

The Alzheimer Society of Ireland Newsletter

Issue 2 Summer 2018

# THE VOICE



## IN THIS ISSUE

**IN THIS ISSUE** – We take a look at Tea Days across the country; our latest charity partner plus lots more.

Pictured above:

Riverdance troupe joins us for Tea Day 2018 at the Orchard Day Care Centre in Dublin.



THE ALZHEIMER  
SOCIETY of IRELAND

## MESSAGE FROM THE CEO

**Welcome to the summer edition of 'The Voice' newsletter. It has been a very busy 2018 so far for everyone! We had such a positive response to our Tea Day campaign this year, proudly supported for the third year running by Medtronic. You came out in your droves to support your local services by getting the kettle on and the pictures and monies you all raised are still being collected. We had a great morning at our Orchard Day Care Centre in Blackrock in Dublin, thanks to all the staff there who looked after us so well.**

We also saw some wonderful entertainment provided by the Dublin-based community choir the Forget-Me-Nots and the phenomenal Riverdance launched their partnership with the ASI and their summer season at the Gaiety Theatre with a fantastic performance. It was a wonderful event and it was great to see so many people with dementia, family carers, board members, branch members, volunteers and staff from all over the country taking part in our flagship fundraising events around the country.

There is fantastic work being carried out by the Irish Dementia Working Groups (IDWG) and the Dementia Carers Campaign Network (DCCN). I'm delighted to report that both groups have been doing great work in the south of the country over the past few months with many new members signing up to put the voice of the lived experience of dementia to the fore. Our advocacy team are in the process of recruiting members in the west of the country – so keep an eye out for that. Of course, you can keep updated with the DCCN through their dedicated Twitter account @DCCNIRL and the IDWG has also just launched their account recently on @IrishDementiaWG. So please do follow them.

I was happy again to see our services continuing to perform extremely well within the community with a total of 184,311 hours delivered in the first three months of the year. Day Care delivered 125,845 hours; Home Care delivered 43,652 hours; and Respite Care delivered 15,969 hours. Our Alzheimer National Helpline experienced 1,514 service users in the first three months of the year, which represents a 13% increase on the same time last year. Our Mobile Information Service is having another successful year with eight outings across the country in the first three months. These figures are very impressive – well done to all involved.

It was great to see our training team win a National Training Award 2018 for Excellence in Digital Learning at the Irish Institute of Training and Development Gala in April. This is the first time that we have won a national training award. This award was in recognition of the Erasmus+ funded Home Based Care – Home Based Education online training course for family carers looking after a loved one with dementia. Big congratulations to them!

In terms of political advocacy, we have called on the Government to make extra funding available for further implementation of the National Dementia Strategy (NDS) following the publication of the mid-term review of the implementation of the Strategy which was launched towards the end of May.

We welcome the publication of this mid-term review as it is a very positive move to have a review of the implementation of this Strategy at the half-way point, so we can get a sense of the emerging gaps in the supports and services for people with dementia and their family carers across Ireland.

It is clear that additional funding will be required to move from this preparatory phase into the establishment of new dementia services and structures. For example, considerable resources will be required to implement the diagnostic and post-diagnostic supports pathways.



Pat McLoughlin, CEO ASI

It was also positive to see it acknowledged in the report that ongoing funding in the budget allocation from the Department of Health will be needed to ensure that the National Dementia Office remains viable and functional.

We will be pursuing these pressing issues in our Pre-Budget Submission 2019 campaign 'Dementia Supports Around Ireland – Building Communities of Care', which has just been launched. Amongst other issues, this campaign will focus on filling the gaps in supports and

services for people with dementia across Ireland that have been identified in the dementia-specific services mapping project that we completed recently with the National Dementia Office (NDO).

The gaps that have emerged are in crucial areas – particularly in the area of post-diagnostic supports such as Dementia Advisers, counselling, cognitive therapies, information and signposting of services and resources and support groups for people with dementia. We will be pursuing all of these issues in the coming months ahead of the next Budget announcement in October.

As you are aware, the EU General Data Protection Regulation (GDPR) is now upon us. Since Friday, May 25th 2018 organisations such as ourselves must closely review our procedures to ensure they respect and protect people's personal data. Our default approach must be that information identifying an individual always belongs to them. We have appointed a Data Protection Officer, Clare Murphy, who will be working nationwide to enhance our internal controls and foster a positive culture around protecting personal data. I would be grateful if you would take time to read our article about the GDPR in this edition.

I am delighted to announce that our organisation will soon take part in the Great Place to Work Programme. The purpose of the Best Workplaces programme is to encourage us to understand how you feel working within the ASI and to learn how the organisation can develop to make it a great working environment. Every person within our organisation has a part to play in creating a great workplace and I hope you will join me in contributing to this very exciting opportunity.

Finally, it really is very heartening to see in these pages so many regional and local fundraising events and information events taking place all over the country – by staff, branch members and volunteers.

Keep up the great work!

**Pat McLoughlin.**

## SELF-ADVOCACY UPDATES

It has been a busy few months for our advocates



L-R - Kathy Ryan from our Irish Dementia Working Group (IDWG), Micheál Rowsome, Dementia Carers Campaign Network (DCCN) member with Cathy Masterson from St. Marys Hospital, Phoenix Park at the presentation of the Diagnosis Campaign at UL & St. Mary's Hospital.



DCCN Chairperson Judy Williams and DCCN member Máire-Anne Doyle with IDWG member Brian Doyle, met former TD and Minister for Justice Nora Owen at the Understand Together Dementia Friendly Garden in Bloom and had a great chat about the challenges and rewards of caring!



The Southern Dementia Working Group is going from strength to strength and member Kevin Quaid travelled to National Office to meet the team and CEO Pat McLoughlin.



Chair of the IDWG Ronan Smith attended a thank you afternoon at the headquarters of KBC Bank and spoke about his personal experience. The team have raised over €130,000 to support services at the ASI. Ronan is pictured here with the KBC team.



DCCN committee member and Board member Ann Twomey spoke at the Dementia in Rural Ireland Conference in Connemara. Ann spoke wonderfully about the lived experience of caring and made a passionate plea to ensure people living with dementia and their carers are valued and supported.



DWG members attended and spoke at the Sonas International Dementia Conference. Jacinta Dixon, Kathy Ryan and Helen Rochford Brennan are pictured here with Head of Advocacy and Public Affairs Tina Leonard and international dementia researcher Dr Steven Sabbat.



Dr Maria Pierce and Dr Fiona Keogh consulted with members of the IDWG on Intensive Homecare Packages for persons with dementia. They presented the research and sought advice, in particular on how to present the lay summary. Members Seamus Byrne, Brian Doyle, Maureen O'Hara, Paddy Butler, Helen Rochford Brennan, Ronan Smith and Anne McGeown are pictured with the Genio team and supporters Maire Anne Doyle and PJ McDonald.



The Eastern Dementia Working Group consulted with the HR team to ensure the voice of the person with dementia is heard at recruitment and throughout the organisation, lots of exciting work planned. HR Officer Deborah Soffe consulting members Seamus Cunningham and Seamus Byrne about what competencies are important for ASI employees.

## RESEARCH ROUND UP

At ASI we jointly hosted a Research Forum with the Dementia Neurodegeneration Network Ireland (DNNI) in April.



The forum brought together stakeholders engaged in dementia research, in order to develop agreement on research needs and prioritisation. It also explored possibilities for dementia funding into the future.

Events like this are crucial to identify what the challenges and gaps in dementia research in Ireland are. By working together with other stakeholders we give hope to dementia research to Ireland in the future.

### Did you know that we are involved in 13 research projects?

One such project is called Promoting Assisted Decision-Making in Acute Care. It aims to develop an educational tool for healthcare professionals which will promote understanding about assisting patients in acute setting to make decisions.

This understanding can be brought into their care planning with older people. Partners in this study include UCD, St Vincent's University Hospital, The Royal College of General Practitioners and Family Carers Ireland.

At ASI we regularly contribute to policy submissions. Recently, we prepared a joint Submission with the All-Party Oireachtas Group on Dementia (APOGD) on the topic of loneliness and dementia.

The APGD comprises members of all political parties and seek a more effective policy response to dementia.

Our Submission considers how people with dementia experience loneliness and reasons why people with dementia can feel lonely and have limited social connections. It also explores how this issue can be addressed and the supports that need to be put in place to support quality of life for people with dementia.

Pictured are **Senator Colette Kelleher** and **Fianna Fail Deputy Mary Butler**.



# ASI NEWS

## Charter Medical Partnership

We were delighted to announce ASI's partnership with Charter Medical for the provision of the Rapid Access Clinic for persons with dementia in February.

The new partnership will enable ASI's Dementia Advisers to refer persons with dementia to the service, which is a public clinic and provides services at no cost to the person with dementia and operates five days a week, Monday to Friday.

The clinic is for people who require an urgent but non-critical review by a Geriatrician. The clinic will initially be limited to patients from the Mater Misericordiae University Hospital and Beaumont Hospital's catchment area.



**Pictured – IDWG member Brian Doyle, Dementia Adviser Jean Scanlon, Charter Medical CEO Stephen Crowley and Dr Emily Kearney.**



## National Training Award

The ASI Training Department was delighted and honoured to win a National Training Award 2018 for Excellence in Digital Learning from the Irish Institute of Training and Development.

The prestigious honour which is in recognition of the Erasmus+ funded Home Based Care – Home Based Education online training course for family carers looking after a loved one with dementia is the first time ASI have won a national training award.

**Pictured – Rosemary Collier, ASI Head of HR, Fergus Timmons, Head of Training, Christine Carr, Training Operational Support Worker and Davina Smith Stakeholder Training and Compliance Officer.**

## MEET PARO – The Baby Seal

The Orchard Day Care Centre in Dublin welcomed their newest employee, PARO the baby seal, an advanced interactive therapeutic robot. The ASI is the first organisation to deploy Paro in a Day Care setting in Ireland, to be used with ASI clients and service users.



Paro is unique and is proven to reduce stress, increase socialisation, stimulate interaction and improve relaxation and motivation for people with dementia. Dr Takanori Shibata the Japanese inventor of Paro met with staff and clients who love having him at the center.



# TEA DAY 2018

We would like to thank everyone who hosted, attended and donated to our Tea Day this year. Your support means so much to the 55,000 people living with dementia and their families

and we couldn't support our services all around the country without your hard work. Here is a taste of the various Tea Day events all around the country.



# TEA DAY 2018



## GREAT PLACES TO WORK SURVEY 2018

The ASI is taking part in a survey of Irish workplaces which is being compiled by the Great Place to Work®. The purpose of this programme is to recognise organisations in which employees are provided with a great work environment. We are hoping that by taking part in this survey, you can help the ASI work towards becoming a better workplace for all of our staff.

Each of us is being asked to participate by completing an on-line/paper based questionnaire. On **Tuesday 4th September 2018** you will receive an email with a link to the 'Best Workplaces' on-line survey or a paper copy of the survey in the post to your home address, and we encourage you to complete the questionnaire.

It is so important to feel free to be honest and candid, honest opinions will create great foundations for moving forward together. Your answers will be treated anonymously and with complete confidentiality. All responses go directly to Great Place to Work® and no one in the ASI will see your individual responses.

This survey will encourage us to understand how you feel working within the ASI and to learn how the organisation can develop to make it a great working environment. As an organisation we would like to establish a culture aligned to the new strategic values and empower you to live those values.



To be included in the results, please complete the survey by Tuesday 18 September 2018 for email and Tuesday 25 September 2018 for postal surveys, or earlier if you can possibly manage it.

Alongside this survey we are creating a cross functional team

who will work on the culture audit of the ASI. We are hoping to have a representative from each type of service within the ASI to join this group. This group will bring together the opinions of their service and feed this back to The Great Places to Work external team to allow us to understand our culture and values better. This group will help to empower us all to live the strategic values and will be key in setting initiatives to do this.

For those of you who are interested in volunteering to be a part of this very exciting working group please email [GPTW@alzheimer.ie](mailto:GPTW@alzheimer.ie). The closing date for emailing requests is Friday 13th July 2018. Spaces on the working group will be limited and the process for assigning people to this group will be selected at random. Each departments volunteers will be categorised together, our CEO Pat McLoughlin will then choose a name from each of these categories completely at random to sit on this working group.

## STAFF PROFILE – DEMENTIA ADVISER ÁINE BENNETT

**My name is Áine Bennett and I am a Dementia Adviser covering the South Dublin and North Wicklow area. Although I am new to this role since March of this year, I have been working with the ASI since November 2016. I spent approximately 16 months working in ASI's Curlew Road Day Care Centre, Drimnagh in Dublin.**

I am a qualified nurse with many years of experience working in the area of dementia care, both professionally as a nurse and personally. I feel my time as a member of the team in ASI's day centre gave me enormous additional insight into dementia and the opportunity to work with individuals at the beginning, middle and approaching end stages of the condition. The passion and dedication of each member of staff in the centre is simply inspiring and I absolutely loved each and every day I spent there.

My new role as a Dementia Adviser involves working with people of all ages who have been diagnosed with dementia, are awaiting a diagnosis

or have a concern regarding their cognitive health and their families. I am now part of a team of 8 Dementia Advisers and we work across 11 counties in Ireland.

The service aims to provide locally based, individualised information, practical tips for coping with everyday life, help to plan for the future and to signpost towards services and supports in the community. I visit people in their own home, in a place of their choice or in a designated clinic. We make the service easy to access, people can contact us directly and referrals can come from ASI's Helpline, services and from healthcare professionals. Referrals can be made by phone or email.

I also deliver talks and presentations to local community groups to help build understanding of dementia, of the supports and services available and how to reach and connect with others within the community.

It is an immensely rewarding role and to think that on any given day you may have the opportunity to help someone or at least attempt to somewhat lighten a load that is already so heavy, with support, encouragement and hope is a true privilege.

**For more about ASI's Dementia Adviser Service visit [Alzheimer.ie](http://Alzheimer.ie) or call 1800 341 341**



## PRE-BUDGET SUBMISSION 2019

We recently launched our Pre-Budget Submission 2019 and this year we are calling on the Government to invest over €11 million towards community supports for people with dementia. The National Dementia Strategy's mid-term review acknowledges that people with dementia and their families are "still dealing with inadequate services and supports".

**€7.415 million**  
for a minimum standard of community services in each county

**€2.31 million**  
to roll out a Dementia Adviser service across Ireland

**€2.24 million**  
to provide 32 Key Workers in every HSE Local Health Office

**€852,000**  
for Dementia Inclusive Community Coordinators across Ireland

It states that additional funding is required and that access to community dementia specific services across Ireland is not equal.

The level of service varies depending on where you live but no county in Ireland has an acceptable level of dementia support. The time to provide funding is now. For further information on how to send a letter to your TD please go to [www.alzheimer.ie](http://www.alzheimer.ie)

### How can you help?

We will be holding some local events across the country during the month of September, where we will invite local politicians to come along and discuss our Budget proposals and allow them a closer look at the mapping results.

If you would like more information about hosting an event please email [lisa.gernon@alzheimer.ie](mailto:lisa.gernon@alzheimer.ie)

## FUNDRAISING

It has been a busy few months with our charity partnerships. Take a look at some of the exciting events, that have helped to raise funds for our services and supports.

On June 13th ASI officially launched their summer partnership with Riverdance. This collaboration saw members of staff, volunteers & advocates attend the world renowned phenomenon Riverdance Opening Night. The 'Forget-Me-Nots' choir also gave an outstanding performance to welcome guests to The Gaiety Theatre in Dublin.

Our Charity Partner for 2018 Intel Ireland, held their first ever Colour Run in Leixlip, Co Kildare, on Friday 15th June. Our Mobile Information Unit and our Fundraising team were on site to help douse the runners in colour! They had a fantastic turn out & the sun stayed shining for the event which raised funds for their charities of choice.



Pictured are: **Above: ASI Fundraising Team & left: 'Forget-Me-Nots' Choir.**

# NEWS FROM AROUND THE COUNTRY

## DONEGAL



Thanks to everyone who turned out for the Vintage Tractor Run & Afternoon Tea in Milford.



Well done to Carrigan Cycle Group who raised €7,500 - split 50:50 between ASI Donegal and Breast Cancer Services in Donegal - cycling from Carrigans to Carlingford and back.

## MAYO



Congratulations to Catherine McLellan & Lorraine Jennings from Castlebar Day Care Centre who completed their Sonas Training in Galway.

## MONAGHAN

Best of Luck to our colleague Gerry Atkinson on his retirement. The team have loved having him for the last six years at Carrickmacross Day Care Centre in Co. Monaghan.



Pictured above: Cronia O'Reilly, Briege Duffy, Catriona Lavelle & Gerry Atkinson



Well done to all the staff at the Drumkill Day Care in Monaghan who served 500 breakfasts at their 'Big Breakfast' event raising in excess of €6.1k. That's a lot of rashers!!

## CORK

A big thank you to the members of the Knit and Natter club who meet in the Bishopstown Library in Wilton Cork. They donated €2,000 from the proceeds of their annual sale of work to our Bessboro Day Care Centre in Cork.



## LONGFORD



Pictured above, from left to right: Patrick Durkin & Paddy Dowd presenting a cheque for €1,640 from their Table Quiz to Jo Canning & Breda Dunne from the ASI Longford Branch.



A massive thank you to the students of Scoil Mhuire National School, Newtownforbes, Co Longford who donated €100 of their confirmation money to the Longford Branch. What a kind gesture! Well done to all concerned.

## CAVAN



Carole Beattie, Cavan Branch Chairperson, James Nevin, Cavan Branch Treasurer & ASI Board Member & Claire Finley Cavan branch member accepted an award for the 'Reminiscence Walk' at the Age Friendly Recognition & Achievement Awards in Cavan.

# NEWS FROM AROUND THE COUNTRY

## GALWAY

Researchers from the Centre for Economic and Social Research on Dementia at NUI Galway hosted a public information meeting called "Let's Talk about Dementia: Perspectives and Experiences from NUI Galway" in order to increase awareness of dementia and dementia research at the University. It was a free event and attendees heard about the latest treatment advances in dementia, saw how technology can help people with dementia, and learned about current national policy initiatives in dementia.



On the left is Rita Harkin, & on the right is Maureen Mannion, Dementia Adviser Galway, with the Mobile Information Unit at the Public Information Meeting on Dementia, held in NUIG.

ASI Galway would like to thank everyone who participated in their sponsored walk. The Galway Camogie board presented a cheque for €3,064 to the Galway Alzheimer's walking team. This money will be used for the development of locally based dementia services in Galway.



Pictured L – R are Gerry Hennelly (Camogie Board), Grace Cunningham ASI, Kay Conneally ASI, Bernadette O'Grady ASI, Dessie O'Brien Camogie Board, Aoife Crosthwaite ASI, Caroline Shaughnessy, ASI Volunteer

## ROSCOMMON



Thanks to Anne & Sean Keegan who held a Pony Drive that raised €200 for the ASI. Pictured above are Marion Murphy, Castlerea Daycare Centre Manager, Anne & Sean Keegan and care worker Cathleen.

## LIMERICK



Limerick Branch Chair Marilyn Sheehan visited students from Villiers School, North Circular Road in Limerick who've been raising funds with various events in the school. Keep up the good work!



Thanks to Kieran Fitzgerald who presented a cheque to Branch Chair Marilyn Sheehan for €5,572 on behalf of all the staff from Stryker Limerick



All the clients in Kilmurry Court love when musicians Jane Murphy, Ivan Thornbury and David Clampett visit them each week to perform; it's the highlight of the week for many. Big thanks to them for donating their time.

## CARLOW

Garden Antics in the first of the Summer Sun at Bethany House Day Care Carlow with client Florie Bradley and Care Worker Deirdre Foster picking the first of the daffodils.



## WICKLOW



Big thanks to Jason Waters who visits regularly with Harvey the dog for some pet therapy at Lily of the Valley. The clients are always delighted when they visit! Pictured - Jason, Harvey & Marie.



A Dementia Awareness presentation was given to the 4th, 5th and 6th classes in Carysfort National School (Arklow) as part of their Grandparents Week. Janet the principal was delighted by how well the children behaved and we were delighted by the extremely clever questions from students. Pictured - Laurence Collins, Wicklow DC Manager & Principal Janet Nuzum.

# THE NEW ERA OF THE GDPR – DATA PROTECTION & OUR CHARITY

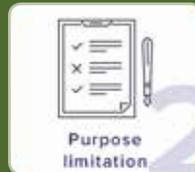
ASI handles medical data and other sensitive information about individuals at our offices and care centres all across the country.

With the new EU data protection law, the GDPR, now in force, our charity must be able to show the regulator that it's adhering to best practice.

## Six basic principals of data processing in GDPR



Transparency and legitimacy



Purpose limitation



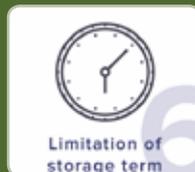
Data minimization



Accuracy



Confidentiality



Limitation of storage term

fundamental human rights. The laws are there, and have been strengthened, to make sure someone can't be laid bare & exploited because they have provided their personal data."

"Think of the all the risks that lurk in modern day society. We must have rigorous processes in place to assure people that their information is safe with ASI. We must rise to new challenges and be prepared to change."

Clare has been conducting training at National office which will be rolled-out to all staff and volunteers. Across the summer, she will consult with regional managers on issues relevant nationwide.

For further information contact [claremurphy@alzheimer.ie](mailto:claremurphy@alzheimer.ie) or telephone 01 207 3800



Clare Murphy was recently appointed ASI Data Protection Officer. She'll be working to raise awareness & ensure practical procedures help the charity meet its obligations.

"People often perceive data protection as something to do with computers. That's all about IT security. It's not," she says. "At its very core data protection is about

## #WHOWEARE

In 2018 we have been publishing #WhoWeAre social media posts each Friday to showcase local supports and services – and need your help to continue this.

We'd like photos from all aspects of ASI daily life – Day Care, Home Care, the DAs, Alzheimer Cafes, Social Clubs, Information, Fundraising, Advocacy, Training etc anything that showcases to the public #WhoWeAre.

Please send your photos or queries to [lisa.gernon@alzheimer.ie](mailto:lisa.gernon@alzheimer.ie)

## HELLO...

Hello, Do you remember me, as I remember you?  
Not so clear, bit confused now, and then I do  
Remember that is.  
Please support and still be my friend  
As this will help me although I will never mend.  
I don't want to feel isolated.  
I know it's sad but remember we're human  
Your resilience is to keep this moving.  
My family will need you, not only me.  
It's them who will suffer that I'm just not me.  
Please support them in any way you can.  
The dementia will take me  
But for now I am still who I am...  
ME.

by Ms Claire Smyth, Care Worker



@alzheimersocirl

TheAlzheimerSocietyofIreland

If you have any queries or would like to submit a piece for The Voice please email: [thevoice@alzheimer.ie](mailto:thevoice@alzheimer.ie)

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