



**Alzheimer's Disease  
International**

*The global voice on dementia*

December 2018  
Volume 28 No. 1

# Global Perspective

A newsletter for Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.



**T**he plenary programme and speakers for the 33rd International Conference of ADI in Chicago have been announced, including the latest science and care findings from doctors **Serge Gauthier, Jeffrey Cummings and Norbel Roman**, and professors **Anders Wimo and Linda Clare**.

Jerry Wylie, Vice Chair of Dementia Alliance International, will open the first session by sharing his experience of the US National Alzheimer's Plan as a person living with dementia, and Susan Ryan, Senior Director of the Green House project,

will talk about the impact of the innovative care model in the US.

For the first time in over 17 years, the ADI Conference will be held in the same week as the Alzheimer's Association International Conference in 2018, offering an unparalleled opportunity to hear from the biggest global gathering of experts in dementia care, research and science, alongside policy, innovation and technology.

See the programme and take advantage of our early bird discount by registering before **30 April 2018**, at: [www.adi2018.org](http://www.adi2018.org)



## Alzheimer's Disease International

*The global voice on dementia*

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### Send us your comments


If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of *Global Perspective* to arrive by 14 June 2018;

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## Editorial

**Paola Barbarino, CEO**



**There is much to report as we near the end of the first quarter of 2018. In January, the year opened with a call from ADI and 15 associations for the World Health Organization (WHO) to address the omission of dementia from the next General Programme of Work that will come into force in 2019. A statement made to the Executive Board resulted in the successful inclusion of dementia, maintaining the landmark momentum to address the disease following the adoption of a Global plan in 2017.**

The Global Dementia Observatory, launched by WHO in December, is now accessible online including a range of data from 21 countries. ADI and associations have an important role to compliment and critically monitor the Observatory as we progress towards the targets of the Global plan for transformed awareness, diagnosis, treatment, care and research by 2025.

In 2018, ADI is planning new publications that will outline the current state of dementia policies in the context of the Global plan, and will be attending the World Health Assembly and other meetings where there are continued opportunities to influence change at the highest level.

More recently, we were disappointed to hear that two high-profile Phase III drug trials had failed to show the desired outcomes for improving cognition – verubecestat and BI 409306. Pfizer, the world's largest pharmaceutical research company, announced that they were discontinuing studies into dementia altogether.

It is important that to recognise that the search for a disease-modifying treatment for dementia continues, and that investment into new research – both in science and care – remains critical. There are signs of hope, including the promising development of a blood test that can identify biomarkers for the development of Alzheimer's disease, and increasing interest in the role of the brain's immune system in the development of dementia. Exploring existing treatments for other conditions, including arthritis, could have a dramatic impact on the speed of development and access to a new treatment.

The ADI team is growing, and there are more details of this on page 4. We are ever more committed to grasp the unique opportunities within the next eight years, and we are excited to announce our new Global Honorary Ambassador, Queen Sofía of Spain.

The programme for the next conference of ADI in Chicago, 26-29 July, is now online and we look forward to this opportunity to bring the global dementia community together at the original home of ADI during this landmark year for dementia, and for the organisation. Take advantage of our Early Bird offer by registering before 30 April: [www.adi2018.org/registration](http://www.adi2018.org/registration)



## ■ News

### Dementia included in draft WHO Programme of Work

Dementia has been recognised in the World Health Organization (WHO) draft 13th General programme of work 2019-2023 following advocacy by Alzheimer associations leading to Member State support at the 142nd Session of the WHO Executive Board in Geneva.

Representatives of ADI attended the meeting, where a statement by Paola Barbarino, CEO, supported by Dementia Alliance International (DAI) expressed concern at the omission of dementia following the landmark adoption of a Global plan on dementia in 2017.

Attention to dementia was also requested in statements made by Member State representatives from Argentina, Chile, Japan, Portugal and the UK.

The draft programme of work outlines the priorities of the WHO for the next five-year period starting in 2019. It is expected to be approved at the World Health Assembly, the gathering of all Member States of the WHO, in May 2018.

### Queen Sofía of Spain becomes an Honorary Ambassador of ADI

Queen Sofía of Spain has become an Honorary Ambassador of ADI in recognition of her significant personal commitment to dementia research and care globally. The Queen is also Executive President of Fundación Reina Sofía and Honorary President of Confederación Española de Familiares de Enfermos de Alzheimer (CEAFA), the national Alzheimer association in Spain.



Paola Barbarino, CEO of ADI, welcomed the Queen as an Honorary Ambassador of ADI, stating, "We are deeply honoured by Her Majesty's acceptance of this role. Queen Sofía's commitment to dementia over the years has been a crucial factor in raising awareness and combating stigma and we look forward to continue our work strengthened by Her Majesty's patronage".

The support of Ambassadors is important to ensure that high level support is achieved for global transformation of the awareness, science and care for 50 million people affected by dementia worldwide.

## ■ Events

22-26 July 2018

**Alzheimer's Association International Conference (AAIC)**

**Chicago, USA**

Email: [aaic@alz.org](mailto:aaic@alz.org)

Web: [www.alz.org/aaic](http://www.alz.org/aaic)

26-29 July 2018

**33rd Conference of Alzheimer's Disease International**

**Chicago, USA**

Email: [conference@alz.co.uk](mailto:conference@alz.co.uk)

Web: [www.adi2018.org](http://www.adi2018.org)



24-26 October 2018

**11th Alzheimer Iberoamerica Congress**

**Guatemala City, Guatemala**

Email: [emerita.alzheimerguatemala@gmail.com](mailto:emerita.alzheimerguatemala@gmail.com)

Web: <http://alzheimeriberoamerica.org>

29-31 October 2018

**28th Alzheimer Europe Conference: "Making dementia a European priority"**

**Barcelona, Spain**

Web: [www.alzheimer-europe.org](http://www.alzheimer-europe.org)



TBC 8-10 November 2018

**ADI Asia Pacific Regional Meeting**

**Colombo, Sri Lanka**

Email: [alzheimers@alzlanka.org](mailto:alzheimers@alzlanka.org)

Web: [www.alzlanka.org](http://www.alzlanka.org)

## News

### Global Dementia Observatory launched by WHO



The development of the Global Dementia Observatory follows the adoption of a Global plan on dementia by the WHO in May and will greatly enhance the ability of stakeholders everywhere to support advances in awareness and research.

Dementia affects 50 million people and will cost the global economy over a trillion US dollars in 2018. By 2050, the number of people living with dementia is expected to nearly triple. ADI has been actively involved in the development of the Observatory, which will compile and monitor significant data on the disease, diagnosis, access to resources, policy and care and support for those affected.

21 countries have so far provided data for the Observatory and this is expected to increase to over 50 countries in 2018, providing a vital database where medical professionals, researchers, civil society and others will be able to access the largest collection of up to date information on dementia, listed by country and region. Information from the Observatory will greatly aid the development of national plans on dementia in more countries – a cornerstone of advocacy by ADI.

Paola Barbarino, CEO of ADI, said, “We welcome this timely and important resource. It will be vital to monitor and share progress as countries work towards the targets in the Global action plan and the overarching goal of creating and delivering effective national dementia plans.”

### Dr Miyake missed by ADI Community

Dr Yoshio Miyake passed away in January 2018. Dr Miyake was well known within the ADI family, and has been described as “opening the door to the world for Alzheimer’s Association Japan.”

Dr Miyake was previously a board member of ADI and was Secretary General of the conference secretariat for the ADI conference in Kyoto in 2004. He played an important role in the development of ADI and Alzheimer Association Japan and will be sorely missed by all.



Dr Miyake with delegates at the 20th International Conference of ADI in Kyoto, Japan

### New faces and staff changes

ADI have welcomed a number of new staff to the office in London. Wendy Weidner joined ADI on 1 March as Research and Policy Project Lead and is responsible for ADI’s participation in the STRiDE (Strengthening responses to dementia in developing countries) project.



Wendy Weidner joined ADI in March

## ■ News

### New faces and staff changes (continued)

Nikki Bayliss, ADI's new Head of Development, and Laura Dabas, ADI's new Membership Manager, will start work on 26 March, following the departure of Anastasia Psoma earlier this year. Anastasia has taken a role at a charity in Greece and we wish her the best.



**Anastasia at the 31st International Conference of ADI in Budapest, Hungary**

Sarah Kerr, who moved from the ADI office in London to working part time in Scotland as Publications Manager, has decided not to return to her work with ADI following the end of her maternity leave. We wish Sarah the best with her ongoing projects and family life.



**Sarah Kerr, Publications Manager has left ADI**

Annie Bliss, who has supported ADI part time since August 2017, will also complete her role in the office at the end of March. Annie played a significant role in World Alzheimer's Month, and more recently on the member survey of ADI associations. We wish Annie the best with her future studies and career.

We look forward to working with the new team in 2018. See the ADI staff page at: [www.alz.co.uk/staff](http://www.alz.co.uk/staff)

### Project We Forgot launch online Community Network



Project We Forgot have launched a new community network informed by a survey of support services for young caregivers, completed by Alzheimer associations in 43 countries.

Findings of the survey showed that developing support services for young caregivers was considered important, but that funding and expertise were key needs for addressing a current lack of support. Almost two thirds of those asked said they were considering developing new services for those under 39 years old in 2018.

Young caregivers for people living with dementia face unique challenges that are often unrecognised – they are especially vulnerable to added stress placed on education and employment, face stigma and in many cases do not identify themselves as, or are not readily considered, caregivers.

The new online network has been developed to support young caregivers to seek peer support, exchange ideas and share experiences and is accompanied by an app so that young caregivers can access the Project We Forgot network on the go. Find out more at:

<https://community.projectweforgot.com/>

### More research needed as results disappoint

Pharmaceutical company Merck have announced the discontinuation of Phase III studies into drug Verubecestat, after trials failed to show a significant impact on Alzheimer's disease. Results followed the news that Pfizer, the world's largest pharmaceutical company, would be ending all research into Alzheimer's disease. More investment is needed to support new research on dementia.



# Members' forum

## EUROPE

### Innovative training for independent living



From 18 to 19 December 2017, Spominčica - Alzheimer Slovenia and Alzheimer Derneği (Turkey) attended a kick-off meeting of AD-AUTONOMY with partners AF Castellón and others in Castellón, Spain.

AD-AUTONOMY aims to improve the quality of life of persons with dementia and their care partners by raising awareness and increasing the autonomy of persons with dementia for decision making and independent living, promoting autonomy through training, supporting the process of empowerment through introducing technology and techniques for emotional management, and developing training methodology with tools.

Stefanija Lukic Zlobec, President of Spominčica, said, *“The main aim of AD-AUTONOMY is to empower persons with Alzheimer’s disease, especially those in early stages of the disease, to stay active in society, to remain autonomous in their everyday activities and keep doing the tasks they are still able and capable to do. In this way they can stay with their families longer, they have higher quality of life and don’t feel a burden to society.”*

Füsün Kocaman, Executive Director of Alzheimer Derneği, added, *“The most powerful and effective aspect of the project is the fact that it involves the end users throughout the development process. Initially they are asked their needs for autonomy to define the requirements of the training and their feedback is used repeatedly to refine the product. This approach ensures the efficiency of the training.”*

AD-Autonomy started in October 2017 and will end in September 2019.

## BANGLADESH

### National awareness seminar on Dementia Care: World scenario and where we are

Alzheimer Society of Bangladesh (ASB) held an awareness seminar in January, attended by family carers, government, academics, healthcare professionals, members of ASB and civil society. Mst. Selina Jahan Lita, Member of Parliament, Adviser to the Society and member of the Global Parliamentary Action Group on Alzheimer’s and Dementia, chaired the meeting, including a special note on the importance of developing a national dementia plan in the country.

There are estimated to be over 460,000 people living with dementia in Bangladesh, and this figure is expected to increase to 834,000 by 2030.

#### ***“People do not know where to go to find support.”***

Mst. Munira Sultana, a family carer, shared her experiences of caring for her mother, who has had dementia for seven years. Her father was unable to care for her mother and Munira urged that greater action was needed to encourage timely diagnosis of dementia in hospitals, to train carers and to provide support services for those affected. She explained that many people did not know where to go to find support.

Other speakers highlighted the importance of building awareness of dementia in rural communities and the way in which action on Non-communicable diseases (NCDs) could support risk reduction for dementia.

Azizul Haque, Secretary General of ASB, explained how the association was providing training and awareness for those affected, while continuing to advocate to the government for a national dementia plan. He welcomed participants to the meeting, where ADI’s ‘Help for Care Partners of persons with dementia’ booklet was distributed in Bengali. Find out more: <http://alzheimerbd.com/>

# Members' forum

## CHINA

### ADI – ADC High level meeting in China



Paola with Xin Yu MD, Director of WHO/Beijing Collaborating Centre for Research and Training in Mental Health and Chair of ADC

Paola Barbarino attended a high-level meeting on implementing community dementia care in China in January, facilitated by Alzheimer's Disease Chinese, WHO Western Pacific Regional Office and the National Health and Family Planning Commission (NHFPC). Other partners at the meeting included the Ministry for Civil Affairs, National Aging Committee, China Disability Union, Beijing Science and Technology Commission and China Central Television.

Participants shared their expertise on the importance of developing a plan in China, that included reviewing global examples of national policies, and local care. 20% of all people with dementia are estimated to live in China. How the health and care system addresses dementia will have a significant impact on the global stage, providing useful insights for other countries to follow.

## BULGARIA

### Respect for people with dementia

Compassion Alzheimer Bulgaria has received an award for respecting the autonomy, dignity and right of self-determination of people living with dementia. The award was one of 12 presented as part of the European Foundation's Initiative on Dementia, in recognition of the Association's project, 'Together we respect, promote and act - Inclusive society for all ages and stages of dementia'.

The award ceremony took place on the 23 January under the auspices of the Bulgarian Presidency of the European Union. The ceremony was preceded by a conference, that offered a stimulating networking and learning space for the Foundations' network of practitioners and stakeholders on the topic, 'Valuing the expertise of people living with dementia.'



## ■ Meetings Roundup

### First Latin America week of Bio Pharmaceutical Innovation



Paola presenting at the First Latin America week of Bio Pharmaceutical Innovation in Mexico City

ADI attended the first Latin America week of Bio Pharmaceutical Innovation in Mexico City in February, where CEO Paola Barbarino spoke during a panel on the person-centred approach to dementia.

Organised by AMIF (the Mexican Association of Pharmaceutical Research Industries), the week included discussion and presentations on regulation, innovation, clinical trials and data, involving several pharmaceutical companies, the Secretary of Health in Mexico and representatives of the G20 and OECD.

### ADI attends second “What if” roundtable on dementia

Chris Lynch, ADI’s Policy, Communications and Publications Director and Deputy CEO, attended the second of a series of events by MSD hosted at the European Parliament in Brussels.

“Overcoming the ethical challenges of early detection and diagnosis” was attended by dementia experts including people living with dementia and their care partners, as well as representatives from technology and innovation companies in the dementia field. It followed a first event in September on ‘The right to dignity’.

### ADI joins Working Group for High Level Meeting on NCDs



**TOGETHER  
LET'S BEAT NCDs**

*Preparing for the third UN High-level Meeting on NCDs, 2018*

Chris Lynch, Policy, Communications and Publications Director and Deputy CEO, has joined the WHO international Working Group in preparation for the high-level meeting on Non-Communicable diseases (NCDs) expected to be held in September 2018.

In 2015, world leaders committed to reduce the impact from NCDs by 2030 as part of the Sustainable Development Goals – the new meeting offers an important mid-term review of the importance of the Goals, that have largely gone unmet.

Dementia is an NCD. Risk factors of many NCDs, such as high blood pressure and lack of physical activity, also increase the risk of dementia. ADI is on the Steering Committee of NCD Alliance, who are advocating for a strengthened response to NCDs in 2018.



## ■ Dementia Alliance International

# The value of being together

The Dementia Alliance International (DAI) Action Group has become very active, and is currently working on various projects for DAI members, including fundraising to enable DAI to sponsor as many members and their care partners as possible to attend the ADI International Conference in Chicago. DAI Board member Jerry Wylie will speak at the Conference on the importance of the USA's National Alzheimer's Plan, that has been recently reviewed in 2017.

In 2018, DAI has also received generous support from Dubhglas Taylor, that has enabled us to expand our Support groups, including providing our support group hosts with more formal training.

Webinars in 2018 have included raising awareness of dementia among school children by Dr Pippa Burns, and focus on social health and cognitive reserve by Prof Myrra Vernooij-Dassen.

Membership of DAI is free and is open to anyone with a diagnosis of dementia. Find out more and join DAI at [www.dementiaallianceinternational.org](http://www.dementiaallianceinternational.org)



### Online support groups

DAI members provide online support groups for people with dementia through online video conferencing. Online support groups are ideal for those who cannot drive to a local group or who live in isolated areas with limited access to services. Find out about more at: [www.dementiaallianceinternational.org/services](http://www.dementiaallianceinternational.org/services)

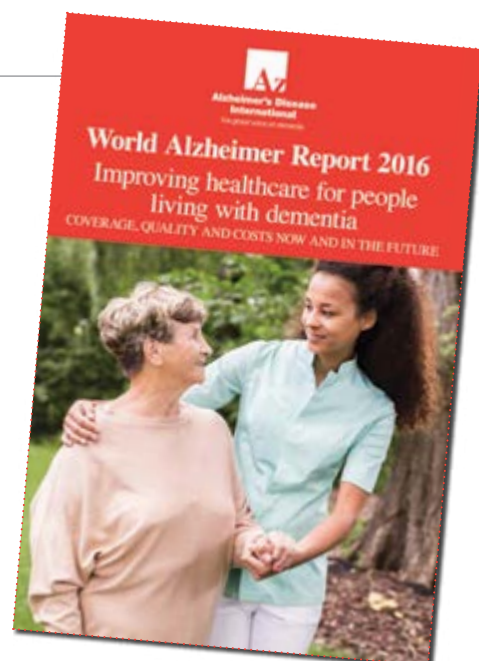


## ■ Global knowledge

ADI produces regular publications on a range of topics including reducing your risk, care and support, and global and regional data on the impact of dementia.

Our World Alzheimer Reports examine different themes with the latest data from research, including prevalence, improving healthcare and challenging stigma.

All publications and summaries are available for download from [www.alz.co.uk/global-knowledge](http://www.alz.co.uk/global-knowledge)



## ■ Living with dementia

# There is a hole in our medical care bucket

**Jerry Wylie**, Vice Chair, DAI, Oregon, USA



**I am about three years into my journey with dementia. The shock is finally over, I have accepted my diagnosis, and it's time to reflect on my journey.**

By January of 2015 I had become very insecure about my ability to do my job as a Business Manager. My ability to be organised, focused, confident, reliable, multitask and remember, were all things that seemed to be suddenly gone. Severe anxiety had also come into my life for the first time.

In June of 2015 at age 62, I called my boss and said, "you need to find a replacement for me because I can no longer pull this sled". Next, I scheduled an appointment with my doctor to tell him what was going on. He scheduled a complete neuropsychological examination for the following month.

In July, I went through a 7-hour neuropsychological exam and sat down with the doctor two weeks

later for his diagnosis. He said, "there is no doubt, you have dementia most likely caused by diabetes, there is no cure, very little treatment and no way to determine how fast it is going to progress".

I asked him "what can we do to help ourselves in our battle against this disease?" He said, "I will send these results to your family doctor who will begin a series of tests to help determine what type of dementia you have and he will start you on medications that may or may not help with the symptoms".

### ***"I felt like I was set up to fail"***

There was "no advice" to eat healthy, "no warning" that depression could become an issue and "no referral" to any kind of support or, information on the disease. My family doctor did begin all the lab tests, brain scans and medication. The only other thing he suggested after me asking that same question, "what can we do to help ourselves?"; was to begin considering power of attorney and end of life wishes. I felt like I was set up to fail by the medical community.

By November of 2015 I had fallen into a deep, deep fog and was overcome by depression. One dark night on the freeway about 1 hour from home, I panicked during a road trip, pulled over, and told my wife I was going to walk home. Every time a truck zoomed by, I contemplated stepping out. Why? I couldn't work, I couldn't drive and it felt like there was absolutely no hope, I had lost all of my purpose in life. My wife searched and searched for me but had to call 911 (emergency assistance). It took another 3 hours and two State Police cars to finally find me.

In December of 2015 I stumbled upon Dementia Alliance International and was immediately connected to weekly Zoom Support chats and a private Facebook support page. My road to acceptance of this diagnoses had finally begun. Through DAI, I found hope which led me to "renewed purpose".

I know now that had even one of my doctors referred me to some sort of link to dementia



## ■ Living with dementia

support, I could have avoided a full year of depression. This is what I call a “Hole in our medical care bucket”. I have been speaking to Rotary Clubs throughout Oregon on this topic ever since. A simple referral is not too much to ask.

“While I still have a voice, I am going to speak loudly.”

Two years after initial diagnosis by private sector doctors, I had become fully qualified for Veteran medical care. The Veteran dementia specialty department decided to re-test me in hopes of definitively defining the type of dementia I have and, see if I had progressed. I was excited about this and the appointment was set up. I first met with my Family Practitioner and told him of my excitement over finally learning exactly what type of dementia I have. He said, “don’t worry about it Jerry, we treat them all the same anyway”. My immediate thought was, “wow, how could a doctor say this”! Later, I found out that the amount of time spent on dementia in Medical School in the USA is nearly non-existent. There is a second hole in our medical care bucket!

There is so much work to be done on behalf of better serving people and families who live with dementia that I have made it my full-time ambition. My clock may be ticking but while I still have a voice, I am going to speak loudly.

Jerry will be sharing his experiences during a plenary session at the 33rd International Conference of ADI in Chicago in July.

**See the draft programme and speakers at [www.adi2018.org](http://www.adi2018.org)**

## ■ Research update

# Blood test may revolutionise dementia diagnosis – and clinical trials



A blood test developed by scientists in Australia and Japan may be able to detect the presence of amyloid-beta, believed to be a key component in the development of dementia, up to 20 years before the onset of symptoms.

Molecular biologist Katsuhiko Yanagisawa at the Center for Development of Advanced Medicine for Dementia in Obu, Japan, and colleagues developed the test that has been trialled by analysing the blood plasma of over 300 people from Australia and Japan.

Still at an early stage, the test was approximately 90% accurate when compared with the results of existing brain imaging and lumbar puncture methods for testing for amyloid-beta.

While more research is needed to confirm the findings, a blood test for amyloid-beta has the potential to greatly reduce the cost of testing for dementia, in a way that is readily available in low and middle-income countries where most people with dementia live.

As well as being non-invasive, when compared to a brain scan or ‘spinal tap’, a key use for the test could be to identify the best individuals to take part in clinical trials, at a much earlier stage before the development of dementia – an important factor that could have a dramatic impact on our understanding of dementia in the future.



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[www.adi2018.org](http://www.adi2018.org)

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 Alzheimer's Disease International



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