’s Hospital has benefited enormously from research funding from CHECT to carry out this important work.”

Dr Carmel McConville

“National Commissioners have worked with the Rb Society, now CHECT, for many years. The involvement of the patient group was been invaluable in working to establish the service in Birmingham and since to ensure continuing improvement and development of both centres. I am sure CHECT will continue to play an important role for at least another 25 years.”

Sarah Watson, from the National
Commissioning Group.

CHECT not only provides information, advice and practical support but has also developed a positive relationship with the services in London and Birmingham leading to improvements in patient care. It is a fantastic example of a patient support group!

Dr Elisabeth Rosser
Consultant Geneticist



Ernie Brown was aged 3 months when he was diagnosed with bilateral Rb. He is now nearly 5, is about to finish his first year at school, and loves swimming.



Harry Burden was 18 weeks old when diagnosed. He is now doing absolutely fantastic. His left eye has been stable for over two years.



Gracie Hyland was diagnosed in November 2011, when she was two years old. Now almost three, she loves singing and dancing.



Fintan Morley-Smith was diagnosed in 2007 with bilateral Rb. He has just turned 5, has had every treatment going, but is thriving in school and still smiling!



Max Banning was diagnosed in 2009, when he was 1. He has had chemo, plaque, laser and cryo and amazes everyone with how happy he is!!!



Scott Muir was diagnosed with unilateral Rb in January 1991, age seven months. He is 22 years old and a healthy, happy young adult.



Abigail Pellet was 19 months old when diagnosed with Rb in her left eye, which was enucleated. Now four she recently got her wish to meet Rapunzel.



Ellie Smith was 20 months when she was diagnosed with Rb in 2009. She is pictured here looking happy and healthy with her 'princess' eye.



Felix Baulch was diagnosed at 4 months old with bilateral Rb. He has undergone lots of treatment and is now a cheeky 3-year-old who loves music and singing.



Amelia Pain was diagnosed with unilateral Rb at 18 months old and her eye was removed in 2009. She is a clever girl, who is very proud of her 'magic' eye.



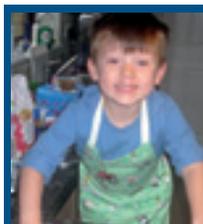
Edward Hall was diagnosed in 2008 with bilateral Rb. After several treatments, including enucleation, he's a happy, sport-loving four-year-old.



Darcey Fryer-Bovet was six months old when she was diagnosed with unilateral Rb. Darcey is now 22 months and living life to the full.



Branwen Rose was diagnosed with Rb and had her right eye removed in July 1987, age 4 years. She is now married with three daughters all Rb-free.



Andreas Holm was diagnosed with unilateral Rb when he was three. He is pictured weeks after enucleation, beaming with joy.



Isaac Stevenson was diagnosed with bilateral Rb age nine months. He is still under the care of the Royal London Hospital but is rallying after chemo.

25 years of the Childhood Eye Cancer Trust by CHECT member Jerry O'Shea

Today our birthday with you we celebrate
Founded 25 years ago on this date,
Evolved through time as The Childhood Eye Cancer Trust,
One simple ambition, to help you we must,

Our journey has been long and protracted,
Many hands have helped, many voices enacted,
A source of help and much-needed support,
Focussed solely on you, we vow never to retort,

An extended family, we have expanded, grown strong,
To launch awareness, recognise what's wrong,
To help you learn to fight and to cope,
For the terror that ensues we offer you hope,

Retinoblastoma: an aggressive attack of our eye,
We listen to your sadness, try to restore you a high,
We can't cure you or make it all right,
But hold you near and see out the night,

Be comforted, others have previously trodden your path,
We follow their footsteps, with you, don't be afraid to laugh,
We are not naive, offering sympathy, all sloppy and wet,
We prefer to be pragmatic, "What about a holiday let?"

We try not to push and seem inherently laid back,
But be in no doubt, retinoblastoma we relentlessly attack,
We ask, we request, even implore a donation,
To fund research, to eradicate, this rare gene mutation,

We are constantly shocked and mesmerised,
By your vision not necessarily through eyes,
Children are beautiful, brave and courageous,
Despite their battle their happiness contagious,

So we raise our glass: a toast to you all,
Our friends, supporters, our workers on call,
Be proud of yourselves, the very ground on which you stand,
To all we salute you and offer out our hand.

Following our appeal on Facebook we have been inundated with photos and tried to use as many as possible. Many, many apologies to those we have been unable to include - we will endeavour to use them in a future edition.



Laura Crawford was born with bilateral Rb in Dublin in 1979. Her community funded her treatment at Barts. She is now a mother studying for a degree.



Corie and Abby White - Corie had unilateral Rb and Abby, bilateral. Corie now works for Channel 4 and Abby co-founded Daisy's Eye Cancer Fund.



Kyle Yeupiksang was diagnosed with bilateral Rb last year, aged 8. He had his left eye removed and his right eye is stable. Kyle is now fundraising for CHECT.