

# *Alzheimer Bulgaria Association* *2011 - 2016*

Dublin, 7<sup>th</sup> of November



# About Alzheimer Bulgaria Association (ABA)

Alzheimer Bulgaria is a non-governmental voluntary organization in community interest, established in 2003. The organization unites the efforts of families and professionals to improve the quality of life of people affected by dementia. The organization provides practical services and support for people with dementia and their caregivers throughout the country.

ABA is a member of :

1. Alzheimer Europe since 2006,
2. Confederation Health Protection since 2009,
3. Eurocarers since 2010.



## *Bulgarian statistics*

- 100 000 dementia related cases
- 50 000 Alzheimer cases
- In 2011, national demographic statistics reports accelerating of aging process (population over 65 increased 20% since 2000)

## *Situation in the country*

- Electronic health care system is not working
- No coordination between the country's different systems - health care, social, municipalities.
- No vision on the health system development
- No national health strategy
- No national plan for dementia

# *What we do?*

- Alzheimer Bulgaria demands a better future for everyone affected by all forms of dementia. With the help of our members and supporters, we campaign for the rights of people with dementia and those who care for them through a combination of detailed policy analysis, lobbying, influencing and direct action.
- Our local services include consultancy for people with dementia, as well as support and befriending services to help partners and families cope with the demands of caring.
- We aim to start a research programme. The research results will help us to improve the quality of life for people with dementia, by tackling questions related to the causes of dementia, investigating good practice in care and treatment, and pursuing a cure.



# *What Alzheimer Bulgaria has done so far*

- We proved in the High Administrative Court that Ministry of Health's current regulation is discriminatory in respect to older people with a dementia and their families
- We raised public debate on adequate social services for families with a sufferer
- We published two books – one helping the families of the dependent one and one for children - to get to know the Alzheimer's disease

## *Our biggest accomplishment so far*

The work of Alzheimer Bulgaria was presented as a good practice at the 6th European Day of Patients' Rights, because of our biggest accomplishment – made the government to reimburse the medicines for Alzheimer's disease!



# *What are the results of the activities*

- Now we have Alzheimer disease included in the reimbursement system in Bulgaria
- The Ombudsman of Bulgaria organised a press-conference on the problems of the families that take care for sufferers with dementia and urged the government for adequate urgent measures





## Our results 2

- The strategy for city Sofia social services 2011-2013 was adopted. It envisages, among other topics, development of social services for dementia sufferers – creation of Daily centers, trainings for caregivers, etc.

There is a strategy,  
but there is no funding  
for the planned  
social services!



## *Projects in 2015 - 2016*

- We finished the project "Let us hear the voice of people with dementia. Their voice is important", funded by the EEA GRANTS.
- In 2015 - 2016 we made 9 Roundtables in 9 different cities in Bulgaria, with families, professionals in the health and social sphere and representatives of municipal authorities.
- The accumulated matter of these meetings were summarized in the Report "Providing adequate health and social services for people with dementia - obstacles and opportunities".

# Projects

1. In 2015 we also started the project with the youth organization of Pleven – “Dialogue of generations. Creating a new understanding of dementia. ”

Within this project we trained 120 students, aged 15-16, how to react if in their family there is a case of dementia.

2. In 2016 we participated in the development of a new health strategy of Bulgaria. We managed to convince the employees of the Health Department to move Dementias from the section "Protection and improvement of mental health" in the section "Health for seniors (65+)”

# Projects

1. In 2016 we finally found funding and start the renovation of a training center in Pleven. We are planning to make open a training center for caregivers there. So far we are facing two main problems: 1<sup>st</sup>, we found funding for the construction works, but we still cannot find funding to ensure the salaries for the staff for the next 5 years. 2<sup>nd</sup>, the lack of trained professionals in the field is making the search for qualified professional very hard.
  2. By the end of 2016 we will launch our final project for this year – “Dementia. What we need to know. When and where to find help”. The goal is to inform women in small villages about the dementia and for their rights as informal caregivers.
  3. “Alzheimer coffee”?
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## *What is our next goal*

- We continue the contact with the different governmental and municipal authorities for coordination of the actions in supporting families with a sufferer
- We want to ensure adequate social protection for the affected persons and families
- We would like to launch and participate in development of a national action plan in the area of dementia which will be backed by sufficient funding
- We would like to open the new training center and ensure qualified training and support for the caregivers.

*Finally: A quote from a wife of a patient*

“Nothing can give us back our lives,  
but everybody has the right to a dignified  
life, after all.”

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Thank you for your attention!

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