



Issue 22

February 2011

SCAMPPS NEWS

The Charity that is...Striving for Children's Additional Medical, Physical and Personal Support in Surrey

Registered Charity No. 1112112

In this issue:

NEW Pilot Babysitting Service launched! – Story Corner – Fundraising News – Summer days Help Lines – Family Fun Day –Bifocals for Children with Down Syndrome – Parent Support Group



And a Happy New Year to all of our readers from everyone at SCAMPPS! If you managed to get through the Arctic Tundra (otherwise known as December) without catching any of the hideous bugs or viruses then give yourself a pat on the back – you did well! Maybe you are starting 2011 with the fear of the VAT increase, or maybe the fuel price increase is causing you concern. Maybe it is finally time for a 'staycation' - always a fan of trendy vocabulary (why use 'name' when you can use 'moniker'?) or maybe you are thinking about giving holidays a miss altogether. Either way, we have some suggestions for economical holidays and great days out for those that like to plan ahead. For a family that likes to knock up a few airmiles we actually only flew once last year, and that was to Scotland. We did a few

calculations and figured out that although it normally takes about 8 hours to get to Edinburgh, by the time we'd got up at silly o'clock to get to Gatwick to check in 2 hours ahead then 1 ½ hours flight followed by ½ hours wait for our bags then a final ½ hour drive to my folk's house, we had clocked up almost 6 hours journey. And then there was the cost. Four return tickets to Edinburgh in half term cost over £400 whereas 4 tanks of petrol (in our tree-hugging, kaftan-loving Hybrid) would be around £240. Don't even get me started on the carbon footprint!

We are all incredibly excited about the launch of our new babysitting service (see page 3) which hopefully will allow our parents to have some well-earned nights out, or even just an extra hand on a day out.

There are hundreds of reasons to be cheerful in 2010!

Save the date! - Family Fun Day – Sunday 5th June

Our annual Family Fun day will be held at Imber Court, Esher on Sunday 5th June and this year promises to be extra special. We are delighted to invite you to experience Colourscape, where you can wander through interconnected chambers and experience the intensity and subtlety of colour. Words cannot do justice to the experience so we urge you to check out the website at www.colourscape.org.uk As usual, the event is entirely funded by SCAMPPS and we will be providing food and refreshments on the day. Those of you who have attended our family days in the past will know it is a great opportunity to meet other families and to just have a great time. We will have more details in the May edition of the newsletter and invitations will follow in due course.



Dates for your Diary 2011

- 11 Feb - Dad's Night Out
- 14th March - Finance Committee meets
- 6th May - Mum's Night Out
- 20th May - Dad's Night Out
- 5th June - Family Fun Day

For more details, visit www.scampps.org.uk

FUNDRAISING NEWS

If you have committed to being a 'new you' this New Year, then it's time to stop talking about doing things and just do them! Run that marathon, swim that channel, go into space...OK, we might be getting a tad carried away. But why not open your own fundraising page, or encourage someone you know to do it? Just go to www.justgiving.com, go the SCAMPPS pages and follow the simple steps to set up your own page. You can raise money from any event such as a child's or adult's birthday party, wedding anniversary, sponsored run/walk/swim or even a diet! Then tell everyone you know about it and get them to donate online which means SCAMPPS can claim back the Gift Aid. What are you waiting for?

We would like to say a big THANK YOU to the following fundraisers...

Selina Masters' tennis tournament raised £350

Charlotte Friend made & sold pieces of jewellery raising £160

SCAMPPS Chairman John's babysitter donated £10

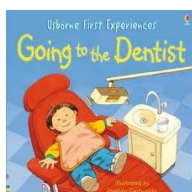
S. Munday donated £25

Claire Whitton, my son's childminder, who donates 10% of her fee

Philip Talbot who saved up his coppers!

One final image to leave with you...one of the Auction items at last September's SCAMPPS Dinner Dance was a meal for 8 cooked in your home by the Kingswood Chef, Mani Kalaiselvan. On Wednesday 12th January, the lucky bidder had the pleasure of enjoying Mani's fantastic food and the meal was served by none other than my husband & SCAMPPS Patron, Terry Sims, who truly entered into the spirit fully adorned in penguin suit! Thanks again to Mani for very kindly donating his time and also to (the other) waiter Sanjay, for helping on the night.

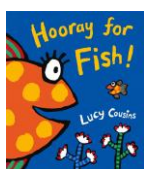
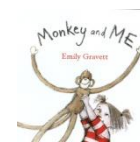
Story Corner The SCAMPPS team recommend their best reads...



Usborne Books have a delightful selection of '**First Experience**' books including *Going to the Dentist*, *Going to the Doctor*, *Going to the Hospital*, *Moving House*, *The New Baby*, *Going to a Party* and many more. Available from Amazon from only £2.50.

Monkey and Me by **Emily Gravett** (suitable for 1-5yrs)

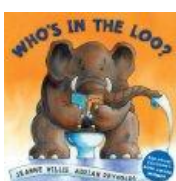
A lovely book full of simple language, repetition and anticipation as you find out who 'Monkey and Me' saw at the zoo. It gives opportunities for signing and acting out the animals seen. It is also good for when your child is learning to read. From £2.99.



Hooray for Fish by **Lucy Cousins** (suitable for 1-4 yrs)

Simple language and lovely bold pictures describing all kind of fish. It gives opportunity to spot your favourite fish on the busy pages and to give your own names to some of the more unusual looking ones. It might even inspire little ones to design their own fish! From £5.03 on Amazon.

The Rough Guide to Accessible Britain is an informative guide for wheelchair users visiting UK attractions. **FREE** to Blue Badge Holders or order online from www.accessibleguide.co.uk for £6.99 including P & P.



Who's on the Loo? By **Jeanne Willis & Adrian Reynolds**

A fun and helpful book designed to encourage children's interest in potty training. From £3.30.



Scampps Pilot Sitting service to be launched soon!!



As some of you may remember we asked Scampps members to complete a questionnaire about your views in relation to Scampps providing a sitting service.

SCAMPPS Membership Details

When you join SCAMPPS we ask you to provide contact details. This is so we can send newsletters and invitations for events etc. We will also keep in contact via email if you provide an email address. You can choose not to register an email address if you would prefer not to receive emails from SCAMPPS.

Hello Dads

Are you receiving SCAMPPS emails? Most of our families have only registered one email address and it is usually for Mum. Families are welcome to register more than one email address. Perhaps Dad would like to receive our emails as well as Mum...this would be especially relevant for the Dad's Night Out invitation emails. If you would like to check or change any of your membership details or register additional email addresses, please contact me giving me the relevant information and your family name.

Thank You. Rosalind -
Membership Secretary.

rosalind.watson@yahoo.co.uk

Following a review of the information we received (Thank you) and discussion we have decided to offer a simplified sitting service from April 2011.

Our initial 12 month pilot will enable us to review the uptake and costings and consider how best to further develop the service. In a time where everyone is watching their pennies we want to ensure the money donated to Scampps is used in the most effective and equitable way for our members. As such we would very much welcome feedback from our members.

The Service

We would like to offer our current family members who have been registered with Scampps for a minimum of six months subsidised sitting up to the value of £30 every three calendar months.

Terms and conditions of the service are available for review on the website (www.scampps.org.uk). You are requested to download the User Agreement and sign and return along with your 1st claim form. Unfortunately, Scampps will not be able to reimburse if you don't sign our user agreement.

Families may use this to go out in the daytime or evening with or without children. For example you may want to go to the cinema or go out as a whole family unit with the additional support of another adult. We don't want to be prescriptive about how you use this; we believe you are the best person to decide what would benefit your family.

You are able of course to add to the £30 should your sitter/carer require more.

It is acceptable to claim several times in that 3-month period as long as the total does not exceed £30.

If you do not make a claim you will not be able to add this to your following 3-month entitlement.



The fixed claim periods are as follow:

April'11-June'11

July'11-September'11

October'11-Dec'11

January'12-March'12.

You would be expected to pay your sitter initially and then claim your entitlement back from Scampps using the claim form downloadable from our website (www.scampps.org.uk) and returning to the address on the form. We will endeavour to process this and reimburse you by cheque within 21 working days.

Families would complete a claim form including the sitters name and their signature.

Scampps is not able to source your sitter at this current time and would urge you to ensure you have the appropriate references and assurances that the person you have to sit for you does have the appropriate skills etc. Nurseries and schools where you children attend are often a great place to find a sitter, as well as recommendations from friends.

As you will appreciate as a charitable organization, people donate with a belief that the charities board will use their money wisely. We believe sponsors will agree this is a worthwhile cause. However, we are relying on our family members to use this subsidy appropriately and in accordance with our terms and conditions. Failure to do so may result in a family being unable to access this service in the future.

We appreciate it can seem overwhelming to some parents/guardians finding a reliable sitter but cannot reinforce how valuable this can be for everyone. So please access this service.

Summer Days

There may still be snow (or at least frost) on the ground but it is time to start planning! Whether you are thinking holidays or just daytrips, here are a few suggestions...

Forestry Commission Holidays



The Commission has various sites throughout the UK where you can either camp or hire one of their new cabins. Gone are the days of the 'barely-more-than-a-garden-shed' type log cabin, their new, contemporary cabins come in various sizes and standards with their high-end lodges featuring flat screen TVs, hot tubs and even night vision goggles! Now that's my kind of camping! But even the economy lodges are very smart and well-furnished. Locations include the Forest of Dean, Yorkshire and Scotland. During the school holidays there a range of Ranger Activities on offer for the kids, including Dusk Watch and Forest Survival. Prices start

from only £437 for a family of 4 in the May half term for a 4 night break.

Visit www.forestholidays.co.uk or tel: **0845 130 8225**

And if you do visit the Forest of Dean, why not check out Pedalabikeaway? Recently voted as one of the Best Active Venues at the Accessible Britain Awards, they can provide bike hire for a range of special needs and include tandem, duet and Victorian trikes.

www.pedalabikeaway.co.uk

Badaguish Outdoor Centre, Cairngorm NP



Located in the majestic Cairngorm National Park near Aviemore, the centre provides 24 hour respite care or you can come as a family and take advantage of the great activities and facilities on offer. Accommodation comes in the form of comfortable 3 star holiday lodges, camping or wigwams (pictured left).

www.badaguish.org or Tel: **01479 861285**

No visit to the Cairngorms would be complete without a trip on the Cairngorm Funicular Railway (www.cairngormmountain.org.uk Tel: **01479 861261**). At almost 3,600 feet the train, café and visitor area are totally

wheelchair accessible and you have a good chance of spotting the resident reindeer. The fabulous Ptarmigan Restaurant is the highest place to eat in the UK - and the hot chocolates are to die for! In season, **Disability Snowsport UK** (www.disability snowsport.org.uk), based in the resort offers a full range of adaptive equipment and instruction to enable children with almost any disability to ski and board.



Crieff Hydro Hotel, Perthshire

If self-catering is not your thing but you still want plenty to keep the children occupied, this is my ultimate UK holiday recommendation. It was well worth the journey as this family-friendly 4 star resort has a fantastic range of facilities and activities on offer. In the half board rate the children stay on full board and this includes 2 sessions of childcare for 2-12 year olds per day - got your attention now? Personally, I'm not a huge fan of 'kids clubs' as I like to spend my holiday with my children but it was nice to have the option and we used it a couple of times during our 3 night stay so that my husband and I could dine in the very nice, grown-ups restaurant without having to fret about high chairs and noise levels. The children could have a 'high tea' at





5 o'clock which provided a great buffet service and then they went off to the Big Country kids club for fun & games. The children loved the swimming pool while we made use of the adult-only spa during one of their sessions. We stayed here in February and there was plenty to keep everyone occupied. If you still prefer the flexibility of self-catering then there are also a number of lodges on-site, nestled in the beautiful Perthshire hillside. And for the Dads - it's only 20 minutes from Gleneagles! Rates from only £168 per room per night for a family room (sleeps 4), adults on half board basis, children on full board including 6 hours childcare per day. Tip: February and

May half-term is NOT a Scottish holiday so take advantage of a good deal!
www.crieffhydro.com or Tel: 01764 655555

Sands Resort, Cornwall

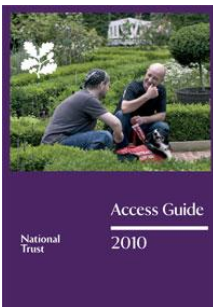
Located above Watergate Bay (think Jamie Oliver's FIFTEEN) on Cornwall's beautiful North Coast, the Sands Resort is an absolute must for families providing every kind of activity and facility you can possible need. With outdoor & indoor pools, adventure play, softplay and children's clubs, there are also great dining options and a spa for the grown-ups. Watergate Bay is famous for surfing and is a truly beautiful spot. The family rooms are spacious and come with great extras such as a baby-monitor and chill box. A room for a family of four on B&B starts from just £165 a night for the Easter break but they also offer Earlybird discounts and free child places so book early.

www.sandsresort.co.uk or Tel: 01637 872864



Drusillas, Near Brighton, West Sussex

An adventure play park/zoo featuring a host of play options, activities and even an area dedicated entirely to Thomas the Tank Engine. In the school holidays they have a varied schedule of events and often have visits from famous TV characters, such as Bob the Builder. But there is a great deal here for older children also with soft play and adventure climbing areas. The entire park is wheelchair accessible and there is even a sensory trail. For more details visit www.drusillas.co.uk



National Trust

With various country homes, gardens and parks across the UK, you may have been put off in the past by the membership fee. The NT has introduced their 'Admit One' policy which allows free access for a carer or companion. Visit their website and look under **Accessibility/Access for All** which provides all the details of how to apply for the card which provides access to any companion of a disabled visitor, he/she need not be named on the card so you can take someone different each time - great news for those of us with willing and able grandparents! You can also download a NT Access Guide and

find details of properties which provide sensory trails & Induction Loop.

Visit www.nationaltrust.org.uk

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BIFOCALS FOR CHILDREN WITH DOWN SYNDROME

The Down Syndrome Association recommends in its literature that bifocal glasses should be considered to remedy visual problems in young children. We asked a couple of ophthalmologists at Sutton Eye Hospital, who said they "didn't do bifocals for children". So we left it there for a while. But I kept reading in journals and newsletters about the work of Dr Maggie Woodhouse of Cardiff University. Around 60% of children with Down Syndrome at primary school age need glasses compared to 5-8% of typically developing children. And a high proportion of them do not focus accurately on nearby objects even when their refractive error (i.e. the extent to which they are short- or long-sighted) is corrected by glasses. Some do manage to focus accurately but draw one eye in (i.e. squint) in order to do so. Dr Woodhouse led a two year study, reporting in 2008, which made the surprising discovery that children wearing bifocals focus more accurately when looking over the top of their bifocals through the distance part of their lens. This suggests that bifocals teach the children to use their own focusing ability. A third of the children prescribed bifocals in the study were able to return to wearing ordinary glasses after an average of 2 years.

As Millie's squint had not improved over the three years she had worn her glasses for long sight, I emailed the Cardiff University Eye Clinic asking if I could bring her along for an appointment. This was followed by a few phone calls to confirm that she was entitled to this treatment on the NHS as it had been over 6 months since her last appointment at Sutton. So I booked an afternoon appointment during the May half term and set about planning a little train trip and a couple of nights at the child-friendly Cardiff Novotel.

The University's Eye Clinic is a state of the art building with a spacious, comfortable and bright reception. And the huge photos on the wall included one of a child with Down Syndrome. It was clear at once that the staff were both professional and welcoming. As for Dr Woodhouse, she was a dream come true. Right from initial introductions, she spoke directly to Millie and gave her the space and time to react. She was endlessly patient, she made the test process lots of fun, and she gave Millie plenty of positive feedback. As a result, Millie did exactly what she was asked to do (possibly a first!), and did it with enthusiasm and concentration. She was prescribed bifocals and fitted with new frames on the spot to ensure that the top of the near segment of the lens would lie at the centre of her pupils. Again, the fitting process was very accommodating of Millie's short concentration span and desire to handle every single frame within reach.



The glasses arrived by post not much more than a week later. Millie was very excited to try her new specs and has barely taken them off since. And a month after our appointment in Cardiff the optometrist at Sutton Eye Hospital noted an obvious benefit from the new glasses.

Millie still calls them her "Maggie glasses".

SCAMPPS Halloween Party



There was a great turn out to our annual Halloween Party. We were delighted to welcome lots of new faces as well as catch up with old friends. Once again Imber Court's generous support of SCAMPPS with their free room hire provided the perfect venue for our party. The children (and many of the adults!) were well entertained by Potty Patrick; there was room for chatting and networking; and even an extra space for those who needed a little time out from the noise and excitement. There was a

fabulous effort all round with the costumes – here's hoping all the face paints came off! The best dressed boy and girl this year went to Billy and Tess. Many thanks to Hazel's excellent organisational skills in putting the whole party together.



Help Lines ...

Parent Support Group

This group is designed for parents with children with additional/special needs aged 0-11yrs. This is an opportunity for parents to share knowledge, experience and offer each other support. The groups will be on the following Tuesdays 9.15 - 10.45: 1st February, 1st March, 29th March, 3rd May, 7th June, 5th July and are to be held at Meadow Sure Start Children's Centre, Sparrow Farm Road, (entrance via Waverley Road) Stoneleigh, Surrey, KT17 2LW. Tel :020 8393 9320.



Your website for
disability information

In partnership with
**MARKS &
SPENCER**

For information on accessibility in a range of locations, just look up this website. You simply enter the name of the town and the type of facility you require (e.g. café, parking, leisure centre etc.) and the site will give you details of a choice of venues. www.disabledgo.info

Fancy a free trip to the cinema?



the cinema exhibitors'
association limited

If your child receives Disability Living Allowance or is registered blind then you can apply for the Cinema Exhibitor's Association card which entitles the holder to 1 free ticket for a person accompanying them to the cinema for 1 year. Visit their website for details of participating

cinemas and to download an application form.

www.ceacard.co.uk

Helpful Tip: Does your child find new experiences stressful or upsetting, or is he concerned about meeting new people? A first trip to the dentist or hairdresser or even a friend's house can cause anxiety in some children. While there are many great children's books available that help to explain the process, some children need to know EXACTLY who they are meeting. Ask the person concerned if you can take a photo of them and show it to the child ahead of time. Some children are reassured when they see a familiar face.

Cerebra is a charity whose aim is to help children of 16 and under with brain injury (both traumatic and acquired) and neurological problems. They have a fantastic website and offer a range of support from counselling, to giving grants, to help with sleep problems. They also have a postal lending library for books and sensory toys. One thing which might be very useful to many families is a downloadable guide to claiming DLA (Disability Living Allowance). Visit them at www.cerebra.org.uk or 0800 328 1159 is the number of the parent support line.



There are now 69 Sure Start Children's Centres in Surrey details of them can be found at www.surreycc.gov.uk. Many of the Sure Start Centres are offering sessions specifically for children with Special Needs and or have a sensory room that can be booked. Here are a couple we know about:

Weybridge Children's Centre has a sensory room (the 'Snoezelen Room') which can be booked for a half hour slot free of charge, 01932 300 106

St Martin's Children Centre, Epsom have a session for children with special needs in half term. 'Young Explorers' will be on Thursday 24th February 10am-12pm. There will be some sensory games and puppetry. 01372 730435

Let us know about any groups you've been to and we'll pass it on in the next newsletter. Whilst we do not endorse any of the recommendations made in the SCAMPPS Newsletter we hope you find them useful. If you have had any positive experiences with services or facilities that you would like to share with our readers then please email us at: newsletter@scampps.org.uk



SCAMPPS

Po Box 503 contact@scampps.org.uk

SCAMPPS



Epsom

www.scampps.org.uk

Surrey

07596 - 666 - 646

IN SURREY

(no calls after 9pm please)

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You can always make a donation to us by cheque, or at:

www.scampps.org.uk with Pay Pal or now at

www.justgiving.com/scampps/raisemoney



Alternatively why not try the following Fundraising initiatives which continue to help us:

Recycle 4 Charity.co.uk



To find out more, contact Helen at Fundraising. All support is hugely appreciated!



To make the deadline for the next Newsletter, please send in any articles or photos by 15th April to

newsletter@scampps.org.uk