

Dates For Your Diary.

Adolescent Weekend 2012
PGL Swindon
12th and 13th May

Fun day and AGM.
Sunday 17th June
At Buckinghamshire Railway Centre.
10am to 4pm

Pantomime Oxford Playhouse
Dick Whittington 12th Jan 2013 2pm
Refreshments afterwards at the Randolph Hotel.

Sharing Information Day
16th March 2013.
Oxford Belfry Hotel.

Spring 2012



O·S·C·A·R

OFFERING SUPPORT to CHILDREN AND RELATIVES

FOR CHILDREN WITH BRAIN OR SPINAL

Pantomime 2012

On the 7th of January Friends of O.S.C.A.R went to the pantomime. Around 100 people enjoyed seeing Mother Goose at the Oxford Playhouse. After the performance refreshments were served at the Randolph Hotel. Thank you to those families who let us know that they could not attend. We only had two spare seats as we were able to fill the others. Next year's pantomime is Dick Whittington on the 12th January at the Oxford Playhouse.



Ellie and Rheannon after the show

Visit our website at <http://www.friendsofoscar.org.uk>

Late Effects Nurse:

We have a new Late Effects Nurse who most of you will be meeting in clinic if you have not already done so. Her name is Laura and the article below introduces her.

Laura Margerison has practiced as a Macmillan Clinical Nurse Specialist working in the field of late effects (long term late effects) and survivorship since August 2011, working as part of the haematology health care team. Her background is in paediatric oncology and haematology, having begun training in 1999. Her role involves co-ordinating the care of patients who are five years or more past the end of treatment for a childhood or young adult cancer. However, may meet patients in clinic prior to this. Her role is multi-faceted, and includes; providing health promotion advice and education. Laura will also act as “key worker” (the main person involved in co-ordinating the young person’s follow up care) within this role Laura will be a point of contact to answer questions, discuss concerns, arrange clinic appointments and signpost to other health care professionals within the late effects team, as well as inform the young person about their previous diagnosis and treatment and subsequent risk of potentially developing a late effect. Laura is also heavily involved in service development, as the late effects service is still in its infancy. This involves attending business meeting, Steering groups and other cancer centres and hospitals to ensure patients in the Thames valley region are receiving the best possible follow up care, by learning from other hospitals and young people themselves to design a service which is effective, appropriate and in line with the National Cancer Survivorship Initiative.

Laura’s plans for the future of the late effects service is to develop nurse led late effects clinics, and assist with the transition of patient’s from children’s to adult services. Laura will also provide every child and young person with a summary at the end of their treatment, outlining the treatment they received. This will assist in communicating their past medical history with health professionals they may come into contact with in the future, such as a midwife or new General Practitioner to ensure young people are assessed and followed up appropriately for as long as it is needed.

You can contact Laura Margerison on 01865 572890. She will also be attending the adolescent weekend.

Gulliver's Land

We were lucky enough last year to be one of the charities selected by Gulliver's Land near Milton Keynes to receive free entrance tickets for their charity weekend on the 8th and 9th October. Despite the change in the weather all the families that attended had a good time.

Pictured below are the Budd family.



The words below have been copied from an email I was sent from the family;

“Just wanted to say thank you for the tickets to Gulliver's Land, had such a wonderful day, weather stayed dry for us, and no queues on any of the rides, went on everything at least twice!! Especially liked the bumper cars! and the chocolate and banana sweet pancakes they had for sale at the indoor play kiosk”.

On behalf of everyone at Friends of O.S.C.A.R I would like to say thank you to Gulliver's Land for selecting us to receive tickets.

Christmas Card SALE

We have reduced the Christmas cards to £2.00 per pack including postage.

If you would like to take advantage of this offer please email the office on carolharrison@utdsl.com or phone 01235 816310.

Fund Raising

We also have an ex patient who has nominated O.S.C.A.R to be the charity of choice for his local golf club. If anyone is interested in taking part in the charity day, it is on the 8th August. Please contact the office for more details. We still have some Christmas Cards left so if you feel you can sell some please let me know. If anyone would like to do a fund raising event we have a gazebo, Shaky tins, collection buckets and merchandise that you can use. If anyone is taking part in an event that requires an overnight stay we are members of the Youth Hostel Association.

Please contact Carol on 01235 816310 or email
carolharrison@utdsl.com

Donations To O.S.C.A.R

We would like to say thank you to a few people who have made donations to O.S.C.A.R recently including Paula Watson who makes Xmas puddings and mince annually and sells and raffles them for us. They must be good as she raised £67.00 this year. Also Helen Dunwoody who has been continuing to collect in sponsor money from the sponsored walk she arranged last year with a group of friends. Helen has also made some contacts in the area that she lives. She has recently been invited to talk about O.S.C.A.R at her local Inner Wheel Group at Uxbridge and they made a donation of £50.00. In 2010 she arranged to sell Xmas cards on our behalf at a local nursery called Sticky Fingers as a result of making this contact she was presented with a cheque for £50.00 last year. We would also like to thank Faye from the same nursery who made and sold cakes and raised £20.00.

Useful Information

matesNdates

We have recently found out about this group. They are a specialist dating and friendship agency for adults with learning difficulties living in Oxfordshire. If you don't live in Oxfordshire it may be worth contacting them to see if there is something similar where you live. Telephone 01993 899980
Email:matesndates@guidepoststrust.org.uk

Child Stroke Support

There is a web based support group for parents whose child has had a stroke it can be found at www.childstrokesupport.com.

The Cinema Exhibitors' Association Card:

If you are in receipt of Disability Living Allowance, Attendance Allowance or are registered blind. You can apply for the above card at www.ceacard.co.uk or ask for a form at your local cinema. There have been changes to the card it now only lasts one year and not three. Everything else remains the same.

The National Blind Children's Society:

Has a wide ranging parent support service for families of children with visual impairment www.nbcs.org.uk tel 08007811444

Airport Guide for those with a disability or reduced mobility:

This guide is available at www.parkat.co.uk/disabled. The guide includes things like travelling with medication along with information for people who have sight and hearing impairments as well as people who have mobility issues.

Guideposts Trust.

There is a group based in Witney called Guideposts. They run afterschool, youth and Fun clubs at a number of venues in Oxfordshire. The clubs offer inclusive all round child care for ages 3-19 the youth clubs are for children aged 11- 19. After school clubs cost £12.50 per session, Holiday Clubs are £28.50 per day. If you live in the Banbury area you could sign up to the creative media course which supports you to use a sound studio, computer animation and digital editing equipment. This is a 10 week course and cost £50.00. If you don't live in Oxfordshire it would be worth getting in touch with them to see if there is anything available in your area telephone 01993 899980/8 website is www.guidepoststrust.org.uk.

Home Start.

For families with pre-school children who would like some extra support, there is a group called Home Start. For more information visit their website at www.home-start.org.uk or phone 0800 068 6368. Home-Start are a national group so there should be one near you.

18 Plus Groups:

We have also recently found out about the 18 Plus Groups. The groups appear to meet once a week but have loads of activities going on at weekends or in the evenings. The groups are for young people aged 18-35 who may or may not have a disability of some type, who would like to meet new people and have some fun. To find out if there is a group near you go to www.18plus.org.uk and scroll down and you will find a list of groups. Many of the groups on the list have their own web sites and you click on them to find out what your local group is doing and where it meets.

Smoke Alarms:

As many of you know the fire service recommends that we should all have at least two smoke alarms in our houses. If you don't have any or yours are old and you think they should be replaced ring 0800 0325 999 and you may be able to obtain new ones free of charge.

Audio Books:

Free postal book service, with a section for children. The Calibre Audio Library can also be visited in Aylesbury Buckinghamshire please phone 01296432339 or go to www.calibre.org.uk

Free e audio books and e books

Oxfordshire County Council has set up a new free lender service for e audio and e books. For more details go to the Oxfordshire County Council website. If you live outside Oxfordshire go to your County Council web site and see if they are offering a similar service.

Free child entry tickets and two for one vouchers:

Free child entry tickets and two for one voucher's can be found at <http://tinyurl.com/3cby6zq>. The offers change so it worth looking at if you are planning a day out,.

Driving

If your child is in receipt of the high rate mobility part of DLA they can apply for a driving license at 16. You can book an assessment at one of the Regional Driving Assessment Centres the nearest is at Eynsham nr Oxford www.rdac.co.uk or phone 08453371540. For a driver assessment you will need to have a full or provisional licence. They will also help with adaption's to your car for carers. They have a fully equipped vehicle.
Driving Tests

Bus Passes for Disabled Adults and Children

We have recently applied for one of these as a family and have been successful. We did not apply before because I did not feel we fitted the criteria set out on the web site. We then contacted the council and discussed it and we were advised to apply. It is free to apply via your local council web site you will need a letter from your doctor and a couple of passport sized photographs.

DONATIONS to Friends of O.S.C.A.R

Nerys Wilkinson & family Flora Marathon
£15.00

Alicja Ginter Contractor Award Scheme UKAEA
£50.00 donation

Recycle 4 Charity. £58.10

Tombola Banbury Christmas Fayre £155.74

Jewellery Envelopes. £10.50

Madley Brook Primary School Collection After Xmas Shows
£334.48

Mrs Robinson £50.00

Devizes Round Table £1560.00

Mrs Dobson John Colet School
Donation instead of sending Xmas Cards. £24.05

David and Karen Fake Lloyds TSB
Quiz Evening and Raffle. Raised in excess of £970.00

Yellow Moon £6.95

Donations in memory of Mrs Anne Russell
£338.75

Bath Half Marathon



Some months ago Tessa Jones contacted the office and said she had managed to get a place to run the Bath Half Marathon and that she would like to raise funds for Friends of O.S.C.A.R.



As you can see from the picture Tessa successfully completed the Bath Half Marathon on the 11th March in two hours and thirty two minutes.

Tessa has raised over £325.00 and we would like to say congratulations and thank you.

The money she has raised will go towards this year's family fun day and AGM on the 17th June at Buckingham Railway Centre.



Offering Support To Children And Relatives
A National Charity Which Supports Families
Of A Child Deceased With A Brain Or Spinal
Tumour

Hello everyone

Firstly I would like to say thank you to Matthew Watson who recently donated a camera to us. Our camera has been well used over the years and was rather slow and old. Matthew has donated a more up to date digital camera.

We would also like to say a very big thank you to Paul Holmes and his team at Devizes Round Table who raised a huge £1560.00. This money will be spent on the adolescent weekend as Paul's wife is a volunteer at the weekends; thank you also to Tessa Jones who has recently ran the Bath Half Marathon for us. Friends of O.S.C.A.R were also lucky enough to be selected by Carphone Warehouse in Didcot as one of the charities to receive £1,000.00 through a staff nomination scheme over the 12 days of Christmas. The nominee was James Harrison and he has requested that the money go towards the adolescent weekend as this is the one FOO event he is able to take part in. Carphone Warehouse in Didcot have also donated a couple of games that we can use as raffle prizes. The Clare Foundation are organising The Red Kite Ramble again this year. It is on the 24th June, and rambles are 5, 10 or 18 miles long through the Chiltern Country Side. Refreshments and plenty of car parking will be provided. Dogs are welcome so long as they are well behaved and walkers clear up after them. Although we are not organising this event any money you raise will go to FOO. If you are interested in taking part please let me know and I will send you the poster with the links on it so you can register.

Our next event will be the Fun Day and AGM which is going to be at Buckingham Railway Centre on the 17th June 2012.

The committee would like to say a big thank you to Amanda Crossley who has had to step down from the committee for personal reasons. Amanda has been a member of the committee for a number of years and has taken part in a number of the fund raising events.

Many of you will have received the following email but for those of you who I don't have email addresses for I have copied the email below. As a committee we feel it important that all families have this information.

There was a Friends of O.S.C.A.R committee meeting on Monday and at this meeting the future of Friends of O.S.C.A.R. was discussed. As many of you are aware this charity was set up to run alongside O.S.C.A.R so that it could offer families that were not treated at the JR the same support as families that are treated there.

When Friends of O.S.C.A.R was set up in 2005 the plan was that the new charity would eventually take over from O.S.C.A.R. and as a result Friends of O.S.C.A.R has been able to take over funding some of the events and activities but not all of them. If Friends of O.S.C.A.R is to move forward and take over these events the charity needs to sustain an income of at least £48,000 per year. Our income for the year to December 2011 was £6560 which includes £1000.00 that has been ring fenced for funding the new Shared Care Diary. Our Expenditure year ending 2011 was £12031. In the past we have been supported by O.S.C.A.R financially but as we planned the O.S.C.A.R account is reducing because we are fund raising for Friends of O.S.C.A.R.

As you will see from these figures if Friends of O.S.C.A.R is to continue as a charity then it needs to be more proactive in raising funds. Friends of O.S.C.A.R has around 100 families on its database and if each family were to raise just £100.00 annually that would give the charity a much needed boost to its finances of £10,000 towards its running costs.

Fund raising is not always about raising money, it may be about networking at your local school or village fete by running a stall that may only raise £20.00. By running such a stall you may give out a leaflet to someone who is involved in fund raising in other ways such a golf club captain or the rotary club member that would like to support us.

Friends of O.S.C.A.R knows this works as a captain at a golf club recommended Friends of O.S.C.A.R as the charity of choice which resulted in two cheques, one for £700 and another for £22,000. By giving out a leaflet at Didcot Street Fair we were nominated as the charity of choice for the Oxford gang Show and this raised £700.00.

We would however like to say thank you to the few parents/families who do support us either with networking or fund raising.

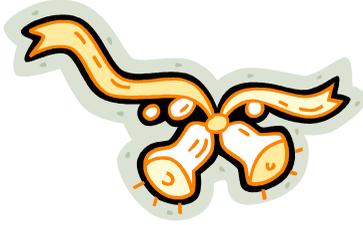
If you can help us, in whatever way please contact the office on 01235 816310.

Devizes Round Table

Last year Friends of O.S.C.A.R was chosen as the charity of choice by Paul Holmes Chair of Devizes Round Table. Back in November Paul and his team organised their annual firework display in Devizes. Despite it being a very wet night they raised a huge £1560.00. Paul presented Friends of O.S.C.A.R with the cheque at the Randolph Hotel after the pantomime. The money will go towards providing activities at the adolescent weekend in May. We would like to say a very big thank you to Paul and all the members of Devizes Round Table for raising the money.



Pictured above are Paul Holmes (on the left of the picture) Chair of Devizes Round Table, presenting cheques to Peter Harrison and Friends of O.S.C.A.R families at the Randolph Hotel after the pantomime.



Congratulations To:

Becky Clifford who got married on the 6th April to Ollie Graham. Many of you will know Becky who is a Play Specialist in the Children's Hospital and a volunteer at the adolescent weekends. Congratulations and may you have a very long and happy life together from everyone at Friends of O.S.C.A.R



We are also like to say congratulations to James Harrison and Simon Cruden who have both been selected to be Olympic Torch Bearers. They will be running through Kidlington and Bicester respectively on the 9th July. Have a great day both of you.

Future Fund Raising Events:

On the 13th May we are having a stall at the Wallingford Car Rally. If the weather is good they normally have around 2000 people attend this event. If anyone has an hour to spare and would like to help, please contact the office on 01235 816310. We have also been invited to have a stall at the Banbury Canal Day which is on Sunday 7th October. Again if anyone would like to do this please let me know. There is also the golf day in aid of O.S.C.A.R as previously mentioned if you would like to take part in this please contact Carol on the above number.

Contact Details

We have had a number of problems recently where families have moved or changed phone number without letting us know and then contacting us to find out why they have not had information sent to them. If you change any of your contact details including email and mobile number please let us know. Even if you don't wish to continue receiving information we can then take you off our contact list. A quick email to let us know change of details is fine. Our contact information is:

Friends of O.S.C.A.R
5 Abingdon Road,
Didcot,
Oxon, OX11 9BL

Phone Number: 01235 816310
Email: carolharrison@utdsl.com

Travel Insurance

This seems to be a problem year round for families we are still keen for you to try Freedom Insurance as they pay us a commission on all policy's sold. Please quote O.S.C.A.R when you phone.

Medi Quote Telephone **0845 8800163**

Essential Travel Telephone **08707353600**

All Clear Travel Insurance. Telephone **08707779339**,
Website **www.allcleartravel.co.uk**

Freedom Travel Insurance. Telephone **08707743760**,
Website **www.freedominsure.co.uk**

Insure and Go. Telephone **08448882787**,
Website **www.insureandgo.com**

One word of advice from a family that has recently been trying to obtain travel insurance please double check all the information given to the company go through it twice if need be. They did find that the information given was not taken down correctly the first time.

If you are having difficulty finding travel insurance please contact the office as I have just been sent a new list of insurers.