DANISH DEMENTIA RESEARCH CENTRE

ANNUAL REPORT 2021

Copenhagen Memory Clinic and
National Information & Education Centre for Dementia

DANISH DEMENTIA RESEARCH CENTRE

Danish Dementia Research Centre
Editor: Gunhild Waldemar
Editorial assistant: Marie Ejlersen
Design: Hofdamerne/Lea Rathnov
Print: Red Hill A/S
Photo: Tomas Bertelsen

www.ddrc.dk
Mail: vide@regionh.dk
Phone: +45 3545 6922

Contents

Gunhild Waldemar, MD, DMSc, professor,
senior neurologist and chair of DDRC

Preface

It is a pleasure to present the 2021 annual report for the Danish Dementia Research Centre (DDRC) with an overview of the activities in our memory clinic as well as our research and national educational programs.

Again, in 2021, the COVID-19 pandemic had a significant impact on our activities and created significant delays in our research programs as well as in our memory clinic. Many of our national educational programs were successfully converted into online formats. Reaching other target groups through online courses will continue to be part of the programs we offer. The annual two-day conference Dementia Days (Demens-Dagene), which was cancelled in 2020 due to the pandemic, was this year organized as an online event. Transmitted from a professional TV-studio in the Tivoli Congress Center, and moderated by a professional TV host, the webinar became a great success.

In 2021 we were proud to announce the approval of DDRC as a member of ERN-RND. The ERN-RND is a European Reference Network (ERN) established by the EU to support patients and families affected by rare neurological diseases (RND) which requires much specialised knowledge, treatment and resources. Many patients with such rare neurodegenerative diseases are referred to our memory clinic and seen on regular follow-up. With the inclusion in ERN-RND, we will get more access to specialists in other European centres and to collaborative research with the aim to improve diagnosis and treatment.

The DDRC authored or co-authored 54 scientific papers, books or book chapters in 2021, 2 phd students defended their thesis on “Dementia and mortality” and “Epidemiology of infections in dementia” and several new phd and postdoc programs were initiated.

Our achievements in patient care, research and education would not be possible without the support from our Danish and international collaborators and scientific advisors. We would like to thank the Danish Ministry of Health and public and private foundations (listed in “acknowledgements”) for financial support to our activities.

About the Danish Dementia Research Centre

ORGANISATION

Located at Rigshospitalet and based in the Department of Neurology, the Danish Dementia Research Centre (DDRC) comprises the following sections: Copenhagen Memory Clinic (with a clinical trial unit), a research unit and a national information and education centre.

The Copenhagen Memory Clinic is a secondary and tertiary referral-based multidisciplinary out-patient clinic offering diagnostic evaluation, treatment and counselling for patients with cognitive disorders and dementia. *The Clinical Trial Unit* conducts sponsored clinical drug trials in neurodegenerative disorders as well as investigator initiated clinical studies. *The Research Unit* comprises clinical and epidemiological research groups, a neurogenetic research laboratory and the Danish Dementia BioBank.

Initiated and funded by the Danish Ministry of Health, the mission of the *National Information and Education Centre for Dementia* is to strengthen and coordinate health research in relation to specific treatment and care interventions in clinical practice and to assure national dissemination and communication of knowledge in collaboration with danish regions and municipalities.

Chaired by Kurt Espersen, Vice-president, Region of Southern Denmark and appointed by Danish Regions, the national steering committee (Styregruppen) monitors the strategic development and performance of the National Information and Education Centre according to predefined objectives and milestones, as outlined in our strategy for 2021-2025. The members of the steering committee are appointed by the Ministry of Health and the Elderly, Danish Regions, Local Government Denmark, the Capital Region of Denmark and Rigshospitalet.

The national scientific advisory board (Referencegruppen) reviews and contributes with advice on major educational and scientific activities. The members of the advisory board are appointed by the Danish Health Authority, KL-Local Government Denmark, Danish Regions, the Danish College 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 www.videnscenterfordemens.dk.

Our national networks represent professional specialists and care staff and contribute with input from municipalities, regions, universities and other educational institutions to our work.

STRATEGY 2021-2025

Five value cards mark our goals and ambitions for creating value and serve to guide a range of specific strategic initiatives towards 2025.

Groundbreaking research

We create value, when our groundbreaking research, analyses and data generate new knowledge which shows new paths to better treatment and care and serves to form evidence for clinical practice.

Interdisciplinary national anchoring

We create value, when we exchange experiences and knowledge nationwide with our target groups across municipalities, regions, sectors, organizations and professional groups.

User-involving innovation

We create value when we strengthen the link from research to innovation and implementation and involve our users in the process.

Attractive evidence bank

We create value when we make current evidence easily accessible in order to strengthen the quality of care for people with dementia and their caregivers.

Active public voice

We create value when we strengthen our availability, visibility, and proactive participation in the public debate in our field.

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.

High quality: 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 care givers.

Respect: We show respect for patients, caregivers, professionals and collaborators and 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 about our goals, methods and results and with regard to our professional relationships.

Special events in 2021




Dementia Days online

In 2021 DDRC's annual Dementia Days conference was streamed as an online event due to the Covid-pandemic. This year's theme was "Health and quality of life", and more than 800 people from across Denmark followed online. Among the keynote speakers were Emeritus professor Bob Woods, Bangor University, United Kingdom. The conference was opened by Sophie Hæstorp Andersen, chair of the Regional Council in the Capital Region of Denmark, and the Minister for Social Affairs and Senior Citizens Astrid Krag presented the 2021 dementia prizes for outstanding employee and caregiver.

Special events in 2021

PhD defense by Lærke Taudorf

In March 2021 Lærke Taudorf, MD, defended her PhD thesis with the title: “Dementia and Mortality. A nationwide registry-based study”.

Her supervisors were: Professor Thomas Munk Laursen, Aarhus University, MD, PhD Ane Nørgaard, Rigshospitalet, and professor Gunhild Waldemar, University of Copenhagen (faculty supervisor).

The official opponents were: Professor Frans Boch Waldorff, University of Copenhagen (chairman), professor Rene Ernst Nielsen, Aalborg University, and professor Maria J. Eriksdottir, Karolinska Institute, Stockholm.

PhD defense by Janet Janbek

In November 2021 Janet Janbek, MSc., defended her PhD thesis with the title: “Epidemiology of Infections in Dementia: Nationwide registry-based studies on hospitalizations and adverse outcomes in Denmark”.

Her supervisors were: Professor Thomas Munk Laursen, Aarhus University, and professor Gunhild Waldemar, University of Copenhagen (faculty supervisor).

The official opponents were: Professor Michael Eriksen Benros, University of Copenhagen (chairman), professor Kaare Christensen, University of Southern Denmark, and professor Carol Brayne, University of Cambridge, U.K.

Lundbeck Foundation Talent Prize

In 2021 Christian Sandøe Musaeus, MD and PhD student at DDRC received the Lundbeck Foundation Talent Prize. The prize was awarded in 2020, but the ceremony postponed to 2021, due to the pandemic. The prize is awarded every year to 3 to 5 scientists under the age of 30, who have produced particularly promising research in biomedical sciences. Christian Sandøe Musaeus received the prize for his innovative studies on the use of quantitative EEG in early diagnosis of dementia and ear EEG for potential use to identify epileptic seizures in patients with Alzheimer's disease.

European Reference Network

The ERN-RND is a European Reference Network established by the EU to support patients and families affected by rare neurological diseases (RND) which requires much specialised knowledge, treatment and resources. In 2021 the DDRC was accepted as part of the network for rare neurodegenerative diseases. Professor in neurogenetics and dementia, Jørgen E. Nielsen coordinates our participation in ERN-RND.

Copenhagen Memory Clinic


6 7

Birgitte Bo Andersen, MD, DMSc, senior neurologist, clinical director
Hanne I. Sørensen, RN, head nurse

Copenhagen Memory Clinic

Copenhagen Memory Clinic at Rigshospitalet is a secondary and tertiary referral-based multidisciplinary out-patient clinic. Since the clinic was established in 1995, it has offered diagnostic evaluation and treatment of patients with cognitive disorders and dementia. We receive 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.

A satellite memory clinic is located on the island of Bornholm. For both 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. Our dedicated multidisciplinary team comprise consultant neurologists, psychiatrists, geriatricians, neuropsychologists, specialist nurses, a clinical geneticist, a social counsellor and medical secretaries.

DIAGNOSTIC EVALUATION AND PLAN FOR TREATMENT AND CARE

The majority of patients 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), PET- PE2i and amyloid PET, routine and biomarker examination of cerebrospinal fluid (CSF), EEG, neuropsychological assessment and psychiatric evaluation. 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 are invited to meet with the specialist physician and specialist nurse, where information and counselling is

SYNDROME	DIAGNOSIS	BLEGDAMSVEJ	BORNHOLM	TOTAL
Dementia		**899**	**87**	**986**
	Alzheimer's disease	412	51	463
	Vascular or mixed dementia	198	16	214
	Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinson-plus syndromes	63	10	73
	Frontotemporal dementia	39	1	40
	Other specific conditions, including Huntington's disease and normal pressure hydrocephalus	82	5	87
	Dementia of uncertain aetiology and alcohol-related dementia	105	4	109
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	**389**	**15**	**404**
No cognitive impairment	Patients with subjective symptoms and no significant pathology	**248**	**8**	**256**
Genetic counselling	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	**182**	**–**	**182**
All completed evaluations (excluding genetic counselling)		**1536**	**110**	**1828**

Classification of new patients who completed a diagnostic evaluation programme in 2021

given on diagnosis and on the treatment and care plan. A short summary is subsequently sent to the patient's general practitioner and community nurse, where relevant. Some patients may be offered a follow-up programme in the memory clinic.

SPECIALISED MEDICAL SERVICES

Patients with rare, complex or familial disorders may be referred from other parts of Denmark (mainly Eastern Denmark) for treatment and follow-up. Genetic counselling and testing 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 Authority, Copenhagen Memory Clinic has been approved as a regional or highly specialised centre in the fields of dementia and neurogenetics for the following services:

- 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, lumbar perfusion and tap tests for patients with suspected normal pressure hydrocephalus (NPH)

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 patient 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 demonstrated a dilated ventricular system. In 2021 there were 357 patients referred for a clinical evaluation of NPH, 128 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 the 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 2021 there were 147 at-risk family members referred. The clinic also offers post-genetic test counselling when needed.

Follow-upprogramme 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 of-

fered 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 we offer counselling for the caregivers as an integral part of the follow-up programme. For fragile patients with severe dementia home visits are offered.

As part of its services the clinic offers courses for patients and caregivers. The courses were cancelled in 2020 and 2021 due to the COVID-19 pandemic.

BORNHOLM MEMORY CLINIC

Led by the Copenhagen Memory Clinic, the outpatient clinic is located at the internal medicine department on Bornholm's Hospital. A team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic, together with a nurse and a medical secretary from Bornholm's Hospital offers consultations one day per week for patients on Bornholm. On one additional day per week a resident in geriatrics see patients under the (online) supervision of a neurologist from the Copenhagen Memory Clinic. The Copenhagen Memory Clinic has also contributed to educational services for health care professionals on Bornholm.

REGIONAL AND NATIONAL COLLABORATION

In 2011 the Capital Region established a guideline ("forløbsprogram") 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. An update of the guideline was completed in 2020.

The Copenhagen Memory Clinic coordinates a collaborative forum for specialists serving in the two local catchment areas: the City of Copenhagen ("planområde BYEN"), and the southern part of the Capital Region ("planområde SYD"). The forum includes specialists from the Departments of Geriatrics and Pallliation at Bispebjerg and Frederiksberg Hospital, psychiatric departments, general practitioners and from the 12 municipalities (responsible for home care and nursing homes) in the area.

In 2016 the national quality registry for dementia was launched, based partly on a previous regional version from the Capital Region established in 2006. The registry, which includes data from approximately 40 memory clinics in Denmark, is monitored by a national steering committee. The Copenhagen Memory Clinic contributes to the registry and is also an active member of the Network of Danish Memory Clinics, coordinated by DDRC.

Copenhagen Memory Clinic in 2021:

1,729 new patients

16,839 physical or virtual visits:
5,795 patients are in a follow-up programme.

Bornholm Memory Clinic in 2021:
107 new patients

Research

Research resources

The DDRC research programs are focused on epidemiological, clinical and translational research in cognitive impairment and neurodegenerative disorders. The majority of our research is funded by grants and donations from public and private foundations. Here we describe our resources, our thematic areas of research, and the international consortia and networks with whom we collaborate, followed by a presentation of researchers in the "Who is who" section. For updates see www.ddrc.dk.

Our clinical research is based on important infrastructure which we have developed in order to have easy access to well structured clinical data, biosamples and national registries which may be linked and combined. Our laboratory facilities offer opportunities for cell and molecular translational research. In addition, our research could not be done without collaboration with expertise and access to infrastructure from our national and international collaborators.

Clinical Trial Unit and Trial Nation Denmark

2021 marked the first full calender-year of operations of the Clinical Trial Unit (CTU) following its inception in March of 2020. Industry-sponsored trials have run at the memory clinic for more than 25 year, but with the formation of the Clinical Trial Unit this area of research has been anchored in a dedicated unit.

At present, the Clinical Trial Unit is staffed by two consultant neurologists (one serving as the director), three study nurses, a research administrator and a lab technician. The unit is located adjacent to the memory clinic, and has examination rooms, an infusion room, fully equipped lab and a dedicated waiting area. In 2021 there was a steady intake of new trials in Alzheimer's disease and Huntington's disease with a trend for the coming year of an increase in new trials. In Alzheimer's disease, a total of two phase 3 trials and two open label extension studies were initiated, in addition to three ongoing trials. In Huntington's disease one phase 1 study was initiated and three additional studies were ongoing but terminated.

DDRC and its Clinical Trial Unit has a leading role in the Danish Network of Memory Clinics actively involved in clinical drug trials. The network is organized by Trial Nation Denmark, a public private partnership with participation from a number of stakeholders such as pharmaceutical companies. The dementia center in Trial Nation has five member clinics of which DDRC serves as the medical lead and coordinating center. The purpose is to improve the ability of the clinics to run trials, to attract more trials to Denmark and to assist pharmaceutical companies with easy access to centers which are able to participate in trials.

Patient cohorts

Patients with a wide range of diagnostic entities and cohorts of healthy controls and gene mutation carriers serve as the foundation of many DDRC research programs:

The memory clinic receives approximately 1.500-2.000 new referrals each year. With informed consent from participants, results from diagnostic investigations are stored in a research database, and they form an important basis for research with the aim of improving diagnostic evaluation, treatment and care for memory clinic patients.

Several large-scale multi center intervention studies (e.g. ADEX, BASIC and DAISY) have been coordinated by DDRC leading to large nationwide patient cohorts with follow-up data. Collaboration on dementia research in selected Danish memory clinics has been established in the ADEX consortium (coordinated by DDRC) – a multicenter Danish research network comprising eight different memory clinics from across the country. The international multi-center study PredictND which successfully terminated in 2018 acquired a cohort of 800 patients and continues in 2021 to produce research results by collaborating partners.

DDRC is a member of several international networks on familial dementia disorders, such as the European Huntington Disease Network (EHDN) and Frontotemporal Research in Jutland Association (FReJA) which provide platforms for professionals to facilitate collaboration throughout Europe. Such networks also have been instrumental in the recruitment of DDRC patients to pharmacological intervention studies.

The ERN-RND is a European Reference Network established by the EU to support patients and families affected by rare neurological diseases (RND) which requires much specialised knowledge, treatment and resources. In 2021 the DDRC was approved as a member of the network for rare neurodegenerative diseases.

Danish national registries

All Danish in- and out-patients who have had contact with a Danish hospital are registered in the Danish national health registries with basic information, such as diagnostic codes and procedures. Access to the nationwide health care registries with the possibility of linking to other national registries makes it possible to carry out large population-based studies. These unique national registries have served as the foundation for our studies in dementia including, quality of health care, validity of dementia diagnosis, pharmacoepidemiology, co-morbidity, andprevalence, incidence and mortality.

Danish Dementia BioBank and clinical cohort research data

The Danish Dementia BioBank (DDBB) contains samples from more than 8.500 patients referred to the Copenhagen Memory Clinic at Rigshospitalet and the Zealand University Hospital Memory Clinic in Roskilde, all of whom have given informed consent for their samples to be used for future research. Whole blood, buffy coat, EDTA plasma and serum are stored for all patients, as well as CSF from approximately 25 % of the patients. All samples are handled and stored according to international biobank recommendations. Furthermore, we collect clinical and paraclinical data to accompany the biofluids, and our database now holds more than 200.000 datapoints associated with the biological specimens.

The Danish Dementia BioBank provides support/infrastructure for a wide range of projects, and in 2021, data and samples contributed to new interpretation of routine diagnostic biomarkers for AD, investigated the potential of non-invasive saliva biomarkers, and participated in multidisciplinary projects in bipolar disease and multiple sclerosis.

Translational Neurogenetics Laboratory

DDRC has an in-house fully equipped laboratory to perform all aspects of cellular and molecular research. We have labs classified for working with genetically modified organisms (class I and class II conditions) in order to work with molecular cloning and viral vectors.

Furthermore, we have equipment to perform various standard molecular biological techniques e.g. PCR, quantitative PCR, Western blotting, flow cytometry and fluorescence microscopy.

We have set up standard routines for reprogramming fibroblasts into induced pluripotent stem cells and for gene editing using the CRISPR/Cas9 technique and differentiating stem cells into e.g. neurons, microglia, astrocytes and organoids.

Thematic areas of research



Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist
Kristian Steen Frederiksen, MD, PhD, senior neurologist, director for Clinical Trial Unit
Anja Hviid Simonsen, MScPharm, PhD, senior researcher

Early diagnosis: Biomarkers

Discovery and validation of early disease markers for AD and other neurodegenerative disorders are key DDRC research areas, which include new biofluid markers, brain imaging and neuropsychology. With an increasing number of investigations obtained in each subject evaluated for dementia, the diagnostic decision becomes more complex. Based on data obtained in the European multicenter study PredictND, we assessed the diagnostic accuracy obtained by a multidisciplinary consensus conference compared to the diagnostic accuracy of a single clinician. The consensus conference performed better on diagnostic accuracy of disease etiology and increased clinicians' confidence. This highlights the importance of a multidisciplinary diagnostic evaluation approach for dementia diagnostics, especially when evaluating patients in the early stages of dementia.

In line with this, choosing the right investigations for an effective and precise evaluation is crucial. Using data from the same collaboration, we compared the clinical impact of FDG-PET imaging and cerebrospinal fluid biomarkers on diagnosis, prognosis, and patient management in patients suspected of Alzheimer's disease. We showed that the two biomarkers had similar clinical impact on diagnosis, but cerebrospinal fluid biomarkers had a more significant value in corroborating the diagnosis of Alzheimer's disease compared to FDG-PET imaging in these types of patients. These results can aid the clinician in choosing the most effective evaluation program.

In a series of studies, we have evaluated saliva as a potential source of AD-related biomarkers. Being easily accessible and in close proximity to the brain, saliva could be an important biomarker source. However, neither an established marker of neurodegeneration (Neurofilament light) nor a new promising biomarker (Lactoferrin) have so far shown a potential for diagnostic biomarkers in saliva. We continue this field of research in a newly established international research network on saliva biomarkers.



Asmus Vogel, MSc, PhD, neuropsychologist, associate professor
Kasper Jørgensen, MSc, neuropsychologist, senior researcher
T. Rune Nielsen, MSc, PhD, neuropsychologist, senior researcher

Early diagnosis: Neuropsychology

In the neuropsychology group we continuously strive to develop and validate tests and scales to characterize cognitive deficits in the early phase of dementia and MCI. We investigate cognitive deficits in patients examined in highly specialized memory clinic functions, in general practice and from targeted groups as persons from ethnic minorities.

In 2021, the first results from the MYSELF study was published. This study aims to identify early clinical markers of Alzheimer's disease, and the results indicate, that newly developed tests tapping personal memories (autobiographical memory) may be impaired in very early Alzheimer's disease – even in the stages where standardized episodic memory tests show no decline. Further, so-called "cognitive stress tests" have been adapted in a Danish context and show promising validity in the diagnosis of MCI due to Alzheimer's disease.

Recently the BASIC case-finding tool was developed by DDRC and successfully validated in Danish memory clinics. In 2021, a nationwide study of the discriminative validity of BASIC in general practice was launched in collaboration with University of Copenhagen, Department of Public Health. BASIC-Q developed for identification of cognitive impairment in community settings, is currently being implemented in Copenhagen. By the end of 2021, ca. 500 employees were trained in the use of BASIC-Q.

Through several years, DDRC has had a strong focus on cross-cultural issues in dementia diagnostics and care, including the development and validation of cross-cultural cognitive tests. In 2021, DDRC played a leading role in founding and implementing the European Consortium on Cross-Cultural Neuropsychology (ECCroN) in collaboration with institutions several other European countries. The main objectives of ECCroN are to improve cross-cultural neuropsychological research and clinical practice in Europe and beyond.

The implementation and validation of these new cognitive measures have important implication for the identification of cognitive deficits in neurodegenerative diseases in both primary sector and in highly specialized memory clinic functions.




Jørgen E. Nielsen, MD, PhD,
professor, senior neurologist,
research director
Lena Elisabeth Hjermind, MD, PhD,
senior neurologist, senior researcher
Patrick Ejlerskov, MSc, PhD, postdoc
Peter Roos, MD, PhD, neurologist,
senior researcher

Inherited neurodegenerative disorders

Neurogenetic research focuses on clinical characteristics, ancillary investigations and basic research on gene function and therapy. Many neurodegenerative disorders, including Alzheimer's disease, frontotemporal dementia (FTD), Huntington's disease (HD) 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. Our 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. We are part of Enroll-HD, a clinical research platform and the world's largest observational study for Huntington's disease families and participates in several clinical trials investigating antisense oligonucleotide therapy in HD. In 2021 we published the first CSF study in HD which points towards a potential effect of treating early HD with immune therapy.



Gunhild Waldemar, MD, DMSc, professor, senior neurologist
Janet Janbek, MScPH, postdoc
Christina El-Ali Jensen-Dahm, MD, postdoc, neurologist

Epidemiology and public health in dementia

Using nationwide registry data, we have analyzed the quality of health care and use of medication in people with dementia, and time trends in incidence, prevalence and mortality in dementia. The impact of co-morbidity is currently under investigation. As an example, we have been able to demonstrate a significant negative impact of dementia on the risk of hospitalization with dementia.

In 2021 two PhD studies in dementia and mortality and on the consequences of infections in dementia, respectively, were completed. We have strengthened our focus on morbidity and health in dementia. Thus, one new post doc programs will continue to investigate the risks associated with infections and possible interventions. A new phd program, with the aim to investigate early symptoms and delay in diagnosis in early onset Alzheimer's disease was initiated.

The research is being carried out in collaboration with the National Centre for Register-based Research at Aarhus University. It is the intention that our research will help provide evidence for creating new guidelines and for DDRC teaching materials.

Laila Øksnebjerg, MSc, PhD, neuropsychologist, senior researcher
T. Rune Nielsen, MSc, PhD, neuropsychologist, senior researcher

Psychosocial interventions and assistive technology

At DDRC we have extensive experience in investigating complex psychosocial interventions for people with dementia and caregivers, including large-scale multicentre studies and implementation research. The most recent is the ReACT study, where we have examined how assistive technology can be designed to support self-management and rehabilitation of people with dementia. The study also explored methods for implementation and adoption of assistive technology.

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 minority ethnic groups in high-income countries, and low and middle-income populations. In the C-CLNT study, we focus on developing and validating a novel cross-linguistic naming test for culture and language sensitive cognitive assessment of language impairment in patients from minority ethnic groups.

International consortia and networks

In DDRC we participate in and contributes to different international consortias ans networks:

EUROPEAN ALZHEIMER'S DISEASE CONSORTIUM (EADC)

EADC is a network of more than 50 European academic centres of excellence working in the field of Alzheimer's disease and other dementias. It provides a forum for expanding scientific understanding and developing ways to prevent, delay, slow or ameliorate the primary and secondary symptoms of AD. The European Commission provided initial funding for EADC, which was established in 2001. DDRC, the only Danish EADC member, has contributed to or directed studies on assessment tools, health economics, biomarkers, cross-cultural aspects of dementia care, and position and guideline papers.

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.

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 enables 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 end of 2021, DDRC's Enroll HD cohort comprised more than 300 participants.

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.

BRAINSTEM – STEM CELL CENTER OF EXCELLENCE IN NEUROLOGY

BrainStem – Stem Cell Center of Excellence in Neurology is supported by Innovation Fund Denmark. The project is coordinated by University of Copenhagen, and its primary partners are 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 reprogramme skin cells from patients with AD and Parkinson's disease to diseased neurons to study the underlying molecular mechanisms in order to develop better diagnostics and to test new drugs.

ERN-RND – EUROPEAN REFERENCE NETWORK – RARE NEUROLOGICAL DISEASES

The ERN-RND is a European Reference Network established by the EU to support patients and families affected by rare neurological diseases (RND) which requires much specialised knowledge, treatment and resources. European Reference Networks (ERNs) are virtual networks connecting healthcare professionals around Europe with expertise in rare diseases which allows them to discuss a patient's diagnosis and care, with their consent, via an online IT platform called the Clinical Patient Management System (CPMS). ERN-RND unites 41 of Europe's leading expert centres in 21 Member States and includes highly active patient organisations. Centres are located in Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Hungary, Italy, Latvia, Lithuania, Luxembourg, Malta, Netherlands, Poland, Slovenia, Spain and the UK.

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, funded by the Nordic Council, comprises six academic memory clinics in the Nordic countries and Lithuania. 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 Zealand University Hospital Memory Clinic in Roskilde are the network's Danish partners.

EUROPEAN CONSORTIUM ON CROSS-CULTURAL NEUROPSYCHOLOGY (ECCRON)

ECCroN was founded in late 2019 and comprises neuropsychologists, neurologists and psychiatrists working with cross-cultural neuropsychological assessment in England, Scotland, France, Spain, Italy, the Netherlands, Norway, and Denmark. The overall objective is to improve cross-cultural neuropsychological research and clinical practice in Europe and beyond. Ongoing projects include development of clinical training resources for neuropsychologists, clinical guidelines for interpreter-mediated cognitive assessment, and validation of cross-cultural cognitive tests for assessment of dementia.

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 ("Nationalt Videnscenter for Demens"), the Norwegian National Centre for Ageing and Health ("Aldring og Helse"), and the Swedish Dementia Centre ("Svenskt Demenscentrum") collaborate to share ideas and have exchanged programmes for the benefit of professional care staff, people with dementia, and family caregivers throughout Scandinavia.

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 in a recent Danish multicenter trial on physical exercise in AD.

Asmus Vogel

– Cognition And Neuropsychological Deficits

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

Jørgen E. Nielsen

– Inherited Neurodegenerative Disorders

Senior consultant neurologist, clinical professor and research director. Main research areas are genotype-phenotype correlations of Winherited neurodegenerative disorders, especially SCA, HD, spastic paraplegias and hereditary forms of Parkinson's disease, AD and FTDs.

Gunhild Waldemar

– Intervention Studies, Epidemiology and Global Health

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

SENIOR RESEARCHERS

Kristian Steen Frederiksen

– Physical Exercise and Clinical Application of Ad Biomarkers

MD, PhD, consultant neurologist. Serves as clinical trials director and national coordinator and PI for drug trials in AD. Main research areas include the effect of physical exercise, prodromal Lewy Body Dementia, and biomarkers in neurodegenerative dementias, with a special focus on brain imaging techniques.

Kasper Jørgensen

– Norming, Validation and Development Of Neuropsychological Tests and Case-Finding Instruments

MSc, neuropsychologist. Main research focus is norming, validation and development of neuropsychological tests and brief case-finding instruments for dementia and mild cognitive impairment.

Lena Elisabeth Hjermind

– Hereditary Movement Disorders and Neurodegenerative Disorders

MD, PhD, consultant neurologist. Serves as national coordinator and PI for drug trials in HD. Main research interest is genotype-phenotype correlations and molecular mechanisms in inherited movement disorders and neurodegenerative disorders.

Troels Tolstrup Nielsen

– Molecular Mechanisms In Neurodegeneration

MSc, PhD and DDRC centre manager. Research focus is on neurodegenerative disorders such as AD, FTD and ataxias. His research centres on finding molecular mechanisms in the inherited neurodegenerative disorder spinocerebellar ataxia type 2 (SCA2).

SENIOR RESEARCHERS

T. Rune Nielsen

– Cross-Cultural Assessment And Dementia In Ethnic Minorities

MSc, PhD, neuropsychologist. Main research focus is cross-cultural cognitive assessment and ethnic differences in dementia.

Anja Hviid Simonsen

– Biomarkers and Biobank

MSc Pharm, PhD 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.

Peter Roos

– Clinical And Molecular Aspects Of FTD Linked To FTD-3

MD, PhD, consultant neurologist. His research focuses on clinically affected and presymptomatic CHM P2B gene mutation carriers from the Danish FTD-3 family.

Laila Øksnebjerg

– Assistive Technology and Cognitive Rehabilitation

MSc, PhD, neuropsychologist. Her research mainly focuses on psychosocial interventions for people with dementia and their family caregivers, user-involvement, and assistive technology.

POSTDOCS

Patrick Ejlerskov

– Molecular Aspects In FTD3

Postdoctoral fellow, PhD, MSc. Research focus on molecular pathways causing or contributing to FTD3 with special emphasis on autophagy, neuroinflammation, and anti-viral immune pathways. In this work he uses induced pluripotent stem cells derived from patients with FTD3 to generate 2-dimentional neurons cultures, 3-dimentional brain organoids, as well as microglia cells.

Camilla Steen Jensen

– Mitochondrial Dysfuntion In Patients With AD

Postdoctoral fellow, MSc. Research focus on fluid biomarkers in AD. Research area is the mitochondria's dysregulation in the pathogenesis of AD, including molecular assays of the brains metabolism and functional assays related to mitochondrial stress in patient derived fibroblast cell lines.

Janet Janbek

– Role Of Infections In Dementia

Postdoctoral fellow, PhD, MScPH. Research focus on the role of infections in dementia (Project IDEM). The project will investigate infections in dementia care as well as the role of infections as risk factors. The project sets out to understand what is involved in infection detection and management in people with dementia.

Christina Jensen-Dahm

– Epidemiology And Register-Based Research

Postdoctoral fellow, PhD, MD. Major research focus is epidemiological studies based on registry data. Current research focuses on medication use (risk associated with analgesics and risk of dementia with use of medication), early onset Alzheimer's disease and influenza vaccination.

PHD STUDENTS

Andreas Appel
– Vaccination And Dementia
His project investigates whether dementia affects the uptake and effectiveness of influenza vaccines among older adults. The projects also explores if influenza vaccination late in life can reduce risk of dementia.

Frederikke Kragh Clemmensen
– Blood Based Biomarkers In AD
Her project investigates the efficacy of longitudinal measurements of novel blood based biomarkers to track the progression of Alzheimer's disease.

Mathias Holsey Gramkow
– Low-Cost And Digital Biomarkers In AD
His project focuses on the low-cost and digital biomarkers pupillometry and actigraphy and their diagnostic and prognostic utility in patients with Alzheimer's disease.

Rebecca Thea Kjærgaard Hendel
– Neuropsychological Changes In Huntington's Disease Gene-Mutation Carriers
Her project investigates neuropsychological changes in Huntington's disease gene-mutation carriers. Focus is on possible impairments in social cognition, apathy, and self-perception in the premanifest and early manifest stages of disease.

Anna Elise Bruus
– Memory Impairment In The Earliest Phases Of AD
Her project focuses on memory impairment in the earliest phases of AD. Possible changes in autobiographical memory and identity is studied in persons with Subjective Cognitive Decline, MCI and AD.

Line Damsgaard
– Fingerprints Of Young Onset AD
Her project focuses on potential early warning signs that may signal young onset Alzheimer's disease, in order to ensure timely diagnosis. It will explore patterns in health conditions and health care utilization preceding diagnosis.

Marie Nathalie Nickelsen Hellem
– Huntington's Disease
Her 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.

Emil Elbæk Henriksen
– The Cellular And Molecular Mechanisms Of SCA2
His project investigates how the genetic mutation in SCA2 affects the mitochondria and the intracellular calcium signaling in stem cell-derived neurons and brain organoids. The outcome of this project will help us understand the disease progression in the early stages.

PHD STUDENTS

Christian Sandøe Musaeus

– Epileptic Seizures In AD

His project assesses subclinical epileptiform activity with continuous EEG monitoring using novel ear EEG registration and correlating findings with MRI hippocampal blood flow assessments. Another area of interest is the use of EEG to assist in the diagnosis of AD and MCI.

Lærke Taudorf

– Dementia And Mortality: A Register-Based Study

Her project investigates time trends of prevalence, incidence and mortality due to dementia from 1996 to 2015, as well as survival after diagnosis. The project also reviews the registered causes of death in individuals with dementia.

Anne-Britt Oxbøll

– Validation Of BASIC-Q

Her project investigates the validity and diagnostic accuracy of a new brief case-finding tool, BASIC-Q, for detection of dementia and MCI in a general practice population. The project will also include a comparison with other cognitive tests.

Anders Toft

– CHMP2B-Mediated FTD: Markers, Models And Mechanisms

His project is a clinical follow-up to clarify the role of neuroinflammation in CHMP2B-mediated FTD3. It includes clinical data, inflammatory biomarkers, and generation of patient-specific neuronal and glial cell models to investigate neuroinflammation on a cellular level.

ASSOCIATED RESEARCHERS (CURRENTLY EMPLOYED ELSEWHERE)

Ane Nørgaard Christensen

– Use Of Psychotropic Drugs In Patients With Dementia

MD PhD. Her research 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 and a neuroblastoma knock-out model.

Helena S. Gleerup

– Biomarkers In Saliva

Her project investigates whether saliva can be a viable biofluid for the detection of biomarkers of neurodegenerative diseases, especially AD.

Kieu Phung

– Cross-Cultural Dementia Epidemiology

MD, PhD. Main research focus is dementia frequency, risk factors and risk modification across different cultures and ethnic groups.

Alix Feldman

– Hearing Loss And Listening Effort With MCI

MA, PhD student. Her project investigates hearing loss in patients with mild cognitive impairment and the association between listening effort and cognitive function using the measurement of pupil dilation. The project also explores avenues for integration between hearing and cognitive care systems.

Rachel Underlien Kristensen

– Register-Based Research On Polypharmacy In Dementia

Her project uses nationwide data to investigate the frequency and time trends of polypharmacy among people with and without dementia to examine potential disparities.

Johanne Købstrup Zakarias

– Epidemiology And Quality Of Dementia Diagnoses

Using nationwide registry data, her 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.

National information and education centre




Karen Tannebæk, occupational therapy specialist, educational director
Marie Ejlersen, MA, director of communications and press
Ann Nielsen, MScPH, PhD, project manager
Laila Øksnebjerg, MSc, PhD, neuropsychologist

National information and education centre for dementia

As a section of Danish Dementia Research Centres, The National Information and Education Centre on Dementia offers nationwide continued education activities, conferences and dissemination of information about dementia to professionals. The centre arranges courses, conferences, network meetings, and offers e-learning programmes, apps and printed publications. The centre is also involved in validating new methods and disseminating nationwide dementia initiatives. DDRC's website and social media are the centre's main platforms for dissemination and interacting with users. Via our courses and conferences, nationwide professional networks, website, social media, newsletters and other activities across professional groups, institutions, and sectors, we keep in touch with thousands of professionals in our target groups.

The year 2021 was special for different reasons. The completion of our new strategy 2025 has been important in the collaboration with both extern partners and internally in the Information and Education Centre on Dementia. Besides that the continued lockdown due to the COVID-19 pandemic has led to creativity in the development of new concepts within courses and dissemination of knowledge.

PROJECTS

The three projects mentioned below are all supported and initiated by the Danish Ministry of Health, in relation to the National Dementia Plan 2025.

Validation of BASIC in general practitioner clinics

BASIC is a new dementia case-finding instrument for use in primary care BASIC was already validated in Danish Memory Clinics and is now being validated in general practitioners clinics across the country in collaboration the University of Copenhagen and University of Southern Denmark. The validation study was delayed due to the COVID-19 pandemic. The

successful development of BASIC has already led to new collaborative studies with the municipality of Copenhagen, and Institute of Public Health, Faroe Islands.

Implementation of DemTool ("Værktøjskassen") in 15 Danish Municipalities. DemTool is a manualised set of methods and tools for psychosocial support, counselling and education for people with dementia and informal caregivers.

Implementation of support from volunteers to patients with dementia in Danish Hospitals Volunteers with specific training in dementia assists patients with dementia and their carers during hospitalization. The volunteers may provide emotional care, safety and wellbeing as an add-on to the professional care for the patients during hospitalization. This project involves 8 hospitals and was delayed in 2021 due to the COVID-19 pandemic. The project also serves to maintain the professional network for dementia friendly hospitals – open to all hospitals in Denmark.

COURSES AND CONFERENCES

National Information and Education Centre on Dementia offers a wide range of courses both nationwide and tailored courses and we have annual conferences, e.g. the Dementia Days conference and our research conference. Due to the COVID-19 pandemic some of the course and conference activities had to be cancelled or converted into online activities in 2021, but despite challenges, 2.247 professionals participated.

I 2021 we had a special focus on the development and implementation of Cognitive Stimulation Therapy (CST) in Denmark. DDRC has 4 approved qualified CST trainers. They are certified to train care professionals in the role as group leaders for CST. We have experienced a high demand for education as CST group leader.

In 2021 we have also focused on the development of new formats for our courses, based on practical learning and on stimulating transfer of knowledge to clinical practice. Blended learning is a concept which combines e-learning with physical courses for various target groups.

In 2021 we have entered a new fruitful collaboration with Danish Society for Patient Safety (PSImprove). Organized by the Danish Health Authority, this collaborative project aims to implement and teach new strategies for managing behavioural disturbances in people with dementia in a wide range of Danish municipalities. DDRC delivers part of the educational task.

Dementia Days (DemensDagene) is an annual conference. It has been held since 1999, and it is Denmark's largest conference on dementia. Every year we convene professionals who work with dementia in a wide range of settings, e.g. staff working in the social or health care services, general practitioners, stakeholder organisations, managing staff and researchers, for this national two-day conference.

In 2021 the Dementia Days was organized as a full online conference, with a TV production and live streaming from Tivoli Hotel & Congress Center in Copenhagen. With the overarching theme "health and quality of life" the program was conducted in 2 parallel tracks during 2 days. The number of registered participants was 579, and many more followed the programme from large screens at their working place. The conference started with an interesting debate "What did we learn from

the COVID-19 pandemic" with participation of leading persons from the National Health Authority, Local Government Denmark, the Danish Alzheimer Society, and DaneAge, as well as DDRC.

ABC DEMENTIA – FREE E-LEARNING COURSES

Offering free access to e-learning is one way of providing easyaccess nation-wide education on dementia to various target groups. The e-learning courses are user friendly, due to the practice-oriented nature of the topics and the varied educational approaches used in the programmes.

Our e-learning programmes are used by thousands of course participants, and in 2021 approximately 20.000 new users had registered. The e-learning programmes are used for introduction of new employees to the field of dementia and for continued education of professionals in municipalities and regions. DDRC has developed five separate e-learning programmes:

ABC Dementia Care addresses dementia from a broader perspective and targets a wide range of professional caregivers. Each module is designed to cover a specific topic, e.g. dementia diseases, behavioural symptoms or communication. On average, about 800 new users are registered each month.

ABC Dementia Challenging Behaviour targets care staff in municipalities and it adds to the e-learning course ABC Dementia-Care.

ABC Dementia for Physicians – Diagnostic Evaluation targets medical doctors under training for specialists in geriatrics, neurology, psychiatry or general medicine, and is also used by other professionals who work with dementia assessments.

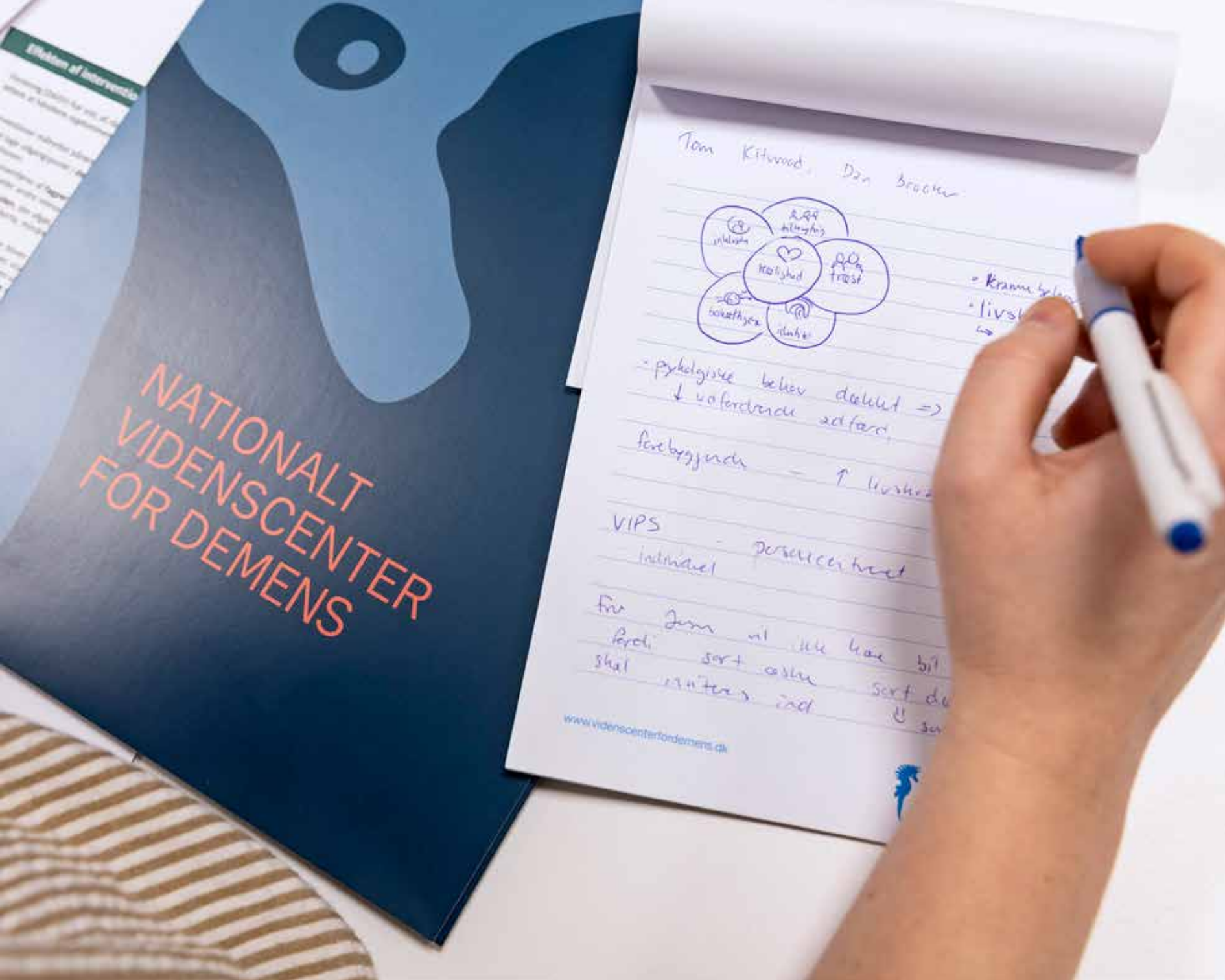
ABC Dementia for Hospitals targets care staff at hospitals who has basic knowledge about dementia.

ABC Dementia-Friendly Hospitals targets all hospital staff. It is a short basic programme that gives a general introduction to dementia, including the challenges that are often seen when a person with dementia is admitted to hospital.

DDRC'S NATIONAL PROFESSIONAL NETWORKS

To promote exchange of knowledge, education and quality programmes, The National Information and Education Centre on Dementia coordinates national professional networks for various groups of dementia professionals and experts.

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 on dementia. Members are multidisciplinary staff such as nurses, medical doctors and neuropsychologists, who mainly work in hospitals, at psychiatric, geriatric or neurological departments. They receive pa-


NATIONALT
VIDENSCENTER
FOR DEMENS
Tom Kitwood
Dan Brooker
www.videnscenterfordemens.dk

tients referred from local general practitioners for diagnostic evaluation of dementia. Network members meet once a year to maintain and further develop national cooperation.

Each of the 98 Danish municipalities has appointed a "dementia ambassador" who participates in *National network of municipality-based dementia ambassadors*. The network was formed to disseminate information about DDRC's activities, and to monitor local needs for education activities. The network also forms an important setting for exchanging knowledge and information among local dementia professionals. The network has one-two annual meetings, and in addition a special newsletter is published six times a year.

Danish Research Network on Psychosocial Methods in Dementia (DaneDem) was formed to promote psychosocial research in dementia in Denmark. The network was inspired by the pan-European network for dementia researchers, Interdem. The aim of the network is to give researchers opportunity to meet and exchange knowledge on various psychosocial methods and research topics, and to promote collaboration and more activity within this field of research. The network has two annual meetings.

Network for Dementia-friendly Hospitals serves as a platform for inspiration and exchange of information about dementia-friendly initiatives in Danish Hospitals. The network is an open-access national network for participants with various mainly clinical background, such as nurses, therapists and doctors who work at hospitals. It is required that participants are interested in dementia-friendly initiatives, but no personal experiences are required. Participants meet once a year to establish and maintain partnerships and corporation across hospitals. Establishment of the network follows the intervention-study of dementia-friendly hospitals from 2017-2019.

COMMUNICATION AND PRESS

The Communication and Press Team continuously supports all activities at The National Information and Education Centre on Dementia by communication skills, marketing, press contact, print and digital materials and development and maintenance of content and technical platform like website, apps and e-learning.

In 2021 we have developed and consolidated our website, where 330.000 visitors accessed our subsites 1.3 million times in total. Visitors on our website are most often professionals who work with diagnostics, treatment or care. But in addition to professionals, journalists, patients, and informal caregivers also use our website to obtain information on dementia. Major new themes that we focused on this year on the website was e.g statistics on dementia, ethnic minorities and Cognitive Stimulation Therapy.

We have also strengthened dissimination of knowledge with a new strategy of social media and newsletter. We have had an increasing number of followers on all our social media platforms. This has also engaged more users and generated more traffic on the DDRC website. We find that LinkedIn and Facebook are useful ways to connect with the public and to

disseminate knowledge about dementia and DDRC's activities. By the end of 2021 we had 2.388 followers on LinkedIn (almost 1000 followers more than the year before) and almost 6.000 followers on Facebook. For strategic reasons we did not focus on Twitter in 2021.

The DDRC newsletter was published with 10 issues in 2021. The newsletter presents news from national and international dementia research, provides information on DDRC's activities, e.g. courses and conferences and drives traffic to our website. By the end of 2021 the newsletter had 7.000 subscribers and an opening rate on 43 %. In 2021 we initiated a process with the purpose to target the newsletter to different groups of subscribers by sharing different content.

In 2021 we have strengthened our visibility, availability and proactive role in the debate in society by initiating a proactive press strategy, that ensures a focused and targeted dissemination of knowledge to relevant medias. We have developed and by now follow a strategy, which ensures optimal use of social media and thereby supports the overall communication strategy of DDRC. In 2021 we have also worked on a language policy to ensure, that the communication is correct, consistent and creates coherence across medias, departments and projects.

DDRC is present in the media on an almost daily basis with comments, interviews, and articles. In 2021 DDRC or spokespersons from DDRC were mentioned in about 610 articles. 64 % of these were online-articles (equivalent to 389 articles), 9 % in nationwide newspapers (equivalent to 54 articles) and 2 % in tv and radio.


Staff in 2021

MANAGEMENT GROUP (per 31/12/2021)

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

Head nurse
Copenhagen Memory Clinic
Hanne I. Sørensen, RN

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

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

Research director
Jørgen E. Nielsen,
MD, PhD, professor,
senior neurologist

Director of Clinical Trial Unit (CTU)
Kristian Steen Frederiksen,
MD, PhD, senior neurologist

Educational director
Karen Tannebæk,
occupational therapy
specialist

Director of communications and press
Marie Ejlersen, MA

Centre manager
Troels T. Nielsen,
PhD, MSc, senior
researcher

Head of administration
Tine Olsen

EMPLOYED AS OF 31/12 2021

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

ADMINISTRATION
Jette Gotlieb Iversen, course administrator
Brit Mouritsen, personal assistant
Lone Schlütter, economy assistant
Tine Olsen, head of administration
Jette Marie Rasmussen, research administrator

NATIONAL PROJECTS, COMMUNICATION AND EDUCATION
Tove-Marie Buk, RN, educational advisor
Casper Christian Christiansen, MA, e-learning and communication officer
Marie Ejlersen, MA, director of communications and press
Thea Emborg, MA, communication officer
Ulla Vidkjær Fejerskov, OT, educational advisor
Hanne Kærsmose Friberg, RN, educational advisor
Elsebeth Glipstrup, RN, educational advisor
Kasper Jørgensen, MSc, neuropsychologist
Jette Gerner Kallehauge, OT, educational advisor, project manager
Mathilde Klinte, projekt assistent
Ann Nielsen, MScPH, PhD, project manager
Elsebeth Refsgaard, RN, educational advisor, project manager
Rebekka Falsing Strangholt, journalist, press- and social media advisor
Karen Tannebæk, OT, educational director
Laila Øksnebjerg, MSc, PhD, neuropsychologist, project manager

RESEARCH
Andreas Appel, MScPH, PhD student
Anna E. Bruus, MSc., neuropsychologist, PhD student
Frederikke Kragh Clemmensen, MD, PhD student, research assistent
Line Damsgaard, MD, PhD student, research assistent
Patrick Ejlerskov, MSc, PhD, post.doc.
Helena Fornitz, stud.med.
Kristian Steen Frederiksen, MD, PhD, senior neurologist, vsenior researcher, CTU director
Mathias Holsey Gramkow, MD, PhD student, research assistent
Steen Gregers Hasselbalch, MD, DMSc, professor, senior neurologist
Rebecca Hendel, MSc, neuropsychologist, PhD student
Emil Elbæk Henriksen, MSc, PhD student
Lena Elisabeth Hjermind, MD, PhD, senior neurologist, senior researcher
Janet Janbek, MScPH, PhD student
Camilla Steen Jensen, MSc, PhD, post.doc.
Clara Mellergaard Jensen, student research fellow
Kasper Jørgensen, MSc, neuropsychologist, senior researcher
Adele Gabriele Marthaler, PhD, post.doc.
Christian Sandøe Musaeus, MD, PhD student
Jørgen Erik Nielsen, MD, PhD, professor, senior neurologist
T. Rune Nielsen, MSc, PhD, neuropsychologist, post.doc.
Troels Tolstrup Nielsen, MSc, PhD, centre manager
Anne-Britt Oxbøll, RN, PhD student
Peter Roos, MD, PhD, neurologist, senior researcher
Anja Hviid Simonsen, MSc Pharm, PhD, senior researcher
Camilla Steen-Jensen, MSc, PhD, post.doc.
Anders Toft, MD, PhD student
Asmus Vogel, MSc, PhD, neuropsychologist, associate professor
Laila Øksnebjerg, MSc, PhD, neuropsychologist, senior researcher

COPENHAGEN MEMORY CLINIC
MEDICAL DOCTORS
Birgitte Bo Andersen, MD, DMSc, senior neurologist, clinical director
Eva Bjerregaard, MD, specialist in family medicine
Kristian Steen Frederiksen, MD, PhD, senior neurologist
Hanne Vibe Hansen, MD, senior psychiatrist
Steen Gregers Hasselbalch, MD, DMSc, professor, senior neurologist
Lena Elisabeth Hjermind, MD, PhD, senior neurologist
Christina El-Ali Jensen-Dahm, MD, PhD, neurologist
Suzanne Lindquist, MD, PhD, associate professor, clinical geneticist
Oskar McWilliam, MD
Jørgen Erik Nielsen, MD, PhD, professor, senior neurologist
Nelsan Pourhadi, MD
Peter Roos, MD, PhD, neurologist
Christina Rørvig-Løppenthien, MD, senior neurologist
Sarah Taudorf, MD, PhD, senior neurologist
Tua Vinther-Jensen, MD, PhD, neurologist
Fia Vosborg, MD

NURSES
Nicole Cordes, RN
Lea Virenfeldt Damgaard, RN
Birgit Grøn, RN
Christina Vangsted Hansen, RN, research nurse
Ane Lund Hjortshøj, RN, research nurse
Lene Iben Hvidkjær, RN
Oda Jakobsen, RN, research nurse
Mette Janerka, RN
Rikke Charite Monberg Jarløv, RN
Hanne Rygaard Jensen, RN
Annette Lauridsen, RN
Mette Nyboe, RN
Hanne Raaschou, RN
Charlotte Skærbæk, RN
Hanne Inge Sørensen, RN, head nurse
Naomi Wakabayashi, RN
Sara Wendel Winther, RN

CLINICAL NEUROPSYCHOLOGISTS
Nadia Falcon Bærnthsen, MSc
Bernadette Unmack Grollenberg, MSc
Anne- Mette Guldberg, MSc, specialist
Jette Stokholm, MSc, specialist
Johanne Asperud Thomsen, MSc
Asmus Vogel, MSc, PhD, associate professor

MEDICAL SECRETARIES
Benthe Friedman
Dorte Hansen
Susanne Lindstrøm
Vicki Fielitz Østergaard Pedersen
Christine K. Rost

SOCIAL COUNSELLOR
Karen M. Sloth
Mehrdad Ahooei

MEDICAL LABORATORY TECHNOLOGISTS
Line Vedel Jespersen
Masumeh Chavoshi

RECEPTIONISTS
Anne-Mette Pedersen
Joan Rysgaard
Bodil Kryger

EXTERNAL MEDICAL CONSULTANTS
Hanne Elkjær Andersen, MD, geriatrician
Michael von Buchwald, MD, psychiatrist
Hanne Pedersen, MD, geriatrician

BORNHOLM MEMORY CLINIC
Diana Utech Kaiser, MD, senior geriatrician, medical director
Maja-Lis Kofoed Petersen, RN
Charlotte Weinrich, medical secretary

STUDENTS
Alma Hjermind
Emilie Holt
Mathilde Bager
Nadia Drinkall

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.

Kristian Steen Frederiksen, co-chair, EAN Scientific Panel on Dementia and Cognitive Disorders, member EAN Scientific Panel on Higher Cortical Functions; appointed member EAN Guideline Production Group; board member, Alzheimer Research Committee under the Danish Alzheimer Association; National coordinator and Principal investigator on a number of phase 3 trials in 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; member, Steering Group, Danish Dementia Clinical Quality Program, member, Scientific Panel on Dementia and Cognitive Disorders, EAN.

Lena Hjermind, PI of the global observational study on HD, Enroll-HD; adviser in the European Huntington's Disease Network (EHDN); member of two EHDN working groups "Genetic testing and counselling" and "Symptomatic treatment and research"; board member, European Dystonia Network; appointed member "Tvangsbehandlingsnævnet", the Danish Patient Safety Authority; appointed member, working group for clinical application of WGS, and national network for neurogenetics, Danish National Genome Center; board member, European Reference Network – Rare Neurological Diseases.

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

Jørgen E. Nielsen, Danish national coordinator and sub investigator of the global observational study on HD, Enroll-HD; board member, international SPATAX network on cerebellar ataxias and spastic paraplegias; advisor, European Huntington's Disease Network (EHDN); appointed member, European Academy of Neurology, scientific panel in neurogenetics; appointed member, working group for clinical application of WGS, and national network for neurogenetics, Danish National Genome Center; board member, European Reference Network – Rare Neurological Diseases.

T. Rune Nielsen, co-founder and member, Nordic Research Network on Dementia and Ethnicity coordinated by the Nordic Welfare Centre; co-founder and member, European Consortium on Cross-Cultural Neuropsycholo-

gy; appointed member, Alzheimer Europe expert group on the development of intercultural care and support for people with dementia from minority ethnic groups; appointed member, International Neuropsychological Society special interest group on Culturally Appropriate Neuropsychological Assessment.

Signe Pertou Ringkøbing, chair, 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 care pathway programme and education 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, reference group Knowledge Center on dignified elderly care; member, follow-up group on national dementia action plan, Danish Health Authority; member follow-up group on Action plan to prevent and deal with extroverted behavior in elderly care; Danish Health Authority.

Asmus Vogel, section editor, Scandinavian Journal of Psychology; member, European research network Brain Involvement in Dystrophinopathies.

Gunhild Waldemar, president Biomedical Alliance in Europe; member, Executive Committee of the European Alzheimer's Disease Consortium; member, Medical and Scientific Advisory Panel of Alzheimer's Disease International; member, Expert Advisory Panel, Alzheimer Europe; Editorial Board member, European Journal of Neurology, member, Board of Trustees and chair, Grants and Prize Committee 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; medical lead, Trial Nation Denmark Dementia Centre; chairman, KFJ clinical research prize committee, University of Copenhagen, member, Institutional Research Council, Rigshospitalet.

Laila Øksnebjerg, member of InterDem a pan-European network on research and dissemination of psychosocial interventions in dementia and member of Interdem taskforces: Positive Health, Assistive Technology; founder of DaneDem, Danish research network on psychosocial methods in dementia; member of the Research Prize Committee at Danish Psychological Association.

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PhD thesis
Le Gjerum

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CONTRIBUTIONS TO MULTICENTRE STUDIES

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UNIVERSITY OF COPENHAGEN
FACULTY OF HEALTH AND MEDICAL SCIENCES

Epidemiology of Infections in Dementia

Nationwide registry-based studies on hospitalizations and adverse outcomes in Denmark

PhD thesis – Jane

Finance and acknowledgements

Finance

The DDRC's total annual budget for 2021 was approximately DKK 57.9 m, distributed almost evenly between internal funding (DKK 29.5 m for memory clinic services) and external grants (DKK 28.4 m for research, contracts and educational activities). Animportant part of our external funding is the grant to National Information and Education Centre for Dementia from the Danish Ministry of Health which was made permanent in 2017.

EXTERNAL FUNDING FOR RESEARCH, QUALITY PROJECTS AND EDUCATION ACTIVITIES 2021 (DKK M)	
New grants received*	**7.2**
New grants accumulated 2007-2021*	**234.5**
External grants spent on specific programmes and projects • National Information and Education Centre for Dementia from the Danish Ministry of Health, including projects • Other external grants for research* • Grant to Danish Memory Clinics**	**23.1** 13.4 7.0 2.7
Conferences, educational courses and products	**1.6**
Research contracts	**3.7**

* excluding the annual main grant from the Danish Ministry of Health
** grant from the Danish Ministry of Health for the development of multidisciplinary memory clinics according to the new recommendations from the Danish Health Authority. A National Dementia Plan initiative

STAFF 2021	
No. of employees/full-time equivalents	**96/76**

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(Støttefonden) og
Fonden til Lægevidenskabens Fremme)

Augustinus Fonden

Axel Juul Muusfeldt Foundation

The Danish Order of Freemasons

Danish Medical Association
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Ellen Mørchs Fond

European Academy of Neurology

European Union

Familien Hede Nielsens Fond

Fonden for Neurologisk Forskning

Frimodt-Heineke Fonden

Gangstedfonden

H. Lundbeck

Huntington's National Association

Innovation Fund Denmark

Jascha Foundation

Kronprins Frederik og
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Lundbeck Foundation

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Rigshospitalet Scientific Committee

Trial Nation Denmark

Toyota Foundation

UNEEG medical

VELUX FOUNDATION

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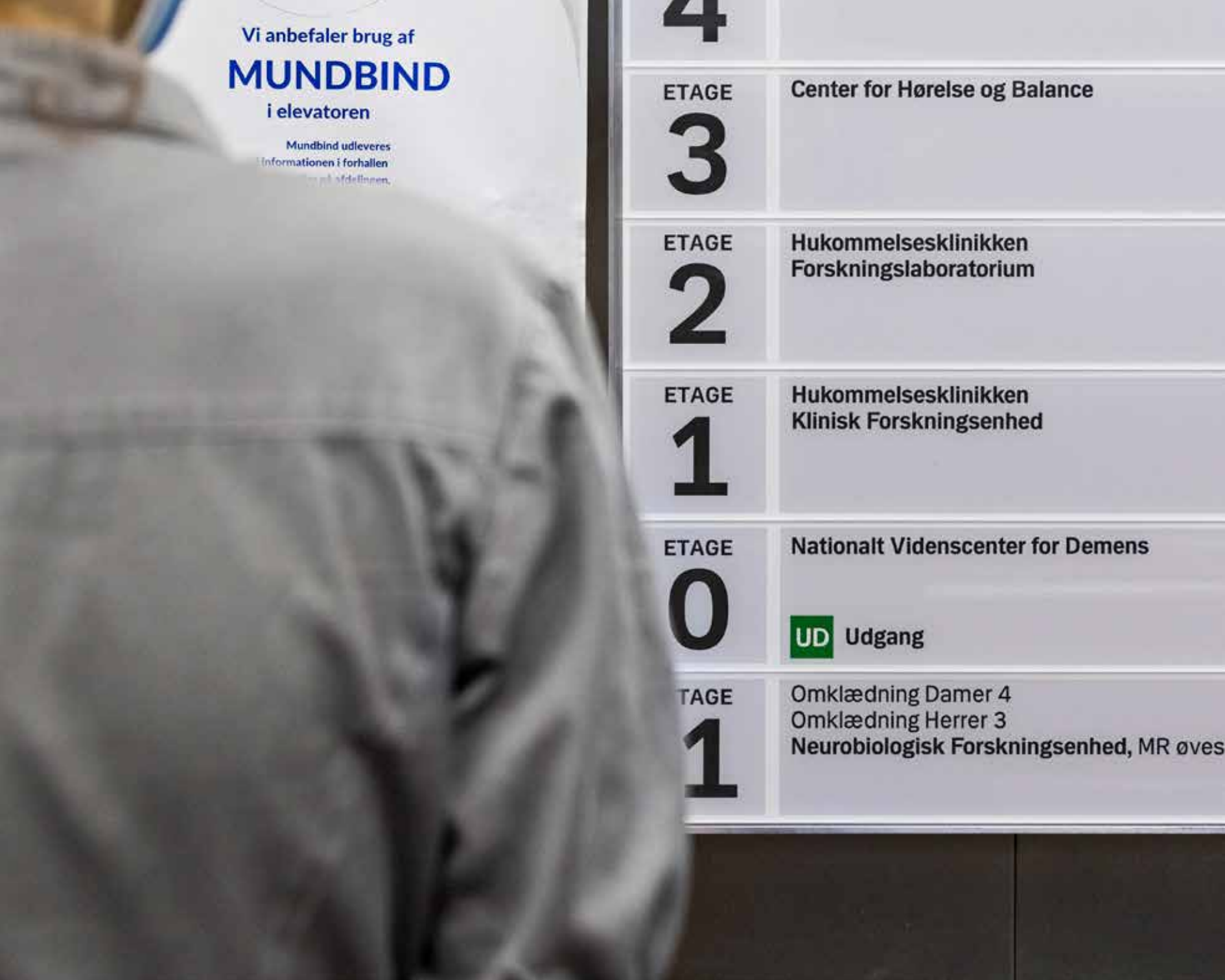
Vi anbefaler brug af
MUNDBIND
i elevatoren
Mundbind udleveres
Informationen i forhallen
4
ETAGE
3
Center for Hørelse og Balance
ETAGE
2
Hukommelsesklinikken
Forskningslaboratorium
ETAGE
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Hukommelsesklinikken
Klinisk Forskningsenhed
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Nationalt Videnscenter for Demens
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Udgang
TAGE
1
Omklædning Damer 4
Omklædning Herrer 3
Neurobiologisk Forskningsenhed, MR øves

DANISH DEMENTIA
RESEARCH CENTRE