



PERSPECTIVE

Commentary: Global Alzheimer's disease and Alzheimer's disease related dementia research funding organizations support and engage the research community throughout the COVID-19 pandemic

Emily A. Meyers¹  | Philippe Amouyel² | Diane E. Bovenkamp³ | Maria C. Carrillo¹ | Geraldine Drexel De Buchy⁴ | Magali Dumont² | Howard Fillit⁵ | Lauren Friedman⁵ | Gregor Henderson-Begg⁶ | Jakub Hort^{7,8} | Andrew Murtishaw¹ | Richard Oakley⁶ | Maï Panchal⁴ | Sharyn L. Rossi³ | Rosa M. Sancho⁹ | Linda Thienpont¹⁰ | Wendy Weidner¹¹ | Heather M. Snyder¹ 

¹ Medical & Scientific Relations, Alzheimer's Association, Chicago, Illinois, USA

² Fondation Alzheimer, Paris, France

³ BrightFocus Foundation, Clarksburg, Maryland, USA

⁴ Fondation Vaincre Alzheimer, Paris, France

⁵ Alzheimer's Drug Discovery Foundation, New York, New York, USA

⁶ Alzheimer's Society UK, London, UK

⁷ Czech Alzheimer Foundation, Prague, Czech Republic

⁸ Memory Clinic, Department of Neurology, Charles University, 2nd Faculty of Medicine and Motol University Hospital, Prague, Czech Republic

⁹ Alzheimer's Research UK, Cambridge, UK

¹⁰ Alzheimer Forschung Initiative, Düsseldorf, Germany

¹¹ Alzheimer's Disease International, London, UK

Correspondence

Emily Meyers, Medical & Scientific Relations, Alzheimer's Association, 225 N. Michigan Ave. Floor 17, Chicago, IL 60601, USA.
E-mail: easmeyers@alz.org

Abstract

The COVID-19 pandemic has disproportionately affected more vulnerable populations, including those living with dementia. Over 50 million individuals worldwide are living with Alzheimer's disease (AD) or other dementia, and it is crucial to continue the fight against the condition during the global pandemic. Since the start of mandated lockdowns in March 2020, charity and non-profit organizations that fund AD and related dementia research continue to respond to the needs of the AD research community, ensuring the momentum continues and accelerates. Members of the International Alzheimer's and Related Dementia Research Funder Consortium, a group of nearly 40 funding organizations that informally convene throughout the year to share updates and information, have taken a number of steps to ensure the continued support of the research community. Even during times of uncertainty, it is essential that the field moves forward to uncover preventions, diagnoses, and treatments for these diseases that affect many millions globally.

KEYWORDS

Alzheimer's disease, COVID-19, dementia, nonprofit, public health, research funding

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial](https://creativecommons.org/licenses/by-nc/4.0/) License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2021 The Authors. *Alzheimer's & Dementia* published by Wiley Periodicals LLC on behalf of Alzheimer's Association.

1 | INTRODUCTION

According to the 2015 Alzheimer's Disease International (ADI) report,¹ nearly 50 million individuals worldwide are living with dementia. The need for interventions to stop, slow, or possibly prevent the progression of dementia have never been more necessary.

Last March, the World Health Organization (WHO) declared a global pandemic, due to a novel coronavirus SARS-CoV-2, the virus that causes the COVID-19 disease. Links between COVID-19 and dementia have continued to emerge, specifically the impact on caregivers and individuals with dementia, and the potential biological correlation of COVID-19 to risks in later life. Further, there has been a decline in dementia diagnosis rates and a high proportion of deaths due to COVID-19 among dementia patients.^{2,3} With the global pandemic, the entire research community experienced many challenges as studies were paused or slowed at institutions and clinical sites around the world.⁴⁻⁶

Chaired by the Alzheimer's Association, the National Institute on Aging and the Alzheimer's Research UK (ARUK), the International Alzheimer's Disease and Related Dementia Research Funders Consortium started in 2012 with representatives from governmental, non-profit/charity, and private philanthropic funding organizations who invest in Alzheimer's disease (AD) and related dementia (ADRD) research worldwide. The consortium convenes informally throughout the year, with meetings centered around information sharing and the initiatives led by contributing organizations.

Participation is open for any organization in the world directly funding AD and ADRD research. Recent discussions have focused on identifying avenues that provide essential support to the research community in the face of the global pandemic, reinforcing our steadfast commitment to advancing the progress of AD and ADRD research, care, and support. This commentary summarizes actions and initiatives instituted over the past year by participants of the Consortium, aimed to continue and increase the necessary momentum of the research and care communities in these challenging times. The examples referenced here are meant to be representative, and are not meant to be exhaustive.

2 | INITIATIVES OF FUNDING ORGANIZATIONS FOR ACTIVE AD/ADRD AWARDEES

For currently funded researchers, short-term response included extending deadlines and adjusting study aims. The many long-term challenges stemming from government mandated quarantines and lab shutdowns include delayed experiments, loss of research samples and cohort data, and workforce retention issues. Nearly every organization swiftly implemented measures to help address the issues that current grant awardees were facing. The Alzheimer's Association notified all active awardees in March 2020 of flexibility around reporting deadlines, willingness to adjust study aims or pause studies, willingness to continue to support salary needs, and more. Similar notifications were sent by BrightFocus Foundation, ARUK, and others.

When possible, funders also provided additional financial support to retain staff. The Fondation Vaincre Alzheimer, Alzheimer's Society UK, ARUK, and others offered cost extensions or additional resources to programs that support doctorate students to mitigate disruptions due to the pandemic. Other organizations offered COVID-relief funding programs, such as the Alzheimer's Association RAPID funding program,⁷ aimed at active awardees to support salary needs, resource replacement, or extended project aims to be inclusive of COVID-related questions. Many funding organizations allowed rebudgeting for unanticipated pandemic-related expenses (such as unanticipated budget needs to ensure proper personal protective equipment for lab personnel), paused grant timelines, and allowed for no-cost extensions up to one year. The Alzheimer Forschung Initiative (AFI) adjusted guidelines for travel and training grants to allow for use during the pandemic; this included covering the costs of online conferences.

In addition, in the UK, when researchers were unable to complete study aims and retain staff as a result of coronavirus restrictions, ARUK supported researchers by encouraging universities to access the Coronavirus Job Retention (Furlough) Scheme, made available by the UK government.⁸

During the early stages of the global pandemic, many research funders including BrightFocus Foundation, Fondation Vaincre Alzheimer, AFI, and others surveyed both awardees and physicians to gain insight into the challenges in the field. Outcomes from the survey indicated a great need for training of professionals and caregivers in dealing with the compounding impact of COVID-19 on the ADRD community.

3 | OPPORTUNITIES TO VIRTUALLY CONVENE THE AD/ADRD RESEARCH COMMUNITY

Restrictions placed on in-person social gatherings during this time significantly impacted the ability to convene scientific conferences and discussions in person. Many organizations used emerging tools that enabled virtual convening to adapt to these restrictions. The Alzheimer's Association International Conference (AAIC) originally planned to occur in Amsterdam, the Netherlands in July 2020 was able to pivot to a virtual format. The Alzheimer's Association opened this conference to attendees with free registration, engaging more than 33,000 individuals from more than 140 countries. In December, ADI also held a virtual international conference with more than 1600 people attending from 120 countries, including many early career researchers from low- and middle-income countries.

Many conferences in 2021 will remain virtual, including BrightFocus Foundation's pre-conference symposium to AD/PD 2021⁹ and ARUK's Annual Research Conference.¹⁰ Virtual conferences allow for the sharing of information, networking, and collaboration between scientists. While it can be difficult to fully re-create these aspects in a virtual space, emerging hybrid models that engage in-person and virtual participation likely will evolve in the coming years.^{11,12}

It is imperative during this time that the ADRD field does not lose new and upcoming researchers. To reinforce this commitment, Alzheimer's Drug Discovery Foundation (ADDF), BrightFocus

Foundation, Alzheimer's Association, ADI, and others hosted virtual programs aimed to engage and support early career researchers. The AAIC Neuroscience Next (AAIC-NN) conference launched as an opportunity for early career researchers to present work, publish abstracts, and network with scientists from all career levels, with more than 5000 attendees. A bright aspect of the virtual format is widespread accessibility.

4 | COVID-19 IMPACT ON CARE AND SUPPORT

The organizations represented in this commentary share missions to address the trajectory of AD and ADRD; in some organizations this includes initiatives to advance care and support. During the global pandemic, professional and family caregivers have been significantly impacted. With orders to remain at home and concerns over potential exposure, there was reduced access to these essential services and in some cases, care transitioned to family or in-home caregivers. A need arose for guidelines and training aimed at assisting caregivers on in-home care, as well as the changes in behavioral and psychological symptoms in AD and ADRD patients. The Alzheimer's Association launched resources on alz.org/COVID and the Association's care and support services nationwide transitioned to a virtual format, ensuring minimal disruption of support groups, educational programming and other opportunities to engage with the community. The Czech Alzheimer Foundation restructured many activities for individuals with AD and ADRD in light of the pandemic, including creating a virtual Alzheimer Café.

Further, the Fondation Vaincre Alzheimer produced a free guide for caregivers with practical advice and informative videos posted online. The French Federation of Memory Centers (Fédération des Centers Mémoires de France) encouraged health professionals in contact with patients to use these resources.¹³ BrightFocus Foundation hosted a number of sessions to discuss caregiving during the pandemic with recordings of these sessions made available online.¹⁴ The organization also recruited physicians to write expert articles on the coronavirus and the impact on people with AD/ADRD, and provided information and tips for protecting people with dementia. From a global perspective, ADI harnessed the innovative support responses of international civil society, health and long-term care, and research communities through a series of COVID-19 webinars and resources.¹⁵

Funding organizations are also contributing to the advancement of research in other ways. For instance, Dr. Philippe Amouyel of the Fondation Alzheimer in France developed the COVID-Score, a simple risk evaluation method that estimates the risk of severe forms of COVID-19 according to your age, sex, and body mass index (www.covid-score.fr). This free tool provides recommendations depending on the scores. ARUK, along with other charities, provided advice to guide and support the Post-Hospitalisation COVID-19 study (PHOSP-COVID), a consortium of clinicians and researchers from the UK who are collaborating to understand the long-term health outcomes of patients who have been hospitalized after COVID-19 infection. The Alzheimer's Association, with researchers at the University of Texas, San Antonio, is

leading a global team from > 30 countries working together with technical guidance from the WHO to study the short- and long-term impact of SARS-CoV-2 on the brain.¹⁶ This study aims to better understand the consequences that may impact the brain, cognition, and function—including underlying biology that may contribute to AD and other dementia.¹⁷

5 | IN SUMMARY

Through this commentary, the funding organizations represented share the steadfast commitment to fund, recruit, and retain research staff in the present and future. A particular focus remains on prioritizing funding opportunities and retaining early-career researchers and clinician researchers in the ADRD field. Last, the research funders are committed to working with funded researchers, and the entire community to facilitate the future of research through enhanced sharing of data and resources. To assist in these efforts, the research funders will continue to evaluate and develop guidelines for data sharing.

AD and ADRD are a global health crisis that has been affecting families long before COVID-19. Even during these times, we must remain steadfast in funding research to find preventions, diagnoses, and treatments.

ACKNOWLEDGMENTS

Thank you to the editors of *Alzheimer's & Dementia* for their guidance as the organizations came together on this manuscript. The authors would also like to acknowledge members of the International Alzheimer's and Related Dementia Research Funder Consortium.

CONFLICTS OF INTEREST

The authors are employees of the organizations as noted. Additional disclosures: Emily A. Meyers, Heather M. Snyder, and Maria C. Carrillo are full-time employees of the Alzheimer's Association. Philippe Amouyel is a scientific advisor for Genoscreen.

ORCID

Emily A. Meyers  <https://orcid.org/0000-0002-0886-6218>

Heather M. Snyder  <https://orcid.org/0000-0002-7665-7696>

REFERENCES

1. Prince MJ, Wimo A, Guerchet M, et al. *World Alzheimer Report 2015: The Global Impact of Dementia: An Analysis of Prevalence, Incidence, Cost and Trends*. Alzheimer's Disease International; 2015.
2. Suárez-González A, Livingston G, Low LF, et al. Impact and mortality of COVID-19 on people living with dementia: cross-country report. *LTCcovid.org*, international long-term care policy network. *CPEC-LSE*. 2020.
3. *Worst Hit: Dementia During Coronavirus*. UK: Alzheimer's Society UK; 2020. <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>
4. Tuttle KR. Impact of the COVID-19 pandemic on clinical research. *Nat Rev Nephrol*. 2020;16(10):562-564.
5. Webster P. How is biomedical research funding faring during the COVID-19 lockdown? *Nat Med*. 2020. <http://doi.org/10.1038/d41591-020-00010-4>

6. Harper L, Kalfa N, Beckers GMA, et al. The impact of COVID-19 on research. *J Pediatr Urol.* 2020;16(5):715-716.
7. Alzheimer's Association Rapid Program in Dementia (RAPID) Funding Grant Program. https://www.alz.org/research/for_researchers/grants/types-of-grants/alzheimers-association-rapid-program-in-dementia
8. In: *Coronavirus Job Retention Scheme: Supplementary Guidance for Research Organisations*. UK: Department for Business, Energy & Industrial Strategy, UK Government; 2020. <https://www.gov.uk/government/publications/coronavirus-job-retention-scheme-guidance-for-research-organisations/coronavirus-job-retention-scheme-supplementary-guidance-for-research-organisations>
9. Common Features of Neurodegenerative Disease: Exploring the Brain-Eye Connection and Beyond; 2021. <https://adpd.kenes.com/common-features-of-neurodegenerative-disease-exploring-the-brain-eye-connection-and-beyond/>
10. Alzheimer's Research UK Research Conference; 2021: <https://www.alzheimersresearchuk.org/research/for-researchers/research-conference-2021/>
11. Sarabipour S. Virtual conferences raise standards for accessibility and interactions. *Elife.* 2020;9:e62668.
12. Bozelos PA, Vogels TP. Talking science, online. *Nat Rev Neurosci.* 2021;22(1):1-2.
13. Letter from Fédération des Centres Mémoires de France. <https://www.centres-memoire.fr/information-covid-19/>
14. BrightFocus Foundation COVID-19 Update. <https://www.brightfocus.org/covid-19-update>
15. Advice and support during COVID-19: General advice and resources from Alzheimer associations. <https://www.alzint.org/resource/advice-and-support-during-covid-19-general-advice-and-resources-from-alzheimer-associations/>
16. de Erausquin GA, Snyder H, Carrillo M, et al. The chronic neuropsychiatric sequelae of COVID-19: the need for a prospective study of viral impact on brain functioning. *Alzheimers Dement.* 2021;17(6):1056-1065.
17. International Brain Study: SARS-CoV-2 Impact on Behavior and Cognition. https://www.alz.org/research/for_researchers/partnerships/sars-cov2-global-brain-study

How to cite this article: Meyers EA, Amouyel P, Bovenkamp DE, et al. Commentary: Global Alzheimer's disease and Alzheimer's disease related dementia research funding organizations support and engage the research community throughout the COVID-19 pandemic. *Alzheimer's Dement.* 2022;18:1067-1070. <https://doi.org/10.1002/alz.12472>