



THE ALZHEIMER
SOCIETY of IRELAND

OASIS

Quarterly Newsletter of the Alzheimer Society of Ireland

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Spring 2005



**Take 5 on
05/05/05
for
Alzheimer Lyons
Tea Day**



**N.I.C.E. Recommendations
'Dementia Matters' – European Conference
Fundraising Events
Media Appeal**

Reflections from the CEO



Maurice O'Connell, Chief Executive

Dear All,

In this Spring edition we ought to talk about the newness of nature and new life. I am less inclined to do that when we are facing the pension repayment saga for those in public long-term residences. Where consecutive Governments have reneged on their responsibilities to older people by not providing appropriate residences for those with a dementia and other people who need nursing care. In the UK, we heard of a preliminary finding of N.I.C.E. (National Institute of Clinical Excellence) regarding the withdrawal of the anti-dementia drugs using efficacy as the reason. But we understand this was because of the cost. This amounts to ageism at its best. And what happens there today could happen to us tomorrow.

We also, as a nation have not understood what it means for our carers to struggle on at home with little or no assistance and then have to pay a considerable amount of money to private nursing homes to care for their loved ones. The investment that carers put in to maintain their loved ones at home is not matched by a Government programme that really supports their efforts.

The new Health Service Executive is emerging. A time for renewal and radical thinking. A time for reorganisation and redirection. A time for listening I hope!

Maurice O'Connell

Dementia Matters

'Dementia Matters'

**Alzheimer Europe's 15th European Conference
Killarney, Co. Kerry from the 9th to the 12th
June 2005**

Planning is well under way for Alzheimer Europe's 15th European conference - 'Dementia Matters' – which we are hosting in the Great Southern Hotel from 9th to 12th June next. The programme has been finalised and is sure to be a 3-day forum of lively debate. We have keynote addresses and workshop presentations from across Europe addressing cross-cutting issues such as the rights of the person with dementia; dementia care practices and challenges; stigma; ageism and dementia; the challenges of demographics on dementia care; intellectual disability and dementia, to name just a few plus updates on the latest psychosocial research.

We hope that this conference will draw people into the world of dementia care, provoking reaction and bringing to the fore the fact that 'Dementia Matters' to all of us.

For further information contact: Conference Organisers at (01) 662 0125 or e-mail alzheimer@conferenceorganisers.ie. Website www.alzheimer-conference.org.



New Appointment

We would like to take this opportunity to welcome Ms Jo Sarah Parada to the Society. Jo joined us on the 14th of February 2005 as HR Officer and is based in National Office. Jo originally comes from Mexico City and lived in England for many years before coming to Dublin 5 years ago. Her background is in the Hospitality Industry and before making the transition to the world of Human Resources she worked as the Ward Catering Manager in St. James's Hospital supervising a team of 145 employees. We wish Jo every success in her new role.



Moving desks ...

We would like to announce that Angela Keegan has taken up the role of Head of HR and Administration. Angela has been with the society for the past 3 years as Projects Manager and will continue to be based in National Office.

Following the departure of David McCarthy, Public Relations Manager; Sarah O'Callaghan (Events Manager) will be looking after PR from now on; and Nuala Dunphy has been appointed Personal Assistant to Maurice O'Connell (Chief Executive)



Some Fond Farewells

We would like to bid a fond farewell to Edward Rowland and Myrtle Sullivan who have left the society. Our heart felt thanks to both Edward and Myrtle for their hard work over the years.

Alzheimer Lyons Tea Day 2005

Take 5 on 05/05/05

This year, our 11th Annual National Tea Day takes place on Thursday, May 5th and once again, Lyons Tea is our main sponsor. All around the country, friends of the Society will 'raise a cuppa' to increase awareness and funds for our services in their local communities.

What better way is there to enjoy a cup of tea with friends, colleagues or family, than in the knowledge that you are raising money to provide dementia-specific support and services to benefit people in your community affected by Alzheimer's disease dementia?

Add to this, the fact that Alzheimer Lyons Tea Day is a FUN and Easy way to make a difference, and you can see why the Society believes we will win the support of 2,500 Tea Day Hosts across the country this year in our efforts to reach our target of €600,000. If everyone does even a little on Tea Day, together it will add up to a lot.



Taking 5 for 05-05-05

David Gillick 400m Gold Medallist pictured with 4-year old ballerina Faye O'Connell Bell 'Take Five' to share a cuppa at the launch of the Alzheimer Lyons Tea Day, which takes place nationally on Thursday 5 May.

All you really need is a kettle and some nice biscuits, which means that whether you're at home, in work or in your local community centre, you can get involved. As always, monies raised locally stay local, so your contribution will go directly to helping provide services and support to people in your area whose lives are affected by dementia.

From a PR point of view, we are supporting this year's Tea Day with a strong radio advertising campaign, which is scheduled to run regionally (on 15 regional radio stations) from 28th March

until 22nd April and nationally on RTE radio up until 5th May. Our media campaign will also have a strong regional focus as we try to highlight the role of the Society and the contribution of Carers across the country.

Hosting a tea party is fun and easy – whether it's at home, at work or in the community hall – simply put on the kettle, brew up a storm and make a real difference for people living with Alzheimer's disease and their carers.

Want to register?

Simply Freephone **1 850 931 931** to receive your special Lyons Tea Pack. We'll provide you with all ingredients needed to host a Tea Party including: Lyons Tea, posters, collection boxes, and raffle tickets.

By the way, it's never too early or late to host a Tea Party. If you would like to host a party before or after May 5th, phone Orla Concannon at 01 284 6616 for more information.

Thank you for your valuable support!



Tea For Two

David Gillick 400m Gold Medallist pictured serving 'Tea for Two' to (l to r): Marie Clare (ASI, Dun Laoghaire) and Ros Shaw with help from the 'Lyons Birds'.

NICE Recommendations Not So Nice

As you have no doubt learned through the media, on 28 February, NICE, the National Institute of Clinical Excellence for England and Wales, published the following preliminary recommendations on the use of drugs in Alzheimer's disease:

- "1.1. Donepezil, rivastigmine and galantamine are not recommended for use in the treatment of mild to moderate Alzheimer's disease (AD).
- 1.2. Memantine is not recommended for the treatment of moderately severe to severe AD, except as part of ongoing or new clinical studies that are designed to generate robust and relevant data on long-term outcomes, disease progression, quality of life and costs.
- 1.3. People currently receiving donepezil, rivastigmine, galantamine and memantine, whether as routine therapy or as part of a clinical trial, may be continued on therapy (including at the conclusion of a clinical trial) until it is considered appropriate to stop."

Whilst Ireland does not have an organisation like NICE and is not in any way bound by their recommendations, this recent publication is of concern to the Alzheimer Society of Ireland and Alzheimer Organisations throughout Europe. We join with 20 other European Alzheimer's Organisations and Alzheimer Europe in **strongly** disagreeing with the recommendations of NICE which would disbar tens of thousands of people from the only available treatment for their condition.

- As stated in the NICE appraisal, enough **clinical evidence** exists to support the use of anti-dementia drugs, since clinical trials have shown them to be effective not only in improving memory, but also in beneficially influencing behaviour and activities of daily living.
- This clinical data on the effectiveness of anti-dementia drugs is **supported by the testimony** of great numbers of people with dementia and their carers.
- Cost-effectiveness models used by NICE fail duly to take into account effects on the **quality of life** of carers of people with Alzheimer's disease. Similarly, cost models for care used by NICE do not take into account the **optimum care** that people should receive but are based rather on actual care provided which is often inadequate and of low quality.
- The existence of anti-dementia drugs has **contributed to** the development of dementia care through an expansion of memory clinics and other specialised services offering **early diagnosis**, advice and support for people with dementia and their carers.

- The discontinued prescription of anti-dementia drugs would take away one of the main reasons for people coming forward for an early diagnosis of their condition who would therefore no longer benefit from other significant advantages of an early diagnosis.
- The NICE recommendations would **discriminate against** a significant proportion of the population who already suffer from stigma and ageist prejudices.

“...join with 20 other European Alzheimer's Organisations and Alzheimer Europe in strongly disagreeing with the recommendations of NICE”

- European citizens should have equal rights to protection and access to health care regardless of their country of residence. The NICE recommendations would disbar British people with Alzheimer's disease from access to treatment options available and reimbursed in the other Member States of the European Union.

Furthermore, The Alzheimer Society of Ireland believes that governments and regulators should not further restrict access to anti-dementia drugs. Treatment should be offered as one part of a care package taking into account the various needs of people with dementia and their carers, and anti-dementia drugs should be made available under national reimbursement systems for people with Alzheimer's disease in all Member States of the European Union. Doctors should be encouraged to discuss the likely benefits and side effects with people with Alzheimer's disease and their carers in a realistic way without raising false hopes.



Volunteers of the Alzheimer National Helpline at a Workshop on Understanding Conflict and Wellness at Work given by Una Coughlan at Airfield House Dundrum Dublin, on 10th March 2005.

Fundraising News

Women's Mini Marathon

The Women's Mini Marathon is scheduled for the June bank holiday, Monday June 6. Last year we broke a record with 384 runners participating in aid of The Alzheimer Society of Ireland - more than double the numbers in the previous year! It was a fun-filled day and it was absolutely wonderful to see so many supporters wearing the Society's t-shirts as they ran or walked along the route. We hope to maintain the momentum and draw just as many (if not more!) runners. To enter, be sure to register directly via the Evening Herald in the Thursday or Saturday editions and then ring Susan Murray at 01 284 6616 for your free t-shirt and sponsorship cards.

No 'half baked' efforts at fundraising in Cavan General Hospital



Presenting the proceeds of a cake sale by the Surgical Unit of Cavan General Hospital are (l to r) Patricia Dolan, Mary Clerkin, Trevor McCay-Morresey (ASI Regional Officer) Mary Kelly, Robert O'Reilly, Brid O'Flynn, Nell McDonald and Martina Campbell.

Balding for Bucks!

There was a great turn-out for and lots of fun at the fundraising evening Head Shave in Gary Byrne's of Bree on 11th February. However, the bar was more of a 'shearing station' than a 'watering hole' as several generous locals turned their precious locks into €1,800 in aid of the Wexford Branch.



Declan Dunne earned extra donations by having his beard of 20 years shaved too! That's generosity.

The branch would like to thank all involved – the staff and management of Gary Byrne's of Bree, Suzanne Kelly, Wallis Bird and all the sponsors and volunteers.

Ennis Branch

Fundraising has been high on the agenda in Ennis in recent months, and hasn't it been successful



Fundraising News *continued*

Letting her actions speak louder than words ... Having braved the cold waters off Sandycove (Dublin) on Christmas Morning in aid of The Society, Emma looks fit and ready for whatever the day (or Santa) has in store.



Ita Wilkie and Mary Boyce presenting the Alzheimer Society of Ireland's Donegal Branch with a cheque for €3590.50 raised at a special fundraising dance in Biddy Friels, Drumoghill. From left are Clare Willies, Ita Wilkie, Julie Monday, Anthony Gallagher (Chairman Donegal Branch), Des Mulligan (ASI Regional Officer) and Mary Boyce. Photo Clive Wasson



Handing over a cheque for €1,000 from Park West Business Park are (l to r) Ruth Savage, Rita Buggy, Edel Byrne and Jean Scanlan (Curlew Road Day Care Centre, Dublin) with Emmer Madden and Mick Arthur (Business Park Manager, Park West). Grateful thanks to all in Park West for their generosity

Branch News

Home Support – North East Region



Receiving Return to Education Programme Certificates are Mary Rogers (l) and Pauline Cashin (r) with Jim Culligan (Fas – Project C.S.O.).



Core Skills Programme

Presentation of Core Skill Programme Certificates to (l to r) Mary Rogers, Catherine Murray and Patricia Ball.

North Cork Branch

Congratulations to the North Cork Branch who were recently honoured with a Community Award from Mallow Sports and Leisure Council at a function held at Cork Racecourse, Mallow. This event, which is among the largest in the Mallow calendar, "is to give recognition both to sung and unsung heroes in the community" according to the Chairman of the organising committee.



After receiving a Community Award, which was presented by Sean Og O hAlpin, are members of the North Cork Branch Committee, the staff of the Day Care Centre and members of the Awards Organising Committee.

Woodstock Day Care Centre (Dublin)

On March 11th Woodstock Day Centre (Ranelagh, Dublin) opened its doors to students from local secondary school Alexandra College, who had fundraised on their behalf. The visit was a great success and both the students and the attendees of the centre enjoyed the interaction and teamwork.



Picture perfect – the students enjoying painting and doing crafts as part of the activities of the Woodstock Day Centre.

Waterford Branch

The staff and clients of the new Pinegrove Day Centre in Waterford held an Afternoon Tea party in aid of the Tsunami Disaster Appeal. Music and 'goodies' were provided and the event was enjoyed by all. The benefits were two-fold, as the baking of cakes and apple pies provided a great deal of

South Tipperary Branch



Left to Right – Kate Brennan (Regional Officer), Eileen Graham (Coordinator), Adi Roche, Claire McCarthy (Solicitor), Rena O'Neill and Elaine Johnson (Committee Members).

Adi Roche and Solicitor Claire McCarthy hosted a very interesting public meeting in Clonmel in January. Adi, being a native of Clonmel, was at home when telling the story of her beloved late father's Alzheimer's. She laughed and cried during her talk and everyone in the hall was deeply moved by her story. Claire then gave a very enlightening insight into that important legal document 'The Enduring Power of Attorney'. She explained, in detail, the value of having this in place since anyone could become incapable (through illness) of making important decisions, which could affect their life.

New Frontotemporal Dementia Support Group

The new Support Network for carers of people with Frontotemporal Dementia (FTD) and other related dementias held its first two meetings on Jan 26th and Feb 23rd in the Holiday Inn, Pearse Street, Dublin 1. Dr Henry O'Connell (MIRA), Dr Brian Murray (Neurologist), Robert Cohen (Neuropsychologist, MIRA) and Mathew Gibbs (Social Worker, MIRA) spoke at these meetings providing valuable insights into the medical and care management aspects of the condition. We hope that these monthly meetings will provide for carers of people with FTD a useful forum on an ongoing basis for peer support and the exchange of information and ideas around effective coping strategies. The next meeting will take place on March 23rd in the Holiday Inn, Pearse Steet at 7.30. If you have any further questions please contact Rose Knott on (4925485) or e-mail rknott@alzheimerie.ie.

enjoyment and stimulation for the clients and it was refreshing to see a client group, normally in receipt of fundraising, fundraising on behalf of others. Congratulations to all involved as €260 was donated to the appeal.

Sincerest Sympathy

The Society wishes to express its deepest sympathy to the family of the late Norman J Stuart, former Chief Executive of The Alzheimer Society of Ireland, who passed away on 4th January 2005.

Norman served as Chief Executive from 1990 to 1999 and made an enormously valuable contribution to the development of the Society at a pivotal time in its history. We will not forget.

May he rest in peace.



IN MEMORIAM

Ms. Catherine Alton	Mrs. Peg McManus
Mr. John Alwell	Mrs. Eileen Mehta
Ms. Muriel Barrington	Mr. Tom Moran
Mr. Liam Benson	Mrs. Irene Morgan
Mrs. Crowley Berlsland	Mrs. Breda Mulhair
Mrs. Annie Carr	Ms. Bernie Mullane
Mrs. Kathleen Cheevers	Mr. Bill Murphy
Ms. Josie Conway	Mrs. Kathleen Murphy
Mr. Jeremiah Coonan	Mr. Liam Nagle
Mr. John Curry	Ms. Kathleen Nally
Mrs. Lily Deane	Mrs. O'Dea
Mr. Kevin Devin	Ms. Bridie O'Hara
Mr. Aidan Doran	Mrs. Anne Palmer
Mr. Joe Doran	Mrs. Gretta Porter
Ms. Teresa Fallon	Ms. Mary Rice
Mr. Matthew Fitzsimons	Mr. Robin Risk
Mr. Maurice Fleming	Mrs. Rogers
Ms. Margaret Forman	Mr. John Ross
Ms. Susan Forster	Mrs. Betty Rourke
Mr. Noel Greenlee	Mr. Edward Ryan
Mrs. Bridget Hughes	Ms. Irene Sharpe
Mr. Jim Kavanagh	Mr. Michael Sheerin
Ms. Carmel Kearney	Ms. Teresa Smith
Ms. Teresa Keeney	Mrs. Julia Stephens
Mr. John Long	Mrs. Sheila Stephens
Ms. Alice Madden	Mrs. Julia Stevens
Mrs. Eileen McCarthy	Mr. George Strathdon
Ms. Mary Kate McIntyre	Mr. Norman Stuart
Mr. Des McMahan	Ms. Margaret Tracey

May they Rest in Peace

Media Appeal – Would You Tell Your Story?

Raising the profile of Alzheimer's disease and the work of the Society, eliminating stigma, representing the views, needs and concerns of all affected by dementia, and campaigning for better statutory services (including specialist services for younger people with dementia) are key objectives of the Alzheimer Society, and therefore they are always at the core of our PR activities. The media and the general public are generous in terms of their interest in and support of the Society and what we do, but in order to understand the real impacts of Alzheimer's disease and dementia they need an insight into the lives of people who have been touched by these conditions either personally or through a loved one. We are regularly asked to source people with dementia or carers/family members, to participate in radio/print interviews or to make comment on a topical issue, and we are keen to enlarge the group of contacts we currently have on our files.

Would you be prepared to tell your story to the media?

If you are interested or if you have any queries / questions on what would be involved please phone Sarah O'Callaghan at (01) 284 6616 / 086 8091772 or e-mail socallaghan@alzheimer.ie.

Research Update - Neuro-Degeneration Conference

Professor Dennis Selkoe of Harvard Medical School, one of the world's leading experts on Alzheimer's disease, was one of a Who's Who of renowned researchers in Dublin in March to attend a conference on medical research into neuro-degenerative diseases. During the conference, Professor Selkoe said that he is optimistic that a number of experimental therapies, currently at clinical trial stage, would turn out to be successful in the next few years and he estimated that within a decade, drugs that halt the progression of Alzheimer's will be available.

oASIs was edited by Sarah O'Callaghan, Alzheimer Society of Ireland

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The comments and views expressed in this issue are often personal and do not necessarily represent the position of the Alzheimer Society of Ireland.