









THE DANISH DEMENTIA RESEARCH CENTRE (DDRC)

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



Annual report 2012









SUMMARY

2012 was a busy year for the Danish Dementia Research Centre (DDRC), with a wide range of activities in all fields of operation. Never before has the DDRC been in contact with so many stakeholders in the field of dementia.

In May 2012 DDRC released its first app for mobile devices, "About Dementia" (*Viden om demens*). Available free of charge, the app was created in collaboration with the Capital Region of Denmark and is targeted professional caregivers. Reception of the app has been very positive with more than 8000 downloads to date.



In 2012 a new international PhD course in Alzheimer's disease (AD) was launched and due to the programme's success DDRC will offer a similar course in 2013 as well. Dementia Days (*Demens-Dagene*), the DDRC's annual national conference for dementia specialists, was held at the Tivoli Hotel & Congress Center and had a record-breaking 1,000 attendees. The DDRC's National Info & Education Centre has also experienced a growing number of attendees on courses offered in 2012.

A new educational project was launched in 2012 involving the development of the first Danish elearning course about dementia care. Targeting professional caregivers around the country, "ABC Dementia" (ABC Demens) is scheduled for completion by the end of 2013 and will consist of 10 modules and the option of taking a final test online. Users will receive a diploma upon successful completion of this basic dementia course. With an increasingly growing number of visitors, videnscenterfordemens.dk has grown to more than 800 pages containing a variety of knowledge, news and tools.

A nationwide multi-centre randomised clinical trial on physical exercise in AD (ADEX) began recruiting and training patients in 2012. Aimed at launching a new agenda for a healthy life style for patients with AD, ADEX has attracted international attention from health care professionals, patients and caregivers as well as from the media. DDRC took part in the launch of a novel technological research program on the development of disease-specific pluri-potent stem cells in AD. New international studies on dementia epidemiology in the Middle East and on cross-cultural aspects of dementia assessments were also initiated in 2012.

The Copenhagen Memory Clinic has managed more patient visits than ever before in 2012 and extended its local collaborative programme on patient pathways. The DDRC research publication rate also increased, and to further support our research in the field of early diagnosis and highly specialised clinical services, a new vacancy for a professorship with focus on dementia research was established together with two new senior consultant neurologists. On the following pages our research and the diversity of our educational activities will be described in more detail.

We look forward to continuing to collaborate on patient care, clinical research and national educational services. We would like to thank our national and international collaborators, the Danish Ministry of Health, the Danish Health Foundation and all other foundations and institutions who financially support the DDRC.



















About the Danish Dementia Research Centre (DDRC) Vision, Mission and Values Organisation and Staff **Copenhagen Memory Clinic** Highly specialised services Patients and families Courses for patients and caregivers Specialist service on the island of Bornholm Regional collaboration Research Biofluid markers, brain imaging and early diagnosis Neurogenetics Patient-specific stem cells derived models for Alzheimer's disease Neuropsychology Epidemiology, clinical course, cross-cultural aspects of dementia care, and health service in dementia Intervention studies Drug trials (contract research) **National Info & Education Centre** Courses and conferences - general aspects First Scandinavian conference for leaders in dementia care Annual Research Conference First international PhD course Dementia Days - a nationwide conference The Migration School The DDRC conference booth New products Website and newsletter DDRC in the media **National and International Networks** Network of Danish Memory Clinics National network of municipality-based dementia ambassadors Nordic memory clinics European Alzheimer's Disease Consortium European Huntingtons' Disease Network EHDN National dementia research and education centres in Scandinavia **Publications 2012** PhD dissertations Scientific papers Books/book chapters DDRC Contributions to cooperative multicenter studies **National and International Posts** International Alzheimer conference to Copenhagen in 2014 Neurology in Europe - towards a new united European Academy of Neurology Acknowledgements

We are committed to provide information about demention diseases

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 – a centre which will strive towards prevention of dementia while creating better quality of life for patients with dementia, as well as for 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 about dementia and associated disorders.

Knowledge is defined here 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 vision 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 the DDRC's 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, Copenhagen University Hospital, and based in the Department of Neurology, is operated as a nationwide service of the Capital Region of Denmark. Initiated and funded by the Danish Ministry of Health and the Danish Health Foundation, the National Info & Education Centre has a project organization with a steering committee and a scientific advisory board.

The steering committee with representatives from the Ministry of Health, the Ministry of Social Affairs and Integration, the Danish Regions, Local Government Denmark, the Capital Region of Denmark and Rigshospitalet monitors the progress of the strategic development and performance of the National Info & Education centre in relation 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 Chorea Association), and the DaneAge Association.

In addition, the DDRC uses *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 throughout the country.



STAFF IN 2012

MANAGEMENT AND ADMINISTRATION

Director

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

Clinical director, the Copenhagen Memory Clinic

2 Birgitte Bo Andersen, MD, DMSc, senior neurologist

Head nurse, the Copenhagen Memory Clinic

3 Hanne Sørensen, nurse

Administration

- 4 Olga Nikroozi, administrative assistant
- 5 Eva Salomonsen, administrative assistant
- 6 ette Rasmussen, research administrator

NATIONAL INFO & EDUCATION CENTRE

- 7 Benedikte Andersen, MSc, assistant information officer 8 Dorthe V. Buss, LLM, PhD, legal advisor
- 9 Christa Vivi Dahl, administrative assistant
- 10 Ane Eckermann, assistant nurse, master in health education, educational director
- 11 Sarah Elizabeth Hvidberg, MA, MLIS, information officer
- 12 Jesper Bøgel Jensen, MA, communication officer
- 13 Ditte Majgaard Jensen, course administrator
- 14 Kasper Jørgensen, MSc, neuropsychologist
- 15 Anja Magnussen, course secretary
- 16 Elsebeth Refsgaard, nurse, educational advisor, project assistant
- Karen Tannebæk, occupational therapist (gerontology), educational advisor

RESEARCH

- 54 Kathrine Bjarnø, medical laboratory technician
- 18 Kristian Steen Frederiksen, MD, PhD student
- 37 Christina Vangsted Hansen, reseach nurse
- 28 Steen G. Hasselbalch, MD, DMSc, assoc. professor, senior neurologist
- 29 Anne-Mette Hejl, MD, PhD, staff neurologist

- 30 Lena Hjermind, MD, PhD, staff neurologist
- 19 Kristine Hoffmann, MD, PhD student
- 38 Oda Jakobsen, research nurse
- 20 Christina Jensen-Dahm, MD, PhD student
- 32 Peter Johannsen, MD, PhD, senior neurologist
- 43 Ida Unmack Larsen, MSc, PhD student, neuropsychologist
- 33 Jørgen E. Nielsen, MD, PhD, senior neurologist
- 21 Troels Tolstrup Nielsen, MSc, PhD, research assistant (post.doc.)
- 22 T. Rune Nielsen, MSc, PhD, neuropsychologist, research assistant (post.doc.), project director
- 23 Tien Kieu Phung, MD, PhD, associated research assistant (post. doc.), project director
- 24 Lise Cronberg Salem, MD, PhD student
- 25 Anja H. Simonsen, MSc, PhD, research assistant (post.doc), project director
- 44 Jette Stokholm, MSc, neuropsychologist
- 26 Tua Vinther-Jensen, MD, PhD student
- 45 Asmus Vogel, MSc, PhD, neuropsychologist, research assistant
- 46 Laila Øksnebjerg, MSc, neuropsychologist

Master Student

Pia Brandt Damborg, Msc

THE COPENHAGEN MEMORY CLINIC

Medical Doctors

- 27 Karima Egelund Bohr, MD, staff physician
- 28 Steen G. Hasselbalch, MD, DMSc, assoc. professor, senior neurologist
- 29 Anne-Mette Hejl, MD, PhD, staff neurologist
- 30 Lena Hjermind, MD, PhD, staff neurologist
- 31 Merete Hørding, MD, senior psychiatrist
- 32 Peter Johannsen, MD, PhD, senior neurologist
- 33 Jørgen E. Nielsen, MD, PhD, senior neurologist
- 34 Erik Søndergaard Poulsen, MD, staff physician
- 35 Lisbeth Regeur, MD, DMSc, senior neurologist

- 36 Lis Christoffersen
- 37 Christina Vangsted Hansen



- 38 Oda Jakobsen
- 39 Annette Lauridsen
- 40 Naomi Wakabayashi
- 41 Anne Willer

Neuropsychologists

- 42 Christian Buhl, MSc
- 43 Ida Unmack Larsen, MSc
- 44 Jette Stokholm, MSc
- 45 Asmus Vogel, MSc, PhD 46 Laila Øksnebjerg, MSc

Medical secretaries

- 47 Bente Friedman
- 48 Dorte Hansen
- 49 Susanne Lindstrøm
- 50 Pernille Munch-Christensen

- 51 Jena Taylor 52 Ulla Thranow
- Social Counsellor

53 Pernille Starnø

Medical Laboratory Technician 54 Kathrine Bjarnø

Students

Thea Brandt Poulsen, Mary Ngo, Line Eckermann, Elsebeth Petersen, Line Lauridsen Vold, Louise Victoria Allivert Holde, Astrid Stokholm Sørensen, Maja Nystrøm-Hansen, Peter Leslie Williams, Casper Hald, Helene Vasegaard Nielsen, Mette Nørgaard Nielsen, Camilla Inge Sørensen, Ida Chenoufi Hasselbalch, Signe Pertou Ringkøbing og Katrine Isabella Wendelboe.



The DDRC Steering Committee. photo from Dementia Days 2012.

From left: Marianne Skov Iversen, repr. for The National Board of Social Services.. Camilla Lund-Cramer, Ministry of Health. Tina Jørgensen, Local Government Denmark. Hanne Jervild, The Health Foundation. Svend Hartling, the Capital Region of Denmark. Nikolaj Mors, the Capital Region of Denmark. Jannik Hilsted, Rigshospitalet, Copenhagen University Hospital. Gunhild Waldemar, professor, director of DDRC. Søren Bredkjær, repr. for Danish Regions.



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

COPENHAGEN MEMORY CLINIC

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.

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, frontotemporal dementia, spinocerebellar ataxia, Huntington's disease)
- Diagnostic evaluation of patients where brain biopsy may be relevant

 Lumbar perfusion tests and clinical evaluation of patients with Normal Pressure Hydrocephalus (NPH).

In 2012 we established two new leading positions as senior consultant neurologists taking responsibility for the management of the Huntington's disease and the Normal Pressure Hydrocephalus programmes.

The 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 at Bispebjerg Hospital.

PATIENTS AND FAMILIES

The Copenhagen Memory Clinic has managed more patient visits than ever before in 2012. New patients are referred for diagnostic evaluation of cognitive, behavioural or other symptoms suggestive for a neurodegenerative condition. Patients with rare, complex or familial disorders may be referred for treatment and follow-up, and genetic counselling is also offered for healthy at-risk family members.

The classification of the 2,000 patients in our follow-up programme differs significantly from that of new patients referred. All patients with MCI, dementia or specific neuro-

Key figures from the Copenhagen Memory Clinic 2006-2012

	2006	2007	2008	2009	2010	2011	2012
New patient referrals	642	737	709	726	842	778	920
Total number of visits	4,015	4,638	4,192	4,811	5,807	5,700	6,770
Patients in follow-up programme	1,153	1,516	1,487	1,648	1,766	1,892	2,038

degenerative disorder 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, DLB, FTD, Huntington's disease, spino-cerebellar ataxias, Down's syndrome with dementia, NPH, and other neurode-

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

In 2012 a total of 877 new patients completed a diagnostic evaluation programme and were classified as follows:

Syndrome	Diagnosis	Number (%)
Dementia	Total	424 (48%)
	Alzheimer's disease (AD)	181
	Vascular or mixed dementia (VaD)	67
	Dementia with Lewy Bodies (DLB), Parkinson's Disease with	
	Dementia, Parkinson Plus Syndromes	33
	Fronto-temporal Dementia (FTD)	21
	Other specific conditions	84
	Dementia of uncertain etiology	58
Mild Cognitive Impairment (MCI)	Amnestic MCI	31 (4%)
Other cognitive profiles or no	This group includes patients with other specific neurodegenerative	312 (36%)
cognitive impairment	disorders without significant memory impairment or dementia,	
	patients with NPH, patients with depression and other psychiatric	
	conditions, patients with sequelae after traumatic brain injury or	
	stroke, and patients with subjective symptoms and no significant	
	pathology.	
Healthy persons	Family members to patients with familial neurodegenerative	110 (12%)
	conditions, referred for genetic counselling	



COURSES FOR 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 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 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. In addition, the consultants from the Copenhagen Memory Clinic have 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 5 memory clinics (and the specialist service on Bornholm), the registry is overlooked by the Scientific Dementia Council in the region and coordinated by the Copenhagen Memory Clinic.

The Capital Region of Denmark also established a guideline ("forløbsprogram") for coordination of patient care pathways between the hospital based memory clinics, mental health centres, other hospital departments, general practitioners, and primary health care in the 29 municipalities. The implementation of the programme started in 2012.

For patients from the city district of Copenhagen ("planområde BYEN"), the Copenhagen memory clinic at Rigshospitalet has specific collaboration programmes with the departments of geriatrics and neurology at Bispebjerg Hospital, Mental Health Centre Copenhagen and Mental Health Centre Frederiksberg, the general

practitioners, and the care institutions and home care in the two city municipalities Copenhagen and Frederiksberg.





RESEARCH

Our clinical and translational research programmes in the fields of dementia and neurodegenerative disorders, 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, non-pharmacological 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 biobank form an important resource for our clinical research. Access to nationwide health care registries allows for very large population-based studies on health service, risk factors and outcome in neurodegenerative disorders. The biobank (The Danish Dementia Biobank) collecting blood and CSF samples from memory clinic patients at Rigshospitalet and Roskilde hospital also serves as the research biobank for the eight memory clinics involved in the ADEX programme (for further details, see below). At the end of 2012 the biobank contained samples from 2225 patients, including CSF from 648. The biobank samples are available for collaborative research studies, some of which were initiated in collaboration with Statens Serum Institut.

In 2012 the research group had 6 PhD students and 4 post.docs. and published 41 papers (see publication list). All our research is funded by external grants and donations from public or private foundations (see acknowledgment section). 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. In this section some of DDRC's research projects in 2012 are described. Research collaborators are listed with each project. For more information see our website and publication lists.

BIOFLUID MARKERS, BRAIN IMAGING AND EARLY DIAGNOSIS

Biofluid markers

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. In 2012 recommendations for CSF biobanking as well as a panel of protein markers for the differentiation between AD and vascular dementia were published.

In a study conducted by Department of Cellular and Molecular Medicine at University of Copenhagen om Molecular on Molecular Markers in AD, the major aim is to investigate the potential correlation between AD and molecular biomarkers: mitochondrial oxygen consumption, reactive oxygen species, nucleotide pool maintenance, 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)

A large part of our brain imaging research is integrated in international multicentre studies. Funded by EU and coordinated by the University of Florence, Italy, the Leukoaraiosis and Disability in the Elderly (LADIS) study was initiated in 2003, with the aim to study the clinical and prognostic significance of unspecific age-related white matter changes (as identified on MRI) in elderly patients with no or minor functional disability. Almost 700 patients from 11 European centres participated in the 4-year longitudinal study. 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. DDRC has studied clinical and imaging correlates to corpus callosum atrophy, and several imaging publications from the LADIS study were published in 2012. For more information on collaborators and results, see: unifi.it/LADIS.

BIOMARKAPD

Further, a new international JPND funded study, BIOMARKAPD, was initiated in 2012 with the aim to validate and harmonize pre-

analytical 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). DDRC takes part in the study by validating CSF biomarkers for amyloid using amyloid PET and by coordinating new guideline papers on the clinical application of CSF biomarkers for AD and PD. The BIOMARKAPD study and its more than 20 partners are coordinated by the Karolinska Institute in Stockholm, Sweden, and the Danish partners of the programme, the DDRC and the Statens Serum Institute, 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/.

Amyloid PET

Since 2008, the centre has collaborated with the PET and Cyclotrone Unit at Rigshospitalet on the clinical application of amyloid brain imaging, and in 2012 research into the added diagnostic value of amyloid imaging was initiated. In collaboration with the Mental Health Centre Copenhagen and the Neurobiology Research Unit at Rigshospitalet, amyloid imaging in depression has been investigated. Further, in collaboration with the Danish Research Centre for Magnetic Resonance at Hvidovre Hospital, studies have been initiated investigating the association between amyloid accumulation and white matter changes.

Quantitative EEG in early diagnosis of AD

In the recently formed Nordic network in dementia diagnostics (NIDD), the role of quantitative EEG in the early diagnosis of AD is studied. The program is funded in part by the Nordic Council (Nord Forsk) and the Kavli Foundation and involves eight academic memory



clinics in Reykjavik, Oslo, Bergen, Stockholm, Kuopio, Tartu, Roskilde and Copenhagen. DDRC participates in collaboration with the Dept. of Clinical Neurophysiology at Rigshospitalet and with Roskilde hospital. The 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*.

Quantitative EEG as a diagnostic tool for AD in persons with Down's syndrome

The aim of this project is to investigate the use of quantitative EEG as a diagnostic marker for AD in patients with Down's syndrome. This study will include two groups of participants with Down's syndrome: 25 individuals without dementia and 25 with dementia due to probable AD, recruited from the Copenhagen Memory Clinic.

PredictAD

PredictAD is an EU funded research project which 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 different biomarkers. Combining this multisource information may enable earlier diagnosis of Alzheimer's disease, but may also provide crucial information used for differentiating between various forms of dementia and for assessing disease severity. Further, it may 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 Copenhagen University Hospital, Rigshospitalet

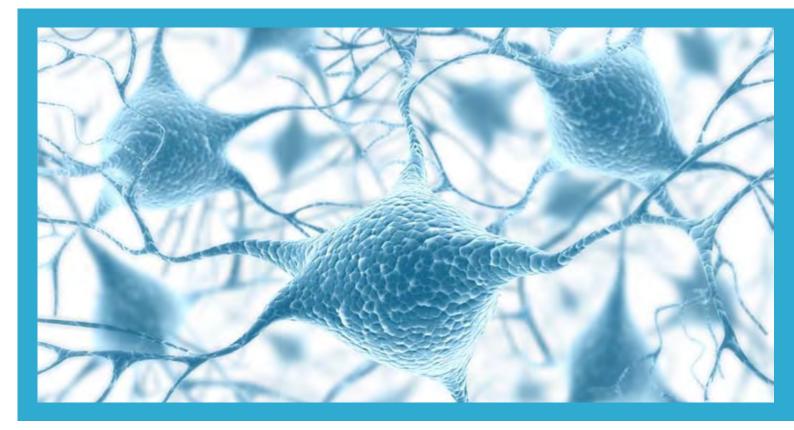
(Denmark). This project is partially funded under the 7th Framework Programme by the European Commission. A software prototype has been developed and validated. The programme will be completed in 2013, but will be further developed, pending new funding. For more information, see *predictad.eu*.

NEUROGENETICS

Neurogenetic research focuses on clinical characteristics, paraclinical findings, treatment and basic research into gene function and therapy. The DDRC is part of the European Huntington's Disease Network, EHDN, which provides a platform for professionals and people affected by Huntington's disease and their relatives to facilitate working together throughout Europe. The EHDN study called REGISTRY is a multi-centre, multinational observational study and the DDRC is one of the largest players in this collaboration contributing with data on more than 300 patients.

Through the SPATAX network, combining the experience of European clinicians and scientists working on hereditary ataxias and paraplegias, we work together to initiate a new clinical and genetic database, to distribute DNA to participating laboratories, to map new loci and to identify new genes (spatax.wordpress.com/).

The international, multidisciplinary Frontotemporal Dementia Research in Jutland Association (FReJA Consortium) was established over a decade ago to investigate frontotemporal dementia linked to chromosome 3 (FTD3), which occurs in a large western Jutland FTD family. The consortium has made major progress in understanding the disease and its wider relevance for neurodegeneration, including defining the clinical charac-



teristics, brain imaging findings, neuropathology and genetic studies culminating in identifying the disease gene, CHMP2B.

In 2012 we provided proof of principle for the knockdown approach for gene therapy and were the first to describe preclinical cognitive dysfunction in a controlled analysis in preclinical carriers of the CHMP2B mutation that determines future development of FTD3.

PATIENT-SPECIFIC STEM CELLS DERIVED MODELS FOR ALZHEIMER'S DISEASE

In 2011 DDRC received a grant from the Danish Advanced Technology Foundation for a three-year consortium project, "Patient-specific stem cell-derived models for Alzheimer's disease". The consortium includes researchers from the Department of Veterinary Clinical and Animal Sciences at University of Copenhagen, Aarhus University, Lundbeck, Bioneer, Pixiegene and DDRC. The overall vision is to establish human neuronal cell lines as models for neurodegenerative disorders, which can be used for drug screening and prediction of the patient subtypes, where a drug or target exerts the best effect. The objectives 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.

NEUROPSYCHOLOGY

The DDRC's neuropsychological research mainly focuses on characterisation of cognitive deficits in the early phase of dementia diseases. In 2012 three papers describing reference data for healthy elderly Danes on different neuropsychological measures were published. In

cooperation with the FReJA Consortium a paper describing cognitive profiles in FTD3 (a familial type of Frontotemporal dementia) was published.

As part of the DDRC's large new project on the clinical and molecular aspects of Huntington's disease, 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) was initiated. This project includes standard neuropsychological assessment of a large patient group and the patients are also tested with a range of more experimental executive tests and tests for social cognition. In addition, comprehensive questionnaires for neuropsychiatric symptoms and personality traits are applied.

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

Diagnostic evaluation of dementia in ethnic minorities
In 2012 a PhD thesis on dementia in ethnic minorities in Europe was completed, focusing on cognitive testing of Turkish immigrants in Denmark. For further information see the section on the "Migrations-skolen" educational programme below.

The North European Cross-Cultural Neuropsychological Test Battery (CNTB)

The CNTB study investigates the validity of a cross-cultural neuropsychological test battery in immigrants with Turkish, Pakistani, formerly Yugoslavian and Polish backgrounds. The project, an international multi-centre study including four centres in Berlin, Oslo, Malmo and



Copenhagen, was initiated to improve the clinical evaluation of cognitive dysfunction in patients with diverse cultural and linguistic backgrounds.

Dementia in Lebanon

This study is part of 10/66 Dementia Research Group (DRG), an international network of researchers who carry out population-based studies onto dementia in developing countries. The specific aims of the study are: 1) To validate the 10/66 DRG one-stage dementia diagnostic instrument in Arabic in order to use it for case ascertainment in a subsequent population-based study 2) To carry out a pilot study in the Beirut and Shouf areas of Lebanon, using the validated 10/66 DRG instrument to diagnose dementia, generating preliminary data about dementia prevalence, and assessing the feasibility of a longitudinal community-based cohort study comprising of 2,500 people older than 65 years 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 was conducted by 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; the Danish Dementia Research Center (DDRC), Department of Neurology, Copenhagen University Hospital, Copenhagen, Denmark; and the Institute of Psychiatry, King's College London, London, UK. The study was funded by the Fogarty International Center, and the American National Institute of Health (NIH) and National Institute of Aging (NIA), with the grant number 1R21AG039333-01 under the program "Brain Disorders in the Developing World: Research Across Lifespan (BRAIN)".

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 analysesic use and use of anti-dementia medication are currently being conducted. The research is being carried out in cooperation with the Centre for Integrated 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. In 2012 a project validating three pain sensitivity tests and a project using pain-evoked potentials in patients with AD were conducted. This research was carried out in cooperation with the Danish Pain Research Center at Aarhus University, the Department of Clinical Neurophysiology at Rigshospitalet and the Multidisciplinary Pain Centre at Rigshospitalet.

Diagnostic evaluation of dementia in young patients

This on-going PhD research programme involves the investigation of several aspects of diagnosing dementia in young patients in Denmark.

- *Validity and quality of dementia diagnoses in young patients*The aim of this study is to investigate the validity of a diagnosis of dementia and the quality of dementia diagnoses registered in the Danish nationwide hospital registers in patients below 65 years of age. From this study one paper focusing on the validity of dementia diagnoses registered in Danish national registers was published in 2012.
- Prospective study on subjective cognitive complaints in young patients

The aim of this study is to investigate the profile of subjective cognitive



 $The {\it first project in ADEX is to investigate the effect of physical training in patients with AD}$

complaints in patients referred to the Copenhagen Memory Clinic in order to identify characteristic profiles of cognitive complaints in young patients diagnosed with neurodegenerative diseases, affective disorders or other diseases as compared to healthy elderly participants.

INTERVENTION STUDIES

ADEX

ADEX is an acronym for "Preserving quality of life, physical health and functional ability in Alzheimer's disease: The effect of physical exercise". ADEX is a Danish multi-centre study with eight Danish dementia clinics, the Institute of Sports Medicine Bispebjerg Hospital and other Danish and international partners (DRCMR at Hvidovre Hospital, the PET and Cyclotron Unit at Rigshospitalet, the University of Southern Denmark, The Vrije University Alzheimer Centre, Amsterdam, Swedish Brain Power, Karolinska Institute, Stockholm), 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 is to investigate the effect of physical training in patients with AD. The goal is that 192 patients will be recruited for a randomised controlled trial and allocated to regular exercise supervised by physiotherapists three times a week for four months or to a control intervention. The outcomes include cognitive and physical tests, assessment of quality of life, and in a sub-sample brain imaging (MRI and amyloid PET) and biofluid (plasma and CSF) markers are also investigated. The first patients were included in 2012. For more information about partners and current status see: videnscenterfordemens.dk/adex.

Danish Alzheimer Intervention Study (DAISY)

The DAISY study investigated the effect of psychosocial intervention for patients in the earliest phases of dementia and their caregivers. It was a randomised trial including 330 persons with dementia and their caregivers. The effect of the intervention was measured on different parameters in patients and caregivers, including health, cognition, quality of life, depression and activities of daily living. Outcomes were measured after 6, 12 and 36 months. Many papers have been published from this study, e.g. on health, quality of life and psychological symptoms (for publication lists, see videnscenterfordemens.dk). The study was completed In 2012, and the main effect article describing the efficacy at 12 months of the early psychosocial counselling and support programme was published in *British Medical Journal*. However, the data from the large clinical cohort will continue to contribute to our research. For more information see: *videnscenterfordemens.dk/daisy*

DRUGTRIALS (CONTRACT RESEARCH)

The DDRC has extensive experience in the conduction of phase 1 to phase 4 clinical pharmacological trials in patients with AD, vascular dementia, MCI, and Huntington's disease. In recent years the focus has been on phase 1 and phase 2 trials. In 2012, 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 Eli Lilly), and a phase 2 study of an amyloid tracer for PET (sponsor GE Healthcare). The clinical trials are being conducted with state-of-the-art imaging techniques in collaboration with the DRCMR at Hvidovre Hospital and the PET and Cyclotron Unit at Rigshospitalet.



NATIONAL INFO & EDUCATION CENTRE

The DDRC's National Info & Education Centre was established to provide education and dissemination of information about dementia, primarily to health care professionals. 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 attendance at 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 – GENERAL ASPECTS

The DDRC runs a wide range of courses and conferences on dementia for health care professionals. 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.

Courses

In 2012 the DDRC organised courses and conferences as well as local courses tailored to the needs of specific groups as requested by municipalities or regional institutions.

For the fourth time, the DDRC published a catalogue of 22 courses,



one-day thematic events and conferences held across Denmark targeting various professional groups working within the health care sector. These activities are also advertised on the DDRC website. In 2012 the DDRC ran courses on a wide range of subjects, such as "meaningful activities", "palliative treatment for patients with dementia" and "visual spatial deficits". 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 "rehabilitation and dementia".

The 41 courses or lectures carried out across Denmark with a total of 1,408 participants in 2012 represent an increasing demand for our



customised courses. Designed to meet a specific purpose or cover a certain subject, customised courses were attended by various professional groups, including new groups, such as speech therapists, audiologists, hearing consultants, specialist teachers and vision consultants. Combined, standard and customised courses organised by DDRC had a total of 3,541 participants in 2012.

The DDRC also took on the task of advising architects in 2012 after being asked to provide suggestions on how to build and/or renovate nursing homes and design dementia-friendly surroundings. Furthermore, the DDRC receives e-mails or telephone calls from students, journalists, patients, relatives and educational consultants daily. We strive to reply to inquiries within 8 days.

Conferences

In 2012 the DDRC held five large conferences, including "Dementia Days" and "Palliative Care for People with Dementia", the latter of which gathered more than 125 participants and was organised in collaboration with, among others, the Danish Knowledge Centre for Palliative Care.

EDUCATIONAL ACTIVITIES 2012

Total number of participants in 2012	3,541
Customised courses	1,408
International PhD course	34
Scandinavian conference for leaders	420
Dementia Days national conference	941
Catalogue courses and thematic events	738

FIRST SCANDINAVIAN CONFERENCE FOR LEADERS IN DEMENTIA CARE

In 2012, three national Scandinavian dementia research and education centres, the Swedish Dementia Centre, the Norwegian Dementia Research Centre, and the DDRC, worked on a joint project for the first time. The three centres organised a conference in Copenhagen bringing together leaders in dementia care from Scandinavia and international researchers and speakers with the aim to address some of the challenges dementia care faces in the future. The aim of the joint conference was to exchange knowledge and experience for the benefit of dementia patients.

Entitled "Bridging the gap: Good dementia care – a question of management?", the conference attracted 420 leaders in dementia care from Sweden, Norway and Denmark. A number of internationally recognised researchers were invited and gave talks, including keynote speaker Professor Dawn Brooker, University of Worcester, England, who gave a presentation on "Person Centred Care: What's Wrong?"

Due to the great success of the initial conference, the goal is to organise a Scandinavian conference focusing on leadership in dementia care every other year, the next one scheduled to take place in Stockholm in October 2014.













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, Copenhagen University Hospital, and attracts scientists and practitioners from across Denmark.

The 2012 topic was "Prevention and risk factors of dementia" and Professor Bente Klarlund Pedersen from the Danish National Research Foundation Centre of Inflammation and Metabolism (CIM) at Rigshospitalet gave the opening presentation, which was on life style and prevention of dementia. Attended by nearly 200 people, the conference also had presentations by various national and international researchers on epidemiological research, risk factors for developing dementia and possible preventive initiatives.

Professor Miia Kivipelto, Karolinska Institute talked about the role of modification of cardiovascular risk factors in the prevention of dementia, while Professor Laura Fratiglioni, also from the Karolinska Institute, gave a talk on the role of psychosocial factors involved in the prevention of dementia.

Associate Professor Kjeld Andersen, Odense University Hospital, gave a presentation on depression, anxiety disorders and dementia, neuropsychologist Kasper Jørgensen from DDRC, gave a brief lecture on the possible effects of coffee intake on the prevention of dementia and Associate Professor Steen Hasselbalch, also from DDRC, presented an update on the preventive effects of physical exercise.



















34 PhD students at the first international PhD course on research in AD

FIRST INTERNATIONAL PHD COURSE

In cooperation with the University of Copenhagen, DDRC organised a course on research in AD for the first time for 34 PhD students. Given in English, the course was designed to attract new researchers to the field of Alzheimer research and to provide an insight into AD for young PhD students from various basic, clinical and epidemiological fields. The course presented a wide spectrum of research in this exciting area, ranging from epidemiological, clinical, biomarker, imaging and translational research. Interesting challenges and pitfalls of the field, with special emphasis on AD, were presented.

Three top international scientists: Professor Knut Engedal, Norway; Professor Ezio Giacobini, Switzerland; and Professor Bengt Winblad, Sweden, as well as several excellent Danish senior researchers in the field were recruited as teachers.



From the neuroimagin work shop

DEMENTIA DAYS – A NATIONWIDE CONFERENCE

Every year the DDRC organises the 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.

Dementia Days took place for the fourteenth time in 2012. Officially opened by the Danish Minister of Health, Astrid Krag, the conference had 941 participants, while over 60 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 "Frie foredrag" and 20 people presented a poster, with Annette Johannsen, Master of Science in Occupational Therapy, receiving the 2012 poster prize for "How to maintain an active life with leisure activities for patients with dementia".

For more information about the 2012 Dementia Days, see: videnscenterfordemens.dk/uddannelse/demensdagene













DDRC conference booth

THE MIGRATION SCHOOL

The Migration School is a cross-national collaborative programme on dementia assessment and care for patients from ethnic minorities in the Oresund Region. The Neuropsychiatric Clinic, Skåne University Hospital, Sweden and the 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 aims to 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 utilization of health service in dementia and on validation of cross-cultural assessment instruments.





THE DDRC CONFERENCE BOOTH

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

In 2012 the conference booth was used on the following occasions:

- January: National Health service conference organised by Local Government Denmark
- May: Dementia Days
- June: National Social service conference organised by Local Government Denmark
- September: Danish Association of Municipal and Regional Coordinators of Dementia annual cource
- October: The first Scandinavian conference for leaders in dementia care.

The distribution of material and professional dialogue that took place with participants at these events was important and rewarding. The release of our new app for mobile devices, "About Dementia", was the biggest hit and attracted the most interest.

NEW PRODUCTS

Most of the educational material produced by DDRC is available free of charge at videnscenterfordemens.dk. New products were introduced in 2012; an app, two guideliners and 11 fact sheets.

New app

The first Danish app to target dementia nurses, social and health assistants and other health care sector professionals is also the DDRC's



The new app "About Dementia"

first app. "About Dementia" (Viden om demens) is available for free for Android, iPhone and iPad.

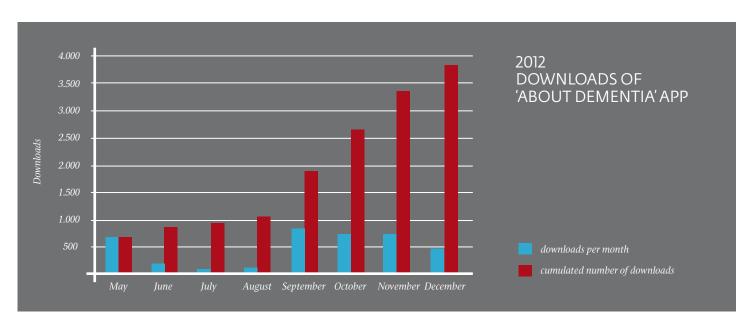
People with dementia are at greater risk for developing other diseases and they often have co-morbidities. They may lose their appetite and forget to drink; dementia can also affect a patient's ability to express pain and discomfort. This combination can be dangerous and requires attention from professional health care staff.

By using the new app, the staff receive support to help identify symptoms and to respond appropriately to changes in a dementia patient's physical condition. Comprised of four parts: observation, consultation, tips and a quiz, the app allows users to test their knowledge about physical symptoms related to mobility, nutrition and pain as well as gastrointestinal issues.

There are many good reasons to refresh one's memory and knowledge within this area, not to mention sharing it with others. The app also contains a glossary.

The app is the result of a collaboration between the Capital Region of Denmark and the DDRC and was sponsored by the Region's programme on chronic diseases.

The Android version was introduced in May 2012
The iPhone version was introduced in September 2012





Users downloaded the app 3,814 times by the end of 2012 and used it more than 19,700 times (sessions).

Guidelines for social workers

The DDRC released two new guidelines for social workers: *Young onset frontotemporal dementia* and *Young onset Alzheimer's Disease*.

In addition to a brief description of the dementia disorder, these guidelines also contain advice for social workers about methodology, a checklist and a guide in which the most common social care needs of patients are listed with relevant suggestions for actions or support measures and their rationale.

Fact sheets

The DDRC has published 11 new fact sheets in Danish on the following topics: *Is dementia hereditary?*, *What is Huntington's disease? Dementia in Parkinson's disease; Acute confusion (delirium); Language impairment in dementia; Apathy; Aggressiveness; Loss of insight; Drug (Pharmaceutical) treatment of Alzheimer's disease; Care and support; and Can dementia be prevented?*

Targeted to persons with dementia and their family caregivers fact sheets are available free of charge on DDRC's website. Both new and updated fact sheets have been welcomed by users. New fact sheets will continue to be made available in 2013.

WEBSITE AND NEWSLETTER

The DDRC website, videnscenterfordemens.dk, is a primary plat-

form for providing information and communicating and 2012 has seen a rise in the number of users and visitors. After undertaking the rewarding development of a new website in 2010, traffic has multiplied since then to an average of 11 to 12,000 visitors monthly, each visitor perusing an average of 4-5 pages.

The number of subscribers to the DDRC's bi-monthly electronic newsletter also continues to grow, reaching more than 3,500 recipients within the health care sector.

The menu item 'About Dementia' on the DDRC website was expanded with the following sub-pages in 2012:

- Is dementia hereditary?
- What is Huntington's disease?

NO. OF VISITORS AND USERS ON THE DDRC WEBSITE 2007-2012

Year	Visitors	Unique users
2007	894	625
2008	12,102	7,784
2009	17,976	9,371
2010	23,699	13,532
2011	90,835	53,739
2012	162,548	98,609



Website

- · Dementia in Parkinson's disease
- Acute confusion (delirium)
- · Language impairment in dementia
- Apathy
- · Aggressiveness and unrest
- · Lack of insight
- Drug (Pharmaceutical) treatment of AD
- Care and support
- Can dementia be prevented?

Public and private players within the health and social care sectors often make links to content on the DDRC website. We are maintaing a link collaboration with Region of Southern Denmark, the Alzheimer's Association, the National Board of Social Services and many other organisations.

DDRC IN THE MEDIA

The staff at DDRC is 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 in short TV and radio reports in 2012.

Throughout 2012 the DDRC was mentioned or appeared 108 times in printed media, 122 times in online media, 10 times in radio programs and 11 times on TV.

2012 Communication	Description	Number
Scientific publications	Scientific papers, books and book chapters (co-) authored by DDRC	46
Public media (newspapers, TV, radio, online media, etc)	Contributions with interviews, expert testimonies, viewpoints, etc.	251
DDRC website	Website visits	162,548
DDRC's App on dementia	Downloads	3,814
DDRC Newsletter	Subscribers	3,500



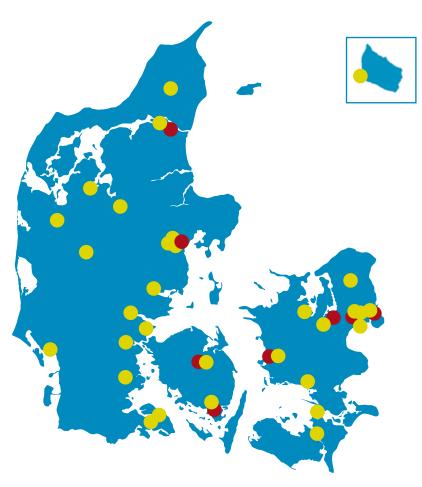
Danish Memory Clinics Network meeting in odense 2012

NATIONAL AND INTERNATIONAL NETWORKS

NETWORK OF DANISH MEMORY CLINICS

The 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 of patients for diagnostic evaluation of dementia. Some memory clinics also offer follow-up and counselling. Multidisciplinary staff members (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 their regional cooperation.

In October 2012 the DDRC organised its 5th annual network conference for all memory clinics in Denmark. There were 110 attendees including physicians, nurses, psychologists, secretaries and therapists. As in previous years the



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



DDRC invited an internationally recognised researcher to give a lecture at the conference, and in 2012 Professor Anders Wallin, Sahlgrenska University Hospital, Sweden gave a lecture on "How to diagnose vascular dementia?" Organised by the DDRC in collaboration with the Memory Clinic at Odense University Hospital, the conference also offered a series of specialised workshops. Valuable input is also received from the memory clinics on the DDRC's educational programme.

NATIONAL NETWORK OF MUNICIPALITY-BASED DEMENTIA AMBASSADORS

In 2009 the 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.

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 the DDRC and the ambassadors is ensured in a variety of ways, including via special news info mails containing information about new publications, news on the website, courses and conferences and an annual meeting for ambassadors.

In March 2012 the network of local dementia ambassadors met in Odense and 73 out of 98 Danish municipalities were represented.

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 of the day was "persons with challenging impairments and needs for care". In addition to exchanging knowledge and experience about this subject, counsellor Karin Moreau Andersen from CFD, the largest provider in Denmark of services for deaf, deafblind and hearing impaired people and Tine Skov Uldall from The National Board of Social Services, gave a talk on the special needs of persons with dementia who become deaf and blind. Åse Hyldgård Larsen, Gitte Dahlgaard, Kirsten Jørgensen and Susanne Kaagaard gave a talk on complicated clinical cases.

NORDIC MEMORY CLINICS

The Nordic Network in Dementia Diagnostics (NIDD) is a Nordic Council (Nor Forsk) financed initiative of eight academic Memory Clinics in the Nordic countries and Lithuania. As the name indicates, the main objective of this network is to look into various aspects of the diagnostic procedure in dementia. DDRC and the memory clinic at Roskilde university hospital are the Danish partners in the programme (more info on *nidd-dementia.org*).

EUROPEAN ALZHEIMER'S DISEASE CONSORTIUM

The 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 setting in which to increase the scientific understanding of and to develop ways to prevent, delay, slow, or ameliorate the primary and secondary symptoms



2012 annual meating for specialists from the Norwegian Centre for Dementia Research, the Swedish Dementia Centre and the Danish Dementia Research Centre

of Alzheimer's disease. Funding for the original realisation of this network was received from the European Commission which supported work 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 (for more information see: <code>eadc.info/sito/pagine/home.php</code>). 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 HUNTINGTONS' DISEASE NETWORK EHDN

The DDRC is part of the EHDN, which provides a platform for professionals and people affected by Huntington's disease and their relatives to facilitate working together throughout Europe. DDRC's staff and patients with Huntington's disease have contributed significantly to clinical cohort studies and intervention studies (more info on *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 Age-

ing and Health, Norwegian Centre for Research, Education and Service Development, and was founded in 1996.

The Swedish Dementia Centre was established in 2008, commissioned by the National Board of Health and Welfare to create a national centre for excellence in dementia care.

The DDRC, the Norwegian Centre for Dementia Research and the Swedish Dementia Centre collaborate and meet once every year in order 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 Norway, Sweden, Ireland, UK, the Netherlands, Luxembourg, Germany, Belgium, Italy, France and Denmark. There is one annual 2 days meeting with networking and 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. www.interdem.org



PUBLICATIONS 2012

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DDRC CONTRIBUTIONS TO COOPERATIVE MULTICENTER STUDIES

- Firbank, M. J., Teodorczuk, A., van der Flier, W. M., Gouw, A. A., Wallin, A., Erkinjuntti, T., Inzitari, D., Wahlund, L-O., Pantoni, L., Poggesi, A., Pracucci, G., Langhorne, P., O'Brien, J. T., LADIS group (2012). Relationship between progression of brain white matter changes and late-life depression: 3-year results from the LADIS study. *British Journal of Psychiatry*, 201(1), 40-45.
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NATIONAL AND INTERNATIONAL POSTS

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· Lena Hjermind

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Chairman 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

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 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 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 90 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*

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 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 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 <code>efns.org/EFNS-ENS-Liaison-Committee</code>; <code>ensinfo.org/ean_news</code>; and from Zohar Argov and Richard Hughes. Creation of the European Academy of Neurology. <code>Neurology 2012;78;137</code>.



AWARDS THE NIELS A. LASSEN AWARD 2012

The director of DDRC, professor Gunhild Waldemar received the annual Niels A. Lassen award in 2012. Established in recognition of the pioneering and outstanding contributions to brain research from Professor Niels A. Lassen (1926-1997), the Niels A. Lassen foundation presents the prize to a leading Danish researcher every year in December.

Photo: Gunhild Waldemar with Professor Hans Henrik Parving from the foundation.



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- Helsefonden (The Danish Health Foundation)
- Højteknologifonden (The Danish Advanced Technology Foundation)
- Lennart Grams Mindefond
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- · Lægeforeningens Forskningsfond
- Indenrigs- og Sundhedsministeriet (the Danish Ministry of Health)
- National Institutes of Health (NIH)
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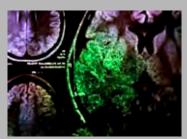
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