

ANNUAL REPORT 2015

REGION

Rigshospitalet • University of Copenhagen

DANISH DEMENTIA RESEARCH CENTRE

Copenhagen Memory Clinic and
the National Info & Education Centre for Dementia



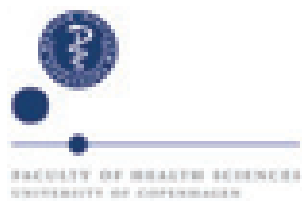
DANISH DEMENTIA
RESEARCH CENTRE



DANISH DEMENTIA
RESEARCH CENTRE

The seahorse in the DDRC's logo resembles an area of the brain shaped like a seahorse, which is why it is called the *hippocampus* (Latin for seahorse). This area of the brain plays an important role in memory.





PREFACE

The 2015 DDRC annual report provides a presentation of the research conducted at DDRC, as well as a general review of our clinical services and national educational activities.

In 2015 the Danish Minister for Health, Sophie Løhde, launched an ambitious plan for developing a “national dementia strategy geared toward 2025”, allocating DKK 470 M toward its development and activities in 2016-2019. A concerted national effort is needed to make Denmark a dementia friendly society by ensuring that all patients have equal access to high-quality diagnostic evaluation and that evidence-based interventions, psycho-social as well as technological and pharmacological, be put into practice with appropriate training and support, but also that resources be made available to stimulate research in prevention and new treatments. DDRC welcomes the national strategy and looks forward to a busy 2016 when the strategic plan will be launched.

In 2015 two University of Copenhagen hospitals, Glostrup Hospital and Rigshospitalet, merged, leading to a fusion of their neurology departments and a plan to combine the Glostrup and DDRC memory clinics in 2016. With approximately 1,600 new referrals per year, the resulting clinic, to be located in two locations, will be one of Scandinavia’s largest. In 2015 DDRC celebrated its 20th anniversary with a joint workshop for staff from Glostrup and DDRC memory clinics. We greatly look forward to the ongoing merger activities taking place in 2016 and to welcoming new colleagues.

DDRC conducts a wide range of epidemiological, clinical and translational research programmes. One of the highlights of 2015 was the conclusion of ADEX, a Danish multi-centre study investigating moderate to high intensity physical exercise in patients with Alzheimer’s disease. The main results were reported at our 2015 Dementia Days conference, which attracted massive public and media interest. A number of scientific publications reporting the effects of training on physical fitness, cognitive and psychiatric symptoms, and biomarkers are

in the pipeline. A training course and a guide for physiotherapists have been developed and several Danish municipalities have implemented physical exercise for patients with dementia. ADEX will continue as a professional research network for the eight participating memory clinics, which are centres of expertise working with common diagnostic criteria and common tests and scales for outcome measures.

ABC Dementia, DDRC’s e-learning platform targeted professional caregivers, attracts an increasing number of users, which now exceeds 10,000. Due to exceptionally positive feedback and evaluations, DDRC plans to develop ABC Dementia for other target groups. With 68 events in 2015, our conferences and courses attract more than 4,000 people on average from across Denmark every year. In particular, the courses tailored to specific groups commissioned by municipalities and regional institutions are popular. We are also very pleased that DDRC is increasingly used as a source of information for nationwide news media, politicians and organisations, which the increased level of activity on all our communication platforms demonstrates.

In 2016 we are looking forward to contributing to the development of the national dementia strategy in collaboration with the Danish Ministry of Health, the Danish Alzheimer Association and the Danish Dementia Alliance. We also look forward to welcoming the European Academy of Neurology and Alzheimer Europe to Copenhagen for the first time, where they will hold their annual conferences, drawing international scientists and patient organisations to Denmark.

We would like to extend a special thanks to our national and international collaborators, to our national scientific advisory board, and to the Danish Ministry of Health and other foundations and institutions that support DDRC financially.



Gunhild Waldemar,
Professor, Director of the DDRC



CONTENTS

Preface	5
Content	7
About the Danish Dementia Research Centre (DDRC)	9
Special events 2015	10
Copenhagen Memory Clinic	15
<i>Highly specialised services</i>	
<i>Patients and families</i>	
<i>Courses for patients and caregivers</i>	
<i>Specialist service on the island of Bornholm</i>	
<i>Regional and national collaboration</i>	
<i>Merger with Glostrup Hospital Memory Clinic</i>	
Research	20
<i>Research highlight 2015 – the ADEX Study</i>	
<i>Early and accurate diagnosis</i>	
<i>Cognitive rehabilitation and new supportive technology</i>	
<i>Familial neurodegenerative disorders paving the way for personalised medicine</i>	
<i>Epidemiology and global health</i>	
<i>Drug trials</i>	
National Info & Education Centre for Dementia	24
<i>Courses and conferences</i>	
<i>ABC Dementia – free online courses</i>	
<i>Research</i>	
<i>Communications and press</i>	
<i>Conference booth</i>	
National Networks	31
<i>Network of Danish Memory Clinics</i>	
<i>National network of municipality-based dementia ambassadors</i>	
International networks	33
<i>Nordic Network in Dementia Diagnostics (NIDD)</i>	
<i>European Alzheimer's Disease Consortium (EADC)</i>	
<i>European Huntington's Disease Network (EHDN)</i>	
<i>National dementia research and education centres in Scandinavia</i>	
<i>North Sea Dementia Group</i>	
<i>Interdem</i>	
Management	34
Staff in 2015	35
Publications in 2015	36
National and international posts	40
National dementia strategy 2025	41
Financing	42
Acknowledgements	42



ABOUT THE DANISH DEMENTIA RESEARCH CENTRE (DDRC)

MISSION

To be a national centre with high international standards for patient services, research and nationwide education.

VALUES

Our six key values serve to guide our priorities as well as our organisational decisions.

Professionalism

Highly ambitious, we constantly strive to reach the highest professional standards, professionalism and innovation with regard to the development of our services.

Commitment

Our commitment is reflected in our work and our dedication to the goal of preventing dementia and improving the quality of life for patients with dementia and their caregivers.

Collaboration

We wish to take advantage of the experience gained from a wide range of activities in dementia care and research by involving our stakeholders and interested parties from all over the country to jointly identify ways to contribute to and be involved in DDRC activities.

Respect

We show respect for patients, caregivers, professionals and groups. We show respect for the ethical challenges related to caring for people with dementia, whose autonomy and functional ability are compromised, and for families with hereditary brain disorders.

Transparency

We assure transparency with regard to our activities and in our professional relationships.

Credibility

We keep our promises and make progress in accordance with our mission and strategic goals.

ORGANISATION AND STAFF

Located at Rigshospitalet – Blegdamsvej and based in the Department of Neurology, the DDRC is a nationwide service. Initiated and funded by the Danish Ministry of Health and the Danish Health Foundation, the National Info & Education Centre for Dementia has a steering committee and a scientific advisory board.

With representatives from the Ministry of Health, Danish Regions and Local Government Denmark and the Danish Health Foundation, the steering committee monitors the strategic development and per-

formance of the National Info & Education Centre according to pre-defined objectives and milestones. A new strategy for 2016-2020 is being implemented.

MEMBERS OF THE STEERING COMMITTEE AT THE CLOSE OF 2015

- Svend G. Hartling, Danish Regions (chair)
- Hanne Jervild, Danish Health Foundation
- Nina Moss, Ministry of Health
- Anne-Sofie Fanøe, Ministry of Health
- Søren Bredkjær, Danish Regions
- Karen Marie Myrmdorff, Local Government Denmark
- Line Sønderby Christensen, Capital Region of Denmark
- Gunhild Waldemar, DDRC

The scientific advisory board reviews and contributes with advice on major educational and scientific activities. The members of the advisory board represent the Danish Health and Medicines Authority, municipalities in Local Government Denmark, Danish Regions, the Danish Medical Association, the Danish Alzheimer Association, the Danish Huntington's Disease Association and the DaneAge Association.

MEMBERS OF THE SCIENTIFIC ADVISORY BOARD AT THE CLOSE OF 2015

- Danish Health and Medicines Authority (vacant Dec. 31 2015)
- Lisbeth Hyldegaard, Local Government Denmark
- Inge Dyrholm Feldbak, Local Government Denmark
- Hanne Elkjær Andersen, Capital Region of Denmark
- Helle Auerbach, Region Zealand
- Lisbeth Uhrskov Sørensen, Central Denmark Region
- Karsten Vestergaard, North Denmark Region
- Annette Lolk, Region of Southern Denmark
- Jørgen Peter Ærthøj, Danish Medical Association
- Frans Boch Waldorff, Danish Medical Association
- Birgitte Vølund, Danish Alzheimer's Association
- Charlotte Hold, Huntington's Disease Association
- Kirsten Dyrborg, DaneAge Association

In addition, DDRC takes advantage of various networks and partnerships, works with local external professional consultants, advisors and teachers, and organises local as well as national events and activities in order to involve interested parties nationwide.

SPECIAL EVENTS 2015

ADEX

In June the ADEX project was ended and the final meeting was held in the National Museum of Denmark. ADEX participants presented their preliminary results from the many scientific studies comprising the project. Based on experiences from the ADEX trial, the seven participating memory clinics agreed on a common set of diagnostic criteria, outcome measures and how to train staff, placing participants in a good position to conduct future multidisciplinary intervention trials.

Research conference on nursing and care

In November DDRC hosted its annual research conference at Rigshospitalet with over 200 attendees. For the first time the topic was nursing and care. Among the speakers were Professor Øyvind Kirkevold, RN, PhD from the Norwegian National Advisory Unit on Ageing and Health.



Dementia Days

In May DDRC held its annual Dementia Days conference. The main topic was “A Dementia-Friendly Society”. The event was attended by 900 participants from across the nation.



Network conference for memory clinics

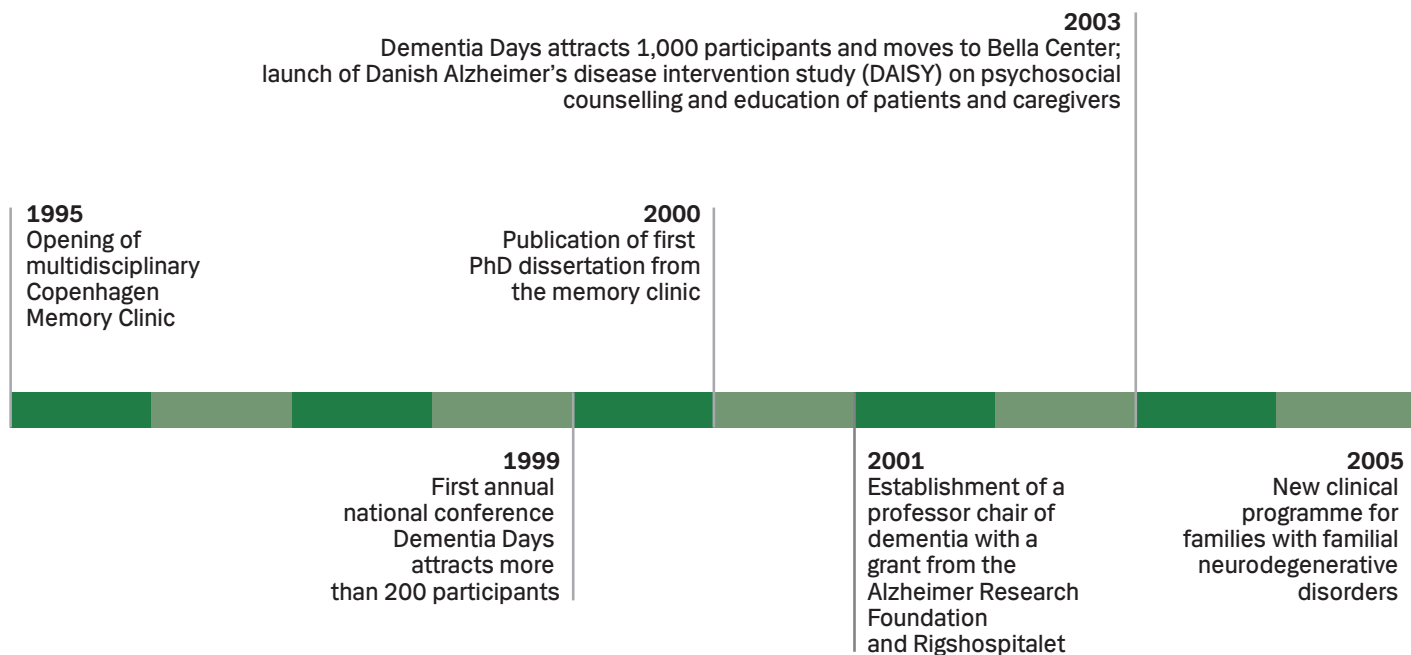
At the annual network conference for memory clinic staff across Denmark, participants had the opportunity to network and be updated on new development in diagnosis and treatment of dementia. The day also featured specific workshops for doctors, nurses, psychologist and secretaries.



Master class with Martin Rossor

In March seventy neurologists, psychiatrists and neuropsychologists from across the country benefitted from Professor Martin Rossor’s knowledge and experience when DDRC held a master class attended by patients and relatives. Martin Rossor from the Dementia Research Centre at the National Hospital for Neurology and Neurosurgery in London began with a lecture on: “The Diagnostic Challenge of Early Frontotemporal Dementia”.

TIMELINE HIGHLIGHTS 1995-2015



Tua Vinther-Jensen's PhD defence

Tua Vinther-Jensen, MD, was awarded a PhD after defending her thesis: "Neuropsychiatric manifestations in Huntington's disease: Clinical and molecular aspects" in December 2015.

From left: Jens Michael Hertz (evaluation committee), Anne Nørremølle (supervisor), Jørgen E. Nielsen (supervisor), Lena E. Hjermand (supervisor), Tua Vinther-Jensen, Bernhard Landwehrmeyer (evaluation committee), Rigmor Højland Jensen (evaluation committee) and Esben Budtz-Jørgensen (supervisor).

2009
Establishment of DDRC network for 98 Danish dementia ambassadors appointed by local authorities

2008
Establishment of DDRC network for Danish memory clinics

2012
Launch of ABC Dementia, a unique, free e-learning programme for professional carers; first Scandinavian conference for leaders in dementia care; first international PhD course

2013
DDRC activities move to Rockefeller building at Rigshospitalet; establishment of new research professorship in dementia

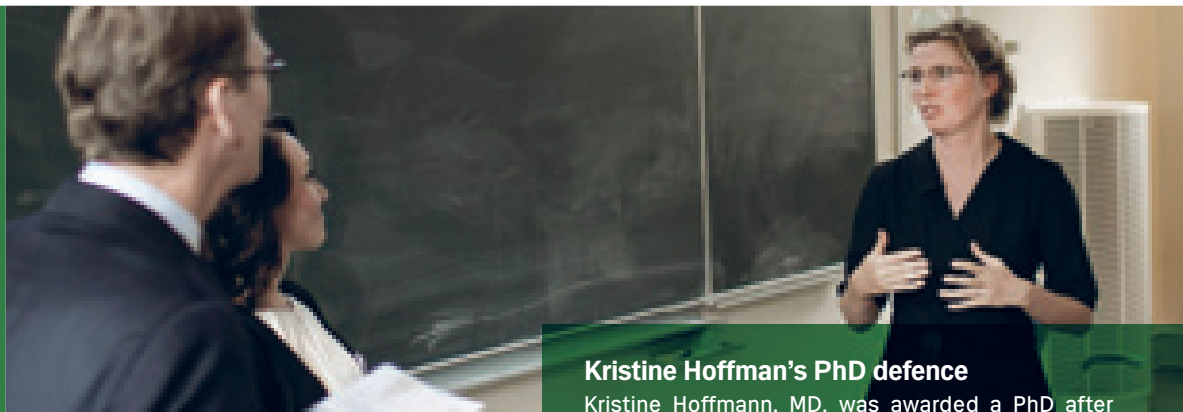
2014
Copenhagen hosts largest international conference on dementia, Alzheimer Association International Conference (AAIC), with 5,000 delegates

2007
Opening of National Info and Education Centre funded by the Danish Ministry of Health and Danish Health Foundation; H.M. Queen Silvia of Sweden and H.R.H. Princess Benedikte visit the memory clinic on official state visit

2010
DDRC receives Global Excellence in Health award from Capital Region of Denmark and University of Copenhagen

2011
Launch of ADEX, a multicentre research programme on physical exercise

2015
DDRC celebrates 10,000th ABC Dementia user; ADEX study concludes but continues as a network of centres of expertise in Denmark



Kristine Hoffman's PhD defence

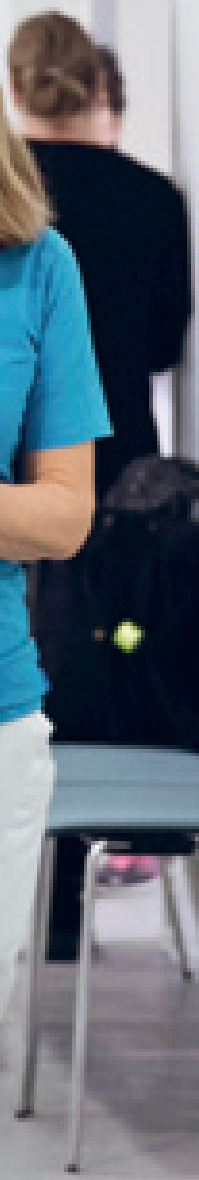
Kristine Hoffmann, MD, was awarded a PhD after defending her thesis: "Preserving Cognition, Quality of Life, Physical Health and Functional Ability in Alzheimer's Disease: The Effect of Physical Exercise (ADEX) study" in November 2015.

From left: Gunhild Waldemar (supervisor), Steen G. Hasselbalch (supervisor), Philip Scheltens (evaluation committee), Kristine Hoffman, Kristian Steen Frederiksen (supervisor), Martin Balslev Jørgensen (evaluation committee) and Miia Kivipelto (evaluation committee).



5

Bilagaavtagning
The original state of paper



COPENHAGEN MEMORY CLINIC

The Copenhagen Memory Clinic, Rigshospitalet – Blegdamsvej is a combined secondary and tertiary referral-based multidisciplinary out-patient clinic. Offering diagnostic evaluation and treatment of patients with cognitive disorders and dementia, the clinic receives referrals from general practitioners, private practice neurologists, psychiatrists and other hospitals. Patients may also be referred from other memory clinics for second opinion evaluations.

Patients with rare (e.g. genetic disorders) or uncertain aetiology may be referred from all Danish regions. Diagnostic evaluation and treatment are managed by a multi-disciplinary team of consultant neurologists, psychiatrists, neuropsychologists, specialist nurses, a social counsellor, medical secretaries and a laboratory technician.

All patients are given a time schedule for a tailored programme for ancillary investigations (e.g. magnetic resonance imaging (MRI), FDG-PET, lumbar puncture, neuropsychological examination) upon first visit at the clinic to improve the quality of the evaluation and to reduce the time from first visit to diagnosis.

HIGHLY SPECIALISED SERVICES

In accordance with guidelines for local, regional and highly specialised medical services from the Danish Health and Medicines Authority, the Copenhagen Memory Clinic has been approved as a highly specialised centre in the fields of dementia and neurogenetics.

KEY FIGURES 2006-2015										
	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
New patient referrals	642	737	709	726	842	778	920	953	1021	965
Number of visits	4,015	4,638	4,192	4,811	5,807	5,700	6,052	6,311	6,920	6,318
Patients in follow-up programme	1,153	1,516	1,487	1,648	1,766	1,892	2,038	2,088	2,044	2,117

In 2015 the listed number of new patients completed a diagnostic evaluation programme and were classified as follows:

SYNDROME	DIAGNOSIS	NUMBER
Dementia	Total	448
	• Alzheimer's disease	175
	• Vascular or mixed dementia	102
	• Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinsons-plus syndromes	24
	• Frontotemporal Dementia	24
	• Normal pressure hydrocephalus	38
	• Other specific conditions including Huntington's disease	26
	• Dementia of uncertain aetiology and alcohol	59
Mild cognitive impairment and other cognitive profiles	Patients with specific neurodegenerative disorders without dementia, patients with depression and other psychiatric conditions and sequelae after traumatic brain injury	214
No cognitive impairment	Patients with subjective symptoms and no significant pathology	155
Healthy persons	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	135



LIFE HISTORY

DATE	PLACE	REASON
1980-1985
1985-1990
1990-1995
1995-2000
2000-2005
2005-2010
2010-2015
2015-2020
2020-Present



COPENHAGEN MEMORY CLINIC

Its services include:

- Second opinion evaluation of patients with possible dementia/dementia with uncertain aetiology
- Rare dementia diseases
- Hereditary neurodegenerative diseases (e.g. Alzheimer's disease (AD), frontotemporal dementia (FTD), spinocerebellar ataxias (SCAs), Huntington's disease (HD))
- Diagnostic evaluation of patients where brain biopsy is considered
- Lumbar perfusion tests and clinical evaluation of patients with normal pressure hydrocephalus (NPH)

These highly specialised services are performed in collaboration with several other specialist departments at Rigshospitalet, for example the Department of Clinical Genetics; the Department of Neurosurgery; the Department of Neuropathology; the Department of Clinical Neurophysiology; and the Department of Clinical Physiology and Nuclear Medicine (the PET and Cyclotron Unit, Rigshospitalet). In 2015 a monthly conference together with specialists from MR and PET was established at the PET section. DDRRC also collaborates with the Movement Disorders Clinic, Bispebjerg Hospital.

NPH

NPH is a complex diagnosis to evaluate. The patients often have multimorbidity and characteristic symptoms such as: gait disturbance, urinary incontinence and cognitive decline, which are also common to several other diseases. When a CT or MRI shows a dilated ventricular system, the patients are referred for further evaluation.

In 2015 there were 207 patients referred for a clinical evaluation for NPH, 86 of whom had a lumbar perfusion test after the clinical examination. All patients are discussed at a weekly conference with the NPH team at the Department of Neurosurgery, Rigshospitalet. The treatment, which can involve insertion of a shunt to drain excess cerebrospinal fluid from the brain, may reverse some of the symptoms and restore functioning.

Genetic counselling

A programme for healthy at-risk family members includes a consultation with a trained psychologist before considering genetic testing. The clinic also offers crisis consultations for patients and relatives, when needed.

Number of patients seen in the follow-up programme in 2015. Data for 2015 extracted from hospital administration database January 2016, selected diagnostic categories.

DIAGNOSTIC CODE (ICD-10)	DIAGNOSIS	NUMBER
G30.1, G30.9, G30.8, G30.0	Alzheimer's disease	924
G91.2	Normal pressure hydrocephalus	362
F04.9, F06.7	Mild cognitive impairment and other mild cognitive disorders	181
G10.9	Huntington's disease	166
Z82.0	Familial disorders/genetic counselling	471
G11.1-4, G11.9, R27.0	Ataxias (including SCAs and FXTAS) and hereditary spastic paraplegia	190
G24.0-2	Dystonia	25
G60.0, G62.9	Familial motor neuron diseases	15
G20, G21, G22, G23.1, G23.8+9, G25.9	Parkinson's disease, including atypical forms	19
G31.8	Frontotemporal dementia and other specific neurodegenerative diseases	199
G 31.9, F03.9	Other (unspecified) neurodegenerative disorders	83
G31.8E	Dementia with Lewy bodies	82
I69.3+4	Vascular dementia	78

PATIENTS AND FAMILIES

New patients are referred for diagnostic evaluation of cognitive, behavioural or other symptoms suggestive for a neurodegenerative condition. Patients with rare, complex or familial disorders may be referred for treatment and follow-up, and genetic counselling is also offered for healthy at-risk family members.

The follow-up programme monitors 2.117 patients. All patients with mild cognitive impairment (MCI), dementia or specific neurodegenerative disorders are offered counselling and follow-up in collaboration with primary health care. Patients with conditions of uncertain aetiology and healthy mutation carriers may also be offered follow-up in the memory clinic. The majority of patients in the follow-up programme have MCI, AD, dementia with Lewy bodies (DLB), FTD, HD, SCAs, NPH, Down's syndrome with dementia, and other neurodegenerative/neurogenetic conditions. Most patients are accompanied by their family caregivers when visiting the clinic, and the social counsellor, specialist nurses, psychologists and medical doctors also offer counselling for the caregivers as an integral part of the follow-up programme.

COURSES FOR PATIENTS AND CAREGIVERS

As part of its services the clinic offers courses for patients and caregivers.

- Early-phase AD patients are offered a course run by a neuropsychologist focusing on the maintenance of cognitive functions as well as an introduction to compensatory techniques related to cognitive deficits.
- A two-session course run by multi-disciplinary staff with weekly meetings is offered four times a year for family caregivers and includes information on symptoms and treatment; legal issues and social services; and treatment, care and practical daily-life issues.

SPECIALIST SERVICE ON THE ISLAND OF BORNHOLM

Since 2011 consultant neurologists and neuropsychologists have worked with the Mental Health Centre Bornholm. Every other week, for one day, a team from the Copenhagen Memory Clinic sees patients on Bornholm. Patients with possible dementia and other cognitive disorders are evaluated and treated in close collaboration with the staff at the psychiatric department. Consultants from the Copenhagen Memory Clinic have also participated in education services for health care professionals on Bornholm.

REGIONAL AND NATIONAL COLLABORATION

In 2006 the Capital Region of Denmark established a quality registry for the diagnostic evaluation of dementia. The registry includes data from all five memory clinics (and the specialist service on Bornholm) and is monitored by the Scientific Dementia Council in the region and coordinated by the Copenhagen Memory Clinic. In 2014 the registry was adjusted to accommodate quality indicators for a national database currently being developed that will be launched in 2016.

The Capital Region of Denmark also established guidelines for coordinating patient care pathways between hospital-based memory clinics, mental health centres, other hospital departments, general practitioners and primary health care in its 29 municipalities. Implementation of the programme began in 2012.

For patients from the city district of Copenhagen, the Copenhagen Memory Clinic, Rigshospitalet has specific collaboration programmes with the Departments of Geriatrics and Neurology at Bispebjerg Hospital, the Mental Health Centre Copenhagen, the Mental Health Centre Frederiksberg, general practitioners, and the care institutions and home care in the City of Copenhagen and the City of Frederiksberg.

The Copenhagen Memory Clinic has organised and takes active part in the Network of Danish Memory Clinics.

MERGER WITH GLOSTRUP HOSPITAL MEMORY CLINIC

In 2015 two University of Copenhagen hospitals, Glostrup Hospital and Rigshospitalet, now named Rigshospitalet – Glostrup and Rigshospitalet – Blegdamsvej merged, leading to a fusion of their neurology departments, which still have two different locations. The next step will involve merging several neurology subsections. The memory clinics from the two hospitals will merge in 2016, but the current plan is to keep out-patient clinics for memory disorders and dementia at both locations to ensure close collaboration between the memory clinics and local municipal care institutions and general practitioners. With approximately 1,600 referrals per year, the resulting clinic will be one of Scandinavia's largest, paving the way to streamlining and improving patient services, subspecialisation, better recruitment of staff and more research.

RESEARCH

The research programmes at DDRC cover a wide spectrum of clinical and translational research, including studies on epidemiology, biofluid markers, brain imaging, neurogenetics, genotype-phenotype correlations, patient-specific stem cells, disease course, neuropsychology, drug trials, non-pharmacological interventions and health service research.

Many different resources form the basis for the research programmes at DDRC, for example patient cohorts representing a wide range of diagnostic entities, cohorts of healthy controls and mutation carriers, and nationwide health care registries. The Danish Dementia Biobank is an important resource for biomarker research and has blood and/or CSF samples from more than 3.000 patients. Furthermore, the biobank stores cell cultures of fibroblasts, induced pluripotent stem cells and stem cell derived neurons from selected patients and controls. Those cells are unique resources for the Neurogenetics Research Laboratory at DDRC, which focuses on clinical characteristics, genetic modifiers and basic research into gene function and therapy.

Our research is funded by external grants and donations from public or private foundations (see Acknowledgements). The health service and intervention research programmes with direct relevance to improving the quality of dementia care in Denmark are funded in part by the Danish Ministry of Health as an integral part of the National Info & Education Centre. The senior research directors, Professor Steen Hasselbalch, Dr Jørgen Nielsen and Professor Gunhild Waldemar supervise the programmes summarised below. In 2015 their research groups counted three student researchers, ten PhD students, three postdocs, three senior researchers and four clinical neuropsychologists and neurologists with shared senior researcher and clinical functions. Our research is conducted in collaboration with a wide range of Danish and international research groups. Below, some of our research programmes are presented.

RESEARCH HIGHLIGHT 2015 – THE ADEX STUDY

The Preserving Cognition, Quality of Life, Physical Health and Functional Ability in Alzheimer's Disease: The Effect of Physical Exercise (ADEX) study is a multi-centre, randomised trial that was conducted between January 2012 and June 2014 in a collaboration between eight memory clinics in Denmark (Aalborg, Aarhus, Odense, Svendborg, Slagelse, Roskilde, Glostrup and Rigshospitalet), and coordinated by DDRC and the Musculoskeletal Rehabilitation Research Unit, Institute of Sports Medicine, Bispebjerg Hospital, University of Copenhagen. Collaborating partners are the PET and Cyclotron Unit, Rigshospitalet; the Neurobiology Research Unit, Rigshospitalet; the Danish Research Centre for Magnetic Resonance (DRCMR), Hvidovre Hospital; CAST Centre for Applied Health Services Research, University of Southern Denmark,

Odense, Denmark; the Department of Geriatric Medicine, Karolinska University Hospital, Huddinge, Sweden; and Alzheimer Centrum, Vrije University Medical Centre.

In July 2015 the first results from the study were reported at the Alzheimer's Association International Conference held in Washington. The ADEX study is the first large, controlled trial of moderate to high intensity exercise in people with mild to moderate Alzheimer's disease. In the ADEX study, 200 patients with mild Alzheimer's disease were randomly assigned to either a supervised aerobic exercise programme (60-minute exercise sessions three times a week for 16 weeks supervised by physiotherapists) or a control group (standard care, no extra exercise). In the exercise groups, after four weeks of adaptation exercise, participants performed aerobic exercise at a target intensity of 70-80% of maximum heart rate for the remaining 12 weeks.

Showing promising results, the study investigated how exercise may have an effect on a range of factors related to Alzheimer's disease, including change in cognitive performance, neuropsychiatric and depressive symptoms, activities of daily living, and quality of life. Patients who participated in the exercise programme developed fewer neuropsychiatric symptoms relative to the control participants. Further, a subgroup of patients in the exercise group who attended more than 80% of the classes and exercised vigorously (raising their heart rate to more than 70% of their maximal rate) had statistically significant improvements on a measure of cognitive function. Physical exercise also improved cardiorespiratory fitness, physical function, dual-task performance and exercise self-efficacy in the patients. While the results need to be verified in larger and more diverse groups of dementia patients the positive effects of exercise on dementia symptoms and physical fitness seen in the ADEX study are promising.

The ADEX project was initiated to establish a platform for future cooperation on dementia research in Danish memory clinics. In parallel with conducting the first project on the effect of physical training in patients with AD, a platform for creating a research alliance between Danish memory clinics with benchmarking to Swedish and Dutch networks has been established. Common diagnostic criteria and scales for outcome measures have been implemented, and rater training has been performed (future rater certification is scheduled). In the international benchmarking, comparisons between the Swedish Dementia Registry (SveDem) and the Danish Dementia Registry were performed. Although the targets of several quality indicators in both registries were met, there were also results of concern, highlighting the need to harmonise diagnostic criteria. The ADEX alliance of eight memory clinics will continue as a network of Danish research memory clinics and welcome associated member clinics for the harmonisation and training activities.

EARLY AND ACCURATE DIAGNOSIS

By using clinical data and results from different biomarkers some of our research projects focus on the discovery and validation of disease markers for AD and other neurodegenerative disorders. Such studies include new biofluid markers, brain imaging and neuropsychology.

The aim of our biomarker research is to discover and validate new biofluid markers for the early diagnosis of AD and for the prediction of disease progression using proteomics and genomics technologies. Most studies on biomarkers are carried out in collaboration with other Danish centres, as well as a wide range of European centres (including in the Joint Programme on Neurodegenerative Diseases, JPND). DDRC is a partner in BIOMARKAPD (funded by JPND), which was initiated in 2012 to validate and harmonise preanalytical and laboratory procedures for cerebral spinal fluid (CSF) analysis and to clarify the clinical application of current and new CSF biomarkers in the diagnosis of AD and Parkinson's disease (PD).

DDRC conducts and participates in several brain imaging studies that include both structural and functional brain imaging. A large part of DDRC brain imaging research is integrated in international collaborative studies such as the BIOMARKAPD study and the Leukoaraiosis and Disability in the Elderly (LADIS) study coordinated by the University of Florence. For several years DDRC has collaborated with the PET and Cyclotron Unit, Rigshospitalet on the clinical application of amyloid brain imaging. Danish collaborators who use state-of-the-art imaging techniques in imaging studies include: the PET and Cyclotron Unit, Rigshospitalet; the Neurobiology Research Unit, Rigshospitalet; and the Danish Research Centre for Magnetic Resonance (DRCMR), Hvidovre Hospital.

PredictND is a European multi-centre research project aimed at improving differential diagnosis. PredictND is a technological decision support tool designed to assist in early diagnosis and monitoring of disease progression. Supported by the EU's Seventh Framework Programme (FP7) programme, the project aims to study the accuracy of the PredictND tool for diagnosing neurodegenerative diseases and the ability of the tool to predict the disease course. Research partners: VTT Technical Research Centre of Finland (coordinator), GE Healthcare Ltd, Imperial College London, University of Eastern Finland, VU University Medical Centre, UPG – University of Perugia and Alzheimer Europe.

DDRC's neuropsychological research mainly focuses on characterisation of cognitive deficits in the early phase of dementia diseases and MCI. In 2015, papers were published on the role of subjective memory complaints in ageing and dementia, and on the validity of cognitive test procedures in different neurodegenerative disorders. Further, several

manuscripts on cognitive impairment and social cognition in manifest and pre-manifest Huntington gene-expansion carriers were published. A Danish multi-centre study on cognitive performances in healthy ageing was initiated with DDRC as the coordinating centre.

COGNITIVE REHABILITATION AND NEW SUPPORTIVE TECHNOLOGY

In 2015 the ReACT study (Rehabilitation in Alzheimer's disease using Cognitive support Technology) was launched. In this study software technology will be developed to fit the needs of people with dementia. The software will be developed in a public-private partnership with an IT company, and it will be based on a user-driven innovation process. The study will address issues of how to implement technology in the daily lives of people with dementia through a programme of cognitive rehabilitation. The proof-of-concept of the integrated programme will be carried out as part of a PhD.

FAMILIAL NEURODEGENERATIVE DISORDERS PAVING THE WAY FOR PERSONALISED MEDICINE

With recent scientific advances it is possible to establish patient-specific stem cells, derived from a skin biopsy, which can be further differentiated into neurons, potentially mimicking the patient's disease. Supported by the Danish National Advanced Technology Foundation, EU's FP7, and Innovation Fund, Denmark, we have contributed to the development of stem cell derived neurons from patients with familial AD, Frontotemporal dementia (FTD), Huntington's disease (HD) and Spinocerebellar ataxia (SCA) in collaboration with partners in academia and industry in a programme directed by professor Poul Hyttel, Department of Veterinary Clinical and Animal Sciences, University of Copenhagen. By applying gene correction therapy on those neuronal cell lines the consortium has succeeded in developing healthy neurons from the same patients, thereby making it possible to gain detailed molecular insight into common mechanisms of neurodegeneration and to uncover novel targets for medical interventions, also relevant for sporadic dementias.

The international, multidisciplinary Frontotemporal Dementia Research in Jutland Association (FReJA Consortium) investigates FTD linked to chromosome 3 (FTD3), which occurs in a large FTD family in western Jutland. The consortium has made major progress in understanding the disease and its wider relevance for neurodegeneration. In 2015 research continued with studies designed to understand the molecular disease mechanism, and neuronal cell lines are now derived using stem cell technology to further explore disease mechanisms and the potential of gene therapy.

RESEARCH

Combining data from the European Huntington's Disease Network (EHDN), which in 2015 became the worldwide network ENROLL-HD, with detailed clinical and neuropsychological evaluations, genetic markers and CSF profiles, we have identified unique fingerprints for patients with different symptoms, highlighting the need and potential for individual treatment.

EPIDEMIOLOGY AND GLOBAL HEALTH

Using nationwide registry data researchers at DDRC investigate the quality of diagnostic evaluation, access to health service, and the use of medication in patients with dementia as compared to the Danish population in general. Projects investigating patterns of the use of opioids and other analgetics, the use of psychotropics and of anti-dementia medication are currently being conducted. The research is being carried out in cooperation with the National Centre for Register-based Research at Aarhus University. A time-course study on the nationwide use of antipsychotics in patients with dementia published in 2015 demonstrated that although the prevalence of antipsychotic drug use decreased from 31.3% in 2000 to 20.4% in 2012, it is still very high. Current studies will aim to investigate the causes of the high prevalence. Another study published in 2015 demonstrated a very high use of opioids in patients with dementia and in nursing home residents in general (41%). Again, new studies will aim to characterise the consequences and background for the high use. The results will contribute to the evidence for creating new guidelines and for DDRC teaching materials.

Researchers at DDRC, and collaborators, also use data from previous clinical cohorts to study long term outcomes. Thus, a study conducted

by collaborators at the Research Unit for General Practice and Section of General Practice, Department of Public Health, University of Copenhagen, based on our DAISY cohort, demonstrated that moderate alcohol consumption (2-3 units/day) was associated with a significantly lower mortality over a period of 36 months.

The DDRC conducted an epidemiological study in Lebanon in collaboration with the American University Beirut and Kings College London supported by the National Institutes of Health, National Institute of Aging and Fogarty International Center in the US. The first study on dementia in the Middle East, the study aimed to investigate the prevalence and risk factors of dementia, and to validate cross-cultural instruments for diagnosing dementia in an Arabic-speaking population. The validation studies were published in 2015 and will contribute to the development of simpler methods for diagnosing and screening of dementia in developing and middle income countries.

DRUG TRIALS

DDRC has extensive experience in the conduction of phase 1 to phase 4 clinical pharmacological trials in patients with AD, MCI and HD, and many patients from the memory clinic are interested in participating in such trials. The cooperation between Danish memory clinics (ADEX network) makes a relevant platform for trials of high quality. In most trials DDRC has a track record of more than 30% above the intended number of patients included. The clinical trials are being conducted with state-of-the-art imaging techniques in collaboration with DRCMR, Hvidovre Hospital and the PET and Cyclotron Unit, Rigshospitalet.

The table below lists the trials that DDRC participated in in 2015:

PHASE	SPONSOR	PROTOCOL	TYPE
1	ACImmune	ACI24-0701	Active A-beta vaccine
2/3	Merck/MSD	MK-8931-017	Beta-secretase inhibitor
3	Roche	WN25203	Amyloid-beta monoclonal antibody
3	Roche	WN28745	Amyloid-beta monoclonal antibody
3	H. Lundbeck	14861A+B	5HT6 antagonist



NATIONAL INFO & EDUCATION CENTRE

The DDRC's National Info & Education Centre was established in 2007 to provide nationwide education and dissemination of information about dementia, primarily to health care professionals and care staff. DDRC communicates to a variety of professionals on a range of platforms, e.g. the DDRC website, training courses, networks, e-learning, press releases, apps, publications and conferences.

COURSES AND CONFERENCES

The National Info & Education Centre offers a wide range of courses throughout the country, in addition to two annual conferences: Dementia Days, which attracts approximately 1,000 participants from many disciplines from across the country, and a research conference presenting new national and international research to a large audience of health care professionals. Every other year DDRC also arranges a two-day conference for leaders in care in collaboration with the Norwegian and Swedish national research and education centres, with the next event in autumn 2016.

In 2015 DDRC organised courses and conferences tailored to the needs of specific groups per request by local authorities and regional institutions. Designed to meet a specific purpose or cover a certain subject, customised courses were attended by various professionals. With 404 participants, blended learning was especially popular in 2015 and required that participants complete ABC Dementia (our free, online course) before attending a customised course.

The 2015 catalogue offered a variety of activities (courses, thematic events and conferences) on a wide range of subjects, such as "Supporting a good and active life" and "The amazing brain", and a PhD course on "Alzheimer's disease and other neurodegenerative dementias".

At thematic events a whole day is dedicated to a particular subject guided by professionals with extensive experience on the topic in question. Examples of thematic events held in 2015 were "Mental illness and dementia" and "Symptoms of dementia".

Annual research conference

Every year a full-day national conference primarily devoted to the latest scientific news within a specific topic of interest related to dementia takes place in November at Rigshospitalet. The conference attracts scientists and practitioners from across Denmark.

On 27 November 2015 more than 200 professionals attended the annual research conference on "Nursing and care: What the research says" to update their knowledge.

International PhD course

For the third time, in cooperation with the University of Copenhagen, DDRC organised a PhD course on AD and other neurodegenerative dementias for 30 PhD students. Conducted in English, the course was designed to introduce new researchers to various Alzheimer's research fields and to provide insight into AD for young PhD students with various basic and clinical backgrounds. The course, which included lectures and workshops comprising hands-on experience with various research tools, presented a wide spectrum of research and addressed some of the most interesting challenges and pitfalls in the field.

Dementia Days – a nationwide conference

Every year DDRC organises Dementia Days, a national two-day conference for dementia specialists and practitioners. As Denmark's largest conference on dementia, it provides a valuable educational opportunity for management and staff working in the social services and health care sector. The chair of the Regional Council of the Capital Region of Denmark, Sophie Hæstorp Andersen, opened the conference, which began on 16 May 2015 and revolved around the theme "A dementia-friendly society". There were 951 participants.

Invited speakers from the United Kingdom, the Netherlands, Norway, Sweden and Denmark presented their views on and experiences with a wide range of topics. During the conference, participants had the opportunity to present results from their own research. Nine participants were selected to give an oral presentation and 17 presented a poster.

ACTIVITIES 2015					
Activity	Courses	Conferences	Thematic events	Customised courses	Total
Events	9	3	2	54	68
Participants	316	1,269	165	2,548	4,343

Dementia coordinator Edith Mathiasen received the 2015 poster prize for her presentation on working with an individually tailored cognitive education programme conducted at VUC in Aalborg, which is an adult centre for education and communication.

ABC DEMENTIA – FREE ONLINE COURSES

ABC Dementia involves modular e-learning for professional caregivers, with each module designed to cover a specific topic, such as dementia disorders, behavioural disorders or communication. The practice oriented nature of the topics and the variety of educational approaches used make the courses especially user friendly. By the end of 2015 nine modules had been produced and the last module is in the pipeline.

When launched in 2013 ABC Dementia targeted basic care staff (home care and nursing homes) and was a new approach designed to reach beyond traditional courses and conferences. Offering free e-learning is one way of providing care staff across the country with easy access to knowledge about dementia. By the end of 2015 ABC Dementia had more than 10,000 users and more users join weekly.

In 2015 we began developing ABC Dementia for physicians. The target group is physicians in training, primarily within geriatrics, neurology, psychiatry and general practice, as well as other interested parties. The content was developed based on a variety of cases and touches on topics such as disease progression, assessment/diagnostics, occurrence and treatment. The e-learning modules are expected to be available in 2016.

RESEARCH

Part of DDRC's research on epidemiology, early diagnostics and intervention is funded by the National Info and Education Centre. Read more on page 20-22.

COMMUNICATIONS AND PRESS

All of our platforms have seen a high level of activity and we have a growing number of followers on social media. This is due to an ongoing strategic approach to public relations and a focused effort in reaching out to our stakeholders and the press in general. In 2015 we also began working on a new visual identity to give our digital and printed materials a more uniform appearance, with implementation of this project to continue throughout 2016.

Website

Our website, videnscenterfordemens.dk, provides information about dementia diseases, risk factors and statistics for people who work with the assessment, treatment and care of individuals with dementia. Materials and tools useful in their daily work can also be ordered on the site. The press, patient organisations and relatives also use our website extensively.

Due to technical reasons in the setup of cookies, we cannot compare website traffic per year from 2012-2015. As of February 2016 it once again becomes possible to register all traffic.

We have seen an increasing number of users and user sessions from 2012-2016. The number of page views dropped from 2013 to 2016, likely due to the improved information architecture implemented in 2014-2015.

Newsletter

Our newsletter is published six times a year and contains information about the latest research and current courses and conferences. In 2015 it was given a new, more readable look. The following list shows the number of newsletter recipients per year:

- February 2013: 3,628
- January 2014: 3,976
- January 2015: 4,288
- January 2016: 4,400

About Dementia app

The app "About Dementia" (Viden om demens) is a widely used observation tool for caregivers. In 2015 the app was used 38,000 times (user sessions) and had 11,150 unique users.





bestemmelse og følelse af inddragelse
fokus på personen frem for opgaven
rutiner
fokusere så meget på de øjeblikke som



NATIONAL INFO & EDUCATION CENTRE

Social media

Facebook is a useful way to create and maintain a relationship with the public and to disseminate knowledge about dementia and DDRC (e.g. activities, courses, conferences), while Twitter is valuable for spreading news about research and building relationships with relevant journalists. Facebook inquiries in particular draw traffic to our website.

- **Facebook: In 2015 we more than doubled the number of followers from 508 as of January 2015 to 1,150 as of January 2016, which is a large jump compared to 120 as of January 2014.**
- **Twitter: As of January 2016 DDRC had 474 followers and tweeted 350 times compared to 290 followers and 248 tweets as of January 2015 and 30 followers as of January 2014.**

DDRC in the press

DDRC's presence in the press has generally grown or remained stable, though our presence on radio and TV was particularly high in 2014 where we hosted the large international conference AAIC. See table below.

DDRC IN THE PRESS				
	2012	2013	2014	2015
Print	108	173	315	313
Online	122	166	301	384
Radio	10	22	45	21
TV	11	16	27	19

CONFERENCE BOOTH

DDRC participated in various events in 2015 with our conference booth, though to a lesser degree than in 2014. Our booth was nevertheless instrumental in promoting direct contact with our target groups, allowing us to generate new contacts and disseminate information about our products to professionals and stakeholders, as well as general knowledge about dementia to the public.

In May 2015 we set up our booth at the annual National Social Service Conference, organised by Local Government Denmark in Aalborg.

DDRC also organised a symposium on dementia with around 150 participants, where the new web-based tool "Test your risk of dementia" was presented. Many of the participants took the test and were given information on prevention.

In June the booth travelled to the island of Bornholm to participate in the People's Meeting, where we were involved in a mobile event, engaging the audience in a discussion on dementia dilemmas on stage in the DanAge Association tent.

Finally, we also presented a booth at the annual course for municipal and regional coordinators of dementia, which is a three-day conference attended by about 350 professionals.



NATIONAL NETWORKS

In order to foster an exchange of knowledge, education and quality programmes DDRC (National Info and Education Centre) coordinates two national networks: a network of memory clinics with representatives from 30+ memory clinics from the five regions of Denmark and a network of local dementia ambassadors with one professional care representative officially appointed by each of the 98 municipalities in Denmark.

NETWORK OF DANISH MEMORY CLINICS

DDRC runs a network of Danish memory clinics, most of which are based in hospital psychiatric, geriatric or neurological departments and receive referrals from local general practitioners for diagnostic evaluation of dementia. Some memory clinics also offer follow-up and counselling. Multidisciplinary staff (nurses, medical doctors and neuropsychologists) participate in the network. The network serves as a platform for dissemination and exchange of information, for harmonising and standardising assessment and treatment methods, and for strengthening local and national collaboration. Network members meet once a year to maintain and further develop regional cooperation.

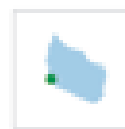
In October 2015 DDRC organised its eighth annual network conference for memory clinics in Denmark. The 2015 conference attracted representatives from all clinics in the country, with 175 people par-

ticipating, including physicians, nurses, psychologists, secretaries and therapists. The main topics covered were: cognitive symptoms associated with stress and depression, assessment and treatment of patients with behavioural disorders, rater training and communication.

NATIONAL NETWORK OF MUNICIPALITY-BASED DEMENTIA AMBASSADORS

Each of the 98 Danish municipalities have appointed a dementia ambassador to disseminate information about DDRC activities and news from other municipalities to local professionals and to monitor local needs for educational activities. Contact between DDRC and the ambassadors is ensured by special news mails (6-8 times a year) and an annual meeting for ambassadors.

In March 2015 the network of local dementia ambassadors met for the sixth time in Odense. Representatives from almost all Danish municipalities were present, along with representatives from the Danish Alzheimer Association, the National Board of Social Services and the Danish Dementia Coordinators (dkdk). The main topic of the day was "The use of sensory integration in the care of persons with dementia". Participants also had the opportunity to share experiences and to network.



Network of Danish Memory Clinics:

- Ordinary memory clinics
- ADEX
- ADEX affiliates



INTERNATIONAL NETWORKS

NORDIC NETWORK IN DEMENTIA DIAGNOSTICS (NIDD)

NIDD is funded by the Nordic Council and comprises eight academic memory clinics in the Nordic countries and Lithuania. As the name indicates, the main objective of the network is to examine various aspects of diagnostic procedures in dementia. DDRC and the memory clinic at Roskilde Hospital are the network's Danish partners.

See: nidd-dementia.org

EUROPEAN ALZHEIMER'S DISEASE CONSORTIUM (EADC)

EADC is a fully functional network of more than 50 European academic centres of excellence working in the field of AD and other dementias. It provides a forum for expanding scientific understanding and development of ways to prevent, delay, slow or ameliorate the primary and secondary symptoms of AD. The European Commission provided initial funding for EADC (see: eadc.info/sito/pagine/home.php). The only Danish EADC member, DDRC has contributed to or directed studies on assessment tools, health economics, biomarkers and cross-cultural aspects of dementia care.

See: eadc.info/

EUROPEAN HUNTINGTON'S DISEASE NETWORK (EHDN)

DDRC is part of EHDN, which provides a platform for professionals and people affected by HD and their relatives to facilitate collaborating throughout Europe. DDRC's staff and patients with HD have contributed significantly to clinical cohort studies and intervention studies.

See: euro-hd.net

NATIONAL DEMENTIA RESEARCH AND EDUCATION CENTRES IN SCANDINAVIA

Norway, Sweden and Denmark have national non-profit dementia research and education centres commissioned and funded by the national boards or ministries of health. The Norwegian Centre for Dementia Research, founded in 1996, is part of the Ageing and Health, Norwegian Centre for Research, Education and Service Development. Commissioned by the National Board of Health and Welfare to create a national centre for excellence in dementia care, the Swedish Dementia Centre was established in 2008 and has been an independent organisation since 2013. DDRC, the Norwegian Centre for Dementia Research and the Swedish Dementia Centre collaborate and meet annually

to share ideas and exchange programmes for the benefit of professional care staff, persons with dementia and family caregivers throughout Scandinavia. A sizeable conference on leadership in dementia care is one of the larger outcomes of this Scandinavian collaboration. The conference is held every other year.

See: demenscentrum.se and aldringoghelse.no

NORTH SEA DEMENTIA GROUP

Twenty-eight members of the network met in Treviso, Italy in 2015. After a short update from all the participating countries, the participants presented dementia care research on the following topics: "The use of new technologies for dementia care training", "Living at home, care and social life issues" and "Family caregivers". The meeting included visits to care homes and a day centre, observing gardening activities and a cognitive stimulation therapy session with a group of people with early stage dementia. We witnessed powerfully positive reactions in individuals with severe dementia.

See: northseadementiagroup.eu

INTERDEM

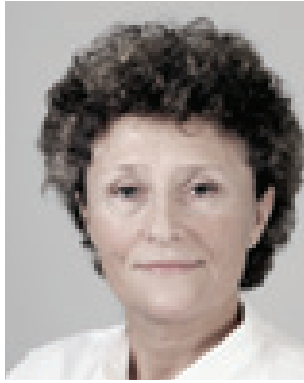
DDRC takes part in Interdem, a pan-European network of researchers collaborating in research on and dissemination of early, timely and quality psychosocial interventions in dementia aimed at improving the quality of life across Europe for people with dementia and their supporters. Academic and clinical researchers from 23 nations are members of the network. The group will meet in Copenhagen in 2016.

See: interdem.org

MANAGEMENT



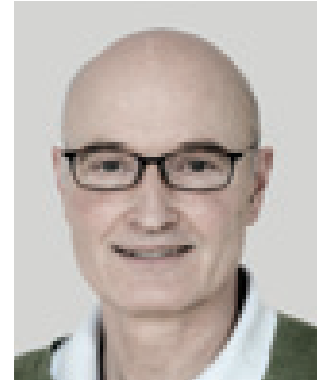
Director
Gunhild Waldemar, MD, DMSc,
professor, senior neurologist



Clinical director
Copenhagen Memory Clinic
Birgitte Bo Andersen,
MD, DMSc, senior neurologist



Head nurse
Copenhagen Memory Clinic
Hanne I. Sørensen,
RN



Research director
Steen G. Hasselbalch,
MD, DMSc, professor,
senior neurologist



Research director
Jørgen E. Nielsen,
MD, PhD, senior neurologist



Educational director
Karen Tannebæk,
occupational therapist
(gerontology)



Research administrator
Jette Rasmussen



**Director of communications
and press**
Mette Tandrup Hansen,
MA

STAFF IN 2015

ADMINISTRATION

Jette Gotlieb Iversen, *course administrator*
Lisbeth Koch, *administrative assistant*
Karin la Cour, *research secretary*
Ditte Majgaard Jensen, *course administrator*
Jette Rasmussen, *research administrator*

NATIONAL INFO & EDUCATION CENTRE

Helle Akselbo, *RN, educational advisor*
Tove-Marie Buk, *RN, educational advisor*
Marie Ejlersen, *MA, communication officer*
Mette Tandrup Hansen, *MA, director of communications and press*
Kasper Jørgensen, *MSc, neuropsychologist*
Elsebeth Refsgaard, *RN, educational advisor, project manager*
Karen Tannebæk, *occupational therapist (gerontology), educational director*

RESEARCH

Anne Siggaard Bie, *PhD, postdoc*
Kathrine Bjarnø, *medical laboratory technician*
Marie Bruun, *MD, PhD student (maternity leave)*
Ane Nørgaard Christensen, *MD, PhD student (maternity leave)*
Tina Elberling, *MD, project director*
Christina Vangsted Hansen, *RN, research nurse*
Steen G. Hasselbalch, *MD, DMSc, professor, senior neurologist, research director*
Anne-Mette Hejl, *MD, PhD, senior neurologist, associate professor*
Lena Hjermand, *MD, PhD, senior neurologist*
Oda Jakobsen, *RN, research nurse*
Peter Johannsen, *MD, PhD, senior neurologist*
Ida Unmack Larsen, *MSc, PhD student, neuropsychologist*
Jørgen E. Nielsen, *MD, PhD, senior neurologist, research director*
Troels Tolstrup Nielsen, *MSc, PhD, laboratory leader, senior researcher*
T. Rune Nielsen, *MSc, PhD, neuropsychologist*
Mikkel Nif Rasmussen, *medical laboratory technician*
Peter Roos, *MD, PhD student*
Nina Rostgaard, *MSc, PhD student*
Anja H. Simonsen, *MSc, PhD, senior researcher*
Camilla Steen-Jensen, *PhD student*
Lea Stevnsborg, *researcher (medical student)*
Jette Stokholm, *MSc, neuropsychologist*
Asmus Vogel, *MSc, PhD, neuropsychologist, associate professor*
Gunhild Waldemar, *MD, DMSc, professor, senior neurologist*
Jonathan Wardman, *PhD, post.doc.*
Johanne Købstrup Zakarias, *researcher (medical student)*
Laila Øksnebjerg, *MSc, neuropsychologist, PhD student*

Associated researchers

Kristian Steen Frederiksen, *MD, PhD*
Kristine Hoffmann, *MD, PhD*
Christina Jensen-Dahm, *MD, PhD*
Tien Kieu Phung, *MD, PhD*
Lise Cronberg Salem, *MD, PhD*
Tua Vinther-Jensen, *MD, PhD*

COPENHAGEN MEMORY CLINIC

Medical doctors

Birgitte Bo Andersen, *MD, DMSc, senior neurologist*
Ghazaleh Doroudian, *MD, junior physician (maternity leave)*
Tina Elberling, *MD, project director*
Hanne Vibe Hansen, *MD, senior psychiatrist*
Steen G. Hasselbalch, *MD, DMSc, professor, senior neurologist*
Anne-Mette Hejl, *MD, PhD, senior neurologist, associate professor*
Lena Hjermand, *MD, PhD, senior neurologist*
Peter Johannsen, *MD, PhD, senior neurologist*
Christina Rørvig-Løppenthien, *MD, staff neurologist*
Susanne Lindquist, *MD, PhD, clinical geneticist*
Jørgen E. Nielsen, *MD, PhD, senior neurologist*
Lisbeth Regeur, *MD, senior neurologist*
Lise Cronberg Salem, *MD, PhD, resident in neurology*
Sarah Taudorf, *MD, PhD, staff neurologist*
Gunhild Waldemar, *MD, DMSc, professor, senior neurologist*

Nurses

Nicole Cordes, *RN*
Christina Vangsted Hansen, *RN*
Lene Iben Hvidkjær, *RN*
Oda Jakobsen, *RN*
Hanne Rygaard Jensen, *RN*
Annette Lauridsen, *RN*
Hanne Inge Sørensen, *RN*
Naomi Wakabayashi, *RN*
Sara Wendel Winther, *RN*

Clinical neuropsychologists

Maria Mimi Bang, *MSc (maternity leave)*
Rune Nielsen, *MSc, PhD*
Selma Nielsen, *MSc*
Jette Stokholm, *MSc*
Asmus Vogel, *MSc, PhD, associate professor*

Medical secretaries

Benthe Friedman
Dorte Hansen
Susanne Lindstrøm
Pernille Munch-Christensen
Ulla Thranow

Social counsellor

Pernille Starnø

Medical laboratory technologist

Kathrine Bjarnø

Receptionists

Anne-Mette Pedersen
Joan Rysgaard

PUBLICATIONS IN 2015

PHD DISSERTATIONS

Hoffmann, K. *Preserving cognition, quality of life, physical health and functional ability in Alzheimer's disease: The effect of physical exercise (ADEX)*. Faculty of Health and Medical Sciences, University of Copenhagen.

Vinther-Jensen, T. *Neuropsychiatric manifestations in Huntington's disease: Clinical and molecular aspects*, Faculty of Health and Medical Sciences, University of Copenhagen.

SCIENTIFIC PAPERS

Berntsen, S., Kragstrup, J., Siersma, V., Waldemar, G., Waldorff, F. B. Alcohol consumption and mortality in patients with mild Alzheimer's disease: A prospective cohort study. *B M J Open* 2015, e007851.

Bocchetta, M., Galluzzi, S., Kehoe, P. G., Aguera, E., Bernabei, R., Bullock, R., Ceccaldi, M., Dartigues, J-F., de Mendonça, A., Didic, M., Eriksdotter, M., Félician, O., Frölich, L., Gertz, H-J., Hallikainen, M., Hasselbalch, S. G., Hausner, L., Heuser, I., Jessen, F., Jones, R. W., Kurz, A., Lawlor, B., Lleo, A., Martinez-Lage, P., Mecocci, P., Mehrabian, S., Monsch, A., Nobili, F., Nordberg, A., Olde Rikkert, M., Orgogozo, J-M., Pasquier, F., Peters, O., Salmon, E., Sánchez-Castellano, C., Santana, I., Sarazin, M., Traykov, L., Tsolaki, M., Visser, P. J., Wallin, A. K., Wilcock, G., Wilkinson, D., Wolf, H., Yener, G., Zekry, D., Frisoni, G. B. The use of biomarkers for the etiologic diagnosis of MCI in Europe: An EADC survey. *Alzheimer's & Dementia* 2015, 11, 195-206.

Bruun, M., Hjermand, L. E., Thomsen, C., Danielsen, E., Thomsen, L. L., Pinborg, L. H., Khabbazzavani, N., Nielsen, J. E. Familial hemiplegic migraine type 1 associated with parkinsonism: a case report. *Case Reports in Neurology* 2015, 1, 84-96.

Clayton, E. L., Mizielinska, S., Edgar, J. R., Nielsen, T. T., Marshall, S., Norona, F. E., Robbins, M., Damirji, H., Holm, I. E., Johannsen, P., Nielsen, J. E., Asante, E. A., Collinge, J., Isaacs, A. M. & FReJA consortium. Frontotemporal dementia caused by CHMP2B mutation is characterised by neuronal lysosomal storage pathology. *Acta Neuropathologica* 2015, 130, 511-23.

Craufurd, D., MacLeod, R., Frontali, M., Quarrell, O., Bijlsma, E. K., Davis, M., Hjermand, L. E., Lahiri, N., Mandich, P., Martinez, A., Tibben, A., Roos, R. A. & Working Group on Genetic Counselling and Testing of the European Huntington's Disease Network (EHDN). Diagnostic genetic testing for Huntington's disease. *Practical Neurology* 2015, 15, 80-84.

Engedal, K., Snaedal, J., Hoegh, P., Jelic, V., Bo Andersen, B., Naik, M., Wahlund, L-O. & Oeksengaard, A-R. Quantitative EEG Applying the Statistical Recognition Pattern Method: A Useful Tool in Dementia Diagnostic Workup. *Dementia and Geriatric Cognitive Disorders*. 2015, 40,1-12

Fereshtehnejad, S-M., Johannsen, P., Waldemar, G. & Eriksdotter, M. Dementia Diagnosis, Treatment, and Care in Specialist Clinics in Two

Scandinavian Countries: A Data Comparison between the Swedish Dementia Registry (SveDem) and the Danish Dementia Registry. *Journal of Alzheimer's disease* 2015, 48, 229-39.

Frederiksen, K. S., Verdelho, A., Madureira, S., Bänzner, H., O'Brien, J. T., Fazekas, F., Scheltens, P., Schmidt, R., Wallin, A., Wahlund, L-O., Erkinjuntti, T., Poggesi, A., Pantoni, L., Inzitari, D., Waldemar, G. & on behalf of the LADIS Study. Physical activity in the elderly is associated with improved executive function and processing speed: the LADIS Study. *International Journal of Geriatric Psychiatry* 2015, 30, 744-750.

Frederiksen, K. S., Hasselbalch, S., Law, I., Højgaard, L., Waldemar, G. Biomarkører ved diagnostik af Alzheimers sygdom i tidlig fase. *Journal of the Danish Medical Association*, 2015, 177, V12140684

Frisoni, G. B., Jack, C. R., Bocchetta, M., Bauer, C., Frederiksen, K. S., Liu, Y., Preboske, G., Swihart, T., Blair, M., Cavado, E., Grothe, M. J., Lanfredi, M., Martinez, O., Nishikawa, M., Portegies, M., Stoub, T., Ward, C., Apostolova, L. G., Ganzola, R., Wolf, D., Barkhof, F., Bartzokis, G., DeCarli, C., Csernansky, J. G., deToledo-Morrell, L., Geerlings, M. I., Kaye, J., Killiany, R. J., Lehericy, S., Matsuda, H., O'Brien, J., Silbert, L. C., Scheltens, P., Soinen, H., Teipel, S., Waldemar, G., Fellgiebel, A., Barnes, J., Firbank, M., Gritsen, L., Henneman, W., Malykhin, N., Pruessner, J. C., Wang, L., Watson, C., Wolf, H., deLeon, M., Pantel, J., Ferrari, C., Bosco, P., Pasqualetti, P., Duchesne, S., Duvernoy, H., Boccardi, M. & EADC -European Alzheimer's Disease Consortium and the ADNI - Alzheimer's Disease Neuroimaging Initiative 2015. The EADC-ADNI Harmonized Protocol for manual hippocampal segmentation on magnetic resonance: Evidence of validity. *Alzheimer's & dementia* 2015, 11, 111-125.

Hasselbalch, S. G. PET med amyloidligander bør ikke anvendes rutinemæssigt i tidlig diagnostik af Alzheimerssygdom – en gennemgang af et Cochranereview. *Journal of the Danish Medical Association*, 2015, 177, 1515-1517

Hoffmann, K., Sobol, N. A., Frederiksen, K. S., Beyer, N., Vogel, A., Vestergaard, K., Brændgaard, H., Gottrup, H., Lolk, A., Wermuth, L., Jacobsen, S., Laugesen, L. P., Gergelyffy, R. G., Høgh, P., Bjerregaard, E., Andersen, B. B., Siersma, V., Johannsen, P., Cotman, C. W., Waldemar, G., Hasselbalch, S. G. Moderate-to-High Intensity Physical Exercise in Patients with Alzheimer's Disease: A Randomized Controlled Trial. *Journal of Alzheimer's disease* 2015, 50, 443-53.

Jansen, W. J., Ossenkoppele, R., Knol, D. L., Tijms, B. M., Scheltens, P., Verhey, F. R. J., Visser, P. J., Aalten, P., Aarsland, D., Alcolea, D., Alexander, M., Almdahl, I. S., Arnold, S. E., Baldeiras, I., Barthel, H., van Berckel, B. N. M., Bibeau, K., Blennow, K., Brooks, D. J., van Buchem, M. A., Camus, V., Cavado, E., Chen, K., Chetelat, G., Cohen, A. D., Drzezga, A., Engelborghs, S., Fagan, A. M., Fladby, T., Fleisher, A. S., van der Flier, W. M., Ford, L., Förster, S., Fortea, J., Foskett, N., Frederiksen, K. S., Freund-Levi, Y., Frisoni, G. B., Froelich, L., Gabryelewicz, T., Gill, K. D., Gkatzima, O., Gómez-Tortosa, E., Gordon, M. F., Grimmer, T., Hampel, H., Hausner, L., Hellwig, S., Herukka,

- S-K., Hildebrandt, H., Ishihara, L., Ivanoiu, A., Jagust, W. J., Johannsen, P., Kandimalla, R., Kapaki, E., Klimkowicz-Mrowiec, A., Klunk, W. E., Köhler, S., Koglin, N., Kornhuber, J., Kramberger, M. G., Van Laere, K., Landau, S. M., Lee, D. Y., de Leon, M., Lisetti, V., Lleó, A., Madsen, K., Maier, W., Marcusson, J., Mattsson, N., de Mendonça, A., Meulenbroek, O., Meyer, P. T., Mintun, M. A., Mok, V., Molinuevo, J. L., Møllergård, H. M., Morris, J. C., Mroczko, B., Van der Mussele, S., Na, D. L., Newberg, A., Nordberg, A., Nordlund, A., Novak, G. P., Paraskevas, G. P., Parnetti, L., Perera, G., Peters, O., Popp, J., Prabhakar, S., Rabinovici, G. D., Ramakers, I. H. G. B., Rami, L., Resende de Oliveira, C., Rinne, J. O., Rodrigue, K. M., Rodríguez-Rodríguez, E., Roe, C. M., Rot, U., Rowe, C. C., Rütger, E., Sabri, O., Sanchez-Juan, P., Santana, I., Sarazin, M., Schröder, J., Schütte, C., Seo, S. W., Soetewey, F., Soininen, H., Spuru, L., Struyfs, H., Teunissen, C. E., Tsolaki, M., Vandenberghe, R., Verbeek, M. M., Villemagne, V. L., Vos, S. J. B., van Waalwijk van Doorn, L. J. C., Waldemar, G., Wallin, A., Wallin, Å. K., Wiltfang, J., Wolk, D. A., Zboch, M., Zetterberg, H. & Amyloid Biomarker Study Group. Prevalence of cerebral amyloid pathology in persons without dementia: A meta-analysis. *JAMA* 2015, 313, 1924-38.
- Jensen, C. G., Hjordt, L. V., Stenbæk, D. S., Andersen, K. E., Back, S. K., Lansner, J., Hageman, I., Dam, O. H., Nielsen, A. P., Knudsen, G. M., Frokjaer, V. G., Hasselbalch, S. G. Development and psychometric validation of the verbal affective memory test. *Memory* 2015, 1-16.
- Jensen, C. G., Lansner, J., Petersen, A., Vangkilde, S. A., Ringkøbing, S. P., Frokjaer, V. G., Adamsen, D., Knudsen, G. M., Denninger, J. W. & Hasselbalch, S. G. Open and Calm-a randomized controlled trial evaluating a public stress reduction program in Denmark. *BMC Public Health* 2015, 15, 1245.
- Jensen, C. S., Hasselbalch, S. G., Waldemar, G., Simonsen, A. H. Biochemical Markers of Physical Exercise on Mild Cognitive Impairment and Dementia: Systematic Review and Perspectives. *Frontiers in Neurology* 2015, 6, 187.
- Jensen-Dahm, C., Gasse, C., Astrup, A., Mortensen, P. B., Waldemar, G. Frequent use of opioids in patients with dementia and nursing home residents-A study of the entire elderly population of Denmark. *Alzheimer's & dementia* 2015, 11, 691-699.
- Jensen-Dahm, C., Werner, M. U., Jensen, T. S., Ballegaard, M., Andersen, B. B., Høgh, P., Waldemar, G. Discrepancy between stimulus response and tolerance of pain in Alzheimer disease. *Neurology* 2015, 84,1575-81.
- Jensen-Dahm, C., Waldemar, G., Staehelin Jensen, T., Malmqvist, L., Møller, M. M., Andersen, B. B., Høgh, P., Ballegaard, M. Autonomic Dysfunction in Patients with Mild to Moderate Alzheimer's Disease. *Journal of Alzheimer's disease*, 47, 681-9.
- Jørgensen, K., Kristensen, M. K., Waldemar, G. & Vogel, A. The six-item Clock Drawing Test - reliability and validity in mild Alzheimer's disease. *Aging, Neuropsychology and Cognition* 2015, 22, 301-11.
- Leitão, M. J., Baldeiras, I., Herukka, S-K., Pikkarainen, M., Leinonen, V., Simonsen, A. H., Perret-Liaudet, A., Fourier, A., Quadrio, I., Veiga, P. M., de Oliveira, C. R. Chasing the Effects of Pre-Analytical Confounders – A multicenter study on CSF-AD biomarkers. *Frontiers in Neurology* 2015, 153.
- Macfarlane, M. D., Looi, J. C. L., Walterfang, M., Spulber, G., Velakoulis, D., Styner, M., Crisby, M., Orndahl, E., Erkinjuntti, T., Waldemar, G., Garde, E., Hennerici, M. G., Bänzner, H., Blahak, C., Wallin, A., Wahlund, L-O. & LADIS Study Group 2015. Shape Abnormalities of the Caudate Nucleus Correlate with Poorer Gait and Balance: Results from a Subset of the LADIS Study. *American Journal of Geriatric Psychiatry* 2015, 23, 59-71.
- Maynard, S., Hejl, A-M., Dinh, T-S. T., Keijzers, G., Hansen, Å. M., Desler, C., Moreno-Villanueva, M., Bürkle, A., Rasmussen, L. J., Waldemar, G., Bohr, V. Defective mitochondrial respiration, altered dNTP pools and reduced AP endonuclease 1 activity in peripheral blood mononuclear cells of Alzheimer's disease patients. *Aging* 2015, 7, 793-815.
- Nielsen, T. R., Antelius, E., Spilker, R. S., Torkpoor, R., Toresson, H., Lindholm, C., Plejert, C. & Nordic Research Network on Dementia and Ethnicity. Dementia care for people from ethnic minorities: a Nordic perspective. *International Journal of Geriatric Psychiatry* 2015. 30, 217-8.
- Nielsen, T. R., Phung, T. K. T., Chaaya, M., Mackinnon, A., Waldemar, G. Combining the Rowland Universal Dementia Assessment Scale and the Informant Questionnaire on Cognitive Decline in the Elderly to Improve Detection of Dementia in an Arabic-Speaking Population. *Dementia and Geriatric Cognitive Disorders* 2015, 41, 46-54.
- Nørgaard, A., Jensen-Dahm, C., Gasse, C., Hansen, H. V., Waldemar, G. Time Trends in Antipsychotic Drug Use in Patients with Dementia: A Nationwide Study. *Journal of Alzheimer's disease* 2015, 49, 211-20.
- Phung, T. K. T., Chaaya, M., Asmar, K., Atweh, S., Ghush, H., Khoury, R. M., Prince, M., Waldemar, G. Performance of the 16-Item Informant Questionnaire on Cognitive Decline for the Elderly (IQCODE) in an Arabic-Speaking Older Population. *Dementia and Geriatric Cognitive Disorders* 2015. 40, 276-89.
- Plejert, C., Antelius, E., Yazdanpanah, M., Nielsen, T. R. 'There's a letter called ef' on challenges and repair in interpreter-mediated tests of cognitive functioning in dementia evaluations: A case study. *Journal of Cross-Cultural Gerontology* 2015, 30, 163-87.
- Reijs, B. L. R., Teunissen, C. E., Goncharenko, N., Betsou, F., Blennow, K., Baldeiras, I., Brosseron, F., Cavedo, E., Fladby, T., Froelich, L., Gabryelewicz, T., Gurvit, H., Kapaki, E., Koson, P., Kulic, L., Lehmann, S., Lewczuk, P., Lleó, A., Maetzler, W., de Mendonça, A., Miller, A-M., Molinuevo, J. L., Mollenhauer, B., Parnetti, L., Rot, U., Schneider, A., Simonsen, A. H., Tagliavini, F., Tsolaki, M., Verbeek, M. M., Verhey, F. R. J., Zboch, M., Winblad, B., Scheltens, P., Zetterberg, H., Visser, P. J. The Central Biobank and Virtual Biobank of BIOMARKAPD: A Resource for Studies on Neurodegenerative Diseases. *Frontiers in Neurology* 2015, 6, 216.



PUBLICATIONS IN 2015

Rostgaard, N., Waldemar, G., Nielsen, J. E., Simonsen, A. H. Cerebrospinal Fluid Biomarkers in Familial Forms of Alzheimer's Disease and Frontotemporal Dementia. *Dementia and Geriatric Cognitive Disorders* 2015, 40, 54-62.

Salem, L. C., Sabers, A., Kjaer, T. W., Musaeus, C., Nielsen, M. N., Nielsen, A. G., Waldemar, G. Quantitative Electroencephalography as a Diagnostic Tool for Alzheimer's Dementia in Adults with Down Syndrome. *Dementia and Geriatric Cognitive Disorders Extra* 2015, 5, 404-13.

Salem, L. C., Vogel, A., Ebstrup, J., Linneberg, A., Waldemar, G. Subjective cognitive complaints included in diagnostic evaluation of dementia helps accurate diagnosis in a mixed memory clinic cohort. *International Journal of Geriatric Psychiatry* 2015, 30, 1177-85.

Travassos, M., Santana, I., Baldeiras, I., Tsolaki, M., Gkatzima, O., Sermin, G., Yener, G. G., Simonsen, A., Hasselbalch, S. G., Kapaki, E., Mara, B., Cunha, R. A., Agostinho, P., Blennow, K., Zetterberg, H., Mendes, V. M., Manadas, B., de Mendon, A. Does Caffeine Consumption Modify Cerebrospinal Fluid Amyloid- Levels in Patients with Alzheimer's Disease? *Journal of Alzheimer's disease* 2015, 47, 1069-78.

Unmack Larsen, I., Vinther-Jensen, T., Gade, A., Nielsen, J. E., Vogel, A. Assessing Impairment of Executive Function and Psychomotor Speed in Premanifest and Manifest Huntington's Disease Gene-expansion Carriers. *Journal of the International Neuropsychological Society* 2015, 21, 193-202.

Valcárcel-Ocete, L., Alkorta-Aranburu, G., Iriondo, M., Fullaondo, A., García-Barcina, M., Fernández-García, J. M., Lezcano-García, E., Losada-Domingo, J. M., Ruiz-Ojeda, J., Álvarez de Arcaya, A., Pérez-Ramos, J. M., Roos, R. A. C., Nielsen, J. E., Saft, C., Zubiaga, A. M., Aguirre, A. & REGISTRY investigators of the European Huntington's Disease Network 2015. Exploring Genetic Factors Involved in Huntington Disease Age of Onset: E2F2 as a New Potential Modifier Gene. *PLoS One* 2015, 10, e0131573.

Vinther-Jensen, T., Simonsen, A. H., Budtz-Jørgensen, E., Hjermind, L. E., Nielsen, J. E. Ubiquitin: a potential cerebrospinal fluid progression marker in Huntington's disease. *European Journal of Neurology* 2015, 22, 1378-84.

Vogel, A., Waldorff, F. B., Waldemar, G. Longitudinal changes in awareness over 36 months in patients with mild Alzheimer's disease. *International psychogeriatrics* 2015, 1, 95-102.

CONTRIBUTIONS TO MULTICENTRE STUDIES

Bečanović, K., Nørremølle, A., Neal, S. J., Kay, C., Collins, J. A., Arenillas, D., Lijla, T., Gaudenzi, G., Manoharan, S., Doty, C. N., Beck, J., Lahiri, N., Portales-Casamar, E., Warby, S. C., Connolly, C., De Souza, R. A. G., Tabrizi, S. J., Hermanson, O., Langbehn, D. R., Hayden, M. R., Wasserman, W. W., Leavitt, B. R. & REGISTRY Investigators of the European Huntington's Disease Network (Joergen E Nielsen, member). A SNP in the HTT promoter alters NF- κ B binding and is a bidirectional genetic modifier of Huntington disease. *Nature Neuroscience*, 807-16.

Dale, M., Maltby, J., Martucci, R., Shimozaki, S. & REGISTRY investigators of the European Huntington's Disease Network (Joergen E Nielsen, member). Factor analysis of the hospital anxiety and depression scale among a Huntington's disease population. *Movement disorders* 2015, 14, 1954-60.

Ihl, R., Bunevicius, R., Frölich, L., Winblad, B., Schneider, L. S., Dubois, B., Burns, A., Thibaut, F., Kasper, S., Möller, H-J. & WFSBP Task Force on Mental Disorders in Primary Care (Gunhild Waldemar, member). World Federation of Societies of Biological Psychiatry guidelines for the pharmacological treatment of dementias in primary care. *International Journal of Psychiatry in Clinical Practice* 2015, 19, 1, 2-7.

Vuono, R., Winder-Rhodes, S., de Silva, R., Cisbani, G., Drouin-Ouellet, J., Spillantini, M. G., Cicchetti, F., Barker, R. A. & REGISTRY Investigators of the European Huntington's Disease Network (Joergen E Nielsen, member). The role of tau in the pathological process and clinical expression of Huntington's disease. *Brain* 2015, 138, 907-18.

BOOK CHAPTERS

Karlsborg, M., Nielsen, J. E. Hereditære ataksier og sygdomme i det motoriske neuron. In: Paulson, O. B., Gjerris, F. & Sørensen, P. S. (ed.) *Klinisk neurologi og neurokirurgi*. 6 udg. FADL'S FORLAG 2015, chapter 23.

Vogel, A., Gerlach, C. Neuropsykologiske forstyrrelser. In: Paulson, O. B., Gjerris, F. & Sørensen, P. S. (ed.) *Klinisk neurologi og neurokirurgi*. 6 udg. FADL'S Forlag 2015, chapter 6.

Waldemar, G., Brændgaard, H. Demenssygdomme. In: Paulson, O. B., Gjerris, F. & Sørensen, P. S. (ed.) *Klinisk neurologi og neurokirurgi*. 6 udg. FADL'S Forlag 2015, chapter 25.

Waldemar, G., Kondziella, D. Neurologiske Sygdomme. In: Haunsø, S., Schaffalitzky de Muckadell, O. B. & Vilstrup, H. (ed.) *Medicinsk Kompendium Lommebog 2015*. Nyt Nordisk forlag Arnold Busck, chapter 45.

NATIONAL AND INTERNATIONAL POSTS

Birgitte Bo Andersen, inspector for the Danish Health and Medicines Authority (appointed by the Danish Neurological Society); appointed member of the Dementia Council of the Capital Region of Denmark; appointed member of the steering committee for implementation of the patient pathway programme for dementia in the Capital Region of Denmark.

Marie Bruun, board member of the Danish Neurological Society (2015/16); member of the local organizing committee for the 2nd Congress of the European Academy of Neurology (EAN) in 2016 in Copenhagen.

Kristian Steen Frederiksen, member of EAN Scientific Panel on Dementia and Cognitive Disorders.

Steen G. Hasselbalch, vice-president, Danish Alzheimer Association; board member, Danish Alzheimer Association; chair of the Alzheimer Research Committee under the Danish Alzheimer Association; member of the Scientific Panel on Dementia and Cognitive Disorders, EAN.

Lena Hjermind, PI of the global observational study on HD, Enroll-HD; CPI and PI of the phase 2 trial "Pride" for treatment of HD; adviser for European Huntington's Disease Network (EHDN) and member of the working groups: "Genetic testing and counselling" and "Symptomatic Treatment and Research" in EHDN; vice-president of the Danish Huntington's Disease Association; member of the working group "Genetics" in the COST Grant work plan, BM1101 European Network for the Study of Dystonia Syndromes.

Christina Jensen-Dahm, member of the working group "Cost Action TD100: Pain assessment in patients with impaired cognition, especially dementia".

Peter Johannsen, chair, the Clinical Quality Database under the Dementia Council of the Capital Region; chair, the Danish National Dementia Registry; advisor on anti-dementia drugs, the Danish Medicines Agency, representing the Danish Neurological Society; Danish national coordinator (and PI) on six clinical trials on AD; scientific adviser for Nasjonalforeningen for Folkehelse, Oslo, Norway; member of the editorial board for *Dementia and Geriatric Cognitive Disorders*.

Kasper Jørgensen, neuropsychology consultant for the National Agency for Patients' Rights and Complaints; board member, Dansk Psykologisk Forlag.

Ida Unmack Larsen, member of the behavioural working group in EHDN; board member, Danish Neuropsychological Society.

Jørgen Nielsen, Danish national coordinator (and PI) of the international SPATAX network on cerebellar ataxias and spastic paraplegias; advisor for EHDN and member of the REGISTRY steering committee of EHDN; appointed member of the research committee at Rigshospitalet.

T. Rune Nielsen, co-founder and member of Nordic Network on Dementia and Migrants; scientific advisory group in Ethnicity and the Dementias Network.

Jette Stokholm, chair, Neuropsychological Specialist Council, Danish Psychological Association.

Tua Vinther-Jensen, member of EHDN biomarker working group and behavioural working group.

Asmus Vogel, section editor, *Scandinavian Journal of Psychology*

Gunhild Waldemar, member of Liaison Committee, European Federation of Neurological Societies (EFNS); member of the transition task force for merging EFNS and European Neurological Society, creating EAN; member of the Medical and Scientific Advisory Panel (MSAP) of Alzheimer's Disease International; member of Expert Advisory Panel, Alzheimer Europe; board member of the Danish Alzheimer Foundation; member of the Board of Trustees and chair of the research committee, the Lundbeck Foundation; advisor, the National Legal Medicine Council, the Danish Ministry of Justice; vice-chair, Dementia Council, Capital Region of Denmark; member of executive committee of the Neurology Council, Capital Region of Denmark; vice-president, the Medical Society of Copenhagen; member of the psychiatry committee, the Danish Health and Medicines Authority

Laila Øksnebjerg, Chair of the board, Danish Neuropsychological Society; co-director of the JPND-supported, pan-European working group "Dementia outcome measures: Charting new territory"

NATIONAL DEMENTIA STRATEGY 2025

In 2015 the Danish minister for health, Sophie Løhde, together with the political parties behind a pool of public funds earmarked for disadvantaged groups, launched an ambitious plan for developing a national dementia strategy up to 2025, allocating DKK 470M toward its development and activities in 2016-2019.

According to the political agreement, the aims of National Dementia Strategy 2025 will focus on:

- Denmark should be a dementia friendly country, where people with dementia can live a life in safety and dignity.
- Treatment and care should be based on the needs and values of the individual person with dementia, and should be organized in frameworks promoting coordinated plans with focus on prevention, early diagnosis and support, best available evidence and more research.
- Family caregivers should be involved actively and have more support.

The number of people with dementia will continue to increase, and the growing cost of medical care and associated societal burden threaten to rise to an overwhelming level as more people live into old age. The past decade has seen remarkable improvements in the quality of care. However, no treatments are yet available to modify or cure the severe brain disorders causing dementia, and knowledge on the best methods of care need to be disseminated. A concerted national effort is needed to make Denmark a dementia friendly society. This will involve ensuring that all patients have equal access to high-quality diagnostic evaluation but also that resources be made available to stimulate evidence-based interventions approached from a psychosocial, technological or pharmacological perspective. Resources are also needed to put results into practice with appropriate training and support and to promote research in prevention and new treatments.

Thus, the launch of the National Dementia Strategy 2025 by the Minister for health is a very important step forward, and the DDRC will be pleased to contribute with knowledge, research, dissemination of evidence, educational activities, and with networking spanning the primary and secondary health care sectors and other relevant sectors.

Global Excellence in Health award

Established in 2010 in close cooperation with the University of Copenhagen and the Technical University of Denmark (DTU), The Global Excellence award is given to hospital and university environments in the Capital Region of Denmark that perform first-rate international level research leading to the development and implementation of new, pioneering healthcare services, treatment methods and products for the benefit of patients.

The awardees are characterised by their unique efforts with in one or more areas, such as the extent and quality of their

research and development, teaching, examination and treatment of patients, and innovation and dissemination of the new knowledge.

The DDRC was awarded Global Excellence in Health in 2010 and in 2014 for outstanding contribution to development of world class health care services in the Capital Region of Denmark.



FINANCING

The total annual budget of the DDRC amounts to approximately DKK 40M, distributed almost evenly between internal funding (for memory clinic services) and external grants for projects and commercial activities (research and educational activities). In 2014 operation of the Na-

tional Info & Education Centre was extended with a DKK 19.2M grant from the Danish Ministry of Health (2016-2018). In 2015 DDRC received an additional DKK 12,6M in grants from external foundations for specific research projects.

External funding for research and education activities 2015 (mill. DKK)	
New grants recieved	12,7
New grants accumulated 2007-2015	123,2
External grants spent on specific programmes	
• Funding given to the National Info & Education Centre from the Danish Ministry of Health	6,6
• Other external grants for research	11,7
Income from commercial activities (conferences, sales)	3,8
Income from research contracts	1,7
Staff 2015	
Number of employees	67
Full-time equivalent funding from	
• Internal sources	28,8
• External sources	26,1

ACKNOWLEDGEMENTS

The Danish Ministry of Health and the Danish Health Foundation supported the establishment and development of the DDRC National Info & Education Centre. We are grateful for support for specific projects from the following foundations:

Absalonfonden
 Alzheimer Research Foundation
 Capital Region of Denmark
 Dagmar Marshalls Fond
 Danish Health Foundation
 Danish Medical Association Research Fund
 Danish Ministry of Health
 Den Danske Forskningsfond
 Desirée and Niels Ydes Foundation
 European Union (FP6, FP7, INTERREG IV A
 Oresund-Kattegat-Skagerrak)
 Faculty of Health and Medical Sciences, University of Copenhagen
 Fonden for Neurologisk Forskning
 Gangstedfonden
 Innovation Fund Denmark (formerly Danish Council for Strategic Research, the Danish National Advanced Technology Foundation and the Danish Council for Technology and Innovation)

Jaschafonden
 Jeppe Juhl and Wife Ovita Juhl Foundation
 Landsforeningen Huntingtons Sygdom
 Lennart Gram Memorial Trust
 Ludvig and Sara Elsass Foundation
 Lundbeck Foundation
 National Board of Social Service, the Danish Ministry of Social Affairs and Integration
 National Institutes of Health
 Nordeeg Funding
 Novo Nordisk Foundation
 PA Messerschmidt and Wife Foundation
 Rigshospitalet Scientific Committee
 Simon Spies Foundation
 Aase and Ejnar Danielsen Foundation

DANISH DEMENTIA RESEARCH CENTRE

ADDRESS

Rigshospitalet
Blegdamsvej 9, section 6911, 6991 & 6922
2100 Copenhagen
Denmark

Visiting address
Juliane Maries Vej 28
2100 Copenhagen

www.rigshospitalet.dk
www.videnscenterfordemens.dk

CONTACT

Management, Research and Education
Tel.: +45 35 45 69 22
vide@regionh.dk

The Copenhagen Memory Clinic
Tel.: +45 35 45 69 11
hukommelsesklinikken@regionh.dk

MEDIA & PRESS

Tel.: +45 35 45 53 18

ANNUAL REPORT 2015

Editor: Gunhild Waldemar
Editorial assistant: Marie Ejlersen
Proofreading: Nancy Aaen
Layout: Nanna Grunwald/Wunderwerk
Tryk: AKAPRINT A/S
Photos: Maj Skibstrup (p. 1, 2-3, 5, 8, 10-11), Tomas Bertelsen (p. 2-3, 6-7, 10, 12-13, 14, 16-17, 22-23, 26-27, 28, 30, 32, 34, 38)
Nationalt Videnscenter for Demens
Printing: 300 copies





DANISH DEMENTIA
RESEARCH CENTRE