



PAMIS e-News Autumn 2016

GSK Impact Award Winners!



In May we were delighted to be in London at the Glaxo SmithKline, (in partnership with the Kings Fund,) IMPACT award ceremony and leadership programme. PAMIS was one of 10 winners out of over 400 applications and very proud to be recognized for our

Innovation, **M**anagement, **P**artnership working, **A**chievements, **C**ommunity focus, **T**argeting need (IMPACT). We have learnt so much by taking part in the process and then on the leadership programme sharing ideas, knowledge and gaining skills with other winners and key mentors from the Kings fund. PAMIS was awarded £30,000 and also had a film made of our work – www.kingsfund.org.uk/audio-video/2016-gsk-impact-awards-pamis. The relationship with the other winners and the Kings Fund will grow and we are now part of an expert network. It is good to see that the work that PAMIS does is recognised at such a prestigious level. PAMIS is inspired by the people we work with and we will continue to provide further opportunities to develop the organisation and promote the contributions that people with PMLD and their family carers make to our world.

Thoughts from Jenny!

We are moving into our next strategy and would like your thoughts on what we should be doing over the next 5-10 years. I would like to share a wee part of the acceptance speech for the GSK impact award to give you a flavour of some of our thoughts about what we need to promote.

“Profound means deep, it means wise, expert, requiring great insight and /or knowledge. PAMIS are an organisation privileged to be working with people with profound and multiple learning disabilities and their family carers. We know that we won the award because of everything that they have taught us. They are the expert educators – teaching us how to care, how to act with compassion, how to work as a team and how to make human connections.”



So part of what we see for the future is the promotion of the crucial and valued role of people with PMLD and their family carers as educators of health and social care practitioners but also of their communities. “Education is a most powerful weapon which can be used to change the world”. We look forward to hearing from you.

New Lottery Funding

PAMIS has been awarded £98,702 from the Big Lottery Fund for the Digital Transitions project. This project which will provide person and family centred support to young people aged 15 to 18 and their families who are in the transition process from secondary education to adult service provision. The project started on the 1st August 2016 and will operate within the local authority areas of **Glasgow City, East Renfrewshire and East Dunbartonshire**, over the next two years.



The project will provide 1:1 family support on all aspects of transition planning. In conjunction with the above support families will have the opportunity to co-produce a PAMIS Digital Passport.

This is an electronic resource highlighting the social, emotional, psychological and physical

care and support needs of the young person. Features of the passport include text, sound, video clips and photographs which can be accessed on the person's technology device by family carers, paid staff and practitioners providing care and support. This will contribute to the Self Directed Support assessment process and the development of an outcome based support plan. It can also be used as a training tool for new staff teams to enable them to have a greater understanding of the individual and their support needs.

If you would like more information please don't hesitate to contact the Project Manager, Elizabeth McBride, who is based in the PAMIS Glasgow office, t: 0141 572 0782 or e:e.z.mcbride@dundee.ac.uk

Storytelling News

Loretto's Story box

Claire Hewitt and Maureen Phillip have been working hard on the development of the multi-sensory storytelling resource which we are developing in memory of Loretto. We now have three stories complete and the craft department at Camphill community, Corbenic near Dunkeld have been hard at work making some of the multi-sensory stimuli for the stories. We have also had lovely sharing sessions with the musicians at Corbenic, who will be recording the music for this resource and who will be performing along with Tayberry multi-sensory storytellers and Claire and Maureen at our international conference next year. We are now working on the books for the resource and you can keep updated on the progress of this on our story blog.



Tayberry multi-sensory storytelling project and PAMIS

PAMIS have been busy developing a multi-sensory

storytelling course in partnership with Tayberry Enterprise for their multi-sensory storytelling apprentices.

Tayberry Enterprise were awarded funding from the government *Keys to Life Fund* to expand the successful Dundee course to other areas and the course began this August. An outreach programme will be offered in Dundee, Angus, Perth and Kinross, Fife and Aberdeenshire in the following months. Look out for more details coming soon. Tayberry's existing multi-sensory storytellers have been participating in the development of the programme of events that we have held while developing Loretto's story box and will be performing at the PAMIS international conference next year.



Therapeutic storytelling



PAMIS were pleased to offer therapeutic storytelling workshops hosted by Dr Michael Williams, the workshops which were attended by staff, volunteers and family carers. The Caring Voices workshop looked at the art of storytelling in relation to creating a personal narrative that could be shared with others and contribute to information sharing, learning and development. As a learning tool the narrative of the personal story about caring, offers the opportunity to inform others about living with those with profound and multiple learning disabilities, and also how shared stories about caring can make a difference to others. It was a brilliant workshop that we hope to develop further and we are keen to run another caring voices workshop with Dr Williams specifically for male family members. We will also be exploring funding to develop some digital stories that will contribute to learning and development, so again look out for further information on this in the coming months.

Creative Art and Poetry workshops



These workshops have been run by Vivienne Crighton who is a facilitator of The Naked Voice and Poetry Depths workshops. These introductory workshops have enabled carers to have time to explore and express their own unique direct experience through the written word of poetry and creative art in a simple and fun way. The outcome of these workshops will be on display at the international conference next year.

For more information on storytelling please go to our storytelling blog <http://blogs.pamis.org.uk/multi-sensory-storytelling/>

A taster of recent Leisure Events

We have had a fun filled summer with many varied leisure events across all the areas in which we work. We continue with the old favourites but have branched out on some exciting new activities. These include Seagull Trust canal trips at Kirkintilloch, a day trip to Blair Drummond Safari Park, carriage driving in Falkirk, Go-Karting in Glasgow, and, to round it all off, the family Magic Show at Hamilton Accies stadium. It's been great to see so many families coming along and having fun together. All families can share photos of their experiences through the PAMIS Facebook page, or through Twitter using the hashtag #pamisfun4all and including @PAMIS_Scotland, We love seeing all those smiling faces!



Golden Ticket



PAMIS are excited about the beginning of a relationship with Dundee Science Centre www.dundeesciencecentre.org.uk. After an evening with the Dundee and Angus Tourist Bureau where PAMIS highlighted the issues of accessible venues and days out for people with PMLD and their families, Dundee Science Centre approached us about how to support the work that we do. We have spoken with them about changing places toilets, accessible exhibits, science based multi-sensory storytelling and so much more. They are an amazingly responsive and creative team and we are really excited about what we might be able to do for the future.

Meantime we have bought a Golden Ticket that enables PAMIS families access to the centre for free for a whole year and starting from August 2016. You will need to book via the Centre, highlight that you are a PAMIS family and then they will allocate you a mutually agreed session. We are hoping this will be the beginning of a number of things that we can do to support parents and carers during holidays and weekends.

If you are at the Science Centre and need to use the changing places toilet there is one in the Dundee office (Monday – Friday) but if we are given notice we can also look at how we could support people at weekends. Hopefully there will be one at the centre in the near future and there are others in Dundee too – please see <http://changingplaces.uktoiletmap.org/>

Since then, we have also had meetings with Glasgow Science Centre – so watch this space for future developments there too!

Postural Care

Local premiere of our Postural Care film:

PAMIS in South Lanarkshire has been working alongside family carers, NHS Lanarkshire, the Scottish Government and August Pictures to develop a film to reach out to families across Scotland. The film looks at the subject of postural care with families and healthcare professionals explaining why it is so important to maintain good body positioning throughout the day and night. After a long period of filming and editing, we were excited to host our local premiere on Wednesday 10th August with all families involved having a sneak preview before our national launch later in the year. The film will be available both electronically and as a DVD. Please get in touch if you'd like to find out more.

Promoting the benefits of Postural Care:



Two of our Postural Care Champions have been out and about sharing their knowledge and helping others understand the need and benefits of 24 hour postural care. Kate Jordan and Frances Cadzow had the opportunity to speak at the Cerebral Palsy Integrated Pathway Scotland (CPIPS) Annual General Meeting in June, presenting to an audience of orthopaedic consultants, physiotherapists and occupational therapists from across Scotland. They shared the work they've been involved in locally raising the profile of postural care and presented a small clip from our Postural Care film.

Frances also had the opportunity to co-present a poster on the benefits of 24 hour postural care at the NHS Scotland Event in June. She co-authored the poster with PAMIS and NHS Lanarkshire specialist physiotherapists, Lynn Frew and Clare Boslem. The poster was presented to an audience of various health professionals, all interested in hearing how implementing good postural care had had a positive impact on her son's life.

Fundraising information from the ACK team

It has been a busy and successful summer for the ACK team. Last week 35 brave souls abseiled 140ft down the Dundee University tower for PAMIS, including; Scottish Health Secretary, Shona Robison; local councillors; couples celebrating their anniversaries; and others wanting an adrenalin rush! Already this has raised over £6,000 with more money expected.



There have been a number of other PAMIS fundraising events over the last few months! 'Thank PAMIS it's Friday' in Aberdeen, 'Thank PAMIS it's Thursday' at the Malmaison Hotel in Dundee, and Eden Mill, Guardbridge raising £1,667. Additionally, many individual fundraisers have contributed with a total of almost £5000 since April. This has involved events such as the Edinburgh marathon, the Women's Great Run 10k in Glasgow, the Great Glencoe Challenge and finally the South Lanarkshire crafty ladies selling their wares.

Thank you to everyone who has been involved with these events.

Please see **Dates for your Diary** for all upcoming events.

Calling all Dads



PAMIS wants to know how we can be useful to you..... Please let us know what matters to you by answering a few questions and have the chance to win an Amazon £20 gift voucher

www.surveymonkey.co.uk/r/2QTYLKR

Mums, please encourage your husband/partner to complete and return so that we can plan events for Dads that will be useful and fun.

New Bereavement and Loss Resource



This fabulous book on bereavement and loss was written by Fiona McDonald, a PAMIS parent. The book works at many different levels and is a wonderful resource for anyone wanting to explain loss. The illustrations in black and white are simple but beautiful, and the story is full of reflection and love.

If you are interested in this resource please get in touch with PAMIS, copies cost £4.00.

Self Directed Support Survey

The Learning Disability Alliance Scotland – LDAS are updating their previous work on Self Directed Support. In order to do this they are asking family carers or paid carers to complete an online survey at www.surveymonkey.co.uk/r/TellusaboutSDS. This information will be anonymous and will be used to inform LDAS on the current developments around SDS.

Camp PAMIS



— A drumming session at Camp PAMIS

Family carers had told us that holidays are a really difficult time for them. In response, students on placement at PAMIS designed a summer programme of activities. This programme, ran over 5 days at Dundee, Camperdown Park and included, African

storytelling, drumming, interactive nature sessions, games, and food fun sessions. This was a pilot but given the response PAMIS hopes to deliver similar sessions in other areas across Scotland. A big thank-you to all the help received from the many amazing PAMIS pals/volunteers who helped so much during the week. We couldn't have done it without you! We all think the staff team led by Lesley Gray and Maureen Phillip did an exceptional job under the guidance of one of the Tayside mums Lisa Ritchie.

Lord Brian Rix



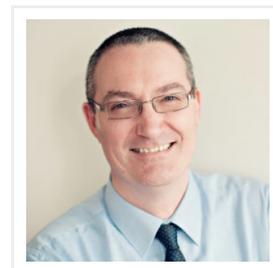
All the team at PAMIS were very sad to hear about the death of Lord Rix. Lord Rix was a great campaigner for improving the rights of people with learning disabilities and actively supported the work of PAMIS. He will be especially remembered at PAMIS for his involvement in the Changing Places campaign and his contribution to our campaigning video – Time for a Change.

New Staff



— Catriona
Jamieson

PAMIS is thrilled to welcome two new members of staff. Catriona will be working on developing digital passports for Grampian families and Jon is the new PAMIS Learning and Development Director.



— Jon Bolton

Both will contribute greatly and will be a great assets to the PAMIS team.

Goodbyes

Linda Camilli who worked on the Transition project in Grampian has sadly left PAMIS and we wish her well for the future.

Dates for your diary

Thurs 1 September – ‘Thank PAMIS it’s Thursday!’ Glasgow, 17:00 to 19:00 Browns Brasserie, George Square, Glasgow
<https://thankpamisitsthursdaybrownsbrasserie.eventbrite.co.uk>

Friday 2 September – Exploring the future for people with profound and complex needs in Lothian – a workshop hosted by PAMIS. Please contact pamis e: pamis@dundee.ac.uk or t: 01382 385154

Thursday 15 September – DadsOnly *Blether* – A chance for Dads to meet up, share stories, experiences, put the world to rights over a cuppa and a sandwich. North Anderson Drive Scottish Fire & Rescue Service Community Wing, Aberdeen AB15 6TP. Contact e: a.j.anderson@dundee.ac.uk or t: 01569 764 221.

Saturday 24 & Sunday 25 September – Loo Tour of Angus. This follows the very successful Loo Tour in 2015 which resulted in the Changing Places toilet being installed at Arbroath harbour. There are three different cycle rides planned over the course of the weekend in Angus of varying lengths to raise the awareness of Changing Places toilets. The different routes will cater for different abilities and including a route suitable for adapted bikes. For more information see www.facebook.com/lootourforchangingplaces.



Wednesday 28 September & Wednesday 5 October – Oral

Healthcare. 2 day workshop for Greater Glasgow & Clyde families at the Adelphi Centre, Glasgow. Please e: e.platt@dundee.ac.uk or t: 0141 572 0782.

Friday 30 September – Charity Golf Event for PAMIS at Fairmount, St Andrews, 10:00 to 18:00, <https://charitygolfdaysforpamis.eventbrite.co.uk>

Tuesday 4 October – Consultation on Disability Benefits. The Steeple, Dundee. See www.sclld.org.uk/events/consultation-disability-benefits.

Friday 28 October – Multi-Sensory Storytelling Workshop. PAMIS, Scottish Storyteller, Claire Hewitt and Tayberry multi-sensory storytellers will be hosting a multi-sensory storytelling workshop and performance at the University of Dundee. Following this in the evening in the University Chaplaincy, Claire and Finland's Anne Marie Toivonen will entertain with a story told in both Scottish and Finnish as well as the chance to hear other tales and listen to some music. This storytelling event will be part of the Scottish Storytelling Festival. For more information e: m.phillip@dundee.ac.uk or t: 01382 385154. 13th – 20th of November – Spend a Penny for PAMIS campaign 2016. Facebook event page: <https://www.facebook.com/events/129553704122549/>

Saturday 28 January 2017 – Along Came Kirsty presents the 6th Annual Burns Supper for PAMIS, Apex City Quay Hotel & Spa, Dundee.

<https://6thannualburnssupperforpamis.eventbrite.co.uk>

Facebook event

page: <https://www.facebook.com/events/602127053285197/>

Saturday 25 February 2017 – ‘Grand Central Glitz’, Grand Central Hotel,
Glasgow. <https://pamispresentsgrandcentralglitz.eventbrite.co.uk>
Facebook event
page: <https://www.facebook.com/events/602127053285197/>

www.pamis.org.uk

PAMIS is a registered charity and the only organisation in Scotland that works solely to support people with profound and multiple learning disabilities and their family carers for a more inclusive life.

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