



Alzheimer's Disease  
International

*The global voice on dementia*

December 2018,  
Volume 28, No. 3

# Global Perspective

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



## mhGAP Forum, 11 – 12 October 2018, WHO, Geneva

**T**his year's **mhGAP (mental health gap) Forum: 'Accelerating Country Action on Mental Health'** took place from 11 to 12 October and gave participants a chance to discuss the progress on the World Health Organization's (WHO) Mental Health Action Plan 2013-2020.

Alzheimer's Disease International (ADI)'s Asia Pacific Regional Director DY Suharya attended the forum in Geneva alongside ADI's Chief Executive Officer Paola Barbarino. DY shared a statement

on behalf of ADI's 94 member associations at the consultation on care pathways for people with dementia: 'Leaving no one behind'.

DY also took the opportunity to speak with WHO Director General Dr Tedros (pictured above) on the importance of strengthening partnership and collaborations in relation to the Global action plan on the public health response to dementia as a tool to help restructure social and healthcare systems and support universal health coverage (UHC). **Continued on page 3**



## 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.

### Want to contribute?

We welcome your contributions. Please get in touch to have your news and stories included in future issues.

### Secretariat

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### Notes on membership

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 [www.youtube.com/user/alzdisint](http://www.youtube.com/user/alzdisint)

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## Notes from ADI

**Laura Dabas**, Membership Manager and Membership Development Programme Lead

**As we near the end of 2018, it occurs to me that I've been working at ADI for 8 months now – how time flies!**

My experience so far has been incredibly inspiring and, as a result of my involvement with ADI, I am meeting so many people who are passionate about improving the lives of people with dementia, their carers and families. Seeing what associations are doing all around the world fills me with hope and gratitude. On a personal note, my grandmother was diagnosed with dementia a few months ago and working with our members is helping me and my family so much. It has been an absolute pleasure to get to know everyone individually - associations across the regions are all so different, yet similar in many other ways.



**DY and Laura in Sri Lanka following the ADI Asia Pacific regional meeting in November**

Over the past few months, I have been lucky enough to attend (and organise!) several events: the Alzheimer Scotland conference in Edinburgh in June; the ADI international conference in Chicago in July (more details on page 8); the Alzheimer University (AU) for emerging associations in London in September; the Alzheimer Europe conference in Barcelona at the end of October (page 8), as well as the Alzheimer University on Advocacy and Marketing Communications, and the Asia Pacific regional meeting in Colombo in November. So much knowledge and so many ideas are shared during the AUs (page 9) and the regional meetings: bonds between countries are truly strengthened and this is a very precious thing. It is our role at ADI to maintain these activities and find other ways to maintain these bonds and work on capacity building with our members. I have witnessed the contagious enthusiasm, hard work and positivity of our members and wider networks and am really impressed to see how you all support and encourage each other.

I hope that our members have also enjoyed the webinars we have been putting on throughout the year. We are planning to hold them more regularly next year and will continue to get members even more involved. Don't forget to join us for the End of Year Members Update Webinar on 4th December - reflecting on 2018 and looking forward to 2019! The webinars are always a great opportunity for interaction on an international level. I am excited for the year to come and look forward to seeing you all soon.

## ■ News

### mhGAP cont'd

ADI's continuous commitment to support the efforts of governments to implement care pathways for dementia takes a personalised human-rights based approach, involving people living with dementia at every stage. After the forum, DY concluded: "Dementia is everybody's business. During the mhGAP discussions, I've noticed more and more WHO member states expressing the importance of having dementia as a national priority in their respective countries. Dementia care pathways are a central aspect of the principal of universal health coverage and must be established universally – that is, across all regions and countries." **Find out more about the mhGAP Forum.**

### ADI staff changes

ADI welcomed back Annie Bliss ([a.bliss@alz.co.uk](mailto:a.bliss@alz.co.uk)) who has re-joined the team as Communications and Policy Officer, having worked with ADI on last year's World Alzheimer's Month campaign. Annie will now focus on delivering ADI's communications plan including campaigns and publications and supporting policy events and activities.



We also welcomed Jenni McGowan ([j.mcgowan@alz.co.uk](mailto:j.mcgowan@alz.co.uk)) who has joined the team part time as Communications and Administration Assistant. She will support in delivering ADI's communications plan, including social media planning and tracking, delivering ADI's e-updates and newsletter, and producing other online content.



### Care matters: "Carers should be considered essential partners"



**Paola Barbarino with the Minister for Labour and Social Welfare of Slovenia, Ksenija Klampfer, and Štefanija Zlobec, President of Spominčica Alzheimer Slovenija**

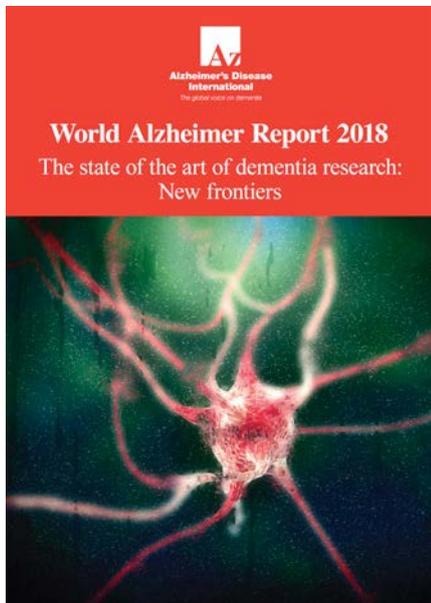
In November, Paola Barbarino attended the UK Dementia Conference in Brighton where she spoke about global care strategies, giving examples of challenges and solutions in dementia care from around the world. In her presentation, she referred to statistics from *Global Estimates of Informal Care*; an ADI report which estimates that, by 2030, informal carers will provide the equivalent care of over 65 million full time workers. She also referenced the 2018 OECD report, *Care needed: Improving the lives of people with dementia* which highlighted that fewer than 40% of OECD countries are able to estimate national dementia diagnosis rates.

While noting that the needs of informal carers are complex and localised, Paola maintained that "carers should be considered essential partners in the planning and provision of care in all settings according to the wishes and needs of the person with dementia." Among her examples of strategies to support care was a care home in Slovenia that she recently visited; the Dom Danice Vogrinec Maribor care home, which has won the EAN-ECREAS (European Centre for Research and Education in Ageing Services) prize for best elderly care facility in Europe.

Paola pointed out that "Slovenia are the first and still only Eastern European State to have a National Dementia Plan." After her visit to the country in September, she explained the significance of this: "In Ljubljana I met with the Minister of Social Welfare and Labour who, together with the Ministry of Health, is really embedding awareness of dementia at all levels of society. It is good to look at successful examples of where civil society - in this case the tireless work of the local NGO Spominčica Alzheimer Slovenija alongside its staff and volunteers - has been pivotal to achieve a turnaround of public opinion and governmental support for dementia care strategies". **Read ADI's report: "Global Estimates of Informal Care" on our website.**

## News

### ADI release World Alzheimer Report 2018



On 21 September, ADI were pleased to announce the release of the World Alzheimer Report 2018: *The State of the art of dementia research: New frontiers* in conjunction with World Alzheimer's Day 2018. The report, written by journalist and broadcaster Christina Patterson, aims to tackle some of the complex questions surrounding dementia research through a wide range of interviews with some of leading lights in dementia research from nine countries.

ADI received some very positive feedback on the new, accessible style of the report and secured broad media coverage. On the day of the report's release, Christina appeared live on Sky News Sunrise (UK) and ADI's Chief Executive Officer Paola Barbarino gave an interview with Al Jazeera. A key message on the day was to reiterate ADI's call for a minimum of 1% of the societal cost of dementia to be invested in research. ADI is extremely grateful to all the interviewees and participants who made the report possible. **As with all ADI resources, you can download and share the report free of charge from the ADI website.**

### ADI hosts new global webinar series

ADI is currently hosting a series of global webinars to provide an open discussion on dementia research and clinical trials. The first webinar: "Let's Talk About Dementia Research: Demystifying Trials, Access and Understanding" was a great success, with over

200 participants joining us from 49 different countries. Chairing the webinar was Professor Craig Ritchie, Chair of Psychiatry of Ageing at the University of Edinburgh and Director of the Centre for Dementia Prevention, alongside ADI's Chief Executive Officer Paola Barbarino. We were also pleased to be joined by Piers Kotting, Programme Director, Office of the National Director for Dementia Research, National Institute for Health Research (NIHR); Dr Gayle Madden, Professional and Practice Development Facilitator, Dementia UK; Alison Searle, Operations Program Leader, Roche; and Eileen and Dubhglas Taylor, who shared their personal experience of dementia trials.

During the webinar, we asked participants several poll questions, including: "What are the barriers to taking part in dementia research?". It was interesting to note how the responses to our poll aligned with a recent Alzheimer's survey released by Banner Alzheimer Institute, Novartis and Amgen (more on page 12), revealing that lack of knowledge and access play a large role in preventing people from taking part in research. Feelings of fear, as well as mistrust in the pharmaceutical industry and stigma were highlighted as significant barriers. We will build on the themes and questions emerging from the discussion in future webinars. Strikingly, however, 80% of participants said they would still volunteer for dementia research.

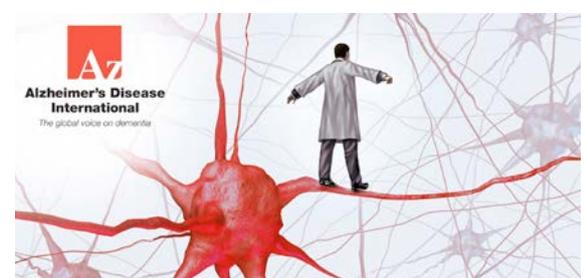
Eileen Taylor, who presented her own experience with dementia trials, said: "Listening to this has kind of given me hope that things might change."

For those who couldn't join us live for our first webinar, it will soon be available to watch online. The series will take a deeper look at barriers and enablers, access to trials in lower and middle income countries and also starting to consider pre-symptomatic and younger volunteers.

The next webinar will take place in early 2019. **Please visit our website and sign up to our newsletter for more information.**



The panelists preparing for the first webinar, including Eileen and Dubhglas Taylor who joined via video link from Brisbane, Australia



## News

### World Rocks Against Dementia: Join the 2019 event!

World Rocks Against Dementia (WRAD) is back for a fourth year, raising funds and awareness for dementia causes around the world through concerts and music events. WRAD has grown immensely since its humble beginnings, founded in the USA by Wayne Mesker and Michael Rossato- Bennett of the Alive Inside Foundation. Through collaboration with Norms McNamara (founder of [Global Purple Angel](#)) it has now become a truly global movement with 85 events taking place across 20 countries in 2018.



WRAD events can be large or small. Any kind of music goes, from rock and country & western to classical or traditional, and the funds raised from the event can be used for any dementia project of choice.

**WRAD 2019 takes place between 22 and 25 March 2019. Please visit the [Facebook page](#) or contact [Purple Angel Movement](#) for more info.**

### Over 84 countries took part in World Alzheimer's Month 2018



Macau Alzheimer's Disease Association's memory walk for World Alzheimer's Month

This year's World Alzheimer's Month was the biggest campaign yet, with events held in over 84 countries. The theme 'Every 3 Seconds', which was adopted by most ADI members, coincided with the ADI and ITN Productions documentary of the same name. The film is available to view on ADI's [YouTube channel](#) and features some of the inspirational work that is taking place around the world in dementia research, care and new technology. **You can read more about the 2018 World Alzheimer's Month campaign, including case studies from a selection of this year's events, on our [website](#).**



Participants of Associação de Parentes e Amigos de Pessoas com Alzheimer (APAZ)'s awareness-raising motorcycle ride in Brazil

## Events

14-18 July 2019  
**Alzheimer's Association International Conference (AAIC)**  
**Los Angeles, USA**  
 Website: [www.alz.org/aaic/overview.asp](http://www.alz.org/aaic/overview.asp)

16-18 August 2019  
**ADI Asia Pacific Regional Conference**  
**Kuala Lumpur, Malaysia**  
 Email: [info@alz.co.uk](mailto:info@alz.co.uk)

7-10 November 2019  
**ADI Caribbean Regional Conference**  
**Saint Mary Parish, Jamaica**  
 Email: [info@alz.co.uk](mailto:info@alz.co.uk)

22-25 November 2019  
**Alzheimer Europe Conference**  
**The Hague, Netherlands**  
 Website: [www.alzheimer-europe.org/Conferences/The-Hague-2019](http://www.alzheimer-europe.org/Conferences/The-Hague-2019)  
 Email: [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org)

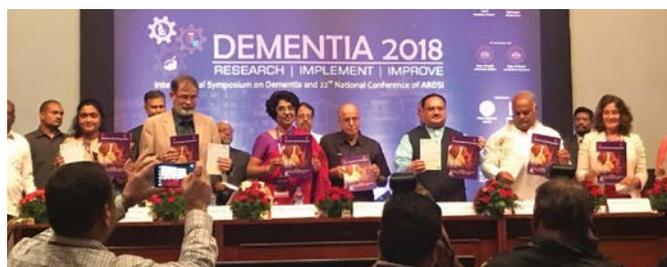
16-18 October 2019  
**Alzheimer IberoAmerica Conference**  
**Ecuador**  
 Website: [www.alzheimeriberoamerica.org](http://www.alzheimeriberoamerica.org)

18-21 March 2020  
**International Conference of Alzheimer's Disease International**  
**Singapore**  
 Website: [www.adi2020.org](http://www.adi2020.org)  
 Email: [info@alz.co.uk](mailto:info@alz.co.uk)

## News

### India and Germany announce national plans

On 9 September, during the National Conference of our member, Alzheimer's & Related Disorders Society of India (ARDSI), the Minister for Health of India announced the government's commitment to a National Action Plan for Dementia, emphasising the need for quality of life to progress as longevity prospects increase. The plan, which will initially focus on risk reduction, diagnosis, care and research, could make an enormous difference to the lives of over 1.3 billion people in the country. ADI's Chief Executive Officer Paola Barbarino, who was on the panel in Bangalore when the announcement was made, described it as "an amazing feeling to take part in such a momentous occasion".



**Honourable Health Minister of India, Jagat Prakash Nadda unveiling the government's national dementia strategy document**

On 20th September, the German Government also announced its commitment to develop and fund a National Dementia Strategy. **Visit ADI's website to find out more about national dementia plans**

## Thank you to our supporters

ADI relies greatly on the generous contributions of our supporters to fund the work that we do. The majority of ADI's funding is derived from companies, charitable trusts and foundations. Collectively, their support funds much of ADI's operational costs, as well as the projects that we run.

Through the support of our sponsors, ADI has been able to: run four Alzheimer University programmes for our members in 2018 offering skills development in advocacy, fundraising, marketing, business modelling and organisational development (read more about ADI's AUs on page 9); run our annual World Alzheimer's Month campaign (see page 5 for more information on this year's campaign); carry out key advocacy events such as our World Health Assembly side event in May 2018; publish reports, including our Plan to Impact Report and the World Alzheimer Report (further details follow on page 4); attend high

level meetings with government officials to continue our efforts to ensure that national dementia plans are developed and implemented; connect funders with our member associations where there is a specific interest and help develop projects that will improve the lives of people living with dementia, such as dementia friendly communities and awareness raising.

We are also thankful to all those supporters that give unrestricted contributions, which are incredibly valuable to a small organisation like ADI to help us work flexibly and respond to external situations as they arise.

Our partnerships are much more than financial support, and ADI has been really pleased to work with Amgen, Novartis and the Banner Alzheimer Institute on the biggest survey to date which looks at attitudes to research participation (more info on page 4); welcome expert speakers from our corporate supporters

to our Alzheimer University and regional meetings of members during the year; and speak alongside our supporters at conferences and other events. We also welcome the gifts in kind and pro bono support that we receive, helping us to run our events and initiatives at a reduced cost.

The ADI team would like to thank all our supporters, including the following companies and trusts, as well as the numerous individuals and organisations that give to us anonymously:

AC Immune • Amgen • Biogen  
 • BioMed Central • Boehringer  
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 Lilly & Company • GE Healthcare •  
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 Medical Nutrition • Otsuka America  
 Pharmaceutical, Inc. • PhRMA • Roche  
 • Van Otterloo Family Foundation

## ■ Dementia Alliance International Update



Valerie Schache, Phyllis Fehr, Alister Robertson, Dubghlas Taylor and Eileen Taylor.

During the last few months, **Dementia Alliance International (DAI)** has been extremely busy. Members attended the Alzheimers New Zealand conference in October, with Board member Phyllis Fehr giving a keynote speech, "Citizenship and Human Rights for people with dementia". Eileen Taylor, Alister Robertson, and other DAI members also gave presentations and co-hosted a DAI Workshop, "Zooming in on Inclusion". You can find all Alzheimers NZ conference abstracts [here](#).

Kate Swaffer (Chair, CEO and Co-Founder) presented at several World Alzheimer's Month events to support ADI members, including in Taipei for TADA and Milan for Alzheimer Italia. For Alzheimer's Italia, Kate supported them with a Call to Action in the form of a video petition, '**Finanziare il Piano Nazionale Demenze: malati e famiglie non possono più aspettare**'.

DAI also ran a series of daily blogs during World Alzheimer's Month themed #Hello to present the uniqueness of our members, which was of great interest to members, families, and professionals, and has resulted in many of them being used in several **educational opportunities** around the world.

Due to the popularity of the series DAI has decided to continue it, and started October with one from **Professor Peter Mittler**.

DAI continues to host webinars, with our November webinar by Associate Professor Lee-Fay Low from Sydney University on **Dementia and Rehabilitation: evidence and opportunities**. This is important considering DAI's position as a founding member of the newly established Global Rehabilitation Alliance at the World Health Assembly and with the increasing demand for rehabilitation and other proactive support aligned to the global action plan on dementia.

Kate Swaffer attended the **mhGAP Forum in Geneva** in October, where for the first time, the WHO hosted a parallel session on dementia. It has been a busy and exciting few months raising awareness and advocating for our rights. **Join DAI, Subscribe to DAI's blogs and newsletter or Donate to DAI.**



## ■ Meetings and Conferences

### ADI Conferences



In July, the 33rd International Conference of Alzheimer's Disease International (ADI) took place in Chicago, USA. Over 750 delegates from more than 65 countries made up the incredibly diverse audience. People with dementia, family care partners, researchers, professional carers and clinicians all came together under one roof to hear presentations by representatives from [Women's Brain Project](#), [NCD Alliance](#), [Dementia Alliance International](#), [The Organisation for Economic Co-operation and Development](#), plus many others.

There was a wonderful range of poster presentations, showcased alongside exhibits from organisations innovating around dementia, from our members and sponsors, plus a movie night on Saturday (complete with Chicago's famous Garrett popcorn!) for the premiere of the ADI and ITN documentary, 'Every 3 Seconds'. The weekend ended on a positive and powerful message, encouraging governments everywhere to support the implementation of the global plan on dementia by working with Alzheimer associations and people with dementia to turn the plan into real action. You can read the full conference report and check out a selection of presentations from the conferences [here](#).

[The 34th International Conference of ADI: Hope in the age of dementia: New science; new knowledge; new solutions](#) will take place in Singapore on 18 – 21 March 2020. **Sign up to receive further updates.**



Chris Lynch (ADI) speaking at the conference in Chicago

### Alzheimer Europe holds successful 28th Annual Conference

The 28th Alzheimer Europe Conference "Making dementia a European priority" was held in Barcelona on 29 - 31 October 2018. More than 800 participants from 46 countries attended the conference, which featured 239 speakers and 175 poster presenters, sharing their research, projects and experiences. A keynote lecture "Will we be able to prevent Alzheimer's disease?" was delivered by Dr José Luis Molinuevo from BarcelonaBeta Brain Research Center (read more from José Luis in our Research Update on page 12.)

Chris Lynch, ADI's Deputy CEO, Membership Manager Laura Dabas, and Board member Birgita Martensson attended this year's conference on behalf of ADI, joined by CEO Paola Barbarino on the final day. Chris presented on the European response to the [Global action plan on the public health response to dementia](#) and joined a Roche symposium on the voice of the carer in the global plan. Chris said: "Alongside the main programme, the Alzheimer Europe conference is also a wonderful opportunity to network, to share experiences and exchange valuable insights. This year in particular we were able to focus on the European response to the WHO global action plan on dementia. Also, with the kind permission of Alzheimer Europe, ADI was able to gather some of our European members, for what was a very engaging post conference meeting.

**Alzheimer Europe's next conference will take place in The Hague from 23 to 25 October 2019. Find out more [here](#).**

## ■ Meetings and Conferences

### ADI holds Alzheimer Universities in three regions



Participants of the AU in Guatemala in October

Over the past few months, ADI has organised three successful AUs: the Alzheimer University for emerging associations in London in September, the Alzheimer University on Sostenibilidad financiera para asociaciones de Alzheimer (financial stability for Alzheimer associations) in Guatemala in October, and the Alzheimer University on Advocacy & Marketing Communications in Colombo in November.

In London, ADI's Events and Administration Coordinator Katie Bingham noted: "For a lot of the attendees, the membership development programme and the AU for emerging associations is where it all begins. It was extremely inspiring to see organisations from around the world at the very start of their journeys, all with such drive and enthusiasm. The passion in the room was contagious. I am excited to watch how each country develops over the coming years and wish them all the best of luck."

In Guatemala, ADI's Regional Director for the Americas Joost Martens coordinated the first AU to take place in the Spanish language, coinciding with the first anniversary of the ADI's regional office for the Americas. Following the AU, Joost concluded that: "the topic of financial sustainability for Alzheimer associations was of great interest to the 18 participants from nine countries, for them to get a taste of entrepreneurial ways of working, of how to secure income for their organisations, without giving up their not-for-profit nature. A combination of external speakers and presentation of successful

experiences of associations from the region gave the right mixture of inputs for the AU.

20 participants from 11 countries attended the Alzheimer University in Colombo supported by Nutricia and the Lundbeck Institute. The event was conducted at the Cinnamon Grand Hotel and was facilitated by ADI APRO with speakers including: Glenn Rees (ADI), Katrin Seeher (WHO), Shenuk Ales (Moody Analytics), Laura Dabas (ADI). Participants took part in a lively discussion, sharing their knowledge on fundraising, marketing communication and advocacy activities from their respective countries.

ADI's Alzheimer University programmes provide essential learning opportunities for Alzheimer associations around the world, helping to build capacity and importantly provide an opportunity for the global exchange of information and mutual support across cultures. The Alzheimer University sparks new thinking and new ideas, ultimately helping associations to strengthen their support to those affected by dementia in their own countries.

**Find out more on ADI's [website](#).**



Joost Martens speaking at the AU in Guatemala

## ■ Meetings and Conferences

### WISH Qatar and Doha Healthcare Week



Dr Heriawan, Amalia Fonk-Utomo and DY Suharya in Doha

In November, ADI facilitated an insightful seminar on Islamic values in dementia care at the Qatar National Convention Centre in Doha in conjunction with the World Innovation Summit of Health (WISH) and Doha Healthcare week. The seminar was made possible by ADI member Alzheimer Indonesia and taken by Dr. Heriawan (geriatrician) and Amalia Fonk-Utomo (advocate and Chairperson of Stichting Alzheimer Indonesia Nederland). The seminar focused on everything from awareness raising to engaging an inter-disciplinary approach in dementia care. At the same time, Hamad Medical Corporation, as representatives of ADI's membership development programme, took the opportunity to invite ADI to present certificates of appreciation to more than 50 interdisciplinary champions who supported a successful World Alzheimer's Month campaign last September. ADI was honoured to be featured in the opening video of WISH Qatar 2018 and have such a prominent role at the conference.

Watch the video [here](#).



ADI's CEO Paola Barbarino appearing in the opening video for WISH Qatar 2018

### 18th World Congress of Psychiatry, Mexico

The 18th World Congress of Psychiatry took place in September in Mexico City and included in its programme a Presidents' Symposium on Dementia. ADI's Chair Glenn Rees was invited to give a paper on dementia and informal carers. It was an opportunity to stress the critical role played by informal carers, particularly in lower- and middle-income countries, the greater understanding that research has provided of the needs of informal carers and the failure to translate important findings from research into carer support programmes.

Read Glenn's speech [here](#).

### First National Dementia Conference held in Vietnam



The First National Dementia Conference was held on 7 September 2018 in Hanoi and was hosted by the Vietnam National Geriatric Hospital in collaboration with the Ministry of Health of Vietnam. The theme of the Conference was "Dementia as a public health priority – the need for the development of a Vietnam national dementia plan". International speakers were invited including the Chair of ADI, Glenn Rees who spoke about the imperative of adopting a national plan and setting priorities. The conference was followed by workshops given by clinicians and researchers from the USA and Australia and work on carer burden is ongoing. Read Glenn's speech [here](#).

## ■ Living with dementia

**Rhys Dalton**

**Back in July, Rhys Dalton joined us for our conference in Chicago to speak alongside his mother (and Dementia Alliance International (DAI) board member) Maria Turner. Rhys and his wife Kayla Whitten are Maria's two primary care partners. For those of you who couldn't make ADI's conference, we wanted to share their story with you.**

I'm Rhys Dalton, I am 25 years old and have just married my mum's other "care partner," Kayla Whitten.

My mum Maria was diagnosed with young onset dementia while I was finishing up my senior year at the University of South Wales in Cardiff, UK. As you might imagine, with my mum based in the USA, I wasn't able to come home on the weekends too much, so wasn't really aware of the extent of the problems she was faced with. I got my degree in aircraft maintenance engineering and I was really looking forward to starting my career in that field as soon as I could after I got back to the states. I was 23 years old at the time and thought I had my life pretty well planned out. I was wrong.

The past two years have been about learning that life doesn't always allow you to plan anything out. Kayla and I have spent a lot of time learning everything that we can about mum's disease in general and about her needs in particular. "People often talk about the 'role reversal' that caregivers and loved ones go through, using phrases such as 'my mum has become my child' or 'I have had to become the parent'."

As we learned more about what mum was able to do, our understanding of our roles as "caregivers" changed dramatically. I'm sure that some of this is due to my mum's character... she is very determined and despite what all her doctors had told her, she was determined that she would live a healthy life and stay positive. Two years later, she is doing exactly that.



**Rhys Dalton and Maria Turner at the ADI conference in Chicago**

There was, and still is, a lot of trial and error about how we live and handle everything from grocery shopping to paying the bills, to going away for the weekend. Having said that, we have persevered and will continue to persevere with the intention of maintaining a good, healthy, happy and loving relationship. Although we have not had the stereotypical experience, Kayla and I do still feel like Maria's son, daughter-in-law, and best friends. We have fought to keep our roles of parent and adult child separate from dementia, so that we can focus on our love and relationships, rather having them being defined only by dementia.

We define ourselves as we always have, meaning Maria is still my mother, I am still her son and Kayla is still her daughter-in-law. We act like roommates, and talk about everything, including dementia, in great depth. Dementia entered our world, we didn't not invite it. It was no one's choice. Dementia has simply been the road we have had to go on, so we are dealing with it as positively as possible.

**Find out more about Rhys, Kayla and Maria on the [Dementia Alliance International website](#).**

## ■ Research update

### World's largest Alzheimer's Survey reveals lack of knowledge is preventing people from volunteering for research

A global survey released in September by Banner Alzheimer's Institute (BAI), Novartis, and Amgen, in association with ADI, revealed that most adults believe a cure for Alzheimer's will be found within their lifetime. The survey showed that 79% of respondents would be willing to participate in Alzheimer's research but 75% had no idea how to get involved.

Paola Barbarino, Chief Executive Officer at ADI, said: "At present, there is no cure and limited treatment options for Alzheimer's, but this survey shows that people are willing to participate in research to hopefully find a cure. We need to demystify and remove awareness barriers to participation in medical research, making all suitable candidates aware of how they can get involved." Read more about the survey [here](#).

Inspired by these findings, ADI has organised a series of global webinars to allow the general public to engage directly with health and social care professionals involved in dementia research. (More on page 4). **Please visit our [website](#) for further information.**

### Barcelona: a hub for Alzheimer's research

**José Luis Molinuevo, Scientific Director of the Alzheimer Prevention Program at BarcelonaBeta Brain Research Center (BBRC)**

Over two weeks in October, Barcelona was a gathering point for Alzheimer's disease researchers, starting with the 11th Clinical Trials on Alzheimer's Disease (CTAD) and closely followed by the 28th Alzheimer Europe Conference (AEC). Probably the hottest topic discussed at CTAD was the role of BACE inhibitors as therapeutic agents, since cognitive decline has been observed in at least two trials. This prompted discussions about its physiology and potential differences among compounds, as well as blood-based biomarkers, which are being perceived as a potential biomarker almost ready to come into practice.

CTAD ignited the spark, closely followed by the fire of AEC. I had the privilege of giving the keynote inauguration talk of AEC, focusing on the challenges and opportunities regarding Alzheimer disease prevention. An intense program followed, generating lively debate and brainstorming around making dementia a priority. Barcelona was thrilled to host these two major conferences at the end of October and researchers were happy to see continued progress in the field.

## STRiDE Update

**Wendy Weidner, Research and Policy Project Lead, ADI**

After months of laying ground work through theory of change (ToC) workshops, training, and rapid situational analyses, the STRiDE project

- Strengthening Responses to Dementia in Developing Countries - is moving at pace.



Rapid situational analyses have been completed in all 7 countries, with a focus on prevalence, provision of care, support and treatment, existing dementia policies, expectations of policy change, key stakeholders and summaries of existing knowledge to identify gaps. Countries have drafted reports and these will soon be available on the [STRiDE website](#).

Based on the ToC workshops and rapid situational analysis, field work sites have been finalised for each of the seven countries. Brazil and Kenya will focus on Work Package Three: Tailoring, refinement, implementation and evaluation of anti-stigma programme in a local community; India, Jamaica, Mexico will concentrate on Work Package Four: Investigation of cost/impacts of unpaid care; and Indonesia and South Africa will focus on Work Package Five: Survey to establish prevalence of dementia and gather data on care receipt and provision.

In early 2019, core fieldwork activities will begin with focus groups on stigma taking place in each country. **You can keep up to date with STRiDE [here](#).**



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