



Alzheimer's Disease
International

The global voice on dementia

December 2017
Volume 27 No. 2

Global Perspective

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

World Alzheimer's Month calls for global response to dementia plan



Famous TV and radio host, Lin Sui-Wei, supports the 'Remember me' campaign led by TADA, Chinese Taipei.

Alzheimer associations and their partners including people living with dementia supported World Alzheimer's Month by holding events to increase awareness of dementia around the world during September.

Associations led campaigns on themes including 'Remember me', with a focus on recognising the warning signs of dementia and understanding the benefits of an earlier diagnosis.

On World Alzheimer's Day, Alzheimer's Disease International (ADI) issued a press release highlighting the global impact of the disease, and calling for every government to develop a national, funded, response to dementia in their country. During the day, the World Health Organization (WHO) published a new series of information sheets on the global plan on dementia, closely developed with ADI. Every September is World Alzheimer's Month. Please support the campaign in 2018 so that we continue to raise awareness.



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 2 February 2018; Editor: James Smith

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Editorial

Paola Barbarino, CEO



During the 4th Sub-Saharan African Regional Conference of ADI in Nairobi, organised in partnership with Alzheimer's Kenya, I stayed at a local hotel with several African members of ADI. During the conference we had heard and shared experiences about serious issues of stigma and denial surrounding dementia in the region.

One night in the lift, I was alone with a young member of the hotel management. He asked, timidly, "Are you here for a conference on dementia?" I responded affirmatively. He said, "Is it true that it is caused by evil spirits?" I said, "No, it is not true, it's an illness like any other" and then I added "In your family?" He said very quickly – "yes, my grandfather, and now my father, we are very tired, we don't know what to do, people say it's the evil spirit, what can we do?"

I gave him the contacts of Alzheimer Kenya's support group, told him he should seek help, that we are here to help. He told me he and his family were really depressed and did not feel they could talk about it with anyone, and felt cut out by their community.

There was a whole tragedy unfolding in that elevator; yet there was also hope. This man felt comfortable enough to ask me, a total stranger, for help, and I felt a wave of gratitude to Alzheimer's Kenya – wholly staffed by volunteers – who are providing hope in this stark landscape.

Our other sub-Saharan African members have real troubles getting their government to even acknowledge that dementia exists in their country. Coming together during World Alzheimer's Month has already made a difference. Associations in Kenya, Lesotho and Zimbabwe have been emboldened to ask for a meeting with their Ministries of Health. Our Kenyan member has started doing outreach work in villages where perception of evil spirits presents a unique challenge to understanding dementia, inspired by our Namibian member.

The time has come for all of Africa to start raising its voice; the man in the lift had to wait until we were alone to ask. The stigma surrounding dementia is still too great.

Events

22-26 July 2018

Alzheimer's Association International Conference (AAIC)

Chicago, USA

Email: aaic@alz.org • Web: www.alz.org/aaic

26-29 July 2018

33rd Conference of Alzheimer's Disease International

Chicago, USA

Email: conference@alz.co.uk
Web: www.adi2018.org



29-31 October 2018

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

Barcelona, Spain

Web: www.alzheimer-europe.org/Conferences

TBC 8-10 November 2018

ADI Asia Pacific Regional Meeting

Colombo, Sri Lanka

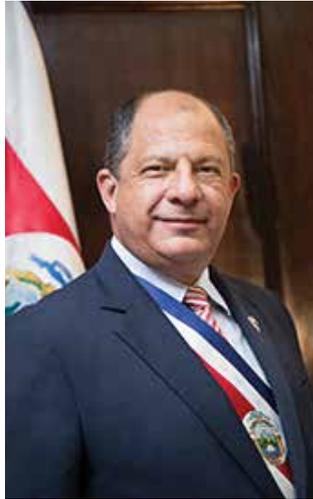
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■ News

President of Costa Rica becomes Honorary Ambassador

The President of Costa Rica, Luis Guillermo Solís Rivera, has become an Honorary Ambassador of Alzheimer's Disease International (ADI) after affirming the commitment of the country to attain targets of the government's *National plan on dementia and other related disorders 2014-2024*.



Dementia affects over 16 million people in Latin America and Costa Rica is one of only 6 countries in the region to develop a plan on dementia. The role of the President will greatly aid the implementation of this plan as a hallmark for others in the region,

The President said, *"Becoming an Ambassador means transcending, and improving, the current living conditions of [people with dementia] and offering hope to the rising elderly populations. If we unite our efforts, we can cause a positive impact worldwide."*

Paola Barbarino, CEO of ADI, said, *"We are delighted to have the support of the President and hope that others will follow this example to raise awareness and act on dementia globally."*

ADI also acknowledges the important work of Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA), who continue to raise awareness and directly support people with dementia and their families.

More governments must develop plans to address an urgent gap in awareness, diagnosis, research and risk reduction, treatment, care and support, working towards the implementation of the World Health Organization (WHO) Global action plan on dementia adopted in 2017.

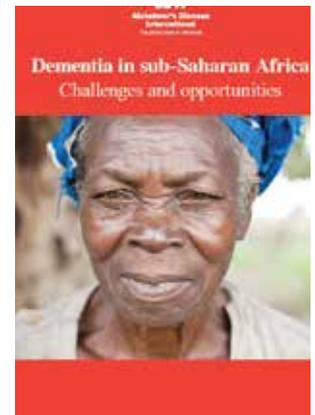
Dementia in sub-Saharan Africa: Challenges and opportunities

ADI has published its first report on the impact of dementia in sub-Saharan Africa (SSA), at the 4th Sub-Saharan African Regional Conference in Nairobi. The report calls for a transformation in the response to dementia, citing a 63% increase in the number of people expected to be living with dementia in the region by 2030 – and an increase of 257% by 2050.

Launched during World Alzheimer's Month, the report highlights new data on the impact of dementia in SSA, the experiences of those living with dementia in the region and the urgent need for governments to act to encourage improved understanding, access to health services and social protection. Download the report at: www.alz.co.uk/Africa

Paola Barbarino, CEO of ADI, says: *"This report provides important evidence of the huge scale of the challenge we face on multiple fronts in sub-Saharan Africa. Not only is dementia hidden socially, but governments must do more to enhance the infrastructure needed to support those affected. We are calling on governments in the region to take the issue up urgently and to follow the recommendations of the World Health Organization's Global Plan of Action."*

Dr Maëlen Guerchet, lead author of the report at King's College London's Global Observatory for Ageing and Dementia Care, says, *"Our review of the evidence highlights the need to develop research that will help promote and inform consideration of dementia in health agendas. Dementia awareness, access to healthcare services and the rights of people with dementia and their families are key aspects to focus on in sub-Saharan Africa where older populations are not given adequate attention."*



Dementia in sub-Saharan Africa: Challenges and opportunities' was published at the 4th ADI sub-Saharan African Regional Conference in September 2017.

News

WHO launch new materials on global plan



The World Health Organisation (WHO) marked World Alzheimer's Day with the publication of new materials on the global plan on dementia. The materials include a new infographic on the global impact of dementia, and factsheets on the importance of the 2017 global plan for civil society, policy makers, health and social care professionals and people living with dementia. Targets of the plan offer the single greatest opportunity for the advancement of dementia understanding, care and science worldwide.

ADI played an active role in the development of the materials, that relate the global targets of the plan into an accessible format. Paola Barbarino, CEO, said, "It is fantastic to see the launch of such important materials by our colleagues at the WHO. The publication of these materials on World Alzheimer's Day is a timely reminder that governments must act now to address dementia in every country."

ADI and ITN Productions to present 'Every Three Seconds'

Alzheimer's Disease International and ITN Productions are producing a news and current affairs-style programme on the impact of dementia.

Someone in the world develops dementia every three seconds. The programme will bring to life what needs to be done to address this trillion-dollar disease, including the new innovations, processes and people who are working vigorously to support and encourage global action on dementia.

'Every Three Seconds' will premiere at the 33rd International Conference of ADI in Chicago on 26-29 July 2018. The programme will also look at how governments across the world can dramatically increase care and support for, and awareness and diagnosis, research and treatment of dementia.



Paola Barbarino, CEO of ADI said: "This programme is an extraordinary opportunity to reduce the stigma attached to dementia worldwide. We will aim to raise the profile of the human, social and economic impact of dementia globally whilst highlighting practical and innovative ways in which we can all make a difference."

Simon Shelley, Head of Industry News, ITN Productions, said: "We're delighted to produce this programme exploring Alzheimer's disease and other dementias that affect a phenomenal amount of people and their families around the world. We want to bring to life the extent of this disease and what is needed to raise greater awareness."

■ News

National plan on dementia adopted in Chile

The government of Chile has adopted a national plan on dementia. The plan is the 30th to be adopted worldwide, and includes key targets for improving awareness, access to care, support and treatment, research and risk reduction of dementia by 2025.

It is estimated that 180,000 people are living with dementia in Chile, resulting in a cost of care per person of almost US \$11,000 every year. The plan follows the examples of existing plans in Argentina, Costa Rica, Cuba, Mexico, Puerto Rico, Uruguay and the USA, and includes a budget of US \$5.5m a year for implementation.

Paola Barbarino, CEO of ADI welcomed the positive inclusion of the rights of people with dementia, and promotion of the dignity, inclusion and quality of life of those affected. She said, *"The plan shows great vision and promise. I wish the Chilean government a successful roll out and implementation and a continuing positive relation with civil society organisations including Corporación Alzheimer Chile, a member of ADI."*

Patricio Espinola, President of Corporación Alzheimer Chile, said, *"My perception is that there is a before, and after, the launch of the Plan. There is optimism and motivational synergy between the medical and scientific community and family and caregivers, because we feel that after much helplessness things are happily changing."*

National dementia plans remain the single most powerful tool to transform dementia care and support for people living with dementia and their care partners. The adoption of a global plan on dementia by the World Health Organization in May 2017 supports the message that all governments should develop a national response to dementia.

Updated report highlights new dementia friendly communities

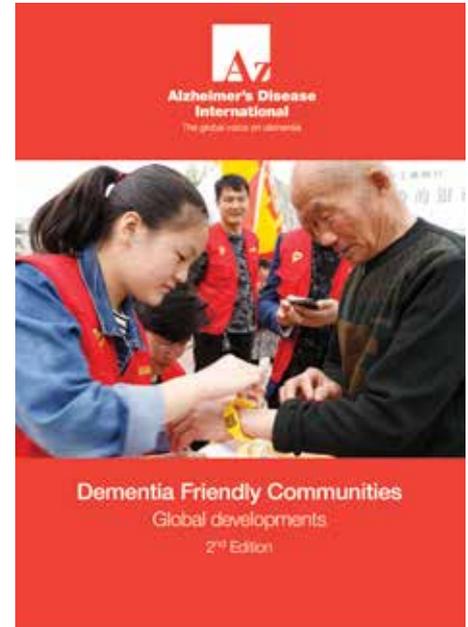
ADI has published an update to its report highlighting examples of dementia friendly initiatives worldwide. The report contains useful information on the implementation, success and monitoring of more than 150 dementia friendly initiatives in over 40 countries.

The update follows the publication of twin reports, Dementia friendly communities: Key principles and Global developments, in April 2016, including new sections with examples of dementia friendliness in Africa and the Middle East, alongside projects in the Americas, Europe and Asia.

Glenn Rees, Chair, said, *"Dementia friendly communities have the power to change the way we think about living with dementia. The examples in this report mark a shift from a focus on meeting the physical and health needs of the person with dementia to supporting the person to achieve the best quality of life reasonably possible through attitude change, the environment and social inclusion."*

"In 2017, this is strengthened by the adoption of the global plan on dementia by the World Health Organisation that urges every government to implement dementia friendly as part of national responses to the disease."

Dementia Friendly Communities: Global developments and Key principles are available for download at www.alz.co.uk/DFC



■ News

Bill Gates invests \$50m into dementia research

Bill Gates has invested US \$50 million in the Dementia Discovery Fund. Alzheimer's Disease International (ADI) applauds the landmark contribution, that it is hoped will aid the development of new treatment options for 50 million people affected by dementia globally.

Dementia will become a trillion-dollar disease in 2018 and is the only major chronic disease area that does not have a cure or effective treatment. Gates acknowledged the financial and human impact of the disease, urging that more research was needed to better understand the disease, that innovation was needed to involve more people in clinical trials and that data can play a critical role to shape the future; *"This is a frontier where we can dramatically improve human life. People should be able to enjoy their later years – and we need a breakthrough in Alzheimer's to fulfil that. I'm excited to join the fight and can't wait to see what happens next."*

Paola Barbarino, CEO of ADI said, *"The entry of such a high profile private investor into the dementia market is welcome news. There is still so little we know about this devastating disease and such a significant and timely contribution towards finding a solution is greatly welcomed."*

"The areas identified by the fund, and innovation in particular, are all of great interest to ADI, our members and partners. We hope that this announcement will reinvigorate the investment environment around dementia and prompt more investors to pool resources."

The Fund provides a platform for collaboration between civil society, industry and government to develop novel and early stage approaches to identifying potential treatments. ADI welcomes the investment by Gates, that supports a new era of collaboration and innovation to improve the lives of people with dementia, their care partners and their families.

ADI appoints Regional Director for the Americas

Joost Martens has been appointed as ADI's Regional Director for the Americas, following the success of the ADI's first Regional Office, in Asia Pacific.

Latin American countries in the region are expected to see the greatest increase in numbers of people living with dementia in the world by 2050.

Joost has close to 30 years of experience working in in development and in humanitarian preparedness and assistance, including as Regional Director of HelpAge International. His new role will actively support and strengthen the role of Alzheimer associations and response to dementia in over 50 countries.



...and welcomes new staff to the ADI office in London

Chris Lynch was appointed in October as Director of Policy, Communication and Publications and Deputy CEO. Chris joins ADI after almost 5 years with Alzheimer Scotland, serving as Deputy Director for Communications, Marketing and Events and he will start on 2 October.



In November, this was followed by the recruitment of Katie Bingham, who has joined the ADI team in London as our new Events and Administration Coordinator. Katie previously worked for Macquarie Bank in asset finance and will support colleagues with the planning for events including the ADI conference, and the day-to-day administration of the office. In 2018, ADI expects to further welcome a Research and Policy Project Lead, who will manage the STRiDE project in partnership with London School of Economics and Political Science (LSE).



■ Meetings Roundup

700 people attend Asia Pacific Regional Conference in Indonesia



CEO Paola Barbarino with Indonesian Minister of Health, Prof Nina Moeloeck, representatives of ADI, ALZI, Ministry of Health and the World Health Organization.

The 20th Asia Pacific Regional Conference of Alzheimer's Disease International (ADI) was hosted by Alzheimer's Indonesia in Jakarta in November.

The conference was attended by over 700 delegates, including representatives of associations in more than 20 countries who shared their knowledge and achievements in the region. 45 representatives from 12 countries attended an Asia Pacific Business Meeting held before the conference, followed the same week by the first meeting of the World Health Organization (WHO) Western Pacific and South-East Asia Offices hosted by ADI in the response to the WHO Global plan on dementia.

Expert speakers presented on a range of topics throughout the conference, including prevention,

diagnosis, and treatment of dementia, dementia care models, architectural design, awareness and policy.

Workshops were held on care, dementia symptoms and rehabilitation, featuring the first ever young caregivers meeting with 130 participants. Indonesian Minister of Health, Nina Moeloeck, spoke at the opening ceremony of the conference, urging a 'Life-Cycle Approach' to dementia that was emphasised in the conference theme.

People with dementia and their care partners were actively involved in the conference, that concluded with a celebration of the 50th Golden Caregiver Meeting and was followed by the Alzheimer University programme on effective fundraising for associations from 12 countries.

■ Meetings Roundup

Wish you were here! Representatives of ADI attend meetings in six countries



The 10th Congress of Alzheimer Iberoamerica was hosted by Asociacion Dominicana de Alzheimer in the Dominican Republic in October

ADI and representatives have advocated for an improved response to dementia in eight separate meetings since the start of October. Since attending the Alzheimer Europe Conference in Berlin, members of ADI have joined annual meetings of the WHO European and Eastern Mediterranean Regional Offices to prioritise the implementation of the global plan on dementia at the regional level. This was followed by a statement submitted by ADI to the WHO Global Conference on NCDs held in Uruguay, urging that dementia be included in efforts to reduce the impact of NCDs globally.

Paola Barbarino, CEO, was also joined by ADI's new Regional Director for the Americas, Joost Martens, and Chair, Glenn Rees, for the 10th congress of Alzheimer Iberoamerica hosted by Asociacion Dominicana de Alzheimer in the Dominican Republic, ahead of the 20th Asia Pacific regional conference of ADI hosted by Alzheimer Indonesia in Jakarta.

Other meetings included the NCD presidential meeting in Costa Rica, where the First Lady received an award from ADI in recognition of the President Luis Guillermo Solís Rivera's new role as Honorary Ambassador.

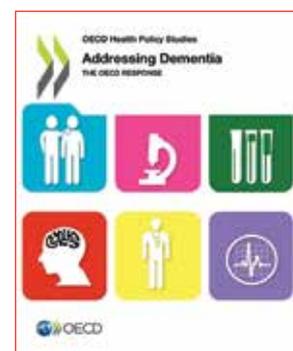
ADI participates in OECD Health Committee in Paris

Paola Barbarino, CEO of ADI, has attended a meeting of the Organisation for Economic Co-operation and Development (OECD) in Paris as part of the development of a new report on the response to dementia in 35 OECD countries. An existing report, 'Addressing dementia: The OECD response' was published in 2015.

The meeting of the Committee in December was attended by representatives of governments including the government of Chile, who shared their experience of developing a national plan following extensive engagement with key stakeholders including Corporación Alzheimer Chile.

Non-OECD countries present included Argentina, Costa Rica, Kazakhstan, Lithuania, Peru and Russia.

A statement by ADI welcomed the focus of the Committee on dementia but urged further action as part of the momentum to realise the targets of the WHO Global plan by 2025. The OECD includes representatives from governments of 35 countries, that can directly influence the adoption of new plans on dementia at the national level. Each government has until the end of January to provide their comments on a draft report, which is expected to be published in April.



The first OECD report on dementia, published in March 2015

■ Meetings Roundup

PAHO meeting hosted at Alzheimer Iberoamerica Conference



An official meeting of PAHO was hosted by Asociación Dominicana de Alzheimer, in the days before the Alzheimer Iberoamerica Conference in October. The meeting of government officials included the participation of Alzheimer associations from the region and concentrated on the development of national responses to and strengthening of healthcare for dementia.

The meeting is an important step in addressing the impact of the dementia in the region, that will see one of the greatest increases of people living with dementia by 2030. It follows the adoption of the global action plan on dementia by the WHO in May, outlining specific targets for the improvement of awareness, diagnosis, research and risk reduction, treatment, care and support.

PAHO published the first regional plan on dementia in the Americas in 2015. Eight countries have now developed national plans on dementia with plans currently in development in Dominican Republic, Columbia and Trinidad and Tobago. Joost Martens, ADI's Regional Director for the Americas said, *"The design and implementation of national plans - in line with the implementation of the global action plan - requires governments and civil society agencies to work together. The invitation by PAHO for both these groups of actors to participate and work together in this meeting is an important confirmation of this vision."*

Alzheimer Bolivia lead training on development of dementia plans

Asociación Alzheimer Bolivia hosted the first International Training Workshop on National Alzheimer Plans in Ibero-America during the 10th International Congress of Alzheimer Iberoamerica in the Dominican Republic in October.

The workshop was organised by Ninoska Ocampo-Barba, President of Asociación Alzheimer Bolivia and Vice President of Alzheimer Iberoamerica, with the support of governmental representatives from Costa Rica and Asociación Costarricense de Alzheimer y otras Demencias Asociadas.

The purpose of the workshop was to train participants in strategies for working with government agencies in the development of national dementia plans, following the adoption of a global plan on dementia by the World Health Organization in May.

Representatives from national associations of Argentina, Aruba, Bolivia, Colombia, Dominican Republic, Ecuador, Mexico and Venezuela attended the workshop, as did a Parliamentarian from Argentina, the Ambassador of Colombia to the Dominican Republic, and representatives of ADI.

The workshop examined the experience of the national plan in Costa Rica, including how to build relations with key stakeholders in each country

Joost Martens, ADI's Director for the Americas, said, *"Bringing together the variety of experiences from across the region with global standards and plan guidelines, provided for an exchange that was of great value to all."*

Workshop facilitator Ninoska added: *"The achievement of common objectives in Iberoamerica was possible with the participation of all those involved and our regional experts, especially Dr Norbel Román."*

Workshops such as this are crucial in increasing Alzheimer associations' ability to work with governments to design and implement national action plans. Currently, five countries in the Iberoamerica region have national dementia action plans in place.

■ Meetings Roundup

Alzheimer University strengthens developing associations



Representatives of Alzheimer associations from Madagascar, Suriname, Tonga, Jordan, Qatar and Bonaire attended the annual Alzheimer University programme for emerging associations hosted by ADI in August. The series of workshops helps strengthen and develop associations, and included sessions with speakers from ADI, the Alzheimer's Society and International Alliance of Patients' Organisations (IAPO). At the end of the programme, participants also took part in a Dementia Friends session run by ADI Honorary Vice President and Dementia Champion, Nori Graham. The six countries have now embarked on ADI's two-year Membership Development programme with action plans developed based on the knowledge gained.

Global action



DY Suharya, ADI Regional Director for the Asia Pacific Region attended the 2nd Global NCD Alliance Forum in Sharjah, UAE. The conference was followed by launch of the WHO Global Dementia Observatory in Geneva, attended by Policy, Communications and Publications Director and Deputy CEO, Chris Lynch. ADI has been actively involved in the development of the Observatory, that will collect and monitor global data on dementia and play a critical role in assessing the impact of current and new interventions in dementia care, research and understanding.

ADI and partners attend mhGAP Forum in Geneva

ADI, Dementia Alliance International (DAI) and Global Alzheimer's and Dementia Action Alliance (GADAA) attended the mhGAP Forum in October, that included two days of meetings and planning with key stakeholders for the implementation of the WHO's Mental Health Gap Action Programme.

Chris Lynch, Policy, Communications and Publications Director and Deputy CEO, attended the meeting where he spoke on the importance of awareness and dementia friendliness at a special session on strengthening the response to dementia under current mental health frameworks.

The meetings also featured a presentation by Kate Swaffer, Chair, CEO and Co-Founder of DAI on the importance of the Global action plan on dementia adopted in 2017.

Kate urged that dementia be considered equally alongside other cognitive disabilities, and that people with dementia be guaranteed rights through adherence to the *United Nations Convention on the Rights of Persons with Disabilities*. This included support for rehabilitation, inclusive societies and earlier support as part of national responses to dementia.

Visit the mhGAP website at http://www.who.int/mental_health/mhgap/en/

Members' forum

KENYA

4th Regional Conference of ADI held in Nairobi, Kenya

The 4th African Regional Conference of ADI was co-hosted by Alzheimer's Kenya during World Alzheimer's Month and featured presentations on challenging stigma, dementia care, policy and the experiences of those affected.

The conference was attended by representatives from over 10 countries in the region and included an address by Dr. K.S. Njuguna, Director of Mental Health at the Ministry of Health, committing to the development of a national response to dementia in Kenya in 2018. This was followed by the first public speech by a person with dementia in the country. The conference also featured the launch of ADI's first report on dementia in Africa, highlighting an urgent lack of awareness and the challenge to increasing the support available to people with dementia and their care partners.

ITALY

Milan conference addresses stigma of dementia



Federazione Alzheimer Italia marked World Alzheimer's Month with over 50 events organised across different regions of the country. On the 19th September, this included a conference in Milan on the theme of *'From assistance to inclusion: how to overcome the stigma of dementia'*. The Conference addressed how Federazione Alzheimer Italia and its partners can provide a voice to those affected by dementia, to research and the importance of dementia friendliness. Paola Barbarino, CEO of ADI, attended the conference, where she spoke on the need for a concerted response to develop national and regional responses to dementia and to strengthen the role of associations in encouraging and monitoring support from governments.

Other events by the Federazione included Memory walks, film screenings, sports events, guided visits of research laboratories and a charitable auction.

PERU

Smartphone with dementia engages young Peruvians



Asociacion Peruana de Enfermedad de Alzheimer y Otras Demencias (APEAD) have launched an animated short film, 'Error de memoria' as part of the campaign to grow awareness of dementia among the younger generation. The film shows a smartphone, Matt, who experiences possible symptoms of dementia, including confusion and disorientation.

The 5-minute clip leads to a dedicated website that provides information on the stages of dementia, alongside the true story behind 'Matt' and the ways you can reduce your risk, such as avoiding smoking, challenging your brain and maintaining an active lifestyle and social life.

An estimated 300,000 people are living with dementia in Peru, where there is currently no specialised healthcare for dementia. The number of people living with dementia in the Andean countries is expected to triple by 2050. Fabiola Napuri, President of APEAD, said, *"We want young people to stop stigmatizing this dementia and approach their loved ones with love, which is what they need the most. We work so that it is understood that Alzheimer's is an incurable condition, but it is treatable."*

The campaign was made possible with the support of telecommunications company ENTEL and advertising agency McCann.

Members' forum

MALAYSIA

Launch of Dementia friendly mall in Kuala Lumpur



The first dementia friendly mall has opened in Kuala Lumpur thanks to the dedication of Alzheimer's Disease Foundation Malaysia (ADFM). Various activities took place at Atria Shopping Gallery in Damansara Jaya, which was developed to be dementia friendly as part of the campaign for World Alzheimer's Month 2017. They included the first indoor Memory Walk, the first Dementia Treasure Hunt organised by professional treasure hunters, and the first dementia- friendly community corner.

With a recorded 120,000 people living with dementia in Malaysia, and many more unrecorded cases, the work of ADFM is vital in raising awareness for people affected by dementia and their families. Dementia friendliness is important to ensure that people affected by dementia can continue to be active members of their community.

Jacqueline Wong, Board Member of ADFM said: *"I hope the beginning of this first-of-its-kind collaboration with Atria mall will be the start of more organisations, large and small, thinking about how they can become more dementia-friendly."*

BRUNEI

Dementia Care Trainers to form new association in Brunei

A new Alzheimer Association is being developed in Brunei, in order to extend support for people affected by dementia in the country. The new association will be formed by 14 dementia Trainers, who developed their experience at the first Dementia Care Skills Training Programme held in Bandar Seri Begawan, Brunei at the end of August in collaboration with the Ministry of Health and facilitated by Alzheimer's Disease Foundation Malaysia (ADFM).

An action booth was set up by Taman Haji Sir Muda Omar Ali Saifuddien in Bandar Seri Begawan in commemoration of World Alzheimer's Month. The event was organised by Health Science (Medicine) undergraduates at Universiti Brunei Darussalam, supported by Brunei's Dementia Care Skills trainers, which comprises of officers from the Ministry of Health, Ministry of Culture Youth and Sports and ADFM. The attendees and members of the public took part in a 'Remember Me' Memory Walk and awareness-raising activities on the importance of earlier detection and diagnosis of dementia

RUSSIA

Success of media campaign raises critical awareness in Russia

Help for Alzheimer's Disease Patients and their Families (ALZRUS) achieved high profile media coverage on the signs and support for dementia throughout World Alzheimer's Month. The campaign featured interviews on Russia's most listened to radio stations and in the countries leading press and television. Maria Gantman, President of ALZRUS, and Vice President Alexandra Shchetkina, spoke at various times during the month, that resulted in a large increase in the number of enquiries and requests for support from people with dementia and their care partners.

ALZRUS Medical Expert Elena Ponomareva also spoke to Russia's TV Channel, first, on the impact of, and recognising the signs of dementia. On World Alzheimer's Day, 21 September, ALZRUS further spoke during a global discussion with dementia experts in Russia and France, on the ways to support people with the disease. The discussion also examined how to support care partners and educate medical professionals, who may live in the rural regions of Russia, and included representatives of Ministry of Social Policy and Municipal Rehabilitation Centres.

The events follow the publication of a brand-new booklet for care partners by the association in Autumn 2017.



■ Dementia Alliance International

Nothing about us, without us: Action by, for and of people with dementia

Kate Swaffer, Chair, CEO & Co-Founder of Dementia Alliance International



As we come to the end of another very busy year of advocacy and activism by DAI members, and others, I would like to thank everyone for their energy and efforts for all people with dementia.

In the last month, the message to remember and respect those impacted by dementia has been even more vocal as we've marked the International Day of Persons with Disabilities, Human Rights Day and also attended the 2nd Global NCD Alliance Forum and supported the call for fairer and affordable access to healthcare on Universal Health Coverage Day 2017. The following is one blog about the forum in Sharjah <https://www.dementiaallianceinternational.org/ncd-alliance-forum-sharjah-update-1/>

We continue to hold regular meetings of our members, including support groups and have a new Brain Health Hub Facebook page and weekly meeting for members and supporters who are focused on lifestyle changes to live more positively with dementia. These are for people with dementia or someone supporting them who wish to share their experiences and find out more about managing dementia with a lifestyle approach.

2017 has also been a pivotal year for people with dementia everywhere, following the adoption of a global action plan on dementia in May. DAI's initial response to the plan is at <https://www.dementiaallianceinternational.org/who-adopts-global-action-plan-on-dementia/>.

DAI has been actively involved in many events, committees and expert advisory groups, as well as

Online support groups

DAI members facilitate and provide online support groups for people with dementia through online video conferencing. Online support groups are ideal for those who cannot drive to their local "in person" support group or who live in isolated areas with limited access to services.

People with dementia can join DAI at www.joindai.org. Anyone can subscribe to DAI blogs and newsletters at www.infodai.org.

Find out about our support groups at www.dementiaallianceinternational.org/services/online-support-groups/

making many submissions on behalf of all people with dementia globally for better care, and will continue to advocate at both the WHO and UN, including for the recognition of equal rights for people with dementia.

At the end of 2017, we have seen our membership grow from its first 8 founding members diagnosed with dementia, to members from over 44 countries in just 4 years. Supporting this process are the dedicated Board, members and volunteers who make up DAI. A list of the incoming Board of Directors for 2018 is now on our website. In November, DAI held its third AGM, and will release its Annual Report in January 2018. You can read my Chair's report on our website, that highlights many of our other highlights from the year, including DAI's first ever public seminar during World Alzheimer's Month.

We wish our members and supporters best wishes for the season and welcome your ongoing support in 2018.

Membership of DAI is free and is open to anyone with a diagnosis of dementia.

The ADI Newsletter regularly includes contributions from people living with dementia and their care partners. If you would be interested to contribute to the newsletter, we encourage you to contact us at info@alz.co.uk

■ Research update

£7.7 million study to strengthen responses to dementia in developing countries

The project, called STRiDE (Strengthening responses to dementia in developing countries), will be led by the Personal Social Services Research Unit (PSSRU) at LSE and will include the Universities of Sussex and Cape Town, as well as ADI member associations and research groups in the seven countries which are part of the project.

The project will run in Brazil, India, Indonesia, Jamaica, Kenya, Mexico, and South Africa to examine current practice, both at a national level and for individual families, to help people living with dementia to live well, and to ensure that family and other carers do not face excessive costs.

A key activity will be to use the understanding of the impact of dementia in various cultural, social and economic contexts to support development and

evaluation of national plans. The project will build research capacity in the seven countries, and it is hoped that it will lead to further research opportunities in those countries and beyond.

Paola Barbarino, CEO of ADI, said: *"The STRiDE project will give a deeper insight into each nation's economic challenges related to public health and dementia. This will better prepare us for the challenge of finding and proposing national solutions to governments."*



Intepirdine results fail to show improvement in cognition

End stage trials for potential new Alzheimer's disease drug Intepirdine have failed to show a significant improvement in the cognition of people with mild to moderate Alzheimer's disease when compared with a placebo.

Pharmaceutical company Axovant announced the results of the Phase III MINDSET trial during World Alzheimer's Month, following excitement that it may represent progress towards achieving the first new treatment for dementia since 2006.

ADI welcomes more research into new treatments, urging that global investment must continue to enhance prevention, earlier diagnosis and care.

Paola Barbarino, CEO of ADI, expressed her disappointment at the results, supporting the message by David Hung, M.D., Chief Executive of Axovant that, *"The fight against Alzheimer's is too important to be derailed."*

Paola said, *"The results from this hugely significant trial are saddening for the almost 50 million people*



who are living with dementia worldwide, and for whom there is no cure."

"ADI continues to call for more research to improve the lives of these individuals and their care partners, and that companies such as Axovant do not give up on dementia. It is critical that research continues to be underpinned by a global effort to improve prevention of dementia earlier in the life course, with more support for diagnosis, access to care and effective support."

Read the press release at <http://investors.axovant.com/news-releases>

■ Research update

Souvenaid results: More research needed into nutrition and dementia

The Lancet Neurology published the full results of a large-scale study into the effects of health supplement Souvenaid® in October. The results do not show a significant improvement in cognition but do show some interesting findings for continuing research into nutrition and dementia.

Souvenaid® is a medicinal drink developed by Nutricia, that contains a combination of fatty acids, vitamins and other nutrients that may be beneficial to brain health. The results of the EU LipiDiDiet clinical trial examined the effect of the supplement on 311 people with Mild Cognitive Impairment (MCI), including the pre-dementia stage of Alzheimer's disease. The trial failed to identify a significant improvement in cognitive function measured through a series of thinking and memory tests after 2 years but showed some reduction in the decline of some people with minor problems with memory.

The study also showed that individuals at an early stage in the development of dementia who drank Souvenaid® daily showed less shrinkage in certain areas of the brain associated with memory.

The number of people living with Alzheimer's dementia is expected to double every 20 years, reaching 75 million in 2030.

ADI welcomes the results of the study, that highlight the important role of nutrition on brain health and continue to inform a better understanding of the impact of possible nutritional interventions on dementia in the future.

More research is needed, but it is important to remember that a healthy diet and active lifestyle play a vital role in overall health and can reduce your risk of dementia, by maintaining brain health and reducing the risk of stroke.

Chris Lynch, Policy, Communications and Publications Director and Deputy CEO said, *"It is interesting to see these results. While the study didn't show the hoped for wider improvements in cognition or evidence of a slowing of disease progression, we are certainly keen to hear more about the findings in relation to*



memory improvements and we welcome Nutricia's commitment to further research in this area".

Dr Serge Gauthier, Chair of ADI's Scientific and Medical Advisory Panel, said, *"Important lessons were learned from this clinical trial, which will improve study designs for future preventive studies."*

ADI urges that individuals worried about, or living with dementia or MCI to always consult their doctor when considering nutritional interventions. Alzheimer associations in over 100 countries provide support and advice for anyone affected by dementia.



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. Every year, our World Alzheimer Report examines a new theme with the latest data from research, including improving healthcare, prevalence and challenging stigma.

All publications and summaries are available for download from www.alz.co.uk/global-knowledge



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