



REGION

DANISH DEMENTIA RESEARCH CENTRE

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



NATIONAL
VIDENSCENTER
FOR DEMENS



DANISH DEMENTIA
RESEARCH CENTRE

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



DANISH DEMENTIA
RESEARCH CENTRE



Rigshospitalet

PREFACE

It is a pleasure to present the 2017 Danish Dementia Research Centre's (DDRC) annual report, which describes our research and provides a general overview of our clinical services, research and national educational services over the past year.

In September 2017 DDRC celebrated its 10th anniversary with an international symposium that attracted international keynote speakers and a large Danish audience and that offered the opportunity to highlight achievements in the field of dementia in Denmark in the past decade.

In January 2017 the Danish Ministry of Health launched the national dementia strategy and action plan at a conference in the Parliament building at Christiansborg, hosted by the Minister of Health, Ellen Trane Nørby, and the Minister of the Elderly, Thyra Frank, with participation of the political parties behind the allocation of DKK 470 m for 23 initiatives in the 2017-2019 action plan. In addition to taking responsibility for implementing three of the initiatives, DDRC is heavily involved in many of the others. Part of the national strategy involved permanently financing DDRC as of 2017, with an extension of our grant to allow for new investments in the ABC Dementia e-learning concept, a step we are extremely grateful for. We were pleased to receive an official visit from Minister Frank after the launch of the plan in February 2017.

An important hallmark of our activities is the coordination of national networks for health care professionals in municipalities and regional memory clinics, as well as for health care instructors and psycho-social researchers. The networks help provide inspiration, innovation, coordination and the exchange of ideas among practitioners, supporting the translation of scientific results to clinical practice to allow the implementation of best practice in the care of people with dementia. In 2017 our educational activities attracted more than 4,000 participants. Our popular e-learning programmes, ABC Dementia for

doctors and ABC Dementia for professional carers, which are available free of charge, now have over 20,000 users. Our national annual conference, Dementia Days, attracted a record 1,200 participants.

Meeting patients with dementia and their caregivers serves as a constant source of inspiration for our research and educational activities. After a merger in January 2017 our memory clinic now has out-patient clinics at two locations, Rigshospitalet – Blegdamsvej and Rigshospitalet – Glostrup, both of which are served by highly professional multidisciplinary staff.

With this 2017 annual report we would like to thank our national and international collaborators and our external scientific and educational advisors. We would also like to extend a special thanks to the private and public foundations that support our work financially.



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

Gunhild Waldemar
Professor, Chair of DDRC



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ABOUT THE DANISH DEMENTIA RESEARCH CENTRE

ORGANISATION

Located at Rigshospitalet and based in the Department of Neurology, the Danish Dementia Research Centre (DDRC) comprises three sections:

- Copenhagen Memory Clinic
- Dementia and Neurogenetics Research Unit
- National Info & Education Centre for Dementia

The Copenhagen Memory Clinic is a secondary and tertiary referral-based multidisciplinary out-patient clinic offering diagnostic evaluation and treatment of patients with cognitive disorders and dementia. It has two sections, Rigshospitalet – Blegdamsvej in Copenhagen and Rigshospitalet – Glostrup in Glostrup.

The Research Unit comprises clinical research groups, a neuro-genetic research laboratory and the Danish Dementia BioBank.

Initiated and funded by the Danish Ministry of Health, the National Info & Education Centre for Dementia has a steering committee and a scientific advisory board.

With representatives from the Ministry of Health, Danish Regions, Local Government Denmark and Rigshospitalet, the steering committee monitors the strategic development and performance of the National Info & Education Centre according to predefined objectives and milestones as outlined in our strategy for 2016-2020.

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 Authority, municipalities in Local Government Denmark, Danish Regions, the Danish Medical Association, the Danish Alzheimer's Association, the Danish Huntington's Disease Association and the DaneAge Association.

For an updated list of members of the steering committee and advisory board see videnscenterfordemens.dk.

VISION

Our vision, "A longer life without dementia – a better life with dementia", provides us with the focus needed to accomplish our goals in finding solutions for prevention of cognitive decline and for improving health care for the benefit of people with dementia.

VALUES

Our four 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.

Respect: We show respect for patients, caregivers, professionals and groups. We show respect for the ethical challenges related to caring for people with dementia. We are dedicated to understanding, including and meeting their needs.

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

SPECIAL EVENTS 2017



Dementia Days

In May DDRC held its annual Dementia Days conference, which was attended by 1,100 people from across the nation. The main topic was “We have a plan!”, with reference to the Danish government’s new action plan for dementia 2025. One of the keynote speakers was Professor Martin Orrell, Director of the Institute of Mental Health, University of Nottingham, United Kingdom.



DDRC celebrated its 10th anniversary

In honour of its ten-year anniversary in September DDRC held a symposium with a variety of international speakers. Professor Bengt Winblad, MD, Karolinska Institutet Department of Neurobiology, Care Sciences and Society, Sweden held a talk on “Pharmacological treatment in the past, present and future”; Professor Knut Engedal, MD, Aldring og helse, Norway spoke about “Treatment of challenging behaviour in dementia”; and Professor Philip Scheltens, MD, Director of the Alzheimer Centre, VU, University Medical Center Amsterdam, The Netherlands focused on “Progress in diagnosing dementia disorders”.





Danish Minister for the Elderly visited DDRC

The Danish Minister for the Elderly, Thyra Frank, visited DDRC in February 2017 to hear about the centre's work and strategic focus areas, including the importance of early diagnosis and the education of the many different professional groups involved.



Master class with Professor Martin Rossor

In March neurologists, psychiatrists and neuropsychologists from across the country benefitted from Professor Martin Rossor's knowledge and experience in a DDRC master class on the diagnostic evaluation of dementia. Professor Rossor chairs the Dementia Research Centre, National Hospital for Neurology and Neurosurgery in London and began the class with the lecture: "An anatomy of errors".





Nina Rostgaard's PhD defense

In November Nina Rostgaard, MSc, was awarded a PhD after defending her thesis: "Frontotemporal Dementia Linked to Chromosome 3: Markers, Modifiers and Mechanisms".

Group photo (from left): Supervisor Gunhild Waldemar and evaluation committee members Bente Finsen, Nina Rostgaard, Charlotte Teunissen and Anne-Marie Gerdes. Not pictured: Supervisors Jørgen Erik Nielsen and Anja H Simonsen.



Conference for memory clinics in Denmark

In October 130 doctors, nurses, neuropsychologists and medical secretaries met in Vejle at a networking conference for memory clinics across Denmark. The goal was to maintain and expand collaboration and harmonisation across professions and regions. The conference covered topics such as the new Board of Health recommendations for the organisation of memory clinics.



Swedish Minister for the Elderly visited DDRC

In September the Swedish Minister for the Elderly, Åsa Regnér, visited DDRC to hear about dementia care in Denmark, but also to learn about the centre's efforts on the dissemination of knowledge, e-learning and networks for professionals in the field.



Research conference on diagnostic evaluation

The annual DDRC research conference was held at Rigshospitalet in November on the theme of diagnostic evaluation. Among the international speakers were Associate Professor Oskar Hansson, Clinical Memory Research, Lund University, Sweden; geriatrician and Professor Marcel Olde Rikkert, Chair of the Department of Geriatrics & Radboudumc Alzheimer Centre, Nijmegen, The Netherlands; and Professor Andreas Monsch, University Center for Medicine of Aging Basel, Switzerland.





COPENHAGEN MEMORY CLINIC

COPENHAGEN MEMORY CLINIC AT TWO SITES

After a merger in January 2017 the Copenhagen Memory Clinic began offering diagnostic evaluation and follow-up of patients with dementia at two sites, Blegdamsvej and Glostrup, in the Copenhagen area through Rigshospitalet. The Blegdamsvej memory clinic is linked to the National Info & Education Centre for Dementia and the Dementia Research Unit. For both sites, general practitioners, hospital departments and private practice specialists from local catchment areas for diagnostic evaluation of cognitive, behavioural or other symptoms suggestive of dementia or cognitive disorders can refer new patients. A dedicated multidisciplinary team of consultant neurologists, psychiatrists, geriatricians, neuropsychologists, specialist nurses, a social counsellor and medical secretaries manage diagnostic evaluation and treatment.

BLEGDAMSVEJ MEMORY CLINIC IN 2017

- **1,111 new patients**
- **5,011 patient visits**
- **2,474 patients in follow-up programme**

The majority of patients (see Table 1) undergo a standard set of examinations and procedures, beginning with a detailed medical history. Cognitive functions are then assessed with the Mini-Mental State Examination and the Danish version of Addenbrooke's Cognitive Examination. Physical and neurological/geriatric assessments, routine laboratory tests, ECG and structural CT or MRI of the brain are also performed. Other supplemental investigations are performed when clinically relevant, for example: fludeoxyglucose positron emission tomography (18FDG-PET), routine and biomarker examination

Table 1. Classification and number of new patients who completed a diagnostic evaluation programme in 2017

SYNDROME	DIAGNOSIS	BLEGDAMSVEJ	GLOSTRUP	TOTAL NUMBER
Dementia		451	348	799
	Alzheimer's disease	169	206	375
	Vascular or mixed dementia	101	63	164
	Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinsons-plus syndromes	37	23	60
	Frontotemporal dementia	20	8	28
	Other specific conditions, including Huntington's disease and normal pressure hydrocephalus	44	6	50
	Dementia of uncertain aetiology and alcohol	80	42	122
Mild cognitive impairment and other cognitive profiles	Patients with specific neurodegenerative disorders without dementia; patients with depression and other psychiatric conditions and sequelae after traumatic brain injury	283	103	386
No cognitive impairment	Patients with subjective symptoms and no significant pathology	96	103	199
Genetic counselling	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	161	-	161
All completed evaluations		991	554	1545



of cerebrospinal fluid (CSF), EEG, psychiatric evaluation and neuropsychological assessment. After completion of the initial examinations and procedures, the multidisciplinary team prepares a standardised consensus report containing a classification of the cognitive profile, the primary underlying cause, concomitant conditions and a treatment plan. Following the consensus meeting, the patient (and caregivers) is invited to meet with the specialist physician and specialist nurse, where information is given on diagnosis and on the treatment and care plan. A short summary is subsequently sent to the patient's general practitioner. Both memory clinics have follow-up programmes.

BLEGDAMSVEJ MEMORY CLINIC

Established in 1995 the Copenhagen Memory Clinic at Rigshospitalet – Blegdamsvej is a combined secondary and tertiary referral-based multidisciplinary out-patient clinic. It offers

diagnostic evaluation and treatment of patients with cognitive disorders and dementia and also receives referrals from general practitioners, private practice neurologists, psychiatrists and other hospitals in the Capitol Region of Denmark. Patients may also be referred from other memory clinics for second opinion evaluations. Patients with rare, complex or familial disorders may be referred from other parts of Denmark (mainly Eastern Denmark) for treatment and follow-up, and genetic counselling is also offered for healthy at-risk family members.

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



- Second opinion evaluations of patients with possible dementia and dementia with uncertain aetiology
- Diagnosis and treatment of developmental disorders with dementia
- Diagnosis and treatment of frontotemporal dementia
- Diagnosis and treatment of rare and late-onset hereditary neurodegenerative diseases, for instance: Alzheimer's disease (AD), frontotemporal dementia (FTD), spinocerebellar ataxias (SCA), Huntington's disease (HD)
- Clinical evaluation and lumbar perfusion and tap tests for patients with suspected normal pressure hydrocephalus (NPH)

Accordingly, specialist neurologists in the above areas, a clinical geneticist and a laboratory technician are also affiliated with the Blegdamsvej clinic.

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; the Department of Neuroradiology; and the Department of Clinical Physiology and Nuclear Medicine (the PET and Cyclotron Unit, Rigshospitalet). A monthly clinical conference is held with specialists from the imaging (MR and PET) departments and four annual conferences are held with the Movement Disorders Clinic at Bispebjerg Hospital.

Normal pressure hydrocephalus (NPH)

Diagnostic evaluation of NPH is a complex task. The patients often have multimorbidity and characteristic symptoms such as: gait disturbance, urinary incontinence and cognitive decline, which are also common to various other diseases. Most patients are referred for possible NPH because their CT or MRI has demonstrated a dilated ventricular system. In 2017 there were ca. 300 patients referred for a clinical evaluation of NPH,

COPENHAGEN MEMORY CLINIC

107 of whom had a lumbar perfusion test after the clinical examination. All patients are discussed at a weekly conference with the NPH team at the Department of Neurosurgery, Rigshospitalet. The treatment, which can involve insertion of a shunt to drain excess CSF from the brain, may reverse some of the symptoms and restore functioning.

Genetic counselling

The Copenhagen Memory Clinic offers a programme for healthy at-risk family members from families with confirmed or suspected late-onset familial neurodegenerative diseases referred for clinical genetic evaluation and counselling. This service is executed in collaboration with Department of Clinical Genetics at Rigshospitalet and includes an evaluation by our specialist in clinical genetics, as well as a consultation with a trained psychologist before genetic testing is considered. The clinic also offers post-genetic test counselling when needed.

Follow-up programme for patients and families

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



NEW CHIEF PHYSICIANS IN COPENHAGEN MEMORY CLINIC

Christina Rorvig-Loppenthien, MD (on left) was named chief physician on 1 March 2017, while Sarah Taudorf, MD was appointed chief physician on 1 November 2016. Both are specialists in neurology and recognised for the skilled medical work they carry out at the clinic.

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

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

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

GLOSTRUP MEMORY CLINIC

Glostrup Memory Clinic opened in 2010 after merging with various dementia units serving the southern districts of the Capital Region of Denmark. The clinic has an experienced multidisciplinary staff, many of whom worked in the previous dementia units based in neurology, geriatric psychiatry and geriatrics. Patients are followed on an out-patient basis identical to the main programme at the Memory Clinic on Blegdamsvej. The Glostrup Memory Clinic also offers home visits as a service for fragile elderly patients. We also work closely with general practitioners and with the 10 local authorities in our catchment area, for instance, via half-yearly meetings with key dementia coordinators, but also through joint educational programmes for family caregivers of newly diagnosed patients. Moreover, we are in frequent contact, either by telephone or electronic correspondence, with the dementia coordinators and with care staff in the patients' local districts.

GLOSTRUP MEMORY CLINIC IN 2017

- **620 new patients**
- **2,426 patient visits**
- **1,000 patients in follow-up programme (approx.)**

SPECIALIST SERVICE ON THE ISLAND OF BORNHOLM

A team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic offers consultations one day a week every other week for patients on Bornholm. Patients with possible dementia and other cognitive disorders are managed in close collaboration with the staff at the local psychiatric department. Consultants from the Copenhagen Memory Clinic have also contributed to educational services for health care professionals on Bornholm. In 2018 the Copenhagen Memory Clinic will have its own satellite service on the island in collaboration with Bornholms Hospital.

INTRODUCING THE EPIC HEALTH CARE SYSTEM

The new electronic medical record software system by Epic had its first full year of operation in 2017 after gradually being implemented in the Capital Region of Denmark and in Region Zealand. Epic, which offers various advantages compared to previous software systems, has profoundly changed the way most clinical employees work, with clinicians now responsible for the time-consuming task of writing patient files instead of using dictation. Consequently, we see fewer patients per day but this has not prevented us from increasing the number of new patients referred and reducing the amount of time before their first visit to four weeks. This is partially due to the fact that telephone consultations have replaced a large number of patient contacts

REGIONAL AND NATIONAL COLLABORATION

In 2011 the Capital Region of Denmark established guidelines for coordinating patient care pathways between hospital-based memory clinics, mental health centres, other hospital departments, general practitioners and primary health care in its 29 municipalities. The guidelines are now under revision. In 2016 the national quality registry for dementia was launched, based partly on a previous regional version from the Capital Region of Denmark established in 2006. The registry, which includes data from approximately 40 memory clinics in Denmark, is monitored by a national steering committee. Apart from contributing to the national dementia registry, the Copenhagen Memory Clinic is also an active member of the Network of Danish Memory Clinics.



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RESEARCH

DDRC research programmes cover a wide spectrum of clinical and translational research, including studies on epidemiology, biofluid markers, brain imaging, neurogenetics, genotype-phenotype correlations, patient-specific stem cells, disease course, neuropsychology, drug trials, non-pharmacological interventions and health service research. Our research is funded by external grants and donations from public and private foundations (see Acknowledgements). The health service and intervention research programmes with direct relevance to improving the quality of dementia care in Denmark as an integral part of the National Info & Education Centre for Dementia are funded in part by the Danish Ministry of Health.

The DDRC research team covers many different academic disciplines and comprises research professors and clinical trial directors (with shared clinical and research positions), post-docs/senior researchers, PhD students, associated researchers and student research fellows (see Who is who). In addition, consultant neurologists and neuropsychologists on the clinical team contribute significantly to our research. Three research nurses (study coordinators) and three research administrators take care of the coordination and financial aspects of our many research programmes.

In 2017 DDRC published 31 papers in peer-reviewed journals and seven book chapters/books (see Publications). One PhD thesis was completed.

The next four sections of the annual report describe:

- Thematic areas of research
- Research resources
- International research consortia and networks
- DDRC researchers – who is who?

THEMATIC AREAS OF RESEARCH

Early diagnosis: Neuropsychology and biomarkers

Discovery and validation of disease markers for AD and other neurodegenerative disorders are key DDRC research areas, which include new biofluid markers, brain imaging and neuropsychology. The biomarker research aims to discover and validate new biofluid markers for the early diagnosis of AD and for the prediction of disease progression using proteomics and genomics technologies. DDRC conducts and participates

in several brain imaging studies on early diagnosis of dementia that include both structural and functional brain imaging, including studies with amyloid-specific PET tracers.

Many biomarker studies are carried out in collaboration with other Danish centres, as well as a wide range of European centres. Neuropsychological research mainly focuses on characterisation of cognitive deficits in the early phase of dementia diseases and MCI. In recent years several studies on cognitive processes in aging have been published, and longitudinal studies of cognitive deficits and personality traits in gene-expansion carriers are being conducted.

Familial neurodegenerative disorders

Neurogenetic research focuses on clinical characteristics, ancillary investigations and basic research into gene function and therapy. Many neurodegenerative disorders, including AD, FTD and ataxias manifest with progressive loss of specific subsets of neurons in the brain. In some diseases genetic mechanisms are involved. Different diseases have different genetic backgrounds, but evidence shows that common mechanisms of neurodegeneration may exist. Some of our research focuses on the identification of common molecular mechanisms in neurodegeneration, e.g. in FTD linked to chromosome 3 (FTD3) and spinocerebellar ataxia type 2 (SCA2).

We are also exploring the cellular environment in patient-derived cell cultures to pinpoint therapeutic targets. The FReJA Consortium investigates FTD linked to FTD3, which occurs in a large FTD family in western Jutland. Research in this disease focuses on the molecular disease mechanism, with neuronal cell lines now derived using stem cell technology to further explore the potential of gene therapy. The Copenhagen Memory Clinic's neurogenetics section is a significant international contributor to research in HD, and our large cohorts of patients are assessed with detailed clinical evaluations, genetic markers and CSF profiles.

Medication and health services

Using nationwide registry data we investigate the quality of diagnostic evaluation, access to health services and the use of medication in patients with dementia as compared to the general Danish population. Using nationwide registry data allows us to study time trends concerning the use of medication among patients with dementia in Denmark. The research

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is carried out in cooperation with the National Centre for Register-based Research at Aarhus University. Recently, projects investigating patterns of use of opioids, other analgetics, psychotropics and anti-dementia medication were conducted. The results of ongoing studies aimed at identifying and defining the consequences and background for the high level of use are incorporated into the national dementia plan, where reduction of antipsychotic use is one of several goals. Our research will help provide evidence for creating new guidelines and for DDRC teaching materials.

Rehabilitation and psychosocial support

We have extensive experience in carrying out large-scale multi-centre intervention studies investigating non-pharmacological treatment in neurodegenerative diseases, some of which examine the effects of psychosocial education programmes or cognitive stimulation. In the ongoing ReACT project we have developed a software programme that meets some of the cognitive support needs of people with dementia. An iterative user-driven innovation process was used to design and develop the software, resulting in an innovative adaptive application devised to support memory, structuring and communication.

Global health and cross-cultural aspects of dementia

DDRC is conducting various studies on cross-cultural aspects of dementia. For some years the centre has studied cognitive functions in various ethnic groups in Denmark and in other European countries to improve diagnostic evaluation and care of European ethnic minorities with dementia. A special interest is the development and validation of cross-cultural cognitive tests and screening instruments for use in low and middle-income populations. Population-based studies have been conducted in Lebanon and a new research project in the Philippines focuses on the attributable risk of vascular risk factors for dementia. Greater knowledge about these factors will aid in designing public health programmes with the ultimate goal of reducing the incidence and prevalence of dementia.

Pharmacological treatments: From first-in-man to proof-of-concept and large-scale clinical trials

DDRC has extensive experience in the conduction of phase 1-3 clinical pharmacological trials in patients with AD, MCI and HD and as advisors for trial design and safety monitoring. The collaboration between Danish memory clinics (ADEX network) represents a platform for Denmark's contribution to interna-

tional trials. On average, DDRC's track record shows that the inclusion of patients is more than 30% above the intended number. The clinical trials are 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.

RESEARCH RESOURCES

Translational Neurogenetics Laboratory

In order to investigate the molecular mechanisms underlying neurodegenerative disorders we work with a variety of techniques within molecular and cellular biology. Our facility is fully equipped to perform all aspects of cellular biological research and has biosafety class I and II laboratories. Using skin biopsies from patients in our memory clinic we establish patient-specific cell cultures to dissect the molecular mechanisms of disease. These patient cells have also been used to induce pluripotent stem cells. These cell models form the basis of our work, in combination with additional advanced techniques such as image cytometry, fluorescence microscopy, viral vector generation and RNA interference.

Danish Dementia BioBank (DDBB)

DDBB was established in 2008 with the aim of collecting biological fluids for biomarker research in neurodegenerative diseases. DDBB contains 6,250 samples from patients referred to the Copenhagen Memory Clinic at Rigshospitalet and the Zealand University Hospital Memory Clinic. Whole blood, buffy coat, EDTA plasma and serum are stored for all patients, and CSF from approximately 25% of the patients. The samples, handled and stored according to international biobank guidelines, have contributed to multiple international biomarker and stability studies.

Clinical cohorts and intervention studies

To investigate how different neurodegenerative processes arise and become manifest, specific patient cohorts, representing a wide range of diagnostic entities, cohorts of healthy controls and gene mutation carriers, are the foundation of many DDRC research programmes. These patient cohorts make up an essential basis for most of our clinical studies, with the aim of improving diagnostic evaluation, treatment and care for patients with dementia and neurodegenerative disorders. Often, intervention studies require a large number



of patients, demanding multicentre collaboration with national and international partners/memory clinics. DDRC coordinated two large-scale multicentre intervention studies (DAISY and ADEX), with more than 200 AD patients in each, resulting in two cohorts for future studies. A formalised platform for future collaboration on dementia research in Danish memory clinics has been established in the ADEX network (which is a multicentre network in Denmark that includes participation from eight different memory clinics across Denmark). In the ADEX network a platform was established creating research alliances between Danish memory clinics with benchmarking to Swedish and Dutch networks.

Danish national registries

Access to nationwide health care registries allows for very large population-based studies on health service, risk factors, medication and outcome in neurodegenerative disorders. All Danish in and out-patients who have had contact with a Dan-

ish hospital are registered in national registries with basic information on clinical diagnoses and procedures. In some of the earliest epidemiological studies, our group examined the validity of dementia diagnoses. Since then, the unique national registries have been the basis for several studies on the use of medication in patients with dementia and on the quality of diagnostic evaluation in various patient groups.

INTERNATIONAL RESEARCH CONSORTIA AND NETWORKS

PredictND

PredictND is a four-year, €4.2m European project focusing on developing tools and means for earlier, evidence-based diagnosis of a range of neurodegenerative diseases. PredictND consortium members include Alzheimer Europe (Luxembourg), Combinostics Ltd. (Finland), GE Healthcare (UK, Sweden), Imperial College of London (UK), Rigshospitalet (Denmark), Uni-

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versità degli Studi di Perugia (Italy), University of Eastern Finland (Finland), VTT Technical Research Centre of Finland Ltd. (Finland) (coordinator) and VU/VUmc (the Netherlands).

BrainStem – Stem Cell Center of Excellence in Neurology

BrainStem – Stem Cell Center of Excellence in Neurology is supported by Innovation Fund Denmark. The project coordinator is Professor Poul Hyttel, University of Copenhagen and its primary partners are the University of Copenhagen, Lund University (Sweden), DDRC at Rigshospitalet, University of Southern Denmark, Aarhus University (Denmark), Bioneer (Denmark), Lundbeck A/S (Denmark) and Innovative Concepts in Drug Development (France). Advanced stem cell technologies are used to re-programme skin cells from patients with AD and Parkinson's disease to diseased neurons to investigate the molecular mechanisms, to develop better diagnostics and to test new drugs.

Frontotemporal Dementia Research in Jutland Association (FReJA)

FReJA is an international multidisciplinary consortium established more than two decades ago to investigate a unique, large FTD-3 family in western Jutland. Basic and clinical scientists in Denmark, Sweden and the UK have made major progress over the years in identifying the disease gene and in understanding the disease mechanisms and their wider relevance for neurodegeneration in general.

European Alzheimer's Disease Consortium (EADC)

EADC is a network of more than 50 European academic centres of excellence working in the field of AD and other dementias. It provides a forum for expanding scientific understanding and development of ways to prevent, delay, slow or ameliorate the primary and secondary symptoms of AD. The European



Commission provided initial funding for EADC and supports working towards standardisation of diagnostic criteria, assessment tools and data collection methods, with a view to a subsequent trial period involving the testing and practical application of the tools agreed upon. The only Danish EADC member, DDRC has contributed to or directed studies on assessment tools, health economics, biomarkers and cross-cultural aspects of dementia care.

Interdem

DDRC takes part in Interdem, a pan-European network of researchers collaborating in research on and dissemination of early, timely and quality psychosocial interventions aimed at improving the quality of life across Europe for people with dementia and their supporters. Members of the network include academic and clinical researchers from 23 nations.

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. One ongoing project involves evaluating quantitative EEG in Dementia diagnostics. DDRC and the memory clinic at Roskilde Hospital are the network's Danish partners.

European Huntington's Disease Network (EHDN) and Enroll HD

DDRC is part of EHDN, which provides a platform for professionals and people affected by HD and their relatives to facilitate collaboration throughout Europe. DDRC's staff and patients with HD have contributed significantly to clinical cohort studies and intervention studies. Enroll HD, initiated in 2012, is the world's largest observational study for HD families. Designed as a clinical research platform, it will enable health care professionals, scientists and families affected by HD to work together towards an improved understanding of HD and better care and treatments. At the close of 2017, DDRC's Enroll HD cohort comprised 231 participants.

National dementia research and education centres in Scandinavia

Norway, Sweden and Denmark have national non-profit dementia research and education centres commissioned and funded by the national boards or ministries of health. DDRC, the Norwegian Centre for Dementia Research and the Swedish Dementia Centre collaborate and meet annually to share ideas and exchange programmes for the benefit of professional care staff, persons with dementia and family caregivers throughout Scandinavia. A sizeable conference on leadership in dementia care is one of the larger outcomes of this Scandinavian collaboration. In 2017 the three centres have worked jointly to organise the 2018 conference to be held in Copenhagen.

North Sea Dementia Group

The North Sea Dementia Group is an association of interested individuals from dementia care practice and research. The theme of this year's meeting at the University of Antwerp in Belgium was Improving Dementia Care across Europe. The meeting included visits to care homes and day care centres.

Joint Programming on Neurodegenerative Diseases (JPND)

Funded by Horizon 2020 and EU member states, JPND is an innovative collaborative research initiative established to tackle neurodegenerative diseases. DDRC has taken part in three JPND-funded research consortia on biomarkers in Alzheimer's and Parkinson's diseases (BIOMARKAPD) on the definition of outcome measures in dementia and on the harmonisation of assessment methods. Two peer-review articles on international recommendations on the use of CSF AD biomarkers were published as a result of this research initiative in 2017.

RESEARCH – WHO IS WHO?

PROFESSORS AND ASSOCIATE PROFESSORS



STEEN G. HASSELBALCH – EARLY DIAGNOSIS, NEUROIMAGING AND BIOMARKERS

Consultant neurologist, clinical professor and research director. Main research interests include diagnosis and pathophysiology of dementia disorders. He has a leading role in several international research collaborations and was the principal investigator (PI) in a recent Danish multicentre trial on physical exercise in AD.



JØRGEN E. NIELSEN – FAMILIAL NEURODEGENERATIVE DISORDERS

Consultant neurologist, clinical associate research professor and research director. Main research areas are genotype-phenotype correlations of inherited neurodegenerative disorders, especially SCA, HD, dystonia, spastic paraplegias and hereditary forms of Parkinson's disease, AD and FTDS.



ASMUS VOGEL – COGNITION AND NEUROPSYCHOLOGICAL DEFICITS

Neuropsychologist and associate professor in clinical neuropsychology. Major research focus is cognitive deficits in dementia diseases and neuropsychological functions, e.g. memory, executive functions and attention. He is initiating and coordinating studies on development and validation of cognitive tests applied in memory clinics.



GUNHILD WALDEMAR – INTERVENTION STUDIES, EPIDEMIOLOGY, GLOBAL HEALTH

Consultant neurologist, clinical professor and chair of DDRC. Main research areas include dementia epidemiology, global health, diagnostic markers, clinical cohort studies and pharmacological and complex interventions.

TRIAL DIRECTORS



LENA ELISABETH HJERMIND – CLINICAL TRIALS – HD

Consultant neurologist, PhD. Directs DDRC's participation in the Enroll-HD cohort study and clinical trials in HD. She also contributes to other studies in familial neurodegenerative diseases.



PETER JOHANNSEN – CLINICAL TRIALS – AD

Consultant neurologist, PhD. Directs DDRC's clinical AD trials, including prodromal-Alzheimer and phase 1-3 trials. He is also involved in studies on familial FTD.

SENIOR RESEARCHERS AND POSTDOCS



ANNE SIGGAARD BIE – SCA2 AT THE CELLULAR LEVEL

Postdoctoral fellow, MSc. Is exploring the cellular environment in patient-derived cell cultures to pinpoint therapeutic targets. By examining SCA2 assisted by large-scale techniques, such as mass spectrometry and RNA sequencing, the aim is to identify the function of ataxin-2 and its cellular milieu.



ADELE MARTHALER – MODELING SCA2 USING PATIENT-DERIVED INDUCED PLURIPOTENT STEM CELLS (IPSCS)

Postdoctoral fellow, MSc. Has generated patient-derived iPSCs that were subsequently gene corrected using CRISPR/Cas9 gene technology. Patient iPSCs and gene-corrected controls will be differentiated into neurons to study the disease phenotype and the role of ATXN2 in the cell type predominantly affected by SCA2. Studies will include electrophysiological assays, global RNA sequencing and functional assays related to autophagy and apoptosis.



T. RUNE NIELSEN – CROSS-CULTURAL ASSESSMENT AND DEMENTIA IN ETHNIC MINORITIES

Postdoctoral fellow, neuropsychologist. Main research focus is cross-cultural assessment of cognitive deficits and ethnic differences in dementia diagnostics, treatment and care. He is initiating and coordinating national and international studies on the development and validation of cross-cultural cognitive tests, and on development of models for culturally sensitive pre- and post-diagnostic support.



TROELS TOLSTRUP NIELSEN – MOLECULAR MECHANISMS IN NEURODEGENERATION

Senior researcher, MSc and DDRC centre manager. Research focus is on multiple neurodegenerative disorders, including AD, FTD and ataxias. His research centres on finding molecular mechanisms in neurodegeneration using two monogenic disorders as models, namely FTD linked to chromosome 3 and SCA2.



KIEU PHUNG – CROSS-CULTURAL DEMENTIA EPIDEMIOLOGY AND PUBLIC HEALTH INTERVENTIONS

MD, neuroepidemiologist and visiting professor at the University of Santo Tomas and University of the Philippines. Main research focus is dementia frequency, risk factors and risk modification across different cultures and ethnic groups. She has conducted population-based studies in Denmark and Lebanon and is currently working on a research project in the Philippines that studies the attributable risk of vascular risk factors for dementia.



ANJA HVIID SIMONSEN – BIOMARKERS AND BIOBANK

Senior researcher, MPharm and director of the Danish Dementia BioBank. Main research focus is molecular and genetic biomarkers for diagnosis and prognosis of neurodegenerative diseases as well as for response to interventions. Coordinator of the Danish Dementia BioBank's participation in international collaborative biomarker projects and projects related to sample quality.



JONATHAN WARDMAN – SCA2 AT THE CELLULAR LEVEL

Postdoctoral fellow, MSc. Is investigating the second-order dysfunction caused by aggregation and interaction of the mutant protein with various aspects of the proteostatic system. Studying the differential responses of SCA2 patient fibroblasts versus controls will make it possible to determine what specific aspects of the proteostatic system are disrupted in SCA2 and to find specific (potentially druggable) cellular targets.

RESEARCH – WHO IS WHO?

ASSOCIATED RESEARCHERS (CURRENTLY EMPLOYED ELSEWHERE)



KRISTIAN STEEN FREDERIKSEN – PHYSICAL EXERCISE AND CLINICAL APPLICATION OF AD BIOMARKERS

MD, PhD. Main research areas are physical exercise in neurodegenerative dementias with regard to treatment and primary prevention. A second area of interest is the application of biomarkers of AD and other neurodegenerative diseases in the clinic, with a special focus on brain imaging techniques.



CHRISTINA JENSEN-DAHM – EPIDEMIOLOGY AND REGISTER-BASED RESEARCH

MD, PhD. Major research focus is epidemiological studies based on registry data. Current research focuses on medication use (analgesics, anti-dementia drugs, psychotropic medication and polypharmacy) in elderly with dementia, diagnosis of dementia and ethnicity.



LISE CRONBERG SALEM – DEMENTIA IN PEOPLE WITH DOWN SYNDROME

MD, PhD. Main research focus is studying diagnostic tools (e.g. quantitative EEG) to improve the diagnostic evaluation of dementia in patients with intellectual disabilities, which may be a difficult task due to their impaired ability to cooperate on common diagnostic methods, such as lumbar puncture and advanced scans of the brain.



LEA STEVNSBORG – REGISTER-BASED RESEARCH ON DEMENTIA IN IMMIGRANT POPULATIONS

MD. Her project investigates the use of anti-depressants and anti-psychotics in immigrant populations with dementia to identify possible inequalities in access to treatment in immigrant populations.

PHD STUDENTS



MARIE BRUUN – DIFFERENTIAL DIAGNOSTICS OF NEURODEGENERATIVE DISEASES

MD. Her PhD project explores the potential of and validates the PredictND tool, a data-driven diagnostic decision support system designed to assist clinicians in differential diagnostics of dementia diseases. She is also studying the properties of quantitative measurements of motor signs as diagnostic or prognostic biomarkers.



ANE NØRGAARD CHRISTENSEN – USE OF PSYCHOTROPIC DRUGS IN PATIENTS WITH DEMENTIA

MD. Using nationwide registry data, her PhD project investigates time trends in the use of antipsychotics and other psychotropic drugs, as well as the extent of the use of antipsychotics in combination with other psychotropic drugs (psychotropic polypharmacy) among patients with dementia in Denmark.



LE GJERUM – OPTIMISING 18F-FDG-PET IN THE DIAGNOSIS OF DEMENTIA DISORDERS

MD. Her PhD project will study the diagnostic impact of 18F-FDG-PET in the dementia diagnosis by evaluating the added value of 18F-FDG-PET in the diagnosis of dementia disorders, and by optimising and evaluating a visual rating scale for cingulate island sign as a biomarker for DLB.



CAMILLA STEEN JENSEN – BIOMARKES AND EXERCISE IN PATIENTS WITH ALZHEIMER'S DISEASE

MSc. Her PhD project investigates the beneficial effect of physical exercise on patients with AD measures in CSF. Various aspects of the biochemical parts of AD are being studied, e.g. the diagnostic biomarkers amyloid-beta and tau.



MARIE NATHALIE NICKELSEN HELLEM – HUNTINGTON' S DISEASE

MD. Her coming PhD project will investigate the role of neuroinflammation in the pathogenesis of HD by examining blood and CSF. The aim is also to look for biomarkers and develop HD stem cells.



PETER ROOS – CLINICAL AND MOLECULAR ASPECTS OF FTD LINKED TO FTD-3

MD. In the search for early markers and for modifiers of FTD-3, his PhD project examines clinically affected and presymptomatic CHM P2B gene mutation carriers from the Danish FTD-3 family.



NINA ROSTGAARD – CSF BIOMARKERS AND MOLECULAR MECHANISMS IN INHERITED FTD-3

MSc. Her PhD project studies biomarkers in CSF to elucidate if there is a clear FTD-3 profile. The aim is also to understand the underlying disease mechanisms of the disease fibroblasts from FTD-3 patients.



LÆRKE TAUDORF – DEMENTIA AND MORTALITY: A REGISTER-BASED STUDY

MD. Her PhD project reviews time trends of prevalence, incidence and mortality due to dementia from 1996 to 2015, as well as assesses life expectancy after diagnosis. It will also investigate whether certain comorbidities are associated with higher mortality. Finally, the project will review the registered causes of death in individuals with dementia.



LAILA ØKSNEBJERG – ASSISTIVE TECHNOLOGY AND COGNITIVE REHABILITATION

Neuropsychologist. Her project (ReACT), which examines rehabilitation in AD using cognitive support technology, involves the design of tailor-made software to support the cognitive functions of people with dementia through a user-involvement innovation process. Technology implementation methods are also under study, with a main emphasis on cognitive rehabilitation.

RESEARCH – WHO IS WHO?

STUDENT RESEARCH FELLOWS (MASTER'S STUDENTS)



FREDERIKKE JEPPESEN KRAGH – QUANTITATIVE MEASUREMENTS OF MOTOR SIGNS IN DEMENTIA

Her study investigates if a quantitative motor assessment provides a more objective, sensitive and standardised measurement of motor dysfunction in AD, FTD and DLB.



RACHEL UNDERLIEN KRISTENSEN – REGISTER-BASED RESEARCH ON POLYPHARMACY IN DEMENTIA

Using nationwide data, her project investigates the frequency and time trends of polypharmacy among people with and without dementia to examine potential disparities.



CHRISTINA STRAND-HOLM MANNICHE – CSF BIOMARKERS IN NPH, VASCULAR DEMENTIA AND AD

Her project investigates the ability of specific biomarkers in CSF to distinguish idiopathic N from subcortical ischemic vascular dementia and AD.



CHRISTIAN SANDØE MUSAEUS – EPILEPTIC SEIZURES IN AD

His coming PhD will assess subclinical epileptiform activity with continuous EEG monitoring using novel ear EEG registration and correlate findings with MRI hippocampal blood flow assessments. A second area of interest is the application of EEG to detect and predict progression of Alzheimer's disease and the use of EEG to assist in the diagnosis of Alzheimer's disease in people with Down syndrome.



JOHANNE KØBSTRUP ZAKARIAS – EPIDEMIOLOGY AND ANTIPSYCHOTIC USE IN DEMENTIA

Using nationwide registry data, this project investigated potential geographical variation in the use of antipsychotics in people with dementia to determine possible factors contributing to the high prevalence of usage.

AWARDS AND DONATIONS



Alzheimer's Research Fund awarded grants to DDRC researchers

On the occasion of World Alzheimer's Day on 21 September, the Alzheimer's Association awarded prizes and donations to researchers and professionals who have made an extra effort for dementia. The research fund awarded 1.8 million Danish kroner to four specific research projects. Among the recipients were two DDRC researchers.

Senior researcher Anja Hviid Simonsen (left) received 308,650 Danish kroner for the project: "Apolipoprotein-E and BDNF: Possible mediators for the effect of exercise in Alzheimer's disease". Her project builds on preliminary results from the ADEX study, which examined the effect of physical training on patients with AD. Her research examines why Alzheimer's patients bearing the gene ApoE4 alleles appear to benefit more from exercising than patients who do not carry the gene.



Neuropsychologist Rune Nielsen received grant from VELUX FONDEN

Neuropsychologist Rune Nielsen, PhD, received 2.3 million Danish kroner on 1 August 2017 for the CLEAR research project, whose aim is to improve the rehabilitation of vulnerable elderly people with an ethnic minority background and dementia.

PhD student Laila Øksnebjerg received 470,962 Danish kroner for the project "Rehabilitation in Alzheimer's disease using cognitive support technology". Her project, which incorporates people with dementia, their relatives and professionals in the development of an app, is designed to provide knowledge about how technology can support memory and structure on a daily basis. In 2017 the app was tested on patients and relatives associated with various memory clinics in Denmark.



Professor Steen Hasselbalch received the Niels A. Lassen prize

Professor and Chief Physician Steen Gregers Hasselbalch, MD, DDRC (left), received the Niels A. Lassen prize, which is named after an excellent scientist and pioneer in the field of neuroimaging, neuropsychiatry and nuclear medicine from Bispebjerg Hospital. The prize was awarded at Bispebjerg Hospital's annual research day on 7 December, Lassen's date of birth (1926-1997). The winner of the prize receives a medal and 25,000 Danish kroner. After the awards ceremony Hasselbalch gave a speech on: "Alzheimer's disease biomarkers: Potentials and limitations".

Professor Gunhild Waldemar received the Nordic Medicine Prize

Gunhild Waldemar, a professor of neurology and the head of DDRC received the 2017 Nordic Medicine Prize for her research on dementia diseases. She shares the prize of one million Swedish kroner with her Swedish colleague Professor Kaj Blennow, University of Gothenburg.



nscenter for



Myrtle Schmitt
Executive Director
National Center for
Public Health and Safety

NATIONAL INFO & EDUCATION CENTRE FOR DEMENTIA

Established in 2007 and funded by the Ministry of Health, the National Info & Education Centre for Dementia provides research, nationwide education and the dissemination of information about dementia, primarily to health care professionals and care staff in Denmark. DDRC communicates with a variety of professionals and societies on a range of platforms via, for example the DDRC website, training courses, networks, e-learning, public media, apps, publications and conferences.

COURSES AND CONFERENCES

The National Info & Education Centre for Dementia offers a wide range of courses throughout the country, in addition to two annual conferences.

The 2017 course catalogue offered 19 different courses, thematic events and conferences with more than 4,000 participants. The catalogue contains a wide range of subjects, e.g. person centred care, diagnostic evaluation, the human brain, dental care, behavioural symptoms, physical exercise and palliation in dementia.

In 2017 DDRC also organised 31 courses and conferences tailored to the needs of specific groups per request by local authorities and regional institutions. Designed to meet a specific purpose or cover a certain subject, customised courses were attended by a broad range of professionals.

Dementia Days – A national conference

Every year DDRC organises Dementia Days, a national two-day conference for dementia specialists and practitioners. As Denmark's largest conference on dementia, it provides a valuable educational opportunity for management and staff working in the social services and health care sector. The Minister for the Elderly, Thyra Frank, opened the conference on 8 May 2017, which centred on the theme "We have a plan", referring to the national dementia plan 2025.

This year's Dementia Days had a record of 1,206 participants, including exhibitors and lecturers. Professor Marin Orrell, University of Nottingham, was among the invited speakers. During the conference there were nine symposiums, with speakers from across the nation presenting their reviews and data on an extensive range of topics. Participants also had the opportunity to present results from their own projects.

Scandinavian conference for leaders in dementia care

Every other year DDRC organises a two-day conference for leaders in care in collaboration with the Norwegian and Swedish national research and education centres. In 2017 we started planning the conference, which will be held in Copenhagen in October 2018. The conference usually attracts hundreds of leaders within dementia care from Sweden, Norway and Denmark.

Annual research conference

Every year a full-day national conference primarily devoted to the latest scientific news within a specific topic of interest related to dementia takes place in November at Rigshospitalet. The conference attracts scientists and practitioners from across Denmark. In 2017 the theme was diagnostic evaluation and among the speakers were Associate Professor Oskar Hansson, Lund University; Professor Marcel Olde Rikkert, Radboudumc Alzheimer Centre; and Professor Andreas Monsch, University of Basel, together with specialists from DDRC.

ABC DEMENTIA – FREE ONLINE COURSES

Offering free e-learning is one way of providing easy-access knowledge about dementia to various target groups across the nation. The practice-oriented nature of the topics and the variety of educational approaches used make the courses especially user friendly. "ABC Dementia – Care" involves e-learning for professional caregivers, with each module designed to cover a specific topic, such as dementia disorders, behavioural symptoms or communication. ABC Dementia for physicians, targets physicians in training, primarily within geriatrics, neurology, psychiatry and general practice.

In 2017 we worked to improve the backend technology for managing our more than 26,000 online users, in addition to developing a new online course aimed at hospital nurses called ABC Dementia for Hospitals, which we hope to launch at Dementia Days 2018.

DDRC'S NATIONAL NETWORKS

To foster an exchange of knowledge, education and quality programmes, DDRC and its National Info & Education Centre for Dementia coordinate national networks across regional, municipal and professional boundaries.



Network of Danish Memory Clinics

Set up by DDRC in 2008, the Network of Danish Memory Clinics 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. Its members, which comprise multidisciplinary staff such as nurses, medical doctors and neuropsychologists, are mainly based in hospital psychiatric, geriatric or neurological departments and receive referrals from local general practitioners for diagnostic evaluation of dementia. Network members meet once a year to maintain and further develop national cooperation.

Network of Danish Memory Clinics:

- Memory clinics
- ADEX Memory clinics
- ADEX affiliates



In October 2017 DDRC held its 10th annual network conference for memory clinics in Denmark, which attracted 135 physicians, nurses, psychologists, secretaries and therapists from more than 30 memory clinics nationwide. There was a variety of afternoon workshops and the main topics presented at the conference were the organisation of diagnostic evaluation in Denmark, the use of psychotropics in patients with dementia, the national quality registry for diagnostic evaluation of dementia and the national dementia plan 2025.

National network of municipality-based dementia ambassadors

Each of the 98 Danish municipalities has appointed a dementia ambassador to disseminate information about DDRC activities and news from other municipalities to local professionals and to monitor local needs for educational activities. Special newslet-

ters sent six times a year and an annual meeting for the ambassadors ensure contact between DDRC and the ambassadors.

Psycho-social Research Network

For multidisciplinary researchers interested in psychosocial interventions, such as cognitive rehabilitation, music therapy and personalised care, the Psycho-social Research Network is the Danish counterpart of the pan-European network Interdem. The network meets at least once a year with the aim of improving psychosocial dementia research in Denmark.

Network for teachers in schools, colleges and continuing education services focused on health care

The network, which comprises representatives from health educational institutions in Denmark, also represents basic edu-

NATIONAL INFO & EDUCATION CENTRE

cation programmes and continuing professional development and further education programmes. The professional basic programmes include training nurses, physical therapists, occupational therapists and psychomotor therapists but also social and health care workers and assistants. Representatives of DDRC also participate.

The aim is to strengthen collaboration and the exchange of experience to stimulate the development and dynamics of dementia education to improve the efforts being made on behalf of people with dementia in Denmark.

Network for external experts

Various external experts from a variety of backgrounds, e.g. physicians, nurses and dentists, with skills in a range of focus areas, are affiliated with DDRC. These experts meet annually and provide important skills on an ongoing basis as, for example, instructors for activities, sounding boards for expert tasks or as consultants on specific tasks. Both the expert consultants and DDRC benefit greatly from the network, which also contributes with ideas for upcoming courses, theme days and conferences.

COMMUNICATIONS AND PRESS – INTERACTING WITH SOCIETY

All our platforms have seen a high level of activity and we have a growing number of followers on social media. This is due to an ongoing strategic approach to public relations and a focused effort in reaching out to our stakeholders and the press in general.

DDRC in the press

DDRC takes pride in offering commentary, articles and statements on dementia-related issues to the public media. With 800 media mentions in 2017, DDRC was present in the press on an almost daily basis. This year TV2 focused on dementia issues for an entire week, with several DDRC experts giving interviews on national television.

Website

Our website, videnscenterfordemens.dk, provides information about dementia diseases, risk factors and statistics for people who work with the assessment, treatment and care of individuals with dementia. Materials and tools useful in clinical practice can be downloaded or ordered on the site. The press, patients





and caregivers also use our website extensively. In 2017 we had 1.2 million page views. More than half of our users visit the website from a mobile device.

Newsletter

Published 6-8 times per year, our newsletter contains information about the latest research and current courses and conferences. At the close of 2017 we had 6,300 newsletter subscribers.

About Dementia app

The About Dementia app is a widely used observation tool for professional caregivers. In 2017 the app was used 55,000 times (user sessions) by 17,200 unique users.

Social media

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

particular draw traffic to our website. As a new initiative in 2017 we launched a DDRC LinkedIn profile, where we share updates of interest to dementia stakeholders and professionals.

DDRC conference booth

The DDRC conference booth was present at various events in 2017, e.g. Dementia Days. The booth is instrumental in promoting direct contact with our target groups, allowing us to generate new contacts and disseminate information about our products to professionals and stakeholders, as well as general knowledge about dementia to the public.

NATIONAL AND INTERNATIONAL POSTS

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

Eva Bjerregaard, appointed member, Dementia Council of the Capital Region of Denmark.

Kristian Steen Frederiksen, member, EAN Scientific Panel on Dementia and Cognitive Disorders; chair, EAN Guideline on "Medical management issues in dementia"; representative, board member, member of executive committee, Danish Alzheimer Association; member, Alzheimer Research Committee under the Danish Alzheimer Association; working group member, National Clinical Guideline "Behavioural and psychological symptoms of dementia", Danish Health Authorities; associate editor, *Journal of Alzheimer's Disease*.

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

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

Peter Johannsen, chair, Danish National Dementia Registry; working group member, Danish National Guideline on Dementia Treatment, the Danish National Board of Health; Danish national coordinator (and PI) on six clinical trials on AD.

Kasper Jørgensen, neuropsychology consultant, Danish Patient Safety Authority; board member, Dansk Psykologisk Forlag; neuropsychology consultant, National Legal Medicine Council.

Mette Møllebæk, appointed member, Dementia Council of the Capital Region of Denmark; appointed member, Steering committee for revision of the patients pathway program for dementia in the Capital Region of Denmark; reference group member, Danish National Board of Health, National Clinical Guidelines.

Jørgen Nielsen, Danish national coordinator (and PI), international SPATAX network on cerebellar ataxias and spastic paraplegias; advisor, EHDN and steering committee member, EHDN REGISTRY; appointed member, Research Committee, Rigshospitalet; appointed member, European Academy of Neurology, scientific panel in neurogenetics.

T. Rune Nielsen, co-founder and member, Nordic Research Network on Dementia and Ethnicity; member, advisory group on dementia in ethnic minorities in the Nordic Dementia Network coordinated by the Nordic Welfare Centre.

Jette Stokholm, neuropsychology consultant, Danish Patient Safety Authority; neuropsychology consultant, National Legal Medicine Council.

Hanne Sørensen, appointed member, dementia council of the capital Region of Denmark, appointed member Steering committee for revision of the patients pathway program for dementia in the capital Region of Denmark.

Karen Tannebæk, member at the Nordic Dementia Network established by the Nordic Welfare Centre.

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

Gunhild Waldemar, board member, Alliance for Biomedical Research in Europe; committee member, European Affairs Subcommittee and member, Management Committee for Scientific Panel of Dementia of EAN; member, Medical and Scientific Advisory Panel of Alzheimer's Disease International; member, Expert Advisory Panel, Alzheimer Europe; member, Board of Trustees and research committee chair, Lundbeck Foundation; advisor, National Legal Medicine Council, Danish Ministry of Justice; vice-chair, Dementia Council, Capital Region of Denmark; executive committee member, Neurology Council, Capital Region of Denmark; president, Medical Society of Copenhagen; psychiatry committee member, Danish Health Authority.

Laila Øksnebjerg, scientific committee member, 13th Nordic Meeting in Neuropsychology, Stockholm 2018; founder, Danish Network on Psychosocial Methods in Dementia (DaneDem); member, Danish Health Authority working group on National Clinical Guideline for Prevention and Treatment of BPSD Symptoms in Dementia.

STAFF IN 2017

MANAGEMENT GROUP (per 31/12/2017)



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



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



**Head nurse
Copenhagen Memory
Clinic – Blegdamsvej**
Hanne I. Sørensen, RN



**Clinical director
Copenhagen Memory
Clinic – Glostrup**
Eva Bjerregaard,
MD, senior neurologist



**Head nurse
Copenhagen Memory
Clinic – Glostrup**
Mette Møllebæk, RN



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



Research director
Jørgen E. Nielsen, MD,
PhD, associate profes-
sor, senior neurologist



Centre manager
Troels T. Nielsen,
MSc, PhD



Educational director
Karen Tannebæk,
occupational therapy
specialist



**Director of communi-
cations and press**
Mette Tandrup Hansen,
MA



Head of administration
Tine Olsen



ADMINISTRATION

Benedikte Andersen, research secretary
 Jette Gotlieb Iversen, course administrator
 Ditte Majgaard Jensen, accounting staff
 Bodil Lykkegaard Kryger, accounting staff
 Tine Olsen, head of administration
 Jette Rasmussen, research administrator

NATIONAL INFO & EDUCATION CENTRE

Tove-Marie Buk, RN, educational advisor
 Marie Ejlersen, MA, communication officer
 Ulla Vidkjær Fejerskov, OT, educational advisor
 Hanne Kærsmose Friberg, RN, educational advisor
 Elsebeth Glipstrup, RN, educational advisor
 Mette Tandrup Hansen, MA, director of communications and press
 Kasper Jørgensen, MSc, neuropsychologist
 Jette Gerner Kallehauge, OT, educational advisor, project manager
 Mette Aurora Højrup Kjær, MA, communication officer
 Ann Nielsen, PhD, project manager
 Christina Aagrén Nielsen, MA, communication officer
 Elsebeth Refsgaard, RN, educational advisor, project manager
 Karen Tannebæk, OT, educational director
 Gunhild Waldemar, MD, DMSc, professor and chair

RESEARCH

Muntadhar Al-Mendalawi, medical laboratory technician
 Anne Siggaard Bie, PhD, postdoc
 Kathrine Bjarnø, medical laboratory technician (maternity leave)

Marie Bruun, MD, PhD student
 Ane Nørgaard Christensen, MD, PhD student (maternity leave)
 Le Gjerum, MD, PhD student
 Christina Vangsted Hansen, RN, research nurse
 Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist, research director
 Marie Nickelsen Hellum, MD, PhD student
 Lena Elisabeth Hjermind, MD, PhD, senior neurologist
 Oda Jakobsen, RN, research nurse
 Peter Johannsen, MD, PhD, senior neurologist
 Jørgen E. Nielsen, MD, PhD, associate professor, senior neurologist, research director
 Troels Tolstrup Nielsen, MSc, PhD, centre manager, senior researcher
 T. Rune Nielsen, MSc, PhD, neuropsychologist
 Mikkel Nif Rasmussen, medical laboratory technician
 Peter Roos, MD, PhD student
 Nina Rostgaard, MSc, PhD student
 Anja H. Simonsen, MSc, PhD, senior researcher
 Camilla Steen-Jensen, PhD student
 Jette Stokholm, MSc, neuropsychologist
 Lærke Roulund Taudorf, MD, PhD student
 Asmus Vogel, MSc, PhD, neuropsychologist, associate professor
 Gunhild Waldemar, MD, DMSc, professor, senior neurologist
 Jonathan Wardman, PhD, postdoc
 Laila Øksnebjerg, MSc, neuropsychologist, PhD student

Associated researchers (excluding students)

Kristian Steen Frederiksen, MD, PhD
 Christina Jensen-Dahm, MD, PhD

Adele Marthaler, PhD, postdoc
Tien Kieu Phung, MD, PhD Lise Cronberg Salem, MD, PhD
Malene Schønning, MD, PhD

COPENHAGEN MEMORY CLINIC

Medical doctors

Birgitte Bo Andersen, MD, DMSc, senior neurologist
Julia Johanna Almer Bromann, MD
Nanna Winther Dombernowsky, MD, resident in neurology
Elsebeth Steno Hansen, MD phd, senior psychiatrist
Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist
Lena Elisabeth Hjermind, MD, PhD, senior neurologist
Peter Johannsen, MD, PhD, senior neurologist
Christina Rørvig-Løppenthien, MD, senior neurologist
Susanne Lindquist, MD, PhD, clinical geneticist
Jørgen E. Nielsen, MD, PhD, associate professor, senior neurologist, research director
Lise Cronberg Salem, MD, PhD, resident in neurology
Sarah Taudorf, MD, PhD, senior neurologist
Gunhild Waldemar, MD, DMSc, professor, senior neurologist

Nurses

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

Clinical neuropsychologists

Nadia Falcon Bærnthsen, MSc
Selma Nielsen, MSc
Signe Pertou Ringkøbing, MSc
Kathrine Ruth, MSc
Jette Stokholm, MSc
Asmus Vogel, MSc, PhD, associate professor

Medical secretaries

Benthe Friedman
Dorte Hansen
Susanne Lindstrøm
Ulla Thranow

Social counsellor

Pernille Starnø

Medical laboratory technologist

Muntadhar Al-Mendalawi, medical laboratory technician
Kathrine Bjarnø (maternity leave)

Receptionists

Anne-Mette Pedersen
Joan Rysgaard

GLOSTRUP MEMORY CLINIC

Medical doctors

Inge Bendix, MD
Eva Bjerregaard, MD, senior neurologist
Michael von Buchwald, MD, psychiatrist
Elsebeth Iversen, MD
Anna Routhier, MD

Hanne Elkjær Andersen, MD, geriatrician
Hanne Pedersen, MD, geriatrician
Per Dyhr, MD, geriatrician
Ragnar Hansen, MD, geriatrician

Nurses

Ulla Lind, RN
Mette Møllebæk, RN
Mette Nyboe, RN
Hanne Raaschou, RN
Charlotte Skærbæk, RN

Clinical neuropsychologists

Anne-Mette Guldborg, MSc, neuropsychologist

Medical secretaries

Christina Appel
Tinna Bendixen
Saida El Idrisi



PUBLICATIONS IN 2017

PHD DISSERTATION

Rostgaard, N. *Frontotemporal Dementia Linked to Chromosome 3: Markers, Modifiers and Mechanisms*. University of Copenhagen 2017.

SCIENTIFIC PAPERS

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CONTRIBUTIONS TO MULTICENTRE STUDIES

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New grants received	7.1
New grants accumulated 2007-2017	154.6
External grants spent on specific programmes <ul style="list-style-type: none">• The National Info & Education Centre for Dementia from the Danish Ministry of Health, including projects• Other external grants for research	9.4 7.7
Total	17.1
Conferences, educational courses and products	4.7
Research contracts	3.9

STAFF 2017	
No. of employees/full-time equivalents	92/73
No. of employees funded by <ul style="list-style-type: none">• Internal sources• External sources	52 40

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