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**Irish Autism Action**  
*Raising Standards*

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# Keep InTouch

News & Views from Irish Autism Action

ISSUE 5

SPRING / SUMMER 2009

## Irish Autism Action:

help us to be a voice for those who have none



On the 2nd of April 2009, World Autism Awareness Day, Irish Autism Action with the help of Keith Duffy pictured above launched Ireland's first Autism Mobile Information Unit which will travel around Ireland and will serve to be a fountain of information for those families who are living with Autism. As our patron would say, "Let's not sit on the information, lets get it out there."

### Mission Statement

Irish Autism Action's mission is to raise the quality of life of individuals and their families affected by autism through ensuring the provision of highest standards in education, care, support, employment and equality of living opportunities in partnership with families.

**"Help us to be a voice for those who have none!"**

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# Messages from our Chairman, Patron & CEO

**Cormac Rennick**  
Former Chairman of IAA

Friends,

It was with great regret that due to work commitments I stepped down as Chairman of IAA. At this time I reflect on the progress made since our original formation in 2000. I am satisfied that IAA is now established as Ireland's leading Autism Charity. I applaud the work in progressing the negotiations to secure recognition of our schools and sincerely hope a positive resolution is within our grasp.

Additionally our help line, diagnostic service and advocacy programme are great achievements that warrant celebration. I wish Marc our incoming Chairman and the new Board every success in their tenure. Rest assured I am not gone for good but merely "on a break". Thank you one and all for the support I received in my time as Chairman.



**Marc de Salvo**  
Chairman of IAA

Friends,

I am honoured to have been selected as Chairman of IAA. My sincere thanks to my good friend Cormac on all IAA achieved in his tenure as Chair. Having settled in over the last number of months I am really excited about our future plans and the positive outcomes they will have for all our members. While it is important to secure recognition of the schools we set up many years ago I believe that it is equally important to ensure that we are a powerful lobby for all children and adults with ASD in Ireland. Our research strategy and reaching out to our members as detailed on page 11 is the start of long term planning and will result in us being able lobby for changes in government policies in the short and long-term. An area of particular interest to me is the bio-medical interventions that have moved on so much since I was involved in hosting the medical conference in Dublin back in 2003. We have a growing number of members who want to get good safe information and debate the options available here in Ireland and abroad, more on this topic is to follow in the coming months.

Communication is always at the core of good teamwork and I believe that the IAA is a team with our members, the council and the board all playing their part in making the IAA as successful as it can be. We are going to review how we communicate with members over the summer and adjust how our meetings are held as a result of the review, I am keen that as we move forward expanding the charity that we make use of our website as possible to keep members informed and allow them to feedback there issues.

**Keith Duffy**  
Patron, Irish Autism Action

Hi Keith here,

Since our last Newsletter, I can't but help feel IAA has gone global, a bit like a good band I know! In January we visited Russia with To Russia With Love, a humbling and most memorable experience. Then last month we did a fundraising trip to Boston and New York. I really feel we are on the threshold of something great. IAA can and will be the most important support for families in Ireland.

You may have heard that I was ill after the London Marathon. Rest assured I am on the mend. No matter how I felt in that race it was an honour to represent all our heroes out there, the families who rise to the challenge each and every day to give their children the best possible future.

I am so pleased to see IAA advancing their strategy and vision. We need to have a clearly thought out and researched plan, but that can only happen if we communicate with each other. We all need to know that we are part of that plan and that our children remain central to what we do as a charity. For those who cannot get to all our meetings, go on our blog, website or facebook. As it says on the cover, Keep In Touch, I know I will.

**Kevin Whelan**  
CEO

I would like to take this opportunity to wish Cormac all the best and to welcome Marc as our new Chairman. I wish them both well in their respective ventures. As this edition goes to print I would like to acknowledge all the support that we have received to date from our sponsors and parents. It is all very much appreciated.

You can contact me on 086 816 3067 or e-mail [kevin@autismireland.ie](mailto:kevin@autismireland.ie)



*Left to right, Keith Duffy Patron, Kevin Whelan CEO and Marc de Salvo Chairman.*

# Meet the Team

## National Office – Mullingar



### Fiona Shaw – PA to CEO Kevin Whelan

My job consists of arranging the CEO's diary, booking conference rooms, providing administrative support within the office. It's a busy and varied role. No two days are ever the same. You can contact the National Office on 044 93 31609.



### Aisling Garry - Accounts Assistant

I process all accounts information and queries for IAA. I also handle enquiries relating to membership of IAA, whether it is an individual or a new group. Because I work with such a dedicated team, I find my work very enjoyable. The enthusiasm shown by staff and members alike makes all the difference to a job. I also enjoy the diversity – one day I could be climbing Croagh Patrick to raise money, the next week I could be in my glad rags working at a fundraising ball! You can contact me on 044 93 30709 or e-mail [aisling@autismireland.ie](mailto:aisling@autismireland.ie)



### Colette Charles – Fundraising Officer

My job consists of organising and managing fundraising programmes and events for Irish Autism Action including Masquerade Balls, Race Meetings, Golf Classics and a wide range of other fundraising initiatives.

You can contact me on 044 93 42576 or e-mail [colette@autismireland.ie](mailto:colette@autismireland.ie). Currently I am on maternity leave so any fundraising queries are to be directed to Sarah McEnerney-Buckley at [sarah@autismireland.ie](mailto:sarah@autismireland.ie)

### Sarah McEnerney-Buckley – Administration

Currently I am covering maternity leave for Colette Charles our Fundraising Officer. In the past I have provided administrative support to various aspects of the organisation which I have enjoyed immensely.



With regard to fundraising my job consists of the same responsibilities as above in Colette's profile. The job also consists of implementing an effective mix of fundraising strategies and targeting a range of fundraising sources. Also the production of our quarterly newsletter is a joint responsibility between Fundraising Officer, Information Officer and CEO.

You can contact me on 044 93 42576 or e-mail [sarah@autismireland.ie](mailto:sarah@autismireland.ie)

## Solas Centre - Dublin



### Sheena Cormican - Solas Administrator

I have a great interest in working within the medical system in particular learning more in relation to special needs. Presently I am the first point of contact for many families who wish to go through the assessment process for autism. I organise the appointments, send out information packs, deal with the fees involved and send out the final multi-disciplinary reports.



The best thing about my role is knowing that I'm involved in helping families get the assessment they need to improve their child's life. Also hearing and learning more about everybody's different experiences and how their lives have been affected.

You can contact me on 01 8531572 or e-mail [solas@autismireland.ie](mailto:solas@autismireland.ie)

### Yvonne Lucas - Counsellor

I provide a counselling service at Solas for parents and family members of children with ASD and Adults with ASD themselves. I enjoy building relationships with my clients and seeing how they gain new perspectives and ways of being through personal therapy – it is really rewarding to see and a privilege to be a part of.



You can contact me on 01 8531572 or e-mail [counselling@autismireland.ie](mailto:counselling@autismireland.ie)

### Marissa Campos-Lupot - Senior Paediatric OT

I hold a Graduate Bachelor's Degree in Occupational Therapy in the Philippines. I have experience in Pediatrics OT for the past 7 years and thoroughly enjoy working with children with disabilities. My role in Solas is to assess children's sensory processing, gross and fine motor skills, visual motor integration, visual perceptual skills, motor co-ordination and personal management skills. I write comprehensive reports based on the assessment administered and work with the Multi-Disciplinary Team for diagnostic formulation. The best thing about my role is that it gives me the opportunity to be part of the MDT diagnostic team. It enhances my skills in the areas of assessment and report writing. It gives me the opportunity to work with children and their families and provide feedback on what their child needs.



You can contact me on 01 8531572 or e-mail [marissa@autismireland.ie](mailto:marissa@autismireland.ie)

# Meet the Team

## Mahrukh Masood - Senior Clinical Psychologist

I joined the Solas Team last November. I have moved here from Pakistan where I worked for more than 10 years, with children, adolescents and adults with special needs. As a Multi-Disciplinary Team leader, my role is to assess children with regard to their cognitive and adaptive functioning in order to evaluate their potential autism related traits. Then the MDT discuss the evidence and provide feedback to families. It is satisfying to work with children and their families, supporting the families in understanding their child's behaviour, and providing advice regarding the most appropriate educational placement for their child.



You can contact me on 01 8531572 or via e-mail mahrukh@autismireland.ie

## Emily Scanlon

I am the co-ordinator of the One Stop Shop for Autism. I have worked in the area of Community Development in a volunteer and professional capacity for the past ten years. My work experience has been varied from research in Nigeria to working in the youth services!



While completing my MSC in Development in 2005 I worked in Gheel Autism Services as a residential support worker. This is where my passion for working with people with Autism began. Currently there is no one website where all information on Autism Services in Ireland is available.

We aim to create an encompassing, informative, easy to access and navigate, interactive (forum), continuously maintained, up to date, linked website on Autism in Ireland. My role is to oversee its development and launch! I will then ensure that it has the most up to date information at all times.

The role allows me to indulge two of my passions in life. I love the internet and technology and this position allows me to gain further insight into websites.

The second could not be more different, I enjoy meeting new people and finding out about their experiences and sharing knowledge. I have learnt a lot since I took the position six months ago and look forward to the future of the project.

You can contact me on 01 8531572 or 087-6573181 or e-mail emily@autismireland.ie

## Sarah Rennick - Information Officer

I am based at the Solas Centre in Dublin. I'm the mum of 2 fabulous ASD kids and married to an amazing man. I have a great network of friends for support – practical and emotional. As most of you will know, autism kind of takes over your life – so.....I find it good to have people around who can bring some balance to my world.



I provide information, primarily to parents who have received a new diagnosis through the Solas Centre, and try to help them find their way through the maze of getting the services their child needs and the support they need. I co-ordinate the Helpline and Support Groups at the Centre and also help compile information for the CEO and Directors.

We would also give presentations or talks to schools, sponsors etc to help raise the profile of the IAA and awareness of autism. The best thing about my role is the parents, the kids and my colleagues. In my free time I like to potter away in the allotment, spend time with friends or watching Stand Up Comedy with my 15yr old Aspie Boy or catching rainbows through crystals with my 13yr old Autie Girl (both are a blissful way to spend precious time)

You can contact me on 01 8531572 or e-mail sren@autismireland.ie

## Rachel Cassen – Advocacy Co-ordinator

I have been working with Irish Autism Action for over a year now as Advocacy Coordinator. This is a new role and involves setting up the service nationally with a team of regional advocates. The Advocacy team meets every six weeks for group supervision and support and as the group approaches the end of the first year of their studies we will begin a hand over of casework. As a parent of a young adult with AS it gives me great satisfaction to know that our advocates not only possess professional expertise, but also carry with them in their work a personal understanding of the challenges that people with autism face. This makes our service unique and we should celebrate this.



The best thing about my role with Irish Autism Action is the lovely people I get to meet and the chance to give something back.

You can contact me on 087 613 0165 or e-mail rachel@autismireland.ie

# World Autism Awareness Day 2nd April 2009

Thursday, April 2nd 2009 saw Irish Autism Action (IAA) announce that it will be funding a major research project relating to prevalence of autism in Ireland.

The research will be carried out by Professor Anthony Staines and Mary Rose Sweeney of Dublin City University. At present, it is estimated that 1 in 166 people in Ireland have an Autistic Spectrum Disorder (ASD) – but international evidence points to higher incidence rates. The announcement was made at a press conference at the Conrad Hotel Dublin and marked the first of a series of events for World Autism Day.

“By examining how many people have ASD we can better understand how the condition comes about,” explained Professor Staines. “Armed with that information we will be better able to plan, target resources and improve treatments.” Professor Staines is a specialist epidemiologist based at DCU since 2007.



He has conducted PhD research into Insulin Dependent Diabetes Mellitus and Acute Lymphoblastic Leukaemia. His work on Diabetes demonstrated that the accepted view that the condition was solely a genetic inheritance was incorrect.

“We have allocated some of the funds raised over the last year to this work as it is vital that we accurately know how many people are impacted by ASD,” explained Kevin Whelan, CEO, IAA. “And that is not just confined to those with the condition but their families and friends. As an organisation we are committed to helping everyone on the entire island who is affected.”

World Autism Day was marked in Ireland with a series of fundraising events involving support from our benefactors O2, DAA, DHL, Roganstown Golf Club and the Hilton Foundation.

The public can continue to show their support by purchasing Irish Autism Action pins, which are available in all O2 retail shops nationwide. The international aspect of the day was reflected in the announced partnership between IAA and Autism Speaks, the American autism advocacy group. This will allow the sharing of information, which will be of immediate use in running the epidemiological research programme launched today. Irish Autism Action also announced plans to develop a Mobile Information Unit to travel throughout the island raising awareness of autism.

## O2

Staff at O2 celebrated World Autism Awareness Day with us on the 2nd April with various activities which they held in the O2 office on Sir John Rogersons Quay.

One of the main fundraising events was to wear blue for Irish Autism Action on World Autism Awareness Day .....a shirt, t-shirt, jumper, blouse, jeans, (you get the idea!) and donate a minimum of €2.

Everyone who donated was entered into a draw for a great prize. There were gorgeous gents and lady’s Raymond Weil watches to give away for the Dublin and Limerick offices. Each limited edition watch is worth €500. These cannot be found in any retail jewellers. A big thank you to Raymond Weil for donating the watches.

A big thank you also to all the O2 staff that took part and went blue for IAA on the day. A grand total of €8,320.54 was raised by O2 for Irish Autism Action on World Autism Awareness Day.

## O2 Penalty Shoot Out

The mini penalty shoot out took place from 11.30am to 3.00pm. Keith Duffy, IAA patron, was there to take a shot at goal. Keith was joined by pals Ken Doherty, Johnny Giles, Brian Ormond, Ger Gilroy, Tom Dunne from Newstalk 106, Bernard Flynn, Niall McCrudden, Rob Ross, and many more.

There was a great turn out from the O2 staff as well, with over 60 staff taking part in the shoot out and many more were there to cheer on their colleagues and show their support for Irish Autism Action.



# World Autism Day

## The Laughter Lounge

The evening portion of the day saw staff of O2 relaxing in The Laughter Lounge while raising funds for Irish Autism Action.



On the night there was not 1 but 4 comedians catering for all tastes and only the funniest! Joe Rooney, Father Damo in Father Ted, Kevin Gildea who played Father Cave and Michael Mee.

Irish Autism Action would like to thank all at O2 for their constant support without which we would not be able to deliver the quality of services which we currently deliver.

## Dublin Airport Authority (DAA)

The DAA Staff Charity of the Year Committee is delighted to announce that a total of €9,600 was collected at Dublin Airport for Irish Autism Action during the annual "flag day" collection held Thursday 2nd April 2009 to mark World Autism Day.

This was a fantastic achievement by all concerned, especially considering the day in question was a relatively quiet one in



terms of passenger traffic. The Committee would again like to express its gratitude, to the more than 80 staff volunteers, who gave so generously of their time, wore the T-shirts, sported the balloons, (and had their photographs taken with Keith Duffy) on the day.

The event could not have succeeded to the extent it did without your commitment, support and enthusiasm.

It's onwards and upwards from here and we will be in touch very soon with notice of the next events planned to support our very worthy Charity of the Year, Irish Autism Action.

## DHL

On the 2nd of April 2009, we called into our corporate sponsor DHL to acknowledge their hard work and support to Irish Autism Action over the last year.



During this time we also collected a cheque from DHL for the magnificent sum of €50,000 that was raised by DHL in the Mercedes C Class Raffle.



## Roganstown Cheque Presentation



Many thanks go to Ian McGuinness and Roganstown Golf Club for an astounding cheque for €24,500 which was raised at a recent Golf Classic.

## News from Our Groups

### Kerry Autism Support Group

In February 2009, the Kerry branch of Irish Autism Action began a six week programme for horse riding with instructor Suzanne Gibbons in Killarney.



Already the benefits are showing and it is now planned to continue the lessons. Complementary ideas involve several techniques and activities which can prove useful when dealing with autism, which divide into three groups.

1. Relaxation Techniques i.e. massages etc
2. Activities that encourage some interaction i.e. music and art
3. Leisure – Among this is horse riding, which encourage and demand a certain degree of active involvement.

Benefits also include achievement of moment with the horse which helps to decrease frustration; a gain in upper trunk control and balance over a moving base. It also encourages muscle control and allows freedom for movement and a sporting challenge. In April we will begin our other activities of music and art.

For further information please contact Susan Dunne at [suesheeydunne@gmail.com](mailto:suesheeydunne@gmail.com)

**“From acorns, Oak Trees grow” - In their infancy we must tend the Saplings. A story of a pioneering adventure.**

In November 2007 the Parents Association of Saplings, Kill agreed to support a project, based on an idea borrowed from the US. That project was the first ever Summer Sleep over Camp to be held in Ireland for children with Autism.

A little after 5.30pm on Monday August 11th 2008 an advance party of 5 Saplings children left Saplings, Kill to pave the way for a fun filled week long adventure at the Scouting Ireland National Camp site in Larch Hill, Dublin 16. On arrival both tutors and children enjoyed a light evening meal. After the P.J's were put on one of the children requested “Shrek 2” as the movie

for the evening, there began, what was to be a standard for the rest of the week, the nightly Movie and Popcorn routine.

After the movie all children got into their bedtime routine, tooth brushing, etc and by 9pm all the children were in bed. Rise and shine was at 7am and Tuesday started frantically as we were expecting the final 7 of our “intrepid dozen”.

On arrival we were all prepared for our first field trip to the National Aquatic Centre. We were met there by the disability liaison officer who assisted us through entering the pool. Water slides, wave machines and fountains were all frequented by our children. After our adventure there, we headed back to Larch Hill for dinner followed by our Mini Olympics, given the year it was.

There was bowling, golf, ball throwing, cricket, and arts and craft activities. Before the Day Campers went home there was the daily visit to the Rewards Store to exchange the tokens they received during the day as reinforcers for edibles, games, toys and sensory toys. After the evening meal our full sleep over campers enjoyed “Jungle Book” and popcorn before retiring to bed by 9pm where we had everyone asleep by 11pm.

Over the next number of days our “intrepid dozen” went sailing in Avon Rí followed by Orienteering, Bowling in the Leisure Plex, treasure hunting in the large meadow in the Camp site, Fort



Lucan and the large outdoor playground near the Camp Lodge. Wednesday and Thursday saw a further 4 campers join the first 5 for the full sleep over camp. Despite the heavens opening on Saturday our spirits were not dampened, we did have forty minutes on the bouncy castle before we abandoned outside, but between a matinee showing of Disney’s “Cars”, and fun filled activities including Moon Sand, Play Dough, Elefun, group songs and much more it was not long before we had to say good bye to our last 3 day campers.

Just before they left we had an opportunity to have a group photo of the first Summer Sleepover Camp at the Totem Pole in the adjoining meadow. After lights out on Saturday evening we

## News from Our Groups

organised everyone's personal items, and did a big clean up so as to be ready for home time after breakfast on Sunday morning August 17th.

Our 9 campers arrived back to Saplings, Kill, where one by one, they went home with their families.

All 12 children participated fully in every activity and event we had planned. Every evening the Education Director contacted each parent to give them a progress report on the day and evening. Remarkable comradeship was seen, tremendous competitiveness, and most of all extraordinary determination to achieve in all tasks that were presented.

Each child took home a Certificate of Participation and an O2 pack, as well, we hope, lasting memories of fun, achievement, and comradeship.



The concept for the Camp was simple; the Aims we identified were that the children would focus on Self help and Socialisation skills during the Camp, and that families would have the opportunity to spend some time with their typically developing children.

Critical input into the IEP's of each of the children identified the Self help or Socialisation skill that had to be worked on and using ABA. Without the co operation of the Education Director of the School this aspect of the Camp would not have succeeded. It is understood that skills learned at the camp have remained with the children who participated. Feed back from parents were humbling, it was gratifying to hear that parents were able to tell the child's grandparents, for the first time, that they were going on a Sleepover Camp this year, or hearing that their child's siblings were jealous because of the fun they were having, or hearing that a child was continuing to pine for the Camp long after it was over.

The Camp wanted to remove "dependence" from our child's lives and replace it with "independence". It was great to hear from a very progressive parent that we should be rejoicing achievement and promoting such a project as the way forward for us and our children.

We chose to focus this Camp with Saplings, Kill this year, in order that we could ensure that all elements of organisation, education and logistics were tested and worked well, if we did not run it there would always be things that we could not foresee or account for.



We believe that we have presented a "gold standard" addition to the resume of the Saplings organisation. It is testimony to the tremendous dedication and professionalism of all those involved in this camp. To the 27 tutors who helped throughout the week, we owe a great thank you. To all the Saplings, Kill tutors who helped in the preparation of the materials and children for the Camp, thank you.

For the support of the parents of the Parents Association of Saplings, Kill and the extraordinary courage of the "intrepid dozen" who participated in the Camp, it would not have been the success it was without you all.

Our vision is that we extend the camp to all the 80+ children in the Saplings schools in the future; this will require a massive inter school co operation and organisation.

Two hundred years ago Lewis and Clark had an idea to open the continent of America from the Atlantic, west, to the Pacific. In August 2008 an idea borrowed from the US went east, across the Atlantic to open our minds to a new opportunity for our children. A big thank you to Irish Autism Action for the respite grant provided towards the cost of the camp.

### PALS Preschool

PALS Pre-school was the former ELI and was started in September 2008. PALS operates from North West Business Park, Blanchardstown. It operates five days a weeks, Monday through to Friday following the school calendar.

PALS Preschool provides early intervention for children with special needs, language delay and/or disorder including Autistic Spectrum Disorder and Down Syndrome. For those familiar with the ELI programme, PALS provides a similar service using the

## News from Our Groups

same playgroup and ABA structure. If you feel that our service may benefit any of your children, we would be more than happy to answer any of your queries. Referral is not necessary. Please feel free to visit our website [www.palspreschool.ie](http://www.palspreschool.ie) for further information



### Megan's Magnificent Birthday Gesture

MOST children rub their hands with glee at the thought of just what (or how much!) they'll get for their birthday, but seven-year old Megan Coogan isn't like most little girls. The thoughtful Carlow girl recently donated all her birthday gifts to the local Saplings School for Children with Autism. Daughter of Aidan and Carina Coogan and older sister to Abbie (3), Megan decided that instead of getting presents for her seventh birthday, she'd make a donation to Saplings instead. "She got so much for her birthday last year that we just decided it was the right thing to do to give something to those less fortunate. We sat down and talked about it and she decided to donate to Saplings because her neighbour and friend Sophie goes to the school," explained Carina.

"No, Megan didn't mind at all, she was delighted. We had a party and everyone gave money to give to Saplings," Carina added. Last Monday morning the Gaelscoil pupil went to the Saplings School in Graiguecullen to make her donation of €340. "It is



very touching that a young child could display such a big heart and be so generous," said Janet Duminy of Saplings School for Children with Autism, Carlow.

### Charity Abseil

Lucy Owens and 16 other participants Abseiled down the d-Hotel in Drogheda on Saturday, November 29th at 12 noon, in aid of the Assistance Dog Programme for Families of Children with Autism. Lucy raised money for an Assistance Dog for her son Joey (2) who was recently diagnosed with Autism.

Lucy & Pats son Luke (9) also has Autism and attends Drogheda ABACAS. Lucy & Pat have 2 girls also Grace (6) & Rachel (18mths).

The programme is run by the charity Irish Guide Dogs, and has been proven very successful for children with Autism, by relieving the stress of managing the child in public situations. It costs € 38,000 to fully train a dog for its lifetime and ongoing training.



The event was supported by the Defence Forces and the d-Hotel. Local participants include Niall Lynch, Raymond Lambe, Dermot Smyth, Ian and Nicola Carolan, Trish O'Reilly, John Byrne and Ann Carolan.

All proceeds went to the charity Irish Guide Dogs, and towards the Joey Owens fund.

### Drogheda Valentines Ball

Celebrities turned out in force on Saturday 14th February 2009 to support the 6th annual Valentines Ball in aid of Drogheda ABACAS School for Children with Autism. Despite the competing attraction of the IFTAs, the increasingly popular event was hosted by City North Hotel and graced by Brian Ormond & Pippa O'Connor, Lorraine Keane & Peter Devlin, Derry & Sallyanne Clarke, TV3's Martin King and singer Mickey Harte.



Brian Ormond and Pippa O'Connor enjoyed last year's ball so much they returned once more to celebrate Valentine's Day. "It's a great night and a great charity," commented Brian, who also revealed that he is inspired by his friend Keith Duffy, whose daughter Mia attended the ABACAS school in Dublin.

Lorraine Keane commented: "I'm a long-time patron of the Irish Autism Action charity. They've been planning this night for ages so I wouldn't have missed it for the world."

A highlight of the North East's social calendar the ball has been selling out for many years and repeated the feat even in these more straitened times. Patrons enjoyed an enviable menu of food

## News from Our Groups

and entertainment and dancing was in swing into the small hours. The event raised over €40,000 to help children with Autism.



Many of the parents from the school attend the event and it is due to the combined efforts of many many people that the event is such a success. Congratulations to Jacinta Walsh and the committee for a job well done. Following the exciting auction the Enemies were joined on stage for a set by Mickey Harte of Eurovision fame to a great reception.

Drogheda ABACAS School opened in 2003 and provides ABA education for 18 children with autism at premises in the heart of Drogheda. The group also provide a support group, pre-school, youth club, information and advocacy services.



### Cling Cling

Irish Autism Action would like to thank the students from, Dundalk Institute of Technology (DKIT) who did a bucket collection for the Drogheda ABACAS School. They also organised a comedy night with Joe Rooney for World Autism Day in McHugh's Pub in Drogheda.

Dave, Sean and John are studying Event Management in DKIT and these events are part of their final year project. This means we all benefit from the experience and we are delighted they chose to support the Drogheda ABACAS School for their event.



### CAN Wexford

Ciara Johnstone and her friends did a muffin sale at school in aid of Cottage Autism Network (CAN). A grand total of €569 was raised from the sale. Ciara's brothers Evan and Daniel both have autism and a day never goes by where Ciara does not endeavour to help her brothers in any way she can. Thanks to Ciara, staff and pupils at St Anne's National School, Wexford for all their efforts and many supports.



### IAA Welcomes New Groups

Irish Autism Action would like to welcome the following groups to our network.

- Brightstars, Cavan
- Autismwest
- Aspergers Action, Galway
- PALS, Dublin
- Jigsaw (D7/11), Dublin
- Speak, Bray. Co. Wicklow
- Speac, Belfast. Co. Antrim

And a very special Irish Autism Action welcome to all of our new individual members.

# News from Our Groups

## Gabrielle's Ball

On the 27th March 2009 Gabrielle McMonagle held her fourth annual Gala Ball in the Mount Errigal Hotel, Letterkenny. The event was supported by Bennett Construction.

A good night was had by all and the night was a great success with €30,662 raised. Both Donegal local groups and the National Charity, Irish Autism Action have benefited from the event.

There was tremendous reaction to the ball. Over 500 guests were seated for dinner. Keith made a huge impression and reduced some people to tears with his very passionate speech about autism and his life with his autistic daughter, Mia.

One of the big success stories from the night was a special charity auction which helped raise €9,000. Special guest and Boyzone star Keith Duffy, used all his charm and humour to make sure the auction would boost funds for the chosen Autism charities. Our sincere thanks to Gabrielle McMonagle and Michael Daly of the Donegal Democrat and a special thanks goes to Christopher Bennett and the team at Bennett Construction for their continuous support to the event.



## The Will of Fat Louis by Derek Dodebier

Fat Louis Will.....  
To Cleo my brother I leave you in bed.  
To Phoofer my son I leave you my house  
To Mortimer my daughter I leave you my knowledge of the world.  
p.s. Mortimer.....Please don't die alone.



Please note Cleo & Phoofer are the remaining cats. Mortimer is a wild kitten found on the farm

(Written by Derek after our cat Fat Louis dies on the farm while we were away)

## Abacas Comedy Night with Joe Rooney

A big thank you to Comedian Joe Rooney for taking part in the comedy gig for the Drogheda Abacas. The night was a great success and a fun time was had by all.



## Poems by Children

*Shaneyboy - By Sarah Mullins (I love my brother Shane.)*

I don't care if he's autistic.  
Cause he's never a big pain.  
And he's really, really mystic.  
My brother Shane loves me.  
I see it in his eyes.  
You may not see,  
When he jumps for a big surprise.  
Times sometimes get tough.  
But I still love my brother.  
I don't get rough.  
Cause things would fall a sunder.  
When times do get tough.  
I'd never fear.  
My brother would not get rough.  
I'm okay when he is near.



(This poem was written by Sarah Mullins (8), about her brother Shane (12)

## Dates for your Diary

### Council Meetings:

Saturday 13th June 2009 at 11am

Saturday 19th September 2009 at 11am

Saturday 21st November 2009, AGM, 11am - 4pm

## Irish Autism Action - The Next Steps 3 Year Strategic Plan

### REACHING OUT - EXECUTIVE SUMMARY

This proposal incorporates Irish Autism Action's mission for the next three years and reflects its commitment to improving the services available to children and adults with autism in Ireland on a 32 county all-Ireland basis.

Specifically, IAA will

Undertake a Study into the Prevalence of Autism in Ireland on a 32 county basis, part of a wider European and USA study. We have already established as partners to this study the following groups: Dublin City University, Trinity College Dublin, Autism Speaks USA, SPEAC Northern Ireland, European Autism Information System Partners, Spain, France, Denmark, Czech Republic, Poland, Germany, Luxemburg, Belgium. The objective of the study will be to:

1. Develop prevalence figures for Ireland using the same methodology as our European partners to facilitate comparative analysis.
2. Once the incidence has been established then undertake an economic study of the whole life cost of autism.
3. To then undertake economic research which will demonstrate the reduction in life long costs which can be achieved resulting from the front loading of investment in early intervention.
4. A comprehensive awareness campaign - is planned with regard to the issue of autism on this island. The awareness campaign will consist of the following:
  - the development of an all Ireland one stop information and resource website for autism
  - the commissioning of mobile information units in the North and in the South. The purpose of these mobile information units will be to ensure that the public in general and more specifically our main stake holders clearly see, understand and are empowered to assist us in achieving our objectives.
  - the provision of an ID card for all in Ireland with the diagnosis of autism and Aspergers. This card to be branded as Irish Autism Action. This will serve a dual purpose in that:
    - a) we will encourage greater membership of a national autism organisation
    - b) we will ensure that relating to our membership and future planning we will have data base information that is accurate and timely.

5. Early Screening – In partnership with Autism Speaks we wish to undertake the piloting of early screening tools to be used by key disciplines in the health field e.g. general practitioners and public health nurses.

The objective here is to develop the early screening tool that works best and in so doing train these key disciplines in its usage.

Following on from this, to then lobby on the back of the prevalence study, the economic study, the awareness campaign and best practise in early screening, the introduction of mandatory early screening of all two year olds on this island.



6. Parent Training – Irish Autism Action in partnership with Sligo Institute of Technology are presently undertaking a pilot autism specific advocacy training programme for parents.

It is our intention through this research to develop a comprehensive range of training programmes for parents and individuals on the spectrum to facilitate and empower them to create the best possible opportunities for quality of life for all families on this island affected by autism.

## Autism Speaks Partnership

Autism Speaks Announces Partnerships with Albania and Ireland Launching First Global Autism Public Health Initiatives

Global Advocacy and Research Organization Reviews Worldwide Autism Science and Research Efforts Second Annual World Autism Awareness Day – April 2, 2009



NEW YORK, N.Y. (April 1, 2009) – Autism Speaks, the world's largest autism science and advocacy organization, announced today a new partnership with the Albanian Children Foundation (ACF) the first international accord in the Global Autism Public Health (GAPH) Initiative. In addition, they announced an agreement with Irish Autism Action to form an advisory committee to facilitate the development of a GAPH partnership. As Autism Speaks marks the second annual World Autism Awareness Day (WAAD), it reviews autism science and research around the world assessing the prevalence, investigating underlying biology and causes of autism spectrum disorders (ASD) in pursuit of treatments. Autism Speaks is currently supporting a host of international projects and multinational research collaborations, some of which are undertaken with outside partners.

For these projects, Autism Speaks share of the spending totals \$10.8 million over multiple years. Countries involved in this research include Australia, Bangladesh, Canada, Denmark, Germany, Finland, India, Israel, Italy, Norway, South Africa, South Korea, Sweden, Taiwan and the UK.

Bob Wright, co-founder of Autism Speaks said, "Approximately 67 million people are affected by autism around the world, and we believe the solutions will come from a community of science and research without boundaries. The work of Autism Speaks in global science and research is an important path to investigate causes, prevention, treatments and a cure for autism; increase international awareness of autism spectrum disorders; and advocate for the needs of all individuals with autism and their families in our global community."

The GAPH Initiative provides support to other countries to move their autism research and awareness forward by enhancing public and professional awareness of autism; developing clinical and scientific expertise/capacity and international research collaboration; and developing and training professionals in early detection and intervention.

In Ireland, Autism Speaks announced an agreement with Irish Autism Action (IAA) to form an advisory committee which intends to facilitate the development of a GAPH partnership.

The committee will be comprised of representatives from IAA, Autism Speaks, members of the Irish autism stakeholder community and expert researchers from Ireland and abroad.

"IAA has made major strides since it's launch" said Dr. Geraldine Dawson. "They are advancing the rights of people with autism nationwide, as well as supporting diagnosis and education. A GAPH-Ireland Initiative will assist them in their new focus on autism research and training."

"Irish Autism Action is delighted to have the opportunity to collaborate with Autism Speaks on this project," said Kevin Whelan, CEO Irish Autism Action. "We see this as a defining moment in implementing policy in Ireland in relation to autism services." Autism Speaks continues the existing international collaboration between both Qatar and the Pan American Autism Awareness and Training Initiative (PAAATI). PAAATI, which preceded the formation of GAPH, involves collaboration between Autism Speaks, the National Institutes of Child Health Development (NICHD), the American Academy of Pediatrics (AAP), the CARSO Health Institute, Clinica Mexicana de Autismo (CLIMA), and the Canadian Institutes for Health Research (CIHR).

Autism Speaks and the Shafallah Center for Children with Special Needs in Doha, Qatar continue their partnership designed to increase global autism awareness and help the Shafallah Center to become an international leader in autism genetics research and service delivery.

For the first time in 2008, Autism Speaks launched funding mechanisms designed exclusively to support international epidemiology research, and committed \$1.5 million to a number of new multi-year projects. In addition to ongoing projects in Bangladesh, India, South Korea, and Taiwan, Autism Speaks' international epidemiology portfolio now also includes the first-ever autism prevalence study in South Africa as well as studies in New Delhi and Goa, India. In South Africa, investigators will not only explore the prevalence of autism but also lay the groundwork to investigate the hypothesized relationship between autism and HIV infection. Lay abstracts of the most recent Autism Speaks International Epidemiological Portfolio follows this release.

Before studies can be conducted around the world, the assessment tools used to diagnose individuals must be translated to ensure cultural sensitivity. As such, Autism Speaks is currently supporting screening and diagnostic instrument translations in Mandarin Chinese, Arabic, Hindi, Bengali, Marathi, Konkani, Korean and Zulu. Combined, these languages are spoken by an estimated 1.75 billion people worldwide.

# Building on Success Autism Initiatives Partnership

The Chinese Mandarin versions of the gold-standard diagnostic instruments, the ADOS and ADI-R, were recently approved and are currently available for research and training purposes.

Autism Speaks also funded a proposal from a sub-group of the International Autism Epidemiology Network (IAEP) focusing on registry-based epidemiology. This project aims to uniquely study autism prevalence and potential environmental and genetic risk factors using a large, combined database, or “registry of registries,” with information from six international sites.

The International Collaboration for Autism Registry Epidemiology (iCARE) includes population based health registry data from Australia, Denmark, Finland, Israel, Norway, and Sweden, with Columbia University and the CDC assisting in data coordination and analysis. The IAEP, co-developed by Autism Speaks and the Centers for Disease Control and Prevention (CDC), now engages nearly 80 research professionals from 30 countries around the world.

The Autism Speaks Baby Siblings Research Consortium (BSRC) involves the work of 23 scientists from 19 institutions across the globe. This work investigates the infant siblings of children with ASD. Different studies focus on how autism is expressed in early behavioral and biomedical symptoms, which in turn will hopefully lead to both early diagnosis and treatment. Key BSRC efforts in the past year include:

- The start of studies investigating genetic and environmental risk factors in high risk groups.
- Autism Speaks launched its first primary BSRC project to study over 1000 sibs and their family members.
- Autism Speaks provided \$5 million in funding to link two continuing studies of high risk siblings as early as pregnancy. One was supported to look at environmental risk factors, and the other is designed to identify neurobiological markers and brain growth patterns in infancy. The Autism Speaks funding expanded both projects to gather additional genetic, environmental and behavioral data and to pool the information pooled across seven sites and 1500 families.
- Autism Speaks facilitated the Toddler Treatment Network to identify goals, objectives and activities to improve measurements, define best practices for parent-implemented interventions, facilitate new researchers into the field, and to disseminate information to parents. Many of these objectives have been met including training on newer measures to identify infants (ADOS-t) and identification of common measures.
- Researchers in Canada validated the use of a standardized measure, called the AOSI, to identify children as young as 18 month of age.

## About Autism Speaks

Autism Speaks is the nation’s largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

Autism Speaks funds more than \$30 million each year in new autism research, in addition to supporting the Autism Treatment Network, Autism Genetic Resource Exchange, Autism Clinical Trials Network, Autism Tissue Program and a range of other scientific and medical programs. Notable awareness initiatives include the establishment of the annual United Nations-sanctioned World Autism Awareness Day on April 2 and an award-winning, multi-year national public service advertising campaign with the Ad Council. Autism Speaks’ family services efforts include the Autism Video Glossary, a 100 Day Kit for newly-diagnosed families, a School Community Tool Kit and the distribution of community grants to local service providers.

Its government relations department, through its Autism Votes initiative, has played a critical role in securing federal legislation to advance the federal government’s response to autism, and has successfully advocated for insurance reform to require insurers to cover medically-necessary autism therapies. Each year, Autism Speaks Walk Now for Autism fundraising events are held in more than 70 cities across the country, as well as Canada and the United Kingdom.

## About the Co-Founders

Autism Speaks was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism.

Bob Wright is Senior Advisor at Lee Equity Partners and served as vice chairman, General Electric, and chief executive officer of NBC and NBC Universal for more than twenty years. He also serves on the board of directors of the Polo Ralph Lauren Corporation and RAND Corporation.

Suzanne Wright has an extensive history of active involvement in community and philanthropic endeavors, mostly directed toward helping children. She serves on the boards of several non-profit organizations and is also Trustee Emeritus of Sarah Lawrence College, her alma mater.

To learn more about Autism Speaks, please visit [www.autismspeaks.org](http://www.autismspeaks.org).

## Autism Initiatives

Autism Initiatives UK was first established in 1972. The charity grew from the work of Pat Minshull who was concerned about the lack of specialised help available for her son Peter, who has autism. A successful fundraising campaign resulted in the establishment of Peterhouse School in Southport. By 1985 Autism Initiatives UK had developed an additional facility, Petersfield Autistic Community in Crosby, which provided services for young adults.



The organisation has continued to grow as it has responded to the needs of individuals with Autistic Spectrum Disorders (ASD) and their families. It is recognised that increased rates of autism and related disorders be accepted as an urgent public health concern and Autism Initiatives have responded to the increased need and now have an acclaimed national reputation for leading the way in supporting people with Autistic Spectrum Disorders.

Currently Autism Initiatives provides direct support for over 600 individuals in over 80 locations throughout the north of England, Isle of Man, Northern Ireland, Scotland and Ireland. Irish Autism Action are exploring the potential of developing a service provider partnership with Autism Initiatives. In this issue we have explained our plans for research partnership which will greatly influence autism policy in Ireland into the future.

Equally, we are conscious of the need to address current service deficits in the following areas:

- Early intervention – for early intervention to occur an early screening programme needs to be developed within Ireland to fast track the delivery of services to those most at risk of developing autism and providing appropriate therapy supports.
- Diagnosis and Assessment – all research states that early intervention is crucial in helping the child reach their maximum potential. Without a diagnosis you cannot secure early intervention. The current waiting time for diagnosis in Ireland is 18 months, 18 months loss of time. IAA have developed the Solas Centre to reduce the wait time from 18 months to 2 months.
- Education – IAA are presently involved with 13 schools which utilise applied behaviour analysis as the key intervention. Education is recognised as the best form of treatment for autism. We are in negotiations with the state to have our schools recognised so as to have a minimum of one special school in every county in Ireland.
- Respite – IAA have developed home based respite programmes to provide parents and siblings with autism free time. This represents an economic use of funding resources to address the needs of a greater number of families.
- Post 18 & Supported Living Services – traditionally within Ireland a residential care model has been applied for children and adults on the autism spectrum. We wish to establish an

alternative model which supports people in living in their own community.

- Advocacy – IAA provide an advocacy service to its members through its National office. This service is acknowledged by our membership as a cornerstone of what we do.

Irish Autism Action feel that it is an imperative that we partner with a well established innovative service provider and we are in negotiations with Autism Initiatives to advance matters to hopefully arrive at a positive resolution by Summer 2009. We are delighted that Geraldine Graydon is closely involved with Autism Initiatives as a board member.

Geraldine is a former director of Irish Autism Action and is well known in the Autism community. Finally, Irish Autism Action's intention if a partnership is finalised is to enter into a pilot project and evaluate its outcome to ensure due diligence is done to the process to preserve the ethos of Irish Autism Action in "Raising Standards".

As part of our research into Autism Initiatives, Marc deSalvo visited their services in Liverpool - *"It had been a while since I had visited any adult autism services so I was delighted to be invited to visit Autism Initiatives in Liverpool in February of this year.*

*We squeezed a lot into our two day visit and I particularly liked the fact that Jim their CEO at our reception meeting encouraged me to ask the difficult questions. We visited some supported living projects and met with the staff on the ground and the adults using the services. At all times we were encouraged to ask any questions regarding how the service was delivered and we got to see how the projects were first planned and then rolled out. The high level of staff training and ongoing support was very clear to see when visiting the various services and what drives these well run services is the policies that the management team in Autism Initiatives have developed over the last 30yrs.*

*Looking at the experience that Autism Initiatives have and the ethos that is very clearly centred around the service user I believe that Irish Autism Action can look at working in partnership with Autism Initiatives rather than trying to re-invent the wheel when it comes to adult services. Over the coming months we are going to look at some joint projects in Ireland and see if we can build upon this partnership in the future.*

*I am a firm believer that we should be planning now for the children that are going to need these types of services in the future and well as ensuring where an adult is currently in an inappropriate service that they would have the opportunity to access a high quality autism specific service, such as those provided by Autism Initiatives."*

## News from the Patron Body – Autism Ireland

### Recognition

All our Pilot schools have applied for recognition to be Special Schools for Children with Autism and Complex Needs. Patron bodies Autism Ireland and Saplings have applied for recognition. The following schools have applied to be members of Autism Ireland:

- Ábalta, Galway
- Abacas Drogheda, Kilnamanagh, Kilbarrack
- The Jonah Project, Waterford
- Stepping Stones
- The Red Door

The most recent contact with the department has been the resolution of the only outstanding matter that needed to be attended to which was a common enrolment policy.

It is anticipated that this will be resolved in the coming week which will then bring us to the final stage of recognition which will involve the Minister for Education formally writing to confirm his recognition of Autism Ireland as a Patron Body of Special Schools for Children with Autism and Complex Needs. Once the recognition process is completed then each member school of Autism Ireland will be allocated a role number.

We will then need to advertise and recruit the relevant additional personnel. The time frame for this will be before the summer break with a view to the new arrangements being in place for September 2009.

Please note that these suggested time frames are on the basis of schools/Boards of Management accepting the terms.

The negotiating team never had the authority to sign up to any deal. It would always be the responsibility of the Boards in this regard.

It should also be noted that once the existing schools become Special Schools for Children with Autism and Complex Needs that should the need be established in other areas in the country then those groups can apply to be this recognised school model under the patronage of Autism Ireland. (i.e. similar to roll out of educate together schools)

In establishing the Patron Body the following should be noted:

- Autism Ireland is NOT Irish Autism Action.
- The memorandum and articles of association for Autism Ireland Patron Body have been made available to all our Stakeholders.

- Autism Ireland the Patron Body will comprise of nominations from each member school.
- Autism Ireland the Patron Body will be a member of Irish Autism Action.
- The Ethos of Autism Ireland is firmly based in teaching the National Curriculum using Evidence Based Interventions in conjunction with the IEP of each child. (please see memo and arts)

In the development of the Patron Body proposal and the Memo's & Articles of Association advice and support was sought and very generously given by Educate Together to whom we wish to express our sincere thanks.

Finally, the negotiating team have circulated a detailed and time framed schedule towards a successful outcome for September 2009.

## New Foroige Youth Social Group

From Monday 11th May Foroige are starting a new Youth Group in Blanchardstown. The purpose of the group is to provide an opportunity for youths to develop social skills, understanding and tolerance of each other in an inclusive environment.

The Group is open to all between the ages of 12 and 18 years including those with Aspergers Syndrome or Autism. The Youth Leaders have received training and have experience in the area of Autistic Spectrum Disorders as well as going through the usual vetting.

Time: 7pm – 8pm (initially)

Venue: The Brace Centre, Blanchardstown Youthreach Building, Main Street, Blanchardstown

Contact: Billy Burke 086 6008526 or 01 8212077

Ages: 12 to 18 years

Foroige in Blanchardstown are also running various Summer Programmes. Contact Billy Burke for more information or visit [www.foroige.ie](http://www.foroige.ie) to see what is available in your area.



# CONFERENCES

## The Red Door's Autism Conference

The Red Door held their third international conference in UCD last December. Over 250 people attended, and they were treated to a great selection of presentations on the theme "Evidence-based interventions for individuals with autism across the lifespan".

Regular speakers from America, Peter Gerhardt, Bobby Newman, Helen Bloomer and Joanne Gerenser, were joined this year by Michael Fabrizio.

These international ABA professionals were joined by speakers from our own ABA schools in Ireland, including Juliet Quinlan from ABACAS Drogheda, Aisling Ardoff from Saplings and Laura Duffy from The Red Door.

Opening the conference, Martina Boylan, spoke of her pleasure at having not only ABA expertise available to the attendees, but she welcomed the conference's two keynote speakers, Joan Crowley O'Sullivan from the Dept of Education's Special Education Support Service (SESS) and, Simon Wallace from Autism Speaks.



Also presenting were Gary Pace from the May Institute and Louise Gallagher from Trinity College Dublin, who gave a presentation on the autism genome project.

Building on the previous conferences, this conference once again offered parents and professionals a wonderful opportunity to see and hear the best experts in the field of Applied Behaviour Analysis. The conference was supported by Irish Autism Action.

Details of the speakers and their presentations can be found on [www.reddoorautismconference.com](http://www.reddoorautismconference.com)

## Treating Autism Conference

It was great to have the company of David Quinn and Finbar Magee MD for this, the second conference on the biomedical approach to treating autism held in the UK from the 12th to the 14th of March 2009. We met many more people from Ireland in amongst the 300 or so attendees.

We settled into the first session given by Bryan Jepson MD from the Thoughtful House Clinic based in Texas. His practice has treated over 2000 patients with ASD.



There are now over 260,000 persons with ASD in the States, with one being diagnosed every two hours. Dr Jepson stated that Autism is as much a disease affecting the human body from the neck down as it is from the neck up. Dr. Leo Kanner who first coined the phrase Autism in 1943 was a psychiatrist and thus autism has remained in the realm of mental disorders whereas the evidence now shows that autism is all about various combinations of oxidative stress, gut, brain inflammation, immune disorders, poor food, bad diet, toxins, organic mercury and other heavy metals, and genetic predispositions.

Dr Jepson's presentation was followed by a parent's story where a couple recovered their 7 years old boy who was diagnosed with early onset Autism. Gut enzymes, food fermentation, an SCD (Specific Carbohydrate Diet) and chelating were amongst the many strategies they adopted with their medical professional. We listened to many presenters, scientists, medical professionals and parents telling their stories and their varied pathways to success in treating and in many cases fully recovering their children or clients from Autism. We left the conference well armed with new information and great hope knowing that many in the medical profession are now waking up to the multifactorial causes of autism and the many ways we can improve the physical health and therefore the mental health of those affected by autism. The Treating Autism website is a great source of reference for those who wish to know more about the biomedical approaches to treating autism.

Questions on above to [gerard\\_ogorman@hotmail.com](mailto:gerard_ogorman@hotmail.com)  
[www.treatingautism.co.uk](http://www.treatingautism.co.uk)

Having established our National Diagnostic and Assessment centre Solas in April 2007 our multi-disciplinary team have conducted over 350 assessments. Solas would like to take this opportunity to welcome our new team members, Senior Clinical Psychologist Mahrukh Masood and Senior Occupational Therapist Marissa Campos Lupot. Mahrukh has come to us from Pakistan and Marissa joined us from Atlas Training. To learn more about our team check out their profiles on pages 2 and 3.



Release continues to provide Speech and Language assessments as part of the multi-disciplinary team. They also provide Speech Therapy sessions in the Solas Centre on Saturdays. Solas would like to take this opportunity to welcome Tori Houghton who will be commencing with Release on 22nd June 2009. We wish Tori all the best in her new role. We would also like to take this opportunity to wish Jennifer & husband Robert all the best in the new journey that they will embark on as parents in the coming months.

Solas has officially launched a counselling service in September 2008 which offers families and professionals the opportunity to explore their feelings in a safe environment.

## Why go to a counsellor?

Most of us feel worried or depressed at some time in our lives and it helps to have someone to talk to, who'll listen and try to understand. Friends and family can be a great support, but they may have problems of their own or you may not want to share intimate details with them. Often it is only when we talk to someone unconnected with our lives that we begin to hear what we are really saying and feeling. Counselling offers you this opportunity.

## What is counselling?

A counsellor is trained to listen carefully to your problems and to support you while you find your own solutions. Counselling provides a safe space for you to explore your feelings in a supportive environment. The relationship between a counsellor and client is confidential and is based on respect and trust.



Counselling may help you to take control of your life and to understand your feelings, which may help you handle them better in the future.

You may learn different ways of behaving and new ways of coping.

Sessions are one-to-one by appointment only (on a weekly basis for as long as required) and last approximately 50 minutes.

## Want to find out more?

If you're interested in finding out more or making an appointment you can call us at Solas on 01 8531572 or email [counselling@autismireland.ie](mailto:counselling@autismireland.ie)

You can view Yvonne's profile on page 2 and turn over the page to read her tips on managing stress and self care.

## ABA Training at Solas

From June 2009 Solas will be hosting pilot training sessions in the basics of ABA for Parents. Places will be limited so book early to avoid disappointment.

'First Steps in ABA' is the first in a series of practical courses developed by The Developing Ability Partnership, led by Dr. Ken Kerr (Director of Services) with contributions from Dr. Phil Smyth, Dr. Claire McDowell (University of Ulster) and Dr. Katrina Duffy (Saplins School).

ABA Training will help you...

- To understand and advocate on behalf of the individual to improve their quality of life.
- To deliver at-home supports in partnership with other services, in order to enhance the quality of life experienced by the individual.
- To develop and design at-home supports tailored to meet individual needs and abilities.
- To support individuals who use challenging behaviour through innovative interventions.
- To develop skill acquisition programs for individuals to enhance all life experiences.

For further information or to book a place on a 'First Steps in ABA' workshop please contact the Solas Centre 01 8531572. Limited places available, should demands be high enough future courses will be offered.



# MANAGEMENT OF STRESS AND SELF CARE

From time to time we all feel under pressure or stressed. While stress in small manageable doses can be a good thing, if we don't learn techniques to manage it, it can result in anything from mild discomfort to extreme anxiety – and it can play significant havoc with our physical and psychological well being.

The pressures of everyday life (especially in the current economic climate) will take its toll, and having children with ASD will bring additional challenges and 'stressors'. Even just being tired can have a dramatic effect on our ability to manage stress.



So it's really important to take time out and look after ourselves.

In an ideal world, 20 minutes a day of uninterrupted relaxation would be prescribed for each of us – listening to a meditation cd, practicing yoga, or breathing exercises are all great ways to encourage deep relaxation.

For many of us this may feel like an impossible ask, but even just a few minutes a day of 'stress busting' exercises will help interrupt the stress cycle and help you feel considerably more relaxed. And if making a few minutes a day for you feels selfish or unreasonable given everything you have going on in your life, it might help to remember that before you can take care of someone else, you need to take care of yourself.

Here's the science bit in case you're interested...

The body deals with stress with the fight or flight response, which sends alarm signals to the hypothalamus in the mid brain. This stimulates the sympathetic nervous system to prepare the body to react through increases in heart rate, muscle tension, metabolism, breathing and blood pressure.

Blood is directed away from the hands and feet and digestive system to support the larger organs (so the extremities often get cold or sweaty, or you get stomach butterflies or digestion slows down) to allow the body to run (flight) if it needs to.

The diaphragm and anus lock so that bodily functions don't hamper escape and vision and hearing also become more acute – these are really primitive survival reactions kicking in.

Specific symptoms of Sympathetic action include dilated pupils, dry eyes and mouth, fast and shallow or held breathing, increased heart rate, hot or cold sweat, increased insulin secretion and inhibited digestion, increased adrenalin, and reduction in sexual sensation and arousal and general irritability and tetchiness.

If this response is frequently provoked by stress, then the body can start to adversely suffer and there can be long term consequences including impaired immune and repair systems, digestive and reproductive problems, high blood pressure, heart problems etc.

The relaxation response, which triggers the parasympathetic branch of the Autonomic Nervous System into action, turns off the sympathetic response and allows the body to return to a normal state – reversing the Sympathetic action symptoms.



When in a relaxed state the pupils narrow, eyes become moist again and mouth waters, heart rate slows and pulse reduces, blood pressure becomes lower, body temperature and digestive system rebalances and sweating subsides, breathing slows down and deepens and the body is generally more at ease.

There is less insulin secretion and adrenalin production slows down in the absence of Sympathetic action (though there are no parasympathetic nerves to these areas). Sexual appetite increases and blood flow returns to normal so the body is warm and has good colour.

The Good News...

Through relaxation we can actively stimulate the relaxation response and allow the body to go into a rest and repair cycle - and over time this can have hugely positive benefits for the nervous system, digestive system, blood pressure and heart and improve general resilience and immune system.

It can also very quickly help us feel more relaxed, focussed and in control.

Here are some '60 second' exercises that can help break up the day and act as great stress busters.

1. Have a little wiggle and a little giggle – great to do on your own or with the kids when you need a distraction. Simple but fun!
2. SOS – sigh out s-l-o-w-l-y. Try counting the out breath to the count of 8, and the in breath for the count of 4. Do this several times and notice the sensation of your chest and abdomen rising and falling as you do so.
3. Cherry picking. Imagine picking cherries (or a fruit of your choice) from the top of a tree and reaching and stretching to pick the fruit. Get right up on your tippy toes to reach the highest ones!



## MANAGING STRESS AND THE IMPORTANCE OF SELFCARE

4. Grounding – Sitting in an upright chair, allow yourself to feel your seat on the chair, your feet on the floor. Push your bum into the angle at the back of the chair. Lift your legs so your knees are straight and let your feet fall back on the floor, so that the weight of your legs and feet falls on your heels. Consciously allow your weight to sink into the chair, letting the floor and gravity hold you. You might want to let your arms fall by your side and to close your eyes. Then lean slightly to the left SLOWLY, and then to the right, feeling your weight on your left buttock, then your right. Breathe deeply while you do so and when you're finished, sigh out deeply and shake any tension out of your arms, legs or shoulders.
5. Shoulder shrugs. Consciously and SLOWLY circle your shoulders, first one, then the other. Play with it by trying to circle your shoulders in opposite directions at the same time, or one by one in the opposite direction. Let your neck join in if it wants to!
6. Mini Yoga: Stand with your feet together, knees straight. Moving SLOWLY, stretch your arms out to the side, elbows straight, palms facing down. Bring your arms up to shoulder height and roll the palms up to the ceiling. Now bring your arms up so that your fingers are pointing up towards the ceiling, your palms are facing one another and your arms are straight and parallel to one another. Interlink your fingers and then roll your palms up towards the ceiling. Feel the stretch along your whole spine as you do this, allowing yourself to modify this if you have any discomfort. Then allow your fingers to separate, fingers pointing towards the ceiling again, palms facing one another, Bring your arms down to shoulder height, roll your palms towards the floor, and let your arms drop. Shake out any held tension as you let go of the stretch. Breathe deeply as you do this exercise and sigh out deeply at the end to really let the tension out.
7. Shake it out: Shake your left hand and fingers up to your wrist, like you were trying to shake your fingers off. Notice the sensation as you do this. Now see if you can shake the whole of your lower arm from the elbow. Then bring the movement all the way up to your left shoulder, as if you were trying to shake all of your left arm off. Stop and notice the sensation in your left arm, hand and fingers. Do exactly the same in your right hand,



fingers and arm. Stop and notice the sensations.

8. Holding on to a chair or window sill for balance, shake your left foot from the ankle, as if you were trying to shake it off. Then try and shake your lower leg from the knee, and then from the hip. Go slowly and notice the sensation. Repeat in your right foot and leg.

### Goodbye to.....

Solas would like to wish all the best to the following:

Sharon Elias in her new role as research assistant to Dr Louise Gallagher at Trinity Collage within the Autism Genome Project.



Alaine Wetherall who is studying for her degree in Speech and Language Therapy in Reading University.

Allan Willis who has provided Solas with Educational Assessments and has returned to private practice in the United Kingdom.

Rebecca Matthew who is travelling across Europe.

### Creative Arts Therapy

Creative Arts Therapy offers a variety of working methods applicable to children and adults presenting on the autism spectrum.



Creative Arts Therapy involves and integrates several forms of expression such as movement, voice work, storytelling, storymaking, music, creative art and creative dance. It is a method of working and playing that uses action methods to facilitate creativity, imagination, learning, insight and growth.



Opportunities are provided for the client to explore ideas, issues or problems using arts derived activities, expressing and exploring feelings, developing spontaneity, imagination and creativity. It also improves self image, self confidence, and the development of social and relationship skills.

For further information contact Olive Caffrey (Member of Irish Association of Creative Arts Therapists) on 086 88 69 446

# RECENT FUNDRAISING EVENTS

## Raymond Weil Timeless Creations

Ten of the country's top artists united to exhibit their specially commissioned works in aid of Irish Autism Action (IAA), featuring a stunning display of mesmerising original artwork.



The moveable exhibition, titled 'Raymond Weil Timeless Creations', raised funds and awareness of autism in Ireland, and was the primary fundraising activity, organised by luxury Geneva watchmaker Raymond Weil for their 2008 charity of choice, Irish Autism Action. Contributing artists include Graham Knuttel, Pauline Bewick, Hillary Orpen, Bernadette Madden, Helen Steele, Carmel Mooney, Denise Hussey, Paul Timoney, Sheila McCarron and Holly Melia.

All art works as well as an exceptional Raymond Weil pink gold ladies timepiece were auctioned in aid of the IAA at 'The Raymond Weil and Keith Duffy Masquerade Ball 2008'.

The theme of 'time' was applied to each of their works, with artists interpreting this in their own individual way. This theme is fundamental to the early detection of autism, as parents race against the clock in order to identify the condition and avail of crucial early treatment.

We are pleased to confirm that Raymond Weil have again chosen Irish Autism Action as their Charity of Choice for 2009.

## Merlin Motor Group Golf Classic

Wednesday 1st October saw Irish Autism Action and Merlin Motor Group team up to host the second Merlin Motor Group Golf Classic kindly hosted by the Mount

Wolseley Hotel, Spa & Country Club in Tullow, Co. Carlow. 31 teams took part in the event with a shotgun start at 9am and 2pm.

At 7pm a champagne reception greeted all the weary golfers and their partners, followed by a fabulous meal and entertainment throughout dinner provided by Cole Page and afterwards danced into the night to the musical talents of Radio Shack.

We would like to take this opportunity to express our sincere thanks to Merlin Motor City and the Morrissey family for their continued support which they offer Irish Autism Action.



## A Night at the Dogs

Merlin Motor Group once again showed their support to Irish Autism Action by hosting a night at the dogs on Thursday 20th November 2008 in Shelbourne Park, Dublin. The night proved to be an enjoyable one for all involved. We all had a little flutter, some of us picking the lucky winners! A fantastic raffle was held on the night which was generously supported by all there.



We would like to thank Merlin Motor Group and Shelbourne Park for their support.

## Masquerade Ball

The third annual Keith Duffy Masquerade Ball took place in the Great Hall in the Royal Hospital Kilmmainham, Dublin. This year it was proudly supported by Raymond Weil Swiss watch maker which followed the launch of the Timeless Creations Event which is previously mentioned in this edition. The evening was hosted by the lovely Caroline Morahan and entertainment was



provided by Cole Page and special musical guests Boyzone. There was a large attendance, with many bidding for fabulous auction items on the night. The night was a great success for Irish Autism Action.

We would like to take this opportunity to express our sincere thanks to Keith and Boyzone for their outstanding performance and also Raymond Weil.

## Celebrity Skating on Ice

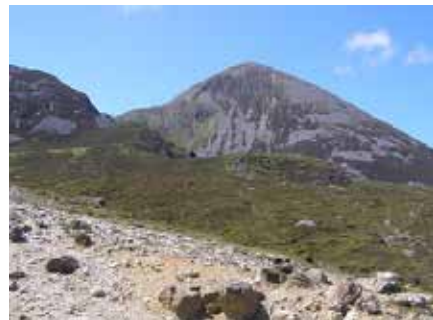
Friday 19th December 2008 saw Brian Ormond proudly supported by Merlin Motor Group skating for Irish Autism Action on The Late Late Show live from the RDS 7up Christmas on Ice.

## RECENT FUNDRAISING EVENTS

There was great enthusiasm among all the supporters and participants. Brian was joined by socialite Lisa Murphy (skating for Down Syndrome Ireland), rugby ace Shane Byrne (skating for Special Olympics Ireland) and former Green Party MEP Patricia McKenna (skating for Children's First). Brian skated into second place. We would like to take this opportunity to thank Merlin Motor Group for sponsoring Brian and supporting Irish Autism Action but also a special thank you to Brian for skating on our behalf. It was very much appreciated. Also thanks to RTE, The Late Late Show and 7-up on Ice for organising the event, and to all who cheered Brian on, either in person by the freezing skate rink, or by Text.



We are completely overwhelmed by the generosity and support from everyone that has got involved with our challenge in any way possible. This event came about due to no ABA (Applied Behavioural Analysis) school in Mayo, with the appropriate educational needs for these kids, therefore the Seven Day in a Row Croagh Patrick Challenge was born. A little boy called Jordan was the main inspiration for this event, however we hope that this fundraiser highlights the challenge that children with Autism face every day and that we can give all children with Autism a suitable education and a better quality of life. From day one, for Johnny, this was all about his love for that boy called Jordan and his willingness for Jordan to get the best of help and care he could. Now that this event has grown so much, all children with Autism in Mayo and elsewhere will benefit from the dedication of one man's idea to climb Croagh Patrick 7 days in a row. This year the event took place from the 11th March to the 17th March 2009 and was a fantastic success with double the numbers of the first year and last year.



### Winning Streak

31st December 2008, saw our patron Keith Duffy along with five other TV and sports personalities go head to head in aid of their respective charities. Congratulations to all who took part.



### Croagh Patrick Seven Day Challenge

This year saw the third annual Seven Day In A Row Croagh Patrick Challenge event which over the last two years has raised a total of €179,000 for Autism. Johnny Oostan and Pat Kearns along with a group of people from Mayo, mainly parents, got together to raise funds for children with Autism in Mayo.

Our main aim is to help fund the opening of an ABA School (Applied Behaviour Analysis) in Mayo. This is now a national event, by which many other counties participate and benefit from the funds raised from the climb.

### Hamleys

The worlds largest toy store, Hamleys have joined Irish Autism Action in raising both funds and awareness for children and families affected by autism. Customers and staff are invited to donate a euro to help build up the lego mosaic for Irish Autism Action. Keith was joined by Lisa, Mia and Jordan to help us start off the fabulous mosaic.

A big thank you to all at Hamleys and all those who have volunteered for the weekends and also those who have added a brick. Your support is very much appreciated.



# RECENT FUNDRAISING EVENTS

## DHL

DHL which has a staff of approximately 2,000 across Ireland in aid of Irish Autism Action held various fundraising events over the past 18 months ranging from pub quizzes and mini marathons to sponsored head shavings.

Friday 6th March 2009 brought great excitement to the town of Swords as DHL's most recent fundraising efforts saw the raffle of a Mercedes C Class.



The event took DHL's total fundraising to €100,000 and featured Keith Duffy who drew the winning ticket. However, our lucky winner Tracy Power was not in Wright's but received a phone call from Keith wishing her congratulations.

Tracy joined the festivities shortly after that and celebrations commenced. On the 2nd of April while visiting DHL, we presented Tracy with her winnings.

As an incentive for staff to sell tickets DHL held an exclusive draw with one lucky staff member winning a holiday in Greece – Congratulations to John O'Hanrahan.

## Northern Trust

In June a group of staff from Northern Trust climbed Lugnaquilla to raise funds for children in the Saplings School in Kildare. They raised €10,000 which has gone towards building a playground for the children in Saplings School, Kildare.



We would like to thank the staff from Northern Trust for all their efforts and time they took out to do the climb. It is very much appreciated.

## Run for Autism

On the 4th of October 2008 a 10 mile Walk and/or Run for Autism took place in Newtownhamilton. People from all walks of life came out in support of the event. Local Councillors and Assembly members attend the event which was a cross community success.

Keith Duffy started off the walk at Newtownhamilton and joined the many others in completing the walk. The event managed to gain the support of over 300 participants and raised a fantastic £35,475. Congratulations to all who took part and a special acknowledgement to all who were involved in organising the event. Well done!

## Skydive For Autism

Rachel Gallagher along with a group of 11 people got together and did a Skydive for Autism. The event also raised awareness among those who sponsored the gang to do the dive.



## Thank You

Thanks to all who have donated prizes for our events including Weekend Breaks, Artwork, Wine Hampers, Golf Packages, Holiday Vouchers, Jewellery, Concert and Football Packages and other sports memorabilia, Electronic Equipment such as Ipods, DVD Players, Mobile Phones etc.

It is very much appreciated and we value your continuous support.

# UPCOMING EVENTS

## BYU - Singers Brigham Young University Singers

The BYU Singers, widely considered to be one of the finest choirs in the United States, have performed in some of the most prestigious concert halls in the world, including Carnegie Hall, the Sydney Opera House and the Kapella in St. Petersburg.



As part of its latest international tour, this exciting ensemble of students from Utah is now coming to Ireland and will perform at the Draiocht Theatre in Blanchardstown at 8pm on 12th May 2009.

During this stunning and joyful concert, there will be beautiful music to please the ear, captivate the heart and celebrate life.

Profits from this event will be donated to Irish Autism Action. Tickets are priced at €15 with concessions (seniors and under 16s) at €13 and are available at the Draiocht box-office, (either in person or by phone at 01 885 2622) or online (with booking fee) at <http://www.draiocht.ie>

To find out more information on the BYU (Brigham Young University Singers) visit their website on <http://singers.byu.edu>

## FDNY Golf Classic

We would like to take this opportunity to extend our thanks to Pfizer and the New York Fire Department who have chosen Irish Autism Action as the beneficiary to their golf classic that they are holding on 29th May 2009 in Greystones Golf Club. 3 ball rumble, BBQ on the 9th and only €300 per team. For more information on the event contact Alan on 087 644 3849 or Mark on 086 826 0439.

**GOLF FUNDRAISER**  
**FRIDAY MAY 29TH**  
**GREYSTONES GOLF CLUB**

- 3 BALL RUMBLE
- BBQ ON THE 9TH
- GREAT PRIZES
- €300 PER TEAM

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FOR MORE INFO CONTACT:  
Alan - 087 644 3849 or 0404 66751  
Mark - 0402 33505 or 086 826 0439

**ALL PROCEEDS TO**

**IAA** Irish Autism Action  
*Raising Standards*

## Swords Boxing Club

Why not come down to the Pavilions Shopping Centre in Swords on 22nd May and cheer on the Swords Boxing Club as they raise much needed funds for Irish Autism Action by holding a Skipathon.



## Life Lasting Success

Following an incredibly successful sell out business and entrepreneur weekend [www.LifeLastingSuccess.com](http://www.LifeLastingSuccess.com) is delighted to announce that they have raised 2,000 euros for Irish Autism Action. To book your seat to the October event featuring Bob Proctor from the movie "The Secret", and support your charity who will receive 50% of your ticket price, go here - [www.LifeLastingSuccess.com/affiliate/autism](http://www.LifeLastingSuccess.com/affiliate/autism).

## Flora Mini Marathon

It's that time of year again for all us women to hit the streets in aid of our favourite charity.

Flora Mini Marathon is on Bank Holiday Monday, 1st June 2009 at 3.00pm starting from Fitzwilliam Square, Dublin 2 to St. Stephen's Green, Dublin 2 (Distance of 10K).

[www.florawomensminimarathon.ie](http://www.florawomensminimarathon.ie)



Pippa O'Connor

## UPCOMING EVENTS

Should you wish to participate in the marathon on behalf of Irish Autism Action please contact Sarah McEnerney-Buckley on 044 93 42576 or e-mail [sarah@autismireland.ie](mailto:sarah@autismireland.ie)

All general enquiries to be directed to Women's Mini Marathon Office, 27 Sandyford Office Park, Sandyford Industrial Estate, Dublin 18. Tel: 01 2930 984  
Email: [info@womensminimarathon.ie](mailto:info@womensminimarathon.ie)

Irish Autism Action would like to express our sincere thanks to Irish Models Pippa O'Connor and Ruth O'Neill for partaking in the mini marathon on our behalf.

### PGA National

On 11th September why not join us for our second round at the PGA National.

Last year saw the Irish Autism Action being chosen by the Mansfield group as their Charity of Choice and a spectacular event being hosted in the PGA, Palmerstown House Estate in Co. Kildare by the Mansfield's. Once again our sincere thanks to Jim Mansfield.



This year's event should prove to be just as spectacular and entertaining so why not get in early to avoid disappointment.

For further information on the event please contact Sarah McEnerney-Buckley on 044 93 42576 or e-mail [sarah@autismireland.ie](mailto:sarah@autismireland.ie)

### Golfing with the Stars for Autism, Mullingar

The 25th of September 2009 will see Irish Autism Action, Bernard Flynn, Ken Doherty and many more Tee up for our 4th annual golf classic event in aid of Autism. A team for this event is €800 which includes golf for 4 persons, a gala meal and a fabulous nights entertainment.

Should you wish to support this event or would like further information please contact Sarah McEnerney-Buckley on 044 93 42576 or e-mail [sarah@autismireland.ie](mailto:sarah@autismireland.ie)



### Trek Peru with Irish Autism Action

Why not join us on a trek to Peru and follow the magical trail of the Incas while supporting Irish Autism Action.



#### Day 1

Dublin/Amsterdam/ Lima Evening at leisure. Welcome Dinner .

#### Day 2

Flight Lima/Cusco. Afternoon tour of city. Evening at leisure.

#### Day 3 Start 4 day/3 night INCA TRAIL CUSCO

HUAYLLABAMBA Trekking along the Urubamba river to the Archaeological site Llaqtapata. Lunch and onwards to Huayllabamba.

#### Day 4

After breakfast, onwards to Pacaymayo. Trek to 4200mts.

#### Day 5

Pacaymayo/Winaywayne; Our journey takes us trekking on the original stone path of the Incas trail with spectacular views of the tropical cloud forests.

#### Day 6

Spectacular trek to the mysterious MACHU PICCHU - THE LOST CITY OF THE INCAS.

#### Day 7

Back to Cusco for day's tour of the city.

#### Day 8

Return flights Cusco/Lima/Amsterdam/Dublin.

Package includes 4Star Full Board Accommodation.

For an entry pack call Freddie Grehan on: 086-858 4144

or email: [info@sportingandspecialevents.com](mailto:info@sportingandspecialevents.com)

Registration fee €300. Minimum sponsorship €5000.

## To Russia With Love

Irish children's Charity To Russia With Love, who have been working in Russia for 10 years now, teamed up with Irish Autism Action in response to a lack of specialist help available in Russia for children with Autism. To Russia With Love were approached by specialist teams in Russia seeking advice in this area and were delighted to work with the Irish Autism Action team on this project.



The Irish group, which included psychologists, parents of Irish Autistic Children, interpreters, and representatives from both organisations including Debbie Deegan the funder & Managing Director of To Russia With Love and Keith Duffy the patron of Irish Autism Action met with Russian parents of children with



autism as well as those working to educate and treat the condition to share experiences and insights.

“In the current economic climate when charities are struggling to fund-raise, it is imperative for organisations like us and Irish Autism Action to look at where they overlap and pool their resources for the benefit of the children”, says Debbie Deegan, founder of To Russia with Love.

“To Russia with Love has always advocated the sharing of knowledge in child development between Ireland and Russia and we feel that the expertise of Irish Autism Action will be of great benefit to Russian children, their parents, those working in the field as well as the children of the 12 orphanages we work with.”

Over the seven days, the group met with groups of parents of children with Autism and provided seminars to professionals working in the area of Autism. They also visited the orphanages where To Russia with Love provide care and support to Russian orphans and the Children's Psychiatric Hospital in Bryansk, bringing toys donated by Hamleys who sponsored the joint project.

This joint project greatly highlighted awareness of the plight of Autistic Children in Russia and was very well received by all involved. Debbie Deegan and Keith Duffy also gave interviews to Russian TV, which will be seen by all across Russia, which will further enhance the success of the trip.

## Dublin Airport Authority Partnership Launch

2009 saw Dublin Airport Authority (DAA) choosing Irish Autism Action as their charity of choice. DAA and its large staff base will make a significant difference to Irish Autism Action through their various fund raising efforts over the next year.

We would like to express our sincere thanks to DAA for choosing us as their charity of choice.

Our partnership with DAA means that already through their passenger numbers more and more people are being made aware of Irish Autism Action. Our sincere thanks for the wonderful opportunity being afforded to us.



## Marks & Spencer

Irish Autism Action are delighted to announce our partnership with Marks & Spencer (M&S). A major fundraising initiative with M&S is planned for June, July and August 2009.



## Celebrating 30 Years

This partnership will represent a greater opportunity for localised fundraising to support our member groups. Lisa Domican of Irish Autism Action will be in touch with all members with more information shortly.

## Telethon - People in Need

Irish Autism Action were recipients of Telethon funding from the People in Need event. Many thanks to all for their fundraising efforts.



## Community Foundation for Ireland

The Community Foundation for Ireland is an expert donor services and grant-making organisation. It was established in 2000 and is a registered charity. Since then individuals, families, businesses and other institutions have set up charitable funds under the umbrella of The Foundation. The Community Foundation helps people to engage in more effective and rewarding philanthropic activity by connecting donors to the most deserving and impactful causes. By 2008, the combined value of permanent donor funds at The Community Foundation was €27 million. Since its inception it has made grants to date on behalf of donors of over €5 million. President Mary McAleese is the Patron, and the Board is comprised of distinguished representatives from the public, private and community and voluntary sectors.



Irish Autism Action are pleased to confirm that we have now become a beneficiary of the Community Foundation for Ireland, for which we are extremely grateful.

## Pavillions Swords

On the 26th March 2009 Swords Pavillions, one of Dublin's premier retail destinations, announced that it is to team up with Irish Autism Action as its adopted charity for 2009 in an attempt to raise much-needed funds for the organisation.

The announcement was made at a launch in Swords Pavillions where Keith Duffy was joined by Ian Hunter, Centre Director, Swords Pavillions along with friends of Irish Autism Action including Irish model, Ruth O'Neill. Speaking at the launch, Ian Hunter, Centre Director, said: "Irish Autism Action is an extraordinary organisation which contributes hugely to the lives of many individuals across the country."

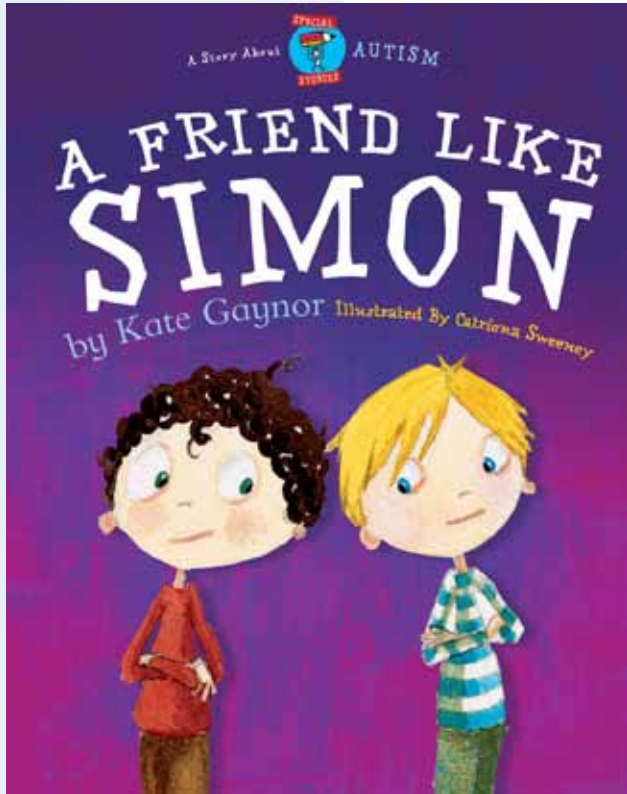


We are delighted to be able to play a small part in contributing to the work of Irish Autism Action through adopting it as our chosen charity for 2009 and we look forward to working with Keith and the charity over the coming year to raise the necessary funds." Kevin Whelan CEO of Irish Autism Action said: "We are delighted with this partnership with Swords Pavillions as not only will it raise valuable funds for our work but it will enhance the public's awareness of the needs of families affected by autism in our community."

To celebrate the launch, a Harley Davidson 'Ultra Classic Electra Glide', which will feature artwork by renowned Irish artist Rasher, will begin its nationwide journey at Swords Pavillions. The Harley will be auctioned to raise funds for Irish Autism Action and can be seen at various locations around the country.

## A Friend Like Simon

Irish publishing house Special Stories Publishing in conjunction with Irish Autism Action has released an exciting and unique new children's book focusing on young children with Autism/ASD.



The book titled 'A Friend like Simon' is beautifully illustrated by Irish artist Caitriona Sweeney and is designed to introduce all children, especially those in mainstream school, to a child with ASD.

The story begins with Matthew greeting his new classmate Simon on his first day at a new school. When Mathew realises Simon is a little different to his other friends, he's just not sure if he wants to have 'a friend like Simon'. However, a school trip to the funfair soon helps to change his mind!

This new book will be a very welcome resource for Irish parents and teachers alike as an introduction to Autism/ASD for other young children.

By making the book available as a resource to primary schools throughout Ireland, IAA and Special Stories hope to highlight the positive aspects of inclusive education and the benefits it can bring to children's lives.

'A Friend like Simon' is the first book of its kind to be published and produced for the Irish market.

The book will be available to the public through all good bookstores nationwide at a cost of €8.99 from August as well as through the IAA and Special Stories websites listed below.

For further information on 'A Friend like Simon' or stockist info please contact [kate@specialstories.ie](mailto:kate@specialstories.ie) or visit the Special Stories website [www.specialstories.ie](http://www.specialstories.ie)

## New Membership / Identity Card

To receive your ID card, please send the following information to Irish Autism Action, 41 Newlands, Mullingar, Co. Westmeath:

1. Full name of child
2. Full postal address
3. Child's date of birth
4. Names of parents and contact details
5. Recent photograph of your child

You can fill in the details on the membership form on the last page of this magazine.



## DHL - PARTNERSHIP

DHL employees across Ireland unite to raise €100k for children with Autism



A successful partnership with Irish Autism Action has been in place for 18 months now. Employees united in their continued efforts to increase awareness of autism in Ireland.

On the 23rd March 2009 employees at DHL in Ireland, part of the world's leading express and logistics service provider, have united to support children's charity Irish Autism Action (IAA) by raising €100,000 for the organisation.

Employees from across the island of Ireland, from all walks of life and areas of the business have come together over the last 18 months to take part in a whole host of fundraising activities ranging from pub quizzes, mini marathons and football tournaments to sponsored head-shaving.

Commenting on DHL's contributions, Irish Autism Action patron and Boyzone member Keith Duffy said: "Irish Autism Action carries out such an important role in raising awareness of the needs and rights of families affected by autism.



It's fantastic to see the enthusiasm that DHL's employees have shown in sacrificing their time to provide support and make a real difference to people's lives."

DHL's most recent fundraising efforts have seen the raffle of a Mercedes B Class car, which took place in Swords this month. With yet another €50,000 this event took DHL's total fundraising to €100,000, which featured Keith Duffy who drew the winning raffle ticket.

Hugh Basham, Managing Director, DHL Supply Chain said: "It's fantastic to see so many DHL staff across the length and breadth of the country united in backing such a worthwhile project.

As a company we try to support charitable causes and it's rewarding to see our staff really take the bull by the horns in adopting this approach. "

Bernard McCarthy, Managing Director, DHL Express added "The whole project has created a feel good factor throughout the entire business with everyone pulling together for such a good cause.

Our employees are passionate about Irish Autism Action and each individual participating has really put their all into it. Even though some now have considerably less hair, there have been no complaints."

The commitment shown by DHL employees in Ireland mirrors



the organisational commitment to corporate social responsibility shown by Deutsche Post DHL employees worldwide. In 2005 Deutsche Post DHL entered into a strategic partnership with the United Nation system.

Deutsche Post DHL contributes logistics expertise and the commitment of highly trained and motivated employees to deliver support in the face of humanitarian need and disaster management.

We would like to express our sincere thanks to the committee and especially Tanya Payne for all their hard work effort and time afforded to Irish Autism Action.

We would also like to thank DHL for extending the partnership with Irish Autism Action for 2009.

**Review of 2008**

It was another successful and important year for O2's charity of choice, Irish Autism Action. 2008 saw the partnership go from strength to strength and as a result of the success the partnership has brought for both IAA and O2, it was decided that IAA would continue as the O2 charity of choice for a fourth year, a decision that has been welcomed with great enthusiasm by both parties.

O2 donated over €120,000 to IAA in 2008 and here are just a few ways this money was raised.

- Through the various methods for O2 employees to donate from their salaries, Cents from Heaven, Payroll Giving and Flex Benefits, over €20,000.00 has been raised.
- Annually O2 give a corporate donation of €35,000 to IAA and a Christmas card donation of €30,000 instead of sending cards.
- April saw the return of Willy Wonka's chocolate bars for sale. They proved very popular among the avid chocolate lovers!
- In the summer of 2008 the Dublin and Limerick Penalty Shoot Outs took place and with your support and O2's Charity Top Up scheme, over €6,000 was raised for IAA.
- October saw the launch of the IAA Affinity Deal, where O2 customers could sign up to have 5% of their monthly call value donated to IAA by O2. The Affinity Deal has been a great success for IAA and O2 with 6500 customers signing up to the deal from the period October to December 2008 and a total of €38,000 being raised for the same period.
- The FoneBack Recycling Scheme raised €26,000 for IAA in 2008 through our new recycling scheme with partner Redeem, launched in October.
- December saw the annual sale of IAA Christmas cards which raised funds through employee purchases of the cards and O2's charity top up scheme.

**2009 – the Year so Far**

O2 employees from Dublin and Limerick climb Croagh Patrick for IAA. Over the St Patrick's weekend a number of O2 employees from Dublin and Limerick took the challenge to climb Croagh Patrick in Co. Mayo for Irish Autism Action (not for the 7 days in the row now, but still a challenge all the same!)

Dave Nixon and Paul Reilly from O2 Retail, and their team 'O2 Team Spirit' managed to reach the top of Croagh Patrick successfully on Saturday 14th March. Known locally as 'the reek' Croagh Patrick stands at 764m and is synonymous with the

annual pilgrimage by thousands on 'Reek Sunday' following in the footsteps of St Patrick. The team managed to get up 'the hill' in one hour & twenty minutes with a speedier gravity-fuelled descent of just under an hour! The team's target of €5000 looks likely to be exceeded, with the help of O2's Can-Do Matching.



Hazel Baznett, Fiona Noctor and Keith Keily, from ReachOut, Fiona Meehan from Corporate Affairs and Kieran Rabitt in Finance all climbed to the top of Croagh Patrick on Sunday 15th. Fiona and Kieran met St Patrick himself on the way down, well a guy dressed as St Patrick, and also spotted a very brave (or mad) participant climbing bare foot....definitely not for the faint hearted!

Marc Pool and the rest of the Reach out Team Leaders, took the challenge on Monday 16th March. Marcs story is one of trials and tribulations with a happy ending!

'We arrived in Westport, Co. Mayo the night before decided that some rest was needed, so at 10pm we were all safely tucked up in our Pjs in preparation for the day ahead.

The next day there were tears, tantrums, thrills and spills, but once we left the car park we started our journey up Croagh Patrick in aid of Irish Autism Action.

Early on, one of our intrepid climbers Sinead 'Maggie Simpson' Sheehan took a tumble, but like a trooper she dusted herself off and carried on. We made it to the summit in little over 2 hours which we were delighted with since the previous day some of the Reach out agents made the trip in less than 2 hours (we were later to find out that this was closer to 5)

As a team building event it was great, everybody encouraged each other and there were lots of laughs along the way. It was physically very tough but we all agreed at the end it was enjoyable and for a very worthwhile cause.....roll on next year.

Thanks again to everyone who took part. The overall total raised will be applying for Charity Top Up to match the figure.

## World Autism Awareness Day in O2

What did the employees get up to for WAAD?

### *Wear Blue for Irish Autism Action!*

All employees in both our Dublin and Limerick offices were asked to Wear Blue for Autism and donate a minimum of €2.

### *Celebs participate in Penalty Shoot Out*

Over 60 O2 employees from across the business in our Head Office in Sir John Rogersons Quay took part in a Penalty Shoot for World Autism Awareness Day. It was a glorious day and a fun day for all involved.



Keith Duffy, Johnny Giles, Ken Doherty, Tom Dunne, Brian Ormond and Ger Gilroy dropped in to take a shot at goal and show their support for IAA. Paul Whelan, our CFO, showed off his goal keeping skills against the celebs, with only one managing to score more than one penalty!

### *Laughter Lounge*

Over 60 people attended the Dublin Sports & Social fundraising night in The Laughter Lounge on Thursday 2nd April.

### *O2 Retail*

All O2 retail stores nationwide will be selling IAA pins in the stores for the months of April and May.

### *Charity Top Up!*

All figures raised will go through O2's charity top process where we will be able to double that figure to €8,320.54

### *O2 Employees Volunteer for Red Door School*

In January 09, the Red Door School for autism moved premises and O2 employees helped them to get their new school ready for action.

Over 25 O2 employees volunteered to help with painting and decorating over three weekends, which not only meant the school was ready to open on time, but it also ensured there was a smooth transition for the kids attending the school.

On April 17th, Eugene Mitchell, Head of Business Partnering in Finance and his team of 35 did a half day of painting/decorating for the Red Door School. An amazing amount of work was achieved on the day much to the delight of Martina Boylan, Director of Education in the school.



## Welcome to....

Irish Autism Action would like to extend a warm welcome to Fiona Meehan who has joined the IAA/O2 partnership team in 2008

We would also like to take this opportunity to welcome back Sinead Smith.



## Farewell Niamh

Irish Autism Action would like to wish all the best to Niamh Griffin who has moved on from her corporate world to the land of teaching.

We wish her all the best in her new career path. You will be great Niamh.



## VIRTUAL WORLD - A PROFILE BY LISA DOMICAN

Some of you may know me as the mouth from the south who campaigned for Applied Behavioural Analysis for her kids for several years in the media and other avenues. At the same time I did a home program using part time tutors from respected ABA schools, while my kids attended a state ASD unit - and that took up a lot of my time and energy.



*My interruptions\**

Almost 12 months ago, they were accepted into a full time ABA school and I suddenly had a bit of head space - but still enough energy; so I started to work for Irish Autism Action part time.

My first job was “The Affinity”, a chance for all IAA groups to connect with our long term sponsors - O2, and raise much needed funds.

For the month of October, existing and new o2 customers could text the word “autism” to 50308 and from that point o2 would donate 5% of their call costs directly to community based autism groups which were members of the IAA.

It was my job to communicate this to the groups and ensure that they spread the word and get as many people to text and join as possible.

As a new parent in a full service ABA school, I could see the enormous advantage of the Affinity because we have fundraised to maintain a fully supervised and supported educational program.

The more people who joined the Affinity, the more these schools could expect to receive in quarterly donations, across all of 2009.

Now that could really help with planning and delivery of services that the state doesn't fund.

It was a great opportunity to help our members in every county and I enjoyed identifying and getting to know the key fundraisers in each group. I learned and then shared the best ways to foster community based support networks, and I am so grateful for their efforts.

The Autism Affinity was a huge success - we raised almost €40,000 in the quarter from October to December to be distributed amongst the county groups. Let's make sure all those people Stay with O2 in 2009 and the groups can continue to collect a similar amount for each remaining quarter.

There are some amazingly hard working parents out there - I call them the “Alpha Mums (and Dads)” who raise literally thousands of euro for their groups and schools and keep them offering the education their children need. We can campaign all we like for the supervision and therapy entitlements but nothing replaces lost time. The imperative is always to supply what the kids need now - whatever it takes.

Like it or not, we are moving into challenging times and it is the local effort and local support that is going to see our kids through. The days of Balls and Golf Days and huge charity auctions might be a little leaner now but - I believe that grass roots community based giving and support will continue.

Time and again the Irish have shown themselves to be a generous and compassionate people who reach into their pockets first and ask what it's about second. And when you have a cause or project that is making a quantifiable difference to the lives of people and families with autism - as all of our member groups do; then you will find that support in your community undiminished - whatever the economic climate.

So my role now is to ensure that we continue to network our communities, to maintain the connections and links we made during the Affinity and to reach out and include as many families as possible under the wider IAA umbrella.

There are many families with a child (or 2) with autism out there who have never attended a support group or council meeting.

They might be too shy to network, or isolated either by distance, circumstances like very high needs or the fact that their child is in mainstream education, but still very much in need of autism specific services and support.

It can be a vicious circle of no network, no support, no chance to get out and meet other parents and learn about services, and then campaign or advocate for provision of support.



*My interruptions\**

And as we said last year, “Children with Autism (seem to) like spending time alone - their parents shouldn’t have to.”

So I thought I should harness the power of the internet, the refuge of the socially awkward (like myself) and use it to connect.

I was also minding the current website. I’ve cleaned up and moved the furniture around a bit but basically it has to stay as is until the new one is ready, so be kind and constructive when you visit. It’s at [www.autismireland.ie](http://www.autismireland.ie)

I also added on a blog on: [irishautismaction.blogspot.com](http://irishautismaction.blogspot.com) - (now where did that idea come from?) which is a little more opinionated and casual than the website, and a darn sight quicker to update. I hope you all enjoy it and leave a few comments now and again - it’s all reinforcement you know!

I also wanted a Gallery to share photos of all that we have achieved as a group of parents, for parents and set up our Facebook page. Go to: [www.facebook.com/home](http://www.facebook.com/home) and join, then search for [irishautismaction](http://irishautismaction)

Well, it has turned into a great way to reach out to individual and group members and keep in touch.

Autism Hours can be very anti-social, but there is always someone around on Facebook when you are and our on-line connections can go on in the midst of bedlam, or the middle of the night without the usual interruptions\*.



So thank you for your support so far. I look forward to meeting more of you online or in person and hopefully continuing to reach out and make more connections that will enrich our combined force.

Join us in our virtual world and become part of the community that supports those families affected with autism.

# AUTISM PARTNERS IN INNOVATION

Autism Partners in Innovation is a coordinated initiative which aims to enhance and support the whole person and family affected by Autism by providing access to information.

A number of different groups working with Autism in Ireland came together to access the funding offered by Enhancing Disability Services Project, which is administered by Pobal.

Further to a number of discussions between the groups and agencies it was agreed that the groups would form a steering committee with a view to working together to create the best possible standards and options to enhance the lives of people with Autism.

The first step in this project is to create a website that will act as a central information point for Autism in Ireland. Currently there is no one website where all information on Autism Services in Ireland is available.

We aim to create an encompassing, informative, easy to access and navigate, interactive continuously maintained, up to date, linked website on Autism in Ireland. This exciting project will launch in September 2009.

Irish Autism Action are the lead agency working in collaboration with Gheel Autism Services, Aspire, Tuisceant, ABACAS and Cork Association for Autism.

Central to the success of the website will be the involvement of IAA members. There are a number of planned workshops over the coming months. Emily Scanlan the project coordinator will be in contact.

If you have any questions or ideas please email:  
emily@autismireland.ie.



Proposed site content

## About autism

- What is autism?
- What is Asperger Syndrome?
- Interventions
- Diagnosis
- Benefits & rights
- Behaviour, communication & play

## Education

- Courses and training
- Courses in your county (interactive flash map)

## Services & Support

- School services
- Adult services
- After diagnosis: support services
- Services in your county (interactive flash map)

## Information for:

- People with an ASD
- Parents & carers
- Partners
- Siblings
- Grandparents
- Professionals
- Info for journalists
- Employers & corporate supporters
- Pupils & students
- People who want to work with people with ASDs

## Information on all Partner Groups

- Name
- Description
- Contact

## News & Events

- Latest news
- Newsletter signup
- Autism in the news
- Courses/Conferences
- Event calendar
- Multimedia
- Image gallery
- Video/Podcasts

## Downloadable publications from One stop Shop website

- Forum (part time mediated)
- Full site search
- Contact
- Links

## ADDITIONAL INFORMATION

Autism Genome Project  
Trinity College Dublin



Below is a brief synopsis of the project and recent findings to date.

**Purpose of the Autism Genome Project (AGP)**

The International Multi-centre Autism Genome Project (AGP) is the biggest autism research project in the world, and aims to identify the genes contributing to autism spectrum disorder.

Over 100 researchers at 15 different University sites in Europe, including Ireland, the United States and Canada are collaborating on this project. The Autism Genome Project aims to identify the genetic causes of autism.

This study will use modern genetic techniques, and match the findings to a detailed clinical examination to try and find out which genes are contributing to the symptoms of autism.

**Purpose of the Autism Simplex Collection (TASC)**

The TASC project is a project related to the AGP that is running at the same time. The Autism Simplex Collection (TASC) is a collection of medical information and genetic material, or DNA, from individuals with autism, as well as from their parents.

The repository holding the genetic material is in Rutgers University, New Jersey in USA. 12 different University sites in Europe, including Ireland, the United States and Canada are collaborating on this project.

The two projects are related and the majority of families are participating in both studies. We will combine the information that is being gathered as part of the TASC program with genetic data to help us to identify genes that are contributing to the risk of developing autism.

**Important Research Findings**

Our research findings have shed light on many potential genetic correlates of ASD, for example AGP research has identified submicroscopic rearrangements in the genome that may contribute to autism in subgroups of individuals (Nature Genetics, 2008) and a region on Chromosome 15 has been identified that may harbour genes for autism in individuals with autism and normal IQ (Biological Psychiatry, 2008) and a region on chromosome 11 has been shown to potentially harbour genes for autism in individuals with delayed phrase speech (Biological Psychiatry, 2008).

The last two years have been an exciting time for autism genetics research. There have been some important papers

published, some of which our group has been involved in. A currently interesting finding is an event called 'copy number variation'. This is where a person can get more (duplication) or less (deletion) genetic material in a particular region than usual.

Sometimes duplications or deletions can affect one or more genes. In general, we have two copies of each gene (one from our mother one from our father).

One of the most common seen 'copy number variant' syndrome in the population is Down's syndrome – where a child gets an extra copy of a chromosome 21. The implications of these studies (which are ongoing) are that we may identify genes involved in autism. These 'copy number variations' sometimes happen in the same region in many different patients.

One example in autism research is a region on chromosome 1 (1q21) region are more at risk of developmental problems. Members of our group were authors on a publication in the New England Journal of Medicine in October 2008 describing this new 1q21 syndrome.

This is a rare syndrome and does not affect all or even many people with autism but it may help to explain a small number of cases.

**New Projects**

We are always trying to find new ways to study autism. We have two projects starting up in 2009. Investigating rates of autism in 1st generation Irish children: We have noticed through our clinical experience that a large number of the children we see are born to parents who have just moved to Ireland.

We are interested to investigate this further to see if there are higher rates of autism in these children compared with children born to native Irish families. If so, we are interested to know if there is any difference in the type of autism, more or less severe or if there are other factors that might have influenced the development of autism.



This research project is starting in July 2009 through the Adelaide and Meath Hospital (incorporating the National Children's Hospital) in Tallaght. The research funds were donated by the National Children's Foundation, Tallaght.

**The TRACT study – (Trinity Research in Autism Connectivity of Tracts)**

With recent advances in brain imaging techniques, we are now able to use Magnetic Resonance Imaging (MRI) for exciting studies in autism. In the TRACT study, we will be using MRI techniques to investigate brain activity and connections between

## ADDITIONAL INFORMATION

brain regions in children with autism/ Asperger syndrome. It is hoped that this study will give us insights into how the brain functions in autism and Asperger syndrome.

In the study, we will be asking participants to perform computer-based tasks (like simple computer games) while they are lying in an MRI machine that takes rapid pictures of the brain.

We are currently recruiting people who have a diagnosis of Asperger syndrome or autism spectrum condition who are attending (or have attended – if >17 years old) mainstream school. We have to use quite strict criteria to ensure that we can compare the brain scans and so all participants must be male, right handed, aged between 14 and 21 and have no metal in their body (this includes braces on teeth).

If you would like more information about this study, please contact Dr Jane McGrath (contact details below).

### Research Team Contact Information

TASC: Dr Louise Gallagher, Dr. Gillian Hughes, Ms. Sharon Elias, Mr. Sean Brennan

The TRACT study: Dr. Jane McGrath

All parties are contactable at 01-8962315.

### I Stim Therefore I am.....

Stimming is a made up word, short for self stimulation. It can be Twirling, SPINNING, clapping, flapping, finger clicking, hand chewing, clothes chewing, tearing, rocking and the list goes on.

It can also be reciting something obsessively like the “Who’s on First” routine from the movie “Rainman” with Dustin Hoffman.



I like to call that “scripting”. Or reciting all the features of a favourite item, like trains or animals, or the entire cast and crew from a favourite film. Or turning things on and off and opening and closing doors, windows or presses. (cupboards) Or focusing intently on a particular detail of an object without really seeing the whole thing.

It can also be asking the same questions again and again.

And some kids can double stim, focusing intently on something and then flapping, or doing a bit of scripting while finger clicking. And it can be intensely pleasurable for the person. They may appear to become absent while they are doing it; disappearing into a private world of ecstasy for a period.



Adults with autism who have overcome their communication challenges have been able to describe to the rest of us the purpose it serves. I heard of a lady who was a university lecturer who did speaking engagements for parents of children with autism. She spoke of how she was able to pass an entire day in the company of students and fellow lecturers knowing that she could go home and indulge in a bit of paper tearing when she finished work. Paper Tearing. She had a stack of newspapers shoulder high in the corner of her sitting room. Sounds no different to a glass and half of Beaujolais to me. Or half a packet of Tim tams. Or a packet of smokes. Healthier in fact.

But the sad truth of the stim, whatever function they serve, is that they make a child or adult stand out as a bit weird. And it can annoy the people around them. It can even upset their parents and loved ones as they appear to use it to block them out.

So what do we do about ‘em?

Stamp them out! Some of you will say. Allowing stims is just lazy teaching I was once told.

I don’t agree. Both for the fact that they are usually harmless and because what replaces them can be worse.

Imagine a kid with Autism as a suitcase stuffed full of sensory needs, that you as a parent is trying to zip up; there is too much in the suitcase so even if you sit on it and get the zip done up for a minute, The zip is going to burst in another spot and stuff will fall out.

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If you do get it shut and maybe strapped up, you know that as soon as you open it all that stuff is going to burst out everywhere; usually at the most inconvenient place possible.

So the first step is to discover the sensory function of the stim, and find a way to reduce or replace it. We do this by way of a functional assessment. What purpose does the stim serve? Is it because the child has numbness and needs to shake or click or flap to “wake up” their hands? Like when your foot goes to sleep and you keep shaking it or when you come back from the dentist after an anaesthetic and you keep playing with your lip. Is it because the area is overly sensitive and they like to comfort it? Like when you have a sore tooth that you keep probing with your tongue or a blind pimple you have to fiddle with. (As in “see, it really hurts when I touch it” “so don’t touch it!” “but I have to....” etc.)

You can try to work this out by recording when and how often the stimming occurs, and in response to what. You should also describe the stim in detail when doing this charting. It really helps to have access to an Occupational therapist or someone who understands the physiology of the body in relation to autism. Behavioural therapists who have worked in schools with a lot of different kids can help too.



A good O.T. will help suggest a replacement activity that serves the same need, but in a more appropriate way. A child that chews or bites things could benefit from regular oral massage with an electric toothbrush or massage toy. Oral B do a thing called a humming bird which is meant for flossing but is a great little gum and cheek massage tool. For rockers and flappers there could be movement activities that balance out the need.

But you must do these on a regular schedule and not just in response to a spell of stimming. That just teaches the child to request the good massage with a stim!

As in: “If I rock in my chair, Mummy will take me to the living room and give me a good squash with the pilates ball” You don’t want it to work like that.

Regularly top up the sensory need with the suggested activities throughout the day so the need to stim does not occur. You can work out how often they need it by recording the frequency of the behaviour. And then trying to replace it just as often.

Teach the child to request the activity for themselves. This can help balance their internal sensory issues and teach them a valuable lesson in self soothing.

And all this work will help to reduce your child’s overall sensory challenges and make the suitcase a little easier to close.

Speaking personally. I feel that many stims are actually a really clever means of self balancing that the child has come up with.

Yes, some stims are genuinely harmful such as face slapping, headbanging or hand biting. So you have to eliminate these as quickly and safely as you can by reinforcing an alternative that serves the same need. Self injurious behaviour should be treated with the utmost priority by everyone involved with your child.

But most stims are actually pretty tame and they just bother you, the parent.

And so I like to suggest that kids be allowed to stim, in controlled circumstances. And there are senior and well respected professionals in the field of Autism Intervention that agree with me.

Letting your child go and have a little bit of a flap or a twirl or even under very controlled circumstances, a little bit of a tear (no currency or cheques please!!) can help them to be happier in their own skin each day.

You can set a timer and allow them the space and time for it on a regular basis. You can even get them to work for it; or schedule it into free time. Give it a name and clearly identify when it is appropriate to do it; and it will give you the power to say when it is not.

We say to our Boo, “No Scripting at homework time” And then “Scripting in the car” or “Scripting on the forest walk”. He has a visual reminder at his work station of what stims he is not allowed and we point to it when he indulges.

By the same token I will then tell Mr Hammie to leave him alone if Boo is having a flap while watching the credits at the end of a film, or walking in the forest while we script the “Rugrats in Paris”.

I have also learned to insert myself into his verbal stims by repeating what he says and asking about aspects of it, until he was forced to “direct me” in the way he wanted it to go. It reduced its power and also made it a valuable speech exercise as I was eventually allowed to correct pronunciation and tenses, plurals etc.

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And the exercise has been brilliant for his articulation; which is pretty darn good it has to be said. So Stims can be used as a power for good rather than evil!!

One of those respected behaviour analysts I mentioned earlier tells the story of a young adult with autism who was undertaking vocational training and had a work placement in a Zoo. The therapist negotiated with the Zoo management to set aside a private space for this young fellow to go and have a twirl break; not the chocolate bar, but a session of spinning and twirling. He could then go and do his job quietly and efficiently in the public eye without scaring anyone.

And stamping them out can also go seriously wrong: I know of another clinical team that decided a patient in a residential hostel was annoying everyone with her habit of opening and closing curtains. So they came up with an extinction program. No more opening and closing curtains. Unfortunately the patient began to smash the windows instead. And everyone longed for the good old days when she used to just open and close curtains. So that is my stand on Stimming; as a sensory need.

Parents and professionals will disagree with me. Sure there are days when I disagree with me. But in the absence of comprehensive behavioural analysis and consultative support, reducing and controlling in my case will have to do.

Support Group - It was so good to have the opportunity to talk with other parents who are in the same situation and get such concrete advice so shortly after getting a diagnosis for my son. I've ordered the 'how does your engine run' book from Thinking Toys and installed a minitrampoline in the sitting room, so hopefully I can encourage my son to self-regulate over the Christmas period. Maybe it'll tire him out a bit before the bedtime routine!

Look forward to meeting up again and thank you so much for this timely initiative.

### Advocacy Course Update

For the first few months I worked on a piece of research exploring advocacy models and services in Ireland and internationally and used this information to write a report on Advocacy for Irish Autism Action. The report recommended the type of advocacy service that might work well for people with autism and their families/carers and helped me to find my feet in the work.

The next stage of the job involved forming a strategic partnership with the Advocacy Studies team in Sligo Institute of Technology who were very keen to work with IAA and the apprentice advocates we had by now recruited from around the country. By

September 2008 eight individuals, all of whom have a relative with autism, started their professional advocacy training with Sligo IT. At the same time I was invited onto the steering committee for the Advocacy programme where I am able to represent the views and concerns of Irish Autism Action and our student advocates. So now we had a team, the team were undergoing training and the idea of a nationwide advocacy service started to look like a reality! The Advocacy team meets every six weeks for group supervision and support and as the group approaches the end of the first year of their studies we will begin a handover of casework.

Right now I am working with the Information Officer and a student on placement with us to develop the policies and procedures to support the work of the Advocacy Service and to make sure that we set ourselves high standards for our practice.

Most of us have just completed child protection training and we are all in an ongoing process of personal and professional development. It is really fantastic to think that soon there will be a team of professional advocates around the country who are a point of contact for individuals who need support in accessing services in health, education or welfare.

As a parent of a young adult with AS it gives me great satisfaction to know that our advocates not only possess professional expertise, but also carry with them in their work a personal understanding of the challenges that people with autism face. This makes our service unique and we should celebrate this.

### Home Tuition Support

Special education teacher available to provide home tuition support to students on ASD spectrum.

Phone 087 2380482 after 3pm.

### Music Sessions

Grainne O' Grady, has worked as an ABA tutor in Cabas Cork and Saplins Rathfarnham. She provides community music group sessions and individual piano lessons to many children with autism in both school and home contexts, in Cork and Dublin.

Grainne's CV and contact details are available from the National Office on 044 93 31609.



# ADDITIONAL INFORMATION

## Remember us

Remember us is an integrated social youth group for young people with special needs, their families and friends. It caters for ages 4 - 18. Areas catered for are North Fingal and surrounding areas.

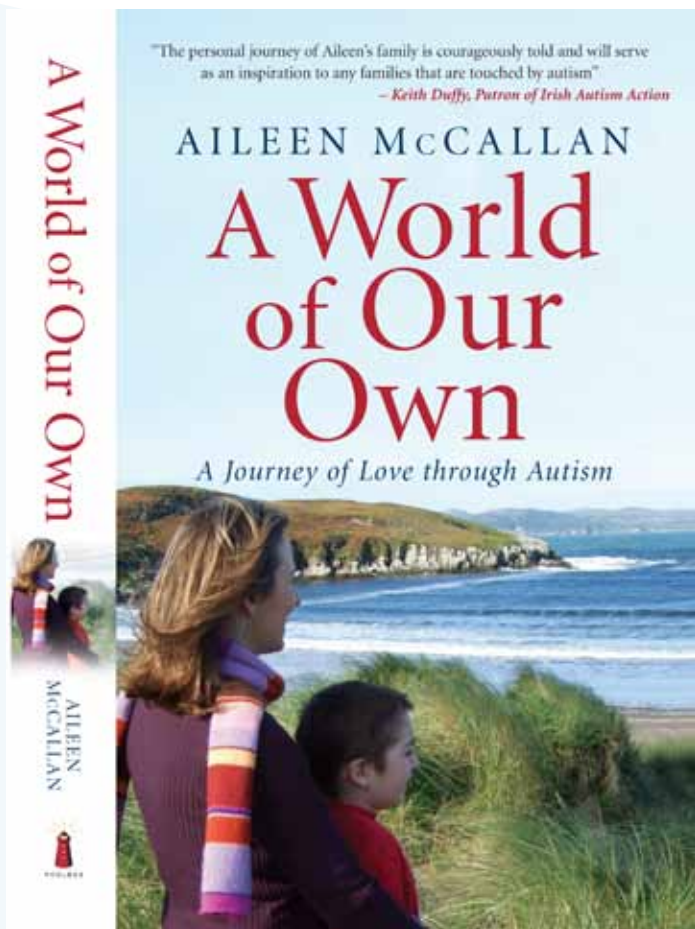


It caters for various types of special needs including Autism. For more information check out their website [www.rememberus.ie](http://www.rememberus.ie)

## A World of Our Own

A World of our Own is a mother's account of how autism challenged her family and changed her life.

Young mother Aileen McCallan is filled with love and joy at the birth of her second son, Cian. Now she feels she can settle into motherhood and a comfortable life.



But it is not to be. From the age of about sixteen months, Cian stops responding to his name; his language fails to develop; he shows little emotional or social connection; he doesn't play like his older brother Christopher; and he screams and writhes at night, wearing down his parents. They face an endless series of assessments and tests as the truth gradually dawns: Cian has autism.

Shocked to discover the lack of support or treatments available for those suffering from autism, Aileen determines to hold onto Cian, to stop her son from slipping away from her.

She spends every waking hour trying to find ways to help him, including Applied Behavioural Analysis (ABA) and a gluten/casein-free diet. It is an uphill battle that strains Aileen's sanity, her family life, her world. She feels caught in a world where there is only Cian and her.

A World of Our Own is a heart-breaking, uncompromising glimpse into a family affected by autism. Ultimately, though, it is a story of the triumph of the human spirit, and of the victory of love over despair.

The book is available in all good book stores nationwide and can be purchased directly for Poolbeg Press on [www.poolbeg.com](http://www.poolbeg.com)

## PECS - Picture Exchange Communications System

Please note that there will be a 2 Day Basic Workshop in Portlaoise Heritage Hotel on the 26th and 27th May 2009.

Benefits of PECS Training:

- increases skills and independence with a functional communication system
- reduces inappropriate behaviours by reinforcing requests and positive communication
- teach your student/child to initiate communication and develop social communications skills
- parents: become a leader in your child's education
- professionals: gain valuable skills and earn CPD credits (13 hours of training)
- learn the 'whys' behind the practice to enable problem solving



# ADDITIONAL INFORMATION

What you will learn:

- everything you need to know to start teaching PECS immediately
- the theoretical background, including how to develop effective educational environments
- a review of visual strategies useful for communication
- strategies for motivating your child/student to communicate
- how to move from a single picture exchange to sentences
- the criteria for transitioning from PECS to other communication modalities

Please note that this workshop is the basic requirement for further training in PECS, such as certification process and advanced PECS training.

For further information check out the website [www.pecs.org.uk](http://www.pecs.org.uk)

## ASD Second Level Visit

This visit was to identify that Irish Autism Action is not just about ABA units or even restricted to primary school children with ASD.



We as an organisation are hoping in the coming years that we can have much more membership in the ASD classes attached to primary schools and secondary schools.

On this visit to the secondary school in Nobber Co. Meath, it was seen that the classrooms were great and the teacher had a very practical approach to delivering high quality education to the teenagers attending.

There was lots of community visits to help the teenagers develop their ability to interact in their own community where they will go on to live when they are adults.

## Servicing Our Members and Groups

The increased awareness of Irish Autism Action has led to significant increase in both individual and group membership.

Presently, the only face to face support we can offer to individuals and/or groups is that of the presence of the CEO.

Such support is unsustainable in the longer term. Our national office and our information officer are also invaluable supports in addressing the needs of our groups.

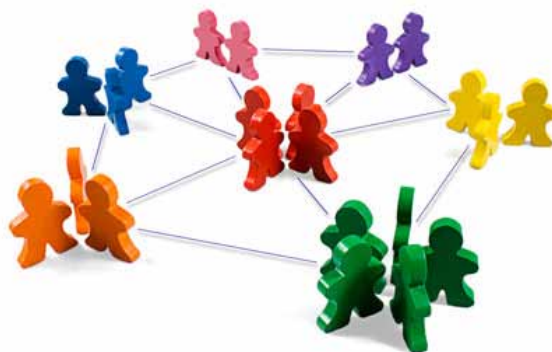
As an organisation we need to:

1. Examine how best we can support groups going forward.
2. Determine how we can facilitate greater ownership and involvement on the part of all membership.
3. Determine how we facilitate voting rights for individual members.
4. Determine how we expand our membership beyond that of the perceived ABA community?
5. Determine how we facilitate membership of individuals on the spectrum?
6. Determine how we ensure our newsletter and Council agendas are set by our membership and/or reflective of their priorities?

Irish Autism Action consider that it would be appropriate to reevaluate how we can enhance our communication with our membership so as to provide the best and timely information possible.

We would envisage that this process would commence in September 2009 and would involve a number of regional get togethers to elicit from our members how we can best serve their needs.

In the meantime should you have any suggestions please feel free to e-mail them to [info@autismireland.ie](mailto:info@autismireland.ie)



# THANK YOU & CONGRATULATIONS

## People of the Year Awards

The Rehab people of the Year awards took place on Saturday 13th September 2009 in City West Hotel. Keith was presented his awarded by Rehab Group Chief Executive, Angela Kerins.

We would like to sincerely congratulate Keith on this achievement and express our thanks to the Rehab Group also.



## Carers Association Award

Irish Autism Action would like to congratulate Mary Condon O'Connor (11years old) who was presented with Ireland's Young Carer of the Year Award. Mary received this award for helping to care for her younger sister Áine who is autistic.



## Bernard Dunne WBA Champion 2009

Irish Autism Action would like to congratulate Bernard Dunne on winning the WBA Super-Bantamweight title against Ricardo Cardoba on the 21 March 2009



## Bundle of Joy

Congratulations to Colette (from IAA) and Simon on the birth of their first baby boy Lucas. We wish them all the best for the future.



## World Autism Awareness Day

Irish Autism Action would like to express their sincere thanks to all the individuals who got out there and raised funds on 2nd April 2009 through collections, coffee mornings, bake sales, purchasing of pin badges etc.



## Merlin Motor Group

Irish Autism Action would like to congratulate Merlin Motors on 35 years in business. It is a fantastic achievement for a business. We wish them the best of luck in a further 35years in the motor trade.



## Flora London Marathon

We would like to congratulate our Patron Keith Duffy on partaking in the London Marathon on 26th April 2009 and completing it in an outstanding 3hours and 52 minutes.



*Thank you also goes to the following for their generous and continuous support:*

O2, DHL, Iris O'Brien Foundation, Hilton Foundation, Pavilions Swords, Marks & Spencers, Dublin Airport Authority, DCU, Gilbeys, Osprey Spa in Naas, Miltown Golf Club Ladies Society, Fáilte Towers, Telethon, Campbell Catering, Ken Berry & Family, Brian Peters - Dark Room Promotion, Rachel Doran, Friends & Family, Cathy Sheehy A+, Hamleys, Dublin Docklands, FDNY, Pfizer, Variety Club of Ireland, Celuplast, Community Affairs, Leopardstown, RTE, The Leaflet Company of Ireland, Stephen Byrne & Rasher, National Game Playing Week, Niall McCrudden, Raymond Weil, Bernard Flynn, Ken Doherty, PGA National, Community Foundation of Ireland, Mercedes Benz, Brown Thomas, Tesco, Paddy Powers John McLoughlin who kindly donated a glider to the Solas Centre, and all those who took part in the Croagh Patrick 7 Day Challenge 2009,

# TESTIMONIALS

## Support Group

It was so good to have the opportunity to talk with other parents who are in the same situation and to get such concrete advice so shortly after getting a diagnosis for my son. I've ordered the 'how does your engine run' book from Thinking Toys and installed a mini trampoline in the sitting room, so hopefully I can encourage my son to selfregulate over the Christmas period. Maybe it'll tire him out a bit before the bedtime routine!

Look forward to meeting up again and thank you so much for this timely initiative.

## Advocacy

Hi my name is Lisa Naughton and I am the mother of a nine year old child with Aspergers Syndrome. I would like to thank all those who sponsor and give generously to Irish Autism Action as well as all the staff, especially Kevin Whelan and Dr Jennifer O'Connor.

My son was expelled from school because of his disability, 22 schools and three counties later we could still not secure him a place in a main stream school and no special needs school would accept him because he is too high functioning. I went to all the proper authorities, spoke to what I thought was all the right people but no one was prepared to help let alone do anything. After all he was just one child, one child that had needs and that was going to cost the state money so better to ignore his rights. Casey spent a total of almost 9 months out of school, my family fell apart, I lost my job and almost lost my home.



That was until I received a miracle in the way of an angel called Kevin Whelan and his team from the IAA. They did what no one else would do, they listened and acted. They offered support educationally and emotionally and gave advice and attended various appeals against the schools who were refusing my son an education. Thanks to those angels and those who donate to them my son is now in full time education in a main stream school and doing wonderfully.

He went from a child who was man-handled, restrained and locked into rooms in his previous school, to a child who receives praise attention and just about a gold star every day for his school work. This is all because IAA took action. They secured one on one tuition for him in the school allowing him to receive ABA in the main stream setting, (thanks to Maeve O'Toole and Paula Hynes) for six months as well as guidance and support from Dr Jennifer O'Connor.

So I would just like to say to all who support and give generously thank you for saving my child, thank you for allowing him to have a chance in life, thank you for giving him and us a future. To Kevin and the rest of the staff at Irish Autism Action, we love you guys, you're our angels.

## Another Viewpoint on Advocacy

As a parent not of this country but unable to leave it due to marriage breakdown and the severity of my son's condition, I knew absolutely nothing of the law or the legal rights of myself as a parent or the legal rights of my child.

I was led to believe, in fact told that I should "just carry on with my own personal development" this left me impotent, I knew nothing, no one, had nothing, had no one, I was seriously considering ending it all, every door I politely knocked on for help was hypothetically firmly shut in my face. I was given the name of Irish Autism Action and immediately felt that someone else was helping me carry the load I could no longer carry solo, I learnt what my rights were and how to ask for them in a way that would be listened to.

I was escorted to very intense meetings that would have buckled the legs from under me had I been alone. I believe such meetings are meant to intimidate and not facilitate anyone.

I was helped to have a voice that could now be heard instead of ignored by everyone.

Without Irish Autism Action I would not now be the strong woman that I am at present who can cope with my son's condition and converse with professionals in the voice that they require so that I am heard and not ignored.

## Identity Card - Parents Feedback

I just wanted to send you this short letter to say a big "Thank You" to IAA. I recently got the IAA ID Card for my son.



I had read the article in your newsletter about one of your members who every year goes to Disney Land Paris – because he enjoys it so much.

We traveled to Disney in February and after showing the ID card we were issued with a special pass which meant we did not have to queue for attractions. Instead of feeling isolated because we had a son with special needs we were made to feel like royalty – and had a brilliant holiday! Thank you so much – Keep up the hard work.

# TESTIMONIALS

## Solas Assessment Post from Rollercoaster

Just wanted to say that the Solas appointment went off ok. The psychologist was lovely and I wish I could put the OT (Marissa) in my pocket and take her home!! We'll have to go back for an SLT assessment (although they have the report of an SLT assessment done through the EIT so maybe that is enough).

Snooky was his usual unresponsive self at times and his usual hyperactive self at other times so they really got to see all aspects of his character. I had to bring Boo and Noo Noo with me and other than a few mad outbursts from Boo and a feed and nappy change for Noo Noo it was grand. Mighty long day though as we set off from the sticks at 7.30am and got home at 4pm. Well worth it and once again thank you to all at Solas.

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## IRISH AUTISM ACTION LTD

### Become a Friend of Irish Autism Action



Please fill in amount you wish to donate in the red box. You can pay by cheque or direct debit:

Make a donation of €'s

Instruction to your Bank or Building Society to Pay by Direct Debit

Please fill in whole form and send it to: Irish Autism Action, 41 Newlands, Mullingar, Co. Westmeath.

1. Name and full postal address of your bank or building society

2. Name(s) of Account Holder(s)

3. Branch Sort Code:

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4. Account Number

5. Instructions to your Bank or Building Society

Please pay Irish Autism Action Direct Debits from the account details on this instruction subject to

Signatures

\_\_\_\_\_

Date:

\_\_\_\_\_

Banks and Building Societies may not accept Direct Debit instructions from some types of accounts

# MEMBERSHIP APPLICATION FORM

IRISH AUTISM ACTION LTD  
INDIVIDUAL APPLICATION FOR MEMBERSHIP



Parents Names:		
Address:		
Home Phone:		
Mobile:		
Fax:		
Business Phone:		
E-mail:		
Name of child with autism:		
Childs Age:		

Mark X See Note 1\*

NOTE 1: Please complete all sections highlighted in Red. Please put an X in any box at the right hand side where you do not wish that piece of information to be circulated to other members of Irish Autism Action.

NOTE 2: Please attach a passport size photo of your child.

The annual fee for individual membership is €20 (This is to include membership card). However, all individuals are encouraged to join up with an IAA group nearest their home, where feasible. Check our website for details of groups in your area.

Please make cheques payable to Irish Autism Action Ltd and return payment & this application form to 41 Newlands, Mullingar, Co. Westmeath.



PASSPORT  
SIZE  
PHOTOGRAPH  
PLEASE ATTACH  
HERE

**For IAA Use Only**

Application ratified by IAA Executive: \_\_\_\_\_ day of \_\_\_\_\_ 2009

Signed: \_\_\_\_\_ (Chairperson)