



## Timely detection of dementia

The First Krems Dementia Conference (5-7 November 2019) was a complete success



Over 100 scientists, clinicians, advocates and other experts from a variety of countries met at the first dementia conference organized by the University of Krems in Austria. Participants came from Austria and neighboring countries like Czech Republic, Poland, Hungary, Italy, Croatia, Bosnia and Bulgaria but also from Germany, France, Netherlands and United Kingdom. The focus of the conference was on timely detection and a conclusion of the conference was, that this is only possible if the public is more aware about Alzheimer's disease and

other dementias, while health care professionals need to know better how they can support people who are diagnosed, and their families, with medical and non-medical support.

As a result, it was agreed to plan a second conference in November 2020, looking at possibilities for joint research efforts between representatives from different countries (by using existing results of earlier projects), explore options for further education and training and advocate within our countries for better policies. It was great to hear that representatives from Bosnia-Herzegovina were able to convince their government to start working on a plan and inviting some key players from the Krems conference for a meeting in Sarajevo in June 2020.

Highlights from the program were shared with the general media in Austria and more specialized publications, for instance for general practitioners.

The program was broken down in some plenary sessions, parallel workshops and poster presentations and visit of the exhibition area, mainly during the breaks. Below is a summary of some of the key lectures and discussions.



Prof. Barry Reisberg, New York University

### **What is meant by "timely diagnosis"?**

Professor Bruno Dubois, neurologist and head of the Neurological Institute of the University Hospital of the Salpêtrière in Paris, one of the keynote speakers at the First Krems Dementia Conference defined "timely diagnosis" in a 2016 publication as: "Timely diagnosis of Alzheimer's disease (AD) refers to a diagnosis at the stage when patients come to the attention of clinicians because of concerns about changes in cognition, behaviour, or functioning and can be still free of dementia and functionally independent. Studies show that the advantages of a timely diagnosis are mainly seen in the fact that earlier interventions can be initiated for the affected person and relatives. This enables better coordinated care planning and better symptom management and prevents crises. Patient safety can be increased, costs are reduced and institutionalisation is delayed. The barriers and challenges that hinder timely diagnosis today include the prevailing nihilism regarding the treatability of dementia, social stigma, the risk of suicide, lack of training for professionals, diagnostic uncertainty or lack of facilities that provide diagnosis. Also, the resistance of health care professionals to diagnose in the absence of a cure or at least of alleviation ("disease modifying") would be an additional hurdle (Dubois et al, 2016). Dr. Rene Thyrian from the German Centre for Neurodegenerative Diseases in Greifswald pointed out in his lecture that the psychosocial support of the persons before and after the medical diagnosis must be ensured in order to achieve positive results as a consequence of the timely diagnosis.



Prof. Bruno Dubois, La Salpetriere

### **Think about a possible dementia much earlier!**

Affected persons complain about memory problems many years before a diagnosis of dementia. In this phase, preventive measures in particular have a chance. Univ. Prof. Barry Reisberg of New York University, who has described the stages of Alzheimer's dementia through his research since 1982, pointed out in his lecture at the Krems Dementia Congress the importance of recognizing these subjectively reported memory problems, which are described by affected persons in the run-up to dementia. Prof. Reisberg reported on a long-term study he had conducted. The results show that people who complain about memory difficulties with subjective reports have a higher risk of developing dementia compared to people who are satisfied with their memory management. These subjective memory complaints must therefore be taken absolutely seriously, said Prof. Reisberg in his speech. For this reason, the development, research and provision of preventive strategies is of utmost importance, emphasized Prof. Reisberg. The first studies that report on the effects of early preventive measures can give us cause for satisfaction. Professor DalBianco, President of the Austrian Alzheimer's Society, spoke about the results of the so-called "Finger Study", which was published by a Finnish research team in 2015. In this study, a multimodal intervention consisting of the treatment of medical risk factors, physical exercise, healthy nutrition and mental stimulation was tested in a randomized controlled trial in risk patients. The results showed a significant delay in the manifestation of dementia symptoms in persons in the intervention group. The results of the Finnish study give reason to hope that, with comprehensive early intervention, the symptoms of severe dementia will not occur in the life span of the individual in about half of the dementia cases (Ngandu et al. 2015).



### **Increase the diagnosis rate urgently!**

In many European countries the diagnosis rate of dementia is low. In Austria, only between 20 and 30% (Austrian Dementia Report year 2014) of affected persons receive a medical diagnosis. This means that in Austria in rural areas approx. 80% and in urban areas approx. 70% of the affected persons do not receive a medical diagnosis and accordingly no optimal support and treatment. Many countries would not be able to report the diagnosis rate as no examinations are available and no corresponding data are collected (OECD 2018). Ireland is the European leader. In Ireland, 74% of those affected receive a medical diagnosis and therefore the support they need (OECD 2018). A major reason for low diagnosis rates is low awareness of dementia and low input from the scientific community. Awareness raising is therefore an important task for society as a whole, according to Marc Wortmann, the former Executive Director of Alzheimer's Disease International (ADI) and leading expert on awareness raising in his workshop at the congress in Krems. On the topic of awareness raising, the multi-award-winning project "Einsatz Demenz" (Use Dementia) by Eduard Dernesch from the Security Academy of the Ministry of the Interior was presented. The follow-up project "Active Community" was also presented by MR Gerhard Lang from the Ministry of the Interior. In both projects, different occupational groups are made "dementia fit" through specific training courses. The police officers set a good example and help to integrate people with dementia into our society through greater understanding for this group of people.

Brigitte Juraszovich presented the Austrian Dementia Strategy, which has been developed since 2015 together with representatives of the provinces and experts (<https://www.demenzstrategie.at>).

Best-practice examples such as the model of the dementia service centre in Upper Austria form the core of the Austrian Dementia Strategy. As of January 2020, 11 dementia service points will be available in Upper Austria as low-threshold offers for early detection and counselling to all affected persons and families. The dementia service points are financed by the Federal Province of Upper Austria and the ÖGK. Measures for early diagnosis and appropriate follow-up treatment give those affected and their families the chance to cope with the disease and to make full use of their life potential. In order to encourage those affected and to actively counteract their concerns regarding their memory loss, it is necessary to raise social awareness of the topic of dementia. A timely diagnosis means that the treatable causes of memory loss can be identified and lifestyle changes can be initiated in good time. Courageous steps on the part of Austrian policymakers are needed to quickly spread these measures. Further scientific studies, which deal with all the necessary topics, are urgently needed.

Many topics are still open - a lot can be done in this field, says the organizer of the conference, Prof. Stefanie Auer.

Therefore the next date 16-18 November 2020: Second Krems Dementia Conference!

Abstracts and program 2019: [www.donau-uni.ac.at/dementia-conference](http://www.donau-uni.ac.at/dementia-conference)

### **Organization and funding**

The program was put together by an international program committee:

Stefanie Auer (Austria)

Iva Holmerova (Czech Republic and Chair Alzheimer Europe)

Osman Kucuk (Bosnia-Herzegovina)

Ninoslav Mimica (Croatia)

Barry Reisberg (USA)

Marc Wortmann (Netherlands)

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