



Newsletter 48 Spring 2011

Angelman Syndrome Support Education & Research Trust

Getting off on
the right foot:
the benefits of
Reflexology

Assert's new
website

Circles of Support:
how others can
help you

How to get your
child's attention,
with the help of
a small bucket!

Registered Charity 1021882

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Useful Stuff

Freepost Address
ASSERT
PO Box 4962
Nuneaton
CV11 9FD

Website
www.angelmanuk.org

Email
assert@angelmanuk.org

Helpline
0300 999 0102
Assert Families - New
Diagnosis - Advice -
Contacts - Support

Assert Shop
Wear your charity with
pride. T-shirts, polo shirts,
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<http://458768.spreadshirt.co.uk/>

Front cover
Ella Court photograph by
Robert Chadwick. We'd
like to use one of the great
photos taken at our 2010
conference on each of our
future covers. If your AS
family member was one of
those photographed and you
do not want their images
used in Assert material
please could you let us know
as soon as possible.

Contents of the Newsletter

You will notice that the
pieces in this newsletter are
drawn from a wide variety
of sources. While we are
keen to promote discussion
and to pass on any views
and experiences, it is also
important to appreciate
that the opinions and views
expressed by contributors
to this newsletter
are personal and not
necessarily those of Assert.

Letter from the Trustees

Cuts, cuts and more cuts... surveys, surveys and more surveys

Welcome to another edition of the ASSERT newsletter, which I trust finds you well and being able to relax in the lovely spring weather. Ok, so this week has been a little warmer and dryer, but this is the UK, so will it last? As for relaxing, I am not sure that word is synonymous with Angelman Syndrome.

Unless you are living in a bubble, you will not have been able to miss all the activity of government, local government and associated service providers trying to cut back in a manner which I can only say is similar to my pruning techniques in the garden. Let's hope a little more life is left in the "plants", than is left in my garden – Claire will testify to this! To partner this trimming season, it seems that many organisations, including the government who obviously wish not to be left out, are producing surveys to canvas opinion as to what services are used, how they are used, and how we would all cope if the services were no longer there. I know for me personally when any survey comes through the letterbox or into my inbox, I am tempted just to send it to its respective wastebasket, however I would encourage all of us to submit our opinions; you never know, it might actually affect the services and provision for our children. Particularly, the government having produced a green paper entitled, "A new approach to Special Education Needs and Disability", we would really encourage you to read this paper, and send the government your thoughts. Ok, so some of it is vague, some of it is fanciful (surely other governments have had those ideas), some of it will never happen, some of it we hope won't happen, but you never know, they might just listen to us. I don't think it is called a green paper just because of its recycling potential! You can read it, and respond at the Department for Education's web site, education.gov.uk.

You will be pleased to hear that we are in the process of planning our next conference, scheduled for September 2012. Some of the many topics we are going to cover, mainly as they are real hot potatoes at the moment, are that of transition, leaving home and finances. We will send out details as soon as we have confirmation so that you can keep the dates free in your diaries.

Here's to a great spring and an even warmer summer.

Jeremy Webb

SIBLINGS - JUST FOR US

Picture the scene. You are sitting down with your mum and dad and your sister - who has Angelman's Syndrome - is about to tuck into the food at her birthday party. Mum and dad have always been quite firm about food - no desert until you've eaten the first course - even at parties! So you gaze on in amazement when your sister turns her nose up at the sandwiches and sausage rolls and heads straight for the trifle.

Surely mum with her finely tuned radar will spot this and step-in? Perhaps dad will intervene?? But NO. No-one stops her. In fact worse than that, they seem to be ASSISTING IN THE CRIME. Excuse me, you think: what's that about??

These things happen in all families don't they, and eventually we grow out of them? Except I have to tell you this was me at my sister Melinda's party just before Christmas... and I stopped being a teenager, erm, sometime back.

This incident didn't really have much to do with Melinda having AS but was more about her being grown-up and knowing what she wants to eat, particularly when it's her party! But it did make me think about our expectations of adults with AS and how they will, and do, have preferences for certain things like everyone else.

It reminded me too that when you are a brother or sister of someone with AS you will always have a brother/sister relationship with them that's quite different to the one your mum and dad have. And like any brother/sister there will be things you like about them, things that annoy you and you'll sometimes be a bit peeved if they seem to be getting preferential treatment...

(whatever age you are).



At the September Conference we asked those that came to the Siblings Forum what made them happy and what made them sad about having a brother/sister with AS and these are some of the things they said:

I'm happy because my brother James always smiles and gives everyone hugs.

My sister is loving. She is also very funny e.g. when we go to the restaurant and the waiter calls out a number to find out whose food it is she always puts her hand up.

Amelia makes me feel special and always comes up with surprises. I feel sad when people stare.

Nothing's bad about my sister, I don't care if she's different but she does hit random people.



Finally, don't forget the facebook page

"My brother/sister has Angelman Syndrome"

We have 42 members now and it's growing all the time so if you are old enough to be on facebook join us and let's hear from you.

Russell Andrews

Circles of Support



Introduction

"A circle of support, sometimes called a circle of friends, is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life. The circle acts as a community around that person (the 'focus person') who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help. The focus person is in charge, both in deciding who to invite to be in the circle, and also in the direction that the circle's energy is employed....."¹ It is a very powerful model to bring about change in a person's life.

Circles and families

Family carers may feel that there is no one else who can support their relative with a learning disability in the way that they can. Although they will want their relative to have friends, social activities and meaningful lives, they may feel that they cannot ask others to get too involved. The concept of circles enables people with learning disabilities and their families to draw others into their support networks. Family members will very often be part of that circle, although some may decide that their role is separate and different. An older family carer may be reassured to know that their son or daughter has a circle of friends when they become too frail or are no longer there.²

The advantages of circles of support

Circles help to build friendships and to overcome social isolation. Often they support people to engage in community activities as well as trying to ensure they get the services they need. They can promote well being as they focus on a person's gifts and help them to realise their aspirations. They can advocate for the person. They enable them to have a vision of what they would like to happen and to see fulfilment of many dreams. They are empowering: the person is always at the centre of the circle.

Setting up a circle

The person with a learning disability chooses the members of their circle. It is likely to include family members, friends and neighbours, some professionals, perhaps a member of their faith community if they belong to one. They help to foster understanding among the groups that support the person. It is a good idea to help the person to look at the skills people are bringing. Sometimes people find it particularly valuable to have someone who is good at finances or knows about the law. This can be useful if they are looking at taking up direct payments or individual budgets or for setting up a trust to look after financial issues.

Running a circle

It is important to find a comfortable venue for meetings where everyone will feel at ease. The group will need to be guided by the person about the frequency and focus of the meetings. They should be enjoyable. Some circles may meet outside the home, for example in a pub or café. The focus person may find meetings difficult and may need to have breaks. Rania's circle was set up in this way, but her parents were surprised that she stayed for the whole meeting.³ They concluded that she valued being so clearly the focus of everyone's attention. Deciding on a facilitator is a very important step in ensuring the group works well. The facilitator will ensure that the group keeps going and records key decisions in a way that

is acceptable to the person. The person may wish to facilitate themselves or to co-facilitate. They may want a family member to do this or may choose someone else from their circle.

Making a plan

The circle will want to find the best way of communicating with one another. Maybe drawing or photographs will be useful tools. The next step for a circle will be to make a plan. They will need to go at the right pace for the focus person. They will want to look at the current situation of the person and then support the person to dream about what they would like to happen. This then will be the goal. Some dreams will be big- such as the person having a place of their own. Others may be more modest, such as joining a dancing group or going on holiday. The important next stage will be to talk about the steps in more detail that will enable the person to achieve their dream and to develop an action plan which will also manage any risks effectively. There are some examples of ways of helping people in planning for their futures (e.g. PATH-Planning Alternative Tomorrows with Hope- Essential Lifestyle Planning and Personal Portfolios.) There are details of these on the Circles Network website (see resources below).

Circles and person centred planning

Valuing People, the 2001 White Paper,⁴ sets out the aspiration for the wishes of the individual to be the driving force for providing services and support. This may bring a wry smile to some family carers, but what can be done to make this more likely to happen? Circles of support can be very valuable in person centred planning. As Barbara McIntosh argues: 'having a circle of support made up of people who know the person well can be really helpful in creating a plan and putting it into action.'⁵ Circles of support and person centred plans are of course not only about services, but about the whole of a person's life.

Circles in Action

Circles are useful for all ages. John's mum described how 'John has had a circle since he was four. Other children have learnt to help him to control his behaviour. He has remained in mainstream school and has been able to develop his hobbies. He now gets invited to parties... The circle has changed and people have come and gone but through it the community network has grown.'⁶

Christian, a young man of 20 has had a circle for four years. There are about 14 people in his circle. He has chosen to meet in various venues; his home, the home of a friend or the pub. The circle helped him to plan a house move and enabled his voice to be heard when he was in hospital. They assist him to choose activities and to lead an active life.

Victoria who is nineteen has chosen a circle which includes her mother, brother, sister and some other family members as well as family friends. She signed that she wanted her own home. Over the last year the circle has supported her to get a council tenancy and she has recently moved into her own bungalow. She goes to college four days a week and the circle will be supporting her to decide what she would like to do on Fridays.

Conclusion

A circle meeting is a very different form of meeting from usual planning or review meetings. The circle is a gathering together of people, who all, in time, become friends. It is designed to be both informal and on-going. There may be times of urgent need when a structured agenda is required, but mostly it should feel like a social occasion. One of the biggest advantages of a circle is that the activity of planning becomes very natural as people are regularly discussing what has happened towards fulfilment of the focus person's goals and aspirations and what needs to happen next. The circle is there for the long haul and will experience the ebb and flow of its members.

Planning within a circle can be relaxed and engaging, with step by step arrangements carefully organised between the most relevant people within the group. No-one needs to feel pressurised.

Continued over

Conclusion continued...

If plans don't work out, adaptations can be swiftly initiated. Difficulties can be tackled as they occur and the group learns to stay positive and to problem solve together.

'To have people to call on, friends to share our troubles and joys with, family and close allies who will assist us and be there for whatever life throws up, most of us aim to achieve such aspirations.'⁷ Setting up a circle is a way of making this happen more effectively, using natural supports within our communities to break down barriers. Circles cannot solve all problems but they can go a long way to promoting inclusion.

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Written by Hazel Morgan, independent consultant for the National Family Carer Network. This information is offered in good faith as an overview. You should follow up the relevant resources before acting on anything referred to. Neither the network nor Hazel can accept any liability regarding this information. March 2007.

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For Information

- ¹ See www.circles.org.uk
- ² *Person Centred Approaches and Older Families* (2005) see www.learningdisabilities.org.uk
- ³ *Building Community through Circles of Friends: A practical guide to making inclusion a reality for people with learning disabilities* (2006) Christine Burke
- ⁴ *The White Paper, Valuing People* (2001) see www.valuingpeople.org.uk
- ⁵ *The Impact of Person Centred Planning* by Eric Emerson, Barbara McIntosh and others (2005) www.learningdisabilities.org.uk
- ⁶ *Count Us In* (2002) from the Foundation for People with Learning Disabilities
- ⁷ From *Choosing Friends* by Mandy Neville in *Everyday Lives, Everyday Choices* (2000) from the Foundation for People with Learning Disabilities

Resources

Circles Network (an organization which aims to build inclusive communities and facilitates the setting up of circles of support)
Potford's Dam Farm
Coventry Road
Cawston
Rugby CV23 9JP
01788 816671
www.circles.org.uk

Circles of Support - Building Inclusive Communities - Video and book set available from Circles Network

Creating the Possible - DVD available from Circles Network

Building Community through Circles of Friends: A practical guide to making inclusion a reality for people with learning disabilities by Christine Burke, available from the Foundation for People with Learning Disabilities 0207 803 1100 fpd@fpd.org.uk, www.learningdisabilities.org.uk

The Inclusive Circle - an article by Mandy Neville, see:
<http://www.sense.org.uk/publications/allpubs/magazine/tsarticles/2000/circle.htm>

Person Centred Planning: Making it work in the UK - by Barbara McIntosh, see: www.learningdisabilities.org.uk

Person Centred Planning: Key Features and Approaches - an article by Helen Sanderson:
<http://www.paradigm-uk.org/pdf/Articles/helensandersonpaper.pdf>

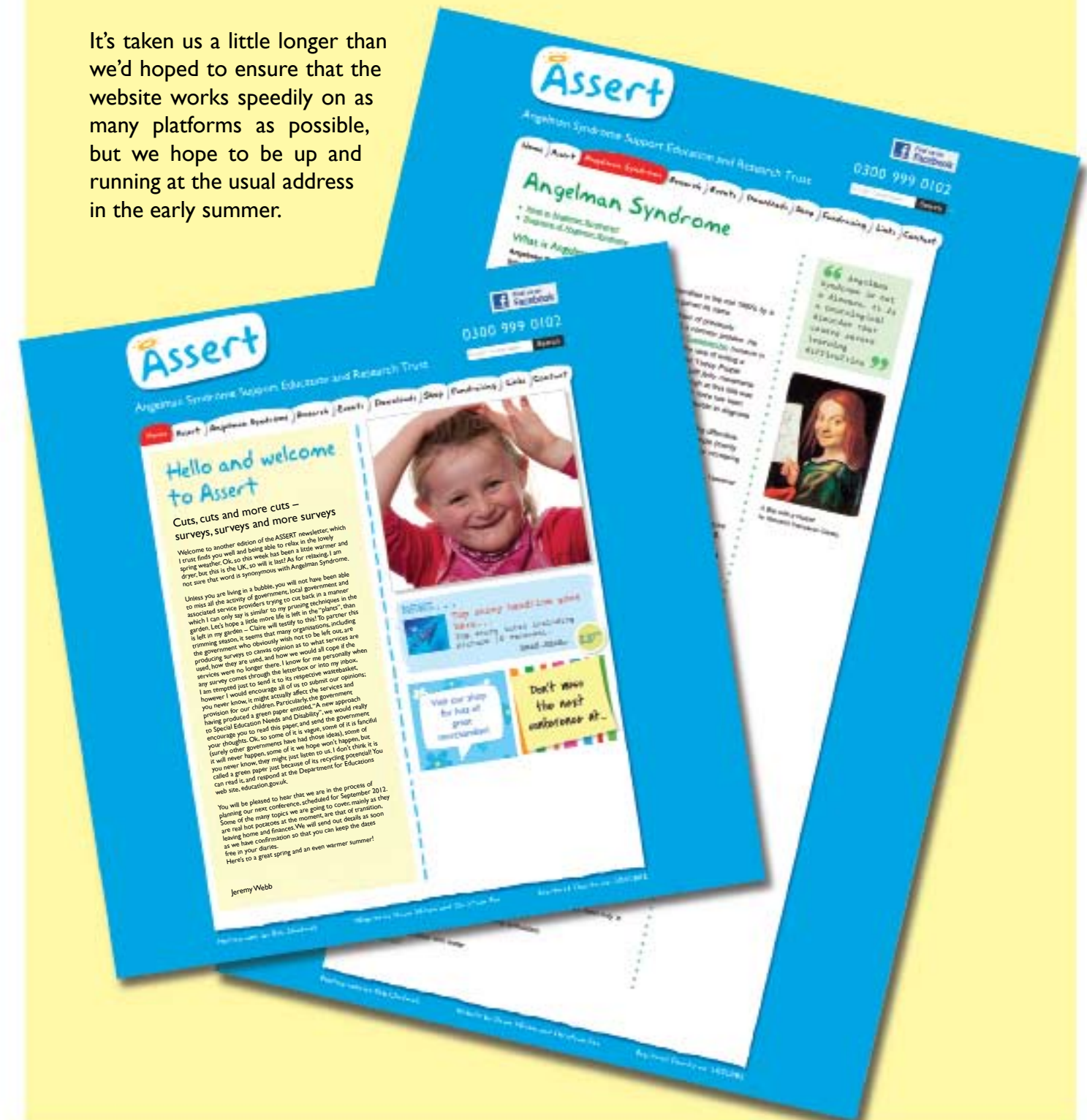
For additional information that will be useful for circles of support, please see separate briefings on:

- Making Decisions: An introduction to the Mental Capacity Act
- Self-Directed Support: Direct payments, individual budgets and In Control

Assert's new website!

Coming soon... Here's a first peek at what we've been working on in the last few months. As promised in our last conference Assert is launching a new website aimed at bringing you all the latest news and information in the Angelman Syndrome community. There will be lots of pages with an overview to AS, latest research, past copies of the newsletter, articles to download, Assert's great merchandise range to buy on-line, helpful links and all the current support and fundraising events in your area.. all presented in a family friendly and easy-to-use format.

It's taken us a little longer than we'd hoped to ensure that the website works speedily on as many platforms as possible, but we hope to be up and running at the usual address in the early summer.



Friends of Assert

As trustees we have been considering how we can draw more people into help with the organising of the activities of the Trust on a voluntary basis and we are particularly keen to move beyond parents and carers as we know these people already have significant pressures on their time.

ASSERT membership has always stretched beyond parents and carers and we wouldn't wish to change this. However we are considering establishing a 'Friends of ASSERT' group which would mainly consist of people who aren't parents/carers who may have more time to give to support events we run.

This may be members of the extended family, friends or people with an interest in Angelman Syndrome without the direct care responsibility. If you are interested in supporting this group or know of people who might wish to be part of it please let me know via the ASSERT website.

Thanks,

Russell Andrews

ASSERT CONTACT REGISTER

Those of you with good memories will recall that we used to have a contact register which listed all the contact details of the ASSERT members who wished to be contactable by other families.

This is something that we are determined to resurrect as it had great value, but to do so we need to ensure that all of the information that we currently hold in the database is correct.

If you would like to appear in the contact register, or you wish to receive a copy of the contact register, please can you send us an email, to angelmanuk@live.co.uk, with the following information:

1. Current email address
2. Confirmation of your current details; name, full postal address, telephone etc.
3. Whether you would like to be included in the contact register
4. Whether you would like to receive the contact register

We are going for a totally fresh start with this, so to be in it, or receive it you must email us by the end of May.

To be in it – Email us!

Looking for A part-time job?

ASSERT needs an Administrative Assistant

The ASSERT trustees are seeking to appoint an administrative assistant to assist the trustees in the day to day running of the charity. We are looking for someone who will be dedicated to the aims of ASSERT and to the successful running of the charity. We are also looking for someone who will be able to support the development of the charity as it enters its next exciting phase.

The job will be 8 hours per week at the hourly rate of £7.50 per hour with a minimum of 360 hours per year worked. Some flexibility within hours worked each week can be negotiated as required. The post will be home-based, the successful applicant will need to have telephone and broadband access.

If you are interested in this post and would like to know more please contact Jeremy Webb or Lisa Court via email at angelmanuk@live.co.uk or via the ASSERT support line 0300 999 0102

Support and Aspiration

A new approach to special educational needs and disability – a consultation

Please take some time to read the Government Proposals regarding Special Educational Needs and disability. Your views and input can help make changes that affect your children's future education.

Support and aspiration: A new approach to special educational needs and disability makes wide-ranging proposals to respond to the frustrations of children and young people, their families and the professionals who work with them.

The vision set out in the Green Paper is informed by the views and expertise of families, teachers, local authorities, health professionals and national and local organisations working with them.

Support and aspiration: A new approach to special educational needs and disability proposes:

- A new approach to identifying SEN through a single Early Years setting-based category and school-based category of SEN
- A new single assessment process and Education, Health and Care Plan by 2014
- Local authorities and other services will set out a local offer of all services available
- The option of a personal budget by 2014 for all families with children with a statement of SEN or a new Education, Health and Care Plan;
- Give parents a real choice of school, either a mainstream or special school; and
- Introduce greater independence to the assessment of children's needs.

We welcome your views on our proposals. The consultation will run from 9 March to 30 June 2011.

<http://www.education.gov.uk/schools/pupilsupport/sen/b0075291/sen-and-disability-green-paper-executive-summary/>

If you require other alternative formats please contact: send.greenpaper@education.gsi.gov.uk



Communicating through the feet

Angela Macleod, MFHT, explains how reflexology has helped a non-verbal client with a rare genetic disorder

My husband Ian and I own and run The Natural Healthcare Clinic in St Albans, Hertfordshire, established in 1994. We pride ourselves on delivering a high standard of professional care in a warm and welcoming environment. Ian is an HPC-registered physiotherapist, while my speciality is reflexology. We also have the services of a counsellor, and a GP who offers homeopathy and acupuncture. As a team, we take a very holistic approach and offer minerals and supplements to use alongside treatments where appropriate.

One of our clients, Ben, has a rare genetic disorder, called Angelman Syndrome (AS). Now 24, Ben first came to the clinic in 2005. His parents were concerned to keep Ben mobile and his past physiotherapy with the NHS had been limited. Ben saw Ian for physiotherapy and his parents were extremely impressed when they noticed a significant improvement.

One day, Ben's parents overheard me discussing reflexology with a client. They were very interested in how the feet mirrored



the body and how the therapist could identify imbalance because, as Ben has problems communicating, they often found it difficult to identify issues affecting his health and well-being. They asked if I would give Ben a reflexology treatment before his next appointment with Ian, to see if I could pick up any imbalances. This was a winning formula for Ben – reflexology prior to physiotherapy – and so we have continued.

Benefits of treatment

As well as helping to improve circulation and mobility to his feet and ankles – both problems for Ben – reflexology has proved an effective way to help other minor issues.

On his first reflexology session, I picked up an imbalance in the shoulder area, which Ian was able to identify and tackle in the physio session that followed (Ben evidently had a very tender spot by his right scapula). Although Ben had not communicated this problem to his parents, they put it down to the way he carried a heavy voice output device over his shoulder, and were therefore able to encourage him to distribute the weight more evenly in the future.

During another session, I noticed an imbalance in his mouth/teeth reflexes. His parents were amazed when, on cleaning Ben's teeth, they found a nasty ulcer tucked deeply into the fold of skin between his gum and cheek. They were able to treat this swiftly, but it took several days.

An imbalance in the gastrointestinal tract reflex was also picked up in another reflexology session.

Ben's parents have been incredibly impressed by the holistic healthcare he has received, and particularly the reflexology. In a letter of appreciation, his mother, Pam, wrote: 'Our journey with you has been a real eye opener and a very helpful one, too. I so hope others will allow themselves the opportunity to discover more about their bodies through your skilled hands – I know Ben enjoys and benefits from his time with you.'

Treating Ben

Before treatment, I explain to Ben what I'm going to do, and I maintain good eye contact at all times, which is very important to him.

As he loves water (interestingly, another behaviour/trait in some people with AS), I always ensure that we have plenty of time to use a foot spa before his reflexology treatment begins. I also use warm towels and only a small lamp while working his feet, as having the room darkened has a calming effect on Ben. Using aromatherapy oils in the treatment room – usually lavender – also seems to soothe him.

As interaction can vary from Ben being calm and quiet to loud and exuberant,

I ensure he is the last client of the day, so that others are not disturbed and we are never rushed.

From the beginning, Ben and I have had a very good relationship. He can be a little cheeky so I do need to adopt a 'firm but fair' approach, but we both really enjoy and look forward to his sessions... perhaps not least because we share some cookies at the end!

What is Angelman syndrome?

Angelman syndrome (AS), first described by a British doctor called Harry Angelman in 1965, is a rare genetic disorder that affects development. It is caused by one of a number of identified irregularities that can occur in chromosome 15.

Symptoms/characteristics may include:

- unusual head shape and facial appearance, with open-mouthed expression, revealing the tongue and widely spaced teeth;
- seizures and disturbed sleep, though these may improve with age;
- severe motor developmental delays, including walking;
- severe learning difficulties, with impaired or absent speech;
- ataxia of gait, jitteriness, awkward arm movements and hand flapping
- excitable behaviour and short attention span;
- frequent (sometimes inappropriate) laughing and happy demeanour.

Most people affected by AS otherwise have good health and live a normal lifespan, though a high level of support is required.

Information sourced from BBC Health (www.bbc.co.uk/) and Angelman Syndrome Support Education and Research Trust (ASSERT, www.angelmanuk.org). For more information about Angelman Syndrome, please visit the ASSERT website above.

This article was first published in, and reproduced with the kind permission of International Therapist magazine (Issue 94, October 2010), the membership journal of the Federation of Holistic Therapists www.fht.org.uk

USEFUL WEBSITES

INFORMATION

Information on Genetics
www.bioedonline.org/workshops/evening-genetics.cfm

Special Educational Needs news
www.senmagazine.co.uk

Reading recommendations
www.scribd.com/doc/36260961/Angelman-Syndrome-From-A-to-Z

PARENTAL SUPPORT

Assert's Facebook page
www.facebook.com/group.php?gid=17790428608

Professionals Supporting Parents
www.right-support.org.uk

People with Profound & Multiple Learning Difficulties
www.pmlnetwork.org

National Family Carer Network
www.familycarers.org.uk

Challenging Behaviour Foundation
www.theCBF.org.uk

KidsOut
www.kidsout.org.uk

MumsNet Special Needs
www.mumsnet.com/Talk/special_needs

Family Fund
www.familyfund.org.uk

Contact a Family
www.caffamily.org.uk

Foundation for People with Learning Disabilities
www.learningdisabilities.org.uk

SIBLING SUPPORT

Assert's Siblings page
www.facebook.com/group.php?gid=142621172447009

THERAPIES & EDUCATION

Management of Angelman Syndrome
http://www.dyscerne.org/dysc/digitalAssets/0/263_Angelman_Guidelines.pdf

Talking Point (speech & language)
www.talkingpoint.org.uk

Intensive Interaction (communication)
www.intensiveinteraction.co.uk

Makaton
www.makaton.org

Gina Davies: Attention therapy
www.attentionautism.com

PRODUCTS

Harnesses
www.childharness.ca/index.html

Safespace Beds
www.safespaces.co.uk

Baby Monitors
www.babymonitorsdirect.co.uk

Orthotic Products
www.gilbert-melish.co.uk

Toys for Disabled Children
www.tfh.com

Brand New!

Assert Merchandising

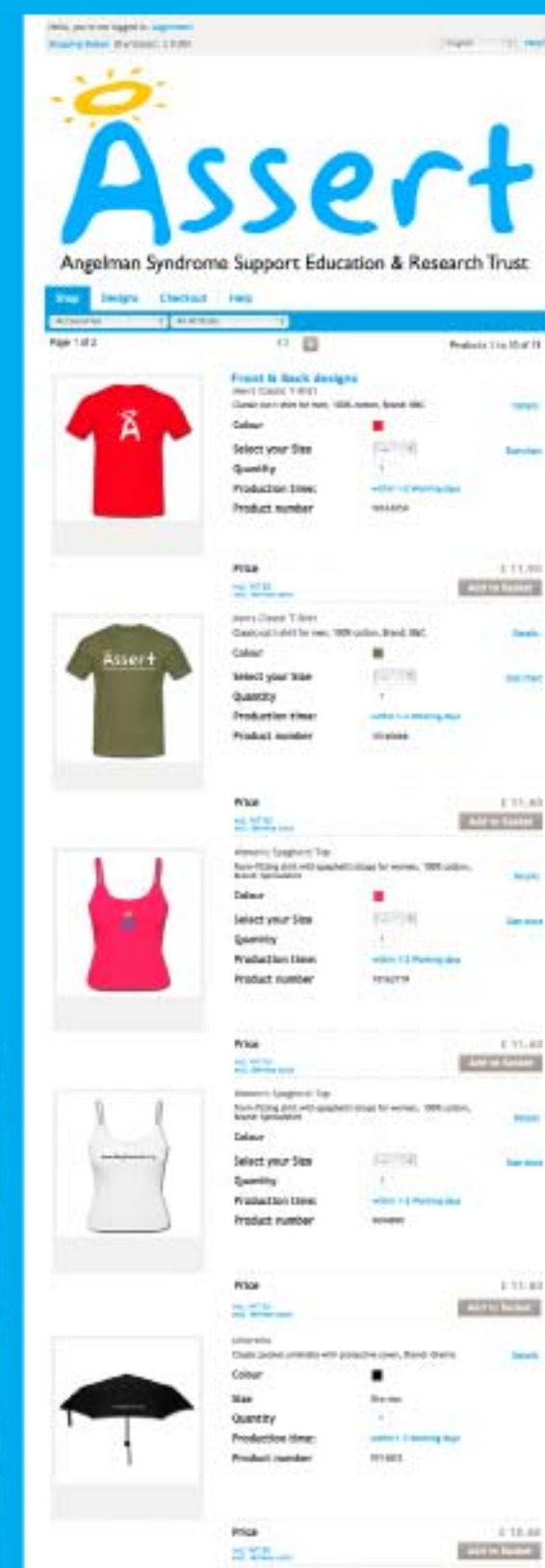
In association with Spreadshirt, our on-line merchandising shop is now open. Whether you just want to support your charity or looking for that perfect gift for friends and family, you'll find something here to please everyone.

This link:

<http://458768.spreadshirt.co.uk/> will take you straight to ASSERT's merchandising page - or you can reach it via the ASSERT website. Select from mens, ladies and childrens clothes, along with some great accessories - you name it we've probably got it, or there's a good chance it's coming soon.

And taking note of your conference feedback we've added some looser-fit shirts along with other great new products.

Shown here are just a few samples of what's on offer. Make sure you bookmark the Spreadshirt site and check back regularly for more great designs soon.



<http://458768.spreadshirt.co.uk/>

Attention Autism

A visit to Gina Davies's workshop

Hi, my name is Antonia Burton. My daughter, Ella (3) has Angelman Syndrome via a sporadic mosaic imprinting defect. She was diagnosed by a geneticist when she was just 2 years old and although we knew she had some degree of developmental delay, it still came as quite a shock when her test results came back positive for A.S. Even the geneticist was quite surprised as Ella seems to show rather mild symptoms. She is totally mobile, says a few words consistently, a couple of other words occasionally and just recently a fair few new sounds are emerging. She feeds herself and tries to help me wash/dress her.

We attended our 1st Assert conference last September which is where we saw a workshop called 'Attention' by Gina Davies. Gina is a trained speech and language therapist and has worked independently for around 20 years. She mostly works with Autistic people but after meeting a number of people with A.S, she has found her method to be extremely beneficial for them too.

The idea behind 'Attention' is to increase the child's concentration and focus. It involves a non see-through bucket of small, highly motivating objects, e.g. light up glasses, wind up toys, slinky, water pistol etc. The bucket belongs to the lead adult and so the toys are not given to the children to play with. The children sit on chairs in a semi-circle facing the lead adult and all other distractions are eliminated - basically anything more interesting than the bucket or the lead adult must be put out of sight. The children will need a supporting adult to sit with them as generally one or more child will fidget or get up and in this instance the adult would just sit them back down without giving eye contact.



Antonia working with Gina's methods at home



(Getting eye contact, as we all know, is something that our Angels are all 'masters' at and definitely distracts them away from what we want them to be concentrating on.)

The lead will then sing "I've got something in my bucket..." before showing 3 or 4 toys to the kids, one toy after the other, showing what it does without talking much, in order to put all focus on that particular toy. The demonstration of each toy needs to be hugely exciting and over the top. The idea is to build attention starting with a session which is just a couple of minutes and building to 20 minutes over six weeks.

It helps to get the child's school or playgroup to also incorporate the 'bucket' as much as possible so it is a consistent method. As well as the 'bucket', other ideas can be used such as sieving flour onto a black background and then drawing a smiley face in it with your finger or pouring brightly coloured liquid onto a flat white shower curtain etc - really anything that's a 'short and visually stimulating demonstration' is going to be good.

This is only stage one of Gina's method and other stages will work to help skills like turn-taking for example. It's amazing actually how long a child (even our Angels) will sit and get joy from just watching something like this. We have begun trying the 'bucket' at home with Ella and her little brother Harry and they are already able to happily concentrate for a good 10 minutes without trying to get up or escape. It has been fantastic so far and I'm hoping that continuing this method at home and at Ella's pre-school will help her concentration, focus and turn taking skills in all situations....
Highly recommended!!

Antonia Burton

For more information on Gina Davies's methods and the workshops she runs, visit her website:
www.attentionautism.com



Gina Davies at her workshop sessions



HOLIDAY REPORT

If you have had a good holiday, write in and tell everyone about it!

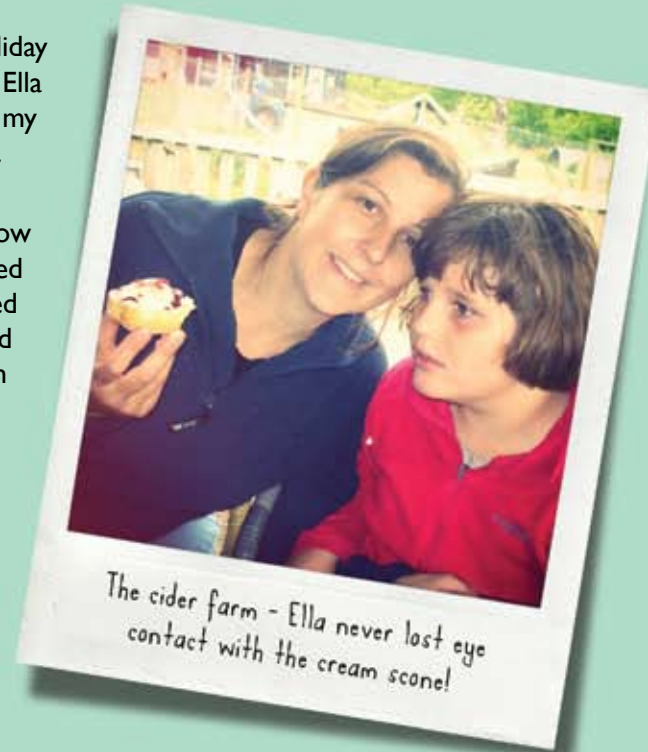
Last August the Court family had a wonderful holiday in Somerset. I took a lot of convincing to take Ella away for the week (as well as our two boys and my husband!) but I have to say it was worth the effort.

Craig scoured the internet to find a suitable bungalow in the Somerset / Devon area as obviously we needed to cater for Ella's needs, and he found what seemed the perfect answer in a 3-bedroomed, good sized bungalow in a lovely little village called Watchet in Somerset. It had a private pool which was shared amongst the 12 bungalows, and we could use it as much as we wanted to.

The village itself has a picturesque small harbour and we had several walks down to the front to watch the boats. The little Co-Op was 2 minutes walk, along with a great Chinese takeaway! The pool was a huge factor in deciding to make the booking. We decided that whatever we did each day, or wherever we went, we would always end up in the pool, even if only for half an hour as that is Ella's absolutely favourite activity. It was only a small pool, but it was perfect. There was only ever one other family in there with us, and we quite often had it to ourselves. The boys and Ella had a great time each day.

Ella has AS and is 8 years old. We also have two younger boys who are 5 and 3. Craig did a lot of research before we went to find out what was nearby. We constantly have to find activities / days out that are suitable for Ella, but also for the boys and this is just as relevant on holiday as it is at home. It's a challenge that seems to get harder as they get older.

But I am very pleased to say we went out and about each day. There was so much to do. We found a cider farm just up the road that also served cream teas – what a perfect combination! Me and Ella were happy with our cakes, Craig was happy with his cider, and the boys were happy with the pigs, chickens and play area.



The cider farm - Ella never lost eye contact with the cream scone!



We didn't have the best of weather, but obviously we still went to the beach!

We went to every kiddies farm in the area (some better than others to be honest). Ella's second favourite activity is ball pools so kiddies farms are a good choice for us as they usually have a soft play area. One of us will sit in the ball pool for at least an hour with Ella, whilst the other one goes round the farm with the boys or play in the park. A lot of our time is spent apart once we arrive at a location, because Ella will want to do one thing, and the boys will want to do another. We meet up again when the kids are hungry!

Tropiquaria is just outside Watchet, so we spent a few hours there. The steam railway to Minehead was a stones throw from the bungalow, so we had a couple of trips to Minehead on the train. One day we happened to go when there was a display by the Red Arrows over Minehead beach, what a wonderful show that was. Another day we had a day pass to Butlins at Minehead. We went to some local beaches, we went to Weston-Super-Mare for the day. (I will add at this point we were only there for a week!) Basically, we would get up each morning and head off for the day, getting back with just enough time for a splash in the pool.

I was nervous about how Ella would sleep in the bungalow as she has a 5 ft Safespace bed at home, and we don't have the travel version. We set off with just a sleepsheet, and all our fingers crossed! Ella had her own bedroom in the bungalow, so we put the mattress on the floor and put on the sleepsheet. Ella has a TV on her wall at home that we leave on all night, so we took the TV screen from the DVD player in the car, and put that on the bedside table. Surprisingly, Ella adapted very well and didn't try to escape too much!

We hadn't been on holiday for a few years, and I was very apprehensive how Ella would manage, well more to the point how we would manage, but actually it was fine. I'm even now considering a holiday abroad this year, so

If anyone is interested in where we stayed, the link is as follows: (the bungalow we stayed in is no longer available but similar bungalows are) www.cottagesomerset.com

If anyone is interested in the sleepsheet, then we have one that is owned by ASSERT and can be loaned out. Please contact me via the ASSERT website for more details.



Watchet Harbour



Happy children on the steam train to Minehead

Lisa Court



The National Year of Communication

Hello, the 2011 national year of communication, is a campaign to increase understanding of how important it is for children and young people to develop good communication skills.

In the 21st century, the ability to communicate - to say what you want to say and to understand what other people are saying - is fundamental.

Speech, language and communication underpins everything we do in life. Babbling babies do not become talkative toddlers by chance. Communication is a skill that we learn and develop and is something we can all improve.

But did you know that in the UK today over 1 million children and young people have some form of speech, language and communication need? This is at least 2 or 3 children in every classroom - and that's the children we know about.

Difficulties with communicating can affect children and young people severely and for life. In areas of poverty, over 50% of children start school with delayed language skills. This puts them at a huge disadvantage to their peers as they struggle to learn and make friends.

Hello aims to make communication for all children and young people a priority in homes and schools across the UK so that they can live life to the full.

Hello 2011

Through this website you will find out about the monthly themes we have devised for the year, free resources to help support children's communication development and find out about events that are happening in your area.

www.hello.org.uk

PRODUCTS



Trabasack 'Connect'

A tray top made of super soft velcro. Uses hook and loop technology (Velcro) to make things easy to attach and hold onto the top of the tray surface.

The surface is a soft fabric that adheres strongly to anything with 'hook' tape on it. Add small 'hook' tape to anything that you wish to stick to its surface: the back of your iPad, remote control, mp3 player, toys, consoles etc. Removable Wipe clean surface also available to buy separately. Designed by parents of a child with Dravet Syndrome.

<http://www.trabasack.co.uk>

'Local Authorities will be obliged to cut almost everything not cemented to the floor by law'

The following is the opening extract from a paper by Steve Broach, Barrister, Doughty Street Chambers, outlining the central legal duties in relation to disabled children and their families with which public bodies must comply.

Although the paper is primarily aimed at commissioners, managers and professionals working in local authorities, Primary Care Trusts (PCTs) and other public bodies it may also be of great interest to many families in the Angelman community.

You can download the complete paper here:

http://www.ncb.org.uk/cdc/resources/cemented_to_the_floor_by_law.aspx

.....

'Cemented to the floor by law' Respecting legal duties in a time of cuts

Writing for The Guardian website on the evening of the Comprehensive Spending Review (20th October 2010), Polly Toynbee suggested that local authorities will be 'obliged to cut almost everything not cemented to the floor by law'. So the question then becomes to what extent vital support services for disabled children, individually or collectively, are 'cemented to the floor' by enforceable legal duties?

Now more than ever it is vital to understand with precision what local authorities and other public bodies must do to support disabled children and what they may do, in other words the distinction between duties and powers. Yet in far too many vital service areas relating to disabled children, the distinction between duties and powers is poorly understood if considered at all. The reality in many areas is that everything provided for disabled children is treated as discretionary, as opposed to other local authority functions such as child protection investigations which are (properly) recognised to be required by law. In fact, as this paper sets out, very many of the services provided to disabled children are provided under duties, not powers. Once the condition(s) for the duty to arise are met there is no discretion – the service must be provided. Importantly, any failure to meet duties may well result in an application for judicial review being brought against the public body in the High Court, dealing with which will be an unnecessary, expensive and time-consuming distraction for hard-pressed staff.

Please see website for full article. Extract taken from:

http://www.ncb.org.uk/cdc/resources/cemented_to_the_floor_by_law.aspx

BOOKSHELF

Jade and the Walking Stick

By Ryan Tipton

£14 Age Level : 4 - 8, Reading Level : 2 - 6

Inspired by the story of a young girl with Angelman Syndrome, Jade and the Walking Stick is a fantastical tale of a special needs child coping with the challenges in her life. Written for the author's daughter, the book symbolizes the developmental milestones common to special needs children through a fantasy fiction narrative. A fable of acceptance and triumph, Jade and the Walking Stick should inspire others to face all of life's challenges with a smile.

ISBN13: 978-1-4415-9818-9 (Picture Book)

<http://www2.xlibris.com/BOOKSTORE/book-display.aspx?bookid=69750>

Angelman Syndrome

by Bernard Dan

This comprehensive guide to the clinical management and basic science of Angelman Syndrome will be of value to clinicians and researchers as well as parents and relatives. Usually £71.25 but available for the special price of only £37.50 to ASSERT members. Contact Assert for a copy of the publisher's pdf file for mailing details.

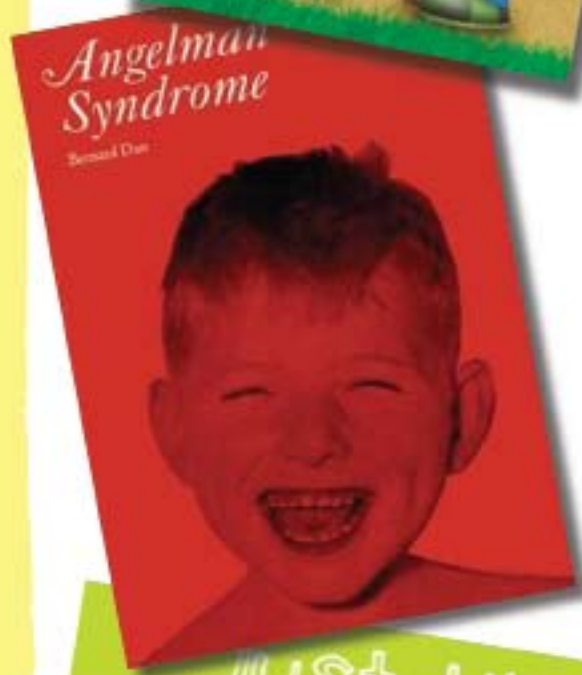
Paperback: ISBN 978-1-898683-55-1

Just Like You

Angels without Voices have created a great children's book called Just Like You. It's written, illustrated and printed all free of charge to help in the fundraising for ASSERT.

There is also a CD of Music from the Movies which features Sam's Song, a very moving song written for ASSERT and all the Angels in the UK.

Both the book and the CD are available to purchase online at www.angelswithoutvoices.co.uk at a cost of £5 each + P&P



ASSERT Bank Account

Please be aware that we now only have our current account. All other accounts are closed. There have been some receipts paid into the other accounts which at the moment the bank are automatically transferring to our current account but I am sure there will come a time when they will not do this. So please do not pay any donations, collection tins etc into these other accounts. If you would like our current account details, please contact the support line.

Lisa Court, treasurer

Please feel free to pass this newsletter to all who wish to read it or who may benefit from its contents. Thanks to all contributors.

REGIONAL MEETINGS

Could you host or help to organise a regional meeting in your area? It could be a coffee morning or a full on fun day. Recent meetings have been held in Special Schools and have proved very successful. Most schools are well equipped for our children with changing facilities, play areas and separate dining areas. Other ideas include local Soft play centres i.e. Wacky Warehouse or community rooms. If you feel that you would like to help families in your area meet up and build relationships then please contact ASSERT and we will help in whatever way we can. Moderate expenses can be covered if necessary.



CLASSIFIEDS

If you would like to advertise to the ASSERT community send your adverts to us and we'll endeavour to publish them in the next newsletter.

Safe Space bed for sale: £2000

Call Michelle Catchpole on 0131 653 4818 (home) or 07826 515 838 (mobile)

Britax Traveller Plus car seats

We have 2 Britax Traveller Plus car seats for sale. The exact specification of the car seat can be found on the Britax website: <http://www.britax.co.uk/car-seats/traveller-plus>

In summary it is a seat that is specifically designed for children that need additional support / security when in the car. It has a 5 point harness and is for children between 15-36 kgs.

We have used one car seat in each car. They have proved invaluable in transporting Ella. She needs the 5 point harness to stop her slipping down, and to keep her sat in a safe and comfortable position.

Ella has now outgrown them. They retail at between £400 - £500. One car seat is in a better condition than the other, so one is for sale at £100 and the other at £50.

Contact me at: lisa.court@ciber.com or phone on 07870 234947.

Adverts are placed by ASSERT members and their accuracy, details and quality of the service provided is not the responsibility of ASSERT; respondents should contact the member directly using the details given and should not contact ASSERT.

DONATIONS

Thank you to everyone who has donated to ASSERT.

Your contributions - no matter how small - all make a difference. Without you there would be no ASSERT and we know how important we are as a support to our families within the A/S community. Many thanks to:

Mrs Tait

Mr & Mrs Longfield
(in memory of John Siddall)

Hilton UK Hotels, Cadogan Square,
Glasgow

The Hilton in the Community
Foundation

Chingford Ladies Golf Club

Mr A J Taylor

Shelley Rigby
(Birmingham Half Marathon)

Mr & Mrs Simpson

Karen Jones

T Harrell

Kevin Burke

Mr & Mrs Lewis

Francis Maxwell LLP

Wincanton Group Ltd

Mrs Archer
(in memory of Alice Barnett)

Mrs Hewitt
(in memory of Kathleen Bowler)

Leicester University
(in memory of Kathleen Bowler)

Bank of New York Mellon

30th Signal Regiment, Gamecock
Barracks

Old Portmuthian Chapter

Malcolm Brown

R Cutajar

Mrs D Brown

The Heart of England
Co-operative Society Ltd Slimming
Club

Janice Alpha Crew

Premier Oilfield Rentals Ltd