



**Alzheimer's Disease  
International**

*The global voice on dementia*

February 2020  
Volume 30, No. 1

# Global Perspective

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



## STRiDE attends talks in London

**D**uring the week of 20 January, STRiDE members from Brazil, India, Indonesia, Jamaica, Kenya and Mexico joined ADI and the STRiDE London School of Economics and Political Science (LSE) team in London for a week-long series of talks and training around Knowledge Exchange, Impact and Engagement plans.

STRiDE (*Strengthening Responses to Dementia in Developing Countries*) is a 4-year long project led by the LSE, in partnership with ADI, Dementia Alliance International (DAI) **and other universities in seven different countries**, including the University of Sussex and the University of Cape Town. The project looks at combining both academia and civil society organisations (Alzheimer's associations and ADI members), to assist countries in carrying out research and turning this into actual policy change through evidence, advocacy and stakeholder engagement – all with the end goal of having a positive impact

on the lives of people who are affected by dementia.

The group held discussions and training on how to effectively plan, measure and demonstrate impact; engage with key stakeholders and communicate emerging evidence; and explore what persuades decision makers to initiate policy change.

During the week, Deputy CEO, Chris Lynch, also took the opportunity to line up interviews with the ADI members, with joint STRiDE lead Adelina Comas-Herrera from LSE and with Paola Barbarino, capturing footage for the forthcoming ADI & ITN productions film "Hope in the age of dementia" that will launch in December at the Singapore conference.

Read more about STRiDE and some of the participants' experiences during discussions in London on **page 13**.



## 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 from ADI

### A successful start to 2020 for STRiDE

I'd like to start our first Global Perspective for 2020 with a message of hope. At a time when the world seems to be polarized on so many issues, it's particularly uplifting when we can demonstrate that at a very basic level, when we work together, we can achieve great things. This is a fundamental theme for ADI and something that many of you will relate to as you read this. But I want to tell you about a transformational week on the STRiDE project that proves that together, we are greater than the sum of our parts.



Wendy Weidner, Policy and Research Lead

STRiDE (Strengthening Responses to Dementia in Developing Countries) is a unique project that combines both academic researchers and civil society. Our Alzheimer associations are Engagement and Impact Leads (EILs) in STRiDE due to their unique perspective and experience in advocacy. Building on these partnerships, the project aspires to go beyond research; to strengthen capacity in each country to conduct research and then to turn that research – using evidence, advocacy, and stakeholder engagement – into actual policy change that will have a positive impact on the lives of people affected by dementia.

In January, EILs from six STRiDE countries gathered in London for a week-long workshop to share learning around effectively planning, measuring and demonstrating impact, engaging with key stakeholders and communicating emerging evidence, and exploring what persuades policy makers to initiate policy change.

A key part of the week was a public and web-based seminar in which each of the EILs spoke about policy making in their own countries. It was humbling to listen to my colleagues share their unique and powerful perspectives from the front-line of dementia advocacy.

The week was transformative for many reasons, but particularly because it reinforced the fact that academic researchers and EILs each bring unique expertise to the project that, when combined, will enable STRiDE to achieve its important aims in each country. This is the strength of STRiDE.

For me, the most profound part of the week was seeing and feeling the absolute bond of mutual trust and faith that grew out of sharing ideas, challenges, possible solutions, stories, laughs, and some tears. These are the joys and struggles of those who work in the dementia field – and we are cemented together in our determination to make things better. I feel so privileged and hopeful to be part of this amazing team that continually proves that together, we are better.

## News

### ADI attends meetings in Rome

At the beginning of December, ADI Chief Executive Paola Barbarino travelled to two separate events taking place in Rome. The first event was hosted by the Vatican's Pontifical Academy for Life and the World Innovation Summit for Health, an initiative of the Qatar Foundation. The second event was a discussion with the Italian Senate.



Senator Barbara Guidolin and Paola at Palazzo Chigi.

The two-day symposium, 'Religion and Medical Ethics: Palliative Care and the Mental Health of the Elderly', focused on the role of religion in approaches to care for older persons. The symposium included Catholic, Muslim and Jewish experts taking part in the interfaith dialogues.

During the symposium, Paola took part in a panel discussion that examined the findings of the **World Alzheimer Report 2019** and its relation to palliative care.

On 12 December, Paola also attended talks with the Italian government at the Palazzo Chigi. During discussions with the Senate, Paola emphasized the economic crisis posed by dementia and the need for more funds to be allocated towards dementia – both nationally and internationally.

Italian Senators Barbara Guidolin and Simona Nocerino also took part in the discussions. Senator Nocerino described her previous role as a carer as an influence on creating a piece of legislation that aims to support carers to continue in paid employment.

On the discussions, Senator Guidolin said: *"This bill, which will soon be converted into law, is the result of the work carried out by the Select Committee, of which I was the rapporteur. We drafted a new text that was signed by all political parties. I emphasize that there is a unequivocal willingness to approve this text, with appropriate modifications, as emerged during the conference at which Paola Barbarino, ADI's CEO, participated, in a short time, so that the family caregivers can finally be protected."*

### ADI attends training for GPs in "Blue Zone" of Costa Rica



Joost Martens with Dr Norbel Roman, Vice President of ASCADA; Dr Elmer Garcia, researcher and coordinator of the Chorotega Research Group in Guanacaste; and Lic. Wady del Hob, Instructor and Treasurer of ASCADA.

On 10 January, Joost Martens, ADI Regional Director for the Americas, and Dr Norbel Roman, Vice President of ADI member Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA) visited the city of Nandayure, Costa Rica. In 2019, Nandayure's municipal council declared the city to be a **Dementia Friendly Community** based on the effective collaboration between local stakeholders, such as general practitioners, the regional hospital, municipal authorities, and ASCADA.

The one-day training session brought together General Practitioners from around the "blue zone" of Costa Rica to learn about early dementia diagnostics, primary intervention and cognitive evaluation instruments, such as the Montreal Cognitive Assessment (MoCA). With instruments such as the MoCA test, doctors can detect early signs of Mild Cognitive Impairment.

The involvement of health professionals is crucial for communities to develop local capacity for dementia detection, and to define dementia care pathways at an early stage.

Dr Norbel of ASCADA said: *"We are on a new track towards the development of community action. Being convinced that the best and most efficient results occur near the home, primary health care services are essential. This means a shift towards community awareness and empowerment. We are more optimistic now."*

**Read more about ASCADA.**



## News

### ADI blog



Youth volunteers and members of the community participate in the Home Music Visit Programme.

For the first month of 2020, the ADI blog featured two blog posts which looked at India's recent policy development around dementia, as well as innovative youth programmes focused around dementia advocacy.

Meera Pattabiraman, Chair of **Alzheimer's Disease and Related Disorders Society of India (ARDSI)**, wrote in the ADI blog about

ARDSI's success in advocating for a national dementia plan with the Ministry of Health and Family Welfare, saying: "...most heart-warming after all of the meetings with the officials in Delhi, was their conviction that national programmes were essential and that ARDSI and the state governments should join hands in setting up special programmes and services to address the needs of persons with dementia."

Our second blog focused on case studies around the different ways that youth around the globe are responding and supporting people and communities who have been affected by dementia. One of these particular programmes includes ADI Member **Alzheimer's Indonesia's** Home Music Visit Programme, which involves youth visiting people living with dementia in their community and singing songs about dementia, including risk reduction.

Read the ADI blog [here](#).

## World Alzheimer Report 2020

The **World Alzheimer Report 2020** will focus on dementia related design and the built environment, looking at progress to date, best practice and innovation across multiple environments including in home/domestic settings, day and residential care, hospitals and public buildings and spaces. The report will have a global perspective of dementia related design that takes a cross cultural approach, reflects regional and economic differences and low- middle- and high- income countries, and will consider urban versus rural settings. It will highlight the role of innovation, entrepreneurship and the importance of aesthetics.

Chris Lynch, Deputy CEO and Director of Policy, Communications and Publications said: "We are delighted to have appointed Professor Richard Fleming, Professorial Fellow, Faculty of Science, Medicine and Health, University of Wollongong, to lead the work. Professor Fleming is an environmental design expert and psychologist who has been involved in the development of services for people with dementia for over 35 years. He

will lead a team of international experts and advisors in creating this report and following the launch we will host a design workshop at our global conference in Singapore 10-12 December."

Read our previous World Alzheimer Reports.



## News

### Fundashon Alzheimer Bonaire launches new community programme



Members of the Ka'L Miminia Day-care centre with children from Kindergarten Jiwiri.

On 8 January, ADI member Fundashon Alzheimer Bonaire launched a new programme that aims to bring together young children and people living with dementia. Children from Kindergarten Jiwiri will visit twice a month to engage in a series of activities, ranging from crafts, playing games and singing with members of the Ka'L Mimina Day-care centre.

The integration programme hopes to stimulate activity and joy for those who are living with dementia, as well as to create respect and awareness for older people and those living with dementia. Fundashon Alzheimer Bonaire hopes that the success of the programme will be able to be continued with primary school children in the future.

When speaking about the programme, Evert Piar, Chair of Fundashon Alzheimer Bonaire, said: *"The most beautiful gift that a generation can give to another is love."*

**Learn more** about Fundashon Alzheimer Bonaire.

### ADI welcomes new staff

ADI welcomes two new additions to the ADI team, **Martin Ayres** and **Deborah Speirs**.

Martin joined ADI in late November as a part-time Finance Assistant. When not at ADI, Martin also works for the charity Higher Mind, which provides access to higher education from underrepresented groups. Martin previously worked as a Finance Manager for St John's Parish Church in Waterloo, as well as in various roles in the City of London within the investment sector.

Deborah has joined ADI on a temporary 3-month basis to help assist in the consulting of our fundraising activities, with a large focus on progressing our new business strategy.

### In Memory

**Dr Jacob Roy Kuriakose**, former Chair of ADI and founder of Alzheimer's and Related Disorders Society of India (ARDSI), sadly passed away on 2 February.



Dr Roy was inspired to create ARDSI after finding that while caring for his father who had Alzheimer's disease, there was little awareness or resources for people with dementia in India.

Dr Roy was a tireless advocate and valued member of the global dementia community and will be deeply missed. Our greatest condolences are with his son, Greg, and the rest of his loved ones from all of the family at ADI.



## ■ Update from Dementia Alliance International (DAI)

### Kate Swaffer, co-founder of Dementia Alliance International, introduces the DAI 2020 Board of Directors and new structure'



In 2020, we announced our incoming Board of Directors, as well as some structural changes we have made. These changes include moving DAI's Annual General Meeting (AGM) to June each year, and the new board positions elected at this meeting becoming effective in the next financial year. All of these changes have been approved in line with our By Laws and have been made to improve our governance. Two non-member positions have also been approved and have been taken up by volunteers. Most other organisations usually have many staff in paid roles, but due to a lack of funding, DAI is still not in a position to do so. We remain indebted to both Sarah and Tamara for their willingness to give of their time and expertise for the benefit of members and supporters of DAI.

DAI has also formalised three formal committees; within these committees, there is a permanent Finance and Fundraising Subcommittee, an Action group, a Membership subcommittee, and other teams (or committees) as required. Finally, we will soon announce our Professional Advisory Council and an International Advisory Board, both groups of members, care partners, advocates, researchers and professionals working together towards global change, for all people with dementia and their families.

### About our new Vice Chair:

Alister is from Napier in New Zealand and was diagnosed with younger onset Alzheimer's in 2014. Soon after his diagnosis he was fortunate enough to attend a day programme run by Dementia Hawkes Bay, which he now attends three days a week. Alister has become an active member of DAI, having been involved in our Action Group and Board. DAI is delighted he accepted the nomination as Vice Chair in 2020. He is also a very active advocate for raising awareness of dementia in NZ and globally.



**Alister Robertson, new Vice Chair for Dementia Alliance International**

### Listen to Alister explain why he is committed to working with Dementia Alliance International.

**Thank you:** DAI also wishes to thank all our strategic partners and sponsors, as well as every single person who so generously makes a donation to DAI. Without your donations and sponsorship, we could not continue to provide free membership and free services to our members and the wider community of supporters, advocates, researchers and health care professionals working to improve the lives of all people with dementia and their families.

**People with dementia can join DAI [here](#).**

**Subscribe to DAI [here](#).**

### 2020 Board of Directors

Chair/CEO, **Kate Swaffer**, Australia  
 Vice Chair, **Alister Robertson**, New Zealand  
 Treasurer, **John Sandblom**, USA  
**Eileen Taylor**, Australia  
**Wally Cox**, USA  
**Christine Thelker**, Canada  
**James McKillop**, Scotland, UK  
**Bobby Redman**, Australia  
**Bill Turner**, Australia

### Two new non-member (volunteer) positions

Secretary, **Sarah Yeates**, Australia  
 Finance Officer, **Tamara Claunch**, USA

### Three Working Committees

Internal Affairs  
 External Affairs  
 Governance



## 34<sup>th</sup> International Conference of Alzheimer's Disease International

10 – 12 December 2020  
Singapore

# Hope in the age of dementia.

*New science. New knowledge. New solutions*



**New Dates  
10-12  
December  
2020**

[www.adi2020.org](http://www.adi2020.org)

 @ADIConference #ADI2020

 Alzheimer's Disease International

 [alz.org.sg](http://alz.org.sg)  @alz\_sg





## ■ Meetings and Conferences

### An update on ADI's 34 International Conference



At the beginning of February, in response to the Coronavirus disease (COVID-19) outbreak in China, the Singaporean Government raised the Disease Outbreak Response System Condition (DORSCON) level to orange, advising against non-essential large events. As such, the difficult decision was made to reschedule ADI's 34th International Conference.

While we know that attendees will be as disappointed as we are, we have remained in close contact with our event organiser, SingEx, and ADI are pleased to confirm that we have re-scheduled the conference for 10-12 December 2020. We are also pleased to affirm that we are automatically carrying forward all registrations, abstracts, speakers and exhibitors, to make the change of date as seamless as possible.

#### ADI to launch film at ADI 2020

In collaboration with ITN Productions, ADI will premiere a new film at our 34th International Conference in Singapore. Building on the theme of the conference, "Hope in the age of dementia", the film will highlight innovation, science and care from around the world.

ADI partnered with ITN Productions in November 2017 for a news and current-affairs style programme which looked at the risk, growth and future response to dementia. The 3-part series premiered at ADI's 33rd International Conference in Chicago.

**Watch 'Every 3 Seconds'.**

### ADI meets with the Organisation for Economic Cooperation

On 21 January, Paola Barbarino and Chris Lynch, CEO of ADI, visited the Organisation for Economic Cooperation (OECD) at their headquarters in Paris to discuss priorities for 2020.

Meeting with Mark Pearson, Deputy-Director for Employment, Labour and Social Affairs, Elina Suzuki and Ana Llena-Nozal, ADI and OECD discussed how to keep the momentum around healthy ageing and dementia going after the impressive commitments made under the Japanese presidency of the G20, and bringing those into focus under the presidency of Saudi Arabia and beyond.

Discussions also focused on preparedness of healthcare systems for a disease modifying drug breakthrough, especially in relation to payers and regulators, accessibility and affordability.

Chris said: *"With the recent news about Biogen applying for FDA approval for aducanumab, preparedness is vital.*

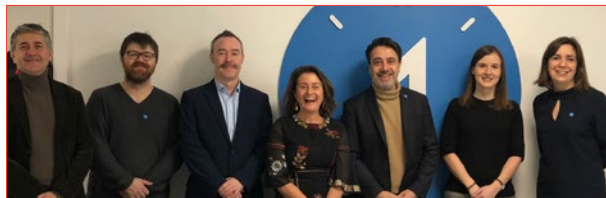
*Globally we are all anxious for disease modifying treatment breakthroughs but it is essential that we work collaboratively to ensure that healthcare systems are ready and prepared".*

**Read more about the OECD [here](#).**



## ■ Meetings and Conferences

### ADI meets with France Alzheimer in Paris



Christophe Roy, Guillaume Frasca, Chris Lynch, Paola Barbarino, Benoît Durand, Laura Dabas and Lorène Gilly.

On 22 January, ADI met with ADI member France Alzheimer et Maladies Apparentées in Paris. Included in the discussions were Benoît Durand, Director General; Christophe Roy, Director for Social Services; Lorène Gilly, Manager of Monitoring Public Policies and Guillaume Frasca, Manager of Studies and Research.

During the meeting, France Alzheimer gave a presentation on the organization and plans to review France's national policy, the Plan Maladies Neuro-Dégénératives 2014-2019. Also discussed were healthcare packages, the latest drug developments, research and global collaborations.

Laura Dabas, ADI's Membership Manager said: *"Thank you France Alzheimer for the warm welcome; it was so interesting and inspiring to hear more about France Alzheimer et Maladies Apparentées' activities and services. ADI appreciates their commitment, dedication and all the fantastic work they have been doing in France."*

**Learn more** about France Alzheimer.

### ADI makes statements on NCDS and ageing at the WHO Executive Board Meeting

The WHO 146th Executive Board took place in Geneva from 3 to 8 February. Although dementia was not specifically on the agenda at this year's meeting, some important decisions were made on topics relating to dementia.

ADI took the opportunity to make two statements, calling for specific actions to fully support people with dementia during the Decade of Healthy Ageing 2020-2030, and for more attention to be given to dementia and other neurological conditions under the auspices of non-communicable diseases (NCDs).

A **proposal on epilepsy** was put forward by the Ministries of Health of China, Eswatini, Guyana, North Macedonia, Russian Federation and Zambia. The proposal encourages Member States to discuss a possible draft resolution on further actions on epilepsy and other neurological disorders for consideration at the World Health Assembly, given the synergies discussed during the meeting under the ambit of brain health. There was also some strong discussion of a proposal by 11 members states on accelerating action to reduce the **harmful use of alcohol**, which is one of the major risk factors for dementia.

ADI looks forward to launching an updated **From plan to impact** report at a special side event at the World Health Assembly in May. Further details to follow.

**Read more** about the Decade of Healthy Ageing.

## ■ Events

26-27 July 2020

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

**Amsterdam, Netherlands**

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

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

20-22 October 2020

**Alzheimer Europe conference**

**Bucharest, Romania**

Website: [https://www.alzheimer-europe.org/Conferences/](https://www.alzheimer-europe.org/Conferences/Bucharest-2020)

**Bucharest-2020**

Email: [info@alzheimer-europe.org](mailto:info@alzheimer-europe.org)

20-22 October 2020

**XIII Congress Alzheimer Ibero America**

**Havana, Cuba**

Website: <https://alzheimeriberoamerica.org/>

10-12 December 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)

## ■ Meetings and Conferences

### ADI attends the NCD Alliance Forum in Sharjah



Annie with Desirée Vlekken, Founder and CEO of 4get-me-not, and performers of the 4get-me-not group.

Annie Bliss, ADI's Communications and Policy Manager attended the NCD Alliance Global Forum in Sharjah, United Arab Emirates (UAE), from 9 to 11 February. She was joined by Desirée Vlekken, Founder and CEO of **4get-me-not Alzheimer's Organization**, ADI's member in the UAE and also met Bina Berry from **ARDSI**, ADI's member in India.

The third of its kind, the Forum is a meeting point for civil society, policy makers, advocates and others operating within the ambit of non-communicable diseases (NCDs). This year, almost 400 delegates from 85 countries met in order to discuss ways of "Bridging the gap" between global promises and the lived reality. The programme focused on three themes: transformative NCD policies and solutions; transformative social movements and voices for change; transformative and inclusive governance. During the opening ceremony, His Royal Highness Sheikh Dr Sultan Bin Muhammad Al Qasimi, Member of the Supreme Council and Ruler of Sharjah, UAE, officially opened the Forum.

Among the interesting presentations, Dr Ren Minghui, Assistant Director General for UHC & NCDs at the World Health Organisation, spoke of the lack of progress towards NCDs thus far, and urged Governments to increase the proportion of GDP they attribute to primary healthcare by 1 percent.

Annie presented in a workshop on *'Building coalitions and social movements to address NCD multi-morbidities: Health systems for people,*

*not siloes for diseases'*. She emphasised the importance of meaningfully engaging people living with dementia and young people in advocacy and policy development, particularly around risk reduction, and the need for better training of primary healthcare practitioners to enhance this engagement and reduce stigma. She said: "I was struck by the excellent diversity among the participants at the Forum, in terms of geography, age and area of expertise. I was inspired by the many young advocates living with NCDs, who cogently demonstrated why there must be 'nothing about us without us'".

Annie was delighted after the Forum to meet with 4get-me-not's performance group, who travel around the UAE visiting care homes to raise awareness of dementia and encourage the elderly residents to live healthy, social lifestyles.

**Read more about the NCD Alliance Forum.**



Annie with Bina Berry of Alzheimer's and Related Disorders Society of India, Delhi Chapter.



## ■ Living with dementia

Eileen and Dubhglas Taylor

### Hope is the key to improving psychological and social well-being: “Oops, there goes another rubber tree plant”

#### Compliments of Frank Sinatra:

*“Next time you’re found, with your chin on the ground.  
There a lot to be learned, so look around*

*Just what makes that little old ant  
Think he’ll move that rubber tree plant  
Anyone knows an ant, can’  
Move a rubber tree plant*

*But he’s got high hopes, he’s got high hopes  
He’s got high apple pie, in the sky hopes*

*So any time you’re gettin’ low  
‘Stead of lettin’ go  
Just remember that ant*

*Oops, there goes another rubber tree plant”*  
(Van Heusen and Cahn, (1959).

“Hope is the little voice you hear whisper, ‘maybe’ when it seems the entire world is shouting, ‘No!’”

**Hope** is a resilient state of mind grounded in the prospect of favourable results despite preceding misfortunes or failures with respect to actions and/or instances in one’s life journey. As a verb, its definitions include: “want something to happen or be true,” “expect with confidence” and “to cherish a desire with anticipation.” It’s a big ask!

Hope is demanding work.

Hope is not Free. The cost is high.

It’s not difficult to understand how a person living with dementia and their care partners look at themselves, the doctors and the medical/political system and dream of something better. It takes resolve and purpose to face dementia and bring into the reality some hope that things could be different.

Yet, even though hope comes with a cost, the reward can be compensating. Recent empirical evidence suggests that hope can lead to better physical and psychological health. Hope give people meaning yielding more positive moods. Sadly, the reverse is also true Hopelessness leads to withdrawal from things that gives life meaning.

There is an increasing suggestion that dementia research is an important source of hope for people living with dementia who are vulnerable and

unwell. This may be attributed to a constant barrage of news items promising a new breakthrough with the promise of a cure for dementia - especially Alzheimer’s Disease since it is the most prominent of dementias.



Dubhglas and Eileen Taylor

Moreover, if the role of facilitating hope in people living with dementia were to be increased by researchers, it may suggest that perhaps they may need to acquire more skills in this area. For a start, having a high level of personal and other awareness along with intentionally having hope in themselves and their work to inspire hope in others.

Researchers that adopt the use of hope enhancing skills need inherent practices for assisting in this work of hope. Failure to identify the emotional costs of working with a person living with dementia who experiences despair may result in the researcher experiencing vicarious trauma.

This then, would suggest that working with people living with dementia demands that the researchers should engage in emotional work and processes to support their work to enhance Hope. Hope is a great motivator and can play a central role of being a therapeutic placebo promoting hope.

This can be a parallel process. Research participants living in hope of cure, and researchers living and working in hope for therapeutic solutions. Both relying on hope.

“Hope is the little voice you hear whisper, “maybe” when it seems the entire world is shouting, “no!””

“Oops, there goes another rubber tree plant.”

**Eileen and Dubhglas Taylor will be speaking at ADI’s 34th International Conference. You can learn more [here](#).**

## ■ Research Update and Innovations

### Thoughts on aducanumab from ADI's Ricardo Allegri

**Ricardo Allegri, member of ADI's medical and scientific panel (MSAP), gives his thoughts on the recent developments around aducanumab.**



Current medications for AD provide symptomatic relief but do not treat the underlying causes of the disease. Aggregation of amyloid- $\beta$  in plaques and abnormal phosphorylated tau deposits in neurofibrillary tangles represents the hallmarks of Alzheimer's disease. Scientists have been developing medications targeted to  $\beta$  amyloid or tau, such as Aducanumab (BIIB037). Developed by Biogen, aducanumab is a human monoclonal antibody that selectively targets aggregated (clumped) forms of amyloid  $\beta$  fibrils.

In March 2019 a planned futility analysis by the aducanumab clinical trials independent data monitoring committee indicated that these trials were unlikely to meet their primary endpoints upon completion. As a result, Biogen decided to terminate all ongoing trials. However, in October 2019 Biogen **announced** that analysis of a larger dataset involving a subset of participants who received the highest dose of aducanumab showed statistically significant, though modest, slowing of decline in cognition and activities of daily living, and also reductions of brain amyloid measured on PET scans and phospho

tau levels measured in cerebrospinal fluid. As a result, Biogen has applied to the U.S. Food and Drug Administration (FDA) for regulatory approval of aducanumab in the U.S. – a decision on this is currently pending.

While Biogen's reinterpretation of its data has caused much conversation and debate, there has been a renewed interest and excitement surrounding anti-amyloid compounds. Though a recent preliminary analysis of the Dominantly Inherited Alzheimer's Network Trials Unit (DIAN-TU) study **revealed** that solanezumab and gantenerumab, two anti-amyloid antibody drugs, did not slow cognitively decline in people with autosomal dominant Alzheimer's disease, these results have been interpreted with caution given that the DIAN-TU study involved a relatively small number of individuals who have a rare form of inherited and young onset AD.

Biogen has also recently launched a new study of aducanumab in a clinical trial that will include 2,400 participants who will receive monthly drug infusions for two years. An FDA decision regarding aducanumab should also be announced within the next few months, leading to the exciting possibility that aducanumab could potentially provide a new, though modest, treatment for people affected by Alzheimer's disease.

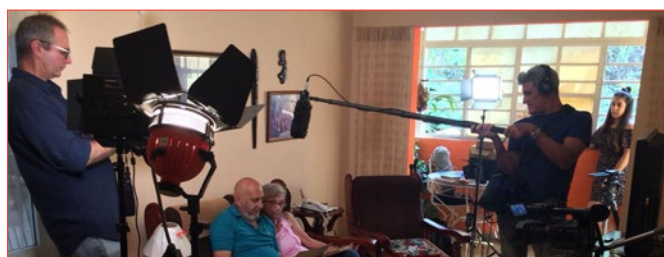
### GBHI and Alzheimer Research Center Havana launch video series for carers

On 5 December, the Global Brain Health Institute (GBHI) and Alzheimer Research Center Havana, in partnership with the UCSF Memory and Aging Center, Cuba Platform, and Medical University Havana, launched a Spanish video series for dementia caregivers based in Latin America.

Titled "Conversando con los Cuidadores" (Talk with Caregivers), the video series aims to highlight the unique burden experienced by carers for loved ones with dementia through practical advice offered by real life carers. The video also seeks to address critical issues experienced by carers, including communication, personal care, and psychological and behavioural symptoms.

Jorge Llibre-Guerra, co-developer of Conversando con los Cuidadores, said: "Almost 79% of those

*providing care for someone for dementia has never received formal training on caretaking or information, Conversando con los cuidadores is tasked to change that picture by providing a training resource. Caregivers face many obstacles when delivering care and this series will alleviate some of the burden related to care by fostering caregiving training."* **Watch the video series.**



Filming for one of the 'Conversando con los Cuidadores' videos.



## STRiDE update



Wendy Weidner, Tara Sani, Rochelle Amour, Imelda Theresia, Rosa Farres, Elizabeth Mutunga, Ishtar Govia, Elaine Mateus and Narendhar Ramasamy.

### Two years into the STRiDE project, research activities are in full swing.

In all seven STRiDE countries, field work focusing on awareness and stigma is well underway. Each country has run focus groups to help understand existing knowledge, attitudes and behaviours towards people living with dementia and carers and their experiences of stigma and discrimination. Each country team is also in the process of finalising their situational analysis that describes the current dementia care, treatment, and support in their country – identifying gaps, but also opportunities for promoting policy change.

Field work focusing on the impact of informal care is ongoing in Jamaica and Mexico, with work due to start in India in the coming months. Work continues across Indonesia and South Africa on pre-testing and translation of the toolkit that will provide dementia prevalence and cost data. Finally, Brazil and Kenya are preparing for phase 2 of their stigma fieldwork, the development of a stigma intervention toolkit and assessment tool.



UK Research  
and Innovation



**Engagement and Impact Leads**, as pictured left, are leading on the development of Knowledge Exchange, Impact and Engagement plans. After an invigorating week of week-long workshops in London which saw discussions of shared knowledge and on a small project on pathways to policy, read some of the views from those who attended:

- *“Research is empowering, it brings hope. The meeting was important, not only as a great opportunity to share experiences and learn from other countries, but also in reminding us to keep our eyes on the impact we hope to achieve through this research project.”*

**Tara Puspitarini Sani • Indonesia**

- *“For me there is a before and after London. It allowed me not only to know better the situation of other STRiDE countries and to see what unifies us, the companions of the NGO's which allowed me to learn and realize what we are missing in FEDMA that will be part of what I take to Mexico to work. The situational analysis and the SWOT developed by the researchers in Mexico will be the basis of the work to develop with the different associations to be a single voice of dementia instead of many little voices seeking to have a greater impact at the federal level.”*

**Rosa Farres • Mexico**

- *“Coming together with NGO leads in London last January was deeply inspirational to me and, I believe, to the whole team. The mutual sharing and caring put us all in the right mindset to take up the challenges one faces when supporting people living with dementia and their caregivers to live well. The discussions and reflections made clear the need for coordinated actions across stakeholders, and the importance of each one within this complex interplay of compromises. There is a lot to be embraced, and the week we spent together made me feel treasured and motivated to carry out the knowledge exchange, impact and engagement approaches and activities, in sync with the Brazilian team.”*

**Elaine Mateus • Brazil**