New global forum in fundraising drive

A new alliance launched this year is the first international group of, by and for people with dementia where membership is comprised exclusively of people with dementia.

“DAI advocates for the voice and needs of people with dementia, providing them with a forum of their own,” said founding board member and group editor Kate Swaffer, from South Australia.

Ms Swaffer (pictured) said DAI’s first major project was to raise funds for people with dementia to attend the Alzheimer’s Disease International conference in Puerto Rico from May 1-5 this year, an urgent need that pushed the idea of this global group forward.

The goal is to raise a minimum of $25,000 to subsidise about 10 people with dementia, and care partners as required, to attend the conference. Contributions can be made via the website www.crowdrise.com/C/dementiaalliance2014.

“In the last few years, the voices of people with dementia around the world have become stronger, led by some trailblazers including Richard Taylor in the US and Christine Bryden in Australia. DAI was officially established in January 2014 to promote education and awareness about dementia, aiming to eradicate stigma and discrimination, and to improve the quality of the lives of people with dementia,” Ms Swaffer said.

She said another advocacy group, Dementia Advocacy and Support Network International (DASNI), was the first organisation set up by people with dementia, in 2001, but its membership is not exclusive to people with dementia.

DAI’s other founding board members are: Janet Pitts (co-chair, US); John Sandblom (co-chair, US); Richard Taylor (PhD, US); Dena Dotson (US); Steve Ponath (US); and Susan Stephen (Canada).

Membership of DAI is open to anyone with any type of dementia. Contact DAI at info@dementiaallianceinternational.org or visit the website at www.dementiaallianceinternational.org

Scientists share in $2.5m of grants

Twenty-nine Australian scientists will share in $2.5 million worth of grants to conduct dementia research, including University of Sydney researcher Dr Zoe Terpening who has received the Hazel Hawke Alzheimer’s Research and Care Fund.

The grants were announced recently by the Alzheimer’s Australia Dementia Research Foundation, the research arm of Alzheimer’s Australia. It supports and funds research to help people living with dementia and their families, including the development of new treatments.

Dr Terpening, from the University of Sydney’s Brain and Mind Research Institute, will use her share of the funding to investigate whether treating sleep breathing disorders, such as sleep apnoea, with continuous positive airway pressure can improve cognitive abilities.

“My research aims to evaluate whether continuous positive airway pressure can improve cognition and daily functioning in people with mild cognitive impairment.”

“This is a relatively simple treatment for sleep apnoea, and if we can show that it improves cognitive abilities by even a small amount, there will be some very exciting implications for clinical practice, and for further research to see if we can potentially delay symptoms of dementia in people at risk of Alzheimer’s disease.” Dr Terpening said.

The foundation has also launched a new interactive website, www.dementiaresearchfoundation.org.au that explains and showcases dementia research in Australia and worldwide.

Applications are now open for the 2014 dementia grants round, with a further $2.5 million available for new and early career dementia researchers.

Care farm set to open in South Australia

Australia’s first income-generating care farm for people living with dementia is set to open in South Australia in June.

Claudia Ait-Touati, Director of Careship Coorong, the organisation behind the proposed care farm in Coonalpyn, south-east of Adelaide, said the project was waiting on funding being finalised, which she hoped would happen before the middle of the year.

“The definition of a care farm is that it has to be a working farm where income is generated through farming, but you also have the care component,” Ms Ait-Touati said.

She said the care farm would grow snails and vegetables and they planned to have small groups of 10-15 people living with dementia tending the snails and preparing them for the gourmet food market.

“We had looked at other stock and I jokingly said we should try snails. [As it turned out] the climate is perfect in SA for snails and they are an ideal activity for people living with dementia,” Ms Ait-Touati said.

“Caring for them is not difficult to learn, the tasks are quite repetitive and although it is not too complex it is labour intensive. Clients would be irrigating and looking for the right snails to harvest, feeding them and looking into the whole process from breeding to marketing and selling them.”

“We’re looking at hiring some houses that are empty in the area so people from the city can come up and stay a few days; a bit like a respite program for the carers of the people with dementia as well,” she said.

People living in the Coorong or Murraylands districts interested in participating in the Careship Coorong pilot group can contact Careship Coorong on 0439 884 685 or info@careship.org.

Powerful message

Up-and-coming British director, writer and filmmaker David Cooper has released a short, but powerful film about dementia which takes just four minutes to watch. The call is a personal account of dementia, as Cooper’s grandmother was diagnosed when he was just 14. He raised the money to make the short film through marathon piano playing sessions outside supermarkets and musical shows at university. It highlights the isolation carers of people with dementia can often experience, and revolves around a call-back radio station where listeners are invited to call in and tell the host how they met their partner. When one older man calls and begins his story, neither the host, nor those listening, expect what follows. Their reactions of sadness, guilt and anger emphasise how dementia is commonly viewed in the community. The film is freely available at http://thecallshortfilm.com