FROM RAISING AWARENESS TO NATIONAL DEMENTIA STRATEGY

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Spominčica
Alzheimer Slovenija

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- **Capital city:** Ljubljana
- **Area:** 20.273 km²
- **President:** Borut Pahor
- **Population:** aprox. 2,100,000
LAKE BLED WITH ISLAND

POSTOJNSKA JAMA - THE LONGEST CAVE SYSTEM IN THE WORLD

TRIGLAV - THE HIGHEST SLOVENIAN MOUNTAIN

SLOVENIAN COAST - PIRAN
ALZHEIMER SLOVENIJA
20 years anniversary in 2017

- Established in 1997 by dr. Aleš Kogoj, from University Psychiatric Clinic of Ljubljana
- GOAL: to help the carers
- Telephone help-line from 1999
- Training program for carers „Forget me not“ from 2000
- The magazine Spominčica from 2000
- Self-help groups for carers from 1999
- Alzheimer Cafes from 2002, more than 60 in Slovenia
- Spominčica is widely spread with 33 branches in Slovenia
SPOMINČICA, member of AE and ADI

- In 2012 full membership of AE at Vienna congress
- In 2014 full membership of ADI in Puerto Rico as 84th state.
- We have received support and a lot of practical information about DEMENTIA STRATEGY
- We got many new and important information from members
25th conference of Alzheimer Europe was under auspices of the President of Slovenia, Borut Pahor
DEMENTIA – PRIORITY OF PUBLIC HEALTH

• **In 2014** on suggestion from **Spominčica** all 8 MEP’s sign the "Alzheimer Europe pledge" that dementia becomes a priority of public health

• **In 2015** the **Glasgow declaration** was signed by:
  - Minister of Health
  - Minister of social affairs
  - Ombudsman Vlasta Nussdorfer
  - Mayor of Ljubljana
  - Neurologists, psychiatrists and others
DEMENTIA MANAGEMENT STRATEGY IN SLOVENIA UNTIL 2020

- Signed in **May 2016**

- The Strategy **focuses on the individual and his needs**, for which a coordinated and responsive operation of law and a multidisciplinary treatment are required

- **Three main goals** will be achieved:
  1. **Early diagnosis** of the disease
  2. **Access to treatment** and antidementia therapy
  3. **Coordinated support** for persons with dementia, their families and carers
SLOVENIAN DEMENTIA STRATEGY

- ADI and AE give us support and information to start and prepare DEMENTIA STRATEGY.
- In 2009 specialists and Štefanija L. Zlobec (Spominčica) as a carer of young onset dementia husband became aware that Slovenia needs a national dementia strategy - the proposal has been given to the Slovenian parliament.
- In January 2010 with the decree of the Minister of Health established the Dementia working group of 10 experts on dementia.
SLOVENIAN DEMENTIA STRATEGY

- In 2014 general director of ADI, Marc Wortmann came to Slovenia and gives us **support for DEMENTIA STRATEGY**
- In August 2014 a meeting was organised with the president of Slovenia, Borut Pahor at his palace in Ljubljana.

- In 2015 the working group finished the **Strategy draft**.
SLOVENIAN DEMENTIA STRATEGY

- **In May 2016** Minister of Health, Milojka Kolar Celarc signed the Strategy.
- **In June 2016** the Minister of Health nominated representatives of the *Action group* for the *preparation of Dementia Strategy 2016-2020*
- **By the end of June 2017** we have to finish the *ACTION PLAN*
DEMENTIA STRATEGY PRIORITIES

1. Awareness and destigmatization of the disease

2. Early diagnosis, treatment and follow-up

3. Access to appropriate treatment and therapy

4. Adapted social programs

5. Supporting research work in the field of dementias

6. Establishment and maintenance of epidemiological data

7. Palliative care for persons with dementia

8. The establishment of regional centres

9. Education of professional staff and planning

10. Protection of rights of persons with dementia
MOPEAD – Models of Patient Engagement for Alzheimer‘s Disease

www.mopead.eu

- 33-month project (October 2016 – July 2019)
- 14 partners from 12 countries
- Funding from Innovative Medicines Initiative (IMI) and the European Federation of Pharmaceutical Industries and Associations (EFPIA)
- The only IMI project with DIRECT PATIENT ENGAGEMENT
## Project Partners

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<th>Participant organisation</th>
<th>Country</th>
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<tbody>
<tr>
<td>Fundació ACE (FACE)</td>
<td>Spain</td>
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<tr>
<td>Eli Lilly and Company Ltd (ELI) (EFPIA)</td>
<td>United Kingdom</td>
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<td>AstraZeneca (AZ) (EFPIA)</td>
<td>USA</td>
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<td>ASDM Consulting (ASDM)</td>
<td>Belgium</td>
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<td>European Institute of Women's Health (EIWH)</td>
<td>Ireland</td>
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<td>GMV Soluciones Globales Internet S.A.A (GMV)</td>
<td>Spain</td>
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<td>Karolinska Institutet (KI)</td>
<td>Sweden</td>
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<td>Kite Innovation (Europe) Ltd (KITE)</td>
<td>United Kingdom</td>
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<td>Spomincica – Alzheimer Slovenia (SPO)</td>
<td>Slovenia</td>
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<td>University of Koeln (UKK)</td>
<td>Deutschland</td>
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<td>University Medical Centre Ljubljana (UMCL)</td>
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<tr>
<td>Vall D'Hebron Research Institute (VHIR)</td>
<td>Spain</td>
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<tr>
<td>VU University Medical Center (VUMC)</td>
<td>Netherlands</td>
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<tr>
<td>Alzheimer Europe (AE)</td>
<td>Luxembourg</td>
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BACKGROUND

- **Late detection** - current clinical paradigm does not support the need for early detection and diagnosis
- Focus is still on later clinical stages of the disease - this creates a **barrier** to access available
  - treatments and
  - support services,
  - **Clinical Trials** in very early stages
MOPEAD project

Assess key tools, mechanisms and processes for:

- **community engagement**: RAISE AWARENESS on the benefits of early diagnosis

- **patient identification**: test 4 different **patient engagement models** - multiple regional project sites across Europe

- **resource utilization**: assessment of models and advocation
Pre-screening process

- Run 1: Open House Initiative
- Run 2: Primary care-based patient engagement
- Run 3: Tertiary care-based patient engagement
- Run 4: Face-to-face engagement

WP2

WP3
MODELS OF ENGAGEMENT

AD CITIZEN SCIENCE
Patient recruitment tool using web-based technologies for citizens. In return for collaboration it will offer reliable information, services and the option to receive further health assessment services.

OPEN HOUSE
Offering to the community the possibility of having their cognitive skills screened by professionals so they could discard incipient AD or other cognitive disorders.

PRIMARY CARE BASED PATIENT ENGAGEMENT
A two-question approach implemented in a PCB-based procedure will identify subjects at increased risk of AD. These individuals will be offered extended diagnostic procedures.

TERCIARY CARE BASED PATIENT ENGAGEMENT
The identification of patients with T2D with MCI will lead us to implement a personalized medicine and to optimize the results of therapeutic approaches.
OBJECTIVES

- Move the AD environment towards EARLY DIAGNOSIS
- RAISE AWARENESS on the benefits of early diagnosis
- Identify, compare and contrast different patient access models - multiple regional project sites across Europe
- Advocate and distribute patient access models
Spominčica 20-year anniversary
20th and 21st October 2017

TERME ČATEŽ SPA

Under the auspices of the President of Slovenia, Borut Pahor

Thank you for your attention!

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