On 11 to 14 October, the annual Iberoamerica Congress was held in Quito under the theme of ‘Know how to age; know how to live’. The conference, which was organised by the TASE Foundation of Ecuador, saw over 1,200 attendees and included a number of high-level presentations from national and international speakers, as well as a range of other activities.

The four-day event included a number of stimulating workshops and sessions spanning topics from non-pharmacological interventions, cognitive and behavioural changes within the different stages of dementia, multidisciplinary approaches to dementia care, dementia friendly communities and dementia plan initiatives.

Noemí Medina, President of Alzheimer IberoAmerica (AIB) said: “The XII Iberoamerica Congress was very successful and very well attended, with a programme developed along four axes aimed at health professionals, medical doctors, family members and the general public. Before the Congress AIB celebrated a successful meeting, in which representatives of the AIB member countries met to reflect on issues of common interest in the region.”

Representation at the meeting included healthcare professionals, caregivers, family members and 15 Alzheimer association representatives, members of both AIB and ADI.

Following the conclusion of the Iberoamerica Congress, ADI and the Pan American Health Organisation (PAHO) held a meeting to continue the relations developed during the regional ‘Let’s Talk About Dementia’ campaign.

Continued on page 9.
Notes from ADI

A month of progress for Latin America and the Caribbean

The month of November 2019 was one of particularly intensive activity for ADI members in the Americas region, with meetings in the Caribbean and with the Congreso Iberoamericano de Alzheimer in Quito.

The Caribbean meetings started off with a STRiDE (Strengthening responses to dementia in developing countries) orientation day, organised and hosted by STRiDE Jamaica, with participation from the Alzheimer associations of seven countries from the region. This orientation day stirred lots of interest and produced ideas of applying some of the STRiDE modules in countries that are not part of the STRiDE programme.

All those present participated in the following days in the ADI Caribbean Alzheimer University and Regional Meeting, which touched upon issues such as Recruiting and Retaining Volunteers; Guidelines for Sustainability; Governance and the role of the Board; and Advocacy for National Plans. The latter brought up the issue of how to achieve some group pressure across the Caribbean, as well as general national plan progression.

Country updates at the Regional Meeting always give remarkable examples of the creativity of associations, like Suriname: too warm to have dementia walks in daytime, they instead organised a torchlight procession in the evening, titled “Out of the dark - be the light in the lives of people”. The Jamaica programme was finalised with a one-day conference from Alzheimer Jamaica.

The week thereafter, the yearly Iberoamerica Congress was held in Quito, organised by the TASE Foundation of Ecuador. A very well structured Congress, with almost 1,200 attendees, included high level presentations from national and international speakers and with many different activities.

The pre-Congress AIB associations meeting and the post-Congress ADI/PAHO ‘conversatorio’ were well attended, with 15 of the 19 Latin American members – both AIB and ADI – in attendance.

The AIB associations meeting highlighted among others things the two projects under the AIB banner; firstly, the study on the caregiver profile in Ibero America, and secondly, the book “El Alzheimer en Ibero America”, which is being promoted with articles from each of the AIB member associations, as well as one from the ADI regional office.

The post-Congress ADI/PAHO meeting was a joint effort of the ADI Regional Office and the PAHO Washington DC Headquarters, building on the relations that had been strengthened during the regional “Let’s Talk about Dementia” campaign. With Dr Enrique Vega and Dr Claudina Cayetano from the PAHO Headquarters present, there was a lively exchange around how to work on issues like awareness raising and advancing national plan development between PAHO country offices, governments and Alzheimer’s associations. All in all a very useful day.
News

Pope Francis addresses World Alzheimer’s Day

On 18 September at the Vatican, Pope Francis highlighted World Alzheimer’s Day during his Wednesday General Audience address. The Wednesday Papal Audience typically draws around 10,000 people.

When noting that World Alzheimer’s Day was approaching soon, Pope Francis called for attention towards the many people around the world who are affected by Alzheimer’s and dementia and the stigmatising attitudes that can lead to violence or abuse. He followed the plea with a prayer for those who are affected, including loved ones and carers, and that they are continuously supported, both in treatment and prevention.

This excellent opportunity for raising awareness came after ADI’s Chief Executive Officer Paola Barbarino met with representatives of the Holy See in Geneva earlier this year.

You can watch the speech in Italian here.

The speech translation in English: “Next September 21st is World Alzheimer’s Day, a disease that affects many men and women, who, due to this disease, are often victims of violence and abuse that trample their dignity. We pray for the conversion of hearts and for those affected by Alzheimer’s disease, for their families and for those who lovingly care for them. I also associate them with prayer, the memory of those suffering from cancer, so that they are also increasingly supported, both in the prevention and treatment of this disease.”

Biogen, Eisai and Green Valley Announcements

Advancements in Alzheimer’s drug research

October and November were important months for pharmaceutical treatment announcements for treating cognitive function and general symptoms of early to mild Alzheimer’s disease.

On 22 October, Biogen and Eisai announced they would be filing for market approval for the drug aducanumab, an investigational drug which has shown promising treatment for early Alzheimer’s disease. Following the review of additional data from the Phase 3 clinical studies of aducanumab, Biogen said that they had found that there were “significant benefits to patients involved in the trials”, with improvements relating to cognition and function.

Following Biogen and Eisai’s announcement, Chinese Pharmaceutical Company Green Valley announced on 2 November that their drug Oligomannate (GV971) had been granted conditional approval by the National Medical Products Administration (NMPA). Green Valley said that oligomannate had “demonstrated to statistically improve cognitive function in mild-to-moderate Alzheimer’s patients as early as week four” following a phase 3 trial which involved 818 patients with mild to moderate Alzheimer’s across 34 Tier-1 hospitals.

Regarding Green Valley’s announcement, Jose Luis Molinuevo, a member of ADI’s Medical and Scientific Panel (MSAP), said: “We are aware that this needs replication in a global trial, but I do prefer to remain hopeful since any new drug for the treatment of AD in its dementia stage is also welcome. We are in need on additional therapies to complement the symptomatic benefit that the current approved drugs offer to AD patients.”

While awaiting further details around the development, timeframes, availability, access and cost, ADI will continue to work with the pharmaceutical sector, regulators and payers to ensure the voices and concerns of people living with dementia are heard.

Read more about these announcements in ADI news.
For the month of November, ADI put together a week-long blog series to highlight the chapters within the World Alzheimer Report 2019 that focus on some of the challenges and innovative responses to dementia within Indigenous populations around the globe.

These challenges include diagnosing dementia when there is no word for dementia in the group of persons you’re working with, as well as challenging the idea that our perspective towards dementia is not the same across all cultures. These challenges have brought about innovative responses, with the introduction of culturally sensitive diagnostic tools and approaches to support for those who are affected by dementia, both personally and as loved ones.

In the blog ‘Stigma and response to dementia in Guatemala’s Indigenous populations,’ María Cecilia López Murga, the Executive of Asociacion Grupo ERMITA Alzheimer de Guatemala, writes: “It is a great challenge because our adults in different communities speak their own languages, but that is our commitment to reach those who need us.”

Read the blog series here.
News

Significant advocacy success at the G20

2019 has been an active and important year of advocacy for Alzheimer’s Disease International (ADI), none more so than during the Japanese Presidency of the G20. Our member in Argentina, led by Noemi Medina, connected us following the handover from Argentina to Japan. ADI became involved with the Civil Society 20 (C20) global health working group in February and again in April, working closely with Noriyo Washizu from Alzheimer’s Association Japan (AAJ). Deputy CEO and Director of Policy Chris Lynch collaborated with colleagues at HelpAge International and NCD Alliance, taking the opportunity to engage directly with key Japan Government Departments, cross parliamentary groups and the media, resulting in dementia and healthy ageing becoming a focal area on the G20 agenda.

The policy pack presented to the Japanese Prime Minister Abe by the C20 global health working group included robust evidence that dementia is one of the main health and social care crises of the century that demands commensurate policy action. In June, this advocacy work paid dividends with the G20 Osaka Declaration including a commitment to implementing “a comprehensive set of policies to address dementia”, including risk reduction, long-term care and dementia friendliness.

In order to continue the momentum from Osaka, working closely with our members, ADI’s Chief Executive Paola Barbarino wrote directly to each G20 Health Minister ahead of the Health Ministers Meeting, asking them to demonstrate strong leadership to the global health community to deliver a unified, strategic and sustainable response to dementia.

Again, our engagements proved fruitful; the Okayama Declaration contained six major commitments to dementia: developing and implementing national dementia action plans; addressing risk factors and enhancing early detection, diagnosis, and interventions, including development of care pathways and strengthening primary health care; raising awareness and overcoming stigma by developing age-friendly and dementia-inclusive environments; promoting research and development; mutual knowledge exchange of initiative for active and healthy ageing.

Alzheimer’s Association Japan (AAJ) has been instrumental to the success of this advocacy effort. Throughout the process, Noriyo Washizu of AAJ engaged with civil society organizations, government ministers and parliamentarians to ensure the meetings resulted in strong commitments to address dementia. Noriyo said: “This is a huge step towards an inclusive world for people living with dementia and their carers. To this end, we reaffirm the responsibility of Japan as a front-runner in the ageing world.”

Chris Lynch is now engaging with the King Khalid Foundation to ensure momentum in C20 preparations for the G20 under the presidency of Saudi Arabia in 2020. Princess Nouf bin Mohammed from the Foundation was invited to write a case study for the World Alzheimer Report 2019 and we look forward to developing our working relationship around the C20.
Spain announces national dementia plan

Spain became the 33rd country to adopt a national dementia plan when the Spanish Ministry of Health, Consumption and Social Welfare announced its implementation on 15 October.

The National Alzheimer’s Plan 2019-2023 includes key targets for improving dementia awareness; person-centred health and social care; services, supports and benefits; and promotion of research, innovation and knowledge. The plan will be of vital support for the 700,000 people currently living with dementia in Spain - a number which is forecast to more than double to 2 million by 2050.

One of the key focuses of the plan is improving diagnostic capacities of the health system, which is crucial for improved access to services, and for reaching the WHO target of a diagnostic rate of 50% for those affected.

Jesús Rodrigo, Executive Director of the Spanish Confederation of Alzheimer’s and other Dementias (CEAFA), said: “The National Alzheimer’s Plan 2019-2023 is an important milestone for the 700,000 people living with dementia in Spain, as well as for their families and carers. We will continue to work closely with the Ministry of Health, Consumption and Social Welfare, as well as the State Dementia Group and the General Secretariat of Health, to ensure the plan achieves its objectives and achieves real, measurable progress for those affected by dementia in Spain.”

Read more about the current national plans in our ‘From plan to impact II’ report.
Hope in the age of dementia:

New science. New knowledge. New solutions

Early bird registration rates end 13 December!

www.adi2020.org

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Alzheimer’s Disease International
alz.org.sg  @alz_sg
Programme highlights

The conference programme will centre around the seven action areas of the WHO’s global action plan and promise to be both very engaging and comprehensive from the diverse international keynote speakers delivering them. Such key note speakers include:

Prof. Miia Kivipelto, Research Director of Neuroepidemiology at Karolinska Institutet and leading on global research into risk reduction. Professor Kivipelto’s presentation will be on ‘Multi-domain prevention: the new treatment paradigm’.

Mr. Shamil Mohamed, retired hotelier and a client at the Lanka Alzheimer’s Foundation’s Activity Centre in Sri Lanka who is living with dementia. His presentation at ADI 2020 will focus on supporting dementia through a friendly environment.

Mr. Michael Schmieder, former director of Sonnweid in Wetzikon – a leading care home for people living with dementia in Switzerland and co-author of the book ‘Dementia, but not stupid: For a new approach to dementia patients’.

Dr. Violet Okech, Consultant Psychiatrist/Counselor and Chair of Adult Psychiatry; coordinator of Mental Health Research, Kenyatta National Hospital (KNH) in Nairobi. Her presentation at the conference will be on ‘Receiving a diagnosis in Africa’.

Dr. Christopher Chen, Director, Memory Ageing and Cognition Centre, National University Health System, Singapore. His major research and clinical interests are in neuroimaging, molecular biology and treatment of stroke and dementia. Dr. Chen also contributed to ADI’s World Alzheimer Report 2018.

A rich parallel programme goes into further depth on the seven action areas, highlighting research and projects happening across the globe.

Accommodation

We are pleased to have the Singapore Hotel Association (SHA) as the Official Housing Bureau for the 34th International Conference of Alzheimer’s Disease International. As a housing bureau, the SHA has vast experience in helping event delegates from all over the world with their accommodation needs. Special rates are available to conference delegates at a range of hotels across the city, either in walking distance or easily accessible by public transport or taxi.

Singapore

A gateway to Asia and beyond, Singapore is a young nation full of vigour and a cosmopolitan city brimming with possibilities. It is home to a bustling Central Business District (CBD), a famous shopping street, a thriving arts and entertainment scene, lively dining and drinking spots, and many must-see attractions.

ADI is proud to announce that Singapore Airlines is the Official Airline for ADI 2020. Visit the ADI 2020 conference website to learn how you could save on flights to Singapore.

Don’t miss out on this chance to join the longest running global conference on dementia in the beautiful city-state of Singapore!
Update from Dementia Alliance International (DAI)

Members of DAI are almost everywhere, as we have members in 49 countries, with new members joining every week. We continue to provide grassroots support, albeit online, through our weekly peer to peer support group, cafés and webinars and other events and activities. A great many people with dementia are busy locally, nationally and internationally, and regularly attend and speak at conferences and other events. DAI members attend meetings and events at the United Nations in New York and Geneva, the World Health Organisation in Geneva, and meetings or specific advocacy events in Lausanne, Washington, Sydney, Canberra, London, and quite literally, cities and towns all over the world. There are too many to list!

The voices of all people impacted by dementia matter, and our advocacy, and for some, activism, is important and is increasing, both in terms of the numbers of people with dementia and/or their families becoming involved, and the ‘volume’ of our voices, not just in numbers, but in terms of who is hearing us. We are being heard, but believe that little has yet changed as new members continue to report they are still not being provided adequate post diagnostic services or support including rehabilitation, and often don’t receive a timely or compassionate diagnosis. Through the work of DAI and ADI and many other organisations, we remain hopeful that this will eventually change.

Please also join us soon for our monthly “Meeting Of The Minds” Webinar being présenté by Dr Allen Power, BeyondBPSD.

For more information about DAI, please visit the DAI website.

Quito cont’d

During the meeting, which included Dr Enrique Vega Garcia, Unit Chief for the Healthy Life Course and Dr Claudina Cayetano, Regional Advisor on Mental Health, a discussion was had on how PAHO country offices could work together on issues like awareness raising and the advancement of national plan development through a triangular relationship with Alzheimer associations and Ministries of Health.

Learn more about ADI and PAHO’s ‘Let’s Talk About Dementia’ campaign.

Events

19-21 March 2020
International Conference of Alzheimer’s Disease International
Singapore
Website: www.adi2020.org
Email: info@alz.co.uk

26-27 July 2020
Alzheimer’s Association International Conference (AAIC)
Amsterdam, Netherlands
Website: www.alz.org/aaic
Email: aaic@alz.org

20-22 October 2020
Alzheimer Europe conference
Bucharest, Romania
Website: https://www.alzheimer-europe.org/Conferences/Bucharest-2020
Email: info@alzheimer-europe.org

20-22 October 2020
XIIl Congress Alzheimer Ibero America
Havana, Cuba
Website: https://alzheimeriberoamerica.org/
ADI Regional Conference in Jamaica

From 5 November to 8 November, ADI Member Alzheimer’s Jamaica hosted the Regional Meeting in Kingston, Jamaica. During the conference, there was a strong emphasis on the need for greater attention and policy action to support people with dementia and their families.

During this time, the STRiDE Jamaica team also held a STRiDE Orientation Day for the Alzheimer’s Associations that had gathered in the capital for the regional meeting and ADI’s Alzheimer University. Team members Ishtar Govia, Rochelle Amour, and Nicolas Elias presented an overview of the STRiDE project to regional members, sharing how the project conducts research, approaches to mapping out dementia care environments and methods to reduce stigma and provide public education.

ADI and the STRiDE Jamaica team will continue to work with the Government to discuss the best approach to dementia policy in Jamaica.

Learn more about ADI’s regional meetings.

Dementia experts meet for Lausanne Dialogues VI

On 13-14 November, the 6th gathering of the Lausanne Dialogues took place in Lausanne, Switzerland. It was an opportunity for international stakeholders and experts on dementia to gather to review the progress, barriers and further action needed in being able to meet the challenge set by the 2013 G8 Summit, with the eventual goal of identifying a means of prevention and treatment of dementia by 2025.

ADI Chief Executive Paola Barbarino opened up the Lausanne Dialogues, where she emphasised the need to focus on readiness and preparedness of world governments in dealing with dementia, particularly in light of recent drug breakthroughs.

Paola said: “Last week I had an intense two days in the same room in Switzerland with industry, payers, regulators, civil society and governments discussing with real focus and purpose what might happen if we have a first pharmacological breakthrough soon. This is the first time I have seen real expectation on people’s faces since I joined Alzheimer’s Disease International.”

Read more about the 2013 G8 Summit.
Meetings and Conferences

Alzheimer Europe Conference

Alzheimer Europe held its 29th Annual Conference on 23-25 October in The Hague under the theme of ‘Making valuable connections’. The conference saw over 900 participants from 46 countries.

DY Suharya, ADI Asia Pacific Regional Director, delivered a presentation on the ‘Forgotten in a crisis: Addressing dementia in humanitarian response’ report. ADI Board member, Birgitta Martensson, also presented ADI’s ‘From plan to impact II: The urgent need for action’ report and took part in a panel discussion on the hidden cost of dementia.

Birgitta said: “The conference program was very rich and interesting, and it was encouraging to see an active participation from a large number of people living with dementia during these sessions. I was delighted to have the opportunity to present the work of ADI towards ensuring every country is moving towards a national dementia plan.”

Learn more about Alzheimer Europe’s conferences here.

Paola Barbarino meets WHO Director-General, Dr Tedros Adhanom Ghebreyesus

On 4 October, Paola Barbarino met with the Director-General of the World Health Organisation (WHO) Dr Tedros Adhanom Ghebreyesus, as well as Deputy Director General Dr Zsuzsanna Jakab, Director of Mental Health and Substance Abuse Dévora Kestel and Assistant Director-General for UHC, communicable and non-communicable diseases Dr Ren Minghu. During the meeting, they discussed options for ensuring dementia is a global health priority, as well as the need for national level awareness, particularly in the African region.

ADI will continue to work closely with the Department of Mental Health and Substance Use, to ensure that dementia becomes and remains a global health priority.

Learn more about the WHO global plan on dementia here.

Alzheimer Italia Forum

ADI’s Research and Policy Project lead, Wendy Weidner, attended and presented at a Forum in Milan on 11 September that was hosted by ADI member Federazione Alzheimer Italia.

The one day gathering, under the theme of “Beyond the stigma to change the image of dementia,” saw experts come together to discuss and present on a variety of topics surrounding dementia and stigma, including: clinical perspectives of dementia, understanding how younger people view dementia and support groups for those living with dementia and their carers.

Wendy’s presentation, ‘Let’s Talk About Dementia: Challenging Stigma’, looked at how ADI is challenging stigma, through initiatives like World Alzheimer’s Month and STRIDE. In addition, Wendy spoke on the importance of ADI including people living with dementia and their families involved in everything that ADI does.

Watch Wendy’s full presentation here.
Living with dementia

Elizabeth Mutunga

The year 1992 was a difficult year. This is when I noticed the changes in my loving Dad. He was a very pleasant man who was fun to be around, but he had become a very aggressive individual whom I did not want to be around anymore. If I had the information I have today, I would have handled him better. Initially I used to regret having fought with him but I realize I did not know any better. Most of all, my experiences led to the birth of Alzheimer’s & Dementia Organisation Kenya (ADOK).

ADOK has been instrumental in creating awareness on dementia and helping caregivers cope with their loved ones living with Dementia by empowering them. Most of the caregivers when they reach out to ADOK, feel like they are suffocating during a journey that is undefined. They then realize they are not alone after getting the initial help which we refer to as “First Aid”, which is like “talk therapy”. Most of them have moved from one doctor or another and more often than not they get a wrong diagnosis. As an organization we direct them to see a doctor who will give them a proper diagnosis. Once they get a diagnosis for their loved ones, we would then invite them to attend our support group. The joy on their faces after they have attended the support group and realizing that they are not alone is a rewarding feeling. Most of them are then willing to be interviewed and thus we will put their stories on our website and social media sites. We have also had them speak both in print and electronic media where we have more people reaching out once they read and listen to the stories. We have also used the Yearly “Mind Walks” as a platform to create awareness.

From the awareness that ADOK is doing, the Ministry of Health reached out to us to partner with them to raise issues on dementia. This has been instrumental as we were called upon to work on the changes on the Bill on Mental Health together with the Kenya Human Rights Commission and the Senate. This led to the publication report called “The Many Faces of Mental Health In Kenya”, which highlighted important issues on Dementia. The Ministry has ensured that we sit in every Technical Working Group so that our voice is heard. Last week the first Mental Health Conference was held in Nairobi and ADOK was one of the panelists called upon to create awareness on dementia care with a human rights approach. The Ministry has been also been working closely with the World Health Organisation (WHO) and they are very determined to ensure that Kenya has a National Plan. The conversations are on-going and we will persevere until the plan is implemented and funded.

ADOK has been instrumental in training health care providers and also the church to address the issue of stigma. Most of the health care providers informed us during the training that they had been taught about dementia in class but never seen cases. When you start explaining the symptoms they soon realize they have encountered people living with dementia and most of them confessed that they thought that they were pretending or just being difficult. There is still a lot to do, and we will continue to have conversations with everyone to bring the change we would like to see in Kenya.

To find out more about stigma and dementia care in Kenya, read the World Alzheimer Report 2019 chapter 4.8, page 121.
Research update

Recent breakthroughs on the treatment of Alzheimer's disease

José Luis Molinuevo, member of ADI's medical and scientific advisory panel (MSAP)

After years of disappointing news regarding trial results in Alzheimer’s disease (AD), recently we have been facing some positive ones. We could say that BAN2401 phase 2 results opened the door for hope, since in their phase 2 trials; they showed not only target engagement and amyloid removal but also a signal on cognition and biomarker downstream effect. More recently, Biogen announced that they are filing to the FDA the results of their phase 3 trials, which are suggesting a cognitive benefit in those patients treated at the highest dose. It is true that we are looking forward to seeing and digesting the data carefully, but nevertheless this is good news that benefits the Alzheimer’s field.

Both announcements suggest that there is sufficient signal in their results for launching a phase 3 (Eisai) and for considering a potential approval (Biogen). I hope that this will result in a renewed interest of companies and investors in the field. In addition, if the results hold, they are telling us that, even at a stage where the brain is not only full of deposited amyloid but also where tau tangles have spread beyond the middle temporal lobe, removing amyloid has an impact at different levels, showing a downstream signal on soluble tau biomarkers and a clinical benefit.

For me, the emerging question would be, what will be the benefit of removing amyloid earlier in the AD continuum, before tau tangles spread beyond the middle temporal lobe? I belong to the group believing that our chances for defeating Alzheimer’s are higher if we go earlier. I am fully aware of the complexities of designing secondary prevention trials: finding the right population, defining primary endpoints, powering the trial (one problem there is that we tend to use data from observational studies which do not account for the placebo effect), attrition rates, to mention a few. I do remain optimistic and hope that others are, and that we can keep on working together to defeat Alzheimer’s disease.

STRiDE update

Wendy Weidner, Research and Policy Project Lead, ADI

In the last couple months, field work has begun in earnest in the STRiDE-based (Strengthening responses to dementia in developing countries) countries. Focus groups on stigma are underway in all seven countries, as is the development of knowledge exchange, impact and engagements plans, which are being led by the Associations in each country team.

The desk review part of an in-depth situational analysis has been completed in 4 countries, with the remaining being completed by the end of December 2019. This work will help lead to a first set of policy recommendations for all countries, as well as preparation cost of dementia estimates and simulation models of future needs for dementia care and resources needed.

You can keep up to date with STRiDE here.