

DANISH DEMENTIA RESEARCH CENTRE

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



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 2018 Danish Dementia Research Centre's (DDRC) annual report, which provides an overview of our clinical services, research and national educational activities over the past year.

Copenhagen Memory Clinic offers diagnostic evaluation and support to patients with cognitive impairment or dementia by referral from general practitioners, specialists or other hospitals from the greater Copenhagen area. For our advanced specialised services (second opinion evaluations, normal pressure hydrocephalus and familial neurodegenerative disorders) we see patients from across Denmark. In 2018 we received 1,915 new referrals, a record number. In September we opened a new satellite memory clinic on the island of Bornholm in collaboration with the Department of Internal Medicine at Bornholm Hospital. Copenhagen Memory Clinic now has out-patient clinics at three sites: Rigshospitalet – Blegdamsvej, Rigshospitalet – Glostrup and Bornholm Hospital.

Mapping the needs of patients with dementia and their caregivers is crucial for the design of our research and educational programmes. Some of our most prominent research outcomes in 2018 were the demonstration of the ability to discriminate between different types of dementia using a combination of diagnostic tests and advanced software based on the EU-funded PredictND project; the launch and international validation of the new Cross-cultural Neuropsychological Test Battery (CNTB); and a PhD thesis presenting detailed phenotypic characterisation of frontotemporal dementia related to chromosome 3 (FTD-3).

In 2017 the Danish Ministry of Health launched the national dementia strategy for 2025 and an action plan with 23 initiatives for 2017-2019. All the initiatives were active in 2018. DDRC was involved in many of them, three of which DDRC is responsible for managing: 1) development of a new case-finding tool for use in primary care; 2) development of a toolbox for psycho-social support, counselling and teaching patients and

caregivers; and 3) development and evaluation of concepts for dementia-friendly hospitals. The first two initiatives were completed in 2018 and will be launched in 2019. We are very grateful to the many professional staff and patient representatives who contributed to our work. DDRC also contributed to the completion of Denmark's first national research strategy, an initiative headed by the Danish Health Authority.

Our educational programmes attracted more participants than ever before, for example the annual DementiaDays conference, which was attended by more than 1,200 people. In 2018 we launched a new ABC e-learning programme, ABC Dementia for Hospitals, for nurses and other hospital staff. Our three ABC Dementia programmes, available on our website free of charge, boast 26,686 users.

Our achievements in patient care, research and education would not be possible without support from the invaluable organisations and people we collaborate with. We would especially like to thank the Danish Ministry of Health and the Elderly and the Danish Health Authority for their excellent collaboration and support, and our national and international collaborators and external scientific and educational advisors for their contribution to our work. Finally, we would also like to thank 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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TIVOLI

Hotel &
Congress Center

DEMENS
DAGENE

Sammen om demens
- også i hjemmet

2018



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 three sections, Rigshospitalet – Blegdamsvej in Copenhagen, Rigshospitalet – Glostrup in Glostrup and a satellite clinic at Bornholm Hospital.

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 (SST), municipalities in Local Government Denmark, Danish Regions, Danish College of General Practitioners, Organisation of general practitioners, 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 and 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 2018



Dementia Days

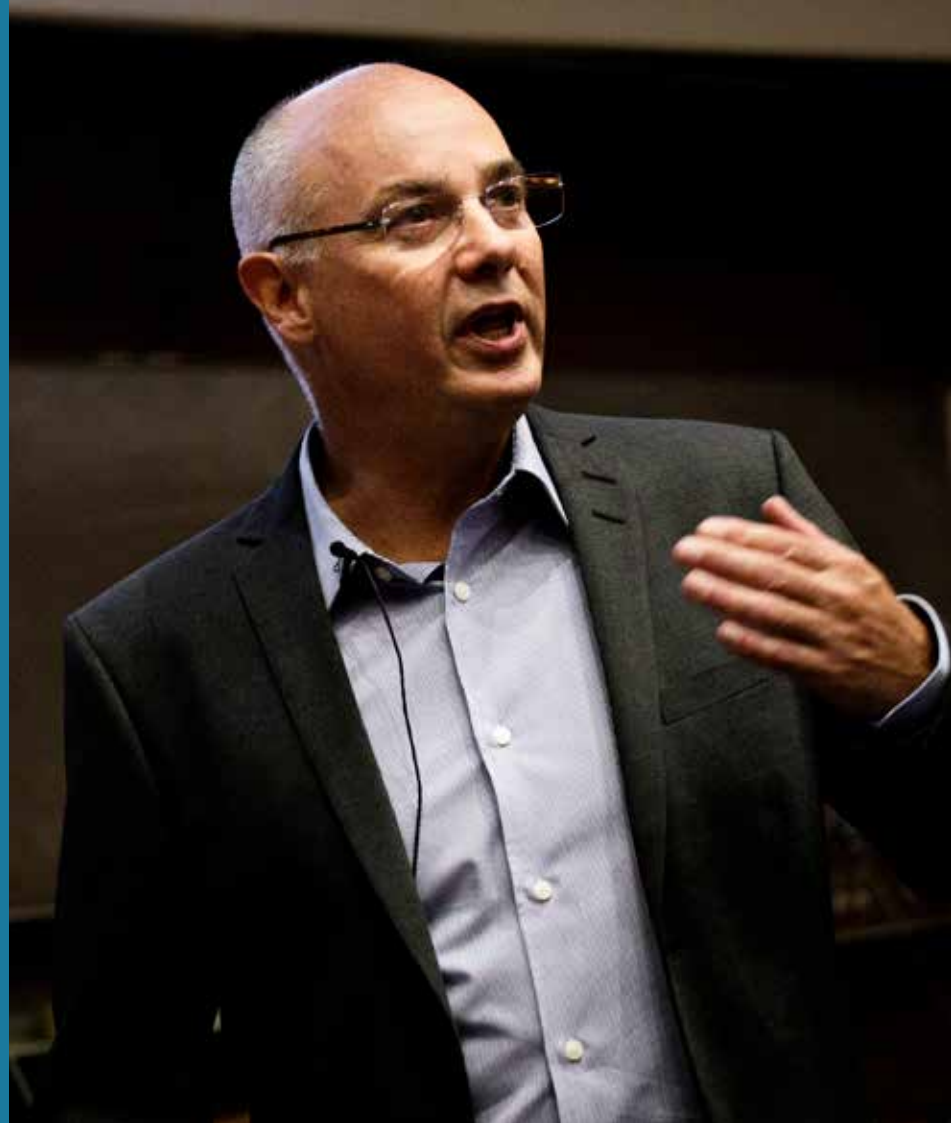
In May DDRC held its annual Dementia Days conference, which was attended by more than 1,200 people from across the nation. The main topic was “United around dementias – today and tomorrow”. Among the keynote speakers were psychiatrist Andrew Sommerlad, University College London, United Kingdom (photo top right) and Chris MacDonald, MSc in Human Physiology (photo bottom right). The conference was opened by the Danish Minister of Health Ellen Trane Nørby, the Danish Minister for Senior Citizens Thyra Frank and Chairman of the Regional Council Sophie Hæstorp Andersen (photo right)



New professor of hereditary neurodegenerative diseases

On 21 September 2018 Chief Physician Jørgen E. Nielsen, PhD held his inaugural lecture at the University of Copenhagen on the occasion of his appointment as a clinical professor of neurology with a particular focus on hereditary neurodegenerative diseases. Professor Nielsen reviewed the development from localisation of individual genes using linkage analysis for gene identification and the subsequent understanding of the disease mechanisms at the cellular level. Through his research and clinical work Nielsen is highly dedicated to developing the best possible treatment for people with rare hereditary neurodegenerative diseases such as Huntington's. In addition to his professorship at the University of Copenhagen, Nielsen is a chief physician at the Memory Clinic, Neurology Clinic at Rigshospitalet and is a director of research at DDRC.

Group photo from left: Dean Ulla Wewer, Professor Jørgen E. Nielsen, Professor Gunhild Waldemar and Medical director Per Jørgensen (Photo: Mathias Løvgreen)



New clinic on the island of Bornholm opened in September 2018

As of September 1st the Memory Clinic's satellite service at Bornholm Hospital was initiated.





Research conference on subjective memory decline

The annual DDRC research conference was held at Rigshospitalet in November on the topic of subjective memory decline. Among the international speakers were Wiesje van der Flier, professor and clinical research director at the Alzheimer Center of the VU University Medical Center in Amsterdam, Holland (left photo), and Giovanni Frisoni, professor of clinical neuroscience and research director at the National Centre for Alzheimer's Disease in Brescia, Italy (photo below).



PhD defense by Peter Roos

In November Peter Roos, MSc, was awarded a PhD after defending his thesis: "Clinical and Molecular Aspects of Frontotemporal Dementia Linked to Chromosome 3 (FTD-3)".

Group photo (from left): Peter Johannsen (supervisor), Gunhild Waldemar (supervisor), Anne-Marie Gerdes (evaluation committee member), Jørgen Erik Nielsen (supervisor), Christer Nilsson (evaluation committee member), Peter Roos, Peter Høgh (supervisor) and James Rowe (evaluation committee member). Not pictured: Troels Tolstrup Nielsen (supervisor).





Master class with Professor James Rowe

In March neurologists, psychiatrists and neuropsychologists from across the country benefitted from Professor James Rowe's knowledge and experience in a DDRC master class on the diagnostic evaluation of dementia. James Rowe, who is a professor of cognitive neurology at the University of Cambridge and an attending physician at Cambridge Memory Clinic, began the class with the lecture: "The expanding phenotype of C9orf72 disease".

North Sea Dementia

DDRC hosted the annual meeting of the North Sea Dementia Group 2018 in Copenhagen. Among the themes were "Quality of Care in Hospitals", "Interventions and Research for People with Dementia", "Prevention", "Qualitative of Care and Life", "Learning about Dementia", and "Dementia, Media and Technology". During the meeting the group visited dementia care centres in the Municipality of Copenhagen.



COPENHAGEN MEMORY CLINIC



COPENHAGEN MEMORY CLINIC AT THREE SITES

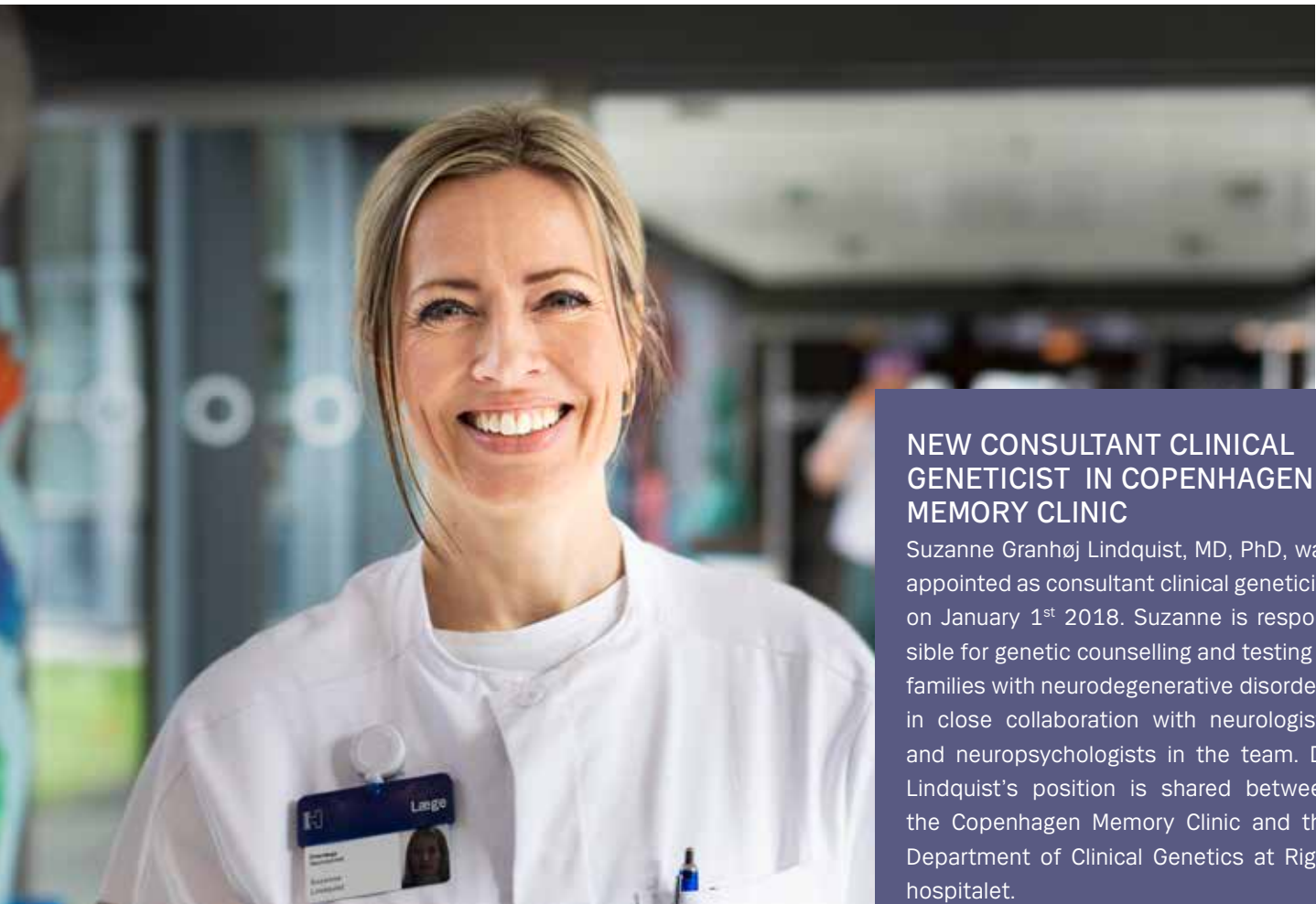
Since a merger in January 2017 the Copenhagen Memory Clinic has offered diagnostic evaluation and follow-up of patients with dementia at two sites, Blegdamsvej and Glostrup, in the Copenhagen area – both are part of Rigshospitalet. In September 2018 a new outpatient satellite clinic was established on the island of Bornholm. For all three sites, general practitioners, hospital departments and private practice specialists from local catchment areas can refer new patients for diagnostic evaluation of cognitive, behavioural or other symptoms suggestive of dementia or cognitive disorders. A dedicated multidisciplinary team of consultant neurologists, psychiatrists, geriatricians, neuropsychologists, specialist nurses, a social counsellor and medical secretaries manage diagnostic evaluation and treatment.

The majority of patients undergo a standard set of examinations and procedures, beginning with a detailed medical histo-

ry. 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 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.

Table 1. Classification of new patients who completed a diagnostic evaluation programme in 2018

SYNDROME	DIAGNOSIS	BLEGDAMSVEJ	GLOSTRUP	BORNHOLM	TOTAL
Dementia		507	364	64	935
	Alzheimer's disease	197	199	40	436
	Vascular or mixed dementia	96	80	16	192
	Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinson-plus syndromes	41	25	2	68
	Frontotemporal dementia	17	14	1	32
	Other specific conditions, including Huntington's disease and normal pressure hydrocephalus	33	8	1	42
	Dementia of uncertain aetiology and alcohol-related dementia	123	38	4	165
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	301	122	6	429
No cognitive impairment	Patients with subjective symptoms and no significant pathology	173	92	1	266
Genetic counselling	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	159	-	-	159
All completed evaluations (excluding genetic counselling)		981	578	71	1630



NEW CONSULTANT CLINICAL GENETICIST IN COPENHAGEN MEMORY CLINIC

Suzanne Granhøj Lindquist, MD, PhD, was appointed as consultant clinical geneticist on January 1st 2018. Suzanne is responsible for genetic counselling and testing in families with neurodegenerative disorders in close collaboration with neurologists and neuropsychologists in the team. Dr. Lindquist's position is shared between the Copenhagen Memory Clinic and the Department of Clinical Genetics at Rigshospitalet.

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) and 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 2018 there were approximately 290 patients referred for a clinical evaluation of NPH, 100 of whom had a lumbar perfusion test and/ or Tap 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. In 2018 108 at-risk family members were referred. 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 neurodegenera-



NEW SPECIALISTS IN COPENHAGEN MEMORY CLINIC

Peter Roos (left photo) is a medical specialist in neurology with a clinical and research interest in hereditary forms of dementia. Lise Cronberg Salem (right photo) is a medical specialist in neurology with a research interest in dementia in younger people and has clinical expertise with cognitive disorders in people with development disorders. Kristian Steen Frederiksen (right photo) is a medical specialist in neurology with a clinical and research interest in Alzheimer's disease. He is also a major contributor to international studies and guidelines for dementia assessment and treatment.



tive 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 offered.

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 cogni-

tive 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.
- Patients with posterior cortical atrophy are also offered a tailor made course.

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 patients. The clinic 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.



BORNHOLM HOSPITAL

In September 2018 a new outpatient clinic was established at the Medical department on Bornholm's Hospital led by the management at the Copenhagen Memory Clinic at Blegdamsvej. A team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic together with a nurse, secretary and senior consultant in geriatrics from Bornholm's hospital offers consultations twice a week for patients on Bornholm. Consultants from the Copenhagen Memory Clinic have also contributed to educational services for health care professionals on Bornholm.

INTRODUCING THE EPIC HEALTH CARE SYSTEM

The new electronic medical record software system by Epic 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 increased staff and 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.

Blegdamsvej Memory Clinic in 2018

- 1,237 new patients
- 5,011 patient visits

Glostrup Memory Clinic in 2018

- 593 new patients

Bornholm Memory Clinic in 2018

- 85 new patients

4,145 patients are in a follow-up programme.

RESEARCH



RESEARCH AT DDRC

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 professors and clinical trial directors (with shared clinical and research positions), postdocs, 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 are responsible for the coordination and financial aspects of our many research programmes.

In 2018 DDRC published 42 papers in peer-reviewed journals and three book chapters (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, including the use of proteomics and genomics technologies. DDRC conducts and participates in several brain imaging studies on early diagnosis of dementia that contain both structural and functional brain imaging, including studies with amyloid-specific PET tracers. In recent years several studies on comorbidity in early diagnosis have been initiated, including multicentre studies on the role of epilepsy in early dementia and MCI, and new studies analysing the use of ear-EEG to examine epilepsy in AD.

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 DDRC have conducted various studies on cognitive processes in aging, as well as longitudinal studies on cognitive deficits and personality traits in gene-expansion carriers. In 2018 DDRC developed a new Danish cognitive screening instrument for use in general practice.

Rare causes of dementia and inherited neurodegenerative disorders

Neurogenetic research focuses on clinical characteristics, ancillary investigations and basic research on gene function and therapy. Many neurodegenerative disorders, including AD, FTD, Huntington's disease 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 neurodegeneration mechanisms 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 DDRC 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. DDRC conducts highly specialised diagnostic exami-

nation and treatment of many rare disorders, including normal pressure hydrocephalus (NPH). The DDRC NPH team is currently studying the effect of treatment and diagnostic procedures.

Public health in dementia

Using nationwide registry data we analyse the quality of diagnostic evaluation, access to health services and the use of medication in patients with dementia compared to the general Danish population. The research is being carried out in collaboration with the National Centre for Register-based Research at Aarhus University and the Section of Social Medicine, University of Copenhagen. Recently, the partnership conducted projects investigating patterns of use of opioids, other analgetics, psychotropics and anti-dementia medication. 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. We also conduct studies on mortality in dementia and on the role of infections in dementia. Finally, we are taking part in studies on the relationship between stress and dementia. 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 interventions. In the ongoing ReACT study we examine how assistive technology can be designed to support self-management and rehabilitation of people with dementia. As part of the study an app has been designed and tested that incorporated user-involvement in an innovative process. The study also explores methods for implementation and adoption of assistive technology.

Global health and cross-cultural aspects of dementia

DDRC is conducting several studies on the cross-cultural aspects of dementia. To improve diagnostic evaluation and care of ethnic minorities with dementia, the centre has studied the assessment of dementia in various ethnic groups in Denmark and in other European countries, as well as barriers to accessing dementia care. 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 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 international trials. On average DDRC's track record shows that the inclusion of patients is more than 30% above the requested 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. In pharmacological trials for dementia DDRC is the national coordinator of the dementia centre in National Experimental Therapy Partnership (NEXT), which is a public-private clinical research partnership involving the regions of Denmark, universities, twelve pharmaceutical companies and one GTS institute, a government-approved, non-profit technological service. NEXT works to optimise clinical trials from start to finish and has established centres in various medical areas. In 2018 NEXT was renamed Trial Nation.

RESEARCH RESOURCES

Translational Neurogenetics Laboratory

To investigate the molecular mechanisms underlying neurodegenerative disorders we work with a variety of molecular and cellular biology techniques. 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. The 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 7,600 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, as well as 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. Furthermore, skin biopsies are taken from selected patients and processed into live fibroblast cultures and stored for future research projects. These cultures have served as the basis for projects studying the molecular mechanisms underlying development of neurodegenerative

disorders and been used in the development of new model systems for neurodegenerative disorders, e.g. induced pluripotent stem cells.

Clinical cohorts and intervention studies

To study how different neurodegenerative processes arise and become manifest, specific patient cohorts representing a wide range of diagnostic entities and 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 interna-

DDRC'S RESEARCH LABORATORY

Used daily, DDRC's laboratory has a biobank that stores blood and CSF samples from patients with dementia and cognitive disorders.



tional 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, a multicentre Danish network comprising eight different memory clinics from across the country.

Danish national registries

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

INTERNATIONAL RESEARCH CONSORTIA AND NETWORKS

PredictND

PredictND was a four-year, €4.2m European project funded by the EU's 7th Framework Programme that drew to a close in 2018. It focused on developing tools and means for earlier, evidence-based diagnosis of a range of neurodegenerative diseases. PredictND was coordinated by VTT Technical Research Centre of Finland Ltd. (Finland) and the consortium members included Alzheimer Europe (Luxembourg), Combinostics Ltd. (Finland), GE Healthcare (UK, Sweden), Imperial College of London (UK), Rigshospitalet (Denmark), Università degli Studi di Perugia (Italy), University of Eastern Finland (Finland) and VU/VUmc (the Netherlands). The collaboration is still very productive and continues to publish data from the project.

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, DDRC at Rigshospitalet,

University of Southern Denmark, Aarhus University, Bioneer, Lundbeck A/S (Denmark), Lund University (Sweden) 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 study the underlying molecular mechanisms with the perspective 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. In 2018 DDRC proposed an initiative focusing on the challenges of early diagnosis in neurodegenerative diseases. This includes a survey of EADC centres on the practice of diagnostic disclosure, biomarker counselling, treatment and follow-up of MCI patients as well as a position paper on the topic.

Interdem

DDRC takes part in Interdem, a pan-European network of researchers collaborating on research and dissemination of early, timely and quality psychosocial interventions aimed at improving the quality of life across Europe for people with dementia and their caregivers. 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 with HD and their relatives to facilitate collaboration throughout Europe. DDRC's staff and families affected by 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 2018, DDRC's Enroll HD cohort comprised 232 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.

Every other year DDRC organises a two-day leadership conference on care in collaboration with the Norwegian and Swedish national research and education centres. In 2018 DDRC hosted the conference, which had 247 participants, in Copenhagen. The theme this year was: Good dementia care is a matter of leadership: How do we maintain a person-centred approach as the disease progresses?

North Sea Dementia Group

The North Sea Dementia Group is an association of interested individuals from dementia care practice and research. DDRC hosted the annual meeting of the North Sea Dementia Group 2018 in Copenhagen, where 25 participants from eight European countries gave presentations on themes such as quality of care in hospitals, interventions and research for people with dementia, prevention, and dementia, media and technology.

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 AD and Parkinson's disease (BIOMARKAPD), on the definition of outcome measures in dementia and on the harmonisation of assessment methods.

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 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



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.



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.

ASSOCIATED RESEARCHERS (CURRENTLY EMPLOYED ELSEWHERE)



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.



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 focuses on the use of antipsychotics and other psychotropic drugs in patients with dementia and investigates the mortality risk associated with the use of psychotropic drugs. The aim is to clarify areas of inappropriate medication use and to help prevent the negative consequences hereof.



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.



MARIE NATHALIE NICKELSEN HELLEM – HUNTINGTON' S DISEASE

MD. Her PhD project investigates 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.



JANET JANBEK – ROLE OF INFECTIONS IN DEMENTIA

MSc. Her project will focus on the role of infections in dementia. The project will describe hospital contacts with infections in persons with dementia and compare them to those without dementia and investigate the impact on mortality. Her project will also investigate the role of infections as risk factors, by taking a life-course approach starting from mid-life.



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.



CHRISTIAN SANDØE MUSAEUS – EPILEPTIC SEIZURES IN AD

His PhD assesses subclinical epileptiform activity with continuous EEG monitoring using novel ear EEG registration and correlate findings with MRI hippocampal blood flow assessments. Another area of interest is the use of EEG to assist in the diagnosis of Alzheimer's disease and MCI.



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 examined clinically affected and presymptomatic CHM P2B gene mutation carriers from the Danish FTD-3 family.



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 survival 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

MSc Neuropsychologist. Her project, ReACT, explores assistive technology for people with dementia. As part of the study a cognitive supportive app has been designed and tested through a user-involving innovation process. Methods for implementation and adoption of assistive technology are also investigated, with emphasis on cognitive rehabilitation and self-management of people with dementia.

STUDENT RESEARCH FELLOWS (MASTER'S STUDENTS)



FREDERIKKE JEPPESEN KRAGH – QUANTITATIVE MEASUREMENTS OF MOTOR SIGNS IN DEMENTIA

Her study investigates whether a quantitative motor assessment provides a more objective, sensitive and standardised measurement of motor dysfunction in AD, FTD and DLB. A second area of interest is different aspects of physical activity and its impact on daily living functions in AD.



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.



JOHANNE KØBSTRUP ZAKARIAS – EPIDEMIOLOGY AND QUALITY OF DEMENTIA DIAGNOSES

Using nationwide registry data, this project investigated potential geographical variation in diagnostic rate and quality of dementia diagnoses to examine possible inequality in the access to appropriate diagnostic evaluation and care for patients with dementia.



CHUQIAO CHEN – DISEASE MODELING OF FRONTO-TEMPORAL DEMENTIA LINKED TO CHROMOSOME 3

Her project investigates relevant molecular mechanisms of distinct Danish and German FTD-3 mutations, using various cell models, including 1) patient-derived fibroblast, 2) induced pluripotent stem cells, derived from patient fibroblasts, 3) a neuroblastoma knock-out model, overexpressing the different FTD-3 mutations.



**NATIONAL INFO &
EDUCATION CENTRE
FOR DEMENTIA**

Established in 2007 and funded by the Danish 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.

THE DANISH NATIONAL DEMENTIA PLAN

In 2017 the Danish Ministry of Health launched the national dementia strategy 2025 and an action plan with 23 initiatives for 2017-2019. All initiatives were active in 2018 and DDRC were involved in many. DDRC has responsibility for managing 3 initiatives:

- A new case-finding tool for use in primary care
- A tool-box for psycho-social support, counselling and teaching of patients and caregivers
- Concepts for dementia-friendly hospitals

DDRC also contributed to the completion of Denmark's first national research strategy, an initiative headed by the Danish Health Authority and published in December 2018.

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.

Course Catalogue 2018

In 2018 the Course Catalogue contained 16 1-3 day activities. The various themes included, for example: nutrition and eating and swallowing difficulties, person-centred care, dementia diagnosis masterclass, physical training, early intervention, pain and delirium, the physically and mentally disabled, music as a tool for presence and wellbeing, become an ABC Dementia instructor and management for dementia 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. This year Dementia Days was held 7-8 May 2018 and covered the theme United around dementia – today and tomorrow.

At the joint symposium, Dr Andrew Sommerlad, University College London; Professor Bengt Winblad, Karolinska Institutet, Stockholm; Birgitte Vølund, chair, Danish Dementia Association; and Gunhild Waldemar, head of DDRC, gave presentations.

During the conference's opening the Danish Minister of Health, Ellen Trane Nørby, and the Danish Minister for Senior Citizens, Thyra Frank, presented the 2018 Dementia Award.

The sessions at the symposium focused on:

- Assessment of dementia – Where are we headed?
- Dementia friendly society
- Meaningful everyday life in a nursing home
- Cognitive functions and the brain in old age
- Data and quality development
- Diabetes and dementia
- Living with dementia
- Dementia allies – Involvement
- Dementia, substance abuse and mental illness
- Reminiscence and cultural activities
- Open lectures, where participants present their own projects

Once again this year, Dementia Days had record attendance with 1,246 participants, including exhibitors and speakers.

During the conference there were nine sessions, with speakers from across the nation presenting their views 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 2018

Every other year DDRC organises a two-day conference for leaders in dementia care in collaboration with Norwegian and Swedish national research and education centres. In 2018 the Scandinavian leadership conference was held for the fourth time jointly with the Swedish Dementia Centre and the Norwegian National Advisory Unit on Ageing and Health.

DDRC hosted the conference, which was held in Copenhagen from 22-23 October 2018 and attended by 247 people. The programme featured 17 presentations by speakers from Scotland, Norway, Sweden and Denmark and this year's title was

“Excellent dementia care is a question of management: How to ensure person-centred care throughout the entire dementia trajectory”.

Johansson, Institute of Health and Care Sciences, Gothenburg; Caroline Ott, Copenhagen Mental Health Centre; and Asmus Vogel, DDRC.

Annual research conference 2018 – subjective cognitive impairment

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. This year, there were 138 participants at the conference, which attracts scientists and practitioners from across Denmark.

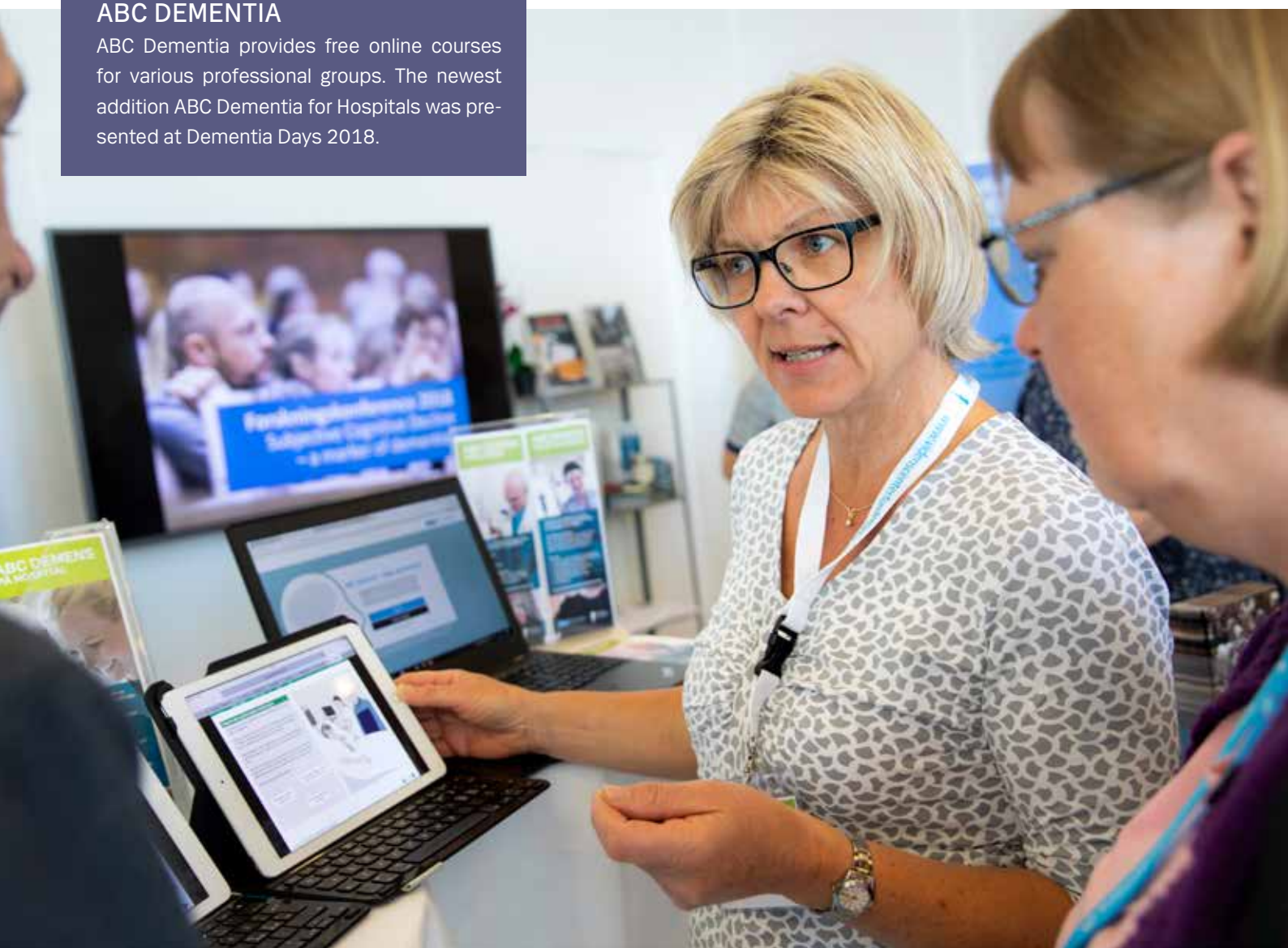
The theme in 2018 was subjective memory impairment and there were presentations by Giovanni Frisoni, professor of clinical neuroscience, University of Geneva; Wiesje van der Flier and Linda Wesselmann, VUmc Alzheimer Center, Amsterdam; Lena

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.

ABC DEMENTIA

ABC Dementia provides free online courses for various professional groups. The newest addition ABC Dementia for Hospitals was presented at Dementia Days 2018.



ABC DEMENTIA – FREE ONLINE COURSES

ABC Dementia – Care

In 2016 a full-fledged basic course for staff working with care was completed that is used for basic and ongoing education in municipalities and regions. Registered users at the end of 2018: 24,575.

ABC Dementia for Physicians

The e-learning course ABC Dementia for Physicians was launched in October 2016 and targets physicians in training but is also relevant for doctors and other professionals who work with dementia assessments. Registered users at the end of 2018: 1,392.

ABC Dementia for Hospitals

In 2018 an e-learning course targeting hospital care staff was launched. Registered users at the end of 2018: 719.

ABC Dementia-friendly Hospitals

E-learning targeting all staff working at hospitals. Work in progress.

Interest in using e-learning as a supplement for developing skills also continues to grow.

Further development of the ABC Dementia concept

In 2018 the overall ABC Dementia concept was further developed and future-proofed, with the implementation of new software allowing DDRC to independently produce e-learning material in the future. Additional staff resources have been allocated for the in-house production of ABC Dementia and an agreement has been reached with LMS, a new administration system supplier. Existing e-learning courses have been transferred to a new, more reliable administration system that provides, for instance, better opportunities for collecting data and supporting users.

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 co-operation.



Network of Danish Memory Clinics:

● Memory clinics ● ADEX Memory clinics ● ADEX affiliates

The annual meeting of the Network of Danish Memory Clinics was held on 10 October 2018 in Vejle and had 114 participants from among the five regions of Denmark. The themes covered national recommendations for cross-sectoral and interdisciplinary courses, the nationwide Clinical Dementia Database, Huntington's disease and ABC Dementia for Hospitals.

As part of the network meeting workshops dedicated to various professional groups were organized. Doctors and psychologists discussed Parkinson's and Lewy body dementia. Nurses and others worked with rater training for the Geriatric Depression Scale and presentations on neuropsychological studies. Secretaries participated in a workshop with presentations on ABC Dementia-friendly hospitals and challenging behaviour.

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 newsletters sent six times a year and an annual meeting for the ambassadors ensure contact between DDRC and the ambassadors. On 15 March the municipal network of dementia ambassadors met for the ninth time in Middelfart, where 61 municipalities were represented as well as the Danish Health Authority, Local Government Denmark, Alzheimer's Association, Dementia coordinators in Denmark and three Danish regions.

DaneDem – a network for psycho-social research

For multidisciplinary researchers interested in psychosocial interventions, such as cognitive rehabilitation, music therapy and personalised care, DaneDem (Danish Research Network on Psychosocial Methods in Dementia) is the Danish counterpart of the pan-European network Interdem. The aim of the network is to provide mutual inspiration, idea development and to be a mutual sounding board. DaneDem meets at least once a year with the aim of improving psychosocial dementia research in Denmark and met for the fifth time in Aarhus on 16 April 2018 and for the sixth time in Nyborg on 24 September 2018. The network continues to grow and currently has 26 members.

Network for faculty teachers of health care educational institutions

This network invites teachers from college- and university-based schools in nursing, assistant nursing, physiotherapy,

occupational therapy, speech therapy, etc., with the aim for strengthen teaching in dementia related topics. The network had its third annual meeting in Odense on April 5, 2018, with 23 participants. Due to low participant rate, the DDRC closed the network and will in the future focus on offering educational activities targeting teachers from health care schools.

Network for external faculty

DDRC often recruit professionals with various backgrounds, e.g. nurses, physicians, physio-therapists, researchers, employed at institutions elsewhere, for teaching activities, advisory boards, guideline writing, etc. DDRC has maintained a network for our external faculty, with annual meetings. The network had its annual meeting on June 22, 2018, after which it was discontinued, due to re-organization of networks. Instead, external faculty experts participate in our specific advisory groups related to their relevant area of expertise.

COMMUNICATIONS AND PRESS – INTERACTING WITH SOCIETY

All of our platforms show a high level of activity. We have a growing number of newsletter subscribers, media mentions, followers on social media and website users. 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 general media. With more than 800 media mentions in 2018, DDRC was present in the press on an almost daily basis. In September national tv channel TV2 focused on dementia issues for an entire week. Several DDRC experts were involved in a documentary and in live broadcasting from our research lab.

Website

In 2018 almost 370,000 users visited the DDRC website and viewed a combined 1.3 million pages with information on dementia diseases, risk factors and statistics for people who work with the assessment, treatment and care. Materials and tools useful in clinical practice can be downloaded or ordered on the site. The press, patients and caregivers are examples of frequent users of our website.



DEMENTIA IN THE MEDIA

Dementia is a frequent topic in the news, for example this interview with the Danish Minister of Health Ellen Trane Nørby during the opening of Dementia Days 2018.

Newsletter

Published 6-8 times per year, our newsletter contains information about the latest research and current courses and conferences. At the close of 2018 we had 7,170 subscribers, which is 900 more than last year.

About Dementia app

The About Dementia app is an observation tool for professional caregivers. The content and design of the app were updated in 2018 and the number of unique users rose from 17,200 in 2017 to 19,500.

Social media

All of our social media platforms have a growing number of followers, engaging users and generating traffic on the DDRC web-

site. 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. On LinkedIn we share updates of interest to dementia stakeholders and professionals.

DDRC conference booth

The DDRC conference booth was present at various events in 2018, 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.

Nadia Falcon Bærnthsen, board member and manager of quarterly meetings and annual assembly, Danish Neuropsychological Society.

Kristian Steen Frederiksen, member, EAN Scientific Panel on Dementia and Cognitive Disorders and Panel on Higher Cortical Functions; 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; board member, Danish Alzheimer Research Foundation, chair, Alzheimer Research Committee under the Danish Alzheimer Association; working group member, National Guideline on diagnosis of MCI and Dementia, Danish Health Authority; member, Scientific Panel on Dementia and Cognitive Disorders, EAN.

Lena Hjermind, PI of global observational study on HD, Enroll-HD; Danish national coordinator and PI of ongoing clinical trial (phase II) and two upcoming clinical trials (phase I/II and phase III) on HD; adviser, EHDN; member of EHDN working groups “Genetic testing and counselling” and “Symptomatic treatment and research”; vice-president, Danish Huntington’s Disease Association; appointed member, The International Parkinson and Movement Disorder Society (MDS), on summer school programme panel of teachers; member, European Dystonia Network.

Peter Johannsen, chair, Danish National Dementia Registry; working group member, Danish National Guideline on Dementia Treatment, Danish National Board of Health; Danish national coordinator on six clinical trials on Alzheimer’s disease.

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

Jørgen E. 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, Rigshos-

pitalet; 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; appointed member, Alzheimer Europe expert group on the development of intercultural care and support for people with dementia from minority ethnic groups.

Signe Pertou Ringkøbing, board member and secretary, Danish Neuropsychological Society.

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 patient pathway programme for dementia, Capital Region of Denmark.

Karen Tannebæk, member, Nordic Dementia Network established by Nordic Welfare Centre; member, Danish Network on Psychosocial Methods in Dementia (DaneDem); member, DDRC professional reference group on dignified elderly care; member, follow-up group on national dementia action plan; member, reference group for handbooks on knowledge-based recommendations for dementia social and health care practice; member, expert group for Behavioural and Psychological Symptoms of Dementia project; member, implementation group for national dementia action plan, Danish Ministry of Health.

Asmus Vogel, section editor, Scandinavian Journal of Psychology; member, working group on “Recommendation for cross-sectorial care pathways for people with dementia (appointed by the Danish Psychology Association), Danish Health Authority.

Gunhild Waldemar, board member (treasurer), Alliance for Biomedical Research in Europe; committee member, European Affairs Subcommittee and member, European Affairs Subcommittee and 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; chair, NEXT-link Dementia.

Laila Øksnebjerg, member, scientific committee, 14th Nordic Meeting in Neuropsychology, Denmark 2021; founder, Dane-Dem.

AWARDS AND DONATIONS



Professor Steen Hasselbalch awarded the HN Prize

This year's annual HN Prize, awarded by the Hede Nielsen Family Foundation, was given to three dementia researchers: Professor and chief physician Steen Hasselbalch, DDRC; Professor Hanne Mette Ochsner Ridder, Aalborg University; and Professor Ulrik Gether, University of Copenhagen, each of whom received 500,000 Danish kroner. Hasselbalch received the award for his work with early detection and diagnosis of dementia.

Photo from left: Ulrik Gether, Steen Hasselbalch, Hanne Mette Ochsner Ridder, deputy chair Peter Sven Sørensen and Hede Nielsen Family Foundation chair of the board Henrik Hede-Nielsen. Photo: Hede Nielsen Family Foundation

DDRC researchers awarded Alzheimer's Research Fund grants

On the occasion of World Alzheimer's Day on 21 September 2018 the Alzheimer's Association presented awards and grants to researchers and professionals for outstanding contributions to the field of dementia. Its Alzheimer's Research Fund awarded 3.4 m Danish kroner to nine specific research projects. Among the recipients were two DDRC researchers.

Associate Professor and neuropsychologist Asmus Vogel (top right) was awarded 450,000 Danish kroner for the project "Measuring memory change in 'asymptomatic' Alzheimer's disease". The aim of the project is to study whether new memory change tools (autobiographical memory tests and measures of subjective memory decline) can detect clinical symptoms of AD at an earlier stage than traditional neuropsychological tests.

PhD student Christian Sandøe Musaeus, MD (bottom right) received 250,000 Danish kroner for the project "Epileptic activity in patients with Alzheimer's disease and Lewy body dementia". The aim of the project is to use a new ear-EEG technology to examine whether patients with AD and Lewy body dementia have hidden epileptic activity. If this is the case it will be possible to reduce symptoms using antiepileptic drugs.



Donation from the Absalon Foundation

Professor and chief physician Steen Hasselbalch and Professor and chief physician Gunhild Waldemar received a donation of one million Danish kroner in May 2018 from the Absalon Foundation to carry out research on AD.

Photo from left: Absalon Foundation chair Jens Jacob Skibsted, Gunhild Waldemar and Steen Hasselbalch. Photo: Michael Alexander

STAFF IN 2018

MANAGEMENT GROUP (per 31/12/2018)



Chair

Gunhild Waldemar, MD,
DMSc, professor, senior
neurologist



Head nurse
Copenhagen Memory
Clinic – Blegdamsvej,
Glostrup and Born-
holm Hospital
Hanne I. Sørensen, RN



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



Clinical director
Copenhagen Memory
Clinic – Glostrup
Eva Bjerregaard,
MD, specialist in family
medicine



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

Jette Gotlieb Iversen, course administrator
Ditte Majgaard Jensen, accounting staff
Bodil Lykkegaard Kryger, accounting staff
Brit Mouritsen, personal assistant
Tine Olsen, head of administration

NATIONAL INFO & EDUCATION CENTRE

Tove-Marie Buk, RN, educational advisor
Marie Ejlersen, MA, communications 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 Højrup Kjær, MA, communications officer
Ann Nielsen, PhD, project manager
Elsebeth Refsgaard, RN, educational advisor, project manager
Mira Marie Petersen, project assistant
Karen Tannebæk, OT, educational director
Gunhild Waldemar, MD, DMSc, professor and chair

RESEARCH

Muntadhar Al-Mendalawi, medical laboratory technician
Anne Sigaard Bie, PhD, postdoc
Kathrine Bjarnø, medical laboratory technician
Marie Bruun, MD, PhD student
Ane Nørgaard Christensen, MD, PhD student
Le Gjerum, MD, PhD student
Christina Vangsted Hansen, RN, research nurse
Steen Gregers Hasselbalch, MD, DMSc, professor, senior neurologist, research director
Marie Nickelsen Høllum, MD, PhD student
Lena Elisabeth Hjerminde, MD, PhD, senior neurologist
Oda Jakobsen, RN, research nurse
Janet Janbek, MSc, PhD student
Peter Johannsen, MD, PhD, senior neurologist
Adele Gabriele Marthaler, PhD, postdoc
Jørgen Erik Nielsen, MD, PhD, associate professor, senior neurologist, research director
T. Rune Nielsen, MSc, PhD, neuropsychologist
Troels Tolstrup Nielsen, MSc, PhD, centre manager, senior researcher
Peter Roos, MD, PhD student
Anja Hviid Simonsen, MSc, PhD, senior researcher
Camilla Steen-Jensen, MSc, PhD student
Jette Stokholm Pedersen, MSc, neuropsychologist
Jette Marie Rasmussen, research administrator
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 (excl. students)

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Tien Kieu Phung, MD, PhD, senior researcher

COPENHAGEN MEMORY CLINIC

Medical doctors

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Julia Johanna Almer Bromann, MD
Nanna Winther Dombernowsky, MD, resident in neurology
Elsebeth Steno Hansen, MD PhD, senior psychiatrist
Steen Gregers Hasselbalch, MD, DMSc, professor, senior neurologist
Lena Elisabeth Hjerminde, MD, PhD, senior neurologist
Peter Johannsen, MD, PhD, senior neurologist
Christina Rørvig-Løppenthien, MD, senior neurologist
Suzanne Lindquist, MD, PhD, clinical geneticist
Jørgen Erik 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
Christian Sandøe Musaeus, MD
Victoria Gunmalm, MD
Gorm Thorlacius-Ussing, MD
Kristian Steen Frederiksen, MD, PhD
Peter Roos, MD, PhD student
Tua Vinther-Jensen, MD, PhD*

Nurses

Nicole Cordes, RN
Lea Virenfeldt Damgaard, RN
Birgit Grøn, RN
Christina Vangsted Hansen, RN
Lene Iben Hvidkjær, RN
Oda Jakobsen, RN
Hanne Rygaard Jensen, RN
Annette Lauridsen, RN
Rikke Charite Monberg Jarløv, RN
Hanne Inge Sørensen, RN
Sanne Voss, RN
H. Naomi Wakabayashi, RN
Sara Wendel Winther, RN

Clinical neuropsychologists

Nadia Falcon Bærnthsen, MSc
Rebecca Hendel, 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 technologists

Muntadhar Al-Mendalawi
Kathrine Bjarnø (maternity leave)
Lærke Borg Østergaard

Receptionists

Anne-Mette Pedersen
Joan Rysgaard

GLOSTRUP MEMORY CLINIC

Medical doctors

Hanne Elkjær Andersen, MD, geriatrician*
Inge Bendix, MD
Eva Bjerregaard, MD, specialist in family medicine
Michael von Buchwald, MD, psychiatrist*
Per Dyhr, MD, geriatrician*
Ragnar Hansen, MD, geriatrician*
Elsebeth Iversen, MD
Hanne Pedersen, MD, geriatrician*
Anna Routhier, MD

Nurses

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

Clinical neuropsychologists

Anne-Mette Guldberg, MSc

Medical secretaries

Christina Appel
Tinna Bendixen
Saida El Idrisi

BORNHOLM MEMORY CLINIC

Diana Kaiser, MD senior consultant geriatrician
Karina Beyer, RN
Maja-Lis Kofoed Petersen, RN
Charlotte Weinrich, medical secretary

* external consultant

PUBLICATIONS IN 2018

PHD DISSERTATION

Roos, P. *Clinical and Molecular Aspects of Frontotemporal Dementia Linked to Chromosome 3 (FTD-3)*: PhD Thesis. Københavns Universitet 2018;1-63.

SCIENTIFIC PAPERS

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CONTRIBUTIONS TO MULTICENTRE STUDIES

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EXTERNAL FUNDING FOR RESEARCH AND EDUCATION ACTIVITIES 2018 (DKK M)	
New grants received*	4.8
New grants accumulated 2007-2018*	169.8
External grants spent on specific programmes	
• The National Info & Education Centre for Dementia from the Danish Ministry of Health, including projects	13.4
• Other external grants for research*	6.8
Total	20.2
Conferences, educational courses and products	5.0
Research contracts	4.2

* excluding the annual main grant from the Danish Ministry of Health

STAFF 2018	
No. of employees/full-time equivalents	114/82
No. of employees funded by	
• Internal sources	66
• External sources	48

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