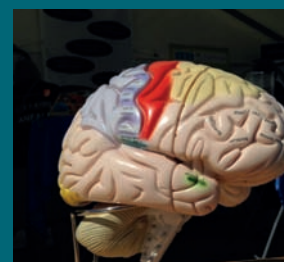
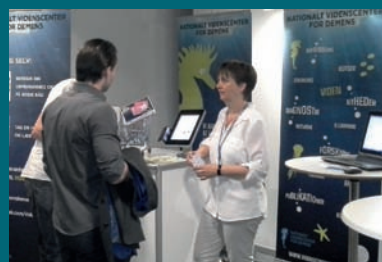




DANISH DEMENTIA
RESEARCH CENTRE



REGION

DANISH DEMENTIA RESEARCH CENTRE

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

Annual report 2014





DANISH DEMENTIA
RESEARCH CENTRE



PREFACE



The past year has witnessed growing political interest in dementia care. The expertise of the Danish Dementia Research Centre (DDRC) has also increasingly been used by politicians, professionals and the press. We have been invited to meetings in the Parliament's health and social welfare committees and have contributed with documentation and scientific reports. We attended the People's Meeting (*Folkemødet*) for disseminating knowledge to a wide audience of people active in the areas of health, social welfare and the elderly. The Dementia Alliance, which is a group of organisations collaborating to exert political pressure on Denmark to become a pioneer in the field of dementia, has also benefited from DDRC's knowledge on research, diagnostics, treatment and care for people with dementia.

We are proud to announce that in 2014 we received an extension of our grant from the Danish Ministry of Health, hence ensuring continued collaboration on patient care, clinical research and national educational services until 2018. The DDRC's Global Excellence - In Health award was extended for an additional five years. The award is given to outstanding hospital and university environments in the field of health care in the Capital Region of Denmark.

For the first time the Alzheimer's Association International Conference (AAIC) was held in Copenhagen in 2014, and almost 5,000 delegates from more than 100 countries participated in the week-long conference in July. DDRC was involved at various levels, for instance as members of the programming committee for planning the unique two-day dementia care track for delegates interested in dementia care and psychosocial research. As a result, our own national conference, Dementia Days, was postponed until May 2015, when we look forward to once again welcoming approximately 1,000 professionals.

In 2014 the Migration School, a cross-national collaboration on dementia assessment and care for patients from ethnic minorities in the Oresund Region, hosted a successful final conference with a turnout of more than 300 attendees.

ADEX, a Danish multi-centre study investigating the effect of physical training in patients with Alzheimer's disease, was completed in 2014 and will be presenting initial results in 2015.

Our educational services, e.g. ABC Dementia, e-learning targeted professional caregivers and courses tailored to specific groups per request by municipalities and regional institutions all over Denmark are more and more in demand.

We are very pleased that DDRC is increasingly used as a source of information for nationwide news media. Due to a more strategic approach to public relations and a more focused effort in reaching out to our stakeholders and the press in general, we have experienced a rise in activity on all platforms.

The 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.

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

Sincerely

A handwritten signature in black ink, appearing to read 'G. Waldemar'.

Gunhild Waldemar, Director of the DDRC

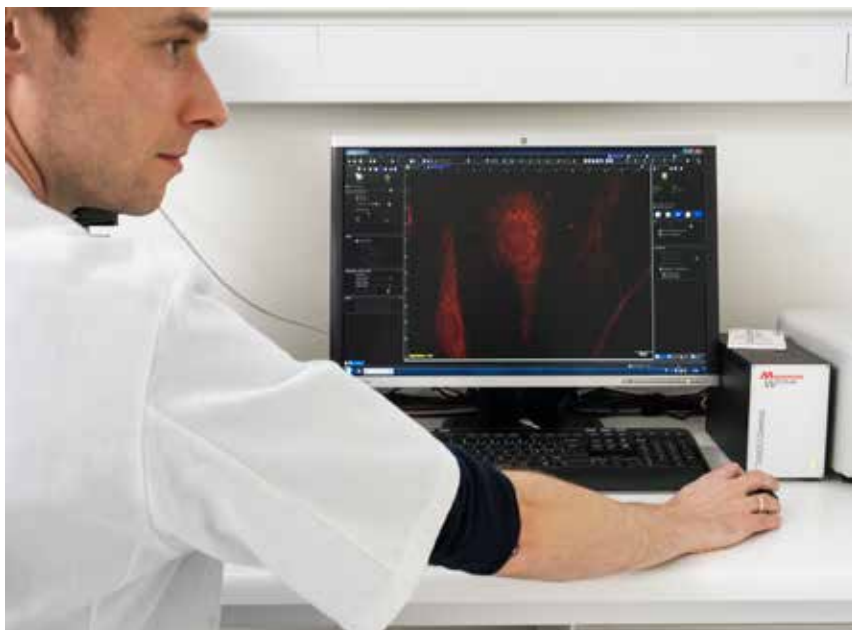


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ABOUT THE DANISH DEMENTIA RESEARCH CENTRE (DDRC)

MISSION

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 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

The DDRC, located at Rigshospitalet and based in the Department of Neurology, is a nationwide service. Initiated and funded by the Danish Ministry of Health and the Danish Health Foundation, the National Info & Education Centre comprises a steering committee and a scientific advisory board.

With representatives from the Ministry of Health, the Ministry of Social Affairs and Integration, the Danish Regions and Local Government Denmark, and the Danish Health Foundation the steering committee monitors the progress of the strategic development and performance of the National Info & Education Centre according to predefined objectives and milestones.

Members of the steering committee at the close of 2014:

- Svend G. Hartling, Capital Region of Denmark (*chairman*)
- Hanne Jervild, Danish Health Foundation
- Gertrud Rex Baungaard, Ministry of Health
- Mads Biering la Cour, Ministry of Children, Gender Equality, Integration and Social Affairs
- Søren Bredkjær, Danish Regions
- Karen Marie Myrndorff, Local Government Denmark
- Line Sønderby Christensen, Capital Region of Denmark
- Jannik Hilsted, Rigshospitalet, University of Copenhagen
- Gunhild Waldemar, DDRC, Rigshospitalet, University of Copenhagen



The Rockefeller building at Rigshospitalet.

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, the National Board of Social Services, 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 (*Ældresagen*).

Members of the scientific advisory board at the close of 2014:

- Knud Damgaard Andersen, National Board of Social Services
- Marianne Jespersen, Danish Health and Medicines Authority
- Inge Dyrholm Feldbak, Local Government Denmark
- Lisbeth Hyldegaard, Local Government Denmark
- Hanne Elkjær Andersen, Capital Region of Denmark
- 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
- Anne Arndal, Danish Alzheimer's Association
- Bettina Thoby, Huntington's Disease Association
- Kirsten Dyrborg, The DanAge Association

In addition the 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.

STAFF IN 2014

MANAGEMENT AND ADMINISTRATION

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 Sørensen, RN

Research directors

Steen G. Hasselbalch, MD, DMSc, professor

Jørgen E. Nielsen, MD, PhD

Educational director

Ane Eckermann, assistant nurse, master in health education,
(until 31.05.2014)

Karen Tannebæk, occupational therapist (gerontology),
(from 01.06.2014)

Administration

Karin la Cour, research secretary

Jette Gotlieb Iversen, course administrator (from 01.10.2015)

Ditte Majgaard Jensen, course administrator

Lisbeth Koch, administrative assistant

Olga Nikroozi, administrative assistant (until 01.06.2015)

Jette Rasmussen, research administrator

NATIONAL INFO & EDUCATION CENTRE

Helle Akselbo, RN, educational advisor

Tove-Marie Buk, RN, educational advisor

Mette Tandrup Hansen, MA, communication officer

Sarah Elizabeth Hvidberg, MA, MLIS, information officer

Kasper Jørgensen, MSc, neuropsychologist

Elsebeth Refsgaard, RN, educational advisor, project assistant

Karen Tannebæk, occupational therapist (gerontology),
educational director

RESEARCH

Kathrine Bjarnø, medical laboratory technician

Ane Nørgaard Christensen, MD, PhD student

Kristian Steen Frederiksen, MD, PhD, associated research
assistant (postdoc)

Christina Vangsted Hansen, RN, research nurse

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

Anne-Mette Hejl, MD, PhD, staff neurologist

Lena Hjermind, MD, PhD, staff neurologist

Kristine Hoffmann, MD, PhD student

Oda Jakobsen, RN, research nurse

Christina Jensen-Dahm, MD, PhD student

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 manager and postdoc

T. Rune Nielsen, MSc, PhD, neuropsychologist, research assistant
(postdoc)

Tien Kieu Phung, MD, PhD, associated research assistant
(postdoc),

Nina Rostgaard, MSc, PhD student

Lise Cronberg Salem, MD, PhD student

Anja H. Simonsen, MSc, PhD, research assistant (postdoc),

Jette Stokholm, MSc, neuropsychologist

Tua Vinther-Jensen, MD, PhD student

Asmus Vogel, MSc, PhD, neuropsychologist, research assistant
(postdoc)



The DDRC team.

Laila Øksnebjerg, MSc, neuropsychologist
 Camilla Steen-Jensen, PhD student
 Marie Bruun, MD, PhD student
 Peter Roos, MD, PhD student
 Nanna Cornelius, PhD student

COPENHAGEN MEMORY CLINIC

Medical doctors

Birgitte Bo Andersen, MD, DMSc, senior neurologist
 Hanne Vibe Hansen, MD, senior psychiatrist
 Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist
 Anne-Mette Hejl, MD, PhD, senior neurologist
 Lena Hjermand, MD, PhD, senior neurologist
 Peter Johannsen, MD, PhD, senior neurologist
 Susanne Lindquist, MD, PhD, clinical geneticist, staff physician
 Jørgen E. Nielsen, MD, PhD, senior neurologist
 Lisbeth Regeur, MD, DMSc, senior neurologist
 Sarah Taudorf, MD, PhD, neurologist, staff physician

Nurses

Lis Christoffersen, RN
 Nicole Cordes, RN
 Christina Vangsted Hansen, RN
 Lene Iben Hvidkjær, RN
 Oda Jakobsen, RN
 Annette Lauridsen, RN
 Anne-Margrethe Manniche, RN
 Naomi Wakabayashi, RN

Neuropsychologists

Maria Mimi Bang, MSc
 Ida Unmack Larsen, MSc
 Selma Nielsen, MSc
 Jette Stokholm, MSc
 Asmus Vogel, MSc, PhD
 Laila Øksnebjerg, MSc

Medical secretaries

Bente Friedman
 Dorthe Hansen
 Susanne Lindstrøm
 Pernille Munch-Christensen
 Ulla Thranow

Social counsellor

Pernille Starnø

Medical laboratory technologist

Kathrine Bjarnø

Receptionists

Anne-Mette Pedersen
 Joan Rysgaard

SPECIAL EVENTS IN 2014

PEOPLE'S MEETING ("FOLKEMØDET")

For four days in June Danish politicians from across the country gather on the island of Bornholm for a political festival, the People's Meeting, which provide an excellent opportunity for the Danish people to meet their elected officials and a range of organisations. DDRC had a booth for the first time at the event in 2014 and hosted five well-attended events.



AAIC – ALZHEIMER'S ASSOCIATION INTERNATIONAL CONFERENCE

AAIC was held in July in Denmark for the first time. DDRC was present with more than 20 posters, nine oral presentations, two chairs and an exhibition booth. Her Royal Highness Princess Benedikte opened the conference and the opening reception was held in Tivoli Gardens.



Gunhild Waldemar, HRH Princess Benedikte and Gerry Sampson, President of the Alzheimer's Association

FINAL MIGRATION SCHOOL CONFERENCE



In September the Migration School project was completed and a final conference held in Copenhagen with 300 attendees from Sweden and Denmark.

The Migration School is the largest research and educational programme in Europe for assessment, treatment and care for patients from ethnic minorities.

SCANDINAVIAN CONFERENCE IN STOCKHOLM

In October 2014 the joint Scandinavian conference “Good dementia care: A question of leadership?” was organised for the second time and held in Stockholm, Sweden.



Wilhelmina Hoffmann, President of The Swedish Dementia Centre and Vibeke Drevsen Bach



Professor Øyvind Kirkevold, Norwegian National Advisory Unit on Ageing and Health



TWO PHD DEFENCES

Lise Cronberg Salem, MD, was awarded a PhD after defending her thesis "Dementia in the young: A diagnostic challenge" in August 2014.



Evaluation committee: Anne Sabers (supervisor), Per Soelberg Sørensen, Gunhild Waldemar (supervisor), Kjeld Andersen, Lise Cronberg Salem, Knut Engedal and Asmus Vogel (supervisor)



Christina El-Ali Jensen-Dahm received her PhD in December 2014. The title of her thesis was, "Pain perception and autonomic function in Alzheimer's disease".



Evaluation committee: Stefan Lauterbach, Gunhild Waldemar (supervisor), Flemming Bach, Christina Jensen-Dahm and Poul Jennum

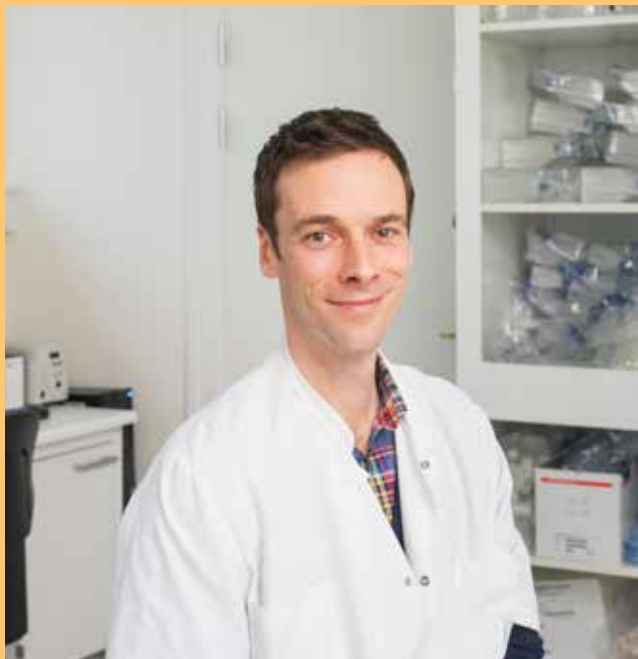


NEW RESEARCH LABORATORY

After moving to the Rockefeller building at Rigshospitalet in 2013, DDRC established its new laboratory for neurogenetics research and biobank in the renovated basement floor in March 2014.



Anja H. Simonsen, MSc, PhD, senior researcher and responsible for the biobank laboratory



Troels T. Nielsen, MSc, PhD, senior researcher and responsible for the neurogenetics laboratory



COPENHAGEN MEMORY CLINIC



In 2014 a total of 1,106 referred patients completed a diagnostic evaluation programme and were classified as follows:

Syndrome	Diagnosis	Number
Dementia	Total	467
	• Alzheimer's disease	201
	• Vascular or mixed dementia	80
	• Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinsons plus syndromes	34
	• Frontotemporal Dementia	22
	• Normal pressure hydrocephalus	41
	• Other specific conditions including Huntington's disease	35
	• Dementia of uncertain aetiology	54
Mild cognitive impairment and other cognitive profiles	Patients with other specific neurodegenerative disorders without dementia, patients with depression and other psychiatric conditions and sequelae after traumatic brain injury	232
No cognitive impairment	Patients with subjective symptoms	345
Healthy persons	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	62

The Copenhagen Memory Clinic at Rigshospitalet 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.

KEY FIGURES FROM THE COPENHAGEN MEMORY CLINIC 2006-2014

	2006	2007	2008	2009	2010	2011	2012	2013	2014
New patient referrals	642	737	709	726	842	778	920	953	1021
Total number of visits	4015	4638	4192	4811	5807	5700	6770	6311	6920
Patients in follow-up programme	1153	1516	1487	1648	1766	1892	2038	2088	2044

In 2014 predefined patient tracks for diagnostic evaluation were introduced. All patients were 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 specialty 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. 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. Our centre also collaborates with the Movement Disorders Clinic, Bispebjerg Hospital.

Normal pressure Hydrocephalus (NPH)

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

In 2014 there were 242 patients referred for a clinical evaluation for NPH, 69 of whom had a lumbar perfusion test after the clinical examination. All patients are discussed in 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

An improved programme was developed in 2014 for healthy at-risk family members and now includes a consultation with a trained psychologist before considering genetic testing. The clinic also offers crisis consultations for patients and relatives, when needed.



CURRENT NUMBER OF PATIENTS IN FOLLOW-UP PROGRAMME

Data for 2014 extracted from hospital administration database February 2015, selected diagnostic categories

G.30.1, G 30.9, G30.8, G.30.0	Alzheimer's disease and mixed dementia	654
G91.2	Normal pressure hydrocephalus	98
F04.9, F06.7	Mild cognitive impairment and other mild cognitive disorders	123
G10.9	Huntington's disease	151
Z82.0	Familial disorders/genetic counselling	217
G11.1-4, G.11.9,G, R27.0	Ataxias (including SCAs and FXTAS), and hereditary spastic paraplegia	156
G 24.0-2, G24	Dystonia	15
G60.0, G62.9	Familial motor neuron diseases	9
G23.1+22,G 23.8+9,G,25.9	Parkinson's disease, including atypical forms	20
G31.8	Frontotemporal dementia and other specific neurodegenerative diseases	106
G 31.9, F03.9	Other (unspecified) neurodegenerative disorders	52
G31.8E	Dementia with Lewy bodies	58
I69.3+4	Vascular dementia	21

PATIENTS AND FAMILIES

The Copenhagen Memory Clinic managed more patient visits than ever before in 2014. 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.

Classification of the 2,044 patients in our follow-up programme differs significantly from that of new patients referred. All patients with mild cognitive impairment (MCI), dementia or

specific neuro-degenerative 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 /neuro-genetic 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 three-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 from the national database which is in preparation and 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 ("planområde BYEN"), 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 organized and takes active part in the national network for memory clinics.

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, 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, information from 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.

The three research groups count nine PhD students and five postdocs. 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 and the Danish Health Foundation as an integral part of the National Info & Education Centre. Our research is conducted in collaboration with a wide range of Danish and international research groups.

BIOMARKER FLUIDS

The aim of our biomarker research is to discover and validate new biofluid markers for the early diagnosis of AD and other neurodegenerative disorders, as well as 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).

BRAIN IMAGING

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 multicentre studies such as 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. Because of the continuous use of clinical amyloid imaging, it has been possible to undertake a large multicentre study on the validation of CSF amyloid using amyloid imaging as the gold standard. Danish collaborators that 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.

QUANTITATIVE ELECTROENCEPHALOGRAPHY (EEG) IN EARLY DIAGNOSIS OF AD

As one of eight European memory clinics, DDRC has participated in the Nordic Network in Dementia Diagnostics (NIDD) since 2007. NIDD examines the role of quantitative EEG in the early diagnosis of AD. This study also forms a platform for a joint PhD study between the memory clinics in Roskilde and Copenhagen. For more information, see nidd-dementia.org.

*Steen G. Hasselbalch,
research director*



PREDICTND

This European multicentre research project addresses the clinical challenge that lies in differentiating between different types of dementia focusing on AD, DLB, FTD and vascular dementia. PredictND is a technological decision support tool designed to assist in early diagnosis and monitoring of disease progression. Supported by EU's FP7 programme, the project aims to study the accuracy of the PredictND tool in regards to 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.

NEUROGENETICS

Neurogenetic research focuses on clinical characteristics, paraclinical findings, treatment and basic research into gene function and therapy. DDRC is part of the European Huntington's Disease Network (EHDN), which is conducting a large multinational observational HD study (REGISTRY) that includes data from DDRC on more than 300 patients, making the DDRC one of the largest players in this collaboration.

The REGISTRY study has provided DDRC with the opportunity to initiate one of the largest longitudinal cohorts of presymptomatic and symptomatic HD gene carriers for investigating early clinical features, imaging, genetic modifiers and biofluid markers.

Through the SPATAX network, which combines the experience of European clinicians and scientists working on hereditary ataxias and paraplegias, we are helping to initiate a new

clinical and genetic database; distribute DNA to participating laboratories; map new loci; and identify new genes (spatex.wordpress.com/). The clinic follows more than 200 patients with ataxia and paraplegia. Spinocerebellar ataxia type 2 (SCA2) is a research focus area with a long-term goal to develop a gene therapeutic approach using ribonucleic acid interference as a tool. Neuronal cell lines have now been derived using stem cell technology. These lines will be used in DDRC's newly established neurogenetics laboratory as disease models and to further explore the potential of gene therapy.

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 2014 research continued with studies designed to understand the disease mechanism, and neuronal cell lines are now derived using stem cell technology to further explore disease mechanisms and the potential of gene therapy.

PATIENT-SPECIFIC STEM CELL-DERIVED MODELS FOR AD

Funded by the Danish National Advanced Technology Foundation, this programme involving models for AD is carried out in collaboration with Department of Veterinary Clinical and Animal Sciences, Faculty of Health and Medical Sciences, Bioneer Inc., Pixiegene Inc., Lundbeck Inc. and the Department of Molecular Biology and Genetics, Aarhus University.

The objectives of the programme are to generate induced pluripotent stem cell (iPSC) lines from well-characterised patients suffering from inherited AD and FTD and to differentiate them

Jørgen E. Nielsen,
research director



into relevant neuronal subtypes that can be used as in vitro cell models to identify drugs and targets for personalised medicine. The DDRC also participates in a Marie Curie initiative supported by the European Union for developing stem cell-derived models of FTD3 and SCA2.

NEUROPSYCHOLOGY

DDRC's neuropsychological research mainly focuses on characterisation of cognitive deficits in the early phase of dementia diseases and MCI. Different research areas include the effect of aging on cognitive performance, the role of subjective memory complaints in ageing and dementia, and the validity of cognitive test procedures in different neurodegenerative disorders. In the past few years several papers on longitudinal changes in cognitive processes have been published.

In recent years studies on social emotion, social cognition and personality changes have been initiated. Studies in these areas have been conducted in patients with FTD and in manifest and pre-manifest Huntington gene-expansion carriers.

Cross-cultural neuropsychological examination has been a research area at DDRC for some years. The Cross-Cultural Neuropsychological Test Battery (CNTB) has been used and a currently ongoing study focuses on the validity of the CNTB in European majority and minority populations. The project focuses on improving the clinical evaluation of cognitive dysfunction in patients with diverse cultural and linguistic backgrounds. The study is an international multi-centre study including nine European centres.

Various cognitive training and cognitive rehabilitation methods have been explored in case studies and in pilot studies at DDRC.

In 2014 focus has been on cognitive rehabilitation in early-stage AD that integrates technology as a primary tool of compensation.

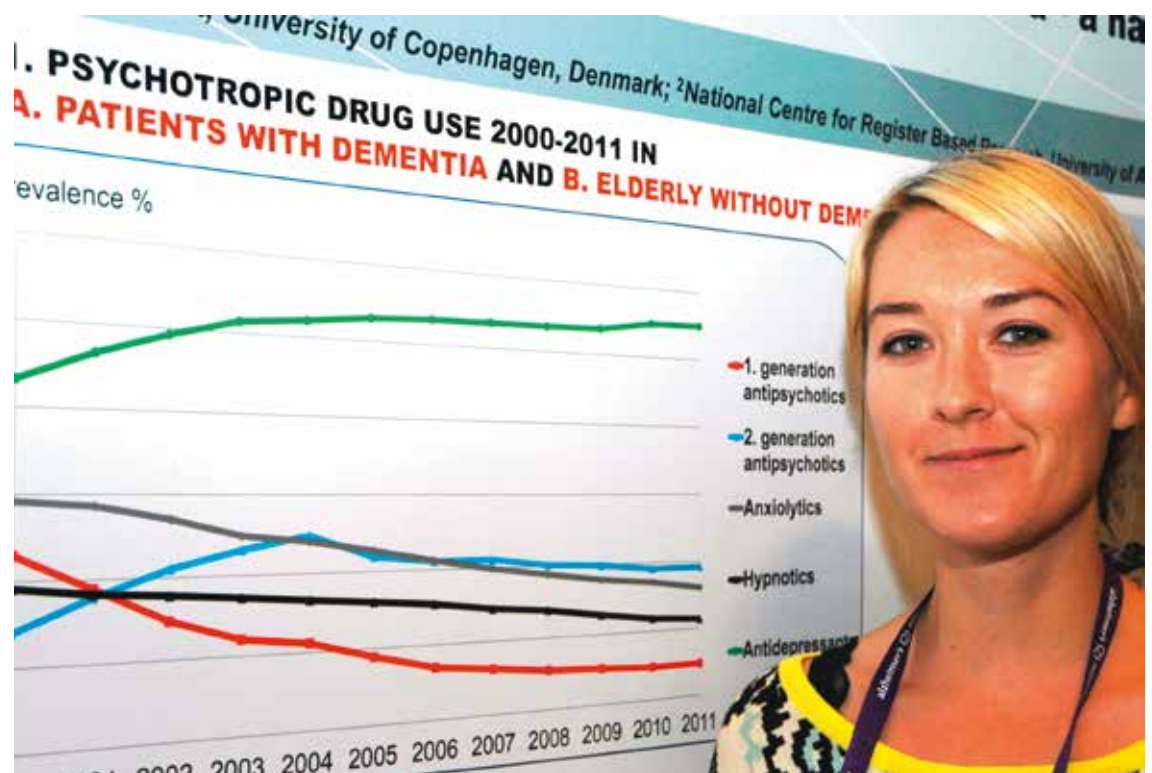
INTERNATIONAL STUDIES: DEMENTIA IN LEBANON

This study is part of the 10/66 Dementia Research Group, an international network of researchers who carry out population-based studies on dementia in developing countries. The study aims to validate diagnostic assessment of dementia in Arabic and to investigate the incidence, prevalence, risk and protective factors specific to the Lebanese population, as well as the barriers to treatment and care for people with dementia in Lebanon.

DDRC is a study partner together with the Department of Epidemiology and Population Health, Faculty of Health Sciences, American University of Beirut (AUB), Lebanon, in collaboration with the Division of Neurology, AUB Medical Center; and the Institute of Psychiatry, King's College London. The study was funded by the Fogarty International Center, American National Institutes of Health (NIH) and the National Institute of Aging (NIA) under the programme "Brain Disorders in the Developing World: Research Across the Lifespan (BRAIN)".

PHARMACO-EPIDEMIOLOGY: PRESCRIPTIONS IN PATIENTS WITH DEMENTIA

Using nationwide registry data this project investigates the use of medication in patients with dementia as compared to the Danish population in general. Projects investigating patterns of analgesic use, psychotropics and use 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.



INTERVENTION STUDIES: ADEX AND DAISY

ADEX, or “Preserving quality of life, physical health and functional ability in Alzheimer’s disease: The effect of physical exercise”, is a Danish multi-centre study comprising eight Danish dementia clinics, the Institute of Sports Medicine, Bispebjerg Hospital and other Danish and international partners, supported by the Danish Strategic Research Council.

The project was initiated to establish a platform for future cooperation on dementia research in Danish memory clinics. The first project investigates the effect of physical training in patients with AD. Patient inclusion was completed in 2014. A sub-sample of more than 40 subjects undergoing brain imaging (MRI and amyloid PET) and biofluid (plasma and CSF) markers will allow for an analysis of the mechanisms behind the effect of exercise. ADEX also serves as a platform for creating a research alliance between Danish memory clinics with benchmarking to Swedish and Dutch networks. For more information about partners and current status, see: videnscenterfordemens.dk/adex.

Danish Alzheimer Intervention Study (DAISY) was a randomised trial that investigated the effect of psychosocial intervention on 330 individuals in the earliest phases of dementia and their caregivers. The effect of the intervention was measured based on different parameters in patients and caregivers, including health, cognition, quality of life, depression and daily living activities.

Many scientific papers have been published from this study, e.g. on health, quality of life and psychological symptoms. For more information, see: videnscenterfordemens.dk/daisy

DRUG TRIALS (CONTRACT RESEARCH)

DDRC has extensive experience in the conduction of phase 1 to phase 4 clinical pharmacological trials in patients with AD, MCI and HD. In recent years the focus has been on phase 1 and phase 2 trials. In 2014 the Copenhagen Memory Clinic participated in an on-going phase 1 study of an active beta-amyloid vaccine (sponsor: AC Immune); on-going phase 2 and 3 studies of a passive beta-amyloid vaccine (sponsor: Roche); a phase 2 study of a beta-secretase inhibitor (sponsor MSD/Merck); and a phase 3 study of a 5HT-receptor antagonist (sponsor Lundbeck). The clinical trials are being conducted with state-of-the-art imaging techniques in collaboration with DRMR, Hvidovre Hospital and the PET and Cyclotron Unit, Rigshospitalet.

NATIONAL INFO & EDUCATION CENTRE

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

The National Info & Education Centre had an unusual year in 2014 because the large international conference, AAIC, was held in Copenhagen for the first time, and DDRC was involved on a variety of levels, for instance as members of the programming committee, speakers, chairs, poster presenters and booth personnel. As a result DDRC's Dementia Days was postponed until 2015 and professionals who would normally participate were encouraged to attend AAIC instead, which offered a special two-day track (Dementia Care Track) designed for delegates primarily interested in dementia care.

Another unusual event attended by the DDRC for the first time in the summer of 2014 was the People's Meeting (*"Folkemødet"*), an annual political festival hosted on the island of Bornholm. As booth holders DDRC arranged five events: two political debates, two Q&A sessions called "Ask the Professor" and a GPS run. We also participated in debates arranged by other organisations. Many people visited the booth during the four days to learn about dementia and the events were well attended.

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 Norwegian and Swedish research and education centres.

ACTIVITIES 2014

Activity:	Courses	Conferences	Thematic events	Customised courses	Total
	6	4	2	61	73
Participants:	216	980	383	3427	5006

*The educational team:
Elsebeth Refsgård,
Helle Akselbo,
Tove Buk and
Karen Tannebæk*



In 2014 DDRC organised courses, conferences and local courses tailored to the needs of specific groups per request by municipalities and regional institutions. Designed to meet a specific purpose or cover a certain subject, customised courses were attended by various professionals. A new approach to teaching was introduced in 2014 – blended learning – where the students were asked to complete ABC Dementia (our free online course) before attending a customised course. This approach proved valuable and will be used more in 2015.

The 2014 catalogue offered a variety of activities (courses, thematic events and conferences) on a wide range of subjects, such as “Frontotemporal dementia”, “Update on Alzheimer’s disease” and “Dental health and dementia”.

At thematic events a whole day is dedicated to a particular subject guided by professionals with extensive experience about the topic in question. An example of a thematic event held in 2014 was “Person-centred care” with Professor Dawn Brooker as the keynote speaker.

In 2014 DDRC was invited to Local Government Denmark’s Conference on Elderly Care and the National Social Service Conference as an organiser of symposia, providing us with the opportunity to reach out to legislators and politicians from all regions of Denmark.

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 November 28 more than 200 professionals attended the annual research conference to get an update on Alzheimer’s disease

research. In addition to senior neurologist Peter Johannsen and Professor Steen Hasselbalch from DDRC four speakers from other research institutions presented their research:

- Professor Peter Elwood, Cardiff University School of Medicine
- Eric Bonsang, PhD in Economics, Maastricht University
- Professor Ian Law, Department of Oncology, Section of Radiotherapy, Rigshospitalet
- Professor Poul Hyttel, Department of Veterinary Clinical and Animal Sciences, Faculty of Health and Medical Sciences, University of Copenhagen





*Gunhild Waldemar and Astrid Norberg
at the Scandinavian conference for
leaders in dementia care*

Scandinavian conference for leaders in dementia care

The three national Scandinavian dementia research and education centres organised a joint conference focusing on the implementation of good dementia care. The conference, entitled “Good dementia care: A question of management?” was held in October in Stockholm, Sweden.

The conference attracted 320 leaders in dementia care from Sweden, Norway and Denmark. A number of internationally recognised speakers were invited, including Paul Edwards, the head of training and practice development at Bradford Dementia Group, University of Bradford. Paul Edwards gave a presentation on “Person-centred leadership” and Astrid Norberg, Sweden’s first professor in nursing research, gave an inspirational speech on “Staff conscience and stress”. The conference also offered a number of smaller workshops. The next Scandinavian conference will be held in Oslo, Norway in 2016.

The final Migration School conference

The Migration School is a cross-national collaborative programme on dementia assessment, treatment and care for patients from ethnic minorities in the Oresund Region. The Dementia Knowledge Centre, Skåne University Hospital, Sweden and DDRC are partners in the programme.

On September 25 a closing conference with an impressive turnout of more than 300 attendees was hosted in Copenhagen. The purpose of the conference was to share the experience and knowledge on ethnic minorities and dementia gathered over the last three years.

Initiated in 2011 the project was funded by the Capital Region of Denmark, the Skåne Region of Sweden and the European Regional Development Fund INTERREG IV A.



*Research and documentation:
Rune Nielsen, Kasper Jørgensen and
Asmus Vogel*



By the end of the project period more than 1,000 health care workers had attended the Migration School's educational programmes. Cross-cultural assessment instruments and publications aimed at health care workers, e-learning and information materials for patients and caregivers have been made available as a result of this project.

ABC DEMENTIA – FREE ONLINE COURSE

ABC Dementia is e-learning divided into modules. Each module covers a theme, e.g. dementia disorders, behavioural disorders, and communication. All themes are presented in a practice-oriented manner and a variety of educational approaches are used, making it very user-friendly. By the end of 2014 seven modules had been produced and more are 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 what traditional courses and conferences do. Offering free e-learning is a way to provide all care staff across the country easy access to knowledge about dementia. By the end of 2014 ABC Dementia had more than 6,500 users and

RESEARCH AND DOCUMENTATION

An active participant in research and documentation activities, the National Info & Education Centre is the main supplier of material for the DDRC website and facts for journalists and professional stakeholders.

Research

In 2014 the National Info and Education Centre published a handful of studies and reviews related to neuropsychology and epidemiology:

- A study of the frequency and severity of semantic deficits in a consecutive memory clinic cohort based on commonly used neuropsychological tests
- A study of the development in awareness over three years in patients with mild Alzheimer's disease using longitudinal data from the Danish Alzheimer Intervention Study (DAISY)
- A study of the reliability and validity of the Clock Drawing Test in Danish patients with mild Alzheimer's disease
- A review of the prevalence of dementia in Denmark based on national and international epidemiological studies
- A review regarding dementia screening of patients with ethnic minority origin
- A study of the use of opioids in patients with dementia.

Documentation

- A revised overview of diagnostic criteria for dementia and for disorders causing dementia has been published.
- A battery of screening tests for dementia loosely inspired by the Queen Square Screening Test for Cognitive Deficits has been developed and published.
- We have launched an online memory test and an online risk calculator for dementia on the DDRC website.
- The virtual toolbox for dementia health care workers and researchers has been supplemented with summaries of neuropsychiatric rating instruments, quality of life rating scales and Danish normative data and reference data for neuropsychological tests.
- A national estimate of the cost of dementia was presented as a poster at AAIC in July 2014 in Copenhagen.

Mette Tandrup Hansen
and Sarah Elizabeth
Hvidberg



COMMUNICATION AND PRESS

We have experienced a rise in activity on all platforms and a growing number of followers on social media. This is due to a more strategic approach to public relations and a more focused effort in reaching out to our stakeholders and the press in general.

Website

- 121,000 users visited the DDRC website 173,000 times in 2014*
135,000 users and 216,000 visits in 2013
98,000 users and 162,000 visits in 2012

* Due to technical changes in the method for registration on our website the numbers are smaller than expected in 2014.

Press 2014

	2014	2013	2012
Print	315	173	108
Online	301	166	122
Radio	45	22	10
TV	27	16	11

15. OKT. 2014 KL. 06:30

15 demente forsvinder og dør på et år

I løbet af det seneste år er 15 demente omkommet efter at have forladt deres hjem eller plejehjem, viser ny opgørelse.

Ældres morfinforbrug bekymrer forskere

Fire ud af ti af de demente plejehjemsbeboere bruger morfinlignende medicin.

22. MAJ 2014 KL. 10:37

Test din risiko for demens

Er du i særlig risiko for at få en demens-sygdom? Få et fingerpeg i en simpel test.

Digital post og demens

Vil du blive klogere på det digitale Danmark og udfordringen med demensrørtes digitale kommunikation med det offentlige? Nationalt Videnscenter for Demens har lavet retningslinjer.

demens, hvis ikke borgere kan honorere de nye krav. Hvad der er den bedste løsning for en person med demens, afhænger af personens lyst og evner, netværket omkring personen samt adgangen til computer og internet.

de ved at henvende sig til Borgerservice og underskrive en fuldmagt. Hvis personen allerede har et Nem-ID, kan velkommande selv lave en e-boks og inde i e-boksen give andre adgang til at læse posten. Læseadgangen giver den fordel, at pårørende, der har læst val-

eller manglende adgang til en computer. Fritagelse for Digital Post er ikke ensbetydende med, at man også er fritaget fra digital selvbetjening. Der findes mange forskellige digitale selvbetjeningsløsninger, som varierer i kompleksitet, og det er derfor

Yngre patienter får fejlagtig demensdiagnose

Når der er mistanke om demens hos yngre mennesker, bliver de ofte undersøgt mindre grundigt end ældre patienter. Det kan betyde fejldiagnoser, viser ny forskning



Newsletter six times a year

5,600 subscribers by January 2015

4,300 subscribers by January 2014

App: About Dementia (Viden om Demens)

19,000 downloads by January 2015

13,400 downloads by January 2014

Social media

Facebook is used to create and maintain relations to the public and disseminate knowledge about dementia and DDRC (e.g. activities, courses, conferences).

By January 2015 we have 508 followers compared to 120 followers by January 2014.

Twitter is used, for instance to spread news about research and create relations to relevant journalists. We began using it in December 2013.

290 followers and 248 tweets by January 2015 and 30 followers in January 2014.

DDRC CONFERENCE BOOTH

2014 was a very busy year for our conference booth, which we used on many occasions. A great deal of new materials were produced and DDRC staff met hundreds of people interested in dementia.

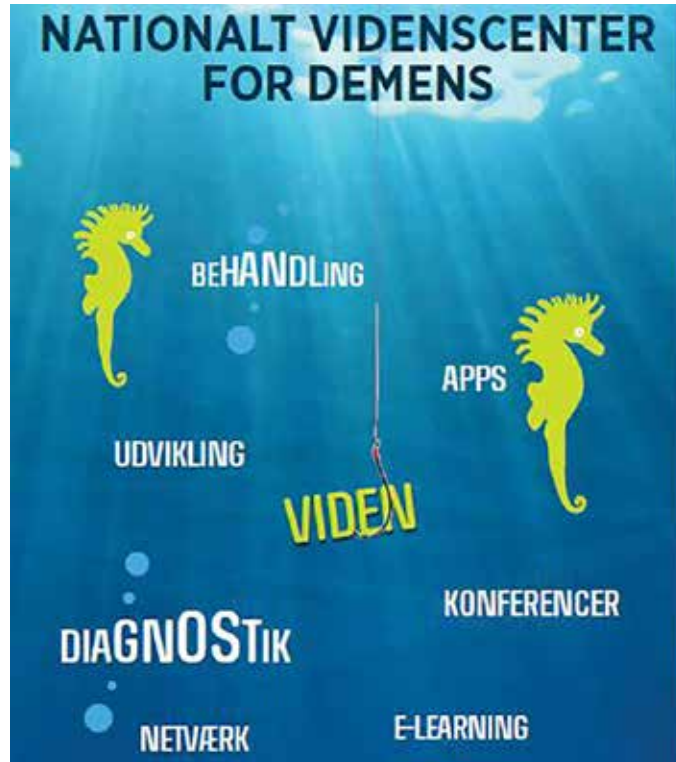
In May the booth was present at the annual National Social Service Conference, organised by Local Government Denmark in Aalborg. DDRC also participated as the organisers of a symposium on dementia attended by around 150 people. At this conference a new web tool "Test your risk of dementia" was presented. Many participants took the test and received information about prevention.

In June the booth travelled to the island of Bornholm to participate in the People's Meeting and was a tent measuring 18m2, providing ample space for numerous games and tests representing different domains of the human brain. The games were engaging and prompted many valuable conversations with the large number of visitors that came past all four days.

The booth was redesigned for the AAIC in July and all of the materials were in English during its five-day stay at Bella Center. An English language web-quiz was written with fun facts about the host country and about the organisation of dementia care organisation in Denmark.

The booth was also present at the annual course for municipal and regional coordinators of dementia, a three-day day conference attended by about 350 professionals.





In September the Capital Region of Denmark hosted Health Days in Øksnehallen and DDRC put up a large booth with games and information materials. Health Days was visited by 16,500 adults and children. The booth staff was made up of medical doctors and nurses from the Copenhagen Memory Clinic and Glostrup Hospital.

The booth also presented materials at the Migration School conference in September and at the two-day Scandinavian conference “Good dementia care: A question of management” in Stockholm, Sweden.

The two online tests, “Test your risk of dementia” and “Recall test”, were great tools for starting a conversation with conference participants. The games representing different domains of the human brain that was used at the People’s Meeting in Bornholm proved to be eye-catching and engaging.

By attending various events, DDRC generates new contacts and spreads information about its products to professionals and stakeholders as well as general knowledge about dementia to the public.

Nationalt Videnscenter for Demens
Slået op af Mette Tandrup Hansen [?] · 26. maj 2014 · Redigeret ·

Svar på 7 simple spørgsmål om dit helbred og livsstil og beregn din risiko for at få en demenssygdom.

Test din risiko for demens
Vi har alle en livstidsrisiko på 20-25 pct. for at få en demenssygdom. Risikoen stiger med alderen, men demens er ikke en naturlig følge af alderdom. Demens skyldes altid sygdom i hjernen.

VIDENSCENTERFORDEMENS.DK

Nået ud til 1.197 personer **Boost opslag**

Synes godt om · Tilføj kommentar · Del · 11 1

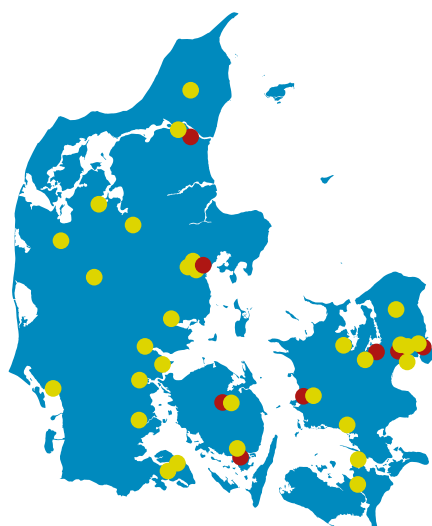
NATIONAL NETWORKS

In order to foster an exchange of knowledge, education and quality programmes DDRC 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 memory clinics are based in 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) participates 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 2014 DDRC organised its seventh annual network conference for memory clinics in Denmark. The 2014 confer-



Network of Danish Memory Clinics (memory clinics are indicated with yellow dots, ADEX centres with red dots).

ence attracted representatives from all clinics in the country, with a total of 142 people participating, including physicians, nurses, psychologists, secretaries and therapists. The main topics covered were NPH, the national dementia database and harmonisation of diagnostic criteria and tools in Danish dementia clinics.

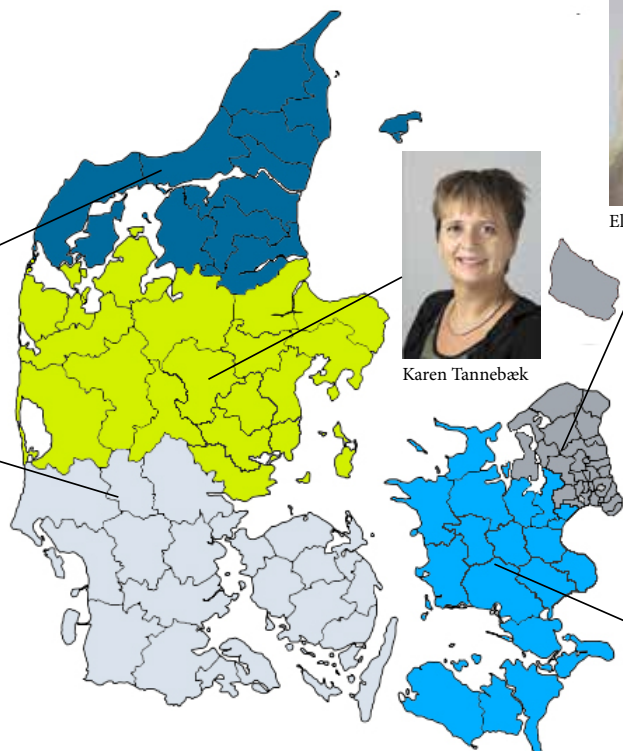


Annual meeting for network of Danish memory clinics, Nyborg strand, October 2014.

Regional coordinators of the national network of dementia ambassadors.



Helle Akselbo



Karen Tannebæk



Elsebeth Refsgård



Tove Buk

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 2014 the network of local dementia ambassadors met for the fifth 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, Local Government Denmark and the Danish Dementia Coordinators. The main topic of the day was "Nutrition for people with dementia".



Annual meeting for network of municipality-based dementia ambassadors, Odense, March 2014.



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 Alzheimer's disease. 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 and supports working towards standardisation of diagnostic criteria, assessment tools and data collection methods, with a view to this being followed by a trial period involving the testing and practical application of the tools agreed upon (see: eadc.info/sito/pagine/home.php). DDRC is the only Danish EADC member and has contributed to or directed studies on assessment tools, health economics, biomarkers and cross-cultural aspects of dementia care.

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 working together 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. 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 large conference on leadership in dementia care (see: National Info & Education Centre for more details) is one of the larger outcomes of this Scandinavian collaboration.

NORTH SEA DEMENTIA GROUP

The North Sea Dementia Group comprises dementia practitioners from 11 European countries who meet annually to share information on dementia care practice and research. Current members are from Belgium, Denmark, France, Germany, Ireland, Italy and Luxembourg, the Netherlands, Norway, Sweden and the UK. In 2014 the network met in Dijon, France. After a short update from all participating countries, the participants presented dementia care research on the following five topics: nursing homes and day care activities, supporting family carers, home care, community and activities, and dementia care practice.

INTERDEM

DDRC is a member of Interdem, a pan-European network of researchers on early detection and psycho-social interventions in dementia. Academic and clinical researchers from 20 nations are members of the network. In 2014 the group met in Copenhagen and the meeting was hosted by DDRC. See: interdem.org.

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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

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Christina Jensen-Dahm

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Chair, Liaison Committee, European Federation of Neurological Societies (EFNS); member of the transition task force for merging EFNS and European Neurological Society (ENS), creating the European Academy of Neurology (EAN); member of the Medical and Scientific Advisory Panel (MSAP) of Alzheimer's Disease International (ADI); chair, the Scientific Committee of the Danish Alzheimer Association; board member of the Danish Alzheimer Foundation; member of the Board of Trustees and chairman 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; member of the editorial board for *Dementia and Geriatric Cognitive Disorders*, *Practical Neurology* and *European Journal of Neurology*

Laila Øksnebjerg

Chair of the board, Danish Neuropsychological Society; co-leader of the JPND-supported pan-European working group "Dementia outcome measures: charting new territory."

FINANCE

Research administrator
Jette Rasmussen



The total annual budget of the DDRC amounts to approximately 30m DKK, almost evenly distributed between internal funding (for memory clinic services) and external grants for projects and commercial activities (research and educational activities). In

2014 the National Info & Education Centre was extended with a grant of 19,2m DKK from the Danish Ministry of Health (for 2016-2018) and the DDRC received an additional 8,7m DKK in grants from external foundations.

KEY FINANCIAL FIGURES

Memory Clinic

DRG production 2014 1,000 DKK	31,910
Annual budget 2014 1,000 DKK	17,502

Research and Education

External grants 2014 (1,000 DKK)	27,932
Danish Ministry of Health	19,200
Other new grants 2014	8,732
External grants cumulated 2007-2014 (1,000 DKK)	111,400
Commercial activities, income 2014 (1,000 DKK) <i>(conferences, products and research contracts)</i>	2,082

Staff 2014

Number of employees (FTE)	68 (55.1)
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AWARDS



Every year on the international Alzheimer Day, September 21, the Danish Alzheimer Research Foundation presents an award to two researchers.

In 2014 one of the research awards was given to senior neurologist Peter Johannsen for his outstanding work with coordination of clinical trials, knowledge of treatment of dementia, excellent teaching skills and valuable work with developing a quality database on diagnosis of dementia.



In 2014 DDRC was reappointed a winner of the Global Excellence - in Health award. Global Excellence - in Health winners are hospital and university environments in the Capital Region that perform world-class international research leading to the development and implementation of pioneering health care services, treatment methods and products for the benefit of patients. DDRC was one of the first 10 winners of the award in 2010.

AAIC 2014 – COPENHAGEN

Almost 5,000 experts in dementia gathered in July 2014 in Bella Center for the annual AAIC, the world's largest dementia conference. Together with DDRC, AAIC arranged a two-day Dementia Care Track primarily for care workers. DDRC helped organise the track and was active as both speakers and chairs. DDRC researchers were present with more than 20 posters, nine oral presentations and two chairs, but also worked with a dissemination booth in the exhibition area.



NEUROLOGY IN EUROPE – TOWARDS A NEW UNITED EUROPEAN ACADEMY OF NEUROLOGY

Since 2009 the director of DDRC, Professor Gunhild Waldemar has worked as a member of the Transitional Task Force, established by EFNS and ENS with the aim to merge the two societies, creating a new united European Academy of Neurology (EAN) representing more than 20,000 neurologists, national neurological societies from 45 countries and individual members. EAN was formerly established in June 2014. The first international conference of the society will take place in Berlin in June 2015, and the Danish Neurological Society will host the second conference in Copenhagen in 2016. The Transition Task Force consists of Professors Jacques de Reuck, Belgium; Detlef Kompf, Germany; and Gunhild Waldemar, Denmark for EFNS, and of Professors Claudio Bassetti, Switzerland; Jose Ferro, Portugal; and Gustave Moonen, Belgium for ENS. EAN intends to be a society open to membership from all over the world and will welcome collaboration with other organisations. Learn more from ean.org and from Zohar Argov and Richard Hughes (2012). *Creation of the European Academy of Neurology. Neurology, 28,137.*



The Transition Task Force (2009–2014) at a meeting in Vienna in March 2014. Back row from left: Detlef Kömpf, Germany; Gustave Moonen, Belgium; Jacques De Reuck, Belgium); front row from the left: Gunhild Waldemar, Denmark; José Ferro, Portugal; and Claudio Bassetti, Switzerland.

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- * Aase and Ejnar Danielsen Foundation

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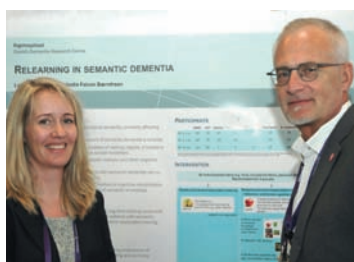
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