

PHOTOS



Many Happy Returns to Frances Binnie from Rett Syndrome Association Scotland
Frances blows out the candles at her special birthday celebrations.



Donation from Hunterston "A" Nuclear Power Station
Caroline receives a cheque on behalf of RSAS from Site Director, Peter Roach.



RSAS Stall at the Glasgow Christmas Fayre 2010
Jacqui, Mary, Alice and Joan take a turn at manning the RSAS fundraising stall.

ABOUT THE RSAS

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Rett Syndrome Association
Scotland
is a Scottish Registered Charity:
Number SCO16645

THE RSAS NEWS WELCOMES ARTICLES AND COMMENTS FROM ALL INTERESTED PARTIES ON ANY ASPECT OF RETT SYNDROME. PLEASE GET IN TOUCH IF YOU HAVE NEWS, IDEAS, OR A STORY TO SHARE. WE WOULD BE DELIGHTED TO HEAR FROM YOU.

RS NEWS

JUNE 2011
EDITION

Rett Syndrome Association **Scotland**

*Good wishes to all the Mothers on this, your day.
Special Greetings.
from Marilys Infante Mesa (Cuba)*

madre
belleza natural



Felicidades Mamá

In this issue:

Curing RS • IRSF News • Muriel's Holiday
New Life Foundation • Acid Base Balance in Rett Disorder
Donations • Forthcoming Events

The following information has been received from Debi Hall who has asked that it be distributed to our families

Help me communicate

by Debi Hall

Hi my name is Debi Hall and I have founded a Scottish charity called *Help me communicate*.

This charity is registered SC042264

Help me communicate will be fundraising to make a large fund available to Scottish retts families. This money will be available to buy communication devices and equipment.

It will be available for both small and large requests. Such as communication switches, toys or other devices and also major devices such as my tobii or other eye gaze devices.

These companies offer support and will tailor the system to suit your families individual needs.

Support will be offered to your family to help you to use the equipment.

I hope that this helps your families to give your children opportunities to discover various ways of communication irrelevant to price tags.

The system will work with requests being sent by post to myself, I will need some confirmation that your child / adult has retts syndrome. A letter from doctor would be adequate. I will need some basic details about what your family would like for their child or what they would like them to be able to do. So that *Help me communicate* can help discover perfect equipment for you. Most of the more expensive equipment is available on a trial basis. We will then correspond with a designated person until we are at the invoice stages when equipment will be paid for and delivered straight to you. I would like to see lots of smiles at this stage!

So that's the plan, at the moment we are in the process of setting up our accounts and informing our prospective clients

of our intentions for *Help me communicate*. We have also planned an event a month May's event was a sponsored climb of Goatfell on Isle of Arran. June's event is a charity football tournament and fun day in East Kilbride Glasgow. July's event is a toddler toddle with children's characters in East Renfrewshire! So I'm hoping these all go well. We are also arranging bag packing in supermarkets, collections and campaigns. So we are very busy and we are desperate for everyone to join in and do individual events for *Help me communicate*.

I hope that you would find this service of use to your family's needs. We need to generate the funds that will hopefully help every family, it will be first come first served, I will not limit the amount of times that we can help families but I will ensure it is fair to all. In times of cuts to the country I hope that, *Help me communicate* serves you all well.

Kind regards Debi Hall.

My contact details are:

Debi Hall

11a Hawthorn Gardens, Clarkston, Glasgow, G76 8BB

Email: debihall@helpmecommunicate.net

I am also available to contact through Facebook.

My phone numbers are:

07545 383993 and 0141 644 4124

Web site comes soon!

As members of the Glasgow Council for the Voluntary Sector (GCVS) as well as holding a stall at their Christmas Fayre RSAS also receives regular information from them. The following item was sent to us by GCVS and will be followed up to see how this will affect donations to RSAS.

GCVS Briefing

UK Budget 2011

Chancellor George Osborne announced the UK Government's 2011 budget this week. Measures contained in the budget include a rise in the personal tax allowance, a scheme to help first time buyers and a 1p decrease in fuel duty, as well as a 2p cut to corporation tax. However, critics say that these gains are more than offset by rises to VAT, cuts to benefits and tax credits and a 1p rise in National Insurance contributions.

The following measures should benefit the voluntary sector:

- Charities will no longer have to obtain signed gift aid declarations on the first £5,000 of small donations per year in order for those donations to qualify for the tax relief.
- Gift aid will be automatically applied to donations of up to £10 benefiting the sector by an estimated £240m.
- 10% Inheritance tax discount for those that leave more than 10% of their estate to charity (40%-36%).

DONATIONS

As always our grateful thanks to all who have supported the RSAS by their fundraising and donations. Without your help we would not survive.

We would like to extend our apologies to anyone who has made a donation but whose name is not included in the following lists. Our accounts are currently being examined prior to the AGM and so the information is not available at present. This matter will be rectified in the next issue.

Margaret J Simpson, Moray

David Nicholls, Ashkirk

Mrs Pamela Heath, Dundee
(in memory of her husband and RS granddaughter)

Kate McMahan, Newtonmore

Magnox North,
Hunterston "A" Nuclear Power Station, North Ayrshire

Rett Syndrome Association Scotland is very grateful to have been left a legacy by Mrs Suzanne Ritchie, Orkney

FUNDRAISING

- Dougie Biggart, Dumfries & Galloway
- Ray Henderson, Glasgow

COLLECTION BOXES

- Hazel Mackay and "Joyce's" in Buckie, 5th collection this year.
- Martha Nimmo and "Spar" in Ayr, 3rd collection this year

Forthcoming Events

AGM and 25th Anniversary Celebration Buffet

The AGM takes place at 2pm on Sunday 19th June at the Premier Inn, George Street, Glasgow, preceded by a celebratory buffet at 12.00 noon. It is hoped that some special guests will be joining us for the buffet to mark the

progress made in the treatment and understanding of Rett Syndrome in the 25 years since the founding of the Association.

The Family Weekend at Badaguish Friday 12th August to Monday 15th August 2011



The weekend is now booked and the organisation has started. Ten families are participating this year and we will also be welcoming Lyn Weekes and Pat Sillery, physiotherapists together with some new RS professionals.

Tracey and Ian of Active Spirit are organising activities for us and Nancy Gunning has again agreed to do our catering. Let's hope for good weather!

Rett Syndrome Clinic

Progress is being made to find professionals in Scotland who will be able to help with the running of the RS Clinic. A date has still to be arranged.

Other Items of Interest

Bishara Smeir, who kindly agreed to help with the production of the RSAS DVD has also come up with some very appealing and updated ideas for a new logo for the Association. The committee has discussed this and it has been agreed that production of new stationary incorporating the logo will go ahead. Watch this space!

It is hoped that the booklet "Music Therapy in the Treatment of Rett Syndrome" will soon be updated and reproduced.

Rett Syndrome and the Developing Brain

At the October 2010 European Rett Scientific Conference in Edinburgh there was much interest in Dr Alison Kerr's book "Rett Syndrome and the developing Brain". All of our stock of books was sold on to delegates and one was sent to Rosie Spike, a member of Mark Bailey and Stuart Cobb's research team at Glasgow University. RSAS has this year made a grant of £7,000 to the team to help progress research into RS.

On receipt of the book we received this reply from Rosie:

7th February 2011

Thank you so much for the book – it is becoming well-thumbed as I have a number of project students working on different Rett-like features in our mouse model.

We have been investigating the distribution of MeCP2 throughout the body using a new 'fluorescent' labelled form of MeCP2. In other studies we have been asking whether the sensory nerve endings in the skin are abnormal in Rett mouse.

Another area that interests us is bone. Fractures are common

in Rett girls so we are studying the skeleton to find out why this might occur. In addition to these studies, we continue to focus on the brain.

Kamal is busy with his work attempting to reintroduce a 'healthy' version of MeCP2 to the brain using modified viruses. I am assisting him with the behavioural testing so we're all pretty busy!

Best wishes,

Rosie

Disabled Children at the Heart of NEWLIFE

Sian Smith of the Newlife Foundation has asked that the following article be brought to the attention of our members.

Newlife Foundation for Disabled Children is a national charity, founded in 1991, that specialises in making life better and brighter for disabled children and their families Newlife achieves this through its services and funding of 4 key areas of action.

Nurse Services

The National Helpline is staffed by a qualified team of Nurses who listen, advise and offer help and support to all who call or contact them. The Nurses use their clinical skills and understanding to provide an invaluable service to families who have a disabled child. Whether you choose to contact them through a call or via the instant-messenger Live Nurse Chat service, Newlife Nurses are a confidential and trusted source of support and information to thousands of families every year. With 123 years of combined experience between them, Newlife Nurses offer immeasurable support and have recently expanded to respond to the growing number of calls to the service. All calls are free on 0800 902 0095.

Equipment Grant Services

Newlife Nurses are the access point for families applying for a grant for equipment relevant to their child's disability. This could be anything from wheelchairs to beds, hoists to seating systems and much more. One free phone call can result in completion of a simple application form for one of Newlife's Equipment Grants or signposting to another funder. Newlife Equipment Grants are non-means tested and often a decision on equipment can be made in days. A new equipment loan scheme 'Just Can't Wait' starts in Jan 2011, and it is targeted to specifically help children with terminal/life-limiting conditions, where the need for equipment at home is urgent. Newlife has spent £5.6 million on Equipment Grants in the last five years.

Medical Research

Newlife believes that medical research holds the key to finding the causes of disabled and life-threatening conditions. By funding this research Newlife aims to improve understanding, diagnosis, treatment, prevention and improve children's health in the UK. Newlife has spent £11 million on research in the last 19 years.

Campaigns and Awareness

Many parents feel alone in the daily struggles and battles they face when looking after their disabled child so Newlife Foundation's campaign and awareness activities help to give them a voice on important issues.

All this help starts with a phone call. Newlife Nurse Helpline (0800 902 0095) is available Monday - Friday 9.30am-5pm and Wednesdays until 7pm. Live Nurse Chat is available during office hours at www.newlifefoundation.co.uk

Newlife ask for no subscriptions or memberships and all services are free. Newlife's Lead Nurse Karen Dobson says: "Our Nurses have great real-life experience and so this service does not operate like a Call Centre. We are real nurses helping real families, facing real difficulties, providing information so do give us a call and we will be pleased to help."

OBITUARY – Denise Neil

We were very sorry to learn of the death of Denise Neil who sadly passed away in May 2011. Denise and her family have been members of RSAS for many years and we send her friends and family our condolences. Denise's family has asked for the following memorial to appear in the Newsletter.

"Denise was a treasure with lovely blue eyes and a cheeky smile. She touched so many hearts and was able to make people feel happy just by being with her.

She loved home life, being in the garden especially on warm, summer breezy days. She loved holidays and company, particularly of older sister Jacqueline, her husband and their two young children. Denise's Nana adored her.

Denise became ill quickly and died of pneumonia on 10th May 2011, aged 39. This happy photograph was taken last summer at Pine Bank Day Centre, Chesterfield where she attended.

We were very proud to have her as our daughter – a beautiful young lady with a big heart.

Thank you Denise for letting us share such a special life with you. We will love you always.

xBxBx

Jim and Anne Neil and family."



During our telephone committee meetings the items discussed are many and varied. Amongst these items discussion has taken place about the scientific research that is ongoing to help alleviate the symptoms of Rett Syndrome and the possibility of finding a cure.

It seems to many people that following Professor Adrian Bird's startling research discovery not much progress is being made on this front and so I am including in our newsletters various relevant articles that appear in the national press and elsewhere and I will also try to include a list of all the papers which were presented at the European Conference in Edinburgh in October, to try to show just how much work is being done all over the world.

It is worth noting that this year RSAS is again helping to fund the research team led by Dr Mark Bailey by making a grant this year of £7,000.

Caroline Groves

The following article by Helen Puttick appeared in The Herald, Saturday 1/1/2011 under the title "Drug trial brings hope of cure for genetic disorder in girls"

Tests come after research breakthrough at Scottish University

by Helen Puttick (article appeared in The Herald, Saturday 1st January 2011)

A TRIAL has been launched to establish whether a drug can reverse the symptoms of a form of autism, in girls, following a breakthrough at a Scottish University.

The US trial will be the first time a drug has been given in an attempt to counter damage caused by Rett syndrome, a devastating condition which leaves sufferers unable to communicate or look after themselves.

It was thought to be incurable until scientists at Edinburgh University were able to reverse virtually all symptoms in mice who had the genetic mutation which causes Rett.

Now doctors in Boston have begun a trial involving a drug already licensed for treating other health problems in

children in the hope it will replicate some of the same effects.

Children with Rett syndrome begin to develop normally as babies but between 12 and 18 months of age they suffer a crisis in which they lose many of their new skills, such as walking and talking, and become distressed. They never recover, although they can survive well into adulthood.

The condition, which mainly affects girls, is almost entirely caused by a faulty gene known as MECP2. Scientists believe it plays a role in shutting genes down. When it does not work nerve cells do not die, but instead fail to develop and function properly.

Dr Adrian Bird, Buchanan professor of genetics at Edinburgh

University, discovered the protein made by MECP2, which goes by the same name. His team went on to create mice with Rett syndrome and to test whether the damage caused by the faulty gene could be reversed if it was – activated effectively.

Dr Bird said: "The answer, to the surprise of everyone, including us, was the condition is very reversible. If you take an animal that is really quite unwell as a result of not having MECP2 and you put back the gene it becomes perfectly well again."

His results, which were published in 2007, have had widespread implications, with scientists finding that other developmental disorders can also be reversed.

Dr Bird said: "People had always thought that once something goes wrong with your brain that is it and you cannot do anything about it, but it is turning out that that is not true."

Neurologists at Children's Hospital Boston are trialing a treatment in 40 Rett syndrome patients aged between two and 12. Rather than using a new drug developed from Dr Bird's research, which would require years of further study, they are testing an existing treatment for short stature which

uses a hormone usually regulated by MECP2. It has been shown to improve several features of Rett-like disease in mice.

Dr Bird, who has met the parents of many children with Rett syndrome, said: "They would give absolutely anything to improve any aspect of this illness, so a significant improvement would mean the world to them."

Rachel Bloom, chair of trustees for the Rett Syndrome Research Trust UK, said families across the country were keen to see the Edinburgh University discovery translated into a treatment as soon as possible.

She stressed there was a difference between this breakthrough and the Boston trial, which is that it is not attempting to fix the faulty gene itself, but said she was hopeful about the results; which are expected in around two years.

Ms Bloom, who has a daughter with Rett Syndrome, said: "Before Dr Bird's work we had no hope. Now we can look at it and say in our children's lifetimes we will have something that will help with the day-to-day symptoms, which would be an absolute relief."

A Holiday for Muriel

by Anne McLeod

Muriel is 26 years old. When she was younger, and smaller, she would go on holiday with her father and me to different places in Scotland, England and Wales. We all enjoyed these breaks very much, but as time passed it became more and more difficult to look after Muriel away from home and so the holidays eventually stopped.

This year Muriel had enough money to go away on holiday again, but I couldn't find a suitable place to take her in the UK. Then I heard from one of Muriel's care workers about a hotel in Tenerife that is suitable for wheelchair users and works closely with a business that hires out equipment e.g. height-adjustable beds, cot-sides, hoists and slings, tilt-back shower chairs etc. I checked the web sites www.marysol.org and www.lero.net and contacted both for more information. The prices were reasonable so I took a deep breath and booked a week in March.

Making all the arrangements was a complicated and long-drawn-out process. With hindsight, I can see that this was partly because I had never taken Muriel abroad before and was starting from scratch: even getting her a passport seemed complicated. Also, I perhaps made extra hassle for myself by prodding the British Airports Authority at Edinburgh to provide a suitable space and a hoist so that Muriel could have personal care carried out before we boarded the plane. I dealt mostly with the Terminal Duty Officer (a rather worrying job title, that) who turned out to be a very nice lady and extremely helpful. In fact, everyone at the airport was helpful once I explained what was needed and why, and I have to say that we were given excellent support. They moved a bed from the ground floor up to a room on the departures level and provided a mobile hoist and sling. (The airport had not been asked for this kind of personal care facility before and they had to scramble about a bit to find a mobile hoist as they had never needed to provide one!)

We arrived at the airport at 5.45 a.m. and were met at the door. We were fast-tracked through the check in and security queues, shown to Muriel's personal care room (which was closed to other passengers until we had finished with it) and helped into our seats on the plane. To my surprise, we were also met off the plane when we got back a week later. VIP treatment indeed!

Other families may wish to note (if they haven't already discovered it for themselves) that airports can and will provide this facility if asked. I certainly felt much better knowing that Muriel was freshened up and as comfortable as possible when we finally embarked on our four and a half hour flight.

Thinking about the airline requirements - I didn't realise I would have to give the weight and dimensions of Muriel's wheelchair and the suitcase containing incontinence supplies, both of which were carried free of charge as 'special luggage'. It was the weight of the wheelchair that caused the problem. In the end, we got it from the dietician, who checks Muriel's weight on a regular basis and has to deduct the weight of the wheelchair from the total weight shown on the platform scales.

I took a chair-sized wedge cushion onto the plane and a square of non-slip webbing to go under it. This made Muriel's seat a little higher at the front so she couldn't slide down. We also put a large cushion under her feet and another between her and the side of the plane. These Heath Robinson arrangements worked well; Muriel was quite relaxed and content to sit still throughout both flights.

The holiday was expensive, as Muriel needs 2 care workers with her. The costs included accommodation, food and air fares for all 4 of us, plus 8 days and 7 nights pay for the care workers (and 2 more days pay each after we got back, because they could not have a weekend break during the 8

Acid-Base Balance in the Rett Disorder

Peter O. O. Julu^{1,2,3} Bengt Engerström^{1,2} Ingegerd Witt Engerström^{1,2} Stig Hansen^{1,4}
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ESRRA
European Scientific Rett Research Association

- 1 European Scientific Rett Research Association
- 2 Swedish Rett Center, Östersund Hospital, Östersund, Sweden
- 3 Breakspear Medical Group, Hemel Hempstead, Hertfordshire UK.
- 4 Institute of Neurological Sciences, South Glasgow University Hospitals, Glasgow, UK
- 5 Department of Clinical Genetics, University Hospital Maastricht, the Netherlands
- 6 Tuscany Rett Centre, Versilia Hospital, Lido di Camaiore, Italy
- 7 Medical Genetic Section, University Hospital of Ferrara, Italy
- 8 King's College Hospital NHS Foundation Trust & King's College London – Regional Neuroscience Centre, London, UK
- 9 Department of Physiology, College of Medicine & Health Sciences, Sultan Qaboos University, Muscat, Sultanate of Oman



Background:

Breathing dysrhythmia is life threatening and determines the cardiorespiratory phenotypes in Rett syndrome

Aims:

To compare the acid-base status in the three cardiorespiratory phenotypes in Rett syndrome.

Method:

Whole venous blood was analysed for partial pressures of carbon dioxide (vpCO₂), oxygen (vpO₂), base-excess, acidity (pH) and ionic bicarbonate ([HCO₃⁻]) using an IRMA TruePoint Blood Analysis System (Diametrics Medical, Inc., St. Paul, Minnesota, USA)

Transcutaneous partial pressures of carbon dioxide (tpCO₂) and oxygen (tpO₂) were measured using a TCM3 transcutaneous blood gas analyser (Radiometer, Copenhagen, DK) as part of the NeuroScope method within 24 hours of sampling blood.



Results:

We studied 38 persons with Rett syndrome, 32 were classical, 6 were variants of which one was male. The vpCO₂ and tpCO₂ correlated well with a coefficient r = 0.4 and error of estimate within 10 mmHg, but there was no correlation between vpO₂ and tpO₂.

	21 Feeble Breathers (55%)	10 Forceful Breathers (26%)	7 Apneustic Breathers (18%)
[HCO ₃ ⁻] mM	25.7 (24.05 – 27.40)	23.6 (22.1 – 25.17)	25.2 (23.5 – 26.95)
vpCO ₂ mmHg	44.7 (39.4 – 49.9)	36.4 (24.3 – 48.6)	37.9 (35.0 – 40.8)
Blood pH	7.388 (7.354 – 7.422)	7.419 (7.364 – 7.475)	7.438 (7.401 – 7.476)
base-excess mM	0.814 (-0.591 – 2.220)	-0.110 (-1.520 – 1.300)	1.586 (-0.341 – 3.512)

Values shown as Mean and (confidence intervals)

Analysis and Conclusion:

1. **tpCO₂ is a reliable indicator of vpCO₂.**
2. **Acid-base statuses are different in the three cardiorespiratory phenotypes.**
3. **Blood pH is kept within normal limits but with high vpCO₂ and base-excess in Feeble and Apneustic Breathers and low vpCO₂ with base-deficit in Forceful Breathers.**

The production of CO₂ is nearly 1 M/hour in resting stage, corresponding to about 300 ltr/24 hours. 98 % of this is eliminated by the lungs through breathing.
In comparison, the production of non-volatile acid is 2 - 4 mM per hour (appr. 0.5% of volatile acid). Therefore, the cardiorespiratory phenotypes in Rett syndrome has great importance.
The Feeble Breathers show pH on the low side of the scale.
The Forceful and Apneustic Breathers are high in pH.
(pH = pK + log base/acid)

The ESRRA Group

Poster displayed by Dr Stig Hansen,
Clinical Scientist, Department of Neurology, Southern General Hospital
at the RS European Conference 2010

Developmental Disease is Re-created in an Adult Model

by Stephen Bajardi, International Rett Syndrome Foundation

(Cincinnati, OH) – An IRSF funded study published today in the journal 'Science' has shown that the childhood disorder Rett syndrome, can be re-established in adult animals by "switching off" a critical disease causing gene in healthy adult animals. The gene was "switched off" in adult mice by use of a sophisticated genetic trick, resulting in the appearance of behaviors typically seen in Rett syndrome. The leading author Christopher McGraw, MD/PhD student, carried out the study in the laboratory of Dr. Huda Zoghbi, a renowned neuroscientist based at Baylor College of Medicine, and director of the Jan and Dan Duncan Neurological Research Institute at Texas Children's Hospital in Houston TX.

In 1999 Dr. Zoghbi's laboratory made a central discovery, identifying the causative link between mutations in the gene methyl-CpG-binding protein 2 (MeCP2) and Rett syndrome. This work led to other studies showing that MeCP2 protein is critical for the proper functioning of nerve cells during development and into adulthood. In 2007 a further study conducted by Dr. Adrian Bird, at Edinburgh University in the UK, showed the neurological symptoms of Rett syndrome can be reversed by reactivating MeCP2 in an adult mouse where the disease is already established. This work provided a critical proof of concept that symptoms of the disorder may be reversible in humans; however, to date it was not known

whether the early developmental period was important in establishing the course of the disease. This new study argues that early expression of the gene does not protect against the development of symptoms if the disease gene is later inactivated.

Commenting on the study, Dr. Zoghbi said "We did this experiment to see if providing MeCP2 early on in life, during critical periods of brain maturation, would be partially protective from loss of this protein in the adult brain. We were surprised to see that the nervous system had no detectable protection when MeCP2 was lost in adulthood. This affirmed that brain cells must have MeCP2 at all times to function normally."

There have been no effective pharmacological treatments developed to treat the disorder although new therapeutic trials are currently underway. This work suggests that therapies for Rett syndrome may need to be continuously maintained throughout the course of an individual's life.

Funding for this work was jointly provided by the National Institutes of Health, the Baylor College of Medicine Research Advocates for Student Scientists, the International Rett Syndrome Foundation (www.rettssyndrome.org), the Simons Foundation and the Rett Syndrome Research Trust.

Charities Reap Rewards of Budget

Article appeared in *The Herald*, Saturday 26th March

Inheritance tax was left untouched by the Chancellor, but anyone who chooses to leave 10% of their estate to charity will see a 10% reduction in their IHT rate.

Danny Cox, head of advice at Hargreaves Lansdown, said: "This is a really good idea and potentially of great benefit to charities. It will have wide appeal to those who dislike paying inheritance tax and would prefer to see part of their estate benefit good causes."

Greg Limb, partner at KPMG, commented: "This is a bit of a surprise, and great news for charities who can now hope to receive more funds from wealthy individuals."

"The Chancellor's ambition that it will be the norm to leave 10% of an estate to charity is perhaps ambitious however – especially as individuals will only actually see a 4% reduction in the net IHT rate, from 40% to 36%."



Cash Boost for Carers Breaks

THE Scottish Government will today announce a £2 million cash boost for providing short breaks for families who have severely disabled children.

The funding is on top of the £1m for short breaks this year and £1m in each of the next four years, making £5m in total, already announced in July last year when the Government's Carers Strategy was launched.

It is expected to prioritise children with complex and exceptional needs and their families. The funding of short breaks is one of the key recommendations of the National Review of Services for Disabled Children - developed jointly by the Scottish Government, Cosla and the For Scotland's Disabled Children Liaison Project - being published today.

Depending on the wishes of individual parents and families, the funding could go towards a short break for the whole family or provision for a disabled child to enjoy time together with other children.

Public Health Minister Shona Robison said: "Carers make an enormous contribution within their families and to our society. That's why we have already committed investment of £5m over the next five years for carers who look after loved ones of all ages.

"But parents looking after children with complex or exceptional needs have exceptionally tough demands placed upon them. Severely disabled children can be entirely reliant on their parents for everything and families can be left utterly exhausted."

Children's Minister Adam Ingram said: "Short breaks can provide a crucial respite for families dealing with the varying demands of looking after a disabled child."

days we were away). I met all my own costs, but the money for Muriel and her care workers came from a trust which was set up by Muriel's father to enable her to go away on holidays. There will perhaps be enough left for another 2 holidays after this one.

Muriel's care workers, Val and Karen, worked hard and long to make this the best possible experience for her and I certainly could not have managed without both of them being there. They (and the hotel staff) coped magnificently with Muriel's inevitable 'stomach upset' (that's a major understatement) and the doctor we called out at 2.45 a.m. came promptly and was very professional and efficient. He was philosophical about our lack of Spanish, too and went over his prescriptions and instructions in English, which we puzzled over but worked out to our own satisfaction after he had left! Muriel seemed well again after 48 hours, but we gave her another quiet day after that to be on the safe side. In the end, she missed one planned excursion but had an

Muriels Column

Thursday 19th May 2011

I'm writing this in the hospital and I don't even understand why I'm here! I was perfectly fine yesterday morning when Mum turned up at my flat (I live with my flat-mate Julie now). We went for a drive in my big orange van and came here. Some people came to see me one after another, all muttering about allergies and blood pressure. They kept putting things on my arm that got tighter and tighter until it hurt. That wasn't very nice, was it?

And Mum left! She just left me, and they took all my clothes away!! Then I must have gone to sleep, I think and when I woke up I felt horrible. I shouted and screamed – anybody would, you know. Mum came back, not before time, and kept saying, "Oh no. What a shame.", and "Don't cry, Sweetie." Honestly, what use is that? She didn't do anything about getting my clothes back or going home. So we're both still here. And let me tell you, my legs hurt all the time and she just keeps saying "Oh dear, Sweetie, don't cry. Here, have some tablets." That's all very well, but I don't want tablets. I want her to do something about my legs. And I don't know why she doesn't understand that. After all, they've been covered in concrete for some reason. You can't miss it.

Anyway, never mind that. I am writing to tell you about my holiday in Tenerife. It was fab. We stayed in a hotel and every time we went outside it was sunny and warm. There were flowers and palm trees everywhere and I didn't have to wear my jacket. I bought some sunglasses and wore my baseball cap. It's got a picture of animals walking along in single file and a message that says, 'Take a Hike!'

The day after we got there I felt a bit funny and in the night everything I had eaten came back out. It wasn't me, it just did it itself. More than once, too. Mum came in and started as usual, with "Oh dear, Sweetie, that's terrible." Etc. etc. She's so predictable. Quite soon after that, a very beautiful man came in and said hallo. (He said it backwards, but I knew what he meant.) I gave him a bright, beaming smile, and what do you think he did? He stuck a big needle in my derriere! "Whoa", I thought, "customs are obviously very different here in foreign parts." Mum said afterwards that I might have got a different response if the room hadn't been reeking of vomit. That woman has absolutely no romance in her soul.

unplanned, professional leg massage instead, which she clearly enjoyed. The rest of the holiday involved several sessions in the outdoor, heated pool with Val and Karen and sizeable doses of rest and relaxation.

The holiday was a great thing for Muriel. In spite of all my anxieties (this was her first time on a plane since she was 5 months old) she was not the slightest bit bothered by the journey and enjoyed all the different sights, sounds, weather, food and people we came across while we were away. For myself, after the stresses and strains of making all the arrangements, I definitely needed a holiday!

We were lucky to be told about Hotel Mar y Sol. Unfortunately, I am not on commission for drumming up business for them, but I will tell you anyway that their rates this year are being held at 2010 levels, so if you've got the money and need a break, check out the websites and go for it!

I was soon a lot better and Mum took me to see a nice young lady, who poured oil on my legs and rubbed them. I really liked it, even though she pressed down quite hard. I think she was only going to do one leg until I held the other one up to remind her to do both. The other days we went walking by the sea, and did some shopping, and stopped in an open air café to have a drink in the sunshine. We watched a lot of people going by. Mum said they were on their holidays too, most likely.

But the best thing was that the hotel had a swimming pool. Even though it was outside, the water was lovely and warm, and some parts had bubbles and waterfalls. I went in 3 times with Val and Karen, who we had invited to come on holiday with us. They were pretty lucky, if you ask me. All they had to do was give me a shower every morning, give me my meals and medicines, push me up and down the hills when we went for walks or out shopping, put my bathers on for the swimming pool (and theirs, of course), and help me to shower and get dressed again afterwards. Oh, and stay with me at night times in case I needed anything. Of course, they also got to meet that lovely nice man at 3 o'clock in the morning. They certainly wouldn't have met him if I hadn't been there. But do you know what? I think they must have been going out on the razzle when I wasn't looking, because by the time we came home again they both looked worn out! (Mum said knackered, but that's just crude.) Val and Karen obviously haven't realised that you're supposed to take it easy when you're on holiday. Perhaps they'll get the hang of it next time.

Well, that's enough about Tenerife. I bet you wish you had been there with us, don't you? I'm waiting now to see what will happen today. I want to go home from the hospital. Here comes Mum. If she's bumbling about again with another handful of tablets but no hammer and chisel to get this cement off my legs, I don't know what I'll do. I might cry. That would serve her right. Still, I always like to keep cheerful so I'm hoping for the best.

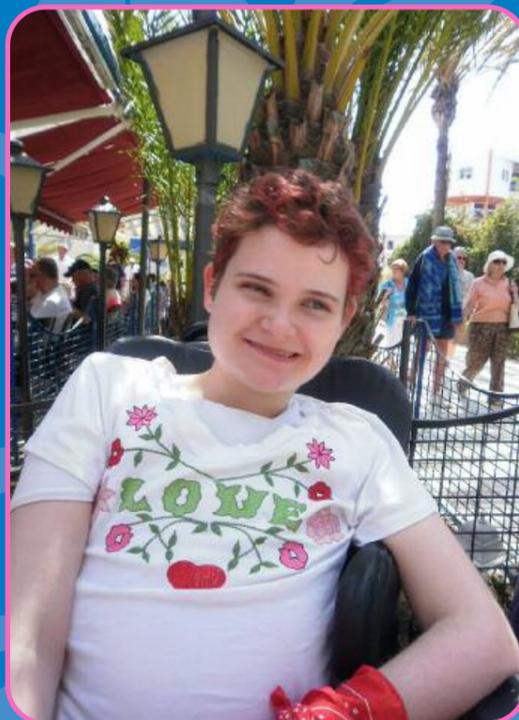
Bye for now.



Muriels Holiday Tenerife 2011



Old biddy wrecking the street cred.



Watching the world go by.



Blue pool muse.

Muriels Holiday Tenerife 2011



Flirting with the waiter again!



The end of another perfect day.