# DANISH DEMENTIA RESEARCH CENTRE

ANNUAL REPORT 2022

**Copenhagen Memory Clinic and**
**National Information & Education Centre for Dementia**

DANISH DEMENTIA RESEARCH CENTRE

Danish Dementia Research Centre
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# Contents


Velkommen til
Nationalt
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for Demens

# Preface

It is a pleasure to present the 2022 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.

In 2020-2021 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. However, in 2022 we caught up with most of the delayed activities. Importantly, the Copenhagen Memory Clinic had a busy year seeing a record high number of new patients (more than 2000).

Many of our national educational programs were conducted as online courses, inspired by the experiences from the COVID-19 pandemic. The annual two-day conference Dementia Days (DemensDagene) took place for the first time in Aarhus. A successful conference it attracted almost as many participants as in previous years in Copenhagen. Our national networks were again able to meet face-to-face and exchange ideas. In 2022 we organized the Scandinavian conference for leaders in dementia care in Stockholm, in collaboration with the Norwegian and Swedish knowledge centers.

We are in contact with many thousand professional carers and specialists in the field of dementia via our website, our (free of charge) e-learning portal, our newsletter and social media. Our website alone had 640,000 visitors in 2022. We are also visible in public media on a daily basis with 641 hits in 2022.

In 2022 we completed recruitment of 275 patients from several general practices across the nation for the validation study of our new tools for timely identification of dementia, BASIC and BASIC-Q.

Several new PhD and post doc programs were initiated in 2022 in the fields of biomarker research, epidemiology and neurogenetic aspects of neurodegenerative diseases. We joined the new “Neuroscience Academy Denmark” where we contribute to the coordination of the research column on neurodegenerative diseases. Two PhD theses in the field of Huntington’s disease were defended in 2022, where we also published a total of 43 scientific papers and 20 books and book chapters.

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.

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

# 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, the national information and education centre, 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 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, The Ministry of 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.

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

**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.

*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 2022


## Dementia Days in Aarhus

In 2022 DDRC's annual two-day conference Dementia Days (DemensDagene) was held outside Copenhagen – this time in Musikhuset in Aarhus.

This year's theme was "Learning for life", and more than 960 people from across Denmark attended. Among the keynote speakers were Wilhelmina Hoffman, director of Silvia Stiftelsen in Sweden, Peter Vuust, brainresearcher and manager of Center for Music and Brain, and Pia Kürstein Kjellberg, project manager from VIVE.

The conference was opened by Stephanie Lose, chair of the Regional Council of Southern Denmark, and the Minister for Social Affairs and Senior Citizens Astrid Krag presented the 2022 dementia prizes for outstanding employee and caregiver.

# PhD defense by Marie Nickelsen Hellem

In June 2022 Marie Nathalie Nickelsen Hellem, MD, defended her PhD thesis with the title: “Huntington’s Disease – Endophenotypes and biomarkers”.

Her supervisors were: Professor Jørgen Erik Nielsen, The Neurogenetics Clinic & Research Lab, Danish Dementia Research Centre, Rigshospitalet, University of Copenhagen, Denmark (Principal Supervisor), professor Esben Budtz-Jørgensen, Department of Public Health, Section of Biostatistics, University of Copenhagen, Post.doc Adele Marthaler, Danish Dementia Research Centre, Department of Neurology, Rigshospitalet, Copenhagen University Hospital and Center manager, PhD Troels T. Nielsen, Danish Dementia Research Centre, Department of Neurology, Rigshospitalet, Copenhagen University Hospital and Assistant Professor Niels Skotte, Novo Nordisk Foundation Center for Protein Research, University of Copenhagen.

The official opponents were: Anne Nørremølle, Associate professor, PhD, Departement of Cellular and Molecular Medicine, University of Copenhagen (chairperson), Carsten Saft, Professor, dr.med., Huntington Zentrum NRW, Neurologische Klinik der Ruhr-Universität, Bochum, ST. Josef Hospital, Bochum, Germany, and Kristian Winge, Associate professor, PhD, Department of Neurology, Odense University Hospital, Clinical Institute, University of Southern Denmark.

# PhD defense by Rebecca Kjærgaard Hendel

In December 2022 Rebecca Thea Kjærgaard Hendel, MSc, defended her PhD thesis with the title: “Apathy, Social Cognition, and Self-Perception: Assessing Neuropsychological Factors in Huntington’s Disease”.

Her supervisors were: Associate Professor Asmus Vogel, Department of Psychology, University of Copenhagen and Danish Dementia Research Centre, Rigshospitalet, University of Copenhagen (Principal Supervisor), Professor Jørgen Erik Nielsen, Danish Dementia Research Centre, Rigshospitalet, University of Copenhagen and Lena Hjermind, MD, PhD, The Neurogenetics Clinic & Research Lab, Danish Dementia Research Centre, Department of Neurology, Copenhagen University Hospital.

The official opponents were: Professor Randi Starrfelt, Department of Psychology, University of Copenhagen (chairperson), Associate Professor Malene F. Damholt, Department of Clinical Medicine and Unit for Psychooncology and Health Psychology, Aarhus University and Professor Roger Barker, Department of Clinical Neuroscience, University of Cambrige.

# New grants and awards in 2022


## The Danish Alzheimer's Association Research Prize in Clinical Research 2022

In 2022, neuropsychologist and senior researcher Rune Nielsen received the Danish Alzheimer's Association Research Prize in Clinical Research for his longstanding research in a challenging but important field of research, namely dementia care in minority ethnic groups. The prize was presented by Her Royal Highness Princess Benedikte on the international Alzheimer's Day, September 21st.

The prize committee highlighted Rune Nielsens work on developing, validating, and implementing methods for cross-cultural cognitive assessment in Denmark, and Europe more broadly. Other work highlighted by the committee included his contributions to international expert groups on cross-cultural neuropsychology and dementia care in minority ethnic groups, and his key role in establishing the Nordic Research Network on Dementia and Ethnicity and the European Consortium on Cross-Cultural Neuropsychology.

The Alzheimer Research Foundation also supported the following projects from Danish Dementia Research Centre:

Frederikke Kragh Clemmensen, MD, PhD-student received a donation for the project "Novel blood-based biomarkers for tracking Alzheimer's disease: a study of disease trajectory and development of disease stage biomarkers in AD" and Gunhild Waldemar, professor, MD, received a donation for the project "Vaccines and Dementia".

# 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.

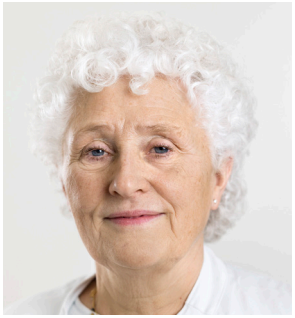
The Alliance aims to speak as a common voice of all its members in seeking to:

- 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

The Alliance intends to:

- promote excellence in European biomedical research
- strengthen the representation of biomedical researchers disciplines and associations
- advocate for increased funding in favour of biomedical research
- improve the health and well-being of all citizens of Europe

Read more about the Alliance here: biomedeurope.org



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 new patients may be referred 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**

In 2022 a record high number of patients underwent diagnostic evaluation in the memory clinic (see table on page 12) who received 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 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 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
- 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).

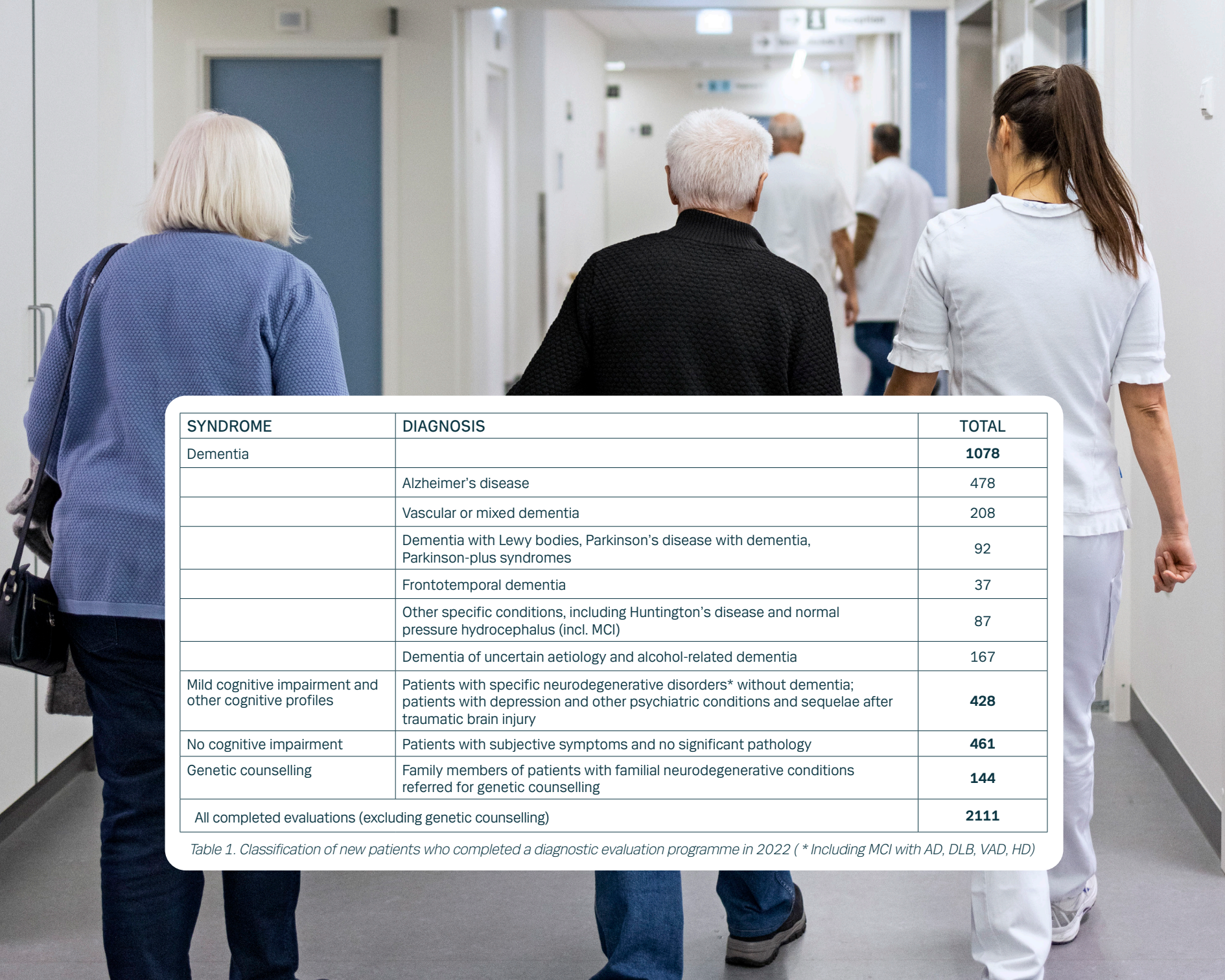
Four annual patient conferences are held with the Movement Disorders Clinic at Bispebjerg Hospital.

*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 2022 there were 327 patients referred for a clinical evaluation of NPH, 114 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 2022 there were 144 at-risk family members referred. The clinic also offers post-genetic test counselling when needed.



| SYNDROME | DIAGNOSIS | TOTAL |
|---|---|---|
| Dementia | | **1078** |
| | Alzheimer's disease | 478 |
| | Vascular or mixed dementia | 208 |
| | Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinson-plus syndromes | 92 |
| | Frontotemporal dementia | 37 |
| | Other specific conditions, including Huntington's disease and normal pressure hydrocephalus (incl. MCI) | 87 |
| | Dementia of uncertain aetiology and alcohol-related dementia | 167 |
| 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 | **428** |
| No cognitive impairment | Patients with subjective symptoms and no significant pathology | **461** |
| Genetic counselling | Family members of patients with familial neurodegenerative conditions referred for genetic counselling | **144** |
| All completed evaluations (excluding genetic counselling) | | **2111** |

*Table 1. Classification of new patients who completed a diagnostic evaluation programme in 2022 ( * Including MCI with AD, DLB, VAD, HD)*

*Follow-up programme for patients and families*
All patients with mild cognitive impairment (MCI), and selected groups of patients with dementia or specific neurodegenerative disorders 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 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 on 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.

**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 Departments of Geriatrics and Palliation 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 (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.

Copenhagen Memory Clinic in 2022:

- 2,013 new patients
- 16,350 physical or virtual visits
- 4,973 patients are in a follow-up programme

Bornholm Memory Clinic in 2022:

- 116 new patients

# 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 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

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 2022 four phase 3 trials and three open label extension studies of Alzheimer's disease were ongoing. One phase 1 study of Huntington's disease was initiated.

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.

# 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 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 2022 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 through-out Europe. Such networks also have been instrumental in the recruitment of DDRC patients to pharmacological intervention studies.

# 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, and prevalence, incidence and mortality.

# 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.

# 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 2022.



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 biofluid markers, brain imaging, and digital biomarkers.

**Highlights in 2022:**

- 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 2022, 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 implemented and validated a new high-throughput and improved method for quantification of biomarkers in cerebrospinal fluid in collaboration with Department of Clinical Biochemistry. This new method contributes a faster diagnostic work-up of patients in the Copenhagen Memory Clinic.
- 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 develop and validate tests and scales for the identification and assessment of cognitive deficits in neurodegenerative diseases in both primary sector and in highly specialized memory clinic functions. Our primary focus is the characterization of cognitive deficits in the early phase of dementia and MCI.

**Highlights in 2022**

- A PhD thesis by Rebecca Hendel on neuropsychological deficits in Huntington's disease was successfully completed. The thesis included four recently published papers on the manifestations of this neurogenetic disease with special emphasis on apathy, social cognition, and self-perception.
- From the MYSELF study on the earliest memory changes in AD we have published a paper on a Danish version of a new type of memory test investigating the use of pro- and retroactive interference which may be specifically impaired in the prodromal stages of AD.
- Our group has developed a picture based cued recall test (Category Cued Memory Test) and a study on the discriminative validity of this test in AD and DLB was published.
- Recruitment for a validation of two case-finding tools for dementia, BASIC and BASIC-Q, in a Danish general practice setting was completed in 2022. The validation took place in 14 general practice clinics with the participation of 275 patients. The project was a collaboration between the Danish Dementia Research Centre and the Research Unit for General Practice at the University of Copenhagen.
- The first results from a study on the association between listening effort (using pupillometry) and the relation with cognitive function in normal-hearing older adults and MCI were published in a PhD thesis by Alix Feldman. The study was completed in collaboration with Technical University Denmark (Management and Engineering).

Jørgen E. Nielsen, MD, PhD, professor, senior neurologist, research director
Patrick Ejlerskov, MSc, PhD, postdoc

# 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 2022**

- In two finalized PhD studies, we completed follow-up studies on a worldwide unique single-site cohort of HD-patients: The PhD-study by Marie Hellem investigated the development of symptoms, the longitudinal drift between endophenotypes, and neuroinflammatory/neuroendocrine markers in the cerebrospinal fluid (CSF) and plasma. CSF oxytocin was significantly correlated to impaired social cognition and psychiatric symptoms of HD, which led to the suggestion of a potential effect of oxytocin on social cognition in HD.

  In the CSF an increased amount of T-helper 17.1 cells was found in the premanifest state which correlated negatively with disease burden score, motor score and the level of neurofilament light chain implying an early involvement of the T-helper 17.1 cells and a thereby a rationale for anti-inflammatory treatment in the premanifest or very early stages. The PhD-study by Rebecca Hendel included four papers on apathy, social cognition, and self-perception in HD.

- We were awarded a 2-year Novo Nordisk Foundation, BRIDGE grant for post doc Erika Villanueva for HD-proteomics and stem cell work.

- We were awarded DKK 5 million from Sygeforsikringen "danmark" to investigate the relationship between viral infections and neurodegeneration and new paradigms for treatment.



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

The overarching aim of our studies in the epidemiology and public health group is to investigate the impact of dementia on health and morbidity in the elderly people, health-related risk factors for dementia and access to health care for people with dementia. The studies are based on health data from the unique Danish registries, mainly hospital records, health care utilization in primary and secondary care, and prescription data, which in 2022 was supplemented with access to the Danish quality registry for diagnostic evaluation of dementia (DanDem). The research is done in collaboration with National Centre for Register-based Research at Aarhus University, Department of Affective Disorders, Aarhus University Hospital Psychiatry, Edinburgh University and Johns Hopkins University.

**Highlights in 2022**

- A new PhD program to be conducted by M.D. Nelsan Pourhadi was initiated with the aim to study the associated risk of developing dementia when exposed to treatment with the common pharmacological drugs 1) proton pump inhibitors 2) opioids, and 3) bladder antimuscarinics, all shown abilities to cause neuro-damaging effects.

- A new (part-time) post doc program to be conducted by MD and specialist in neurology Christina Jensen-Dahm was initiated with the aim to study the risks associated with opioids in elderly with and without dementia.

- In continuation of a previous PhD program, we published a paper demonstrating that patients exposed to antipsychotics had a significantly higher adjusted risk of death (hazard ratio: 1.35, 95% confidence interval: 1.27-1.43) than unexposed patients.

- We published a nationwide observational study demonstrating that hospital-diagnosed sleep disorders may increase incident dementia. The study attracted attention at the AAIC as well as the EAN conferences and the news article based on the conference presentation was appointed “top-10 paper” by Medscape.

- We also contributed to publications on risk factors for dementia from other Danish research groups.

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 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.

In the TIMING study, we focus on identifying challenges in clinical practice for dementia diagnostics in minority ethnic populations in European memory clinics and on validating BASIC, BASIC-Q, and several cross-cultural cognitive tests across majority and minority ethnic groups in Denmark and several other European countries.

# International consortia and networks

In DDRC we participate in and contributes to different international consortias 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 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 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 2022, 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 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 reprogram 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. The program was terminated in 2021, but research collaboration between University of Copenhagen and DDRC is continuing.

**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 several European countries, and the Unites 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, 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.

**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 centers 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 2022 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. 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.

**T. Rune Nielsen**

**– Cross-Cultural Assessment and Dementia in Ethnic Minorities**

Neuropsychologist, PhD supervisor, lecturer. Main research focus is cross-cultural cognitive assessment and ethnic differences in dementia.

**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.

**Jørgen E. Nielsen**

– Inherited Neurodegenerative Disorders

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

**Asmus Vogel**

– Cognition and Neuropsychological Deficits

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

## 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.

**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.

## SENIOR RESEARCHERS

**Kasper Jørgensen**

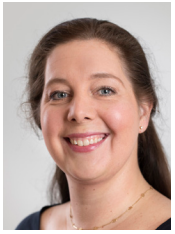
– Norming, Validation and Development of Neuropsychological Tests and Case-Finding Instruments

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

**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.

**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.

**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.

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.

**Tua Vinther-Jensen**

– Neurogenetic Disease, Primary Clinical Research

Postdoctoral fellow, PhD, MD. Major research focus is phenogenotyping 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.

**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.

**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.

## PHD STUDENTS

**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.

**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.

**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.

**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.

**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-QuIC technique.

**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.

## 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.

**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.

## PREGRADUATE RESEARCHERS

**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

**Clara Mellergaard**

– Prodromal Symptoms in Lewy Body Dementia

In this project, the objective was to examine the earliest symptoms of Lewy Body Dementia

**Mathe Uhre Hansen**

– Amyloid and Clinical Profiles

His project aim is to characterize a cohort of patients with both CSF and PET amyloid assessments in order to asses their clinical and biochemical profiles.



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

# National information and education centre for dementia

As a section of Danish Dementia Research Centre, 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. In 2022 the continued lockdown due to the COVID-19 pandemic 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, as part of 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. Validation of BASIC in general practitioner clinics across the country in collaboration with the University of Copenhagen and University of Southern Denmark was completed in 2022. Results from the validation study follows in 2023. The successful development of BASIC has already led to a new international collaborative study, the TIMING Study, in which BASIC will be validated in eight European countries.

*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 increase the quality of 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 assist 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 eight hospitals across the country. 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 annual conferences, e.g. the Dementia Days conference. Due to COVID-19 many activities were affected, delayed or cancelled. Many courses have been conducted as online courses in stead. In 2022 3,289 professionals participated in our courses and conferences.

I 2022 we had a special focus on the development and implementation of Cognitive Stimulation Therapy (CST) in Denmark. DDRC has four 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 we have created a national network for CST leaders to support implementation.

In 2022 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 2022 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.

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, general practitioners, stakeholder organisations, managing staff and researchers, for this national two-day conference.

In 2022 the Dementia Days took place in Aarhus Musikhus. With the overarching theme ”Learning for life” the program was conducted in three parallel tracks during two days. The number of registered participants was 965.

**ABC DEMENTIA – FREE E-LEARNING COURSES**

Offering free access to e-learning is one way of providing easy access 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. The e-learning programmes are applied 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.

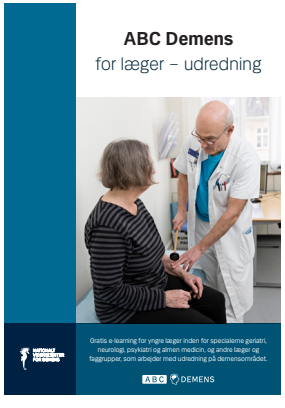
ABC Dementia Challenging Behaviour targets care staff in municipalities and it adds to the e-learning course ABC Dementia-Care.

ABC Dementia for Physicians – Diagnostic Evaluation targets medical doctors in specialist training for 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 have 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, 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 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 patients 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 in primary care. 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 backgrounds, such as nurses, therapists and doctors from hospitals. Participants meet once a year to establish and maintain partnerships and corporation 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 on Dementia with communication skills, marketing, press contact, printed and digital materials and development and maintenance of content and technical platform for website, apps and e-learning.

## Our website

In 2022, 640,000 users visited our website which corresponds to 1,4 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.

This year we focused on initiating a user survey of our website. We have also presented a new topic on legal aspects of dementia end a series of new videos in which professionals introduce various aspects of dementia.

In 2022 we have integrated the new strategy of social media and newsletter into our operation and development of these. We still have an increasing number of followers on all our social media platforms. This has engaged more users and generated more traffic on the DDRC website.

We find that LinkedIn and Facebook continue to be useful ways to connect with the public and to disseminate knowledge about dementia and DDRC's activities. By the end of 2022 we had 3425 followers on LinkedIn (more than 1100 additional followers than the year before) and 6365 followers on Facebook, which is an increase of several hundred.

Especially on LinkedIn we have focused on producing more elaborate posts about our daily work in the DDRC and news about dementia, which gets a good response. The special attention towards LinkedIn is due to the presence of some of our main target groups here.

The DDRC newsletter was published with 11 issues in 2022. 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 2022 the newsletter had more than 7300 subscribers, which is an increase by several hundred, and in addition our opening rate also continues to increase and is now around 45 %.

We launched a new proactive press strategy during the past year, with the aim to direct and manifest the attention towards DDRC as the main source of information about dementia with societal as well as professional relevance from the perspective of health care professionals. With targeted dissemination of knowledge to relevant media and visibility and availability for journalists and in the public debate, we will continue to ensure that facts about dementia are correct and updated.

## DDRC in the media

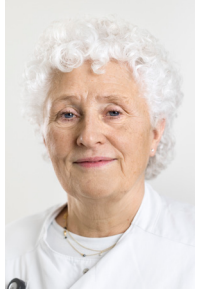
DDRC is present in the media on an almost daily basis with comments, interviews, and articles. In 2022 DDRC, or spokespersons from DDRC, were mentioned in about 641 articles, which is an increase of 5 % since 2021. 65 % of these were online-articles (equivalent to 416 articles), 23 % in nationwide newspapers (equivalent to 147 articles) and 12 % in tv and radio.

# Staff in 2022

## MANAGEMENT GROUP (per 31/12/2022)

**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

**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 2022

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

**ADMINISTRATION**
Pia Hansen, economy assistant
Eva Havskjær, course administrator
Brit Mouritsen, head of administration
Lone Schlütter, economy consultant
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
Frederikke Kragh Clemmensen, MD, PhD student, research assistent
Line Damsgaard, MD, PhD student, research assistent
Patrick Ejlerskov, MSc, PhD, post.doc.
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
Emil Elbæk Henriksen, MSc, PhD student
Lena Elisabeth Hjermind, MD, PhD, senior neurologist, senior researcher
Janet Janbek, MScPH, PhD student
Clara Mellergaard Jensen, student research fellow
Kasper Jørgensen, MSc, neuropsychologist, senior researcher
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, post.doc.
Troels Tolstrup Nielsen, MSc, PhD, centre manager
Anne-Britt Oxbøll, RN, PhD student
Nelsan Pourhadi, MD, PhD student
Peter Roos, MD, PhD, neurologist, senior researcher
Anja Hviid Simonsen, MSc Pharm, PhD, senior researcher
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
Kristine Hoffmann, MD
Katrine Decker Iversen, MD
Christina El-Ali Jensen-Dahm, MD, PhD, neurologist
Johanne Loft Larsen, MD
Suzanne Lindquist, MD, PhD, associate professor, clinical geneticist
Filippa Orlien Lindskov, MD
Jørgen Erik Nielsen, MD, PhD, professor, senior neurologist
Peter Roos, MD, PhD, neurologist
Christina Rørvig-Løppenthien, MD, senior neurologist
Sarah Taudorf, MD, PhD, senior neurologist
Tua Vinther-Jensen, MD, PhD, neurologist

NURSES
Nicole Cordes, RN
Lea Virenfeldt Damgaard, RN
Birgit Grøn, RN
Christina Vangsted Hansen, RN, research nurse
Oda Jakobsen, RN, research nurse
Rikke Charite Monberg Jarløv, RN
Hanne Rygaard Jensen, RN
Jeanette Westerlund Johansen, NR
Nadia Larsen, NR
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
T. Rune Nielsen, MSc, PhD, neuropsychologist
Jette Stokholm, MSc, specialist
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# 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; 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; 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.

**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; mem-

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

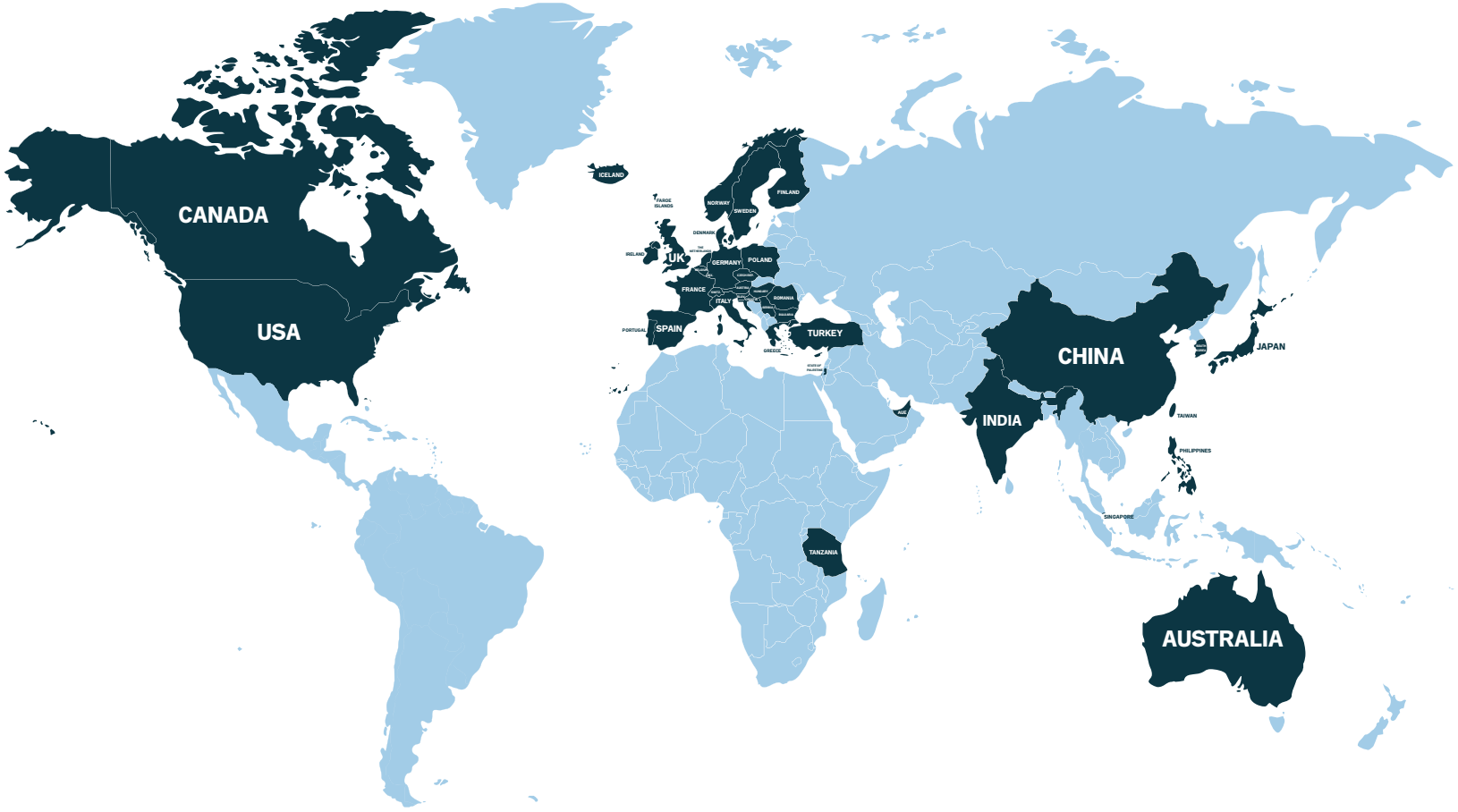
**Asmus Vogel**, section editor, Scandinavian Journal of Psychology; member, European research network Brain Involvement in Dystrophinopathies.

**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 in psychosocial interventions in dementia, and member of Interdem taskforces: Social Health, Assistive Technology; founder of DaneDem, a Danish research network on psychosocial methods in dementia; member of the research prize committee at Danish Psychological Association; board member of Danish Gerontopsychological Society; member of Alzheimer Research Committee under the Danish Alzheimer Association.

# Publications in 2022

Graphic illustration of DDRC international collaboration. In 2020-2022 DDRC has published scientific papers with institutions in countries marked with dark blue color.



PHD DISSERTATIONS

Hellem, MNN. *Huntington's Disease: Endophenotypes and biomarkers. Faculty of Health and Medical Science*, University of Copenhagen 2022.

Hendel, R. Apathy, *Social Cognition and Self-Perception: Assessing Neuropsychological Factors in Huntington's Disease*. Faculty of Social Sciences, University of Copenhagen 2022.

SCIENTIFIC PAPERS

Appel, AM, Brønnum-Hansen, H, Garde, AH, Hansen, ÅM, Ishtiak-Ahmed, K, Islamoska, S, Mortensen, EL, Osler, M & Nabe-Nielsen, K. Socioeconomic Position and Late-Onset Dementia: A Nationwide Register-Based Study. *Journal of Aging and Health* 2022;34(2):184-195.

Ásbjörnsdóttir, B, Henriksen, OM, Lindquist, S, Møller, LB, Sidaros, A & Nielsen, JE. Widening the spectrum of spinocerebellar ataxia autosomal recessive type 10 (SCAR10). *BMJ Case Reports* 2022;15(3):1-4. e248228.

Axenhus, M, Frederiksen, KS, Zhou, RZ, Waldemar, G & Winblad, B. The impact of the COVID-19 pandemic on mortality in people with dementia without COVID-19: a systematic review and meta-analysis. *BMC Geriatrics*. 2022;22(1):1-9. 878.

Bertelsen, L, Diederichsen, SZ, Frederiksen, KS, Haugan, KJ, Brandes, A, Graff, C, Krieger, D, Højberg, S, Olesen, MS, Biering-Sørensen, T, Køber, L, Vejlstrup, N, Hasselbalch, SG & Svendsen, JH. Left Atrial Remodeling and Cerebrovascular Disease Assessed by Magnetic Resonance Imaging in Continuously Monitored Patients. *Cerebrovascular diseases* 2022;51(3):403-412.

Carlsen, JF, Backlund, ADL, Mardal, CA, Taudorf, S, Holst, AV, Munch, TN, Hansen, AE & Hasselbalch, SG. Can Shunt Response in Patients with Idiopathic Normal Pressure Hydrocephalus Be Predicted from Preoperative Brain Imaging? A Retrospective Study of the Diagnostic Use of the Normal Pressure Hydrocephalus Radscale in 119 Patients. AJNR. *American journal of neuroradiology* 2022;43(2):223-229.

Carlsen, JF, Munch, TN, Hansen, AE, Hasselbalch, SG & Rykkje, AM. Can preoperative brain imaging features predict shunt response in idiopathic normal pressure hydrocephalus? A PRISMA review. *Neuroradiology* 2022;64(11):2119-2133.

Damsgaard, L, Janbek, J, Laursen, TM, Erlangsen, A, Spira, AP & Waldemar, G. Hospital-diagnosed sleep disorders and incident dementia: a nationwide observational cohort study. *European Journal of Neurology* 2022;29(12):3528-3536.

Daveau, RS, Law, I, Henriksen, OM, Hasselbalch, SG, Andersen, UB, Anderberg, L, Højgaard, L, Andersen, FL & Ladefoged, CN. Deep learning based low-activity PET reconstruction of [11C]PiB and [18F]FE-PE2I in neurodegenerative disorders. *NeuroImage*, 2022;259. 119412.

Diederichsen, SZ, Frederiksen, KS, Xing, LY, Haugan, KJ, Højberg, S, Brandes, A, Graff, C, Olesen, MS, Krieger, D, Køber, L & Svendsen, JH. Severity and Etiology of Incident Stroke in Patients Screened for Atrial Fibrillation vs Usual Care and the Impact of Prior Stroke: A Post Hoc Analysis of the LOOP Randomized Clinical Trial. *JAMA Neurology* 2022;79(10):997-1004.

Feldman, A, Patou, F, Baumann, M, Stockmarr, A, Waldemar, G, Maier, AM & Vogel, A. Listen Carefully protocol: an exploratory case-control study of the association between listening effort and cognitive function. *BMJ Open* 2022;12(3):e051109.

Franzen, S, Bekkhus-Wetterberg, P, van den Berg, E, Calia, C, Canevelli, M, Daugherty, JC, Fasfous, A, Goudsmit, M, Ibanez-Casas, I, Lozano-Ruiz, Á, Mukadam, N, Narme, P, Nielsen, TR, Papma, JM, Pomati, S, Watermeyer, TJ & European Consortium on Cross-Cultural Neuropsychology (ECCroN). Cross-cultural neuropsychological assessment in Europe: Position statement of the European Consortium on Cross-Cultural Neuropsychology (ECCroN). Neuropsychology, Development and Cognition. Section D: *The Clinical Neuropsychologist*. 2022;36(3):546-557.

Frederiksen, KS, Jensen-Dahm, C & Waldemar, G. Behandling af medicinske komorbiditeter ved demens. *Ugeskrift for Laeger* 2022;184(45). V04220275.

Gleerup, HS, Simonsen, AH & Høgh, P. The Added Value of Cerebrospinal Fluid Neurofilament Light Chain to Existing Diagnostic Methods and Biomarkers in a Mixed Memory Clinic Cohort of Consecutive Patients. *Journal of Alzheimer's disease reports* 2022;6(1):121-127.

Gusatovic, J, Gramkow, MH, Hasselbalch, SG & Frederiksen, KS. Effects of aerobic exercise on event-related potentials related to cognitive performance: a systematic review. *PeerJ* 2022;10:e13604.

Hellem, MNN, Cheong, RY, Tonetto, S, Vinther-Jensen, T, Hendel, RK, Larsen, IU, Nielsen, TT, Hjermind, LE, Vogel, A, Budtz-Jørgensen, E, Petersén, Å & Nielsen, JE. Decreased CSF oxytocin relates to measures of social cognitive impairment in Huntington's disease patients. *Parkinsonism & related disorders* 2022;99:23-29.

Hendel, RK, Hellem, MNN, Hjermind, LE, Nielsen, JE & Vogel, A. An Exploratory Study Investigating Autonomy in Huntington's Disease Gene Expansion Carriers. Journal of Huntington's disease 2022;11(4):373-381

Hinge, C, Henriksen, OM, Lindberg, U, Hasselbalch, SG, Højgaard, L, Law, I, Andersen, FL & Ladefoged, CN. A zero-dose synthetic baseline for the personalized analysis of [18F]FDG-PET: Application in Alzheimer's disease. *Frontiers in Neuroscience* 2022;16. 1053783.

Holm Hansen, R, Talbot, J, Højsgaard Chow, H, Bredahl Hansen, M, Buhelt, S, Herich, S, Schwab, N, Hellem, MNN, Nielsen, JE, Sellebjerg, F & von Essen, MR. Increased Intrathecal Activity of Follicular Helper T Cells in Patients With Relapsing-Remitting Multiple Sclerosis. *Neurology: Neuroimmunology and NeuroInflammation* 2022;9(5).

Holm Hansen, R, Højsgaard Chow, H, Talbot, J, Buhelt, S, Nickelsen Hellem, MN, Nielsen, JE, Sellebjerg, FT & von Essen, MR. Peripheral helper T cells in the pathogenesis of multiple sclerosis. *Multiple Sclerosis Journal* 2022;28(9):1340-1350.

Islamoska, S, Hansen, JM, Hansen, ÅM, Garde, AH, Waldemar, G & Nabe-Nielsen, K. The association between migraine and dementia - a national register-based matched cohort study. *Public health* 2022;213:54-60.

Jansen, WJ, Janssen, O, Tijms, BM, Vos, SJB, Ossenkoppele, R, Visser, PJ, Aarsland, D, Alcolea, D, Altomare, D, von Arnim, C, Baiardi, S, Baldeiras, I, Barthel, H, Bateman, RJ, Van Berckel, B, Binette, AP, Blennow, K, Boada, M, Boecker, H, Bottlaender, M, den Braber, A, Brooks, DJ, Van Buchem, MA, Camus, V, Carill, JM, Cerman, J, Chen, K, Chételat, G, Chipi, E, Cohen, AD, Daniels, A, Delarue, M, Didic, M, Drzezga, A, Dubois, B, Eckerström, M, Ekblad, LL, Engelborghs, S, Epelbaum, S, Fagan, AM, Fan, Y, Fladby, T, Fleisher, AS, Van der Flier, WM, Förster, S, Fortea, J, Frederiksen, KS, Johannsen, P, Madsen, K, Waldemar, G & Amyloid Biomarker Study Group. Prevalence Estimates of Amyloid Abnormality Across the Alzheimer Disease Clinical Spectrum. *JAMA Neurology* 2022;79(3):228-243.

Karlsson, WK, Højgaard, JLS, Vilhelmsen, A, Crone, C, Andersen, B, Law, I, Møller, LB, Nielsen, TT, Nielsen, EN, Krag, T, Svenstrup, K & Nielsen, JE. Novel Homozygous Truncating Variant Widens the Spectrum of Early-Onset Multisystemic SYNE1 Ataxia. *Cerebellum* 2022;21(3):514-519.

Knorr, U, Simonsen, AH, Jensen, CS, Zetterberg, H, Blennow, K, Akhøj, M, Forman, J, Hasselbalch, SG & Kessing, LV. Alzheimer's disease related biomarkers in bipolar disorder - A longitudinal one-year case-control study. *Journal of Affective Disorders* 2022;297:623-633.

Li, S, Cui, G, Jørgensen, K, Cheng, Z, Li, Z & Xu, H. Psychometric Properties and Measurement Invariance of the Chinese Version of the Brief Assessment of Impaired Cognition Questionnaire in Community-Dwelling Older Adults. *Frontiers in Public Health* 2022;10:908827. 908827.

Løhde, LW, Bentzon, A, Kornblit, BT, Roos, P & Fink-Jensen, A. Possible Tacrolimus-Related Neuropsychiatric Symptoms: One Year After Allogeneic Hematopoietic Cell Transplantation: A Case Report. *Clinical Medicine Insights: Case Reports* 2022;15.

Musaeus, CS, Waldemar, G, Andersen, BB, Høgh, P, Kidmose, P, Hemmsen, MC, Rank, ML, Kjær, TW & Frederiksen, KS. Long-Term EEG Monitoring in Patients with Alzheimer's Disease Using Ear-EEG: A Feasibility Study. *Journal of Alzheimer's Disease* 2022;90(4):1713-1723.

Musaeus, CS, Johansen, LB, Hasselbalch, S, Beyer, N, Høgh, P, Siebner, HR & Frederiksen, KS. Sixteen weeks of aerobic exercise does not alter resting-state connectivity of the precuneus in patients with Alzheimer's disease. *Current Alzheimer Research* 2022;19(2):171-177.

Nguyen, QTR, Ortigoza Escobar, JD, Burgunder, J-M, Mariotti, C, Saft, C, Hjermind, LE, Youssov, K, Landwehrmeyer, GB & Bachoud-Lévi, A-C. Combining Literature Review With a Ground Truth Approach for Diagnosing Huntington's Disease Phenocopy. *Frontiers in Neurology* 2022;13:817753. 817753.

Nielsen, EN, Ásbjörnsdóttir, B, Møller, LB, Nielsen, JE & Lindquist, SG. Episodic ataxia type 2 (EA2) with interictal myokymia and focal dystonia. *Cold Spring Harbor Molecular Case Studies* 2022;8(6). a006236.

Nielsen, TR, Nielsen, DS & Waldemar, G. A personalized dementia care intervention for family carers from minority ethnic groups in Denmark: A pilot study. *Dementia* 2022;21(2):477-488.

Nielsen, TR, Nielsen, DS & Waldemar, G. Feasibility of a culturally tailored dementia information program for minority ethnic communities in Denmark. *International Journal of Geriatric Psychiatry* 2022;37(1).

Nørgaard, A, Jensen-Dahm, C, Wimberley, T, Svendsen, JH, Ishtiak-Ahmed, K, Laursen, TM, Waldemar, G & Gasse, C. Effect of antipsychotics on mortality risk in patients with dementia with and without comorbidities. *Journal of the American Geriatrics Society* 2022;70(4):1169-1179.

Oernbo, EK, Steffensen, AB, Gredal, H, Poulsen, HH, Rostgaard, N, Rasmussen, CH, Møller-Nissen, M, Simonsen, AH, Hasselbalch, SG, Juhler, M & MacAulay, N. Cerebrospinal fluid osmolality cannot predict development or surgical outcome of idiopathic normal pressure hydrocephalus. *Fluids and Barriers of the CNS* 2022;19(1):52. 52.


APATHY, SOCIAL COGNITION, AND SELF-PERCEPTION
ASSESSING NEUROPSYCHOLOGICAL FACTORS IN HUNTINGTON'S DISEASE
PhD Thesis

Oernbo, EK, Steffensen, AB, Razzaghi Khamesi, P, Toft-Bertelsen, TL, Barbuskaite, D, Vilhardt, F, Gerkau, NJ, Tritsaris, K, Simonsen, AH, Lolansen, SD, Andreassen, SN, Hasselbalch, SG, Zeuthen, T, Rose, CR, Kurtcuoglu, V & MacAulay, N. Membrane transporters control cerebrospinal fluid formation independently of conventional osmosis to modulate intracranial pressure. *Fluids and Barriers of the CNS* 2022;19(1):65. 65.

Pourhadi, N, Mørch, LS, Holm, EA, Torp-Pedersen, CT & Meaidi, A. Vaginal estrogen and association with dementia: A nationwide population-based study. *Alzheimer's & dementia* 2022;18(4):625-634.

Roos, P, Johannsen, P, Lindquist, SG, Brown, JM, Waldemar, G, Duno, M, Nielsen, TT, Budtz-Jørgensen, E, Gydesen, S, Holm, IE, Collinge, J, Isaacs, AM, Nielsen, JE & Frontotemporal dementia Research in Jutland Association (FReJA) consortium. Six generations of CHMP2B-mediated Frontotemporal Dementia: Clinical features, predictive testing, progression, and survival. *Acta Neurologica Scandinavica* 2022;145(5):529-540.

Schnier, C, Janbek, J, Lathe, R & Haas, J. Reduced dementia incidence after varicella zoster vaccination in Wales 2013-2020. *Alzheimer's & dementia* 2022;8(1):e12293.

Skov, SS, Nielsen, MBD, Krølner, RF, Øksnebjerg, L & Rønbøl Lauridsen, SM. A multicomponent psychosocial intervention among people with early-stage dementia involving physical exercise, cognitive stimulation therapy, psychoeducation and counselling: Results from a mixed-methods study. *Dementia*, 2022;21(1):316-334.

Talbot, J, Højsgaard Chow, H, Mahler, M, Buhelt, S, Holm Hansen, R, Lundell, H, Vinther-Jensen, T, Hellem, MNN, Nielsen, JE, Siebner, HR, von Essen, MR & Sellebjerg, F. Relationship between cerebrospinal fluid biomarkers of inflammation and tissue damage in primary progressive multiple sclerosis. *Multiple Sclerosis and Related Disorders* 2022;68:104209.

Thomsen, TH, Jørgensen, LB, Kjær, TW, Haahr, A, Vogel, A, Larsen, IU & Winge, K. Clinical Markers of 6 Pre-dominant Coping Behaviors in Living With Parkinson Disease: A Convergent Mixed Methods Study. INQUIRY: *The Journal of Health Care Organization, Provision, and Financing* 2022;59:469580221129929.

Torkpoor, R, Frolich, K, Nielsen, TR & Londos, E. Diagnostic Accuracy of the Swedish Version of the Rowland Universal Dementia Assessment Scale (RUDAS-S) for Multicultural Cognitive Screening in Swedish Memory Clinics. *Journal of Alzheimer's Disease* 2022;89(3):865-876.

Uwishema, O, Frederiksen, KS, Correia, IFS, Mahmoud, A, Onyeaka, H & Dost, B. The impact of COVID-19 on patients with neurological disorders and their access to healthcare in Africa: A review of the literature. *Brain and Behavior* 2022;12(9):e2742.

Vogel, A, Jørgensen, K & Larsen, IU. Normative data for Emotion Hexagon test and frequency of impairment in behavioral variant frontotemporal dementia, Alzheimer's disease and Huntington's disease. *Applied neuropsychology. Adult* 2022;29(1):127-132.

BOOKS

Øksnebjerg, L, Hasselbalch, SG, Lolk, A & Vølund, B. *Forstå Demens*. Hans Reitzel, Copenhagen 2022. 372 p.

BOOK CHAPTERS

Hasselbalch, SG. & Frederiksen, KS. Demensdiagnostik. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;107-118

Frederiksen, KS & Hasselbalch, SG. Fysisk træning og aktivitet for mennesker med demens. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;185-190.

Guldberg, A-M & Hasselbalch, SG. Toksisk påvirkning af hjernen - alkohol, polyfarmaci og afhængighed. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;101-106.

Hasselbalch, SG, Ringkøbing, SP & Stokholm, J. Demenssygdomme. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;27-74.

Hasselbalch, SG, Høgh, P & Lolk, A. Medicinsk behandling af demens. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;147-159.

Hjermind, LE & Nielsen, JE. Demens og bevægeforstyrrelser. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;75-81.

Hvass, A-M & Lindquist, SG. Arvelige ændringer i koagulationssystemet og hæmoglobinsygdomme. In L Sunde & E Østergaard (ED), *Medicinsk genetik*. FADL's Forlag, Copenhagen 2022;331-335.

Jørgensen, K. Risikoreduktion og forebyggelse af demens. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;137-144.

Lindquist, SG. Arvelige neurologiske sygdomme. In L Sunde & E Østergaard (ED), *Medicinsk genetik*. FADL's Forlag, Copenhagen 2022;229-244.

Lindquist, SG & Hasselbalch, SG. Demens og arvelighed. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;129-135.

Nielsen, TR. Etniske minoriteter. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;259-267.

Roos, P & Vogel, A. Den normale hjerne. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;11-25.

Tannebæk, K. Demensvenlig indretning. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;231-237.

Waldemar, G. Huske. In A Langballe, BS Nielsen, D Travn, K Hundevadt & TY Højrup (ED), *Ord: Encyklopædi*. Politikens Forlag 2022;111.

Øksnebjerg, L, Fejerskov, UV & Tannebæk, K. Kognitiv stimulationsterapi. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;203-208.

Øksnebjerg, L. Psykosociale indsatser. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;161-168.

Øksnebjerg, L. Rehabilitering. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;191-202.

Øksnebjerg, L & Tannebæk, K. Teknologi til mennesker med demens. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;221-229.

Øksnebjerg, L. Yngre med demens. In L Øksnebjerg, SG Hasselbalch, A Lolk & B Vølund (ED), *Forstå Demens*. Hans Reitzel, Copenhagen 2022;251-257.

LETTER

Høck, AN, Jensen, SR, Sværke, KW, Brennum, J, Jespersen, B, Bergdal, O, Karlsborg, M, Hjermind, LE & Løkkegaard, A. A randomised double-blind controlled study of Deep Brain Stimulation for dystonia in STN or GPi - A long term follow-up after up to 15 years. *Parkinsonism & related disorders* 2022;96:74-79.

OTHER PUBLICATIONS

Gleerup, HS. *Lactoferrin in cerebrospinal fluid and saliva is not a diagnostic biomarker for Alzheimer's disease in a mixed memory clinic population*. Master's Thesis 2022.

Mellergaard, C. *Characterising the prodromal phase in dementia with Lewy bodies*. Master's Thesis 2022.

Nguyen, QTR, Ortigoza Escobar, JD, Burgunder, J-M, Mariotti, C, Saft, C, Hjermind, LE, Youssov, K, Landwehrmeyer, GB & Bachoud-Lévi, A-C. *Corrigendum: Combining Literature Review With a Ground Truth Approach for Diagnosing Huntington's Disease Phenocopy* 2022.

# Finance

The DDRC's total annual budget for 2022 was approximately DKK 69.4 m, distributed almost evenly between internal funding (DKK 33.6 m for memory clinic services) and external grants (DKK 35.8 m for research, contracts and educational activities). An important 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 2022 (DKK M) | |
|---|---|
| **New grants received*** | **13.9** |
| **New grants accumulated 2007-2022*** | **248.8** |
| **External grants spent on specific programmes and projects**<br>• National Information and Education Centre for Dementia from the Danish Ministry of Health, including projects<br>• Other external grants for research*<br>• Grant to Danish Memory Clinics** | **27.2**<br>13.3<br>10.2<br>3.7 |
| **Conferences, educational courses and products** | **5.1** |
| **Research contracts** | **3.5** |

* 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 2022 | |
|---|---|
| **No. of employees/full-time equivalents** | **95/83** |

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Absalon Foundation

The Alzheimer Research Foundation

A.P. Møller Fonden (Den A.P. Møllerske Støttefond (Støttefonden) og Fonden til Lægevidenskabens Fremme)

Augustinus Fonden

Axel Juul Muusfeldt Foundation

The Danish Order of Freemasons

Danish Medical Association (Læge Søren Segel og hustru Johanne Wiibroe Segels Forskningsfond)

Danish Ministry of Health

Direktør Emil C. Hertz og Hustru Inger Hertz's Fond

Dronning Margrethe og Prins Henriks Fond

Ellen Mørchs Fond

European Academy of Neurology

European Union

Familien Hede Nielsens Fond

Fonden for Neurologisk Forskning

Frimodt-Heineke Fonden

Gangstedfonden

Helsefonden

H. Lundbeck

Huntington's National Association

Innovation Fund Denmark

Jascha Foundation

Kronprins Frederik og Kronprinsesse Marys Fond

Lundbeck Foundation

National Foundation for Medical Research and Innovation, NFMRI (Australia)

Novo Nordisk Foundation

Parkinson Association

P.A. Messerschmidt & Hustrus Fond

Rigshospitalet Scientific Committee

Toyota Foundation

Trial Nation Denmark

TrygFonden

UNEEG medical

VELUX FOUNDATION

World Health Organisation (WHO)

Aase and Ejnar Danielsen Foundation

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