

DANISH DEMENTIA RESEARCH CENTRE

ANNUAL REPORT 2023

Copenhagen Memory Clinic and
National Information & Education Centre for Dementia



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Preface

It is a pleasure to present the 2023 annual report for the Danish Dementia Research Centre (DDRC) with an overview of the activities in the memory clinic as well as our research and national educational programs.

In 2023 the Copenhagen Memory Clinic received again almost 2000 new patients – while reducing the waiting time to first visit considerably. We are in continuous contact with several thousand professional carers and specialists in the field of dementia across Denmark via our website, our (free of charge) e-learning portal, our newsletter and social media. Our website alone had 1,6 mio. visits in 2023. We were also visible in public media on a daily basis with more than 800 hits in 2023. The annual two-day conference Dementia Days (DemensDagene) and our courses and network meetings continue to attract many participants from across the country, in 2023 amounting to a total of 2651 participants.

In 2023 we completed three projects commissioned and funded by the Danish Ministry of Health: 1) Validation and implementation of a new tool for timely identification of dementia in primary care (BASIC and BASIC-Q), 2) Implementation and evaluation of DemTool (“Værktøjskassen”), a harmonized set of tools for improving psychosocial support, counselling and education for people with dementia (and their caregivers), targeted to professional carers. 3) Implementing support from volunteers for patients with dementia in Danish hospitals.

Towards the end of 2023 we were funded to initiate three new programs on 1) new models for diagnostic evaluation of dementia, 2) reducing the use of antipsychotics in people with dementia, and 3) upgrading our free-of charge ABC Dementia e-learning with new sessions.

We welcome proposals for new collaborative research programs, based on our patient cohorts, data and biobank, which are described in this report together with our thematic areas of research. In 2023 we published a total of 49 peer-reviewed scientific papers in international journals.

Our achievements in patient care, research and education would not be possible without the support and inspiration from people with dementia and family caregivers in the memory clinic and our user involvement group, and from collaborators to whom we are very grateful. We would also like to thank the Danish Ministry of Health and public and private foundations (listed in “acknowledgements”) for financial support to our activities.



Gunhild Waldemar, MD, DMSc, professor,
Chair, DDRC

About the Danish Dementia Research Centre

ORGANISATION

Located at Copenhagen University Hospital – Rigshospitalet and based in its Department of Neurology, the Danish Dementia Research Centre (DDRC) comprises the following sections: Copenhagen Memory Clinic (with a Clinical Trial Unit), the research centre, the National Information and Education Centre for Dementia, and an administrative secretariat.

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 centre 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 the 98 Danish 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 for Dementia 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, The Ministry of the Elderly, Danish Regions, Local Government Denmark (KL), 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, Local Government Denmark (KL), 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.

An important backbone of DDRC, our national networks represent professional specialists, researchers and care staff and contribute with input from municipalities, regions, universities and other educational institutions to our strategy and activities.

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 organizational decisions.

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 caregivers.

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 2023



Dementia Days 2023

Organized since 1999, our annual two-day conference Dementia Days (DemensDagene) is the largest conference on dementia – and one of the largest on health care – in Denmark. In 2023 the Dementia Days took place in Tivoli Congress Center in Copenhagen with more than 1000 participants. With the overarching theme “Quality and Documentation”, the program was conducted in plenary sessions and three parallel tracks during two days.



New clinical research associate professor

Kristian Steen Frederiksen was appointed clinical research associate professor at the Department of Clinical Medicine, Faculty of Health and Medical Sciences, University of Copenhagen.

He will contribute as a member of the faculty to the educational activities at the Department of Neurology and at the University of Copenhagen while further developing his own research group within Lewy body dementia and Alzheimer's disease.



Presidency Biomedical Alliance in Europe

In December 2021, the chair of the Danish Dementia Research Centre, professor Gunhild Waldemar was appointed President of the Biomedical Alliance in Europe for 2022 and 2023. BioMed Alliance is a unique initiative of 36 leading European medical societies that together include more than 400,000 researchers and health professionals.

The Alliance aims to speak as a common voice of all its members in seeking to:

- facilitate and improve biomedical research in Europe
- develop a framework for better training and mobility of researchers and healthcare professionals in Europe
- represent its members being medical associations in common policy and strategic matters
- improve public understanding of medical science in Europe



Opening of the Dementia-friendly Garden and the exhibition area

On August 21, 2023 her Royal Highness Princess Benedikte inaugurated the new garden and exhibition area in DDRC.

Remaining as independent as possible in the home-environment is important for persons with dementia and their caregivers. Small changes in everyday life can have a significant impact on safety, independence and the feeling of well-being. Our new exhibition area – including a dementia-friendly garden, kitchen and living area and small assistive technology – serves as inspiration for professionals as well as patients and caregivers on how they can organize their home environment in order to ensure independent living as long as possible.

For those who may not have the possibility to visit our centre a new digital platform provides similar information (in Danish only): www.hverdagslivetmeddemens.dk

HRH Princess Benedikte was accompanied by Jannick Brennum, vice-director at Rigshospitalet, Lars Gaardhøj, chairman of the Regional Council for the Capital Region and Gunhild Waldemar, chair of DDRC when cutting the ribbon.

The opening session was also attended by Mads Lebech, chair of A. P. Møller Fonden, Max Meyer, chair of TrygFondens regional committee Copenhagen, Kurt Espersen, vice-president, Region of Southern Denmark and chairman of the DDRC steering committee.

The dementia-friendly garden and exhibition area were supported with grants from the A. P. Møller Fonden, Dronning Margrethe og Prins Henriks Fond, Kronprins Frederik og Kronprinsesse Marys Fond and TrygFonden.



New grants and awards in 2023

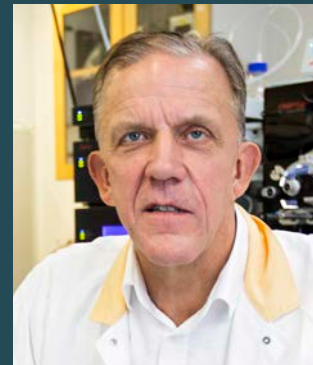


The Danish Alzheimer's Association Research Fund

At the annual grants and award ceremony organized by the Danish Alzheimer Association on September 26, 2023, three researchers from DDRC received financial support from the Alzheimer Research Foundation to their research: PhD student Oskar McWilliam, senior researcher Anja H. Simonsen and PhD student Mathias H. Gramkow.

KFJ Award to Kaj Blennow

Copenhagen University Hospital - Rigshospitalet's International KFJ Award is named after Kirsten and Freddy Johansen. Their foundation donates the DKK 1.75 mio award annually to an internationally high-ranking researcher. In 2023, the award went to Swedish Professor Kaj Blennow, who is recognized as a global leader in the development of biomarkers for the diagnosis of Alzheimer's disease and a close collaborator of the research team at DDRC. The award was presented by Kirsten and Freddy Johansen at a ceremony on November 9, 2023.







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 and private practice neurologists and psychiatrists and from other hospitals in the Capital Region of Denmark. Patients may also be referred from other memory clinics for second opinion evaluations and from other regions in Denmark for our highly specialized functions. A satellite memory clinic is located on the island of Bornholm.

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

In 2023 a record high number of patients underwent diagnostic evaluation in the memory clinic who received again very positive evaluations from patients and caregivers in the national patient survey. The majority of patients undergo a standard minimum 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 in subsamples of referred patients, 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 (MDT) prepares a standardised consensus report containing a classification of the cognitive profile, the primary underlying cause, concomitant conditions and a treatment plan. Following the weekly MDT meetings, the patient and caregivers are invited to meet with the specialist physician and specialist nurse,

where information and counselling is given on diagnosis and on the plan for treatment and care. A short summary is subsequently sent to the patient's general practitioner and community nurse, where relevant.

All patients with mild cognitive impairment (MCI), and selected groups of patients with dementia or specific neurodegenerative disorders from the local catchment area 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. Most patients are accompanied by their family caregivers when visiting the clinic, and we offer counselling and courses for the caregivers as an integral part of the follow-up programme. For fragile patients with severe dementia home, visits are offered.

BORNHOLM MEMORY CLINIC

Led by the Copenhagen Memory Clinic, the outpatient clinic is located at the internal medicine department in Bornholm's Hospital. A team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic, together with a local 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 sees 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.

COLLABORATION WITH THE BISPEBJERG-FREDERIKSBERG MEMORY CLINIC

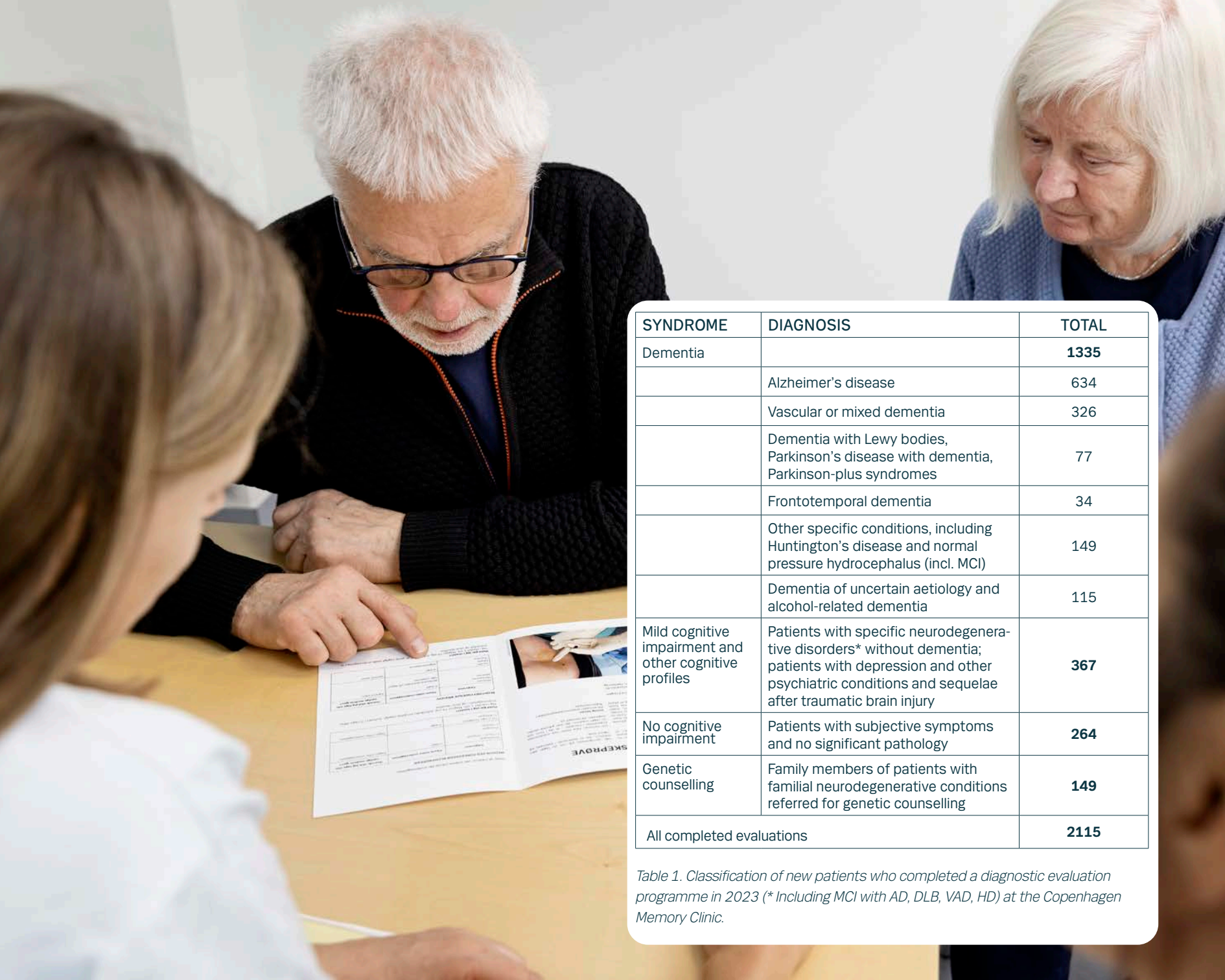
The Copenhagen Memory Clinic and the memory clinic based in the geriatric department in Bispebjerg-Frederiksberg hospital (BFH) share responsibility for referrals from the central Copenhagen district ("BYEN"). A specialist in neurology from the Copenhagen Memory Clinic

takes part in the weekly MDT conference at BFH, reviewing all new patients.

SPECIALISED MEDICAL SERVICES

Patients with rare, complex or familial disorders may be referred from all parts of Denmark (mainly Eastern Denmark) for treatment and follow-up. 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 and 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



SYNDROME	DIAGNOSIS	TOTAL
Dementia		1335
	Alzheimer's disease	634
	Vascular or mixed dementia	326
	Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinson-plus syndromes	77
	Frontotemporal dementia	34
	Other specific conditions, including Huntington's disease and normal pressure hydrocephalus (incl. MCI)	149
	Dementia of uncertain aetiology and alcohol-related dementia	115
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	367
No cognitive impairment	Patients with subjective symptoms and no significant pathology	264
Genetic counselling	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	149
All completed evaluations		2115

Table 1. Classification of new patients who completed a diagnostic evaluation programme in 2023 (* Including MCI with AD, DLB, VAD, HD) at the Copenhagen Memory Clinic.

- 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)
- Diagnostic 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 Neuro-radiology; and the Department of Clinical

Copenhagen Memory Clinic in 2023:

- 1,945 new patients
- 15,036 physical or virtual visits

Physiology and Nuclear Medicine (the PET and Cyclotron Unit, Rigshospitalet).

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, also common to various other diseases. Most patients are referred for possible NPH because their cranial CT or MRI demonstrated a dilated ventricular system.

In 2023, 278 patients were referred and met the criteria for a clinical evaluation of NPH (total number of referred patients was 430), 91 of whom had a lumbar perfusion test and/or Tap Test following the initial examination. All patients are reviewed at a weekly MDT conference with the NPH team at the Department of Neurosurgery, Rigshospitalet in order to identify patients suited for neurosurgical in-

tervention. 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 2023 there were 149 at-risk family members referred. The clinic also offers post-genetic test counselling when needed.

REGIONAL AND NATIONAL COLLABORATION

In 2011 the Capital Region established a guideline ("forløbsprogram") for coordinated patient care pathways between hospital-based memory clinics, mental health

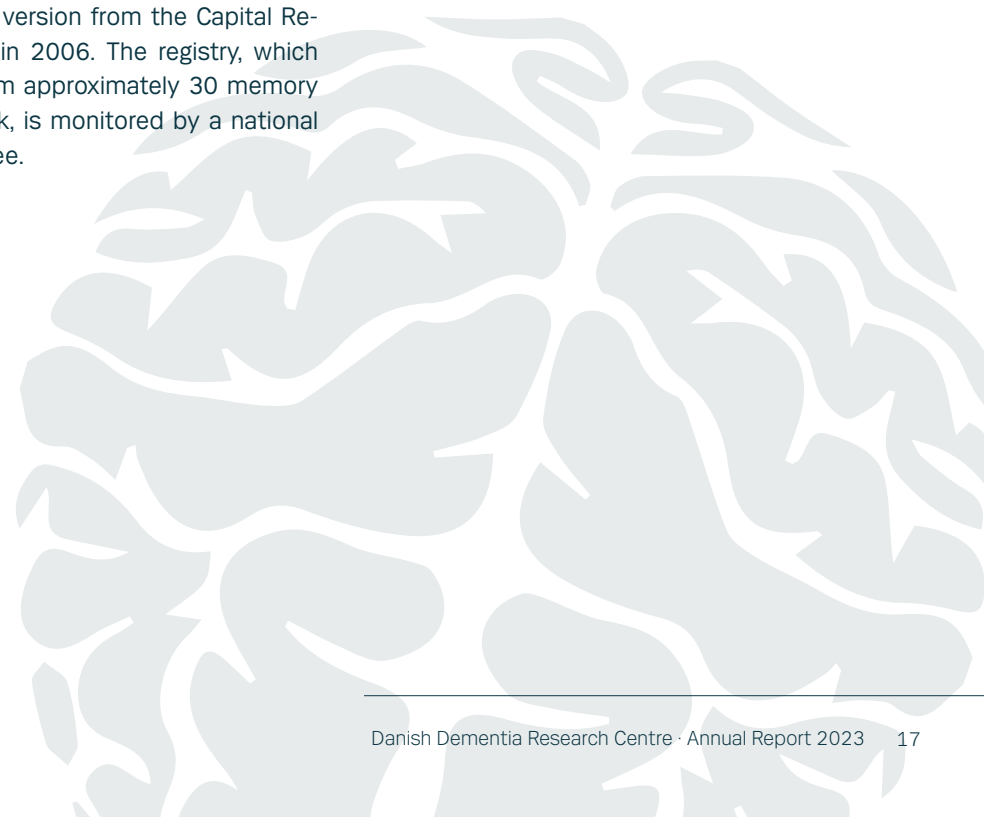
centres, other hospital departments, general practitioners and primary health care in its 29 municipalities. An update of the guideline was completed in 2020.

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 Copenhagen Memory Clinic and the memory clinic at the department of Geriatrics at Bis-

pebjerg-Frederiksberg Hospital, and psychiatric departments in the two districts, as well as general practitioners and dementia care coordinators from the 12 municipalities (responsible for home care and nursing homes) in the area.

In 2016 the national quality registry for dementia (DanDem) was launched, based partly on a previous regional version from the Capital Region established in 2006. The registry, which includes data from approximately 30 memory clinics in Denmark, is monitored by a national steering committee.

The Copenhagen Memory Clinic contributes with data to the registry and is also an active member of the Network of Danish Memory Clinics, coordinated by DDRC.





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 clinical research is based on important infrastructure which we have developed in order to have easy access to well structured clin-

ical data, biosamples and national registries which may be linked and combined. Our laboratory facilities offer opportunities for cell and molecular translational research. We offer access to our resources to external collaborators. 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

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, a fully equipped lab and a dedicated waiting area. In 2023, two phase 3 trials were initiated and one open label extension study and 2 phase 3 trials of Alzheimer's disease were ongoing. In Huntingtons disease, one phase 1 trial was initiated, 1 ongoing and one phase 2 trial ongoing.

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 centres which are able to participate in trials.

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.

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 2.000 new referrals each year. With informed consent from participants who are willing to participate, 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 multicentre Danish research network comprising eight different memory clinics from across the country. The international multi-centre study PredictND which successfully terminated in 2018 acquired a cohort of 800 patients and continues in 2023 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), the Genetic Frontotemporal dementia Initiative (GENFI) and Frontotemporal Research in Jutland Association (FReJA) which provide platforms for professionals to facilitate collaboration through-out Europe. Such networks have also been instrumental in the recruitment of DDRC patients to pharmacological intervention studies.

Danish Dementia BioBank and clinical cohort research data

The Danish Dementia BioBank (DDBB) contains samples from more than 13,000 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 and infrastructure for a wide range of projects, and in 2022, data and samples contributed to the validation and implementation of improved routine diagnostic biomarkers for AD, investigated the potential of non-invasive saliva biomarkers, and participated in multidisciplinary projects in bipolar disease and Huntington's disease as well as basic research projects elucidating the mechanisms behind cerebrospinal fluid formation.

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, such as the prescription registry and the quality re-

gistry for dementia (DanDem), 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 validity of dementia diagnosis, pharmacoepidemiology, comorbidity, quality of health care, and prevalence, incidence and mortality.



Thematic areas of research

Inspired by patients and informed by our professional experience our research aims to advance knowledge within epidemiology of dementia, neurogenetic disorders, early diagnosis and interventions. Here we present our thematic areas of research with highlights from 2023.



Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist
Kristian Steen Frederiksen, MD, clinical research associate
professor, 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 biofluid markers, brain imaging, and digital biomarkers.

Highlights in 2023

- Our group has started a longitudinal study of biofluid and digital markers in early Alzheimer's disease. The aim is to improve prognostication with the use of low-cost markers, such as activity monitoring, measurements of pupillary reflexes and markers of neurodegeneration in blood.
- In 2023, a collaboration between Departments of Pathology and Department of Otorhinolaryngology, Head & Neck Surgery and Audiology and DDRC was commenced in order to investigate early markers of Lewy Body dementia using cutting-edge new technology.
- We assessed the potential usefulness of the circulating levels of Neurofilament light for the differentiation between patients with or without a neurodegenerative disease in a large and deeply phenotyped consecutive cohort of patients. Neurofilament light chain in blood could detect patients with a neurodegenerative disease with 80% sensitivity and specificity.
- We assessed MRI features as prognostic markers of shunt response in a deeply phenotyped cohort originating from our idiopathic normal pressure hydrocephalus patients as part of our research collaboration with Departments of Neurosurgery and Neuroradiology.



Asmus Vogel, MSc, PhD, neuropsychologist, associate professor
Kasper Jørgensen, MSc, 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 with inherited dementia diseases.

Highlights in 2023

- A new PhD project of cognitive and behavioural manifestations of Huntington disease was initiated. The project includes substudies on emotion regulation, apathy, and memory functions in genemutation carriers.
- In collaboration with the Centre of Hearing and Balance at Rigshospitalet we were awarded DKK 2.48 million to perform a study on the possible association between cognitive dysfunction and hearing impairments in healthy older persons and in MCI patients.
- From the MYSELF study we have published papers describing the role of subjective cognitive impairment in early AD and Subjective Cognitive Decline.
- Further validation of two case-finding tools for cognitive impairment, BASIC and BASIC-Q, has begun in several Western European countries. BASIC-Q has been implemented in the City of Copenhagen as a case-finding tool aimed at older citizens.



Jørgen E. Nielsen, MD, PhD, professor, senior neurologist, research director
Patrick Ejlerskov, MSc, PhD, senior researcher, group leader

Inherited neurodegenerative disorders

The exact disease mechanisms of most neurodegenerative conditions are still unknown, and effective treatments are lacking. We have built up a broad range of resources that can provide a paradigm for translational research into neurodegeneration by elucidating common disease mechanisms in rare genetic disorders, with clinical and genetic overlaps and common pathologies with e.g. Alzheimer's disease and Parkinson's disease.

Highlights in 2023

- A new PhD programme was initiated on Huntington's disease focusing on apathy across time and regulation of emotions, conducted by psychologist Emilie Najbjerg Birkebæk Poulsen.
- Another PhD program, funded by Neuroscience Academy Denmark, was initiated on investigation of the impact of vesicular trafficking in neurodegenerative diseases with focus on extracellular vesicles and autophagy in frontotemporal dementia, conducted by MSc Cecilie Madsen.
- Furthermore, we are part of a new multidisciplinary PhD project by MD Cecilie Videbæk in a Danish Adrenoleukodystrophy study.
- In continuation of an ongoing PhD programme, we published a paper on an unbiased quantification of the CSF proteome in members of the Danish CHMP2B-FTD family indicating a disturbance in the classical complement pathway among presymptomatic carriers and an over-activation of the complement cascade in symptomatic carriers which will be new therapeutic avenues to explore in future studies.
- We were awarded a 2-year project grant in clinical and translational medicine from the Novo Nordisk Foundation for post doc Anders Toft's project "Familial frontotemporal dementia: Towards early immune markers and new therapeutic avenues" and further support was obtained from the Danish Parkinson Association to continue our studies on autophagy in viral-induced Parkinson's Disease.



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

Epidemiology and public health in dementia

The overarching aim of our studies is to investigate health-related risk factors for dementia, the impact of dementia on health and morbidity. The studies are based on health data from: national hospital records, the Danish quality registry for diagnostic evaluation of dementia (DanDem), data on health care utilization in primary and secondary care, and prescription data. The research is conducted in collaboration with National Centre for Register-based Research at Aarhus University, Department of Affective Disorders, Aarhus University Hospital Psychiatry, Edinburgh University in the U.K., and Johns Hopkins University in the U.S.

Highlights in 2023

- In one study, we showed that users of proton pump inhibitors had a higher risk of de-

mentia, and we noted differences depending on the age at dementia diagnosis.

- In another paper, we demonstrated that persons with young-onset Alzheimer's disease generally have a higher healthcare utilization than their age- and sex-matched controls in the years preceding Alzheimer's disease diagnosis.
- A third published study showed a higher risk of dementia in persons with hospital contacts due to infections, but little evidence was noted for autoimmune diseases, leading to novel hypothesis regarding the role of the immune system for dementia risk.
- Several abstracts have been presented at international conferences including the

AAIC. An abstract of an unpublished study was highlighted by the AAIC media team and resulted in attention from e.g., the CNN. The study showed that new opioid use is significantly associated with an increased risk of mortality in older patients with dementia, especially in the first 2 weeks after initiation.

- A new research year student Mihaela Ivošević joined our team in 2023 to work on a review paper that gathers evidence on current practices of decision-making processes involved in detecting infections for people with dementia.
- We also contributed to publications on risk factors for dementia from other Danish research groups.



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

Cross-cultural aspects of dementia

To improve diagnostic evaluation and care of people from minority ethnic groups with dementia, the centre has studied the assessment and care 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 in low and middle-income country populations.

Highlights in 2023

- A new PhD program to be conducted by MSc Daniel Kjærgaard was initiated with the aim to improve diagnostic accuracy of dementia in diverse patient populations by exploring the performance of blood biomarkers for Alzheimer's disease and cross-cultural cognitive screening tests in culturally diverse populations.
- In the TIMING study on improving timely diagnosis of dementia in vulnerable minority ethnic groups, a survey on assessment of dementia in patients from minority ethnic groups was completed in 2023. The survey was conducted among members of the European Alzheimer's Disease Consortium. Also, a cross-linguistic naming tests (Copenhagen Cross-Linguistic Naming Test) was developed, and a validation study was published.
- We published a study demonstrating that a widely used neuropsychological test of nonverbal abstraction is highly influenced by cultural and educational factors when applied to low-educated recent immigrants.
- We also contributed to publications on cultural neuropsychological test bias, cross-cultural neuropsychological test validation, and cultural aspects of frontotemporal dementia from international research groups and consortia.

International consortia and networks

In DDRC we participate in and contribute to different international consortia and networks:

EUROPEAN ALZHEIMER'S DISEASE CONSORTIUM (EADC)

EADC is a network of more than 60 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 coordinated 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 Program 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 2023, DDRC's Enroll HD cohort comprised more than 333 participants.

FRONTOTEMPORAL DEMENTIA RESEARCH IN JUTLAND ASSOCIATION (FReJA)

FReJA is an international multidisciplinary consortium established more than three decades ago to investigate a unique, large family with fa-

miliar frontotemporal dementia (CHMP2B-FTD) 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.

THE GENETIC FRONTOTEMPORAL DEMENTIA INITIATIVE (GENFI)

GENFI is a group of research centres across Europe and Canada with expertise in familial FTLD, and is co-ordinated by Professor Jonathan Rohrer at University College London. The aim of the study is to understand more about genetic FTLD, particularly in those who have mutations in the progranulin (GRN), microtubule-associated protein tau (MAPT) and chromosome 9 open reading frame 72 (C9orf72) genes. GENFI investigates both people who have developed symptoms and also people who have a risk of developing symptoms in the future because they carry an abnormal genetic mutation. By studying these individuals who are destined to develop the disease later in life we can understand the development from the very earliest changes. The key objectives of GENFI are therefore to develop markers which help identify the disease at its earliest stage as well as markers that allow the progression of the disease to be tracked.

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. 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 several European countries, and the United States. 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 and recommendations for interpreter-mediated neuropsychological assessment, and research on dementia epidemiology in minority ethnic groups 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 programs for the benefit of professional care staff, people with dementia, and family caregivers throughout Scandinavia.

DYSTONIA EUROPE

Dystonia Europe was formed in 1993 as European Dystonia Federation — the European umbrella organisation for national dystonia groups. From 2012, Dystonia Europe has become the platform at the European level for all dystonia stakeholders, to benefit patients and their families by promoting more interest in dystonia and by working together with medical and healthcare specialists as well as researchers.

EUROPEAN DLB

The DDRC has become members of the European DLB consortium, an international network of centres conducting research in Dementia with Lewy Bodies.

Who is who in research

Conducted by a multidisciplinary group of clinical and basic scientists, our research programs are led by group leaders (professors, associate professors and senior researchers). Here we present our researchers.

Only full time researchers and clinical staff members or group leaders with dedicated research time in 2023 are presented here.

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 including normal pressure hydrocephalus.



Jørgen E. Nielsen

– Inherited Neurodegenerative Disorders
Senior consultant neurologist, clinical professor and research director. Main research areas are genotype-phenotype correlations and molecular biology of inherited 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 epidemiology, public health, diagnostic markers, and interventions in dementia.



Kristian Steen Frederiksen

– Lewy Body Dementia and Biomarkers in Neurodegenerative Dementia Disorders
MD, PhD, consultant neurologist, clinical research associate professor. Serves as clinical trials director and principal Investigator for drug trials in AD. Main research areas include prodromal Lewy Body Dementia, biomarkers in neurodegenerative dementias.



T. Rune Nielsen

– Cross-Cultural Assessment and Dementia in Ethnic Minorities
Neuropsychologist and associate professor. Main research areas are cross-cultural neuropsychological assessment and dementia and care in minority ethnic groups. He has a central role in several national and international research collaborations on development and validation of cross-cultural tests.



Asmus Vogel

– Cognition and Neuropsychological Deficits
Neuropsychologist and associate professor in clinical neuropsychology. Major research focus is cognitive deficits in dementia diseases including on development and validation of cognitive tests applied in memory clinics.

SENIOR RESEARCHERS



Patrick Ejlerskov

– Neurodegenerative Diseases, Autophagy, and Innate Immune Pathways

Senior researcher, group leader, PhD, MSc. Research focus on cellular pathways with special emphasis on autophagy, neuro-inflammation, and anti-viral immune pathways, using induced pluripotent stem cells derived from patients with dementia to generate neurons, brain organoids, and microglia.



Lena Elisabeth Hjermind

– Hereditary Movement Disorders and Neurodegenerative Disorders

MD, PhD, consultant neurologist. Serves as national coordinator and PI for observational and intervention clinical trials mainly in hereditary neurodegenerative disorders. Main research interest is genotype-phenotype correlations and molecular mechanisms in neurodegenerative disorders.



Kasper Jørgensen

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

MSc, neuropsychologist. Main research areas include norming, validation and development of neuropsychological tests and brief case-finding instruments and epidemiological modelling of the potential for reduction of dementia risk.



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.



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.

POSTDOCS



Marie Bruun

– Disclosure of Biomarker Results

Postdoctoral fellow, PhD, MD. Based on the ERAPerMed supported study EDAP-AD, her research aims to develop an evidence-based model for disclosure of biomarker results in persons with subjective cognitive decline and mild cognitive impairment.



Rebecca Thea Kjærgaard Hendel

– The Link Project

Postdoctoral fellow, PhD, MSc. Her research project examines the association between impaired hearing and memory functions (The Link Project). As impaired hearing has been found to be a major risk factor for dementia, this project seeks to examine the association more thoroughly in a Danish cohort.



Janet Janbek

– Role of Infections in Dementia

Postdoctoral fellow, PhD, MScPH. Research on the epidemiology and public health aspects of dementia. Specific focus is 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.



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.



Tua Vinther-Jensen

– Neurogenetic Disease, Primary Clinical Research

Postdoctoral fellow, PhD, MD. Major research focus is phenotyping in neurogenetic disease. Current research focuses on ataxia and how currently patients are diagnosed and the clinical workup is done.

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.



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.



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.



Cecilie Madsen

– Cellular Secretion of Vesicles in Dementia

Her project aims to investigate how small vesicles secreted by brain cells are changed in FTD-3 and AD, using clinical samples and patient-derived brain cells. She will investigate if these vesicles can be responsible for disease progression and if infections have an impact on the cellular vesicles.



Oskar McWilliam

– Early Signs, Symptoms, and Biomarkers of Lewy Body Diseases

The overarching objective of this project is to identify early clinical warning signs and biomarkers in prodromal and manifest DLB with the novel RT-QulC technique.



Christian Sandøe Musaeus

– Epileptiform Discharges in AD

His project assesses subclinical epileptiform discharges 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.



Anne-Britt Oxbøll

– Validation of BASIC-Q

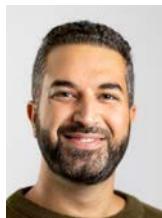
Her project investigates the validity and diagnostic accuracy of a new brief case-finding tool, BASIC-Q, for detection of cognitive impairment in a general practice population and to investigate the use of and attitudes towards BASIC-Q among community-based health care professionals.



Emilie Poulsen

– Behavioural Changes and Cognitive Deficits in Huntington's Disease

Her PhD project investigates some of the under-researched aspects of neuropsychological symptoms, including emotion regulation, apathy, and memory processes, in Huntington's disease gene-mutation carriers.



Nelsan Pourhadi

– Common Pharmacological Products and Risk of Dementia
Using the national Danish health registries, his project investigates the use of commonly prescribed pharmacological products and the risk of developing dementia disorders.



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.

PREGRADUATE RESEARCHERS

Mihaela Ivosevic

Her project aims to synthesize knowledge on the current practices for detecting infections in people with dementia and their determinants.

Laura Storm Næsberg

Her research focuses on the clinical impact of cerebrospinal fluid biomarker profiles in memory clinic patients.

Nikolai Sulkjær Sjølland

His project focuses on digital biomarkers for the assessment of symptoms in patients with dementia.

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.



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.



Linda Feng

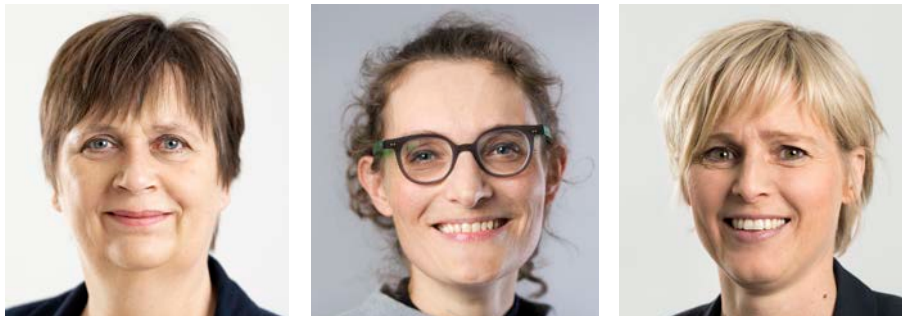
– Imaging Biomarkers in Lewy Body Dementia
Her project aims to validate the Cingulate Island Sign Scale for the diagnosis of Lewy Body Dementia.



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.





Karen Tannebæk, MPG, occupational therapy specialist,
educational director
Marie Ejlersen, MA, director of communications and press
Ann Nielsen, MScPH, PhD, program manager

National Information and Education Centre for Dementia

As a section of Danish Dementia Research Centre, The National Information and Education Centre for 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 programs, apps and printed publications. The centre is also responsible for developing and 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, newslet-

ters and other activities across professional groups, institutions, and sectors, we keep in touch with thousands of professionals in our target groups.

In the summer 2023 we organized the formal opening of our new on-site exhibition area in the Danish Dementia Research Centre. Her Royal Highness Princess Benedikte inaugurated the exhibition area which includes a dementia-friendly garden and an indoor kitchen and exhibition area. Remaining as independent as possible in the home-environment is important for persons with dementia and their caregivers. Small changes in everyday life can have an impact on safety, independence and

the feeling of well-being. Our new exhibition area serves as inspiration for professionals as well as people with dementia and caregivers on how they can ensure independent living as long as possible. For those who may not have the possibility to visit our centre a new digital platform provides similar information (in Danish only): www.hverdagslivetmeddemens.dk

PROJECTS

The three projects mentioned below were all commissioned and supported by the Danish Ministry of Health, as part of the National Dementia Plan 2025.

Validation of BASIC in general practice

BASIC is a new dementia case-finding instrument for use in primary care. A validation study of BASIC in general practice across the country in collaboration with the University of Copenhagen and University of Southern Denmark was completed in 2023. One scientific publication describing the validity of BASIC-Q (a questionnaire version for primary care staff) was published at the end of 2023 and in 2024 a publication regarding the validity of BASIC will follow. The successful development and validation of BASIC has already led to a new international collaborative study, the TIMING Study, in which BASIC will be validated in eight European countries in the forthcoming years.

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. Demtool has been tested in 15 municipalities across the country. The results so far indicates that DemTool is a valuable concept, which increases the quality of support, counselling and education for people with dementia and informal caregivers. A new

research program with data from the Demtool project will be launched in 2024.

Implementation of support from volunteers for patients with dementia in Danish hospitals

The project was finalized in 2024. In the project volunteers with specific training in dementia assisted patients with dementia and their carers during hospitalization. The volunteers provided emotional care, safety and wellbeing as an add-on to the professional care for the patients during hospitalization. The project involved eight hospitals across the country. A video and other tools were developed for implementation in other hospitals.

New projects in 2024

In November 2023, the DDRC was commissioned to conduct three new projects in 2024-2027: 1) developing new models for diagnostic evaluation of dementia in Denmark; 2) reducing prescriptions of anti-psychotic medication to people with dementia in general practice – in collaboration with “Quality in General Practice”, 3) upgrading ABC Dementia e-learning.

COURSES AND CONFERENCES

National Information and Education Centre on Dementia offers a wide range of courses (both nationwide and tailored courses) and annual conferences, e.g. the Dementia Days conference. In 2023 2.651 professionals participated in our courses and conferences.

In 2023 we had a special focus on the development and implementation of Cognitive Stimulation Therapy (CST) in Denmark. DDRC has three 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 and during the last two years we have educated more than 400 group leaders and have created a national network for CST leaders to support implementation.

In 2023 we have continued a fruitful collaboration with the 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.

Delirium og demens



Our annual two-day conference Dementia Days (DemensDagene) has been held since 1999 and is the largest conference on dementia in Denmark. 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, physicians, leaders in health care, researchers, national authorities in health care, and stakeholder organisations, for this national conference.

In 2023 the Dementia Days took place in Tivoli Congress Center in Copenhagen. With the overarching theme “Quality and Documentation” the program was conducted in plenary sessions and three parallel tracks during two days. The number of registered participants was 1067.

ABC DEMENTIA – FREE E-LEARNING COURSES

Offering free access to e-learning is one way of providing easy access nationwide 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 programs.

Our e-learning programmes are used by thousands of course participants. The e-learning programs are applied for introduction of new employees to the field of dementia as well as for continued education of professionals in municipalities and regions. DDRC has developed seven separate e-learning programs. See box right.

NATIONAL PROFESSIONAL NETWORKS

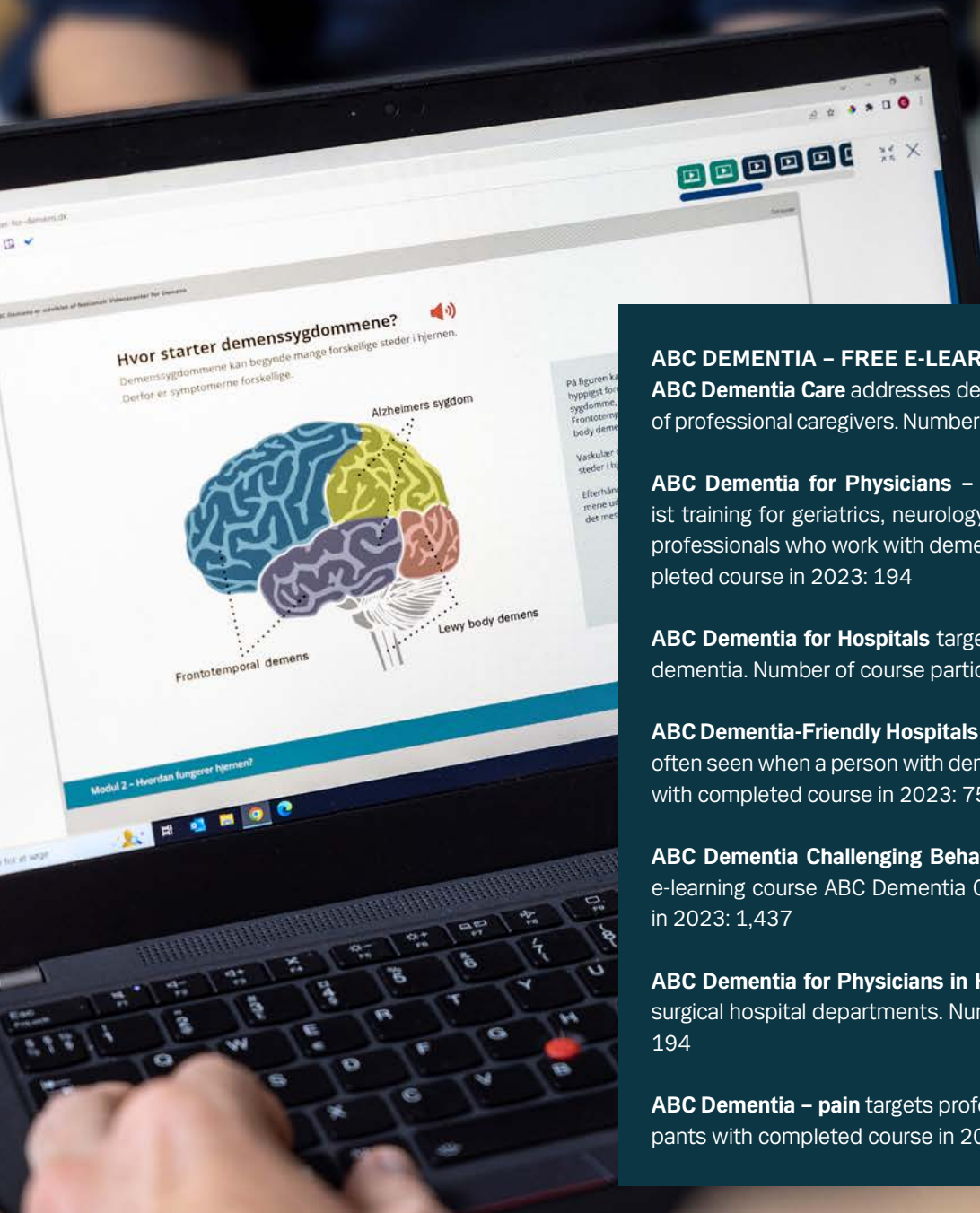
To promote exchange of knowledge, education and quality programs, we coordinate national professional networks for various groups of dementia professionals and experts.

The Network of Danish Memory Clinics serves as a platform for dissemination and exchange of information, for harmonising and standardizing 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 patients referred from local general practitioners for diagnostic evaluation of dementia. Net-

work 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 the 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 in primary care. The network also forms an important setting for exchanging knowledge and information among local dementia professionals. The network has 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 provide researchers with the 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.



ABC DEMENTIA – FREE E-LEARNING COURSES

ABC Dementia Care addresses dementia from a broader perspective and targets a wide range of professional caregivers. Number of course participants with completed course in 2023: 3,840

ABC Dementia for Physicians – Diagnostic Evaluation targets medical doctors in specialist training for geriatrics, neurology, psychiatry or general medicine, and is also used by other professionals who work with dementia assessments. Number of course participants with completed course in 2023: 194

ABC Dementia for Hospitals targets care staff at hospitals who have basic knowledge about dementia. Number of course participants with completed course in 2023: 688

ABC Dementia-Friendly Hospitals targets all hospital staff and addresses the challenges that are often seen when a person with dementia is admitted to hospital. Number of course participants with completed course in 2023: 750

ABC Dementia Challenging Behaviour targets care staff in municipalities and it adds to the e-learning course ABC Dementia Care. Number of course participants with completed course in 2023: 1,437

ABC Dementia for Physicians in Hospitals targets physicians working in internal medicine and surgical hospital departments. Number of course participants with completed course in 2023: 194

ABC Dementia – pain targets professional caregivers in primary care. Number of course participants with completed course in 2023: 317

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 backgrounds, such as nurses, therapists and doctors from hospitals. Participants meet once a year to establish and maintain partnerships and cooperation across hospitals. The network was established as a follow-up of our pilot project on dementia-friendly hospitals in 2017-2019.

COMMUNICATION AND PRESS

Communication and Press continuously supports all activities at The National Information and Education Centre for Dementia with communication consultancy, marketing, press contact, printed and digital materials and development and maintenance of content and the technical platforms for DDRC's website, apps and e-learning.

This year we focused on initiating a user survey of our website. We have also presented a new topic on legal aspects of dementia and a series

of new videos in which professionals introduce various aspects of dementia.

Website

Our website has been developed in several areas throughout 2023. The front page has been given a visual boost, so that it appears more modern and dynamic. For example, the top banner alternate between three to four different images, from which users can click on to strategically selected pages, e.g. registration for the Dementia Days, a new video with a special focus.

From the video slider on the front page, users can have easy access to a new video page. The site has been developed with a special focus on recognition from streaming services, so that it appears manageable and inviting.

The first phase of the planned user survey of the website was completed in 2023. The questions were designed to uncover the users' professional background, place of employment, local region and purpose of the visit to the website. A total of 1,417 people answered the questions, most of whom were social and health assistants

employed at care centers in the Capital Region, who were looking for news about dementia.

Out of the 1,417 users who attended the survey, 400 has consented to take part in the second phase of the user survey, which is to take place in 2024.

OUR WEBSITE

In 2023, 520,000 unique users visited our website which corresponds to 1,6 million visits in total. Visitors on our website are most often professionals who work with diagnostics, treatment or care. But in addition journalists, patients, and informal caregivers also use our website to obtain information on dementia.

Social media and newsletter

In 2023, we have continued to strengthen our dissemination of information about dementia and DDRC's activities through two selected social media (Facebook and LinkedIn) and DDRC's newsletter. The focus on these channels is on branding of the centre as an attractive knowledge bank for our users and an active community voice. The purpose is to create visibility of our role as an interdisciplinary national centre and generate traffic to the website.

By the end of 2023, DDRC had 4,361 followers on LinkedIn, a total annual increase of 1,005 followers, and 6,653 followers on Facebook, a total annual increase of 235 followers. The relatively large increase in the number of followers

on LinkedIn is mainly the result of an updated content strategy focusing on longer and more substantial posts and video content.

The DDRC newsletter was published with 10 issues in 2023. 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 2023 the newsletter had more than 7800 subscribers, a total annual increase by approx. 600, a continued opening rate around 45 % and a slight increase in the click-through rate (from 7 to 9.3 %), an indication that our growing number of subscribers continues to find the newsletter relevant.

DDRC IN THE MEDIA

DDRC is present in the media on an almost daily basis with comments, interviews, and articles. In 2023 DDRC, or spokespersons from DDRC, were mentioned in different medias about 868 times (Hypefactor), of these, 515 were in online media, 151 in print media, 127 on radio, 73 on social media and two on TV.

Staff in 2023

MANAGEMENT GROUP (per 31/12/2023)



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, clinical research
associate professor, senior
neurologist



Educational director
Karen Tannebæk, MPG,
occupational therapy
specialist



**Director of communications
and press**
Marie Ejlersen, MA



**Laboratory manager
and manager of Danish
Dementia BioBank**
Anja Hviid Simonsen,
MSc Pharm, PhD, senior
researcher



Head of administration
Brit Mouritsen

EMPLOYED AS OF 31/12 2023

CHAIR

Gunhild Waldemar, MD, DMSc, professor,
senior neurologist

ADMINISTRATION

Lisa Coleman, assistant
Pia Hansen, economy assistant
Eva Havskjær, course administrator
Brit Mouritsen, head of administration
Lone Schlütter, economy consultant

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
(maternity leave)
Ulla Vidkjær Fejerskov, OT, educational advisor
Hanne Kærsmose Friberg, RN,
educational advisor
Elsebeth Clipstrup, RN, educational advisor
Kasper Jørgensen, MSc, neuropsychologist
Nina Kotschenreuther, social media specialist
Nille Kroun, MA, communication officer
Ann Nielsen, MScPH, PhD, project manager
Elsebeth Refsgaard, RN, educational advisor,
project manager
Karen Tannebæk, MPG, OT, educational director

RESEARCH

Andreas Appel, MScPH, PhD student
Marie Bruun, MD, PhD, post doc, neurologist
Frederikke Kragh Clemmensen, MD,
PhD student, research assistant
Line Damsgaard, MD, PhD student,
research assistant
Patrick Ejlerskov, MSc, PhD, senior researcher
Kristian Steen Frederiksen, MD, PhD, neurolo-
gist, CTU director, clinical research associate
professor
Mathias Holsey Gramkow, MD, PhD student,
research assistant
Steen Gregers Hasselbalch, MD, DMSc,
professor, senior neurologist

Rebecca Hendel, MSc, PhD, post doc
Emil Elbæk Henriksen, MSc, PhD student
Lena Elisabeth Hjermand, MD, PhD,
senior neurologist, senior researcher
Mihaela Ivosevic, research student
Janet Janbek, MScPH, PhD, post doc
Christina El-Ali Jensen-Dahm, MD, PhD, post
doc, neurologist
Kasper Jørgensen, MSc, neuropsychologist,
senior researcher
Daniel Kjærgaard, MSc, PhD student
Oskar McWilliam, MD, PhD student
Christian Sandøe Musaeus, MD, PhD student
Jørgen Erik Nielsen, MD, PhD, professor,
senior neurologist
T. Rune Nielsen, MSc, PhD, neuropsychologist,
associate professor
Laura Storm Næsberg, research student
Anne-Britt Oxbøll, RN, PhD student
Nelsan Pourhadi, MD, PhD student
Emilie N. Poulsen, MSc, PhD student
Peter Roos, MD, PhD, neurologist,
senior researcher
Anja Hviid Simonsen, MSc Pharm, PhD,
senior scientist, laboratory manager
Nikolai Sulkjær Sjælland, research student
Anders Toft, MD, PhD student
Tua Vinther-Jensen, MD, PhD, post doc,
neurologist
Asmus Vogel, MSc, PhD, neuropsychologist,
associate professor

COPENHAGEN MEMORY CLINIC

MEDICAL DOCTORS
Birgitte Bo Andersen, MD, DMSc,
senior neurologist, clinical director
Thor Ruben Bak, MD
Eva Bjerregaard, MD, specialist in family
medicine
Marie Bruun, MD, PhD, neurologist
Signe Eiland, MD
Kristian Steen Frederiksen, MD, PhD, neurolo-
gist, CTU director, clinical research associate
professor
Hanne Vibe Hansen, MD, senior psychiatrist
Steen Gregers Hasselbalch, MD, DMSc,
professor, senior neurologist

Ida Chenoufi Hasselbalch, MD
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Theis Hornshøj Mouritsen
Alexander Pedersen
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National and international posts

Birgitte Bo Andersen, 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; , member, Expert Advisory Panel, Alzheimer Europe, Associate editor, Alzheimer's Research and Therapy.

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; appointed member, EAN Scientific Panel on Dementia and Cognitive Disorders; appointed member, Dementia Council of the Capital Region of Denmark.

Lena Hjermind, PI of the global observational study on HD, Enroll-HD; appointed member of the program committee of the European Huntington's Disease Network (EHDN)/Enroll-HD Conferences; 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.

Daniel Kjærgaard, board member, Danish Neuropsychological Society; member, European Consortium on Cross-Cultural Neuropsychology.

Oskar McWilliam, member of National Neurological Treatment Guidelines for Neurodegenerative Diseases (nNBV), board member of DANMODIS, member of Counsel for Neurological Education in East Denmark.

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, coordinator, Nordic Research Network on Dementia and Ethnicity; co-founder and member, European Consortium on Cross-Cultural Neuropsychology; member, International Neuropsychological Society special interest group on Culturally Appropriate Neuropsychological Assessment; Program Chair, International Neuropsychological Society Annual North American Meeting.

Signe Pertou Ringkøbing, chair, Danish Neuropsychological Society.

Christina Rørvig-Løppenthien, member, Steering Group, Danish Dementia Clinical Quality Program

Jette Stokholm, neuropsychology consultant, Danish Patient Safety Authority.

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. Member of the Occupational Therapist Association's specialist board.

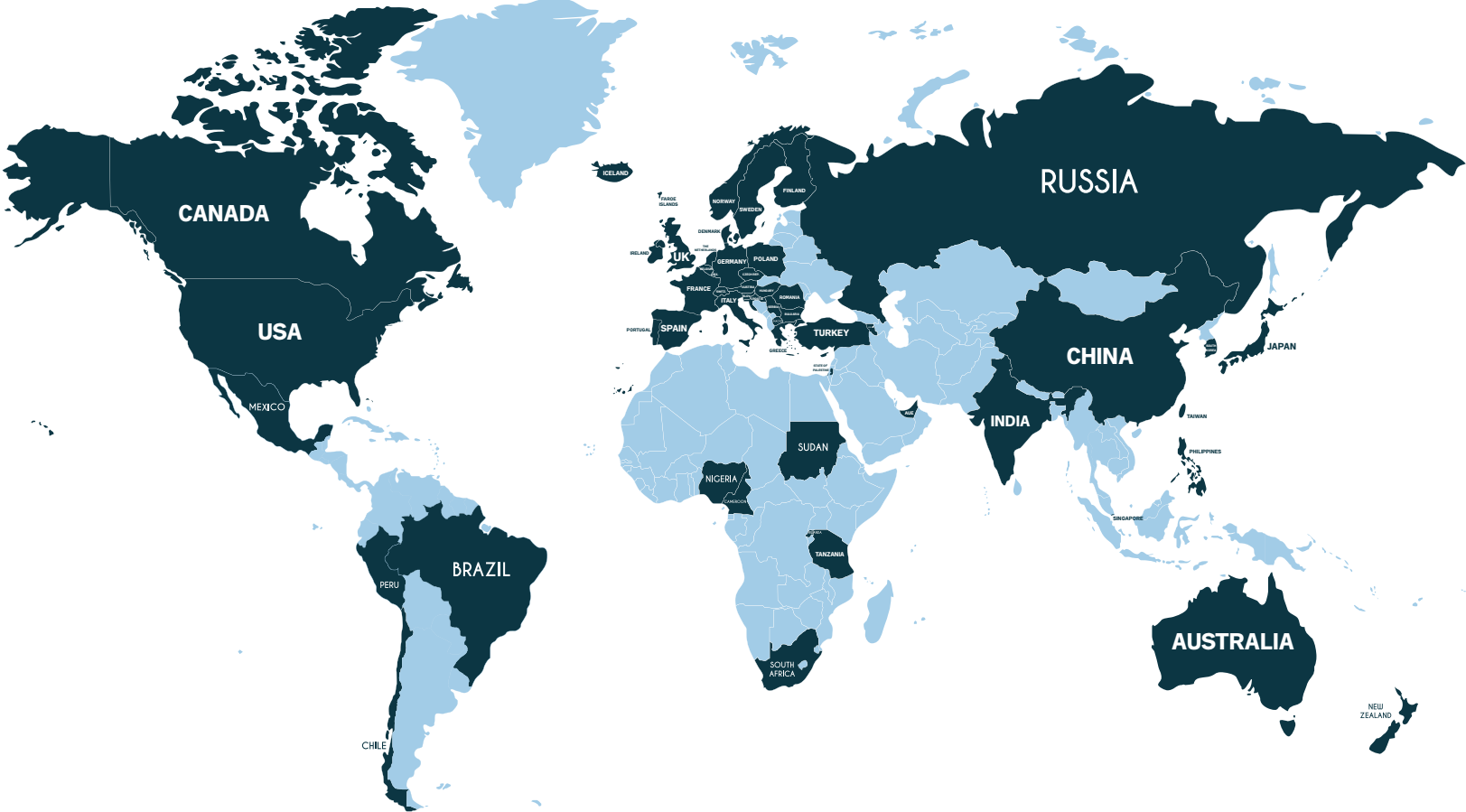
Tua Vinter-Jensen, appointed member, European Academy of Neurology, scientific panel in neurogenetics.

Asmus Vogel, 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 (until April 2023); advisor, National Legal Medicine Council, Danish Ministry of Justice; 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.

Publications in 2023

Graphic illustration of DDRC international collaboration. In 2020-2023 DDRC has published scientific papers with institutions in countries marked with dark blue color.



MASTER THESIS

Feng, LR. *Clinical Validation of the Cingulate Island Sign Visual Rating Scale in Dementia with Lewy Bodies*. Master's Thesis 2023.

Sjælland, NS. *Digital biomarkers for the assessment of non-cognitive symptoms in patients with dementia with Lewy bodies – a systematic review*. Master's Thesis 2023.

Wolner, SH. *Cerebrospinal Fluid Levels of Synaptosomal-Associated-Protein 25 in Alzheimer's Disease: a Systematic Review and Analysis of Clinical Samples from the Danish Dementia Biobank*. Master's Thesis 2023.

SCIENTIFIC PAPERS

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LETTER

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CONTRIBUTIONS TO MULTICENTRE STUDIES

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Finance

The DDRC's total annual budget for 2023 was approximately DKK 63.2 m, distributed almost evenly between internal funding (DKK 32.5 m for memory clinic services) and external grants (DKK 30.7 m for research, contracts and educational activities). An important

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EXTERNAL FUNDING FOR RESEARCH, QUALITY PROJECTS AND EDUCATION ACTIVITIES 2023 (DKK M)	
New grants received*	5.9
New grants accumulated 2007-2023*	255.3
External grants spent on specific programs and projects	21.0
<ul style="list-style-type: none"> • National Information and Education Centre for Dementia from the Danish Ministry of Health, including projects 11.0 • Other external grants for research* 10.0 	
Grant to Danish Memory Clinic**	5.6
Conferences, educational courses and products	4.1
Research contracts	3.5

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

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STAFF 2023	
No. of employees/full-time equivalents	100/89

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Augustinus Fonden	Gangstedfonden	Parkinson Association
Axel Juul Muusfeldt Foundation	GN Foundation	P.A. Messerschmidt & Hustrus Fond
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