

CHAS Chat

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PHOTO: Paul Hampton

MAKING A DIFFERENCE

Supporting families now and in the future

CHAS NEWS

WELCOME

Welcome to the Autumn/Winter 2011 issue of CHAS Chat. There has been lots happening over the past six months, so read on to find out more.

Thanks to supporters like you we are able to care for people like the Wallace family (see pg3) who only had five precious days with their daughter after she was born. On pg4 you can read about how CHAS helps hundreds of families with bereavement support when their child, brother or sister, or grandchild has died.

Inside you'll also find some new and simple fundraising ideas, such as completing a Gift Aid form to increase the value of your donations, registering for the CHAS Chill schools initiative, shopping online or doing a sponsored activity. However you choose to lend your support, thank you for choosing CHAS.

CHAS is a charity that provides the only hospice services in Scotland for children and young people who have life-shortening conditions for which there is no known cure. CHAS runs two children's hospices, Rachel House in Kinross and Robin House in Balloch, and a home care service called CHAS at Home.

CHAS AT HOME

The CHAS at Home service continues to develop with the recruitment of two part-time nurses and one full-time support worker in Aberdeen. The team, who are due to start in October 2011, will offer much needed support to families throughout the North East of Scotland in their own homes when they need extra support in between hospice visits or when they are too ill to travel.

CHAS RESEARCH

Children with rare life-limiting conditions are affected by a wide range of symptoms but up until now little has been known about the characteristics of the symptoms or the impact on the child and family. So CHAS commissioned a research project, undertaken by The Cancer Care Research Centre, University of Stirling, to gain a greater understanding by speaking to families and practitioners. The ground breaking findings have now been published and will help families who are new to caring for a child with a life-limiting condition and aid professionals when they are supporting families. View the summary report on the CHAS website at www.chas.org.uk or contact Ros Scott on 0131 444 1900.

FIRST MINISTER'S VISIT

Scotland's First Minister the Right Honourable Alex Salmond MSP made his first visit to Rachel House in March. After a tour of the hospice, the First Minister met families and took time to speak to the CHAS Young Adult Council about their frustrations with the current Scottish Health Care system, including the lack of physiotherapy available to them.



THE FIRST MINISTER MET PAUL AND SEAN ON HIS VISIT.

CHAS CHILL



To coincide with a new school term in August 2011, CHAS is launching CHAS Chill, a new fundraising initiative for primary schools. CHAS Chill is a fun, easy way for pupils to raise money for CHAS while taking part in an activity that makes them feel 'chilled out' - which is exactly what children visiting our hospices for a short stay enjoy doing, to make them feel rested and energised.

Why not register for a free event pack today? The pack includes activity ideas and a chillometer which is a fun way to keep track of how much money you are raising during your event. Call your local fundraising office (see back page) or visit www.chas.org.uk/fundraising-as-a-school for more details.

AWARD FOR EXCELLENCE

CHAS was honoured to receive a 'Committed to Excellence' Award in June 2011 in recognition of the hard work and dedication of staff and volunteers at CHAS. The Award was presented at the prestigious Scottish Awards for Business Excellence gala lunch organised by Quality Scotland. The coveted award recognises the important role staff and volunteers play when providing vital care and support to children, young people and their families across Scotland.

PRECIOUS MOMENTS

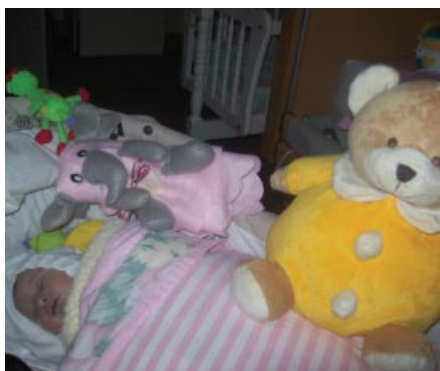
Many families visit Robin House and Rachel House over a number of years. However, CHAS also cares for families who need short term, emergency care for their child, such as the Wallace family.

Andrew and Joanne Wallace were delighted when their daughter McKenzie was born but just five days later she died in their arms at Rachel House.

24 hours after McKenzie was born she was rushed to Yorkhill hospital where they discovered she had three rare conditions - Ivemark Syndrome which causes organ problems, a rare heart disease and a hole in the heart. Andrew and Joanne were told McKenzie only had a few weeks to live and so the family were transferred to Rachel House.

Andrew clearly remembers that day, "It all moved so quickly and later on that afternoon we were in an ambulance coming to Rachel House. When we arrived, it was like a weight being lifted off our shoulders. McKenzie wasn't wired up to machines anymore - she was just a wee baby. McKenzie was dressed, there were no nurses, no noises. It was fantastic."

Both CHAS hospices offer the highest quality of care and support for children and young people nearing the end of their lives. They also provide a safe, calm and positive environment where families can spend precious time together. Andrew explains, "It was



MCKENZIE WALLACE



MUM JOANNE CRADLES HER DAUGHTER MCKENZIE.

amazing. I got to be a dad instead of looking at a baby through a plastic cover that was over a cot to keep her warm (in hospital). When we came to Rachel House we got to hold McKenzie, as well as to dress her and feed her normally. It was great.

"You really couldn't ask for better than this place for the kids and for us."

"Joanne got to be a real mum and I got to be a real dad - I got to feed McKenzie and spend some time with her. It was great. We were getting some photographs taken and she just fell asleep and passed away. It was good the way it happened, she wasn't in any pain or anything, but it was all so sudden. The staff at Rachel House were fantastic all the way through."

Andrew and Joanne had to face the awful reality of registering McKenzie's birth and death on the same day. Andrew said, "It was horrible but Rachel House were there for us. Nothing is too much trouble and if they can help in any small way, they do.

"When McKenzie passed away we were given as much time as we wanted. They had a room prepared, like a normal bedroom but a wee bit cooler. There was a crib, her pictures, lights and music playing in the background. It was a beautiful room. It was fantastic. We got to say our goodbyes. Some family members came as well and got to see her in nice surroundings. It was a great experience. It's strange to say that, but it was a nice experience."

The family are still in touch with the family support team at Rachel House who offer bereavement support. Andrew is very appreciative of the ongoing support and says, "Rachel House are still there for us, they still say "phone us anytime", and they are still there in the background.

"I never ever thought anything like this would happen to me. I never thought this would happen to anyone I know. Unfortunately bad luck can strike anybody. You never know when someone you know or yourself might need a facility like this. It's fantastic. You really couldn't ask for better than this place for the kids and for us."

KEEPING MEMORIES

"Although their child has died, their memories stay alive."

"Facing life without someone you love is a rollercoaster ride. There are days when you can't do anything because the pain is so intense. Then you have days you manage to do something but feel guilty because you feel like you are betraying them by moving on," says Evelyn Cairns, one of the CHAS Chaplains at Rachel House.

Helping families to cope after the death of their child is a huge and ever increasing part of what we do at CHAS. With a dedicated family support team at both hospices, made up of Social Workers, Chaplains, Activity Team members and Support Workers, we are able to offer bereavement support to families long after the death of their loved one.

Evelyn says, "There is a huge gap in their lives and they can feel they've lost their sense of purpose and identity as they've been caring for the person day in, day out, over a number of years. Life will never be the same again, but CHAS can help families who use Rachel House, Robin House and CHAS at Home on a very difficult journey and to learn to live with their loss in time."

Remembering days

One important way we help families is by organising Remembering Days twice a year at both hospices. These moving occasions are not only for mums and dads, but also brothers, sisters and even grandparents where they can all return to the hospice and remember the special person in their lives.

PHOTO: Paul Hampton



ABOVE: FAMILIES WROTE MESSAGES TO THEIR LOVED ONES TO CREATE THE WINGS OF A DRAGONFLY DURING REMEMBERING DAYS. THE DRAGONFLY IS SYMBOLIC AS THE STORY 'WATER BUGS AND DRAGONFLIES' IS USED TO HELP EXPLAIN DEATH TO CHILDREN.

The Remembering Days are part of the healing process. Last year over 300 people attended services held over two days at each hospice, Rachel House and Robin House.

The services, held in marquees in the hospice gardens and decorated with beautiful flowers, is a non denominational service given by CHAS Chaplains. The service includes songs and readings, and

The future may seem uncertain but CHAS is there to help.

the most poignant part is when the name of every baby, child and young person who has died is read out. Lesley McNab, CHAS Family Social Worker, explains, "For parents, to hear their child's name read out means so much to them - they are still a part of their lives."

The power of memories

After the ceremony, families are given a token of remembrance and invited to express their thoughts and feelings by adding a message, poem or drawing in the hospice memory books or perhaps as part of an art activity.

It's an opportunity for families to look back and remember. Evelyn says, "It's a very difficult day, but it's also incredibly uplifting."

ALIVE

PHOTO: Paul Hampton



ABOVE: THE ORDER OF SERVICE INCLUDES PRAYERS, SONGS AND READINGS TO REMEMBER THE CHILDREN WHO HAVE DIED.

Although their child has died, their memories stay alive. One mum comes across from France because it's so important to her.

"It's the one day where families can show it's ok to feel all those emotions. One mum said to me, "It's great when you come back because you just talk about the children as though they are still around". It's not denying that they've died; it's not that at all. It's honouring their memory and that they are still part of them and their lives."

Lesley adds, "Families reflect and take pleasure from memories they have of their child during visits to the hospice and they can share stories with staff and other families, helping them to feel close to their child."

"It's a very difficult day, but also incredibly uplifting."

Volunteer support

The Remembering Days are hugely important dates in the CHAS calendar and they are organised in no small part thanks to our dedicated hospice volunteers - many of whom knew a lot of the children and young people who are being remembered. Our volunteers are such an instrumental part of everyday life in the hospices that it is no surprise that they also play a vital role in poignant occasions like these. The volunteers help with every aspect of the day, from car parking and welcoming families, to offering their delicious home baking and making stunning flower arrangements. The last Remembering Day at Rachel House involved 33 volunteers, covering 40 slots in six different roles, to help make it all run like clockwork.

Facing the future

Grief is a very personal thing so as well as the Remembering Days, CHAS also offers individual and tailored bereavement support, such as telephone support, group meetings or a face-to-face chat, to help family members cope with day-to-day life. The future may seem uncertain but CHAS is there to help - and that's why your support, whether it is giving your money or your time, is so important.

Evelyn says, "Ultimately we would hope that a family would get to the point where they can return to some level of normality and enjoyment of living, while still remembering and honouring the memory of their child. We will do whatever is in our power to help to make that happen."

TEN REASONS TO GO ON A HOSPICE TOUR



PHOTO: Paul Hampton

SEE THE MULTI SENSORY ROOM ON A HOSPICE TOUR.

1. Discover where your donation goes - your tour guide will show you around the hospice.
2. Tours are free.
3. Hear some stories about families CHAS helps.
4. You can bring up to seven guests.
5. We'll do our best to give you a time slot that suits you.
6. Refreshments are available - including delicious home baked goods!
7. There will be an opportunity to buy CHAS Christmas cards - be well prepared for Christmas.
8. Afterwards, share your experiences with family, friends and colleagues to help spread the word about CHAS.
9. You won't get another chance until spring 2012.
10. It's only a phone call away to book your tour - give us a call! Rachel House tours in Kinross take place on Wednesday 21 and Thursday 22 September. Call 01577 865222. Robin House tours in Balloch take place on Wednesday 28 and Thursday 29 September. Call 0141 779 6180.

JOIN TEAM CHAS

We have delved into the minds of a runner, a cyclist and a walker to find out what inspired them to raise money for CHAS whilst doing their favourite sport. Could you do a sponsored activity and join Team CHAS? It doesn't have to be a gruelling activity - it could be something as simple as going for a nice walk, so everyone can join in the fun regardless of ability or age.

RUNNER PROFILE: ALAN HARWOOD



Alan has raised over £5,500 for CHAS by running the London and Edinburgh Marathons - he even ran more than 13 miles to drop off his sponsorship money!

1. Why did you run for CHAS?

"Running is my mid-life crisis - I couldn't afford a sports car! I don't particularly enjoy running and I'm not very good; but I do like beer and chips, so it is a bit of a trade off! CHAS do amazing work and fill a need not met by NHS resources. The people who work and volunteer in Rachel House and provide support services are all remarkable. They are genuine heroes."

2. What is your favourite run?

"I travel a lot in my job and my running shoes go everywhere with me, but my favourite run is through the Botanic Gardens in Singapore."

3. Which person (living or dead) would you most like to run alongside?

"There are so many people. I ran with Richard Branson at the London Marathon; I passed him after around 17 miles, but I don't suppose he remembers me!"

CYCLIST PROFILE: MARK NORTHWAY



Mark is a keen cyclist and cycled around all four of his employer's Beatson's Building Supply sites in Scotland, covering 100 miles and raising over £2,100 for CHAS.

1. Why did you cycle for CHAS?

"Because I can! We have a moral responsibility to do the best in our lives for those around us. If we all do our bit the world would be a better place."

2. What is your favourite cycle?

"The first is the 'two pint' run - a short 20 mile route from Falkirk, through Bo'ness to a pub with a great view over to Linlithgow. The other is a more serious training run of 60 miles from Falkirk, through Kilsyth, towards the Campsie Hills then turning back through the Carron Valley and home."

3. Which person (living or dead) would you most like to cycle alongside?

"Miguel Indurain - Spanish born five time winner of the Tour de France from 1991-1995."

WALKER PROFILE: STUART ROBERTSON



Stuart works for Forth Dimension Displays in Fife and along with two friends raised £280 by walking the West Highland Way for CHAS. Forth Dimension Displays have raised over £2,100 for CHAS.

1. Why did you walk for CHAS?

"I'd had many conversations in the pub with my friends about walking the West Highland Way and as my workplace was supporting CHAS we decided to make it a sponsored event."

2. What is your favourite walk?

"It's now the West Highland Way! I enjoyed it so much I did the whole route again during my holidays. During the sponsored walk we carried all of the kit we needed and rough camped, however when I went back and did it again I decided to go for a bit more luxury."

3. Which person (living or dead) would you most like to walk alongside?

"Tony Soprano from the Sopranos - I'm sure he would have lots of interesting stories to tell!"

SHOP

CHRISTMAS CARDS

Don't miss out on the CHAS Christmas card **early bird offer** with free postage on all orders over £40 received by Friday 30 September 2011.

To see our wide range of Christmas card designs and gifts, visit our online shop at www.chas.org.uk/Shopping. Not only will you save money and be well prepared, you'll also be helping CHAS families this Christmas.

Orders can only be placed through the online shop, by post or by telephone as Christmas cards are no longer held at local CHAS fundraising offices. You can also visit the CHAS Gift Shop in Kinross or temporary Christmas card shops - see www.chas.org.uk for more details.

Groups can request a sample pack of Christmas cards by contacting Heather at retail@chas.org.uk or 01577 864692. Alternatively why not call your local fundraising office to invite a speaker to give an update on CHAS and they can bring along a sample pack at the same time.



TIARA APPEAL



PHOTO: Les Gallagher, The Scottish Sun.

HOST MISS SCOTLAND LOOKING GLAM AND RAISING MONEY FOR CHAS.

The Scottish Sun's Miss Scotland Tiara Ball held in May 2011 raised a fantastic £70,000 for CHAS to build a specially adapted area for young adults at Rachel House. The glamorous star-studded evening was hosted by Lorraine Kelly and Miss Scotland Nicola Mimmagh after Nicola set Scottish Sun readers the challenge to raise funds for CHAS through her Tiara Appeal.

The money raised will fund a new space for teenagers and young adults to enjoy at Rachel House as the current space no longer meets their needs. Nicola's two cousins use Robin House and she has seen first hand the difference CHAS has made to their lives and other families, so it's a charity close to her heart.

The new space will be up to four times the size of the current young adult 'den' and the young adults have been very involved in deciding the design and interior style of the area. The main emphasis will be providing the young adults with as much independence as possible, including automatic doors and lighting so that they're not relying on their carers all the time. Look out for photos in the next CHAS Chat.

AUCTION PRIZES

We're always looking for auction prizes to raise money for CHAS at black tie fundraising dinners. If your business has a product or service that could be auctioned off to raise funds, please get in touch. Trips on sea planes, hotel stays, meals out and spa vouchers are just some of the items that have raised thousands of pounds for CHAS. Thank you.

SNAP UP DESIGNER CLOTHES

Are you looking for designer clothes and accessories but don't want to spend a fortune? Then go to the CHAS ebay site www.bit.ly/chasebay which has donated items from big names such as Burberry and Dolce. Here's one outfit that was snapped up:

Moschino 100% silk dress
EBay: £46.09
Approx. retail price: £300

Anya Hindmarch straw beach bag
EBay: £50.00
Approx. retail price: £295

Dolce & Gabbana shoes
EBay: £19.99
Approx. retail price: £280

Go now to www.bit.ly/chasebay to see what treats you can buy for yourself, or family and friends. Pick up a great bargain, look great and feel good too knowing you're supporting CHAS.



GIVE MORE - SPEND THE SAME

Do you know you could add an extra 25p for every £1 you donate to CHAS at no extra cost to you thanks to Gift Aid? Read on as Stuart Parry, CHAS Finance Manager, explains.

Q. So what exactly is Gift Aid?

A. Gift Aid is a scheme that allows charities such as CHAS to reclaim tax that supporters have already paid on the money that they generously donate to us. If you pay Income Tax or Capital Gains Tax and give a donation from your own funds, then your donation is considered to be from money that has already been taxed by the government. Gift Aid is a way for the government to pay this tax back to CHAS, the charity.

Q. It sounds like that could get complicated.

A. Not at all! It actually couldn't be more straightforward. As long as the donation you make is your own money and you pay tax (such as Income Tax, tax on a private pension or savings account or Capital Gains Tax) all you need to do is agree to Gift Aid and CHAS does the rest.

Agreeing to Gift Aid can be as simple as signing the declaration form below and returning it to any CHAS office or saying yes to Gift Aid over the phone. Once CHAS has this information any donation you make will be worth 25% more.

Q. How much is Gift Aid actually worth to CHAS then?

A. In 2010-11 CHAS reclaimed £168,574 in Gift Aid and this is the equivalent of a whole week of our total care costs which is incredible! With your help we can continue to make the most of this fantastic government scheme.

Many thanks Stuart, that's really helpful.

If you haven't done so, please take the time to fill in the declaration form below and send it back to CHAS Head Office (see form below for address). CHAS will do the rest. If you have any questions, don't hesitate to get in touch with your local fundraising office.



PHOTO: Paul Hampton

YOUR GIFT AID DECLARATION HELPS US CARE FOR FAMILIES.

CONTACT US

CHAS Glasgow
tel: 0141 779 6180
email: glasgow@chas.org.uk

CHAS Kinross
tel: 01577 865222
email: kinross@chas.org.uk

CHAS Edinburgh
tel: 0131 444 1515
email: edinburgh@chas.org.uk

CHAS Aberdeen
tel: 01224 645000
email: aberdeen@chas.org.uk

Gift Shop
tel: 01577 865557
email: retail@chas.org.uk

Bazaar (charity shop)
tel: 01577 861380
email: retail@chas.org.uk

Bazaar 2 (charity shop)
tel: 01577 865190
email: retail@chas.org.uk

Head Office
tel: 0131 444 1900
email: info@chas.org.uk

Canal Court
42 Craiglockhart Avenue
Edinburgh EH14 1LT

Please pass this newsletter on to family and friends so more people can hear about the work of CHAS.

Did you know you can receive this newsletter by email? Let us know if you would prefer to receive it electronically by emailing us at info@chas.org.uk

www.facebook.com/childrenshospiceassociationscotland
www.twitter.com/supportchas



Children's Hospice Association Scotland
Sharing the Caring

GIFT AID DECLARATION FORM

Please tick the box below and help us to claim at least 25p in every pound that you have given to CHAS (at no cost to you).

Please treat all gifts of money that I have made in the past four years and all future gifts of money that I make from the date of this declaration as Gift Aid donations.

For your donation to qualify for Gift Aid, you must pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April one year to 5 April the next) that is at least equal to the amount of tax CHAS will reclaim on your gifts for that tax year.

Forename: _____ Surname: _____

Home Address: _____

Postcode: _____

Signature: _____ Date: _____

Please complete your details in full to enable us to claim Gift Aid. Thank you.

Head Office and Registered Office: Canal Court, 42 Craiglockhart Avenue, Edinburgh EH14 1LT.
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