

Full potential

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Down's
Syndrome
Scotland

helping people realise their potential



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 @DSScotland #FullPotential

Growth and change

This is my last issue of *Full Potential* as its editor. Four years ago, I created our first issue of *Full Potential* magazine. It was a joy to create a visually pleasing magazine full of helpful information and showcasing all the wonderful things that people with Down's syndrome were accomplishing at all ages and stages. I referred to that issue as my baby.

Four years on, the magazine has grown and it is still my baby. However, it's time for me to move on and let my baby grow and gain a new editor. By the time you read this, I'll have left my role at DS Scotland for a new challenge and the new Communications Officer will be the *Full Potential* editor. I have no doubt that they will continue to allow *Full Potential* to grow and adapt with you and your needs.

I want to thank you for sharing your wonderful stories, videos and photos with me. I have been extremely lucky to meet some amazing individuals with Down's syndrome (of all abilities) and their families and each person has left an impact on me. Because of you, I will always be passionate about Down's syndrome and challenging the stigma often associated with the condition. Thank you.

Meanwhile, the work at Down's Syndrome Scotland is still ongoing and growing! As our Family Support Service has continued to grow in response to demand, we need to continue updating our information and services. Part of this update is to create a new Down's Syndrome Scotland website!

Our current website was created in 2009 when we didn't have a Family Support Service, a Fundraising Team, grants for carers, consultation submissions to the Scottish Government, training to health and education professionals or Facebook and Twitter pages. Now that we're providing more information and support to families and professionals, we want our website to showcase this and to have a higher level of functionality.

In 2012, we sent a website survey out to our supporters and we have used the responses to help shape our new website. Our new website will go live on 31st May 2015. Keep an eye out for it and in the meantime, email us on info@dsscotland.org.uk if you would like to share your thoughts about our website or if you have any good practice websites for us to consider.

"Because of you, I will always be passionate about Down's syndrome and challenging the stigma often associated with the condition. Thank you."

This autumn also brings our annual conference on Saturday 15th November. We've listened to your feedback from our last conference and we'll be offering more workshops, more time to network with other families/professionals and more time to visit our exhibition stands. See our conference flyer to view this year's workshop topics and to book your place at our conference. Alternatively, you can book your place(s) online at www.dsscotland.org.uk/conference.

So let us know what you think about this issue of *Full Potential*. Did you like it? Will you, a family member, a friend or colleague be taking part in Down's Syndrome Awareness Week 2015 or our 2014 conference? We'd love to see photos of all the great things that people with Down's syndrome and their families are doing! Please e-mail us at editor@dsscotland.org.uk or tweet us @DSScotland using #FullPotential in your tweet. Your tweet or e-mail may appear in the next issue of *Full Potential's* letters section!

Of course, we continue to be reachable via Facebook (Down's Syndrome Scotland), by e-mail (info@dsscotland.org.uk) and by post at: Down's Syndrome Scotland, 158/160 Balgreen Road, Edinburgh, EH11 3AU. Thank you for your feedback and we look forward to responding to your comments, letters and e-mails.

Wishing you and Down's Syndrome Scotland all the best for the future,

Heather Irish
 Editor of *Full Potential*

UNITED KINGDOM

ENGLAND

Why studying babies could help scientists understand Alzheimer's disease



(17 July 2014) - A new study at Birkbeck, University of London (ranked among the top 1 percent universities in the world) is researching the links between babies with Down's syndrome and Alzheimer's disease in adults.

The study hopes it will lead to a better understanding of the

protective factors and risk factors associated with Alzheimer's.

Babies with Down's syndrome are being studied because one of the genes implicated in the development of Alzheimer's disease (the APP gene) is located on chromosome 21, of which people with Down's syndrome have an extra copy.

All individuals with Down's syndrome will ultimately develop the amyloid-beta plaques typical of Alzheimer's brain pathology yet not all people with Down's syndrome will get dementia in adulthood. Researchers are keen to find out what is protecting some people with Down's syndrome from developing dementia while others are vulnerable to it.

The research at Birkbeck's Babylab will focus on individual differences and sub-groups of babies with Down's syndrome and compare them with older adults with Down's syndrome with and without dementia to try and identify what these protective/risk factors are.

Professor Annette Karmiloff-Smith will be leading this study.

She said: "The study of babies with Down's syndrome may lead to treatments that could slow down the cognitive decline seen in Alzheimer's disease, or even reverse it. By identifying risk factors for dementia during infancy, we may indeed be able to target preventative treatments for individuals with Down's syndrome and for the general population. With dementia expected to affect 1 in 85 adults globally by 2050, this is one of the most exciting projects that I have been involved in during my 36-year research career."

Scientists from Birkbeck's Babylab will conduct a series of experiments with babies and infants with Down's syndrome. These will be undertaken during two consecutive half days in London, or one of the researchers can visit the family home for some of the tasks and then the family would visit the Babylab for just half a day.

The tests include behavioural assessments through observation of the child with their parent or caregiver; eye tracking and electrophysiological assessments using a totally non-invasive

electroencephalogram (EEG) (pictured to the left) while the baby watches videos on a screen; and parental questionnaires about their baby's sleeping routines, eating habits, medical history and early development. The researchers will also be collecting DNA samples from saliva to look for genetic markers of increased risk or protection from dementia.

The research group is currently looking for 150 babies and toddlers (aged 6 months to 5 years) with Down's syndrome to take part in the non-invasive behavioural tests.

All travel and hotel expenses will be reimbursed and babies and toddlers throughout the UK are invited to take part.

If you would like your child to take part in the research, please contact Professor Karmiloff-Smith by email on downsyndrome@bbk.ac.uk or phone on 020 7079 0778.

WORLD

SWITZERLAND

Number of children with Down's syndrome increases in Switzerland

(14 July 2014) - The number of births of babies with Down's syndrome rose in Switzerland from 2003 to 2012.

The number of births rose to 89 out of 82,164 births in 2012 from 40 out of 71,848 in 2003.

Gynecologist Daniel Surbek said that the results are only partly due to women in Switzerland having children at an older age.

Surbek, chief doctor at the University Hospital of Bern said a growing number of women either refuse to have a prenatal diagnosis or they decide to accept having the child despite a positive test for Down's syndrome.

Surbek said he was personally astonished by the number of women who, despite receiving detailed explanations, decline to have prenatal testing for Down's syndrome.

Since 2012, new non-invasive tests have been available in Swiss hospitals. This blood test samples the mother's blood to more accurately diagnosis whether the unborn baby has Down's syndrome.

The impact of the new tests has yet to be reflected in the statistics.

"I start with the principle that with these new tests the number of children with Down's syndrome is going to stabilise, even drop a little," said Surbek.

To read the full The Local news article by Malcolm Curtis visit <http://tinyurl.com/DSincrease>.



new study



Feeding and autoimmunity in children with Down's syndrome

By: Dr Georgina Williams, Paediatrician at The National Institute for Health Research Bristol Nutrition Biomedical Research Unit in Nutrition, Diet and Lifestyle at University Hospitals Bristol, NHS Foundation Trust and the University of Bristol

The Feeding and Autoimmunity in Down's Syndrome Evaluation Study (FADES)

The FADES study is an exciting new study following babies with Down's syndrome from birth to see how events in their early lives may influence certain autoimmune conditions, which children with Down's syndrome are at increased risk of developing. The study is being undertaken at the University of Bristol but will be recruiting babies under the age of 8 months from across the UK and following them until they are 5 years old.

Autoimmunity and Down's syndrome

Most babies and children with Down's syndrome will not develop autoimmune conditions but compared to their peers they are more at risk of developing conditions where the body reacts against its own cells. These include conditions such as thyroid problems, diabetes and coeliac disease. If we are able to identify factors that increase the risk of these conditions developing then hopefully in the future we will be able to lower this risk.

What does the study involve?

If new parents are interested in taking part, the majority of the study can be done at home and would not require additional appointments. The study includes detailed questionnaires that can be completed online or on paper. These ask about their baby's feeding, the issues that families have with feeding and what support they receive.

From this study, we may be able to help families in the future by identifying the issues with feeding, dispelling myths and

identifying where support could be improved. The questionnaires will also ask about medical conditions, infections and a little bit about family history.

The study will also involve collecting samples including some cells, collected by rubbing the inside of the baby's cheek with a soft swab. These will be used to look at the baby's genes especially those we know that are associated with autoimmune conditions.

We will also collect poo samples to look at the natural bacteria that live in the gut which is considered to have an effect on the development of immunity. Urine samples will be collected to see if there are any signs of any of the babies developing diabetes although we expect that very few will develop diabetes during the 5 years that they are in the study. We will also collect small blood samples from heel pricks, which will be used to see if there are any antibodies associated with autoimmune conditions.

A little about the Research Team

The study is being led by Professor Julian Hamilton-Shield, Dr Kathleen Gillespie and Dr Georgina Williams. Professor Hamilton-Shield and Dr Gillespie both have a long standing interest in children with Down's syndrome and have previously published articles on Down's syndrome and diabetes.

Contact Us

If you are interested in finding out more about this study please contact us at fades-study@bristol.ac.uk or telephone 0117 342 1756. You can also visit www.bristolnutritionbru.org.uk.

here comes the SUN



By: Jo Hughes
Family Support Service Officer (West of Scotland)
DS Scotland

We went on our first holiday abroad to Spain this year. Similar to most parents, I was very anxious about the logistics and managing the journey - the airport being one of my biggest worries. Here are a few tips to consider when planning your own holiday.

Resort

Find out as much as possible about the resort that you are staying at including your accommodation and what they can offer. Request things in advance. Although requests can never be guaranteed by most providers, they can make a difference to your holiday. Consider requesting a quieter location for your accommodation, safety gates, a step for the loo and assistance travelling from your resort reception to your accommodation when you arrive and depart.

If it's your first time going abroad then a short flight may be a good idea. Flights to some parts of Europe are only around two hours and there are some good resorts only a 15 minute taxi drive from the airport.

Also think about the heat. Going away at Easter, October school holiday or early summer means temperatures can be a bit milder than full summer. Heat + frustrated/anxious kids = not a good mix. This can bring additional challenges to your holiday.

Find out about the quiet areas on the resort to plan how to support your child if it all becomes a bit too much. Are there kids clubs? Find out the sessions that might be suitable and what support they can provide.

The more you research, the better equipped you are to minimise any unexpected difficulties that cause tension and anxiety when you get there. Cover all your bases and remember to always have a plan B!

Airport

Discuss your child's disabilities and request special assistance with your airline. Assistance can be provided free at the airport according to individual needs. Assistance at security and while boarding the plane allows you to skip the queues and negotiate tricky plane steps. Special assistance may also take you by airbus directly to the plane and air lift you up to the doors to directly access your seats. It might be worth reserving your seats too so that you can pick the easiest for getting on and off the plane and being near the toilet. Make sure you book assistance for both outbound and return flights.

When we travelled to and from Spain, special assistance was waiting to escort us off the plane. They took us straight through passport control, to baggage, stayed with us until we got our bags and supported us through to the arrivals lounge. Jack (my son with Down's syndrome and Sensory Processing Disorder - see the Spring 2014 magazine for my article on this disorder) loved it. I think he felt like a celebrity and was directing the assistant where to go pointing ahead shouting, "That way!"

Most airports also have a quiet room that you can request access to keep your child calm and relaxed if the airport departure lounge is too noisy or busy.





Page 5 photo: Jack enjoying the Spanish sun; **Top photos (l-r):** Jack receiving special assistance to board the plane; Jack excited about takeoff; Jack on the beach; Jack enjoying the beach with his dad; Jack enjoying the sun.

If your child needs special items in order to feel secure on the plane, it may be possible to get special permission to bring them on board even if they would not normally be allowed. Speak to your airline to discuss this. Jack listens to music and watches videos on a mini MP3 player, which he was allowed to keep switched on during take off and landing - not that this was needed as he loved the sensation of the plane taking off and kept shouting, "Again!" His music did help to distract him from the engine sounds though.

One huge benefit of using the airport special assistance was that it also reduced my and my husband's anxiety as we knew we had extra help to get through some of the stages of the journey that we knew Jack would find extremely challenging. It meant we were more relaxed too.

Communication and Supporting Understanding

Keep your child informed about the trip to take away the fear of the unknown. Use lots of pictures and books for each stage of the journey to remove any unpredictability, which often causes fear.

It is fairly easy to create a holiday storybook using photos and brochures to sit and talk through with your child in the weeks before you go. The holiday storybook should include each stage of the holiday such as: how you are getting to the airport, inside the airport, on the plane, getting from the airport to your resort, where you are going to stay, what's on the resort, places you are going to visit etc. Talk about sounds that they might hear or things they may feel. Get your child involved with taking photos and sticking pictures into the book. It will all help to support their understanding and become accustomed to the experience.

Many holiday companies now have online videos for their resorts, which you can continue to show your child weeks in advance so that it can familiarise them with the new location. If your resort doesn't have a video, check out YouTube – lots of people share their holiday videos on there and people who give reviews on Trip Advisor often post photos too.

Visit the airport a few times prior to your trip so that you can take photos and let your child acclimatise to the environment. Observe how they react to the environment so that you can plan for the day. Most airports have special assistance staff that can provide you with an awareness trip through the airport and are happy to answer any concerns you may have.

You can create a personal airport story using photos you have taken to talk your child through what happens on the day to

help manage their expectations (DS Scotland's Family Support Service can provide you with a template for this). Also, think about visiting the airport toilets. Unfamiliar toilets can also create fear and uncertainty. If your child uses an insert seat at home think about taking a travel one (such as the Toddle Loo) with you.

Usborne has a great series of First Experiences books. We read the *Going on a Plane* book with Jack every day for a few weeks before we travelled. They also have a sticker book for keeping them busy at the airport, which my younger son loved.

Many children with Down's syndrome can become anxious when away from home. Some items such as toys, pillows, blankets, clothing or other familiar objects can provide security and reduce stress. Without the familiar routine of home and school, many children can feel unsettled and anxious so consider maintaining some of your home routine during your holiday. Your child needs to know what to expect. The more predictable you can make it - the better. Take usual visuals that you would use at home and create a simple visual holiday timetable using photos of activities you will do or places you will visit. Post this on the wall with Bluetak. Don't forget to include some "chill out" time for them too. New experiences can be really tiring and your child could easily become overwhelmed so it's really important they have dedicated quiet times throughout the day to absorb their new surroundings and relax for a while.

Important items to consider

If your child needs regular medication, request a letter from your GP that confirms what your child's medications are. Carry this with your hand luggage. Most airlines request that medicines are carried in your hand luggage. You can get a waiver from them to allow you to carry this and other necessary items (continence products, liquid medicines above the 100ml carry on limit, etc.) in addition to your standard baggage allowance. If you're going to Europe take a EU EHIC card with you too to cover any unexpected medical expenses while abroad.

Remember to organise holiday insurance and advise them about your child's disability and any pre-existing conditions they need to be aware of. There are companies that now specialise in providing travel insurance for people with disabilities and pre-existing conditions.

If you're going to visit any theme parks or activity centres, check out their disability service. Many now offer a fast track pass that allows you to use an alternative entrance or to jump to the front of the queue to reduce any additional anxiousness waiting in queues.



Meet
Amy }

My name is Amy Clark and I am 14 years old. I have a big brother called Cameron and a big sister called Katie. I live with mum, dad, Cameron and Katie in Eaglesham, near Glasgow.

We have a dog called Izzy, two cats called Crash and Tizer and a snake called Maisie.

I go to the Isobel Mair School and I really love it.

I like gymnastics, swimming, walking Izzy and meeting friends.

I started doing gymnastics when I was five years old. My sister Katie was going to a class at Bellahouston Sports Centre and my mum noticed that there was a class that would suit me. So I joined the City of Glasgow Gymnastics Club.

When I started there was only Artistic Gymnastics being taught. This is the gymnastics that you see where they use the floor and apparatus such as the beam and the vault. I enjoyed this but when a new coach called Mags arrived she started to teach us Rhythmic Gymnastics and I really loved it. This is where we have to do routines to music using equipment such as hoop, ball, ribbon, clubs and rope. My favourite is the ribbon.

I love everything about gymnastics. I meet up with Martha and Codi who started at the same time as me and we are best friends. I love learning the routines and doing them to music. I train every Wednesday evening and Saturday afternoon.



Left and top photos: Amy competing in Rhythmic Gymnastics at the 2013 Great Britain Special Olympics in Bath; **Top right photo:** Amy with friend Alison who will join her in LA; **Bottom right photo:** Amy (c), aged 5, with gymnast friends Martha and Codi.

Last year I was chosen by my coach to take part in the Special Olympics National Games in Bath.

The competition is held every four years. It took place over four days in August 2013 and nearly 2,000 athletes with learning difficulties took part in 12 sports. This was a really fun event and I had 17 family members and four friends cheering me on. I came home with five silver medals and one gold medal. Because of my success, the national coach chose me to represent GB in the World Special Olympic Games. This will be held in Los Angeles in July 2015.

My other friend, Alison, another Rhythmic Gymnast from my club will be going to the Special Olympics with me. There are three Artistic Gymnasts from the club going too with their coach Angela.

I've never been to the States before. I will be in Los Angeles for about two weeks and am really looking forward to it. I definitely want to go to the beach. My mum had to look up LA on a map before agreeing that that would probably be okay.

I had my first training camp in Runcorn in May where I met my new coach and the rest of my team mates. There are another six girls from all over Great Britain in the Rhythmic Gymnastics team. I am the youngest.

Help Amy get to the World Championships

Amy and her team have a huge fundraising challenge - £13,800 for six gymnasts and their coach to attend the games.

Visit their Giving page if you'd like to help:
<http://shareagift.com/Pages/3570>



Dear DS Scotland...



Here's a photo of my son Alex who is 16. Alex took part in a dressage competition at The Drum RDA at the end of May and had great fun despite the rain. He is very sociable and enjoys horse riding at Ravelrig RDA. Alex also goes to Shoogle and Blether drama club on a Tuesday and a Saturday morning group for young people with Down's syndrome.

Joyce Boyd, parent, Edinburgh, via e-mail

I live in the United States and have a 19 year old daughter with Down's syndrome. I decided quite some time ago that I wanted to get a tattoo in honour of her, but I had never found a design that really "spoke" to me. I read about the tattoo fundraiser that you did last year and I fell in love with the design! THAT was the design that "spoke" to me! Thank you for your help!

Debby Brackin, parent, Iowa, USA, via e-mail

I cannot thank you enough. I am working with a family that has a 51 year old daughter with Down's syndrome and your publication on dementia will be very useful for them. Many thanks.

Pat Pakos, service provider, Massachusetts, USA, via e-mail

Just to say how amazing this week [Awareness Week 2014] has been in relation to the awareness you have been raising and we have just watched Scotland Tonight. What a message you are sending out to people to dispel myths and increase awareness of Down's syndrome

Keep up the good work! My JustGiving page is at £341 for now and I'm pushing to get it much higher within the next two weeks and beyond [the Paris Marathon].

Again, just wanted to encourage you in the work you are doing, we had a great first visit from Jo [Family Support Service Officer for the West of Scotland] and I'm really glad we were made aware of Down's Syndrome Scotland.

Paul Ferrie, parent, Motherwell, via e-mail



Inspirational briefing from @DSScotland at lunchtime in Parliament. Time to raise awareness and bust those myths.

Alison Johnstone MSP for Lothian, via Twitter

Tweet us your thoughts @DSScotland #letters

Share your voice

Do you have opinions, ideas, thoughts or accomplishments that you would like to share with us and the readers of Full Potential? Please e-mail us at editor@dsscotland.org.uk or post us a letter to **The Editor 158-160 Balgreen Road, Edinburgh EH11 3AU** to be included in the next magazine.

introduce DEBATE engage
reflect EXPAND comment reflect
question contemplate explain
SHARE discuss understand congratulate

Ageing adults with Down's syndrome and their families



By: Nancy Jokinen, Assistant Professor, School of Social Work, University of Northern British Columbia

Adults with Down's syndrome are living longer lives and their families are also ageing. This article highlights the lives of adults with Down's syndrome and their families who have reached middle-age and beyond and the challenges to support services in meeting the needs of these families.

What makes the experience of older-aged families of adults with Down's syndrome unique? These families have lived through tremendous changes in professional thought and altered social policies, and they have decades of experience. Previously, professionals promoted institutionalisation and community support was nonexistent or nominal. Yet, many parents persevered and raised their child with Down's syndrome at home and they had little choice but to be self-reliant. Some parents continue to co-reside with their son or daughter with Down's syndrome and support is frequently reciprocal - parent(s) and adult son/daughter support each other. In many families cross-generational support (the role of primary support passes from a parent to a sibling or other younger relative) is an expectation and indeed, occurs. Some families have formal explicit plans for this while, for others, plans are informal and gradually put into place.

How do families use services?

As might be expected, service use varies among these families. The individual and/or family may receive very little service or

be involved in a 24-hour, 7 day per week service. The way the family perceives the service is likely to affect its use. Some families see formal services primarily in terms of 'respite' for the parents; others value services for offering additional dimension to the life of the adult with Down's syndrome. Other individuals and families have never accessed services or have withdrawn from service use for any number of reasons. This can have devastating results when something happens to the primary carer.

Life events and transitions

Many individuals and families, although not all, want to maintain current arrangements for as long as possible - to age in place. Several things can intervene to change this. A change in the health status, and/or the onset of chronic conditions, of any family member, potentially alters both familial support and living arrangements. If parents have continued to co-reside with their son or daughter with Down's syndrome, at some point, alternative living arrangements will be needed when they are no longer able to manage independently or with the death of the parent(s).

Perhaps the most significant challenge faced by older-aged families occurs when a family member develops Alzheimer's disease. Little has been written about how families of adults with Down's syndrome cope when either a parent or an adult





Page 13 photo: A man and woman with Down's syndrome enjoying their relationship; **Top photo:** Three sisters enjoying each other's company. Siblings can often become the primary carer of a person with Down's syndrome later in life.

with Down's syndrome develops Alzheimer's.

Another factor is that transfer of familial support from one generation to another may not be easy for, or even welcomed by, either the adult with Down's syndrome or the relative(s) involved, especially if it has not been discussed and planned for.

What support is needed?

Families need information and support to make choices, plan for transitions and manage life events. Services need to offer support both to the adult with Down's syndrome and to the parents and other family members.

Families need support to age in place and remain in the caring role if they choose this. Active outreach and follow up services can reduce the risk of social isolation for these families.

Families need dual-care options - supports, including accommodation, with a dual focus to meet the needs of both generations. Care options for both generations are currently challenging because they straddle the existing service systems.

To do this effectively, services need to engage with the families and utilise the wealth of their experience.

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Article reprinted with permission from Voice, Down Syndrome Victoria and Down Syndrome NSW Members Journal April 2012.

Support for older parents

Our Family Support Service is an all-through-life service to support people with Down's syndrome and their families at all ages and stages. No question is too big or small. Contact your bespoke Family Support Service Officer.

West of Scotland: Jo Hughes on 01563 533 473

Southeast of Scotland: Joanna Coulter on 0131 313 8613

Northeast of Scotland & Orkney: Vikki Stillwell on 01241 871 430

Highlands, Islands and Moray: Shona Robertson on 01463 237 489

The importance of planning ahead

By: Joanna Coulter, Senior
Family Support Service
Officer, DS Scotland

What happens as your child reaches the end of secondary school can be a stressful time for any parent. It is a time of moving into the unknown and thinking about the future. This is an especially stressful time for parents/carers of a young adult with additional support needs and for the person themselves.

The terminology 'transition' is often used when talking about the movement of a child or young adult with additional support needs from one educational establishment to another, or to another service. The Scottish Transitions Forum has created a document 'Principles of Good Transitions 2' designed for all professionals to follow, during the transition period. The aim of this document is to increase collaborative working therefore making transitions a smooth process for all and to make sure no opportunities are lost and full potential is gained.

The Seven Principles of Good Transitions

- ▶ All plans and assessments should be made in a person-centred way.
- ▶ Support should be co-ordinated across all services.
- ▶ Planning should start early and continue up to age 25.
- ▶ Young people should get the support they need.
- ▶ Young people, parents and carers must have access to the information they need.
- ▶ Families and carers need support.

- ▶ Legislation and policy should be co-ordinated and simplified.

Planning for a teenager with Down's syndrome who will be leaving secondary school ideally needs to start two years before the date of move. So if your child is due to leave school at 16 years old, transition needs to start at 14, and if they are leaving at 18 years old, transition needs to start at 16. Early intervention is beneficial in many ways. It gives time to:

- ▶ Be person centred and consider where the young adult wants to be.
- ▶ Explore opportunities in depth, visiting places and talking to people.
- ▶ Gain specific life skills that may be needed. Examples: learning how to use public transport independently, counting money and telling the time. It might be possible for the life skills training to be incorporated into their Individual Education Plan at school in preparation.
- ▶ Identify if any resources would be useful and available to support the transition.
- ▶ Explore and discuss any changes that might happen to the young adults' financial benefits.
- ▶ Involve the adult health and social work services where required.
- ▶ Explore possible legal options such as guardianship.

Most importantly, think holistically and have the young adult in the centre.



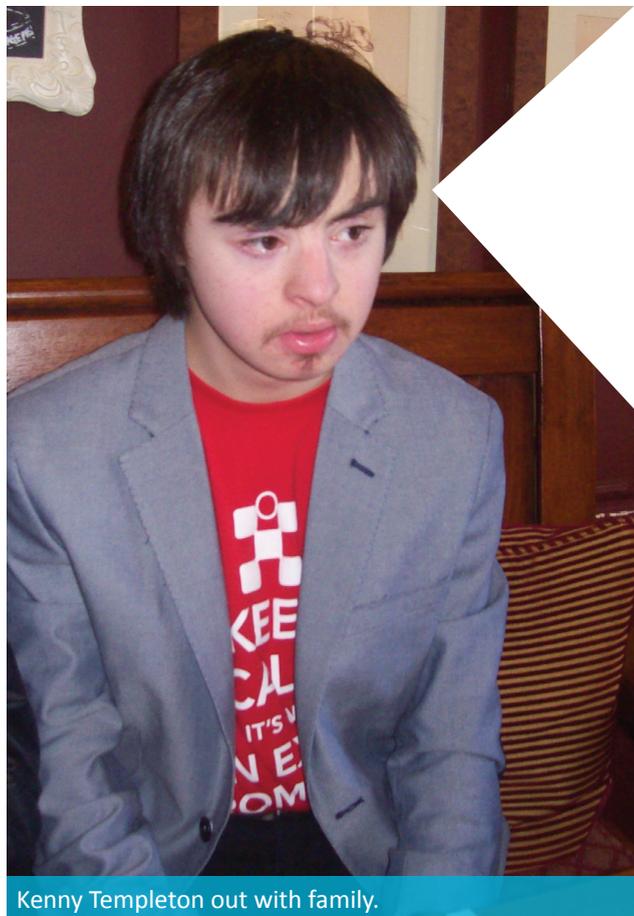
Education staff should take the lead in coordinating transition services, and each local authority should have a coordinated approach to transitions, abiding to the Principles of Good Transition.

That said, at present this is sadly not happening consistently throughout Scotland. As a parent or carer, we would suggest you push all professionals to get involved as early as possible in the transition period in order to work together using a person centred approach, and of course we can assist you with this.

The Family Support Service is available to provide support and advice during the transition process. We can attend transition meetings, provide suggestions and ideas to help support the transition, signpost to appropriate agencies, and provide training and support to the local authorities and schools.

We recently supported Kenny who is an 18 year old who has now left secondary school. He has a diagnosis of Down's syndrome and Autistic Spectrum Disorder. He lives at home with his parents, who are a great support. Kenny's parents contacted DS Scotland's Family Support Service five months ago, asking for some support to help them think about and move towards making plans for after school.

Since Kenny's family contacted us, a Family Support Service Officer (FSSO) worked closely with Kenny and his family and attended reviews and Multi-Disciplinary Team



Kenny Templeton out with family.

Support for transitions

DS Scotland's Family Support Service can provide support on all transitions including the following:

Nursery school to primary school
Primary school to secondary school
Secondary school to adult services

Phone our Family Support Service on 0131 313 4225.

transition meetings in school to prepare Kenny and adult services. One of the key objectives for Kenny and his family were to develop Kenny's independence skills both at school and at home.

Kenny, his family and the FSSO worked on increasing the use of a visual timetable, which provided some structure, routine and reassurance for Kenny once he left school. The FSSO had also researched apps for Kenny's iPad that would continue to promote independence at home. A personalised communication passport, which is often a booklet that includes the adult's likes, dislikes, hobbies, family and friends, was also developed. This allowed others to understand Kenny and the people who are close to him. Kenny's transition was originally scheduled for winter 2014 but his transition into adult services has been so successful he has now left early and adjusted positively into full-time adult services.

"I am very pleased with the input and additional support information that Jo Hughes, our Family Support Service Officer, has supplied us with," said Anna Templeton, Kenny's mum. "To find out Kenny's full entitlement in the past has proved difficult to obtain. Down's Syndrome Scotland is doing an excellent job."

If you would like any further transition information or support, please contact DS Scotland's main line on 0131 313 4225 who will assign you to the Family Support Service Officer within your area.

Useful resources:

Scottish Transition Forum <http://scottishtransitions.org.uk/>

Enquire <http://enquire.org.uk/>

ENABLE Scotland Transitions www.enable.org.uk/families/transitionintoadultlife

Toilet Training

your

child

by:

Jo Hughes
Family Support Service Officer
(West of Scotland)
DS Scotland

Toilet training: You can start at any age, the earlier the better and it's never too late to try! It is a big step in your child's independence and far less work for you than having to manage changing nappies throughout the day. We have just successfully toilet trained our own son at the age of six and his confidence and independence have grown as a result.

Preparation is key. To get started, here's a quick checklist:

- 1. Keep a record:** It's useful to keep a diary of your child's toilet habits for a week or so before you start training so that you have an idea of when they naturally need to use the toilet. You can then plan their visits around this to allow them more chance of success.
- 2. Visual prompts:** Use a simple sign that you teach and encourage them to associate with going to the toilet. (The Makaton sign for toilet is a fist held up to the shoulder with

the middle finger pointing upwards.) Teach them the word you want them to use when using the sign and be consistent to use it every time. Reading a book about going to the toilet or watching a video may help. YouTube has some good ones such as Elmo's Potty Time, which can help to support understanding. Taking them to the toilet with you when you go is also useful so that they can see it is a natural part of everyday life.

3. Clothing: Have lots of easy pull up & down clothing. Keep plenty of spares near the toilet so that any accidents can be quickly dealt with.

4. Seating: Have a seat that your child feels safe to sit on. They need to feel relaxed and secure. If you are using the toilet rather than a potty, consider adding a foot step and hand rails, which can offer extra support. Your occupational therapist can help with this. Balance is crucial to build confidence when





FUNDRAISING FOCUS

Autumn 2014 Issue 5
www.dsscotland.org.uk



Down's
Syndrome
Scotland

helping people realise their potential



BLAZING A TRAIL!



There have been so many exciting things happening since the spring edition of *Fundraising Focus*. Fundraising during Awareness Week surpassed our expectations and raised over £40,000 during the month of March, thanks to you and all of your wonderful fundraising efforts.

There were a number of firsts for fundraising: the first-ever RACE 21, first-ever Firewalk, and our first-ever Aberdeen Fundraising Ball. Down's Syndrome Scotland also employed their first Community Fundraiser. Pippa Morrice joined the fundraising team in March and got off to a blazing start by participating in our Firewalk. Pippa will be focussing on volunteer recruitment and the volunteer speaker programme.

It is with many wonderful memories that I bid farewell to Down's Syndrome Scotland as I move on to new horizons. I'd like to take this opportunity to say a massive thank you to all of you that have fundraised for this fabulous cause and for all the friendships I have made. I wish everyone at Down's Syndrome Scotland all the best for the future and hope that they will continue to thrive with your help and wonderful support.

Sharon Kane
Fundraising Manager
sharon@dsscotland.org.uk

A MILLION THANKS



Former professional boxer, Gary Jacobs gets things underway at Race 21 with the help of Grace and Dawn

RACE 21

Indigo Social Media sponsored our first-ever RACE 21 event at Rou in East Renfrewshire. Over 160 people took part for this fun one mile twist. Teams of three were joined together with 'chromosome ties.' abilities had a brilliant time and we raised over £6,000. Thanks to a and a special thanks to our Trustee Karen Gilligan, girls from Hutch School, Strathclyde Warriors Cheerleaders, our entertainers on the sponsor Indigo Social Media. RACE 21 is coming to four locations t Scotland in March 2015. For more information and to register go to org.uk/race21 or contact pippa@dsscotland.org.uk

AWARENESS WEEK 2014

Many of our fundraisers dug deep to the bottom of the sock drawer to get some snazzy socks for Awareness Week. Our Do A Dish campaign continued with coffee mornings being held throughout Scotland, from the Isle of Lewis to Edinburgh. Tracey and the two Julies celebrated World Down's Syndrome Awareness Day by holding a ceilidh, raising over £1,200 whilst having an amazing time. Our very own ABC co-worker Katy Lironi organised SANDFEST, a fun music festival in the local village raising £3,000! A Motown evening organised by

Emma Ochia Events was a great success and raised over £1,300.

Many schools really took on the fever of Awareness Week and encouraged pupils and staff to get involved and raise money, from kilt walks to wearing odd socks to school. The High School of Glasgow raised £3,375 - the most a school has ever raised for DS Scotland! This with the amazing amounts raised by many primary schools throughout the country resulted in the most successful fundraising year for schools to date! If you think your local school would like to be involved in 2015 please contact Pippa for a schools fundraising pack.

TO ALL OF YOU!



Sharon with Katie Devlin & Adam Macnaughton from Glasgow High School

Artist Cheryl Lord, with the couple who won her donated painting

Laura Hunter & Michelle Kelly complete the West Highland Way for DS Scotland

Muddy Trails fundraisers Julia Jamieson, John Falconer, Rae Crossan, John Mcstea and Angy Cheney

Rouken Glen Park
5 mile run with a
s. All ages and all
all of our runners
chesons' Grammar
ne day and our
s throughout
to www.dsscotland.org.uk.



Strathclyde Warriors Cheerleaders

VOLUNTEER SPEAKER PROGRAMME

Our Volunteer Speakers Programme came about because we wanted to give young adults with Down's syndrome (DS) the opportunity to talk publicly about what they have achieved, to demystify some of the myths and to raise awareness. We pair up someone with DS with someone who doesn't have DS. The two collaborate (with help and training from DS Scotland) to create a short, informal presentation that they deliver jointly to groups such as The Woman's Guild, The Rotary Club, Church groups, schools or youth clubs. The speaker without DS gives a short presentation on the background of Down's Syndrome Scotland and its aims and then hands over (and provides support if required) to the person with DS who delivers their presentation on their key achievements, hobbies and ambitions.

We are always looking for adult volunteers with and without DS to participate in this programme and help make it a success. If you would like to offer your time to this please contact Pippa: pippa@dsscotland.org.uk.

YOUR STORY

A message from two inspirational fundraisers... Hi, we are Ashley and Nicola and we are mummies to Eilidh who was born premature at 30 weeks. Eilidh has Down's syndrome and several health complications that are associated with it. She was in intensive care for 13 weeks but thankfully made good progress and was able to come home in November. In March of this year she had open heart surgery. Eilidh is the most amazing, determined and strong person we have ever met and brings so much happiness to our lives. Since her birth, we have had excellent support from DS Scotland and their Family Support Service Officer Jo. As such we decided to spend 2014 raising awareness of Down's syndrome. A group of close family and friends have agreed to take part

in a variety of challenges and hope to raise money for DS Scotland. It started with the muddy trials in March and will end with the Glasgow Half Marathon in October with a few 10ks, marathons, the West Highland Way and a mountain in between. The support and dedication from our friends and family has been amazing. We are so proud of each and every one of them. The determination Eilidh has shown has inspired us do this. When the training gets hard and we want give up, we think of her. The past 10 months has been really tough for Eilidh, but she fought through it. If she can get through that we can push ourselves to cross the finish line. If anyone would like to join us or support us please visit our Just Giving page www.justgiving.com/eilidhsfundraisers or contact: Pippa@dsscotland.org.uk



Firewalk fun!

ALL ABLAZE! OUR 2014 FIREWALK

Wow! The Firewalk was an amazing experience. On May 9th, 23 brave supporters took part in DS Scotland's first firewalk at the Hawes Inn, South Queensferry. Blaze organised the event and prepared the daredevils for the roaring fire that

awaited them! Many of the staff team joined their fellow fundraisers, raising over £10,000. Anna, one of our fabulous, firewalking fundraisers, said, "That was an incredible experience! When can we do another one?" Watch this space!

FUN FUNDRAISING!

MARATHONS

Nineteen people took part in the Edinburgh Marathon Festival. The distance together with the inclement weather made it a real challenge, which made the achievement even more special. All of our fantastic fundraisers made it and raised lots of money for us in the process. Just because a UK Marathon is not challenging enough, two of our wonderful fundraisers, Graeme Allan and Paul Ferrie ran the Paris marathon too.

SPARTAN RACE

Have you ever wanted to crawl through mud, jump over fire, wade through muddy water, climb cargo nets and 6ft walls? Well this one is for you! We have 24 people signed up to date, we are trying to get 40 people!

We are looking for supporters to face this 5k, extreme challenge in Edinburgh on 21st September and raise money for Down's Syndrome Scotland. For more information contact Pippa at Pippa@dsscotland.org.uk.

TREK MONGOLIA

Following the success of the Big Small Isles Challenge and our relationship with wonderful fundraiser and author Uuganna Ramsay, DS Scotland is organising a trek to Mongolia in Autumn 2016. Full details are to be announced but it's never too early to register an interest and to start fundraising! To find out more, contact Pippa at pippa@dsscotland.org.uk.

FUNDRAISING BALL

Everyone at DS Scotland is excited about our 'Forever 21' Fundraising Ball. This will be held on Saturday 8th November at the Grand Central Hotel, Glasgow. We hope everyone will come along to enjoy the fun, prizes and entertainment - and leave feeling 21 again! Our first-ever ball in Glasgow in 2012 was a huge success and we hope this one will be even better. Check out our video for a snapshot of the night, look for yourself if you were there and see what you missed if you weren't. But please don't miss this one! I'm sure it will be fabulous! To book your tickets go to dsscotland.org.uk/glasgowball.

ABERDEEN DINNER

Thanks to everyone who helped organise and attended our Fundraising Ball in Aberdeen on World Down's Syndrome Day. Stephanie Scott gave a fantastic speech about her life at the Ardoe House Hotel. Guests enjoyed a fantastic dinner and finished the night off by boogieing to the amazing Silver City Soul Review. Amongst all that fun, £10,000 was raised for DS Scotland.

LEGACY

Many people choose to leave a gift in their will. This is very easy to do and can be as much or as little as you like. A gift in your will can mean a lifeline for a new family. If you would like more information on how you can do this please contact Pippa at pippa@dsscotland.org.uk.



Race 21 participants, proudly display their medals



It can be helpful to have a few books or other items near the toilet for your child to look at to allow them to feel comfortable.

sitting on the toilet. This will ensure that they feel relaxed and not fearful of falling!

Some smaller potties are not suitable (or comfortable) for older children. There are some good mini toilet-type potties on the market that have larger seating areas, removable inner bowl and a lid. A toilet-insert seat is also a good option. The Keter Toilet Trainer is a great little seat and step.

A travel toilet seat is a good option that lets your child feel confident using different toilets when outside the home. I have used many and the best I have found is the Toddle Loo. It fits most toilet seats and folds into a compact travel bag. It's also worth buying a radar key so that you can access the locked accessible toilets. These are available from www.fledglings.org.uk.

5. Timing: Mastering toilet training does require consistency and a rigid routine, so pick a time to start when you know that there aren't going to be many disruptions and you can give it 100 per cent. It's really important that home and nursery/school offer the same guidance too. It's a good idea to plan a few days when you can stay at home just to focus on creating a consistent routine.

6. Rewards: Lots of praise will ensure your child remains confident and motivated. Think about keeping a few books/items near the toilet so they can look at them. This will help them stay focused, sit for the time required and take any pressure off feeling a need to perform. Giving them a high five after every trip will keep them feeling positive that their efforts are recognized. A sticker or reward chart kept on the toilet door can also be useful.

Once you get started, it is recommended that daytime nappies are removed to allow them to fully experience the process of pulling pants up and down and feeling the sensation if they have an accident.

Frequent and regular visits to the toilet are needed every 20-30 minutes initially, especially after eating and drinking. Giving your child a large drink 20 minutes before can help them to wee when they get there. After five minutes, whether or not they used the toilet, they should be taken through the routine of wiping themselves, flushing the toilet and washing hands etc. Give lots of praise so that they see this as a positive experience. The time between loo trips can then be extended as your child's awareness develops and you are having success in staying dry.

Remember to keep this experience positive. They will make mistakes but keep very calm and remain consistent, so that your child does not become upset or anxious if they get it wrong. When an accident happens, just simply take them to the toilet to get cleaned up, talk about what they did, what they should have done (emptying the accident from their pants into the toilet can help with association), complete the toilet routine with them and giving a high five/reward. Disruptions or changes in their life can often set them back with toileting but just simply go back to the basics again and eventually they will get back on track.

Sometimes toilet training doesn't go to plan and there can be other issues affecting your child's ability to maintain continence. Some children may have over active bladders or are not yet producing the correct hormones to manage their bladder effectively. If you have any concerns regarding your child's difficulties with toilet training, please do contact your local area continence nurse or DS Scotland's Family Support Service team on 0131 313 4225.

Useful information:

www.eric.org.uk Great website for toileting training and issues for parents and carers including practical tips, advice and free visual resources.

www.twinkl.co.uk/resource/t-c-124-visual-timetable-using-the-toilet-1 Free to register with access to free resources and visual supports.

www.drylikeme.com Dry Like Me is an absorbent liner that can be used to allow your child to go without a nappy but still have some reassurance for accidents if needed. You can get free samples from them to try out first and can buy them in most major supermarkets in the nappy aisle or direct from their website. They have early days ones too, which are great if you are out and about and need a bit of backup in case of an accident. Useful for the taxi to school.

Further support

If you live in Scotland, your local health authority will have a Continence Advisory Service. Please contact your local NHS to enquire further.

DS Scotland's Family Support Service can also support you. Phone them on **0131 313 4225**.

Promoting Continence

in

children & young people

by:

Julie Scobie
Lead Continence Nurse Advisor
NHS Ayrshire and Arran

Childhood incontinence (bladder and/or bowel) is often a distressing condition for the child, young person and their family. There is often difficulty in school where children may be verbally abused or bullied because they are perceived as different to their peers. They may be actively excluded from physical activities, not confident to attend social events such as 'sleepovers' and may become withdrawn and have increased emotional issues due to their condition.

Children diagnosed with continence problems in NHS Ayrshire & Arran are referred to the health visitor or school nurse for initial assessment and then referred if required to the Paediatric Continence nurse who has the advanced knowledge,

skills and expertise in assessing and treating bladder and bowel dysfunction.

Parents' needs for information and support in relation to their fears and concerns about their children's continence issues is highlighted in consultations with GPs, Paediatricians, hospital, community and school nurses.

The children's families require ongoing support to ensure appropriate continence management, adherence to suggested treatment regimes, minimising hospital admissions for continence issues and maintenance of a good quality of life.

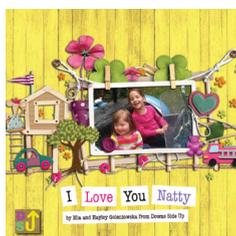
Liaison with schools and other agencies is also a very important part of the care package.

Inappropriate use of medication and continence products can be avoided if an appropriate level of nursing knowledge and expertise is available. It has been recognised that an expert team approach delivers the optimum service in relation to Children and Young People's continence services and that this should be the model of service for all children and young people in Scotland and which NHS Ayrshire and Arran aims to deliver.





inside the sister's story



I Love You Natty: A sibling's uplifting introduction to Down's Syndrome

By: Mia and Hayley Goleniowska from Downs Side Up blog (©2014)

Publisher: Downs Side Up

Price: £5.99 (Amazon paperback)/ free to borrow a DS Scotland library copy for DS Scotland members

Nine year old sister Mia Goleniowska from Cornwall published a book to help other children who become siblings to a child with Down's syndrome.

Mia found it difficult to understand why her baby sister Natty had to spend time in the Neonatal Intensive Care Unit when she was born. Natty was born with Down's syndrome, which was accompanied by a heart condition.

Her parents, Hayley and Bob, did not know that their new baby would have the condition before she was born, so the whole family went through a steep learning curve of what life would be like with a child with additional needs.

Hayley writes the award-winning and internationally renowned blog, Downs Side Up. When she discovered notes and poems around the house written by Mia to her little sister, she collected them, soon realising that they were the basis for a book.

Excerpt

Mummy and daddy explained that Natalia has Down's syndrome. She has an extra chromosome in every building brick of her body, which I think looks like a jelly bean. It is just a part of who she is, like we both have brown eyes.

Lots of people say she looks like me when I was a baby, but I think she looks like mummy and I look like daddy.

She might always be a bit smaller than me and need extra help to learn to do things in her own way.

We all need extra help sometimes. I find it hard to tie my shoelaces on my walking books by myself, and mummy thinks of fun ways of helping me learn my times tables too.

When I visited Natalia in the Special Care Baby Unit I thought she was really beautiful.

When the nurses let me hold her she would try to open her eyes and look up at me.

I think she remembered my voice from the time when she was in mummy's tummy, before she was born.

Mia's drawings and family photographs are included in this introduction book to Down's syndrome. It has been endorsed by eight leading UK charities including DS Scotland.

"This is exactly the kind of book I searched for when Natty was born to read with Mia at bedtime," said Hayley. "I believe it will have a positive impact on new parents as well."

You can purchase I Love You Natty on Amazon for £5.99 plus postage and packing.

If you're a DS Scotland member, our library can lend you a copy of this book for free. If you're a DS Scotland member, request the book through our website: www.dsscotland.org.uk/library.

 Tweet Hayley @DownsSideUp to let her know what you think of Mia's new book



Often the question is asked, “Should children with additional support needs go to a residential camp with their peers from mainstream?” It’s sometimes seen as a huge dilemma but it is in fact far from being one!

The reality is that all children, with careful and sensible planning and support can and should go to school camp. Not only does it benefit them from a physical and emotional perspective but it also benefits their peers, the adults who go with them and other people they meet when there.

I have attended school camp many times and just recently went with a Primary 7 class from Tollcross Primary School in Edinburgh with Daniel who has Down’s syndrome. In school he participates fully with the rest of his class in everything, with occasional adjustments being made in order to make sure he gets the best out of his school day.

“As part of our P7 class we would not have considered any other course of action than for Daniel to attend the residential experience with his peers,” said Headteacher Alice Brown of

Tollcross Primary School. “The trip to Benmore is very much part of our P7 curriculum and Daniel’s entitlement is the same as any other child. The support of Daniel’s family, his class teacher, the pupil support assistant and the staff at Benmore helped us to achieve a positive and life-changing week for Daniel. He was challenged to take part in wide-ranging outdoor activities from climbing and abseiling to orienteering and was an enthusiastic participant in his group. There were times when activities had to be adapted to meet his needs but this had been planned and prepared for. Daniel’s classmates and the other children in the centre included him in evening activities and free time in a very supportive way. I think he enjoyed that time a great deal too! Daniel’s P7 residential week at Benmore is proof that, with the right support in place, inclusion can be a real success story.”

Often, parents feel the only way their child can go to camp is if one of them goes too. This is usually because they are concerned about sleeping, toileting, mealtimes or the activities their child may be involved in. Generally it is best if the child





Page 17 photo: Daniel enjoying the muddy outdoors; **Top photos (l-r):** Daniel (bottom left) with his friends at their dorm; Daniel and a friend having fun in a waterfall; Daniel rock climbing.



goes to camp without them.

Very often parents are understandably anxious when they realise activity schedules will include climbing or abseiling but their child is more likely to react negatively to these activities if a parent is there because as we all know, children very quickly pick up on their parents' anxieties.

"It was important for Daniel to take part in his P7 camp but I knew that there needed to be a lot of planning before it would be a successful trip," said Helen Hayes, Daniel's mum. "I had a meeting with his learning assistant to make sure she knew of Daniel's morning and night routines and also to give fair warning that Daniel may sit down and refuse to move if he became tired or scared. I was also happy that if the staff felt an activity was too difficult or dangerous for Daniel that he could do something else. However, when he came back and I heard he had done a 50ft abseil I couldn't have been more proud! I know he would not have done this if I had been there, as I am scared of heights so I am very grateful to the staff at school and camp for giving Daniel a rewarding and memorable trip."

Top Tips for Residential Camp

1 School will usually have a meeting scheduled several months in advance for all parents outlining the proposed visit to camp. Make sure you go! It's really important that you hear the anxieties that the other parents might have too.

2 You probably already know your child's support assistant at school but if that person isn't able to go to camp, make sure you meet beforehand, the person who will be replacing the assistant. Be assured the school will let the camp know well in advance that your child will be going and will let them know of any special dietary, medical or physical needs your child has.

3 Talk with your child about camp and about the sorts of things he/she will be doing.

4 Make sure you meet with school staff so you and they can have any questions answered.

5 Along with a staff member, create a written protocol regarding your child's personal care (if applicable) and his/her morning and bedtime routines. Remember the school staff never sees your child at these times, so don't assume they will know what to do.

6 It's also important that you make sure any medication and plenty of personal care items if required are packed and clearly labelled.

7 Agree with school staff before camp if you want your child to phone home or if you will be happy with a text or two from staff keeping you posted.

8 Be clear beforehand if there are activities you would prefer your child not take part in. When this happened with our trip, we ensure the pupil was paired in another group so he was still participating fully.

"Daniel had an amazing attitude, which encouraged me to get him involved in as much as possible," said Iona, the Benmore Residential Camp worker. "There were certain activities I knew we could try. He may not have been able to manage all the activities but just giving him the opportunity was important. Daniel worked with me in some activities whereby I could give him a job which helped the group get more out of their experience, this way he was included but perhaps not taking part in the actual challenge.

Residential camp is an exciting adventure for all children, especially those who have never been away from home or who have never taken part in outdoor pursuits. It not only challenges them physically but emotionally and socially as well. So don't be afraid to let your child take part as he/she will face all sorts of challenges and will have lasting memories of the experience!

Phone DS Scotland's Family Support Service on 0131 313 4225 for more support for school trips.



By: Sharon Kane, Fundraising Manager, DS Scotland

Everyone's a winner!

There are a number of ways you can support Down's Syndrome Scotland. However, we have introduced a new way of supporting us that gives you a chance to be a winner too!

September 2014 is the launch of Down's Syndrome Scotland's first-ever 500 Club.

So, what is our 500 Club? We are looking for people to make a regular donation of £5 per month or £60 per year. Each member will be allocated a personal number. First come, first served! So get in quick and be number 1!

Each month an independent adjudicator will generate a random number from 1 to 500. If they pick your 500 club number then you win £500!

500 people (max) donate £5 per month

1 person wins £500 per month

What will your £5 per month provide?

In one year your donation will enable a Family Support Service to visit a family that have just had a baby with Down's syndrome, to help them cope with their emotions and prepare for their future.

Join up and pass it on!

If you can help by joining our 500 Club that would be great. Please also pass the information on to your family and friends and encourage them to help Down's Syndrome Scotland. Our 500 Club is limited so you will have the same chance of winning. However, the more contacts you have sign up the more chance you will know the monthly winner. They may even treat you with their winnings!

To register

Go to www.dsscotland.org.uk/500club or email Miriam at Miriam@dsscotland.org.uk to be sent a registration form.

Take part in our Christmas raffle!

Last year we held our first-ever Christmas Raffle! The winners were: Leanne Lennox winning the 1st prize of £1,000; 2nd prize winner Susan Conti winning a HDTV and 3rd prize winner Lynne Hough winning an LCD TV.

This October we'll be sending you raffle tickets for you, your friends, family and colleagues to purchase, with a chance to win some great prizes! Keep an eye out for the tickets arriving in your post this October. Good luck!





Raising funds, & raising awareness

By: Sharon Kane, Fundraising Manager, DS Scotland

Top row (l-r): Race 21 kicks off in Glasgow; the Watson family sharing their lots of fun socks; Calum showing his fab cakes and biscuits for his school. **Middle photo, right column:** the McAlpine family taking part in our Glasgow Race 21 event. **Bottom photo, right column:** DS Scotland national office windows covered in photos of people with Down's syndrome for Awareness Week.



Down's Syndrome Awareness Week 2014 was amazing! So many people supported Down's Syndrome Scotland by taking part in organised events or organising their own, with their own twist. It was really exciting as a fundraiser to see how creative and inventive people can be raising money and awareness too!

Race 21

Our first-ever Race 21 sponsored by Indigo Social Media, attracted over 160 participants and raised over £6,000. The aim for 2015 is to take it to a further three cities: Aberdeen, Dundee and Edinburgh, whilst growing the race in Glasgow.

We are hoping to get 1,000 runners of all ages, all abilities to take part throughout the country. We are also looking for volunteers to help the organising group and to marshal on the day.

If you are interested in volunteering, please contact Pippa on pippa@dsscotland.org.uk. For more information and to register, please go to www.dsscotland.org.uk/race21.

Lots of Socks

In 2015 we are going sock silly and asking everyone to do the same! In order to raise awareness, we are encouraging supporters to wear odd socks, lots of socks, silly socks, socks in an odd place etc.

Your friends/family/colleagues can show their support by making a text donation by texting SOCK£3 to 70070, taking a sock selfie and/or encouraging their workplace or local school/ church to participate.

Supporters will be issued with information cards. So when you're asked:

"Why are you wearing that bright yellow elephant sock outside your trousers?"

You can say:

"I am raising awareness of Down's syndrome. I'm doing the hard bit perhaps you could show your support by making a text donation?"

Then give them a small business card with the details.

It's that easy! We hope lots of socks will raise lots of awareness and lots of money! Full details are on the website or contact Miriam for a fundraising pack Miriam@dsscotland.org.uk.

Do a Dish

If baking and dining is more your thing then why not hold a bake sale? Don't go out to dinner, instead invite friends over, hold a dinner party and ask guests to make a donation for Do a dish for Down's syndrome!

Hair-raising

Lots of hairdressers took part in Awareness week and displayed our 9 facts in their shops, and encouraged customers to make a donation in March 2014. If you know any hairdressers who would be happy to help in March 2015 please get in touch with Pippa on pippa@dsscotland.org.uk.

Thank you to all who took part in Awareness Week and our events last March, please help again and let's make 2015 even better!

Down's Syndrome Awareness Week 2015 will run from Monday 16th-22nd March 2015.

Lots of Socks photo competition

During March 2014, we saw some wonderful sock selfies! For 2015, we're asking you to take sock selfies and also take part in our photo competition. Take a photo of your socks in an unusual, interesting or wacky place. Socks on the beach? Yes, please! Email them to info@dsscotland.org.uk. Winners will be announced late March 2015.



IM

Ian MacGregor

By: Mairi Donaldson, sibling

MY BROTHER Ian MacGregor was born on 26th March 1951 in Inverness. Ian had Down's syndrome but that didn't matter - he still accomplished a lot during his life. He was a very loving, happy person who had many friends and who was loved by lots of people. When Ian was a year and a half we moved to Thurso, where he became well known to many as he used to spend time looking over the garden wall and talking to everyone who passed.

When Ian was about nine he learned to ride a tricycle with the help of family. He spent hours riding around the garden on his trike.

One time, a friend gave Ian a bundle of motor magazines, which he enjoyed. He was soon able to recognise nearly every type of car on the streets regardless of colour. We never understood how he could do this as each make had so many models but he could name them all!

My mother taught Ian to read and write a bit but as there were no classes in Thurso we moved to Glasgow when he was 11. Ian attended a junior occupation centre followed by an adult centre when he was 18 where he did handcrafts, reading and writing.

When Ian was about 22 he had a minor stroke and we were told by a neurologist that he was really a very old man and didn't have long to live! However, Ian lived another 40 years.

From his 20s onwards, Ian learned to swim a breadth of the pool in Tenerife unsupported. He went to Tenerife several times as well as Spain and Portugal.

Ian also loved music of any kind. He conducted the Cale Orchestra at their annual concert from his seat in the audience. Ian loved pipe bands too and danced at many ceilidhs.

Photos (l-r): Ian swimming in Tenerife in 2004 and playing the guitar in September 2008.

Ian had several eye operations and unfortunately went blind in January 2000. However, this didn't stop Ian. He still continued to go to the gym, to swim and to go tenpin bowling. Old age did catch up with Ian and he was confined to a wheelchair but he still went to his centre every day and to the local RNIB centre once a week.

Ian also attended respite which he loved. Thanks to a wonderful team of carers we were able to care for Ian at home except for the last two weeks of his life.

Ian developed aspiration pneumonia and passed away in hospital very peacefully in July 2013 at the age of 62. Ian is missed by so many people - it's amazing to see how many people knew him.

LEAVE A LEGACY

There are a number of ways to support DS Scotland, now and in the future. Leaving a gift in your will is one way you can help ensure that the charity will be there supporting people with Down's syndrome and their families for many years to come. Contact DS Scotland on 0131 313 4225 to find out more.





Top row photos (l-r): Speaker Stephanie Scott holding her Press and Journal article; 3D puppet workshop; delegates networking in between workshops. **Bottom row photos (l-r):** delegates attending the Wills and Trusts workshop; parents viewing Special iApps for children with Down's syndrome.

2013 Down's Syndrome Scotland Conference

By: Heather Irish, Communications Officer, DS Scotland

Last November, 93 parents, adults with Down's syndrome, carers and professionals flocked to Cumbernauld for our 2013 Conference. The conference provided morning and afternoon workshops to attendees with a variety of focuses including: planning for your future; the NHS Liaison Nursing Service; managing behaviour; communication apps for tablets; education transitions; improving communication skills; access to work; a dad's workshop and arts and crafts for adults with Down's syndrome.

The day began with Stephanie Scott's speech on her full life including working at the Aberdeen Press and Journal and her night's out with her girlfriends. Our keynote speaker Peter Scott, ENABLE Scotland Chief Executive, spoke to the delegates about the work that still needs to be done for people with Down's syndrome.

The delegates later dispersed into their chosen morning workshops. In the Planning for the Future workshop, a delegate said that "it raised important issues for parents to

consider and action."

Another delegate felt that the Liaison Nursing Service workshop was "a great workshop - really informative."

After delegates enjoyed their sit-down lunch; networked with other parents, professionals; attended our AGM; bought Christmas cards and viewed the exhibitors area, the afternoon workshops commenced.

All of our delegates attending our afternoon workshops rated them good or above.

A couple of delegates from our Education Transitions workshop said that they "loved the interactive nature of the session" and one delegate "is rethinking secondary choices."

An attendee of our Improving Communications Skills workshop said, "that they learnt new things" and another suggested that "more time should be spent on strategies as it was very helpful."

Overall, the conference was "a great day, well organised" and another delegate said that they "really enjoyed this conference".

Thank you to all who attended the conference and filled in our evaluation forms. We hope to see you this November!

BOOK OUR 2014 CONFERENCE

Our 2014 Conference will be held on Saturday 15th November at the Westerwood Hotel in Cumbernauld.

For more information on workshop topics, our early bird rates and to book, view our conference flyer inserted in this issue. Alternatively, book your place on www.dsscotland.org.uk/conference.

What are you looking forward to at this year's conference? Tweet us @DSScotland #conference

DS Scotland Events

November



► Our **Forever 21 Gala Dinner** will be held on Saturday 8th November at the Grand Central Hotel in Glasgow. The evening will include a dinner, music, dancing, auction, raffle and more. It will start at 7:30 pm. Tickets are £60 per seat or £600 for a table of 10. For more

details or to reserve seats visit our website: www.dsscotland.org.uk/gala.



► Our 2014 Down's Syndrome Conference will be returning to the Westerwood Hotel in Cumbernauld on Saturday 15th November. For more information on workshop topics, our early bird rates and to book, view our conference flyer inserted in this issue. Alternatively, book your place on www.dsscotland.org.uk/conference.

February



► Visit the free **Six Percent exhibition** at Birnam Arts and Conference Centre (near Perth) throughout February! Vikki Stillwell, our Family Support Service Officer for the Northeast of Scotland will also be at the exhibition every Wednesday from noon to

2 pm during February to answer any queries you may have about Down's syndrome.

March (our busiest month!)



► Our **Do a Dish for Down's Syndrome fundraising and awareness campaign** is back! Throughout March, families, friends, co-workers, schools and hairdressers make food and bring it to dinner parties, company potlucks or to the hair salon for clients.

Our campaign coincides with **Down's Syndrome Awareness Week** (16th - 22th March) and **World Down's Syndrome Day** (21st March). More details as well as downloadable leaflets are available on www.dsscotland.org.uk/dish.



► Get tied up with 2 of your friends/family members and join our **Indigo Social Media Race 21** event in Aberdeen, Dundee, Glasgow and Edinburgh throughout March!

Details TBC. www.dsscotland.org.uk/Race21



► Grab those fun socks out the drawers and wear them on World Down's Syndrome Day (21st March) and take part in **Lots of Socks!** Whether you're giving a presentation at work, at school or at the shops - wear lots of socks, colourful/patterned socks, one sock, tall or short socks. Why not ask someone to sponsor you to raise funds for DS Scotland?

Sponsors can text **SOCK21 £3 to 70070** - every little bit helps!

DS Scotland Branch Events



► Our **Central Branch** holds its popular **Activities Club** for all ages fortnightly on a Saturday from 2-4 pm. This family club welcomes everyone and costs £2 per family. Activities include arts and crafts, board games, pool, toys for young children and babies and much more! The group meets

at the Grange Community Education Centre, Redding Road, Brightons, Falkirk FK2 0AA.



► Our **Edinburgh and Lothians branch** offers the **Parent, Baby and Toddler group**, which meets on the first Friday of the month from 2-4 pm and provides an opportunity for chat and support. The group meets at the Enable Hall, 95

Causewayside, Edinburgh.

► Our **Grampian Branch** holds a **Pool Group** once a month for people with Down's syndrome 18 years or older. The group meets every third Monday of the month at Riley's Pool and Snooker Club, 9 Bridge Place, Aberdeen AB11 6HZ. There are no membership fees and the games of pool are free! Attendees can also catch up on the latest sport on the venue's large screen TV. For more information on the Pool Group contact Margaret Pittendrigh on 01224 316 947 or John Reed on 07542 546 817.

► Our **Tayside and Fife Branch** offers a **Beat It Out Drumming Session** once a month from 2-3:30 pm at St Mary's Church Hall, High Street, Newport. This is a great opportunity for children aged 12 to adult to make some noise. This group combines music and art provided by the branch's music teacher.

► Our **West of Scotland Branch** holds a **new Pre-5 Toddlers Group in Motherwell which includes a sing and sign session**. The group is open to parents, children and siblings. Come along for a chat, coffee, songs, games and sing and sign sessions. The group is free but donations are gratefully received. Held on the first Saturday of each month from 3-5 pm at Dalziel St Andrews Church Hall, 43-47 Merry Street, Motherwell ML1 3XW. Contact Audrey O'Neill on 07718 240 801.

► Visit www.dsscotland.org.uk/getinvolved/branches for more activities offered through our branches in: Ayrshire, Central, Edinburgh and Lothians, Grampian, Tayside and Fife and West of Scotland.

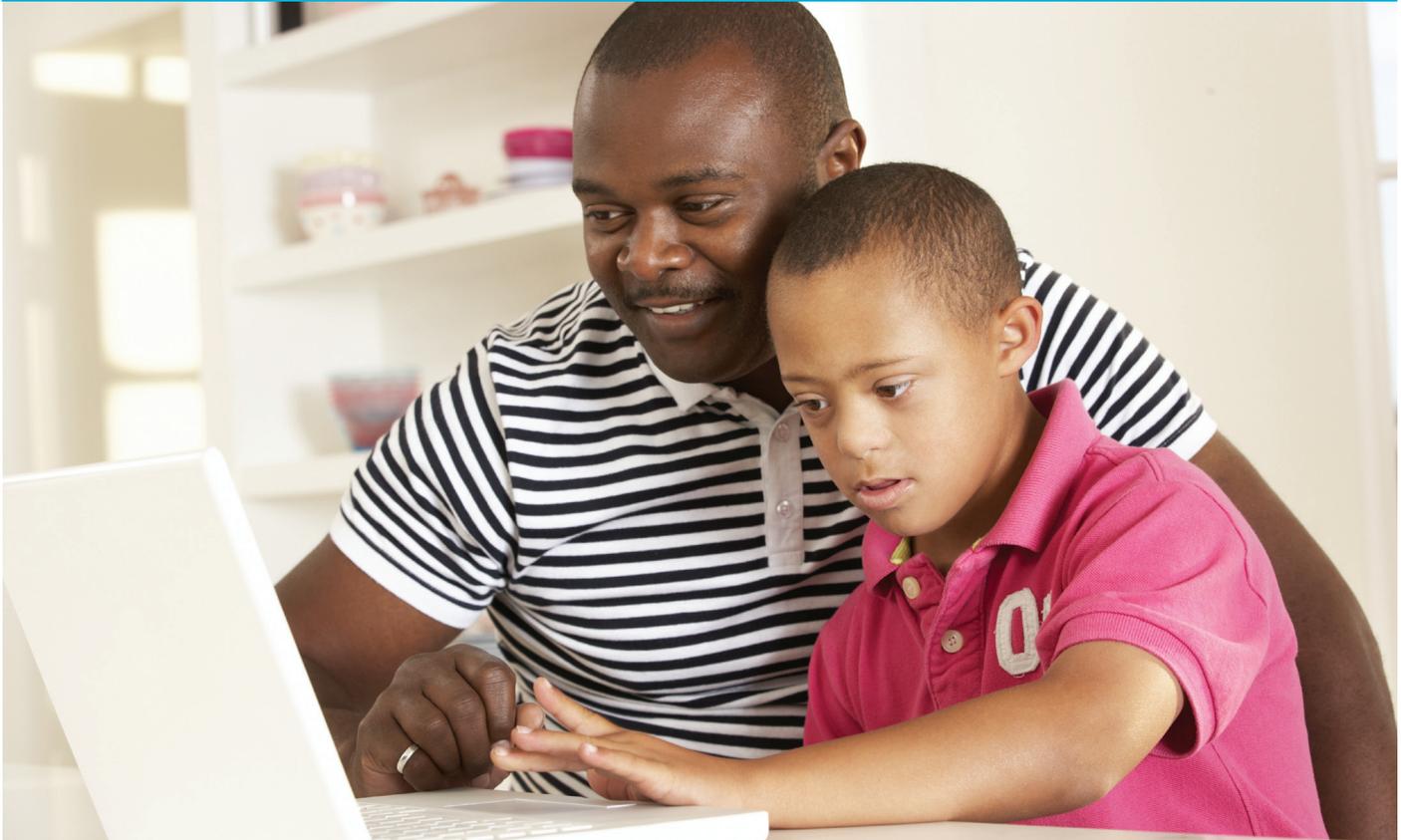
More event listings

We have more exciting 2014/15 events planned. View our *Fundraising Focus* supplement, which is included in this issue of *Full Potential* to see the great opportunities!



Self-Directed Support

By: Rachel Le Noan, Policy Officer, DS Scotland



It has been a few months since the introduction of Self-Directed Support (SDS), which offers people four options for choosing how their support is delivered:

- ▶ **Option 1:** "I get the money to spend on support I choose." (direct payments)
- ▶ **Option 2:** "I tell the Council how to spend the money."
- ▶ **Option 3:** "I let the Council decide how to spend the money."
- ▶ **Option 4:** "A mix of options 1, 2 and 3."

SDS aims to improve the care and support that users of services receive by giving them more control and choice over their lives. It is meant to empower people by enabling them to choose the services they want and allowing them to make informed choices. SDS also intends to facilitate a person's participation in their community.

The first option - which has been available to many people for a few years - has been much talked about as it means that people manage their own budget and arrange their own support. Under this arrangement, you also become an employer. Being an employer can be overwhelming and option 1 is therefore not for everyone. It is important to carefully consider all the options available and not hesitate to ask for more advice. Authorities have now a duty to explain the effect of each option and to 'signpost' you to further sources of information and support if needed.

It will take time for SDS to be fully implemented across Scotland and some amongst you will get to experience it sooner than others. Nonetheless it is always helpful to know how new policies affect your lives and I would be interested to hear your views on SDS over the next year or so. Which option did you choose and why? How easy was the process? According to you, what are the pros and cons of the new system? Overall, do you feel it has improved your quality of life and the wellbeing of the person you care for? Please feel free to send me any thoughts (either positive or negative) you may have on this issue.

Evidence from our members is valuable for our policy work. Your personal experiences can help us develop recommendations for local and national authorities on how to improve services for you.

More information about SDS is available on the following website: <http://guidance.selfdirectedsupportscotland.org.uk/>.



Rachel is our Policy Officer. She submits consultations to the Scottish Government and oversees our Policy Panel to gather evidence on important issues. She can be reached at rachel@dsscotland.org.uk.

If you would like to share your experience of SDS please contact Rachel on 0131 313 7452.

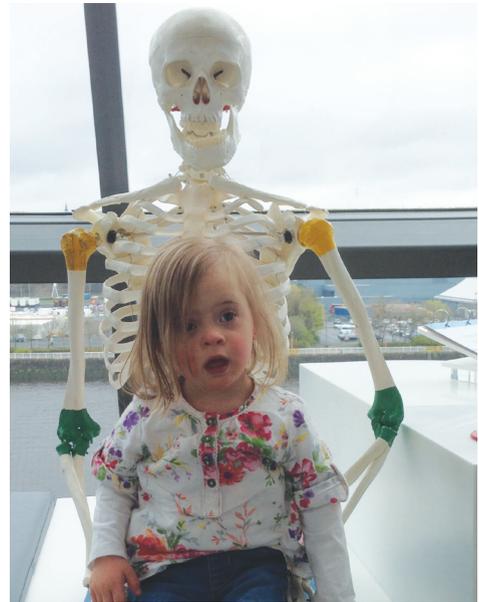
Want to explore SDS in detail? Attend our conference workshop delivered by Edinburgh Development Group.



Adelaide, 6 months, with big brother Bennet aged 4



Eilidh, 8 months, giving her mum a gorgeous smile



Elsa, 2, sitting with Mr Skeleton at the Glasgow Science Centre



Todd, 3, staying cosy in his knitted hat



Teighan, 4, enjoying a sunny day



Emily strikes a pose



Adam, 6, loves to swing



Marie, 12, enjoying a day out with her mum



Claire, 25, trying on her mum's old wedding dress



About Down's Syndrome Scotland

Down's Syndrome Scotland works to help people with Down's syndrome reach their full potential by providing information and support to them, their families, carers and professionals.

We work to improve the quality of life for everyone in Scotland with Down's syndrome and their families.

For more information visit our website at www.dsscotland.org.uk or call us on **0131 313 4225**.

How to get involved

There are many ways to become involved with Down's Syndrome Scotland. Whatever your circumstances, we welcome all who are interested in networking with others through local branch activities or national events and those interested in volunteering their time whether it's planning and participating in a fundraiser or becoming a parent contact. For those short on free time, you can keep updated on our events and information through social media sites - Facebook and Twitter.

Volunteer

Please contact the national office or visit www.dsscotland.org.uk/volunteer to find out about ongoing and future projects.

Fundraise

If you have an idea for a fundraising event for Down's Syndrome Scotland, please log onto our website at www.dsscotland.org.uk/fundraise where there is information, forms and posters provided to help you plan, organise and publicise your event.

Donate

More information on donating is available online at www.dsscotland.org.uk/donate and on this issue's back cover.

Contact

To find out what's happening in your local area check out the Branches page of our website - www.dsscotland.org.uk/branches.

Connect

Search for us on popular social media sites - Facebook and Twitter. Keep notified on our most up-to-date information and events and network with other members, parents and supporters by becoming a fan of **Down's Syndrome Scotland** on Facebook. If you would like to keep updated on related information in the third sector follow us **@DSScotland**.



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Down's
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helping people realise their potential

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Down's Heart Group

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Disclaimer

Articles in this newsletter reflect the opinions of the contributors. These are not necessarily the views of Down's Syndrome Scotland.

On our cover



One year old Lucas, who was born deaf, enjoys the outdoors. He is the son of Kine Engeseth and Scott Taylor.

Full potential

DONATE



Donation Form

Name:.....

Address:.....

..... Postcode:.....

Phone number:.....

Message to charity:.....

Please circle the amount you would like to donate:

£10 £15 £20 £25 £30 £35 £40 £45 £50 Other:.....

giftaid it To qualify for Gift Aid you must pay an amount of Income Tax, and/or Capital Gains Tax at least equal to the tax that we reclaim on your donations in the tax year. (Currently 25p for every £1 you give).

(Please tick the box) Please treat this donation and all future donations to Down's Syndrome Scotland until I notify you otherwise as Gift Aid.



Down's Syndrome Scotland

helping people realise their potential

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Down's Syndrome Scotland
 158/160 Balgreen Road
 Edinburgh EH11 3AU

0131 313 4225
info@dsscotland.org.uk

Or go to our website - www.dsscotland.org.uk/donate - to make an online donation.

If you would like to become a regular donor and set up a standing order please contact the office above or e-mail Ed@dsscotland.org.uk.