

RACE NIGHT

ST. ANTHONY OF PADUA SOCIAL CLUB
MOSSLEY HILL
LIVERPOOL 18

SATURDAY 6TH MARCH 2010

7.30PM

TICKETS £3

RAFFLE

AUCTION

LATE BAR

PLEASE CONTACT THE SECRETARY ASAP FOR YOUR TICKETS

Telephone: 0151 427 2699 or email anne.wilde1@btinternet.com



contact us

W www.downsyndromeliverpool.org.uk

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📄 Down Syndrome Liverpool, PO Box 1,
Mossley Hill District Office, Liverpool L18 4SD

downtime



Melanie C supports local mum in successful fundraising night for Down's Syndrome Association

Local Widnes mum Nicola Houghton, hosted a fundraising night at The Widnes Vikings Stadium on Saturday 6th February in aid of The Down's Syndrome Association and raised an impressive £1889.00, bringing the total raised so far at £4847.00.

Nicola is currently in training for the vigorous challenge she has set for herself of trekking across The Great Wall of China at the beginning of April 2010. Her six year old daughter Jessica is her inspiration for the China Trek and has Down's syndrome herself.

The night was a huge success and guests enjoyed dancing the night away to live music from River Deep, whom Mel C's mum

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www.downsyndromeliverpool.org.uk

Registered Charity No. 1097276

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• Father Christmas enjoyed his time with our children so much he promised to come back next year to visit us

Christmas fun with DSL

Over the Christmas period we held three events for our members, the first being our Annual Christmas Party on Saturday, December 5th at St Anthony of Padua Social Club.

The party as always was very well attended and hopefully everyone managed to get a seat. The buffet was delicious, everyone enjoyed themselves and there was the usual excitement when Father Christmas arrived. It was great to see the children's faces as they tore open their presents. Father Christmas mentioned to me that he really enjoyed our party and would love to visit us again next year!

A big thank you to Eliza for the buffet and to Sandra and her staff who always make us feel so welcome.

We only just had time to clear up and get ready for the next day, as on Sunday, 6th December many of our families boarded the Polar Express courtesy of Merseyrail.

What a wonderful day we all had. The children were handed their packed lunch as they boarded the train and had an array of beautifully decorated carriages to visit.

"it was great to see the children's faces as they tore open the presents"

You could dance and sing in the X-Factor carriage, be a prince or princess in the Disney carriage or be amongst the animals in the Jungle Book carriage.

We were entertained by magicians, balloon artistes, face

painters and a DJ. The children danced, sang, laughed and even got to have their picture taken with Father Christmas. People looked on amazed as our train went through the stations.

Thank you Merseyrail it was a truly magical day.

We had a few days rest before holding our bowling night on Friday, 11th December. This event

was for teenagers and older people with Down's syndrome and their families. It was a really good evening, you could hear happy shouts of "strike"

and groans when the ball did not quite connect with the skittle.

Everyone enjoyed a buffet and two games of bowling it was also a chance for the youngsters to catch up and chat to each other.

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Welcome to the first Downtime issue of 2010, since our last newsletter Down Syndrome Liverpool has been very busy.

We had a very successful event at The Yellow Sub in October, this is now becoming very popular with an increasing number of families attending. It is one of the few places you can get something for all age ranges - yes even the adults joined in.

We held our AGM in November of 2009 which was well attended and I am pleased to say that we now have a full compliment of Trustees.

Tots to Teens provided the entertainment at the Halloween party which took place after the AGM all of the children attending had a really good time and there were a number of very scary costumes on display!

At the AGM one of our members raised the issue of re-applying for the Disability Blue Badge Scheme. The rules have

changed and this has caused problems for some families re-applying to the Scheme. This is down to how some GP's are interpreting the new rules.

Both myself and my (newly installed) co-Chair George Whitton attended a Local Authority Select Committee to put forward the case that children and young people who have Down's syndrome have a range of needs that should entitle them to the Blue Badge. We were given a good hearing and there was a fair bit of debate. The result is that the PCT responsible for GP training in Liverpool will be asked to consider and incorporate our position into their GP Training regime.

Christmas is always a busy time for us here at DSL and this year was no different. Once more we organised the annual Christmas party, a very big thank you to all of those involved, it does take time and commitment to deliver what is a sizeable event.

Also in the weeks leading up to Christmas we had our ever popular Bowling Night designed for young people and their families. This took place at Hollywood Bowl, Edge Lane and once again it proved to be a really good night out.

Alongside these Christmas celebrations we had the opportunity to collect at Liverpool's Central Station as part of our year-long partnership with Merseyrail, despite awful weather we had a great response from our members to collect donations - a sincere thanks to everyone who braved the cold.

Merseyrail also provided a fantastic occasion inviting us to take our places on The Polar Express, I received very positive feedback from a large number of families who went on the trip.

A very big thanks once again to Sally Ralston and her colleagues from Merseyrail for organising this event.

Sadly our partnership with Merseyrail has come to an end, it has meant a huge boost to DSL as we are still counting but the total sum raised which stands at over £25,000.00!! This also brings a great responsibility to use those funds wisely, nor can we rest on this but rather use it as a platform to continue with our fund raising in order to provide the range of support and activities DSL has developed over the last two years.

As I write this we are preparing for our Charity Race Night on March 6th, maybe this time I'll hit a winning streak! Well you can but live in hope!

Thanks to all my fellow trustees for their commitment and hard work over the last several months and to those of our wider membership who gave of their time and energy during the Christmas period to make all of the above possible.

John Hogan

Fundraising mum nears £5000 mark



• River Deep performing at Nicola Houghton's fundraising evening at Widnes Vikings' Stobart Stadium.

• From page 1

is the lead singer, and the disco was provided by Broadway Entertainment. There was a bountiful of raffle prizes to be won including a top prize of two West End Musical tickets for Blood Brothers, donated by Melanie C with a meet and greet of the former Spice Girl.

Other prizes included VIP hospitality tickets for The British Touring Car Championship at Oulton Park, donated by Mel C's race car driver brother Paul O'Neill and a meal for two at 3345, Parr Street, Liverpool.

Jessica attends Oakfield Primary School, Widnes who raised £62.00 when they had a

non-uniform day, a special thanks to Headmaster Mr Moss, school staff, parents and Jessica's school friends.

Nicola is walking the Great Wall of China to raise awareness of Down's syndrome and challenge negative stereotypical views society still holds about those with Down's syndrome.



• Fun on Merseyrail's Polar Express

Festivities a big hit with members

• From page 1

Thank you to the staff at Hollywood Bowl and especially Jenny who organised the event and made sure we were all looked after.

Over the Christmas period we had a chance to collect at Liverpool's Central Station, a big thank you to everyone who gave up their time and braved the freezing cold. We collected a total of £585. Thanks for your help it was really appreciated.

Margaret Hogan



DSL challenge Liverpool City Council after members' problems with blue badge scheme

Following on from my comments in the Chair's Report this outlines in a bit more detail what George Whitton and I presented to the Local Authority Select Committee on January 12th this year.

After the AGM I contacted Councillor Jane Corbett Chair of the Select Committee on Education and Skills. Jane's advice was to ask a public question of the Committee and assured us that she would have it on the agenda. I would like to thank her for her help in this matter.

Public Question - Education and Skills Select Committee.

Down Syndrome Liverpool.

My name is John Hogan I am currently Chair of Down Syndrome Liverpool a local parent/carer led registered charity.

The aim of DSL is to support families affected by Down's syndrome and to enhance the lives of those who have the condition. Currently DSL has over 100 members in Liverpool.

Disabled blue badge scheme - children and young people who have Down's syndrome

I have recently been approached by members who have had problems either getting a disabled driver blue badge for their child/young person or failing to have their badge renewed.

It would seem this is due to the guidelines issued to local authorities setting out the criteria whereby blue badges can be issued.

The problem identified by those I have spoken to is the emphasis on physical impairment in the guidance to GP's who are asked to complete the form needed by those requesting/renewing their blue badge.

One family in particular has had a really distressing experience with their local GP, in the way he has interpreted this guidance.

As I understand it, if someone is in receipt of the higher rate of Disability Living Allowance the issue of a blue badge is automatic. However for those on the lower rate, and this includes many children and young people with Down's syndrome, a doctor needs to complete a form issued by the Local Authority highlighting the nature of the applicant's impairment and how this

prevents walking a certain distance unaided. This form gives little space for the referencing of a severe learning disability as a reason for the issue of a blue badge.

For children and young people who have Down's syndrome, it may well be the case that there is no 'physical' impairment that would prevent them walking 50 meters.

However the nature of their learning disability means that they might often stop and sit down if required to walk any distance (not a pleasant experience trying to move a 10 year old who decides to do this), they also have very little sense of danger in relation to road safety, having the blue badge has meant a real reduction in the stress levels of children and parents and, the enhanced safety of children.

Unfortunately there is no space on the current form to reference a severe learning disability as a valid criteria for getting a blue badge, and in the case I mentioned above regarding the GP, it was explicitly stated by the GP that he could not do so, the family lost their badge.

Every Child Matters/Liverpool Children's Plan

Liverpool City Council's Children's Plan has highlighted disabled children as a group in particular need of support from the Local Authority in relation to meeting the five Every Child Matters outcomes, in relation to the above I would suggest giving parents and children the opportunity to access the disabled blue badge promotes both the health and well being of the child and their safety.

Public Question

On behalf of Down Syndrome Liverpool, my question to the Education and Skills Select Committee is this:

Can the Education and Skills Select Committee support guidance being given to local GP's in the City of Liverpool that enables them to take account of a severe learning disability such as Down's syndrome when considering an assessment request on behalf of a child applying for the disabled blue badge scheme?

Thank You

John Hogan
Chair
Down Syndrome Liverpool.

DSL and Archbishop Blanch join to deliver training for teachers teaching children who have Down syndrome

Down Syndrome Liverpool has agreed to partner Archbishop Blanch School in delivering training to teachers from Liverpool schools who will be working with pupils who have Down Syndrome in their classes during the 2010 - 2011 school year.

Archbishop Blanch has responsibility for a budget that is earmarked to develop teacher skills in the city, and has proposed that some of this budget is spent enhancing the skills of teachers who will be teaching pupils with Down syndrome.



DSL has had some initial discussion with Archbishop Blanche around a possible programme for this training and has liaised with the Down Syndrome Association to deliver the training. The date set for this event is June 9th 2010.

We are letting our members know about this as early as possible. We will keep you informed and when we have more details of the training programme we will ask you to inform your child's school of the event and ask that you encourage your child's SENCO/teacher to come to this training.

There will be more detail in our next edition of Downtime and our new Facebook group.

John Hogan

Calling all budding photographers!

My Perspective is proud to be a part of the hugely successful Shifting Perspectives supported by GlaxoSmithKline.

For the past five years, we have been showcasing work from a fantastic collection of photographers who all have a personal link with Down's syndrome. Recently the DSA has been approached by a number of photographers with Down's syndrome which has given us the idea to start My Perspective. It's now YOUR turn to demonstrate your photography skills.



The Down's Syndrome Association is pleased to announce the launch of My Perspective - the first ever photography competition for people with Down's syndrome!



We are looking for you to send us images of your friends, family, pets, places you've visited or anything else that interests you!

Winning entries will be announced at an exclusive awards ceremony in June at a secret location in London. Prizes will be awarded to the winner and two runners up, with ten special highly commended prizes.

The winning entries will be displayed at the Proud Gallery, Camden later in the year and the winning image will become

a permanent part of the Shifting Perspectives touring exhibition.

The submitted images, up to three per person, will be judged by a panel of professionals and all those shortlisted will be notified by 14th May 2010.

Images need to be sent to the following address by Friday 16th April 2010:

My Perspective
Down's Syndrome Association
Langdon Down Centre
2a Langdon Park
Teddington
TW11 9PS

or emailed to:
myperspective@downs-syndrome.org.uk

You can either download and complete an entry form from the DSA website and submit along with your image/s.

Or you can fill in the form and enter online (www.downs-syndrome.org.uk). Make sure to have your photos ready to upload.

Please note that any images received after the deadline will not be entered into the competition. Unfortunately, images cannot be returned unless sufficient postage is included.

For a full set of the rules and terms and conditions of the competition, please visit www.downs-syndrome.org.uk

Fire Support
The Safe at Home safety equipment scheme is an initiative to help families keep their children safe from accidents in the home.

FREE safety equipment on offer to families include:

- Safety Gates
- Window Restrictors
- Fire Guards
- Locks for Cupboards
- Corner Cushions
- Smoke Alarms

FREE supply and fitting by a fully trained professional FREE of charge.

In order for families to be eligible for this FREE service they must be in receipt of any of the following:

- Income Support
- Job Seekers Allowance (Income Based)
- Income based and employment allowance
- Tax credits AND a valid NHS tax exemption certificate
- Disability Living Allowance
- Housing Benefit
- Council Tax Benefit

Anybody that would like to sign up to the scheme will need to visit their local SureStart Children's Centre.

Liverpool SureStart Children's Centres

Albion SureStart Children's Centre 100-102 Albion Street Liverpool L3 1AA Tel: 0151 236 1111	Albion SureStart Children's Centre 100-102 Albion Street Liverpool L3 1AA Tel: 0151 236 1111	Albion SureStart Children's Centre 100-102 Albion Street Liverpool L3 1AA Tel: 0151 236 1111
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Inclusion and equity helps us to see the child rather than the condition

The following thought provoking article is reproduced from Bradford Down Syndrome Training and Support Service

INCLUSION

How we refer to children affects the way they are perceived. By talking about "children with Down syndrome" or "children with a learning disability" rather than a "Down's child", "Down syndrome child" or a "learning disabled child" helps us to see the child rather than the condition. All children are children first and foremost, whatever their ability. Using positive language influences attitudes. People's attitudes and their willingness to accept children and people, whatever their ability is crucial to inclusion.

Through the years there have been many words used to label children with Down syndrome - all negative. In some schools in Ontario, Canada, where children of all abilities have been included in mainstream schools since 1969, terminology is very positive. Any child who needs a modified curriculum, whether because they are gifted or have a learning disability are referred to as EXCEPTIONAL because they are the exception to the

typical child. This is a wonderfully positive term that does not distinguish between abilities and promotes a positive attitude.

Inclusion comes down to ATTITUDE, to be able to think outside the box, to be open to new ideas and change, to be flexible and ready to modify. Attitude is key. It can be a barrier to good inclusion or it can be a driving force that makes inclusion work.

People's attitudes and their willingness to accept children and people, whatever their ability is crucial to inclusion

EQUITY

The meaning of the word inclusion can often be misunderstood resulting in practice that is not really fully inclusive. For example, a child being treated just the same as all

of the other children in class because he/she is part of the class and therefore must be seen to be dealt with/spoken to the same as you would the other pupils. This can sometimes lead to exclusion. What is happening is that the child is being treated "equally the same" as his/her mainstream peers. Treating a child equally does not necessarily result in good inclusion.

Equity is a word that is now being used instead of inclusion. Equity means treating everyone fairly and according to their

To illustrate: imagine a plasterer making an uneven surface even by spreading plaster over it. We can compare the uneven surface to the varying needs of the children in the classroom; some have greater needs than others. The "plaster" is the input needed to make the surface level and smooth, and the act of "spreading" by the "plasterer" can be compared to the challenge faced by the teaching staff and pupils in the school. The "input" must be spread in order to make everyone equal. Some pupils will need much more than others if the surface is to be smooth and level.

This is NOT the same as treating everyone equally - something that can happen when inclusion is misunderstood. In fact using the analogy above the result would be the creation of another uneven surface.

Good equity leading to smooth, beneficial and productive inclusion requires flexibility and a willingness to think and act outside the box. Sometimes it may be necessary to change longstanding rules. There is always a solution, always a way to include a child; equity and flexibility is key.

needs. Some children have greater needs than others and thus need more input, a modified or differentiated resources and/or curriculum.

Equity is the act of making everyone equal.

Liverpool Children's Services consultation questionnaire

Some of our membership who have chosen to have their e-mail details registered with DSL will have received a questionnaire from us on behalf of Liverpool Children's Services, regarding childcare in Liverpool, this is just a reminder to send this back to the Local Authority as soon as possible.

For those of you who haven't registered your details with us the following explains what the questionnaire is about.

Local Authorities have a duty, under The Childcare Act 2006, to undertake an annual assessment of childcare and to provide impartial information and advice to parents and carers seeking childcare, and to people interested in working in childcare (childcare can be full day care provided by a day nursery or childminder, before and after school clubs and holiday care etc).

One key responsibility is to ensure enough childcare is available to parents who wish to work, train or are in education. This childcare needs to be of good quality, flexible and respond to parents' needs, be sustainable in the long-term, and be sufficient - which in simple terms means there is enough, but not too much, to meet the demand.

We need you as parents, carers and families to tell us how we can improve services for children who have a special educational need or disability, and to help us to shape the childcare that you may need to suit your needs.

If you would like to know more about this and if you do not have an e-mail address contact: Jeff Kendall Childcare Sufficiency Assessment and Consultation Officer on 0151 225 6277 or email: jeff.kendall@liverpool.gov.uk

What will you be doing to mark World Down Syndrome Day?



March 21st 2010 was chosen by Down Syndrome International (DSI www.ds-int.org) to mark World Down Syndrome Day (WSDS www.worlddownsyndromeday.org) with the inaugural day being launched in Singapore in 2006.

The date (21st day of 3rd month) was chosen to signify the uniqueness of Down syndrome in the triplication (trisomy) of the 21st chromosome.

Together let's make March 21st a worldwide celebration. If you can't do anything else, please wear blue & yellow to show your support and spread awareness!

If you are planning an event of any type, please join the WSDS Facebook group and post details there so that everyone can see how much is going on and items can be added to World Down Syndrome Day website.

DSL trustee visits Dublin for 10th World Down Syndrome Congress



Down Syndrome Liverpool Trustee George Whitton was lucky enough to be able to attend the 10th World Down Syndrome Congress held at the City University in Dublin.

This was a four day conference covering topics from toilet training to bullying to independent living for adults with Down syndrome.

The congress consisted of many parts running side by side, firstly there was the Down Syndrome Medical Interests Group (DSMIG) which is a group of doctors that meet several times each year and share their experiences and research results to try and forward our knowledge and understanding of the condition.

There was also a programme organised for the adults with Down syndrome to encourage international relationships so they could share experiences and discuss issues that were important to them. I can't say much about this as us mere mortals weren't allowed anywhere near!

Also there were activities laid on for young people with Down syndrome and their siblings, such as football training at Croque Park and a trip to the Guinness factory, where I think the parents had quite a good time.

The congress was opened by Down Syndrome Ireland, one of the first speakers was the Down Syndrome International president, Penny Robertson, and her daughter who opened with

the line "my mum always talks about Down syndrome, I think she should be Down syndrome". This really set the tone for the congress, one of an open, friendly community come together to share information and experiences.

From the first few talks the theme of the congress became clear, our children/brothers/sisters/friends can achieve anything they want as long as they have our support

and love, but more than this though, like any child, they need us to expect them to achieve. Like any child they need us to let them take risks and push the boundaries, because however scary this might be, if we don't they will not achieve their full potential.

This was beautifully demonstrated over the weekend by many people with Down syndrome displaying their achievements for us all to see.

There was a 14 year old boy who during a presentation came on stage in front of over 1000 people and played the violin beautifully. There were presentations given by adults who had been to university and lived in shared accommodation and fully embraced university life. This could only be achieved if they and the people around them truly believed this could be done.

At the closing ceremony Ireland handed over to South Africa, where the next congress will be held in 2012, the presentation was given by a man with DS in perfect English despite the fact this was his second language.

There was so much information shared over the weekend that I am still trying to digest it months later. If I tried to include the information in this article, I'm not sure we could afford the printing costs. I have included a list of the useful websites that were mentioned at the congress and I am more than willing to chat to anyone who would like to find out more.

In this brief summary of my time in Dublin I really wanted to get across the awe I was in just watching such competent young people and adults dealing with their disability and really wearing it as a badge of honour.

I also wanted to express how important it is for us to believe in our children and also demand that others do and not put up with second best for them as they deserve so much more than this.

'my mum always talks about Down syndrome, I think she should be Down syndrome'

Useful websites

www.downsyndromeliverpool.org.uk

This is our own website full of pictures and information and a copy of the newsletter.

www.specialfriendsonline.com

Social networking site, along the lines of facebook, for people with additional needs, parents and carers.

www.ds-int.org

The website of Down Syndrome International

www.downs-syndrome.org.uk

The national down syndrome association that has lots of information and advice on many topic areas.

www.dsmig.org.uk

This is the website for the down syndrome medical interests group and contains advice, book reviews and guidelines they have produced.



2010 marks DSA's 40th anniversary of providing help for people with Down's syndrome.

Back in 1970 the Down's Syndrome Association started as a small support group of parents helping other parents.

During the past 40 years they have grown into a highly respected national charity covering ALL aspects of living with Down's syndrome. Still at the core of everything they do is the fundamental ethos of providing help to its members and all those who surround the person with Down's syndrome, their families, carers and other relevant professionals.

DSL group now on Facebook



Down Syndrome Liverpool now have a group on Facebook. If you are a member of the popular social network website then look us up and join.

The group has all the latest DSL news and information as well as photographs from our events.

It is already proving quite popular with members uploading their own photos and sharing their views on the DSL group wall.

Committee corner

Anne Wilde



DSL secretary Anne Wilde pictured with her daughter Molly.

Hello, my name is Anne Wilde. I am married to Joe and we have three children, James 11, Molly 8 and Sam 6. We became members of Down Syndrome Liverpool when Molly was a baby and I have been honoured to be a Trustee of the charity for just over six years now.

In my first year as a Trustee I was the New Parent Contact for the charity and really enjoyed going out and meeting our new parents and their families. I hope in that role I was able to offer some help and advice.

For the last five years I have held the office of the charity Secretary, initially only to plug the gap when Clare Fagan relocated, but somehow I have found myself voted in again and again!

I really enjoy the post to be honest as I make lots of contact with members, mainly through telephone conversations, e-mail or of late facebook is proving very popular, and it also helps me put a face to a name. I really try my best to answer all enquiries as fast as I can. If I can't help you, I normally know a man who can!

I have most members e-mail on the database now, which is easier to send out notices etc. Don't forget to e-mail me yours if you haven't done so already!

I have worked full-time in a Runcorn secondary school for the last 17 years. I teach Art and Technology there and I also have the envious responsibility of the pastoral care of nearly 200 teenagers!! However my own three children still manage to give me the run around every day of their lives!

Life is an endless round of football, swimming, dancing etc and I am really proud of all my children's achievements.

Molly is a real source of inspiration to me. Her determination is constant and she has a real stubborn streak, which helps her to realise her goals. For the last eighteen months she has been involved with Spartacs Gymnastics who are based in Edge Hill University. She trains every Sunday from 10am till 3pm up at the university. She has just been selected to join the display team, representing Great Britain in the World Gymnaestrada in Switzerland in 2011 and I can't tell you of how proud I am of my little girl.

The one thing I have learnt during my time with DSL is never to underestimate our children. They are so different and so unique and just given the right encouragement or a push in the right direction; they can achieve so much and have a real contribution to make in our society.

We want your stories
This is your newsletter, USE IT. Let other members share your experiences

Featured web site

www.specialfriendsonline.com

This site has already seen many friendships develop around the world where parents/carers, volunteers and family members have been able to talk to other people who understand them and their day to day experiences. The highlight of some of these friendships is when the members get to meet each other at events etc. around the world.

Another useful website, this is a site for people with learning/intellectual disabilities, their parents/carers and family members. If you know of a website that may be of interest please let us know emailing us and we will do our best to feature it.