# #28

#### COMPLETE

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Page 1: Tenth Session of the OEWG on Ageing15-18 April 2019, UN Headquarters, New York

#### **Q1** Name of the organization:

Alzheimer's Disease international (ADI)

#### **Q2** The purpose of the organization:

Alzheimer's Disease International (ADI) is the global umbrella organisation of Alzheimer associations, representing 94 organisations and has been in official relations with the WHO since 1996. Our vision is prevention, care and inclusion today, and cure tomorrow. Our mission is to strengthen and support Alzheimer associations, to raise awareness about dementia worldwide, to make dementia a global health priority, to empower people with dementia and their care partners, and to increase investment in dementia research. Our strategic priorities include making dementia a global health priority, reducing stigma, strengthening membership, facilitating research.

Q3 Information as to the programmes and activities of the organization in areas relevant to the human rights of older persons:

In April 2016, members of Alzheimer's Disease International (ADI) formally adopted a Rights Based Approach to dementia advocacy in support of the ongoing efforts of partners Dementia Alliance International (DAI) to guarantee the rights of people living with dementia globally. We advocate for equal access to the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) and the UN Sustainable Development Goals (2015), including producing publications on these topics, accessible here: https://www.alz.co.uk/human-rights. We encourage the inclusion of a rights based approach to the development of national dementia plans in response to the WHO Global action plan on the public health response to dementia 2017-2025. There are a growing number of examples of plans with strength in this area. In January 2018 we successfully pushed for the specific inclusion of dementia, under ageing, as part of the WHO General Programme of Work 2019-2023. We continue to engage with the NGO Committee on Ageing, Geneva and a growing network of NGOs operating in the sector.

**Q4** Confirmation of the activities of the organization at the national, regional or international level:

International: Multilateral engagement including WHO, UN, OECD and G7/G20. WE work closely with the WHO teams including mental health, NCD and ageing. Annual World Alzheimer's Month campaign; World Alzheimer Reports; WHO, Alzheimer Universities; Twinning; ADI International Conference; other reports including on rights of persons with dementia.

Regional: Regional Directors in Asia Pacific and the Americas; collaborate with WHO regional offices; regional conferences and meetings; Train the Trainers programme, STRiDE research project; 10/66 Research Group; forthcoming PAHO awareness-raising campaign.

National: National dementia plans; supporting member organisations to develop capacity and advocacy skills; Dementia Friendly Communities/Initiatives.

### Q5 A list of members of the governing body of the organization and their countries of nationality:

Glenn Rees (Australia)

Dale Goldhawk (Canada)

Andrew Ketteringham (UK)

Serge Gauthier (Canada)

Faraneh Farin (Iran)

John Grosvenor (UK)

Mariella Guerra (Peru)

Birgitta Martensson (Switzerland)

Gerry Sampson (USA)

Kate Swaffer (Australia)

Ang Peng Chye (Singapore)

**Q6** List of financial sources and contributions, including governmental contributions:

Dues from member associations

Amgen

Biogen

Van Otterloo Family Foundation

Eisai

Anonymous (Trust)

Home Instead

Janssen / Johnson and Johnson

Eli Lilly

London School of Economics

**Lundbeck Foundation** 

Mary Oakley Foundation

McGill Center for Studies in Aging

Merck / MSD

Nutricia / Danone

Otsuka

PhRMA

Roche

TauRx

Other income

Q7 Copies of the annual or other reports of the organization with financial statements (File size limit is 16MB):

#### ADI-annual-report-2017.pdf (1.3MB)

**Q8** Please attach additional copies if needed (File size limit is 16MB):

Respondent skipped this question

**Q9** Please attach additional copies if needed (File size limit is 16MB):

Respondent skipped this question

**Q10** A description of the membership of the organization, indicating the total number of members, the names of organizations that are members and their geographical distribution:

ADI has 94 member associations, with 6 additional countries in our development programme. Alzheimer and dementia associations are non-profit organisations which support people with dementia and their families.

Argentina – Asociación de Lucha contra el Mal de Alzheimer (ALMA)

Armenia – Alzheimer's Disease Armenian Association

Aruba - Fundacion Alzheimer Aruba (FAA)

Australia - Dementia Australia

Austria - Alzheimer Austria

Barbados - Barbados Alzheimer's Assocation

Belgium - Ligue Nationale Alzheimer Liga

Bermuda – Alzheimer's Family Support Group

Bolivia – Asociación Alzheimer Bolivia (AAB)

Rospia Harzagovina Ildružania AiD/Association AiD/ Sarajova

DUSTIIA FIELZEYUVIIIA - UULUZELIJE AIR/ASSUUALIULI AIR/ - SALAJEVU

Brazil - FEBRAZ - Federação Brasileira de Associaçãoes de Alzheimer

Bulgaria - Compassion Alzheimer Bulgaria

Canada - Alzheimer Society of Canada

Cayman Islands - Alzheimer's and Dementia Association of the Cayman Islands

Chile - Corporacion Alzheimer Chile

PR China - Alzheimer's Disease Chinese

Costa Rica – Asociación Costarricense de Alzheimer y otras Demencias Asociadas (ASCADA)

Croatia - Alzheimer Croatia

Cuba – Sección Cubana de la Enfermedad de Alzheimer

Curação - Stichting Alzheimer Curação

Cyprus - Association for the Support of Persons with Alzheimer Disease (Cyprus) (will son become The Cyprus Alzheimer Association)

Czech Republic – Česká alzheimerovská společnost

Denmark - Alzheimerforeningen

Dominican Republic - Asociacion Dominicana de Alzheimer

Egypt – Egyptian Alzheimer Society

El Salvador - Asociacion de Familiares Alzheimer de El Salvador

England, Wales, NI – Alzheimer's Society

Finland - Alzheimer Society of Finland/Muistiliitto ry

Germany – Deutsche Alzheimer Gesellschaft

Ghana - Alzheimer's and Related Disorders Association Ghana

Gibraltar - Gibraltar Alzheimer's & Dementia Society

Greece - Panhellenic Federation of Alzheimer's Disease and Related Disorders

Guatemala – Asociación ERMITA, Alzheimer de Guatemala

Honduras - Asociación Hondureña de Alzheimer

Hong Kong SAR China - Hong Kong Alzheimer's Disease Association

Hungary - Hungarian Alzheimer Society

India – Alzheimer's and Related Disorders Society of India (ARDSI)

Indonesia - Alzheimer Indonesia

Iran - Iran Alzheimer's Association

Ireland - The Alzheimer Society of Ireland

Israel - Alzheimer's Association of Israel

Italy - Federazione Alzheimer Italia

Jamaica - Alzheimer's Jamaica

Kenya - Alzheimer's & Dementia Organisation Kenya

Japan - Alzheimer's Association Japan

Lebanon - Alzheimer's Association Lebanon

Lesotho - Dementia Lesotho

Macau SAR China - Macau Alzheimer's Disease Association

Macedonia - Association of Alzheimer Disease - Skopje Macedonia

Madagascar – ONG Madagascar Alzheimer

Malaysia – Alzheimer's Disease Foundation Malaysia

Malta - Malta Dementia Society

Mauritius - Alzheimer Association Mauritius

Mexico - Federacion Mexicana de Alzheimer (FEDMA)

Monaco – Association Monégasque pour la recherche sur la maladie d'Alzheimer

Morocco – Association Marocaine d'Alzheimer et Maladies Apparentées (AMAMA)

Myanmar - Alzheimer's Association Myanmar

Namibia – Alzheimer Dementia Namibia (ADN)

Nepal - Alzheimer and Related Dementia Society Nepal

Netherlands - Alzheimer Nederland

New Zealand - Alzheimers New Zealand

INOW AGGICING THE TRANSPORTED THOSE AGGICING

Nigeria - Alzheimer's Disease Association of Nigeria

Norway - Nasjonalforeningen for folkehelsen

Oman - Oman Alzheimer's Society

Pakistan - Alzheimer's Pakistan

Peru – Asociacion Peruana de Enfermedad de Alzheimer y Otras Demencias (APEAD)

Philippines - Alzheimer's Disease Association of the Philippines

Poland - Polish Alzheimer's Association

Puerto Rico – Asociacion de Alzheimer de Puerto Rico

Republic of Korea – KAD (Korean Association for Dementia)

Romania - Romanian Alzheimer Society

Russia - Help for patients with Alzheimer's disease and their families

Saudi Arabia - Saudi Alzheimer's Disease Association

Scotland - Alzheimer Scotland

Singapore – Alzheimer's Disease Association Singapore

Sint Maarten - Sint Maarten Alzheimer Association

Slovak Republic - Slovak Alzheimer's Association

Slovenia - Spominčica

South Africa - Alzheimer's South Africa

Spain - CEAFA

Sri Lanka - Lanka Alzheimer's Foundation

Sweden - Alzheimerforeningen i Sverige

Switzerland - Alzheimer Switzerland

Syria - Syrian Alzheimer and Memory Diseases Society

TADA Chinese Taipei

Thailand – Alzheimer's and Related Disorders Association of Thailand

Trinidad and Tobago – Alzheimer's Association of Trinidad and Tobago

Tunisia – Association Alzheimer Tunisie

Turkey - Turkish Alzheimer Society and Foundation

UAE - 4get-me-not Alzheimer's Organization

Uruguay - Asociación Uruguaya de Alzheimer y Similares (AUDAS)

USA - Alzheimer's Association

Venezuela – Fundación Alzheimer de Venezuela

Zimbabwe – Zimbabwe Alzheimer's and Related Disorders Association

Q11 A copy of the constitution and/or by-laws of the organization (File size limit is 16MB):

ADI bylaws July 2018.pdf (132.7KB)

**Q12** Please attach additional copies if needed (File size limit is 16MB):

Respondent skipped this question

**Q13** Please attach additional copies if needed (File size limit is 16MB):

Respondent skipped this question

## **Q14** Contact information:

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### Q15 Website

www.alz.co.uk