

Providing family respite breaks and practical support to seriously-ill children



Annual Review 2011-2012

What we do

Sebastian's Action Trust is a charity providing respite breaks and practical support for seriously-ill children and their families.

Our charity was established in 2004 to fulfil the last wish of nine-year-old cancer patient Sebastian Gates, whose vision was for a place where other children battling life-limiting or life-threatening conditions could spend precious time with loved ones, away from hospitals, hospices and gruelling treatment.

This wish became a reality in July 2011 when The Bluebells, a purpose-built house funded, designed and constructed by the charity, opened its doors. Nothing like this previously existed in the UK, making The Bluebells the first of its kind and Sebastian's vision all the more exceptional.



A note from our Director:

The Bluebells is still in its first year of operations but already it has surpassed our hopes and expectations. It is quickly establishing itself as an exceptional facility offering the support, peace, privacy and space much needed by families living with the day to day struggle of their child's condition.

We know we still have a great deal to learn but we are delighted with the many positive and appreciative letters we have received from our families following their time at The Bluebells. We really do see each and every one of them as "ours" as we are not a single visit destination: our aim is to walk alongside these families for as long as they wish, helping where appropriate in a myriad of ways.

We have been incredibly fortunate to have received so much support over the past eight years; without this we simply never would have realised Sebastian's wish. In these challenging economic times it is all the more important that we secure the financial viability of The Bluebells before looking to increase our service provision to meet demand, which is our ultimate aim.

Thank you for helping us to give precious times to so many families in need of the support we offer. We are very proud of The Bluebells and hope you will share in this sentiment as we reflect upon an

exciting and action packed year.

and

Jane Gates Director, Sebastian's Action Trust



Respite breaks Why are they so important?

Swimming together as a family for the first time was an experience we'd never expected to have. We relaxed, we had everything we needed and really look forward to coming back again soon.



The Bluebells is

the only purpose-

built respite break

centre in the UK,

giving opportunities

to enjoy normal

pleasures in the

company of family

and loved ones,

free of charge,

all year round.



This is honestly our dream holiday. Will had so much space to get around and it is all accessible. Will loved the pool and seemed happier in the water than out! The staff were amazing and we felt at home from the minute we arrived. Thank you – it was amazing!

The Cleary family

44 families enjoyed respite breaks at The Bluebells in 2011 (July-Dec) 109 respite breaks are confirmed for 2012, with families coming from 25 counties The Bluebells is a place for laughter, love, noise and fun. Our team is dedicated to making every visitor feel truly special, enabling families to make the most of precious time with their children.

So many family units break up as a result of the stresses of coping with a child's illness.

Our respite breaks offer time and space, away from treatment, hospitals and hospices, to build happier, stronger families.

> 92 day visitors used our facilities in 2011, with a further 500 booked for 2012

Who we help

We offer respite breaks to the families of children and young people with life-limiting and life-threatening conditions.

Where we help

We do not have a restrictive geographical catchment area and we already support families in the South East, principally from Berkshire, Hampshire, Surrey, Buckinghamshire and Oxfordshire.

We are happy to welcome families from outside these areas and since the opening of The Bluebells our support has extended to a national level, with respite applications being met following requests from families in Scotland and Wales, as well as further parts of England.

We think The Bluebells is a noble venture. It is already impacting on so many lives and to think it is free of charge is truly incomprehensible. Generations of families will appreciate this dream. Thank you so much for giving beyond yourselves. Such a lovely time for the whole family – it's been a long while since we had any break, let alone one like this.

The Adeloye family



Our respite breaks – the facts:

We will have provided 153 respite breaks in our first 18 months in operation. Geographically, we have supported the following numbers of families:



- 57 in Berkshire
- 37 in in the wider South East (Surrey, Oxon, Bucks)
- 8 in London
- 18 in other parts of England
- 3 in Scotland
 - in Wales

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In the past 18 months we have worked with 37 hospitals, 4 hospices and countless healthcare professionals throughout the UK. Our aim is to continue widening our scope for support and to develop new partnerships with other organisations committed to supporting seriously– ill children and their families.

Practical support

Being able to offer meaningful assistance to stressed families at critical times is central to all we do.

Every family's situation is unique and we aim to respond by giving practical and appropriate help where and when it is needed. Currently the services offered below are only available in restricted areas but it is hoped we can expand our remit in the future.

Some of the many initiatives we have undertaken in 2011 and 2012 include:

Emergency transport – providing a door-to-door service from home to hospital or hospice takes away the worry of getting to appointments safely and on time.

We provided our transport service on more than 80 occasions in 2011/12 (until April 2012).

Wellbeing therapy – giving carers a break from their 24-hour demanding role, which promotes their wellbeing whilst coping with a child's condition.

We have supported more than 40 families at home in 2011/12.



Sibling support – our Activity Days provide special outings and the chance to meet others facing equally difficult, isolating times.

We organised four Activity Days in 2011/12, giving special treats to 130 children.

Help at home – our family support workers alleviate some of the pressures in the home as well as being a listening ear during stressful times.

We have supported more than 20 families at home in 2011/12.

Bereavement care – Reflections is a support group founded by bereaved parents, giving those facing the loss of a child the chance to meet others who have experienced such personal tragedy.

More than 200 people attended our 2011 service of thanksgiving.

When Adam wasn't well enough to visit a farm, one of his last wishes, expressed shortly before he died, the team from Sebastian's Action Trust arranged for the farm to come to him. This was a lovely gesture – it shows how they could respond to our changing situation and were willing to do whatever they could to help us make Adam's final days full of special memories we will always treasure.

The Khan family







What our families tell us about our service

With a son that has relapsed with Leukaemia and two other autistic siblings, we had almost given up hope of a holiday – this was the first time in five years that we'd managed to get all five of us away together!



The Bell family

Being able to celebrate Matilda's fourth birthday at The Bluebells was nothing short of a miracle. It was just before she went back into hospital for more chemotherapy and it was wonderful to be like a normal family.

The Shand family



A wonderful place to make friends. We enjoyed staying at The Bluebells. The team are friendly, we loved cooking with Lauren and the pool is marvellous!

Grace Akinyemi (age 7)





We have had the best time ever! Being able to swim, with Simon, as a family, is something we never get to do and it is one of those things other families take for granted. Having the special beds and hoists mean we have everything we need for our son's condition- that doesn't happen elsewhere.

The Cox family



This visit was planned last minute and was such a treat. It gave us some quality family time before Noah has surgery later this week. The twins had a great time and they love 'their' holiday house!



We have loved just being a family here. Being able to see Alicia-Mai do everything with us has been amazing. Knowing that we can come back again is a huge bonus – we're so glad you are here for us when we need you.

The Hart family

The Chatteris family



Time together – priceless!
The Murray family

With a lot of help from our friends

As a charity that does not receive any statutory funding, we are entirely dependent upon charitable giving and our own fundraising endeavours. We receive financial and in-kind support from a growing number of sources, ranging from corporate organisations, trusts and foundations to schools, clubs and individuals.

Bluebells Sponsors:

Airworld Alastair Mundy Anne & Jonathan Stokes Ascot Fire Brigade Trust Badenoch Trust EC Harris Fernbank Flooring Company Les Trois Vallees Charity Lochailort Investments Limited Louis Baylis Trust Malcolm Burke Medical Media Michael Shanly Charitable Trust Pam Porter Memorial Fund Samantha Higgins Trust Southwood Golf Club Tour Players Foundation **TR Properties** UCS A number of private individuals and organisations who wish to remain anonymous. To date we have 21 Bluebells Sponsors; ideally we aim for 52.

We are enormously grateful to all who give so generously to our cause; who in one way or another have worked with us to provide meaningful assistance at critical times to the children and families we support.

The lists below relate to giving in the 2011-May 2012 period.

Other Support:

Apollinium Trust AWBS Barclays Basingstoke BBC Children In Need BJP Insurance Brookfield Aviation BTS Cigna Childwick Trust Coutts Charitable Trust Dodo Juice & DW Echo Trust GE & Moira Robertson Global Angels & Ed Bussey Herbert & Peter Blagrave Trust Hewlett Packard (Hook) Jenningsbet Langland MSG Group Dominos NS&I Rowan Bentall Charitable Trust RBS Siemens Stanlake Lake Wine Estate True Colours Trust Vodafone Waitrose

Thank you for helping me each week to get Abdullah to hospital. Without your support we wouldn't be able to cope with the four times weekly visits for vital treatment – you are a lifeline to us.

The Baig family

A final word from our roving Ambassador, Charlie

In recent years we have come to know and love Charlie Crick and his wonderful family. Born with a complex heart condition with many other complications, 14-year-old Charlie has undergone a lifetime of pain, uncertainty and unrelenting physical, emotional and psychological challenges. We are proud to walk alongside the Crick family, helping where we can.

This is an extract of what Charlie wrote shortly before his most recent operation, on this occasion to fuse his spine:

A couple of years ago I was bullied at school for being different; I was very unhappy because I was very ill. If it weren't for Sebastian's Action Trust I would not have the positive attitude to life that I have today. I am now going to have my 59th operation. It will be a huge step but with the support and love from Sebastian's I will get through this. To sum up the last four years it has been amazing, fantastic and I'm overjoyed with love for the support you've given me. Thank you x





Being able to support incredible youngsters like Charlie is a privilege. Thank you to all who have chosen to endorse and assist in our endeavours.

With continued support we will help many more children like Charlie who face constant challenges and an uncertain future.





Charlie on the 27th April, 2012, having just received the Pride of Bracknell Child of Courage award.



Sebastian's Action Trust



Bluebells Opening Day 5th July, 2011

Easter Egg Hunt 31st March, 2012





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