

Leicestershire Down's Syndrome Group

Friendship



Fun Family

Leicestershire
Down's
Syndrome
Group

www.leicesterdownsgroup.co.uk



Affiliated to the
Down's Syndrome
Association

Up, Up and Away

Awareness Week
Balloon Release



LDSG Chair's Report

Michal Hardy, March 2011

We held our AGM in March this year and our Chairperson, Michal, gave this report on what we have been doing in 2010.

LDSG has a membership of in excess of 160 members, and it's with great sadness that I have to report that three weeks ago one of our younger members, Jack Adcock, sadly died.

The committee have sent flowers and a condolence card to the family, and I feel it would be appropriate for us to take a moment's silence to remember Jack, and particularly his family, his parents Nicola and Vic, and his sister Ruby.

As you will know 'Downs Syndrome Awareness Week' is almost with us and runs from the 21st to the 27th March. To mark the occasion we are planning a balloon release on Sunday 27th March to take place at Victoria Park ... The committee feel that this occasion would be a good event to mark Jack's memory, by releasing balloons in his favourite colour.

Over the past year your committee have worked hard in raising money, and arranging outings and activities, at least one per month over the past year.

I would like to thank all members of the committee, for their dedicated support and time that they have given over the past year.

This year a number of our long serving members are standing down from the committee. Their experience and dedication has been key to the success of the group over a number of years, long before I was involved. They will be sorely missed!

As you will see from the Treasurers report ... we have again been successful in attracting considerable grants from various organisations, which have really enabled us to have a full programme of events and activities. With a special thanks to Lynne who worked so hard to secure these grants.

The year started with a trip to the cinema, we've had two discos, attended by members ranging in age from a few years to 55 years. A trip to Drayton Manor Park (despite the football event taking place) was enjoyed by over a hundred family members.

A sports day was held at Brockington College where members were able to sample a range of sports. Also a late summer picnic was held at Stonehurst Family Farm.



Again the Christmas Fayre took place at Wigston in early November, and particular thanks to Shirley who has organised this over a good number of years.

Whilst this winter we really didn't need to go indoors to sample snow, a good number of members and their families attended the Snow Dome at Tamworth in November.

At Christmas all members were given a £10 gift voucher, which they were able to spend at Argos, and the year ended with a trip to the pantomime at Loughborough Town Hall, where we saw Cinderella.

A number of Friendship n' Fun activities took place throughout the year, targeted at specific ages. For example soft play, ten-pin bowling, swimming, 'Go Kids Go'. And of course the Friday coffee mornings have continued throughout the year.

So for the following year, we are planning to continue this level of activity but we can't do it without your help.

In addition to the activity you do see, there's plenty of work behind the scenes that you don't. The committee have sorted out several items over the last year -

A child protection policy has been developed

A code of Conduct for the committee members

Risk assessments for every activity that we undertake

Our thanks go to Victoria for maintenance and development of the Database and web site. Also the newsletter, special thanks to Angela, and please keep your contributions coming. The information leaflet for new parents is still in circulation.

In addition we also continue to fund - *Speech and language therapy*

We part fund hobbies or activities for your children and adults.

We provide a one off £100 grant to mainstream schools that take our children

A number of parents from the group attend De-Montfort University listening scheme. This is a really valuable activity where we speak to the student doctors, nurses, social workers, midwives, pharmacists, and now teachers.

As you can see your committee have been very active over the last year, we all owe them a debt of gratitude. Thank you to all of you, and particularly those that have served for such a long time - Judy, Teresa, Gill, Phil, Lynne, Angela and Simon.

Treasurer's Report - End of Year 2010

Dawn McIntyre

Bank Statement 31/12/10	9,356.61	Incorrectly recorded expenditure	
Unpresented cheques		101206 (0.61)	cash bk 145.10, bank 145.71
101268 29.62		101208 (40.00)	cash bk 240.00, bank 280.00
101270 29.62		101233 6.00	cash bk 98.82, bank 92.82
101272 20.00		101234 0.50	cash bk 255.50, bank 255.00
101274 110.99		101239 (821.50)	cash bk 255.50, bank 1,077.00
101275 48.00		101240 (183.39)	cash bk 114.56, bank 297.95
101276 18.00		101251 (9.00)	cash bk 323.73, bank 332.73
101279 32.80	(289.03)	101256 10.00	cash bk 150.00, bank 140.00
	<u>9,067.58</u>	101257 63.00	cash bk 400.00, bank 337.00
Cash book balance 31/12/10	10,834.77	101259 80.00	cash bk 1,600.00, bank 1,520.00
Nov balance 6850.70 not 8416.44	(1,565.74)	INCOME	
Sept - addition error	(39.75)	Differences in banking recorded and amount on statement	
Adjusted cash book balance 31/12/10	<u>9,229.28</u>	20/09/2010 30.00	cash bk 151.25, bank 181.25
Income banked but not in cash book		October (5.00)	cash bk 876.00, bank 871.00 - (817.00 + 54.00)
28/01/2010	269.90	08/11/2010 1.00	cash bk 1,414.00, bank 1,415.00
Lost cheques still in cash book		In cash book but not on statement	
101190 20.00		29/11/10 (183.85)	
101191 142.50		On statement not in cash book	
101253 56.50		30/11/10 204.25	
101254 21.00		8/11/10 109.00	
		12/07/10 <u>68.00</u>	
		9,067.58	

For your information

Policy for part-funding of activities/hobbies, Speech Therapy sessions and the School Grant

One aim of the Leicestershire Down's Syndrome Group (LDSG) is to support individuals with Down's Syndrome to pursue activities and hobbies, by part-funding them.

This policy aims to provide some guidance to ensure clarity on -

- What type of activities can be supported and details of the school grant
- How members of the group are made aware of this support
- What level of funding is available per year
- What the process is for accessing the funding

This is to ensure transparency and equity within the aims of the LDSG, and so ensure compliance with the Charities Commission.

Activities/Grant details

Activities and hobbies that have been supported include various sporting and other interests including swimming, horse riding, trampolining and dancing. It is envisaged that any activity that an individual would like to pursue will be looked upon favourably. Each individual will be able to access £100 per financial year.

To support language development the group offer to half-fund regular speech therapy sessions with a nominated therapist. The hour long sessions take place six weekly, and there are approximately 5 sessions a year. These currently cost £40 - £20 from the member, and £20 from LDSG.

If your child is in full time mainstream education the group can provide your child with a £200 educational grant. This grant is to be used for something to aid in your child's education, such as books, equipment or staff training. If your child goes into mainstream secondary education then another £200 grant will be available.

Communication

All current members will be written to with details of these schemes, as will new members as part of the welcome information.

There will be a yearly reminder in the newsletter and it will be advertised on our website.

The process

For hobbies and the educational grant, please send receipts including details of the hobby or school and what has been purchased, to the **Treasurer** at 50 Link Road, Anstey, LE7 7BW. The money will be refunded to you. For speech therapy you will be sent a request for funds after each session.

Jack - a celebration

by Nicola, Jack's Mum

Our gorgeous little man with that cheeky smile, and cheeky ways no one will ever forget. Jack broke so many hearts wherever he went, he was like a magnet, everyone loved him.

Jack loved life, and life loved Jack.

He loved books, dancing, music, food, dvds like Toy Story, the Gruffalo and the Wiggles.

He saw the Gruffalo at John Lewis, and then we went to De Montfort Hall to see it, and he loved it every time. He enjoyed going to see shows there and at the Curve, and last May Jack went to Birmingham to see the Wiggles. He knew every song and would sing and dance.

He enjoyed playing football with his friends and cousins. He used to go to watch LCFC with his dad every home game. Jack and his Dad had season tickets. He loved his jeep and motorbike, which he had a lot of fun on.

Jack had just swum a full length on his back, and got his 25 meters badge. We were so proud, and so was Jack. He loved jumping into the pool and he was great at diving.

He loved school, and was everyone's friend. Jack loved discos and was invited to every party at school - Mr Popular we used to call him, and he used to enjoy having his friends round for tea every monday after school.

We had just made the biggest decision we'd ever had to make - Jack was going to move from mainstream to special school for year 3, this September, 2011.

Jack went to Euro Disney with Wishes For Kids in November 2010, and had the time of his life. He loved all the characters. We were all able to go with him, his Mum Dad and sister.

Jack loved his little sister, Ruby. He used to pinch her toys and wind her up, so she would chase him around the room - she misses him lots.

Jack was always smiling and happy.

He loved animals, and he was so gentle with all his pets - a dog called Becks, a rabbit called Buggy and a goldfish. Jack loved farm parks, and enjoyed stroking and feeding all the animals, especially the pigs.

He had so much fun and experienced so much in life with the help of LDSG, and we thank you so much for that.

We miss him so so much. I'm sure he would have still been here given the correct treatment. Our life is empty, painful and horrible without Jack, and it will never be the same again.

He was an amazing son, such a special little boy who was one in a million.



Balloon Release

Awareness Week

LDSG took over a corner of Victoria Park to mark Down's Syndrome Awareness Week in March, with a colourful Balloon Launch of 500 yellow and blue balloons.

As blue was his favourite colour we chose those to represent Jack, and they were a lovely sight as they soared away up into the sky.

But there was lots more going on than just the balloons. We had entertainers, henna and face painting, hot and cold food stalls and acres of cup cakes!

It was a relaxed and informal atmosphere, and it was good to offer families the chance to make contact with us, who might find it difficult to do so otherwise.

The Awareness Week is about raising the profile of Down's Syndrome and LDSG in our communities, and we did just that in a fun and enjoyable way.



Golf Day

Just for Jack

Oliver Donaghue and Tim Miller of **Hinton Groundworks** held a golf day at Cold Ashby Golf Club on May 13th this year, and succeeded in collecting £1600 for LDSG.

The golf day was held in memory of Jack, and the winner took away the 'Jack Adcock Memorial Cup'. This trophy will be presented to the winner of a golf day each year.

Many thanks to the sponsors of the event for making this golf day possible, in memory of a wonderful boy.



Fish n' Chips

... and mushy peas

We all remember a lovely evening's treat the group enjoyed a while ago, and we decided to do it all over again.

What better way to get together than a summer evening at **Grimbsy Fisheries**, munching our way through a Fish n' Chip supper. Not forgetting the lashings of squash and bowls of ice cream to finish off.

Quite a few full tummies after that, and very happy faces all round.

This is likely to become a regular feature of our events diary, and we'd like to say a big thank you to all the staff who welcome us to their restaurant.



Support Group

The Friday Group is moving on

The monthly group is on the move to a new venue at **St Saviours Sure Start Centre** in Leicester, and as Friday seems a difficult day for a lot of our members to get together, we are changing to Thursdays for our once monthly meetings.

Flyers will be sent to all our members with full details of where and when the Support Group will be meeting.

Further information is available on tel. 07757 800312 or e.mail info@leicesterdownsgroup.co.uk

All family members are welcome, and we'd love to meet you there.

Speak Up!

For Babies

Speak Up! Is launching a weekly term time communication support and signing group, on Thursday mornings for babies up to 18 months, in November 2011.

Contact **Su Carr** 0116 2388368 or **Helen** 0116 2251353 for more details.

Leicestershire Down Syndrome Monthly Support Group

We are on the move.

Starting from Thursday 7th July 10am until 12pm.

Our new venue will be

St Saviours Sure Start Centre
10 St Saviours Road,
Leicester.
LE5 3GE.

Tel: 0116 2211774

The support group will run on the following dates:

Thursday 4th August 1pm until 3pm
Thursday 8th September 10am until 12pm
Thursday 6th October 10am until 12pm
Thursday 3rd November 10am until 12pm
Thursday 1st December 10am until 12pm

Come along and join us, meet for a chat, share experiences.

We offer support to all family members and would love to meet you.

If you would like any further information then please call 07757 800312 or email info@leicesterdownsgroup.co.uk

Coffee Mornings

Or tea if you'd prefer.

One of our members, Judy Warner, holds an informal Coffee Morning for parents/carers of members who are in the 16+ age group.

They meet up one thursday each month, at Abbey Sports & Leisure, Slater Street, Leicester, from 11.00am to 1.00pm, sometimes until later.



All sorts of issues are raised and information passed on whilst enjoying a coffee and a chat, and if you want lunch you can buy delicious sandwiches from the centre.

We recognise that there can be difficult times for all sorts of reasons and it helps to chat to other parents/carers in similar situations.

All sorts of information is exchanged, from transition from school to college, changes in benefits, relationships regarding our young people, in fact all sorts of issues.

If you are interested in joining Judy and would like more information please contact her on tel.no. 07910 722712.

Too much paper?

Electronic mailing

In order to reduce our costs for postage and stationary, we are now starting to send our invites and information via e-mail wherever possible.

E-mails will come from the following address info@leicesterdownsgroup.co.uk

Please make sure that we hold the correct details for you, in order to receive all the most up to date information.

If you haven't heard from us for a while please check your spam folder, or check that we have your correct e-mail address.

You can send your details to us at the address above or telephone 07757800312.

What do you think?

Give us your views on what we do

Please tell us your views on the Leicestershire Down's Syndrome Group and what we do, by filling out a questionnaire which will be sent out shortly.

We offer a range of activities for our members and are always looking to include new things. We would like to know your thoughts on what kinds of events and activities we could offer, and whether we could improve access to our activities.

How we can get the right balance of Family activities, and Friendship n' Fun events (which offer the person with Downs Syndrome the opportunity to spend time with their peer groups).

We are updating our website shortly, and would like to know how we can make it more effective. Is there anything else we could use it for?

Currently we concentrate on running events for our members, help fund hobbies and speech therapy and provide an educational grant. Are there other things you think we should do instead?

You can also complete the online survey at <http://www.surveymonkey.com/s/ZY5DPZ3>

Please find time to help LDSG by filling out the questionnaire and giving us your views.



What's On ...

Up and coming events to look out for

Please remember the person with Down's Syndrome should be accompanied to all events by a parent or carer.

SUPPORT GROUP

Thursdays from 7th July, 2011

10am - 12pm

ST SAVIOURS SURE START CENTRE
10 ST SAVIOURS RD, LEICESTER LE5 3GE
0116 2211774

DRAYTON MANOR

24th July 2011

TAMWORTH
STAFFORDSHIRE B78 3SA

PICNIC AT THE FARM

11th September, 2011

STONEHURST FAMILY FARM
MOUNTSORREL, LEICESTERSHIRE

SOFT PLAY

September, 2011

Under 5's

Details to be announced

OUTDOOR PURSUITS

October, 2011

Friendship n' Fun 11-16 & 16+ groups

Details to be announced

SWIMMING

October, 2011

Details to be announced

DON'T FORGET

To check out our website for the latest information on events -

www.leicesterdownsgroup.co.uk

Committee Members

and other contacts

LEICESTERSHIRE DOWN'S SYNDROME GROUP

www.leicesterdownsgroup.co.uk

Tel: (Voice mail only) **07757 800312**

Chairperson

MICHAL HARDY

Vice Chairperson

VICTORIA BOWEN

Secretary

(UNFILLED)

Treasurer

DAWN MCINTYRE

50 Link Rd
Anstey
Leicestershire LE7 7BW
0116 2368133

E-mail Controller

JILLY HUMPHRY

Health & Safety

LUKE FEATHERS

Fundraising

SARAH BASSETT

Committee Members

FERDOZ AMOD

RICHARD BLACKMAN

LEENA CHANDE

PAM HAMMOND

CLAIRE TONG

Newsletter

ANGELA SHELDON

Christmas Fayre

SHIRLEY WILLS

0116 2811401

National Office

DOWN'S SYNDROME ASSOCIATION

Langdon Down Centre
2A Langdon Park
Teddington, Middlesex TW11 9PS
0845 2300372/020 86145100

Down's Heart Group

SARAH SMITH

17 Tyers Close, Thurlaston
Leicestershire LE9 7TW
01455 888344

Website Host

SPECNET LTD.

Unit 9, Hill Top Works, Earl Shilton
Leicestershire LE9 7DP
01455 447928