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Global Perspective

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

54,821 endorse Global Charter

On World Alzheimer's Day 2008, 21 September, ADI released the Global Alzheimer's Disease Charter, a document highlighting the current dementia epidemic we are facing and calling for governments and stakeholders across the world to adopt six key principles to improve the lives of people with dementia and their carers.

An accompanying petition ran alongside the Charter, inviting people across the world to sign in support of the Charter's six principles. On 30 April 2010 the petition was closed and a total of 54,821 signatures were received from 124 countries and territories, marking an unprecedented amount of support of the global dementia movement.

The Charter was developed by ADI's advocacy working group, made up of representatives of Alzheimer associations around the world, as part of ADI's work aimed at the World Health Organization (WHO). The aim of the Charter was to encourage the WHO to make dementia a global health priority, therefore recommending that governments around the world take action to improve services for people with dementia in their country.

A supporting viral campaign, sponsored by Novartis, was developed to assist in the launch of the Charter. This campaign included a touching film, *A Cup*



The Global Alzheimer's Disease Charter website at www.globalcharter.org

of Tea, which highlighted the emotional effects dementia often has on families and the supporting petition was also made available online.

ADI's member associations translated the Charter in order to reach as broad an audience as possible and, as a result of this, the Charter was made available in 17 languages. In order to further broaden the reach of the document, paper petition forms were also sent to out to ADI members to use during their campaigning activities.

The launch of the Charter received strong media coverage in various parts of the world and *A Cup of Tea* was posted on 30 media outlet websites. The film received over

10,000 views on websites such as MySpace and YouTube.

The Charter was promoted widely by ADI's member associations and details of these awareness-raising efforts can be found on pages 2 and 3.

The Charter will be presented to the WHO during the World Health Assembly, which takes place the week commencing 17 May 2010. It is hoped that the document will encourage the WHO and governments around the world to make dementia a health care priority and the text will continue to be used by ADI and its members in future advocacy work.

The Global Alzheimer's Disease Charter is still available to view online at www.globalcharter.org

Thanks to all who signed



I would like to thank everyone who has taken the time to read the Global Alzheimer's Disease Charter and sign the petition in support of the adoption of these vital principles.

When I realised the amount of support there has been for this extremely valuable document I saw it as a great

mark of respect to people with dementia and their caregivers all over the world. The feelings that come with finding out that a loved one has, or may have, dementia can make for a very lonely and particularly difficult experience. The stigma associated with the disease often means that people are afraid or ashamed to speak out about dementia.

Campaigns such as this one provide us with the opportunity to see that we have companions in all parts of the world who are as concerned as we are about this terrible situation we are facing. It is comforting to know that we do not stand alone in this fight for better care and support for people with dementia and their caregivers.

Thank you again to everyone who has shown support of the Global Alzheimer's Disease Charter. We hope that it will be instrumental in developing the services needed so desperately by people with dementia and their loved ones regardless of where they live.

Princess Yasmin Aga Khan President Alzheimer's Disease International



I am thrilled to see that so many people have recognised the importance of this Charter. The number of cases of dementia is continuing to rise all of the time and, with new advances in research, we are constantly finding more and more people affected by this awful disease.

It is time for action to be taken by governments in every country to recognise the true scale of dementia and the impact it is having on individuals, on societies and on the global economy. There are so many people in need of a diagnosis or better care and I hope this Charter and your support will encourage these decision makers to put dementia on their list of priorities.

Your time and support is so greatly appreciated and I would particularly like to thank our member associations across the world who have been so active in promoting the Charter. They have worked so hard and reached so many people who may not have known anything about dementia previously.

We look forward to presenting the Charter and results of the petition to the World Health Organization in May. Thank you for adding your voice to ours in persuading these key organisations to take action to improve the lives of people with dementia and their carers.

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Members promote Charter worldwide



The Greek Minister of Health signs the petition in Athens

ADI member associations across the world united to promote the Global Alzheimer's Disease Charter on World Alzheimer's Day 2008 and have continued to encourage support of the document during other recent awareness-raising campaigns. Signatures for the petition were collected at conferences, meetings of support groups and workshops worldwide, while press releases were sent out by a large number of Alzheimer associations and press conferences were held to gather momentum.

ADI member associations were particularly active in promoting the Charter through email, encouraging all their contacts to endorse the Charter and pass word on to their own contacts. Others used their newsletter or magazine to rally support.

TADA Chinese Taipei officially launched their Charter promotion campaign on 7 June 2009. The association developed their own online petition to run alongside ADI's and more than 20,000 signatures were received in the first three months alone.

Asociación de Lucha contra el Mal de Alzheimer in Argentina distributed translated instructions of how to sign the petition and publicised the campaign through their website. They also approached health professionals in public hospitals and the health authorities within the Buenos Aires government, requesting that they endorse the Charter.

During their World Alzheimer's Day events in 2008, Hong Kong Alzheimer's Disease Association invited all 12 of their VIP guests from national government and



The Director of Social Welfare speaks at the TADA press conference set up by TADA Chinese Taipei to launch the Charter

educational institutions on to the specially allocated Global Charter stage and asked them to sign the petition in front of a 300-strong audience. Participants at the Association's World Alzheimer's Day family funfair were also asked to show their support by signing a display of the Global Charter.

The Athens Alzheimer Association, part of the Greek Association of Alzheimer's Disease and Related Disorders, developed their own Greek Alzheimer Initiative based on the text used in the Global Charter. The aim of the initiative was to make dementia a public health priority in Greece and signatures of support were collected online. The association also sent letters to health officials and local authorities promoting the launch of the Charter.

Many more of ADI's members made the Charter available to their local or national governments. Among these were the Iran Alzheimer Association, who sent a brochure about the document to all ministries, and the Lanka Alzheimer's Foundation in Sri Lanka, who presented the Charter at a meeting with the Director of Health and the Deputy Director of Planning at the Ministry of Health and Nutrition. A representative of CEAFA in Spain also read the Charter during a press conference involving the Minister of Health.

ADI would like to thank all of those members who have worked so hard to promote the Global Charter. Without their time and effort it would never have been possible to gather so much support.

Dementia – a global epidemic

An estimated 36 million people worldwide are currently living with dementia. This number is estimated to increase to 66 million in 2030 and to 115 million in 2050. Much of the increase is attributable to increases in the numbers of people with dementia in low- and middle-income countries.

Not only are the numbers reason for concern, but Alzheimer's disease and other forms of dementia have an enormous impact on societies; it can be called an epidemic that is increasing its pace with the 'graying' of the population around the world. Poor recognition, underdiagnosis and stigma cause significant problems for people with dementia and their families in countries of all sizes and communities of all income levels.

What is dementia?

Dementia is the general term used to describe brain disorders that primarily affect a person's memory and behaviour. Alzheimer's disease accounts for 50-60% of all cases of dementia. Other types of dementia include vascular disease, dementia with Lewy bodies and fronto-temporal dementia.

Memory loss, the most common symptom of dementia, is not the same as ordinary forgetfulness. While we might forget the name of a movie we saw last night, a person with dementia may forget that they saw the movie at all. Other symptoms of dementia include difficulty performing familiar tasks, problems with language, disorientation, decreased judgment and mood swings. Eventually those affected are unable to care for themselves and need help with all aspects of daily life.

Currently there is no cure for most causes of dementia, which makes the work of Alzheimer associations vital; there is a wealth of advice, support and information made available by Alzheimer associations around the world.

The six principles of the Global Alzheimer's Disease Charter

The following six principles should be adopted to make Alzheimer's disease and other dementias a global priority:

- Promote awareness and understanding of the disease
- 2. Respect the human rights of people with the disease
- 3. Recognize the key role of families and carers
- 4. Provide access to health and social care
- 5. Stress the importance of optimal treatment after diagnosis
- Take action to prevent the disease, through improvements in public health

Estimated numbers of people with dementia around the world now and in the future

