



DANISH DEMENTIA  
RESEARCH CENTRE



# DANISH DEMENTIA RESEARCH CENTRE (DDRC)

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

Annual report 2013

REGION

Rigshospitalet · University of Copenhagen



DANISH DEMENTIA  
RESEARCH CENTRE



# PREFACE



2013 was an eventful year for the Danish Dementia Research Centre (DDRC).

In November, an old dream came true when the DDRC moved into the Rockefeller Complex at Rigshospitalet, uniting the DDRC Memory Clinic, administration, researchers and information and education centre under the same roof for the first time and with new space for our neurogenetics research laboratory and biobank.

In May 2013 Steen G. Hasselbalch was appointed professor of cognitive neurology and dementia. His inaugural lecture was entitled "Dementia and dementia diseases: Development in concepts, diagnostics and treatment". Established as part of our *Global Excellence in Health* programme, the professorship will strengthen our biomarker and neuroimaging research, based on the growing number of patients attending our memory clinic.

During Dementia Days, the DDRC's annual national conference for dementia specialists, the initial modules of our new e-learning course targeted professional caregivers, ABC Dementia, were launched. At the close of 2013, more than 2,900 users had registered and the number continues to grow.

More than 3,600 participants attended our nationwide courses and conferences in 2013. Our international PhD course on Alzheimer's disease (AD) was offered for the second time. In January, the Migration School, a cross-national collaborative programme on dementia assessment and care for patients from ethnic minorities in the Oresund Region, hosted its first event in Malmö, Sweden, with 300 attendees, marking the beginning of a wide range of educational activities.

The number of visitors on [videnscenterfordemens.dk](http://videnscenterfordemens.dk) grew rapidly in 2013, communicating with users via social media, facebook and twitter, also proving to be a valuable addition to our services. We are very pleased that the DDRC is increasingly used as a source of information for nationwide news media.

The DDRC annual report presents the diversity of the research conducted at the DDRC in more detail, as well as a general review of our national educational activities.

We look forward to continuing to collaborate on patient care, clinical research and national educational services, and we are very proud to host the Alzheimer Association International Conference (AAIC) in Copenhagen in 2014. We would like to thank our national and international collaborators and the Danish Ministry of Health, the Danish Health Foundation and other foundations and institutions who financially support the DDRC.

Sincerely,

A handwritten signature in black ink, appearing to read "Gunhild Waldemar".

Gunhild Waldemar  
Director of the DDRC



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# ABOUT THE DANISH DEMENTIA RESEARCH CENTRE (DDRC)

## VISION

Our vision is to create a national centre with high international standards for patient services, research and education. The goal is to strive towards prevention of dementia while creating better quality of life for patients with dementia, their relatives and caregivers.

## MISSION

The three main DDRC units each have a specific mission.

### 1) Patient care

- \* To offer general and specialised diagnostic evaluation, treatment and counselling in accordance with best international standards
- \* To take a leading position in specialised areas such as familial, rare and complex neurodegenerative disorders
- \* To train health care professionals in clinical dementia care and in highly specialised services

### 2) Research

- \* To carry out research in the field of dementia and genetic neurodegenerative diseases via national and international cooperation with a special focus on:
  - Research leading to a better understanding of risk factors and disease mechanisms and thus new options for prevention and treatment
  - Research contributing to the development of new professional health care methods within diagnostics, treatment and care in dementia, providing new evidence for clinical practice

### 3) Education, training and information

- \* To collect, exchange and disseminate health care knowledge about dementia through national and international cooperation
- \* To serve as a nationwide up-to-date, comprehensive, unbiased source of information on dementia and associated disorders. Knowledge is defined not only as research-based knowledge and evidence but also as practice-based knowledge and knowledge gathered from national and/or international quality development programmes.

## 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 and professionals and strive to understand, involve and fulfil the needs of our target



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**

#### *Project 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, the steering committee monitors the progress of the strategic development and performance of the National Info & Education Centre according to predefined objectives and milestones.

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 Organisation of General Practitioners in Denmark, patient organisations

(the Danish Alzheimer Association and the Danish Huntington's Disease Association), and the DaneAge 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 2013

## MANAGEMENT TEAM



*Director*  
Gunhild Waldemar,  
MD, DMSc, professor



*Administrative director*  
Jette Rasmussen



*Research director*  
Steen G. Hasselbalch,  
MD, DMSc, professor



*Research director*  
Jørgen E. Nielsen,  
MD, PhD



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



*Head nurse*  
Copenhagen Memory Clinic  
Hanne Sørensen,  
nurse



*Educational director*  
Ane Eckermann,  
MHE,  
assistant nurse





## ADMINISTRATION

*Karin la Cour*, research secretary  
*Ditte Majgaard Jensen*, course administrator  
*Anja Magnussen*, course secretary  
*Olga Nikroozi*, administrative assistant  
*Jette Rasmussen*, administrative director

## NATIONAL INFO & EDUCATION CENTRE

*Benedikte Anna-Theresia Andersen*, MSc, assistant information officer  
*Ane Eckermann*, MHE, assistant nurse, educational director  
*Mette Tandrup Hansen*, MA, communication officer  
*Sarah Elizabeth Hvidberg*, MA, MLIS, information officer  
*Kasper Jørgensen*, MSc, neuropsychologist  
*Elsebeth Refsgaard*, nurse, educational advisor, project assistant  
*Karen Tannebæk*, occupational therapist (gerontology), educational advisor

## RESEARCH

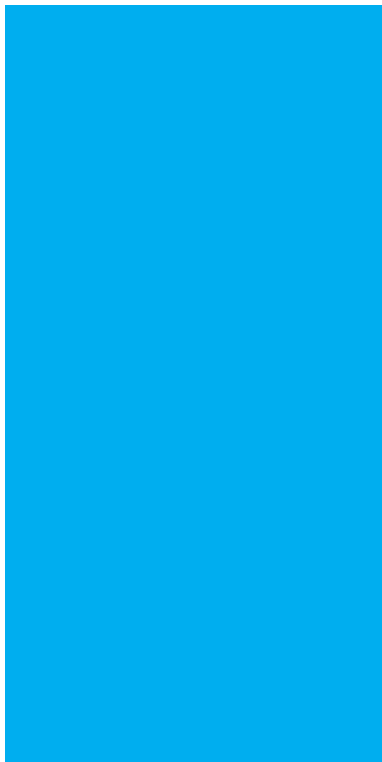
*Kathrine Bjarnø*, medical laboratory technician  
*Ane Nørgaard Christensen*, MD, PhD student  
*Pia Brandt Danborg*, research assistant  
*Kristian Steen Frederiksen*, MD, PhD student  
*Christina Vangsted Hansen*, research nurse  
*Steen G. Hasselbalch*, MD, DMSc, professor, senior neurologist, research director  
*Anne-Mette Hejl*, MD, PhD, neurologist  
*Lena Hjermind*, MD, PhD, neurologist

*Kristine Hoffmann*, MD, PhD student  
*Oda Jakobsen*, 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, research assistant (postdoc)  
*T. Rune Nielsen*, MSc, PhD, neuropsychologist, research assistant (postdoc), project director  
*Tien Kieu Phung*, MD, PhD, associated senior researcher  
*Nina Rostgaard*, MSc, PhD student  
*Lise Cronberg Salem*, MD, PhD student  
*Anja H. Simonsen*, MSc, PhD, research assistant (postdoc), project director  
*Jette Stokholm*, MSc, neuropsychologist  
*Tua Vinther-Jensen*, MD, PhD student  
*Asmus Vogel*, MSc, PhD, neuropsychologist, senior researcher  
*Laila Øksnebjerg*, MSc, neuropsychologist

## COPENHAGEN MEMORY CLINIC

### Medical doctors

*Birgitte Bo Andersen*, MD, DMSc, senior neurologist, clinical director  
*Hanne Vibe Hansen*, MD, senior psychiatrist  
*Steen G. Hasselbalch*, MD, DMSc, professor, senior neurologist  
*Anne-Mette Hejl*, MD, PhD, senior neurologist  
*Lena Hjermind*, MD, PhD, senior neurologist  
*Peter Johannsen*, MD, PhD, senior neurologist



*Susanne Lindquist, MD, staff physician*  
*Jørgen E. Nielsen, MD, PhD, senior neurologist*  
*Erik Søndergaard Poulsen, MD, physician*  
*Lisbeth Regeur, MD, DMSc, senior neurologist*  
*Peter Ross, MD, staff physician*  
*Sarah Taudorf, MD, staff physician*  
*Gunhild Waldemar, MD, DMSc,*  
*senior neurologist*

#### *Nurses*

*Lis Christoffersen*  
*Christina Vangsted Hansen*  
*Lene Iben Hvidkjær*  
*Oda Jakobsen*  
*Annette Lauridsen*  
*Hanne Sørensen, head nurse*  
*Naomi Wakabayashi*

#### *Neuropsychologists*

*Christian Buhl, MSc*  
*Nadia Falcon Bærnthsen, MSc*  
*Jette Stockholm, 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*

# IMPORTANT EVENTS

## INAUGURAL LECTURE

On 1 May 2013 senior neurologist Steen G. Hasselbalch MD, DMSc was appointed a professor chair in cognitive neurology and dementia disorders. His inaugural lecture, entitled "Dementia and dementia disorders: Development in concepts, diagnostics and treatment", was well-attended and took place on 1 November 2013 at Rigshospitalet.

## PHD DEFENCE

On 30 August 2013 Kristian Steen Frederiksen MD defended his PhD thesis 'Corpus callosum in aging and dementia'. The defence took place at Rigshospitalet and was followed by a reception. The thesis was submitted to the graduate school of the Faculty of Health and Medical Sciences, University of Copenhagen, Denmark.

The overarching objective of the thesis was to investigate the morphological changes in the corpus callosum in aging and dementia in relation to its role in cognitive and motor decline.

### *Evaluation committee*

- \* Marianne Juhler, professor, MD, DMSc, Department of Neurosurgery, Rigshospitalet, Copenhagen University Hospital, Denmark (chairperson)
- \* Murali Doraiswamy, professor, MBBS, FRCP, Psychiatry and Behavioral Sciences, Duke Institute for Brain Sciences, Duke University Medical Centre, Durham, USA
- \* Leif Østergaard, professor, MD, MSc, PhD, DMSc, Center of Functionally Integrative Neuroscience and MINDLab, Aarhus University; Department of Neuro-radiology, Aarhus University Hospital, Aarhus, Denmark



*Professor Gunhild Waldemar, Vice Dean Birthe Høgh, professor Steen Hasselbalch and CEO of Rigshospitalet Torben Stentoft.*



*Professor Steen Hasselbalch, PhD Kristian Steen Frederiksen, Ellen Garde, Professor Marianne Juhler, Professor Murali Doraiswamy, Professor Gunhild Waldemar and Professor Leif Østergaard.*

# COPENHAGEN MEMORY CLINIC



## PATIENTS AND FAMILIES

The Copenhagen Memory Clinic, 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. A multi-disciplinary team of consultant neurologists, psychiatrists, neuropsychologists, specialist nurses, a social counsellor, medical secretaries and a laboratory technician manages diagnostic evaluation and treatment.

New patients are referred for diagnostic evaluation of cognitive, behavioural or other symptoms indicating 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 Copenhagen Memory Clinic managed more patient visits than ever before in 2013. The diagnostic classification of the 2,088 patients in our follow-up programme differs significantly from that of new patients referred. 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, Alzheimer's disease (AD), dementia with Lewy bodies (DLB), frontotemporal dementia (FTD), Huntington's disease (HD), spinocerebellar atoxias (SCAs) or Down's syndrome with dementia, NPH and other neurodegen-

erative /neurogenetic conditions. Most patients are accompanied by their family caregivers when visiting the clinic. The DDRC's social counsellor, specialist nurses, psychologists and medical doctors also offer counselling for the caregivers as an integral part of the follow-up programme.

## 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, with services including:

- \* Second opinion evaluation of patients with possible dementia/dementia with uncertain aetiology
- \* Rare dementia diseases
- \* Hereditary neurodegenerative diseases (AD, FTD, SCAS, HD)
- \* Diagnostic evaluation of patients where brain biopsy may be relevant
- \* Lumbar perfusion tests and clinical evaluation of patients with normal pressure hydrocephalus (NPH)

The 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, the Department of Neuroradiology, and the Department of Clinical Physiology and Nuclear Medicine. Our centre also collaborates with the Movement Disorders Clinic, Bispebjerg Hospital.

Head nurse Hanne Sørensen  
(left) and clinical director,  
Birgitte Bo Andersen (right)

## KEY FIGURES FROM THE COPENHAGEN MEMORY CLINIC 2006-2013

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

## CURRENT NUMBER OF PATIENTS IN FOLLOW-UP PROGRAMME

(Data for 2013 extracted from hospital administration database March 2014)

G.30.1, G 30.9, G30.8	Alzheimer's disease (AD)	564
G30.0	Alzheimer's disease with early onset	162
G91.2	Normal pressure hydrocephalus (NPH)	111
G10.9	Huntington's disease (HD)	152
Z82.0	Familial disorders/genetic counselling	216
G11.1-3, G.11.9, R27.0	Ataxias (including spinocerebellar and fragile X-associated tremor/ataxia syndrome )	105
G 11.4, G 82.1- 82.4	Hereditary spastic paraplegia	67
G 24.0-2, G24	Dystonia	18
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	10
G31.8	Frontotemporal dementia (FTD) and other specific neurodegenerative diseases	127
G 31.9, F03.9	Other (unspecified) neurodegenerative disorders	41
G31.8E	Dementia with Lewy bodies (DLB)	44




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## DIAGNOSTIC CLASSIFICATION OF NEW PATIENTS REFERRED IN 2013

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<i>Syndrome</i>	<i>Diagnosis</i>	<i>Number</i>
Dementia	Total	492
	* Alzheimer's disease	219
	* Vascular or mixed dementia	73
	* Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinsons plus syndromes	28
	* Frontotemporal Dementia	22
	* Normal pressure hydrocephalus	62
	* Other specific conditions incl. Huntington's Disease	31
	* Dementia of uncertain aetiology	57
Mild cognitive impairment	Amnestic mild cognitive impairment	40
Other cognitive profiles or no cognitive impairment	Includes patients with other specific neurodegenerative disorders without significant memory impairment or dementia; patients with depression and other psychiatric conditions; sequelae after traumatic brain injury or stroke; and patients with subjective symptoms and no significant pathology	412
Healthy persons	Family members of patients with familial neurodegenerative conditions, referred for genetic counselling	97

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## EDUCATION OF PATIENTS AND CAREGIVERS

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

- \* The Copenhagen Memory Clinic offers its early-phase AD patients 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 quarterly 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 will see 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. The consultants from the Copenhagen Memory Clinic have also participated in education services for health care professionals on Bornholm.

## REGIONAL COLLABORATION

In 2006, the Capital Region of Denmark established a quality registry for the diagnostic evaluation of dementia. Including data from all five memory clinics (and the specialist service on Bornholm), the registry is supervised by the region's Scientific Dementia Council and coordinated by the Copenhagen Memory Clinic.

The Capital Region of Denmark also established guidelines for coordination of patient care pathways between hospital-based memory clinics, mental health centres, other hospital departments, general practitioners, and primary health care in the 29 municipalities it covers. The implementation of the programme started in 2012.

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

# RESEARCH

Our clinical and translational research programmes include studies on epidemiology, biofluid markers, brain imaging, neurogenetics, genotype-phenotype correlations, patient-specific stem cells, disease course, early diagnosis, neuropsychology, cross-cultural aspects of diagnosis and treatment, nonpharmacological interventions and health service research.

The patient cohorts representing a wide range of diagnostic entities, the clinical quality registry, data from healthy controls and mutation carriers, and the Danish Dementia Biobank form an important resource for our clinical research. Access to nationwide health care registries allows for large population-based studies on health service, risk factors and outcome in neurodegenerative disorders. The Danish Dementia Biobank collects blood and cerebral spinal fluid (CSF) samples from memory clinic patients at Rigshospitalet and Roskilde Hospital and serves as the research biobank for the eight memory clinics involved in the ADEX programme (see below). At the end of 2013, the biobank contained samples from 2509 patients, including CSF from 827 of them. The biobank samples are available for collaborative research studies, some of which were initiated in collaboration with Statens Serum Institut.

In addition to publishing 33 papers in 2013 (see publication list), the research group had six PhD students and four 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. This section describes some of DDRC's research

projects, including research collaborators. For more information, see our website and publication lists.

## BIOFLUID MARKERS, BRAIN IMAGING AND EARLY DIAGNOSIS

### *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. Furthermore, we aim to correlate the markers with clinical and imaging markers of disease.

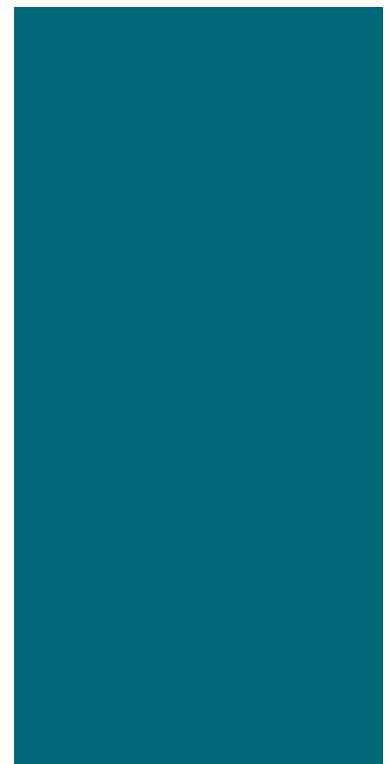
For example, in a study conducted by the Department of Cellular and Molecular Medicine, University of Copenhagen, on molecular markers in AD, the major aim is to investigate the potential correlation between AD and molecular biomarkers, e.g.: mitochondrial oxygen consumption, reactive oxygen species, nucleotide pool maintenance, and induction and repair of DNA strand breaks. DDRC collaborates and contributes with patients (fresh blood samples for analysis of peripheral blood mononuclear cells of AD patients, clinical data, correlative analysis).

Collaborators in biomarker studies are Statens Serum Institut; the Department of Cellular and Molecular Medicine, University of Copenhagen; the Department of Medicine, Aarhus University; the Department of Neurology, the National and Kapodistrian University of Athens; and a wide range of European centres in the Joint Programme on Neurodegenerative Diseases (JPND) research programme BIOMARKAPD (see below).

### *Leukoaraiosis and Disability in the Elderly (LADIS) study*

A large part of our brain imaging research is integrated in international multicentre studies. Coordinated by the University





of Florence, the LADIS study was initiated in 2003 in order to study the clinical and prognostic significance of unspecific age-related white matter changes (as identified on magnetic resonance imaging (MRI)) in elderly patients with no or minor functional disability. Almost 700 patients from 11 European centres participated in the four-year longitudinal study supported by EU-FP6. DDRC participated in collaboration with the Danish Research Centre for Magnetic Resonance. The large clinical and imaging data set from the LADIS cohort continues to serve as a resource for investigations in clinical and imaging correlates to vascular brain changes in the elderly. Several imaging publications from the LADIS study were published in 2013. For more information on collaborators and results, see: [unifi.it/LADIS](http://unifi.it/LADIS).

#### **BIOMARKAPD**

BIOMARKAPD, funded by JPND, was initiated in 2012 in order to validate and harmonise preanalytical and laboratory procedures for CSF analysis and to clarify the clinical application of current and new CSF biomarkers in the diagnosis of AD and Parkinson's disease (PD). In 2013, as a co-leader, DDRC took part in the study by validating CSF biomarkers for amyloid using amyloid PET in more than 400 subjects from four European clinical centres, and a publication is in progress. Furthermore, DDRC coordinated the effort to produce new guideline papers on the clinical application of CSF biomarkers for AD and PD. The papers will be submitted in 2014. The BIOMARKAPD study and its more than 20 partners are coordinated by the Karolinska Institute, Stockholm, Sweden, while the Danish partners in the programme, the DDRC and Statens Serum Institut, are supported financially by the Danish Strategic Research Council. For more information on collaborators and results, see: [neurodegenerationresearch.eu/initiatives/biomarker-transnational-call/results-of-funding-call/biomarkapd/](http://neurodegenerationresearch.eu/initiatives/biomarker-transnational-call/results-of-funding-call/biomarkapd/).

#### **Amyloid PET**

Since 2008, the centre has collaborated with the PET and Cyclotron Unit, Rigshospitalet, on the clinical application of amyloid brain imaging, and research continued in 2013 with amyloid imaging in the ADEX study (see below). Because of the continuous use of clinical amyloid imaging, it was possible to undertake a large multicentre study on the validation of CSF amyloid using amyloid imaging as the gold standard (described above in BIOMARKAPD). In collaboration with the Neurobiology Research Unit, Rigshospitalet, and the Danish Research Centre for Magnetic Resonance, Hvidovre Hospital, studies on the association between amyloid accumulation and white matter changes are continuing.

#### **Quantitative EEG in early diagnosis of AD**

In 2007, the Nordic Network in Dementia Diagnostics (NIDD) was formed and its first joint study examines the role of quantitative electroencephalography (EEG) in the early diagnosis of AD. The programme received a three-year grant in 2009, in part from the Nordic Council and the Kavli Foundation. The network involves eight academic memory clinics in Reykjavik, Oslo, Bergen, Stockholm, Kuopio, Tartu, Roskilde and Copenhagen. DDRC participates in collaboration with the Department of Clinical Neurophysiology, Rigshospitalet and with Roskilde Hospital's regional dementia centre. The inclusion of patients and controls in the EEG study ended in 2013 with 395 patients and 120 controls. The data are now under evaluation.

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](http://nidd-dementia.org).

Another study investigates the use of quantitative EEG as a diagnostic marker for AD in patients with Down's syndrome.

The study includes two groups of participants with Down's syndrome: 17 individuals without dementia and 21 individuals with dementia due to probable AD. The inclusion phase has been completed and the results are now under evaluation.

#### *PredictAD*

PredictAD, which is funded by EU-FP7, will study imaging biomarkers (MRI, PET FDG and amyloid PET), EEG measurement and blood-based markers (proteomics and metabolomics), and develop methods for combining data from various biomarkers. Combining this multi-source information may enable earlier diagnosis of AD, but may also provide crucial information used for differentiating between various forms of dementia and for assessing disease severity. It may also allow for improved detection of disease progression and treatment efficacy monitoring. PredictAD consortium members are VTT Technical Research Centre of Finland, GE Healthcare (UK), Nexstim Ltd. (Finland), University of Eastern Finland, Kuopio (Finland), Imperial College of London (UK), Karolinska Institutet (Sweden), University of Milan (Italy), and Rigshospitalet (Denmark).

A software prototype has been developed and validated. The programme was completed in 2013 but will be further developed in PredictND, which is a new project also funded by EU-FP7 that is to be initiated in 2014.

## **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 provides a platform for professionals and people affected by HD and their relatives to facilitate working together throughout Europe. The EHDN study, called REGISTRY, is a multi-centre, multinational

observational study for which DDRC has contributed data on more than 300 patients, making it 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. Two PhD projects involving these topics were initiated in 2012. Data collection was completed in 2013 and CSF and molecular-genetic analyses are on-going.

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 ([spatax.wordpress.com/](http://spatax.wordpress.com/)). The clinic is following more than 200 patients with ataxia and paraplegia. Spinocerebellar ataxia type 2 (SCA2) is a focus research 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 the 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) was established over a decade ago to investigate 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, including defining the clinical characteristics, brain imaging findings, neuropathology and



genetic studies culminating in identifying the disease gene, CHMP2B. This line of research has continued with studies designed to understand the disease mechanism caused by mutated CHMP2B. In addition, 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 was launched in 2012 in collaboration with DDRC, 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 into relevant neuronal subtypes that can be used as in vitro cell models to identify drugs and targets for personalised medicine. The DDRC contributes with human fibroblast cell lines from well characterised patients with familial disorders, and with functional studies of the neuronal cell models and cross validation with CSF markers. Human neuronal cell lines have been established and validation is on-going. We also participate in a Marie Curie initiative supported by the European Union for developing stem cell-derived models of FTD3 and SCA2.

### **NEUROPSYCHOLOGY**

The DDRC's neuropsychological research mainly focuses on characterisation of cognitive deficits in the early phase of dementia diseases.

As part of the DDRC's large project on the clinical and molecular

aspects of HD, a PhD project investigating cognitive deficits and personality traits in this patient group (both patients in the pre-manifest and manifest phase of the disease) has been initiated. Patient inclusion for this project was completed in 2013 and more than 100 gene carriers and a control group were examined with standard neuropsychological testing, a battery of executive tests (of an experimental nature) and tests for social cognition. Comprehensive questionnaires on neuropsychiatric symptoms and personality traits were also used.

In 2013, the research group had several papers describing test performances on cognitive tests published. These data can be used as reference data for clinical examinations of patients referred to memory clinics. We also conducted studies on the frequency of semantic memory deficits in a mixed memory clinic population and longitudinal assessment of awareness in AD in 2013.

### **EPIDEMIOLOGY, CLINICAL COURSE, CROSS-CULTURAL ASPECTS OF DEMENTIA CARE, AND HEALTH SERVICE IN DEMENTIA**

#### *The European Cross-Cultural Neuropsychological Test Battery (CNTB)*

The CNTB study investigates the validity of a cross-cultural neuropsychological test battery in European majority and minority populations, including immigrants with Turkish, Pakistani, Moroccan, Yugoslavian and Polish backgrounds. The project, an international multi-centre study including nine centres in Amsterdam, Antwerp, Belgrade, Berlin, Brussels, Copenhagen, Malmø, Oslo and Thessaloniki, was initiated to improve the clinical evaluation of cognitive dysfunction in patients with diverse cultural and linguistic backgrounds. In addition, the CNTB is being validated in a poorly educated sample in Rio de Janeiro, and specific tests from the battery in



*Members of Dementia in Lebanon research group: Monique Chaaya, Kieu Phung, Gunhild Waldemar, Samir Atweh and Rune Nielsen.*

Izmir and Beirut. Preliminary analyses of data from 220 elderly control subjects with Danish, Turkish, Pakistani, Polish and Yugoslavian backgrounds suggest that the CNTB has excellent cross-cultural properties.

#### *Dementia in Lebanon*

This study is part of the 10/66 Dementia Research Group (DRG), an international network of researchers who carry out population-based studies on dementia in developing countries. The specific aims of the study are:

- 1) To validate the 10/66 DRG one-phase dementia diagnostic assessment in Arabic in order to use it for case ascertainment in a subsequent population-based study; and two brief screening instruments, the Rowland Universal Dementia Assessment Scale (RUDAS) and the Informant Questionnaire for Cognitive Decline in the Elderly (IQCODE), as alternative strategies.
- 2) To carry out a pilot study in the Beirut and Shouf governorates of Lebanon using the validated 10/66 DRG instrument to diagnose dementia: to generate preliminary data about dementia prevalence and to assess the feasibility of a longitudinal community-based cohort study comprising 2,500 people over the age of 65 randomly selected from all regions of Lebanon to provide knowledge about the incidence, prevalence, risk and protective factors specific to the Lebanese population, and the barriers to treatment and care for people with dementia in Lebanon.

The study is being carried out at 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; DDRC, Denmark; and the Institute of Psychiatry, King's College London,

London, UK. 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)".

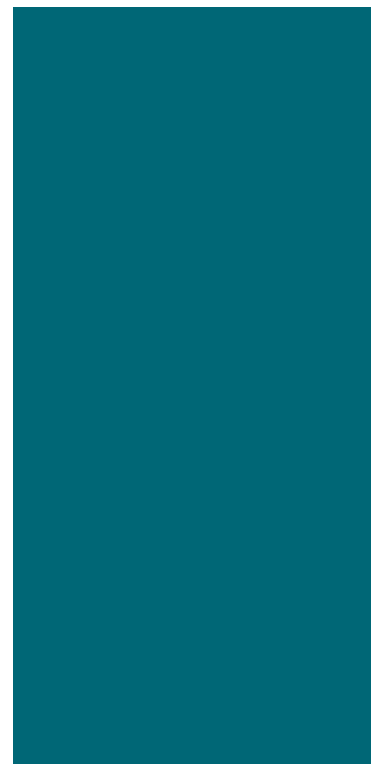
In a study population in which half the participants have no formal education, the validation study showed that the 10/66 Dementia Research Group one-phase diagnostic assessments is an excellent tool for case ascertainment in epidemiological studies (Phung et al., in press JGPN), while Rowland Universal Dementia Assessment Scale (RUDAS) and Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) are good screening instruments for clinical practice (manuscripts in preparation). RUDAS and IQCODE can be combined to increase screening accuracy (manuscript in preparation). Data collection for the pilot study is complete. The results from this study will be published beginning in 2014.

#### *Pharmaco-epidemiology: prescriptions in patients with dementia*

The aim of this project is to investigate the use of medication in patients with dementia as compared to the Danish population in general. The research is based on nationwide registry data. Projects investigating patterns of analgesic use, psychotropics and use of anti-dementia medication are currently being conducted. In 2013, a PhD project designed to assess use and risk associated with antipsychotics and antipsychotic polypharmacy was initiated. The research is being carried out in cooperation with the National Centre for Register-based Research at Aarhus University.

#### *Assessment and management of pain in dementia*

In 2010, a PhD project on pain in dementia was initiated



using different neurophysiological methods to investigate if the perception of pain in patients with AD differs from that of cognitively intact healthy elderly. With the inclusion of patients finalised in 2013, the project will be concluded in 2014. This research was carried out in cooperation with the Danish Pain Research Center, Aarhus University; the Department of Clinical Neurophysiology, Rigshospitalet; and the Multidisciplinary Pain Centre, Rigshospitalet.

### *Prospective study on subjective cognitive complaints in a mixed memory clinic population*

In this project, a ten-item quantitative questionnaire on subjective cognitive complaints was applied consecutively to patients referred to the Copenhagen Memory Clinic. More than 300 patients participated in this study in 2013. The first project from this study investigates the quantity and characteristics of young and elderly patients with dementia as compared to patients with subjective complaints due to other disorders.

## **INTERVENTION STUDIES**

### **ADEX**

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. At the end of 2013, the inclusion target of 192 patients was reached. The study’s methods were published in 2013 and the project will be completed in 2014, at which point the effect of physical exercise on e.g. cognition, quality of life and functional

activity will be reported. 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](http://videnscenterfordemens.dk/adex).

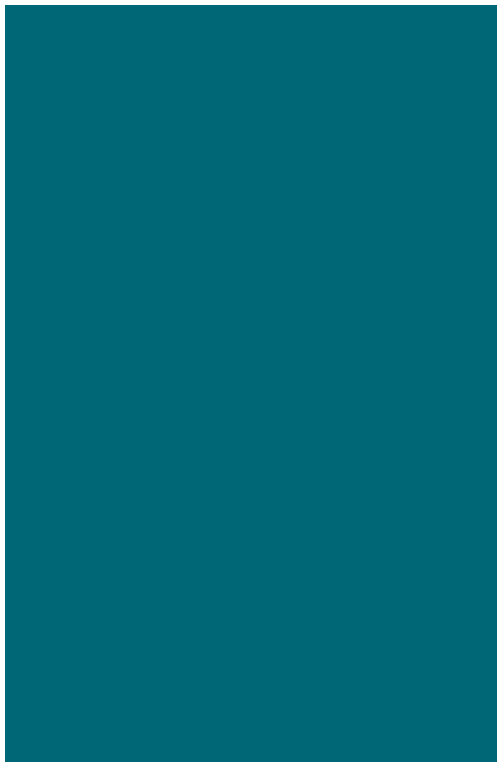
### *Danish Alzheimer Intervention Study (DAISY)*

The DAISY study 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 (see [videnscenterfordemens.dk](http://videnscenterfordemens.dk) for a list of publications). In 2013, an article describing the long-term efficacy at the 36-month follow-up and a paper reporting the results from the cost analysis of the intervention were published. For more information, see: [videnscenterfordemens.dk/daisy](http://videnscenterfordemens.dk/daisy)

### *Cognitive rehabilitation*

In recent years, various cognitive training and cognitive rehabilitation methods have been explored in case studies and in pilot studies at DDRC. These studies have involved patients with MCI, early-stage AD and semantic dementia. In 2013, our main focus was cognitive training for patients with semantic dementia and on piloting a project on cognitive rehabilitation in early-stage AD that integrates technology as a primary tool of compensation.



### *Drug trials (contract research)*

The DDRC trial unit 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 2013, the Copenhagen Memory Clinic participated in an on-going phase 1 study of an active beta-amyloid vaccine (sponsor: AC Immune), an on-going phase 2-3 study of a passive beta-amyloid vaccine (sponsor: Roche), a phase 2 study of a gamma-secretase inhibitor (sponsor BMS), and a phase 2 study of an amyloid tracer for PET (sponsor GE Healthcare). At the close of 2013, three new protocols were in the process of being initiated. The clinical trials are being conducted with state-of-the-art imaging techniques in collaboration with the Danish Research Centre for Magnetic Resonance, Hvidovre Hospital and the PET and Cyclotron Unit, Rigshospitalet.

# NATIONAL INFO & EDUCATION CENTRE

The DDRC's National Info & Education Centre was established to provide nationwide education and dissemination of information about dementia, primarily to health care professionals and basic care staff. The DDRC communicates to a variety of professionals on a range of platforms, e.g. the DDRC website, training courses, e-learning, apps, publications 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 introducing new national and international research to an audience of around 350 health care professionals.

## COURSES AND CONFERENCES

As education and research are two key aspects within the field of dementia, our courses and conferences are designed to help professionals navigate between the practical challenges and professional and scientific aspects related to various dementia diseases.

In 2013, DDRC organised courses, conferences and local courses tailored to the needs of specific groups as requested by municipalities or regional institutions. Designed to meet a specific purpose or cover a certain subject, customised courses were attended by various professional groups. DDRC invited more international speakers to participate in courses and conferences in 2013.

For the fifth time, the DDRC published a catalogue presenting activities for 2013 held across Denmark targeting various professional groups working within the health care sector. The DDRC website also advertises these activities. In 2013, DDRC ran courses on a wide range of subjects, such as "care for people with dementia from ethnic minority groups", "diagnosing and treating dementia in mentally handicapped patients" and "language disorders in dementia". At thematic events, a whole day is dedicated to focusing on a particular subject guided by professionals with extensive experience about the topic in question, for instance alcohol and dementia or HD.

In 2013, DDRC held four large conferences, including Dementia Days. DDRC events attracted a total 3,683 participants in 2013, which represents an increase compared to previous years.

## ACTIVITIES 2013

Activity:	Courses	Conferences	Thematic events	Customised courses	Total
	11	4	4	32	47
Participants:	425	1,326	564	1,368	3,683



*Neuropsychologist Laila Øksnebjerg and professor Myrra Vernooij-Dassen at the research conference.*

## 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.

The 2013 topic was “Focus on cognition, training and rehabilitation and dementia”. Professor Bob Woods from Dementia Services Development Centre Wales, Bangor University, was the keynote speaker. Attended by nearly 200 people, the conference also had presentations by, for example, Professor Myrra Vernooij-Dassen, the Netherlands and Professor Hanne Mette Ochsner Ridder, Aalborg University, Denmark.

## INTERNATIONAL PHD COURSE

For the second year in a row, in cooperation with the University of Copenhagen, DDRC organised a PhD course on research in AD and other neurodegenerative dementias for 26 PhD students. Conducted in English, the course was designed to introduce new researchers to the field of Alzheimer research and to provide an insight into AD for young PhD students from various basic and clinical fields. The course presented a wide spectrum of research in this exciting area, ranging from epidemiological, clinical, biomarker and imaging research to translational research. The course format included lectures and hands-on experience with various research tools in workshops. The course presented interesting challenges and the pitfalls of the field, with special emphasis on AD.

Three top international scientists, Professor Knut Engedal, Norway; Professor Ezio Giacobini, Switzerland; and Professor Murali Doraiswamy, USA, as well as several excellent Danish senior researchers in the field were recruited as lecturers.

## DEMENTIA DAYS – A NATIONWIDE CONFERENCE

Every year, DDRC organises Dementia Days, a national two-day conference for dementia specialists and practitioners and Denmark’s largest conference on dementia. An educational opportunity for leaders and staff working in the social services and health care sector, the conference programme is prepared in collaboration with the DDRC scientific advisory group. Our two networks of local ambassadors and professional advisers are also consulted to help identify topics and speakers.

Karen Hækkerup, the Danish Minister for Social Affairs and Integration, officially opened the 15th annual Dementia Days, which had 920 participants. At the conference, invited speakers from Denmark and Scandinavia presented their views and experiences on 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 a talk at the symposium with free communications and 22 people presented a poster. Mary-Ann Frost from Hjørring Municipality received the 2013 poster prize for her project “The Common Thread”.

Dementia Days 2013 attracted more exhibitors with booths than ever before, including one who set up a large Snoezelen tent, which is a controlled multisensory environment.

For more information about 2013 Dementia Days, see: [videnscenterfordemens.dk/uddannelse/demensdagene](http://videnscenterfordemens.dk/uddannelse/demensdagene)

In 2014, the annual Alzheimer Conference (AAIC) will take place in Copenhagen in July, which means the 16th annual Dementia Days will be postponed until 11-12 May 2015.





## THE MIGRATION SCHOOL

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

The project is financed by the Capital Region of Denmark, the Skåne Region of Sweden and the European Regional Development Fund INTERREG IV A. Initiated in 2011, this three-year project will collect and distribute information, conduct research and develop educational programmes on assessment and care of patients from ethnic minorities with dementia. The research focuses on investigating and documenting patterns in the utilisation of health service in dementia and on validation of cross-cultural assessment instruments.

 **Migrationsskole**  
for demensplejen i Øresundsregionen

 **Interreg IV A**  
ØRESUND – KATTEGAT – SKAGERRAK

At the end of the project period in October 2014, more than 1,000 health care workers will have attended the Migration School's education programmes and acquired unique specialist knowledge and training in the field of dementia and ethnic mi-

norities. In addition, cross-cultural assessment instruments and publications aimed at health care workers, as well as information materials and e-learning for patients and relatives, will be available in a number of languages as a result of the programme.

## THE DDRC CONFERENCE BOOTH

DDRC has developed a mobile conference booth to disseminate knowledge about dementia and to present new products from DDRC to key stakeholders.

In 2013, the conference booth was present at the following events:

- \* January: National Health Service Conference, organised by Local Government Denmark. Attended by politicians and officials
- \* May: Dementia Days in Copenhagen, organised by DDRC
- \* May: Conference for elderly, local politicians, organised by the National Association of Senior Citizens Councils
- \* May: National Social Service Conference, organised by Local Government Denmark. Attended by 1,300 politicians, officials and other interested parties
- \* September: Danish Association of Municipal and Regional Coordinators of Dementia, annual course

The distribution of material and professional dialogue that took place with participants at these events was important and rewarding. The release of the new e-learning tool, ABC Dementia, attracted a great deal of attention and initiated many interesting conversations. By attending various events, DDRC generates new contacts and ideas for local courses tailored to specific target groups.

## NEW PRODUCTS

Most of the educational materials produced by DDRC are avail-



able free of charge at [videnscenterfordemens.dk](http://videnscenterfordemens.dk). New products were introduced in 2013: the first four modules of ABC Dementia – e-learning for professionals, a guide on cultural differences in the perception of dementia amongst ethnic minorities and 24 fact sheets in foreign languages.

#### ABC Dementia

ABC Dementia is e-learning divided into modules. Our first ABC Dementia programme is targeted basic care staff (home care and nursing homes). Each module covers a theme, e.g. dementia dis-

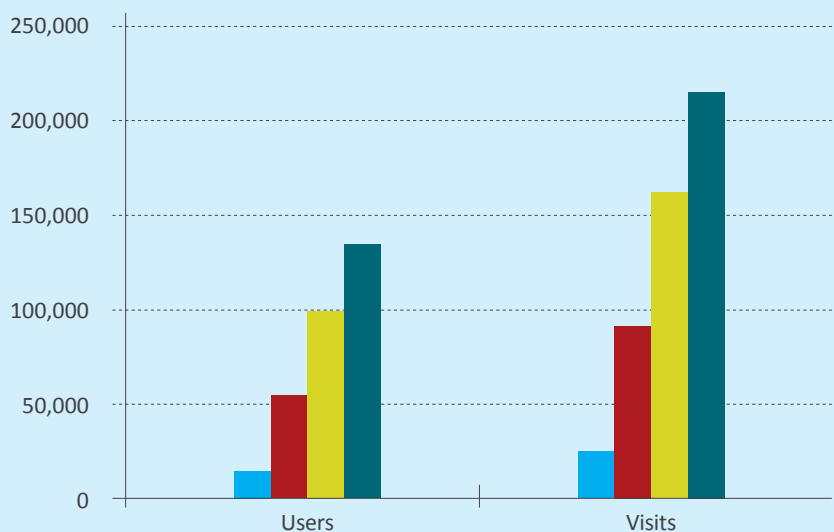
orders, behavioural disorders, how the brain functions, dementia care and communication. The themes are presented in a practice-oriented manner and different educational approaches are used, making it user-friendly.

The first four modules of ABC Dementia were launched at Dementia Days 2013 and attracted much attention. Users were invited to try ABC Dementia and project manager Karen Tannebæk gave well-attended short presentations on the modules. DDRRC distributed postcards, pencils and flyers to

### VISITS TO THE DDRRC WEBSITE, 2010-2013

2013: The website had 135,000 unique users who visited the website 216,000 times

- 2010
- 2011
- 2012
- 2013





spread knowledge about our new e-learning project, which is available to care professionals free of charge.

By the end of 2013, ABC Dementia had more than 2,900 registered users across Denmark.

#### *Guide – Perceptions of dementia in ethnic minorities*

In autumn 2013, DDRC published a guide as part of the Migration School project describing differing perceptions of dementia in six minority language or cultural groups. The guide, “Perception of dementia among people with different cultural and linguistic backgrounds”, is a practical tool and support for professionals who work with ethnic minorities in Denmark.

The guide contains information about six population groups in the Oresund Region comprising immigrants from: Arabic-speaking countries, Iran, Pakistan, Poland, Turkey and former Yugoslavia. Available free of charge, the guide can be downloaded from the DDRC website.

#### *Fact sheets*

The DDRC had four fact sheets translated into six different languages: Arabic, Farsi, Polish, Serbo-Croatian, Turkish and Urdu on the following topics: *What is dementia?*, *Alzheimer's disease*, *Vascular dementia*, and *Depression and dementia*.

Other fact sheets for individuals with dementia and their caregivers are also available free of charge on the DDRC website. The four fact sheets mentioned above target professionals working with ethnic minorities in Denmark and have been welcomed by users. New fact sheets will continue to be made available in 2014.

The app “About dementia” continued to draw attention in 2013

and by the end of the year it had been downloaded 11,665 times and had an average of 2,085 active users monthly.

## WEBSITE AND NEWSLETTER

### *Website*

The DDRC website, [videnscenterfordemens.dk](http://videnscenterfordemens.dk), is a central platform for providing information about dementia in Danish. The number of website users and visits increased throughout 2013.

Public and private stakeholders and NGOs in the health care and social sectors often link to content on the DDRC website. Traffic to our website from social media platforms is also increasing, in addition to a rapidly growing number of smartphone and tablet users. The most popular content on the website is information about various different dementia diagnoses, dementia care practice and education.

### *Social media*

In 2013, DDRC became active on Facebook and Twitter (from December 2013), posting news about dementia research and information on our activities 4-5 times a week. Through social media platforms, DDRC can connect with journalists and a broader audience, making it easy to follow our work and taking part in the conversation on dementia.

### *Newsletter*

DDRC's bi-monthly e-newsletter now reaches 4,300 subscribers in the health care sector and the number continues to grow.

## DDRC IN THE MEDIA

Staff at DDRC are available to provide information, facts and data to support health care professionals, students and journalists from various media. Several DDRC specialists have given



interviews to newspapers and/or appeared on TV and in radio programmes in 2013.

### CONSULTANCY

The DDRC also took on the task of providing consultancy services for care homes on how to build and design dementia-friendly homes. The DDRC also receives e-mails and telephone calls daily from students, journalists, patients, relatives and educational consultants.

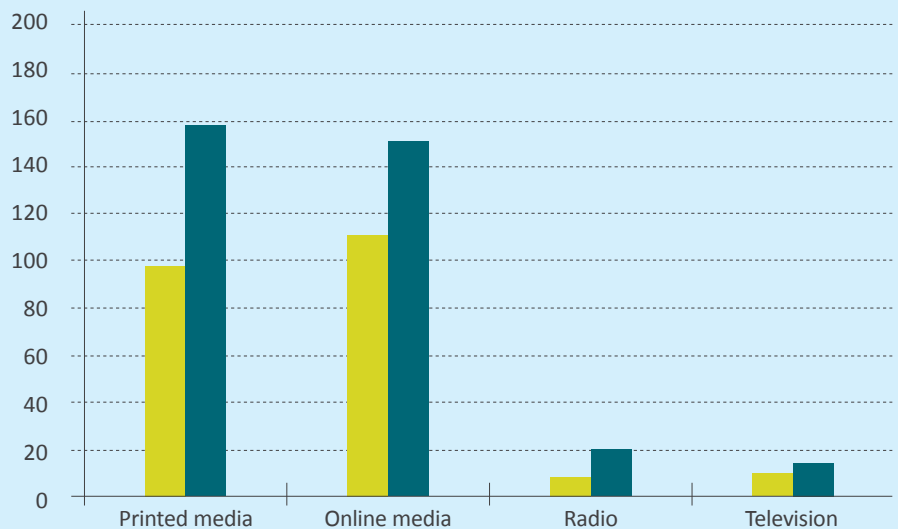
### STUDY VISITS FROM ABROAD

In 2013, DDRC welcomed a group of visitors from Belgium who wanted to learn about life with dementia in Denmark. The group visited DDRC and various care homes. A group of health care professionals from Germany also visited and was introduced to the National Clinical Guidelines for Dementia and The Danish National Dementia Plan.

### DDRC IN THE MEDIA, 2012-2013

2013 mentions:  
 Printed media: 173  
 Online media: 166  
 Radio: 22  
 Television: 16

■ 2012  
 ■ 2013



# NATIONAL AND INTERNATIONAL NETWORKS

## NETWORK OF DANISH MEMORY CLINICS

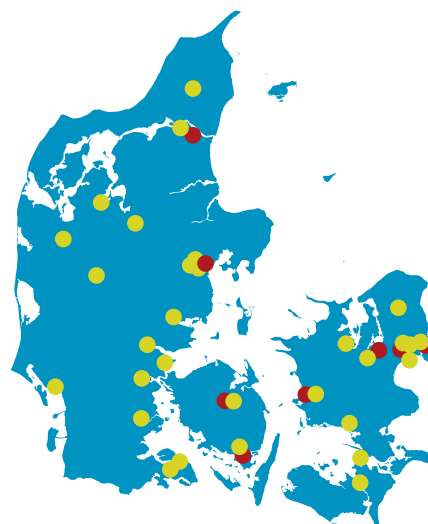
DDRC has created a network for Danish memory clinics. Most memory clinics are based in psychiatric, geriatric or neurological departments and receive referrals from local general practitioners for diagnostic evaluation of dementia. Some memory clinics also offer follow-up and counselling. Multidisciplinary staff (nurses, medical doctors and neuropsychologists) 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 2013, DDRC organised its sixth annual network conference for memory clinics in Denmark. The 2013 conference attracted representatives from every clinic in the country, with a total of 120 people participating, including physicians, nurses, psychologists, secretaries and therapists. The two main topics covered were FTD and the newly released National Clinical Guidelines for Dementia.

Organised by DDRC in collaboration with the Memory Clinic at Odense University Hospital, the conference also offered a number of specialised workshops. Valuable input was also received from memory clinics in DDRC's educational programme.

## NATIONAL NETWORK OF MUNICIPALITY-BASED DEMENTIA AMBASSADORS

In 2009, DDRC formed a network of local ambassadors with the purpose of mapping all the dementia programmes implemented under the auspices of the municipalities. Another objective was to identify unmet needs for education and research in Danish municipalities and to ensure a broader promotion of all DDRC initiatives and results.



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

Each of the 98 Danish municipalities has appointed a dementia ambassador, who will disseminate information about DDRC activities and news from other municipality ambassadors to local professionals and monitor local needs for educational activities. Contact between DDRC and the ambassadors is ensured in a variety of ways, including special news info mails containing information about new publications, news on the website, courses and conferences and an annual meeting for ambassadors.

In March 2013, the network of local dementia ambassadors met in Odense for the fourth time. Representatives from the Danish Alzheimer Association, the National Board of Social Services, Local Government Denmark and the Danish Dementia



Coordinators participated in this meeting. The main topic was “Dementia in the young”. PhD student Lise Cronberg Salem and two municipalities that organise special measures for this patient group were invited to speak at the meeting.

### **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](http://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](http://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 in order 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](http://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 is part of the Ageing and Health, Norwegian Centre for Research, Education and Service Development and was founded in 1996. 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.

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.

### **NORTH SEA MEETING**

The North Sea Dementia Group is a network 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. There is one annual two-day meeting with networking and a visit to local dementia services.

### **INTERDEM**

DDRC is a member of Interdem, a pan-European network of researchers on early detection and psycho-social interventions in dementia. See [interdem.org](http://interdem.org).

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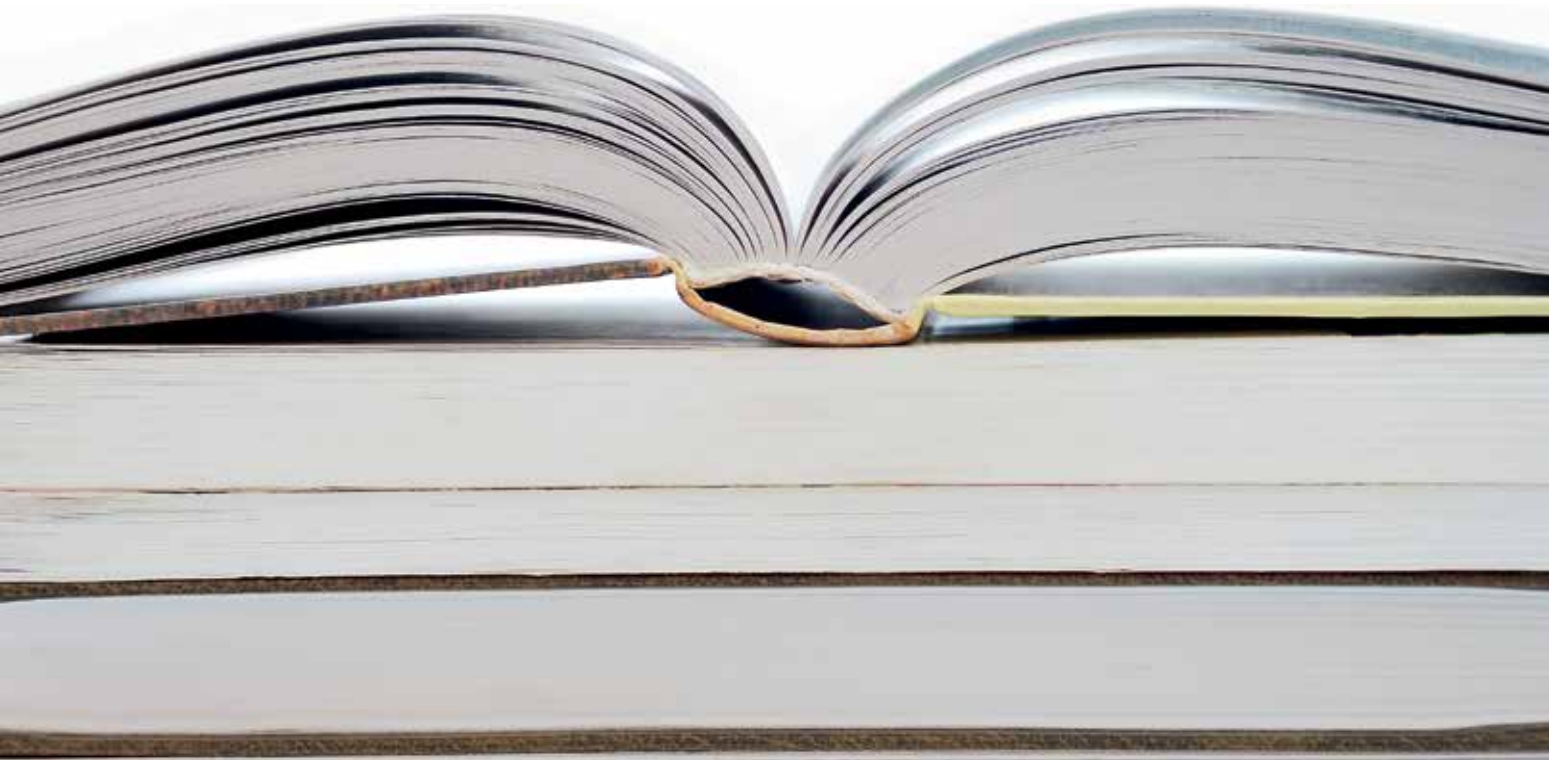
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# NATIONAL AND INTERNATIONAL POSTS

## *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

## *Ane Eckermann*

Chairman, Danish Association of Municipal and Regional Coordinators of Dementia

## *Steen G. Hasselbalch*

Vice-president, Danish Alzheimer Association; board member, Danish Alzheimer Association; chairman, sub-committee for clinical guidelines, Dementia Council of the Capital Region; member of the advisory group on "National clinical guidelines for dementia", the Danish Health and Medicines Authority (appointed by the Capital Region of Denmark); member of the Scientific Panel on Dementia, European Federation of Neurological Societies; member of the editorial board, Journal of Cerebral Blood Flow and Metabolism

## *Lena Hjermand*

Member of the work group "Genetics" in COST Grant work plan, BM1101 European Network for the Study of Dystonia Syndromes; investigator in Registry 3 in EHDN; member of the working groups: "Genetic testing and counselling" and "Symptomatic Treatment and Research" in EHDN; vice-president, the Danish Huntington's Disease Association; board member, the Danish Huntington's Disease Association

## *Kristine Hoffmann*

Board member, Young Neurologists, Neurosurgeons and Neuro Physiologists (YNNN)

## *Christina Jensen-Dahm*

Member of the work group "Cost Action TD100: Pain assessment in patients with impaired cognition, especially dementia"

## *Peter Johannsen*

Member of the working group "National clinical guidelines for dementia", the Danish Health and Medicines Authority (appointed by DDRC); member of the research committee, Danish Alzheimer Association; chair, Clinical Quality Database under the Dementia Council of the Capital Region

## *Kasper Jørgensen*

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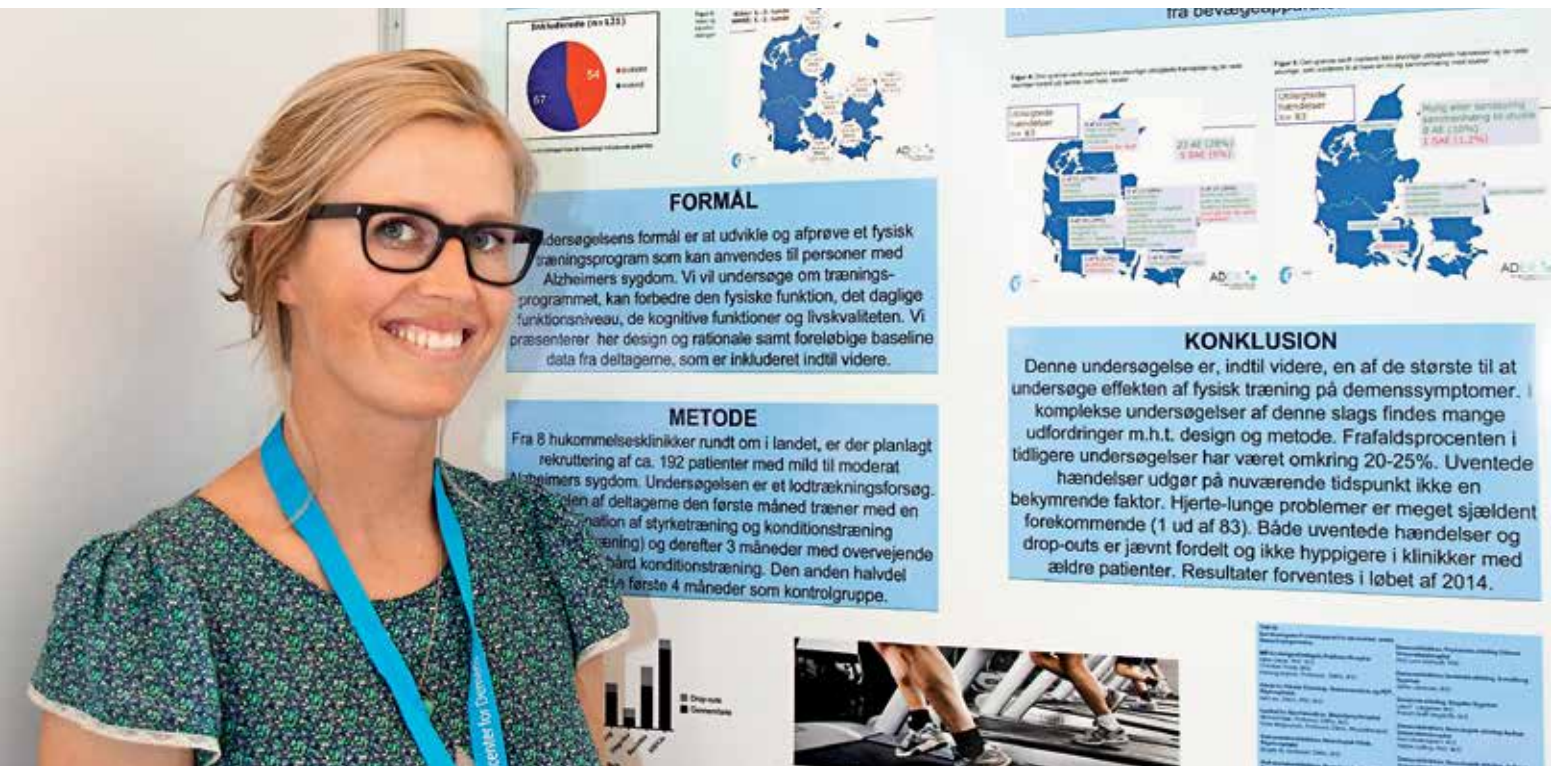
Member of the behavioural working group in EHDN; board member, Danish Neuropsychological Society

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**Laila Øksnebjerg**

Chair of the board, Danish Neuropsychological Society; member of the advisory group on “Development of methods to improve care of persons with dementia and behavioural disturbances”, National Board of Social Services

# AWARDS



Research assistant Anja Hviid Simonsen received an award from the Danish Order of Freemasons for her work with biomarkers for diagnosing Alzheimer's disease.

*In picture:  
Anja Hviid Simonsen, DDRC and  
Grandmaster Hans Martin Jeppesen.*



The Danish Alzheimer Research Foundation's research prize was awarded to educational director Ane Eckermann for her long-time contribution to the field of dementia.

*In picture:  
Chairman Anne Arndal,  
The Danish Alzheimer's Association,  
Ane Eckermann, DDRC and Chairman  
of the Alzheimer Research Foundation  
Asger Aamund.*

# FINANCE

The total annual budget of the DDRC amounts to DKK 30 million. The annual internal budget (clinical staff and running costs) from Rigshospitalet for the Copenhagen Memory Clinic is DKK 16,4 million. The operational costs of our research and all national educational services are based on project-related external grants and donations from public and private foundations, and on “commercial activities” (e.g. conferences and contract research), amounting to an annual average of DKK 14 million, including the fixed DKK 6,2 million grant from the Danish Ministry of Health and the Danish Health Foundation for the National Info & Education centre. Since 2007 researchers at DDRC have attracted external grants for research and educational activities, amounting to a total of more than DKK 98 million.

## INTERNATIONAL ALZHEIMER CONFERENCE TO COPENHAGEN IN 2014

The Danish Alzheimer Association and DDRC are proud to host the 26th Alzheimer’s Association International Conference (AAIC) in Copenhagen in July 2014. Organised by the U.S. Alzheimer’s Association, it is the world’s largest conference on dementia, and every year thousands of dementia researchers and experts gather at the conference for a week of sharing knowledge and new discoveries. Keep updated on [alz.org/aaic](http://alz.org/aaic)



## 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 the 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 will be formally 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 Kömpf, Germany, and Gunhild Waldemar, Denmark, for the EFNS and Professors Claudio Bassetti, Switzerland, José Ferro, Portugal, and Gustave Moonen, Belgium, for ENS. The EAN intends to be a society open to membership from all over the world and will welcome collaboration with other organizations. Learn more from [efns.org/EFNS-ENS-Liaison-Committee](http://efns.org/EFNS-ENS-Liaison-Committee); [ensinfo.org/ean\\_news](http://ensinfo.org/ean_news); and from Zohar Argov and Richard Hughes. Creation of the European Academy of Neurology. *Neurology* 2012;78;137.



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

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## DANISH DEMENTIA RESEARCH CENTRE *Nationalt Videnscenter for Demens*

### Annual report 2013

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