DANISH DEMENTIA RESEARCH CENTRE

ANNUAL REPORT 2024

Copenhagen Memory Clinic and
National Information & Education Centre for Dementia

DANISH DEMENTIA RESEARCH CENTRE

Contents

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

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

Preface

It is a pleasure to present the 2024 annual report for the Danish Dementia Research Centre (Nationalt Videnscenter for Demens) with an overview of our activities in patient care and research as well as national educational activities.

Two new reforms were launched by the Danish Government in 2024: the health reform (Sundhedsreformen) and a reform program for elderly care (Ældrereformen). DDRC will follow the implementation of both reforms closely with the aim to contribute to best practice in the field of dementia for the benefit of patients. In 2024 we were honored by official visits by the Danish Minister of Senior Citizens Mette Kierkgaard, and the Swedish Minister for Older People and Social Security Anja Tenje, and their delegations.

Funded by the Ministry of Health, we initiated two new nationwide projects in 2024 on 1) developing new models for diagnostic evaluation of dementia – a shared model between primary care and memory clinics; 2) reducing the use of antipsychotics in people with dementia. – in collaboration with KiAP (Quality in General Practice). We were also grateful for funding for an upgrade of the ABC Dementia e-learning program. The e-learning can be accessed free-of-charge from our website continues to attract many professionals from various disciplines. A total of 12.707 completed a course in 2024, where two new programs on delirium and infections were launched. The annual two-day conference Dementia Days (DemensDagene) and our nationwide courses and network meetings attracted more than 3.000 participants in 2024. Furthermore, we are in contact with thousands of professional carers and specialists in the field of dementia, who are users our website, newsletters or social media profiles. Our website alone had 1,7 mio. visits in 2024.

In 2024 we published a total of three PhD theses and more than 50 scientific papers in international journals. We welcome proposals for new collaborative research programs, based on our patient cohorts, data and biobank, which are described in this report together with our thematic areas of research. The Copenhagen and Bornholm memory clinics received more than 2.000 referrals in 2024, where a new teaching program for patients (and their caregivers) with Mild Cognitive Impairment (MCI) was launched.

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

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

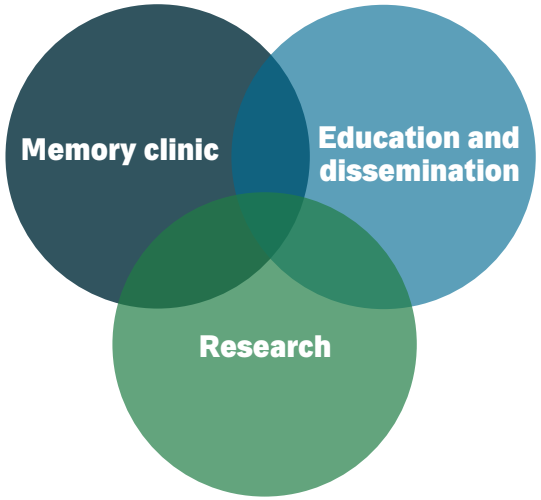
About the Danish Dementia Research Centre

ORGANISATION

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

The link between patient care in the memory clinic, research and nationwide education and dissemination under the same umbrella is a unique strength of DDRC and offers the opportunity of shared positions. Furthermore, the organisation strengthens the evidence behind our educational services and ensures that our research and education programs are continuously inspired by the need of our patients.

Initiated and funded by the Danish Ministry of Health, the mission of the National Information and Education Centre for Dementia is to strengthen and coordinate health research in relation to specific treatment and care interventions in clinical practice and to assure national dissemination and communication of knowledge in collaboration with Danish Regions and the 98 Danish municipalities.



Chaired by Kurt Espersen, Vice-president, Region of Southern Denmark and appointed by Danish Regions, the national steering committee (Styregruppen) monitors the strategic development and performance of the National Information and Education Centre for Dementia according to predefined objectives and milestones, as outlined in our strategy for 2021-2025. A national scientific advisory board (Referencegruppen) re-

views and contributes with advice on major educational and scientific activities. For an updated list of members of the steering committee and advisory board, see www.videnscenterfordemens.dk.

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

STRATEGY 2021-2025

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

Groundbreaking research

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

Interdisciplinary national anchoring

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

User-involving innovation

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

Attractive evidence bank

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

Active public voice

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

VISION

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

Special events in 2024

Dementia Days 2024

Organized since 1999, our annual two-day conference Dementia Days (DemensDagene) is the largest conference on dementia – and one of the largest on health care – in Denmark. In 2024 the Dementia Days took place in Tivoli Congress Center in Copenhagen with more than 1000 participants. With the overarching theme “Equality in Health”, the program was conducted in plenary sessions and four parallel tracks during two days.

Visits from two ministers in DDRC

The Swedish Minister for Older People and Social Security Anna Tenje visited the National Information & Education Centre for Dementia on april 22nd with the Swedish ambassador Charlotte Wrangberg among others to learn about the organization of dementia in Denmark and about the work of the National Information & Education Centre for Dementia.

On October 30th the Danish Minister of Senior Citizens Mette Kierkgaard visited National Information & Education Centre for Dementia to learn about our activities and about the new dementia-friendly garden.

3 PhD defenses in 2024

In April **Christian Sandøe Musaeus**, MD, defended his PhD thesis with the title "Long-term outpatient ear-EEG monitoring for detection of epileptiform discharges in patients with Alzheimer's disease and Lewy body dementia".

Assessment committee: Rigmor Højland Jensen, Professor, Copenhagen University Hospital – Rigshospitalet, Sándor Beniczky, Professor, Aarhus University Hospital and Alice D. Lam, Assistant Professor, Harvard Medical School and Massachusetts General Hospital, USA.
Supervisors: Gunhild Waldemar, Professor, and Kristian Steen Frederiksen, Associate Professor, both from DDRC, Copenhagen University Hospital – Rigshospitalet.

In September cell biologist **Emil Elbæk Henriksen** defended his PhD thesis with the title "Advancing SCA2 Research. Proteomic Characterization, Autophagy Modulation and Cerebellar Organoid Model Development".

Assessment committee: Henriette Pilegaard, Professor. Faculty of Science, University of Copenhagen, Denmark, Peter Broos, Associate Professor, Aarhus University Hospital and Margarida Diogo, Associate Professor, University of Lisbon, Portugal.
Supervisors: Jørgen Erik Nielsen, Professor, and Patrick Ejlerskov, Senior researcher, both from DDRC, Copenhagen University Hospital – Rigshospitalet.

In October **Anders Toft** (MD) defended his PhD thesis with the title "CHMP2B-mediated frontotemporal dementia – Markers, models, and mechanisms".

Assessment committee: Finn Sellebjerg, Professor, Copenhagen University Hospital – Rigshospitalet, Bente Finsen, Professor, University of Southern Denmark and Jonathan Rohrer, Professor, University College London, United Kingdom.
Supervisors: Jørgen Erik Nielsen, Professor, and Patrick Ejlerskov, Senior researcher, both from DDRC, Copenhagen University Hospital – Rigshospitalet and Adrian Isaacs, Professor, University College London, United Kingdom.

Awards in 2024

The Danish Alzheimer's Association Research Fund

At the annual grants and award ceremony organized by the Danish Alzheimer Association in September 2024 three researchers from DDRC recieved financial support from the Alzheimer Research Foundation to their research: PhD student **Cecilie Madsen** (the grant was recieved by senior researcher Patrick Ejlerskov to the left), PhD student **Daniel Kjærgaard** and Post Doc **Janet Janbek**.

Award from Danish Neurological Society (Prize for Young Researchers)

MD and PhD at DDRC **Christian Sandøe Musaeus**, recieved "The Prize for Young Researchers" from Dansk Neurologisk Selskab.

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

Copenhagen Memory Clinic

Copenhagen Memory Clinic at Rigshospitalet is a secondary and tertiary referral-based multidisciplinary out-patient clinic. Since the clinic was established in 1995, it has offered diagnostic evaluation and treatment of patients with cognitive disorders and dementia. We receive referrals from general practitioners and private practice neurologists and psychiatrists and from other hospitals in the Capital Region of Denmark. Patients may also be referred from other memory clinics for second opinion evaluations and from other regions in Denmark for our highly specialized functions. A satellite memory clinic is located on the island of Bornholm.

Copenhagen Memory Clinic in 2024:

- 2,035 new patients
- 18,000 physical or virtual visits

Our dedicated multidisciplinary team comprise consultant neurologists, psychiatrists, geriatricians, neuropsychologists, specialist nurses, a clinical geneticist, a social counsellor and medical secretaries. The Copenhagen Memory Clinic and the memory clinic based in the geriatric department in Bispebjerg-Frederiksberg hospital (BFH) share responsibility for referrals from the central Copenhagen district ("BYEN"). A specialist in neurology from the Copenhagen Memory Clinic takes part in the weekly MDT conference at BFH, reviewing all new patients.

Following diagnostic evaluation, all patients with mild cognitive impairment (MCI), and selected groups of patients with dementia or specific neurodegenerative disorders from the local catchment area are offered counselling and follow-up in collaboration with primary health care. Patients with conditions of uncertain aetiology and healthy mutation carriers may also be offered follow-up in the memory clinic. Most patients are accompanied by their

family caregivers when visiting the clinic, and we offer counselling and courses for the caregivers as an integral part of the follow-up programme.

In 2024 we launched a new teaching course for patients diagnosed with Mild Cognitive Impairment (MCI) due to Alzheimer's disease. The aim of the course was to provide patients and their caregivers with useful information on the condition and advice on preventive measures.

BORNHOLM MEMORY CLINIC

The outpatient satellite clinic on the island of Bornholm is located at the internal medicine department in Bornholm's Hospital. A team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic, together with a local nurse and a medical secretary from Bornholm's Hospital offers consultations one day per week for patients on Bornholm. On one additional day per week a resident in geriatrics sees patients under the (online) supervision of a neurologist from the Copenhagen Memory Clinic.

Bornholm Memory Clinic in 2024:

- 137 new patients
- 877 physical or virtual visits

SPECIALISED MEDICAL SERVICES

Patients with rare, complex or familial disorders may be referred from all parts of Denmark (mainly Eastern Denmark). 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)
- Diagnostic evaluation, lumbar perfusion and tap tests for patients with suspected normal pressure hydrocephalus (NPH)

The highly specialised services are performed in collaboration with several other specialist departments at Rigshospitalet.

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 offered in collaboration with the Department of Clinical Genetics at Rigshospitalet. In 2024 190 family members were referred. The clinic also offers post-genetic test counselling when needed.

REGIONAL AND NATIONAL COLLABORATION

There is a close collaboration with the geriatric memory clinic at Bispebjerg-Frederiksberg Hospital om referrals from the city of Copenhagen.

In 2011 the Capital Region established a guideline ("forløbsprogram") for coordinated patient care pathways between the four hospitalbased 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 contributes with data to the national quality registry DanDem and is also an active member of the regional and national networks of memory clinics, coordinated by DDRC.

DIAGNOSTIC CLASSIFICATION OF NEW PATIENTS REFERRED FOR DIAGNOSTIC EVALUATION TO THE COPENHAGEN AND BORNHOLM MEMORY CLINICS IN 2024

Based on data from the DanDem quality registry[1]

DAGNOSTIC CATEGORY	NUMBER OF PATIENTS
Alzheimer's disease	617
Cerebrovascular disease	203
Mixed Alzheimer's disease	118
Dementia with Lewy Bodies	71
Frontotemporal dementia	36
Parkinson's disease	7
Atypical Parkinson's disease	4
Huntington's disease	6
Other specific neurodegenerative disorder	25
Normal Pressure Hydrocephalus	99
Alcohol-related disorder	31
Psychiatric disorder	63
Other specific conditions	64
Uncertain etiology[2]	352
No/subjective cognitive impairment[3]	339
Total	2035

1) In addition, 190 healthy family members from families with hereditary disorders were referred for genetic counselling.
2) This category includes patients in whom follow-up was needed for clarfication of diagnosis and patients in whom detalied diagnostic work-up was not possible.
3) This category includes patients with familial neurodegenerative disorders without cognitive impairment.

About our research

The DDRC research programs are focused on epidemiological, clinical and translational research in cognitive impairment and neurodegenerative disorders. Most of our research is funded by grants and donations from public and private foundations.

The 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.

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) to work with molecular cloning and viral vectors. The laboratory has 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, and organoids.

Clinical Trial Unit and Trial Nation Denmark

The Clinical Trial Unit is located adjacent to the memory clinic, and has examination rooms, an infusion room, and a fully equipped lab. In 2024 we conducted trials in phase 1, 2 and 3 in patients with Alzheimer's disease and Huntington's disease.

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. DDRC serves as the medical lead and coordinating center for dementia diseases.

Danish Dementia BioBank and clinical cohort research data

The Danish Dementia BioBank (DDBB) contains samples from more than 15.000 patients who have consented for their data to be used for research. Whole blood, buffy coat, EDTA plasma and serum are stored for all patients, as well as CSF from approximately 25 % of the patients. In addition to these samples, we collect clinical and paraclinical data and our database now holds more than 200.000 datapoints associated with the biological specimens.

Danish national registries

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

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 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 multicenter intervention studies have been coordinated by DDRC leading to large nationwide patient cohorts with follow-up data. As an example collaboration on dementia research in selected Danish memory clinics has been established in the ADEX consortium (coordinated by DDRC) – a multicentre Danish research network from across the country.

DDRC is a member of several international networks on familial dementia disorders, such as the European Huntington Disease Network, and the Genetic Frontotemporal dementia Initiative and Frontotemporal Research in Jutland Association.

Thematic areas of research

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



Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist
Kristian Steen Frederiksen, MD, clinical research associate professor, senior neurologist
Anja Hviid Simonsen, MScPharm, PhD, senior researcher

Early diagnosis: Biomarkers

In the biomarker group the main research focus is to investigate biochemical, imaging and digital biomarkers for the early diagnosis, prognosis and monitoring of patients with neurodegenerative diseases.

In 2024 the research projects in our group included:

- AROMA: investigating the presence of alpha-synuclein and neurological symptoms in patents with anosmia.
- TRACK-AD: investigation of pupillometry in a mixed memory clinic cohort. We found that pupillometry is a promising added biomarker in the diagnostic evaluation of AD.
- In a consecutive and heterogeneous cohort of 250 subjects we found that a combination of plasma biomarkers could detect amyloid pathology potentially replacing lumbar puncture.

Using hand-held quantitative pupillometry, the light reflex is recorded within seconds and is able to inform on the probability of neurodegenerative disorders by applying an in-house developed model.

Asmus Vogel, MSc, PhD, neuropsychologist, associate professor
Kasper Jørgensen, MSc, neuropsychologist, senior researcher

Early diagnosis: Neuropsychology

In the neuropsychology group we continuously strive to develop and validate tests and scales to characterize cognitive deficits in the early phase of dementia and MCI.

We investigate cognitive deficits in patients examined in highly specialized memory clinic functions, in general practice and from targeted groups as persons with inherited dementia diseases. Highlights in 2024 are:

- A new PhD project of cognitive and behavioural manifestations of Huntington disease was initiated. The project includes substudies on emotion regulation, apathy, and memory functions in genemutation carriers.
- In collaboration with the Centre of Hearing and Balance at Rigshospitalet we were awarded DKK 2.48 million to perform a study on the possible association between cognitive dysfunction and hearing impairments in healthy older persons and in MCI patients.
- From the MYSELF study we have published papers describing the role of subjective cognitive impairment in early AD and Subjective Cognitive Decline.

The red dot refer to the eight memory clinics that have baeen involved in an international multicenter validationstudy of BASIC and BASIC-Q. The greem dot refers to the validation in Danish general pracsis.

- Further validation of two case-finding tools for cognitive impairment, BASIC and BASIC-Q, was initiated in several Western European countries. BASIC-Q has been implemented in the Municipality of Copenhagen as a case-finding tool in older citizens

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

Inherited neurodegenerative disorders

The exact disease mechanisms of most neurodegenerative conditions are still unknown, and effective treatments are lacking. We have built up a broad range of resources that can provide a paradigm for translational research from common cellular disease mechanisms to clinical pathologies such as Alzheimer's disease (AD), Frontotemporal dementia (FTD), and amyotrophic lateral sclerosis (ALS). In 2024 the research projects in our group included:

- Investigations of dysregulation of the innate antiviral immune pathways and autophagy-interfering viruses in relation to neurodegenerative disease
- Investigations of dysregulated cellular pathways in 2D neuronal and microglia cultures and 3D brain organoids generated from patient-derived pluripotent stem cells and their isogenic controls.
- Investigation of extracellular vesicles in cerebrospinal fluid (CSF) and iPSC-models as novel biomarkers and potential treatment modalities in FTD and AD.
- A longitudinal cohort study of cognitive and behavioral manifestations in parallel with changes in CSF biomarkers in Huntington's disease.

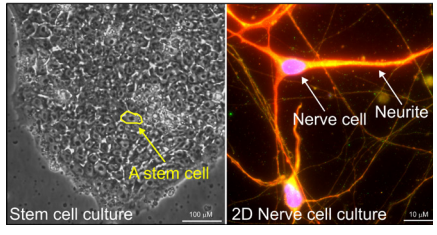


Figure 1. 2D cell models for research experiments. The stem cells are generated from skin biopsies taken from patients at the Memory Clinic at Rigshospitalet. The stem cells grow in clusters and a single stem cell is shown in the yellow ring. From stem cells, we generate microglia (immune cells of the brain) and neurons. The neurons develop 'long arms' called neurites, which are used to communicate with other neurons.

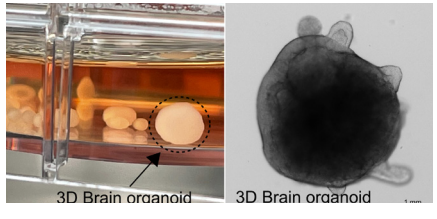


Figure 2. 3D brain organoids for research experiments. Brain organoids are also created from stem cells, and they form small cell spheres. It takes 2-6 months to obtain a mature brain organoid, which forms an 3D organization that better represents a human brain.



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

Epidemiology and public health in dementia

Our group focuses on dementia epidemiology by utilizing the Danish national register and other nationwide data to explore the health and wellbeing of persons with dementia and caregivers. We aim to further knowledge and translate it into practice/policy on dementia prevention, diagnosis, and care.

In 2024, our research projects included:

- Exploration of fingerprints/markers of young-onset Alzheimer's Disease to improve timely diagnosis.
- Studies on links between commonly used medications (e.g., opioids) and dementia development and the potential adverse events for people living with dementia.
- A focus on the role of infections in dementia, building on decades of debated hypotheses in the field.
- Investigating the trends and benefits of influenza vaccination in people with dementia.
- Initiating studies on the health/wellbeing of family caregivers for people with dementia.

The Public Danish Registers

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

Cross-cultural aspects of dementia

The main focus within this area is to investigate dementia diagnostics and care in minority ethnic groups and to develop and validate novel cross-cultural assessment methods, in Denmark and Europe.

In 2024, the research projects included:

- An investigation of the influence of ethnicity on diagnostic accuracy of plasma p-tau217 for identification of Alzheimer's disease in memory clinic patients (performed in collaboration with the Clinical Memory Research Unit at Lund University, Sweden)
- Development of clinical recommendations on interpreter-mediated neuropsychological assessment (performed in collaboration with the European Consortium on Cross-Cultural Neuropsychology).
- A 14-year follow-up survey on assessment of dementia in minority ethnic groups in Europe. The survey explored current practices for assessing dementia in patients from minority ethnic groups and whether these had changed during the last 14 years.
- Cross-cultural validation studies for two casefinding tools for cognitive impairment (BASIC and BASIC-Q) in multicultural memory clinic populations across six European countries.

Participants representing six European countries contributed to the closing meeting for the project: Timely Diagnosis of Dementia in Minority Ethnic Groups in Europe (TIMING).

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 2024 are presented here.

PROFESSORS AND ASSOCIATE PROFESSORS

Steen G. Hasselbalch
– Early Diagnosis, Neuroimaging and Biomarkers
Consultant neurologist, clinical professor and research director, DMSc. Main research interests include diagnosis and pathophysiology of dementia disorders including normal pressure hydrocephalus.

Jørgen E. Nielsen
– Inherited Neurodegenerative Disorders
Consultant neurologist, clinical professor and research director, PhD. Main research areas are genotype-phenotype correlations and molecular biology of inherited neurodegenerative disorders, especially Huntingtons disease, Spinocerebellar ataxias, Spastic paraplegias and hereditary forms of Alzheimers disease and Frontotemporal dementias.

Gunhild Waldemar
– Intervention Studies, Epidemiology and Global Health
Consultant neurologist, clinical professor and chair of DDRC, DMSc. Main research areas include epidemiology, public health, diagnostic markers, and interventions in dementia.

Kristian Steen Frederiksen
– Lewy Body Dementia and Biomarkers in Neurodegenerative Dementia Disorders
Consultant neurologist, clinical research associate professor, PhD. Director of the Clinical Trials Unit and PI in AD drug trials. Main research areas include prodromal Lewy Body Dementia, Alzheimer's disease, biomarkers and interventions in Alzheimer's and Lewy body dementia.

T. Rune Nielsen
– Cross-Cultural Assessment and Dementia in Ethnic Minorities
Neuropsychologist and associate professor, PhD. Main research areas are cross-cultural neuropsychological assessment, including development and validation of cross-cultural measures, and dementia care in minority ethnic groups.

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

SENIOR RESEARCHERS

Patrick Ejlerskov
– Neurodegenerative Diseases, Autophagy, and Innate Immune Pathways
Senior researcher, group leader, PhD, MSc. Our research focuses on cellular pathways with special emphasis on autophagy, neuroinflammation, and anti-viral immune pathways, using induced pluripotent stem cells derived from patients with dementia.

Kasper Jørgensen
– Norming, Validation and Development of Neuropsychological Tests and Case-Finding Instruments
MSc, neuropsychologist. Main research areas include norming, validation and development of neuropsychological tests and brief case-finding instruments and epidemiological modelling of the potential for reduction of dementia risk.

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.

CLINICAL RESEARCHERS

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

POST DOCS

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

Rebecca Thea Kjærgaard Hendel
– The Link Project
Postdoctoral fellow, PhD, MSc. Her research project examines the association between impaired hearing and cognitive functions among older adults. Impaired hearing has been found to be a potential risk factor for dementia and this project seeks to examine the association more thoroughly in a Danish cohort.

Janet Janbek
– Role of Infections in Dementia
Postdoctoral fellow, PhD, MScPH. Research on the epidemiology and public health aspects of dementia. Specific focus is on the role of infections in dementia (Project IDEM). The project will investigate infections in dementia care as well as the role of infections as risk factors.

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

Emil Elbæk Henriksen
– CAG-repeat disorders and brain organoid models
Investigating cellular mechanisms of CAG-repeat disorders, focusing on ATXN2 polyglutamine expansion effects in patient-derived cells. Developing and optimizing iPSC-derived brain organoid models to study disease pathology and test future interventions.

POST DOCS

Anders Toft
– CHMP2B-mediated frontotemporal dementia: Markers, Models and Mechanisms
His project aims to clarify the role of neuroinflammation in genetic FTD. It includes clinical data, inflammatory biomarkers, and differentiation of patient-derived stem cells into neuronal and glial cell models to investigate neuroinflammation on a cellular level.

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.

Jose Lombardia Gutierrez
– Molecular Aspects of Viral-induced Dementia
Postdoctoral fellow, PhD, MSc. Research focus on the relationship between anti-viral immune intracellular pathways, autophagy, and the accumulation of neurotoxic proteins. He uses induced pluripotent stem cells derived from patients with neurodegenerative diseases to generate neuronal cultures where he studies how viral infections interfere with autophagy and lead to protein aggregation.

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.

PHD STUDENTS

Birna Ásbjörnsdóttir
– Endophenotypes, biomarkers and the permeability of the blood-brain barrier in Huntington´s disease.
Her project is a longitudinal cohort study of clinical manifestations in Huntington´s disease gene expansion carriers in parallel with changes in CSF biomarkers, blood based biomarkers and the permeability of the blood brain barrier.

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

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

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

Helena S. Gleerup
– Performance and Utilization of Blood Biomarkers in the Diagnostic Evaluation of Dementia Disorders in a Mixed Memory Clinic
Her project investigates the diganostic accuracy and integration of blood-based biomarkers in the diagnostic evaluation of various dementia disorders.

PHD STUDENTS

Daniel Kjærgaard
– Blood and Diversity (BlooDiv)
His two international projects aim to improve dementia diagnostics, particularly for minority ethnic groups using novel cross-cultural cognitive tests and blood-based biomarkers of Alzheimer's disease.

Cecilie Madsen
– Cellular Secretion of Vesicles in Dementia
Her project aims to investigate how small vesicles secreted by brain cells are changed in FTD-3 and AD, using clinical samples and patient-derived brain cells.

Oskar McWilliam
– Early Signs, Symptoms, and Biomarkers of Lewy Body Diseases
The overarching objective of his projects are to identify early clinical warning signs and biomarkers in prodromal and manifest Lewy Body disease with the novel RT-QuIC technique.

Emma Sofie Kjær Pedersen
–Improving health and wellbeing in family caregivers of people with dementia
Her project aims to ultimately improve the quality of life for family caregivers by identifying health issues linked to caregiving, validating measures of carer-related quality of life, and assessing the effects of the Danish DemTool intervention trial.

Emilie Poulsen
– Behavioural Changes and Cognitive Deficits in Huntington's Disease
Her PhD project investigates some of the under-researched aspects of neuropsychological symptoms, including emotion regulation, apathy, and memory processes, in Huntington's disease genemutation carriers.

Nelsan Pourhadi
– Commonly used Medications and Dementia
Using the national Danish registries, his project investigates the use of commonly prescribed drugs and the risk of developing dementia. He will further examine polypharmacy in people with and without dementia.

ASSOCIATED RESEARCHERS (CURRENTLY EMPLOYED ELSEWHERE)

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.

Christian Sandøe Musaeus
– Epileptiform Discharges in AD
His project assesses subclinical epileptiform discharges with continuous EEG monitoring using novel ear EEG registration and correlating findings with MRI hippocampal blood flow assessments.

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 co-ordinated studies on assessment tools, health economics, biomarkers, cross-cultural aspects of dementia care, and position and guideline papers.

PREDICTND

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

EUROPEAN HUNTINGTON'S DISEASE NETWORK (EHDN) AND ENROLL HD

DDRC is part of EHDN, which provides a platform for professionals and people with HD and their relatives to facilitate collaboration throughout Europe. DDRC's staff and families affected by HD have contributed significantly to clinical cohort studies and intervention studies. Enroll HD, initiated in 2012, is the world's largest observational study for HD families. Designed as a clinical research platform, it enables health care professionals, scientists and families affected by HD to work together towards an improved understanding of HD and better care and treatments. At the end of 2023, DDRC's Enroll HD cohort comprised more than 333 participants.

FRONTOTEMPORAL DEMENTIA RESEARCH IN JUTLAND ASSOCIATION (FReJA)

FReJA is an international multidisciplinary consortium established more than three decades ago to investigate a unique, large family with familial frontotemporal dementia (CHMP2B-FTD) in western Jutland. Basic and clinical scientists in Denmark, Sweden and the UK have made major progress over the years in identifying the disease gene and in understanding the disease mechanisms and their wider relevance for neurodegeneration in general.

THE GENETIC FRONTOTEMPORAL DEMENTIA INITIATIVE (GENFI)

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

ERN-RND – EUROPEAN REFERENCE NETWORK – RARE NEUROLOGICAL DISEASES

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

INTERDEM

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

NORDIC NETWORK IN DEMENTIA DIAGNOSTICS (NIDD)

NIDD, funded by the Nordic Council, comprises six academic memory clinics in the Nordic countries. The main objective of the network is to examine various aspects of diagnostic procedures in dementia. One ongoing project involves evaluating quantitative EEG in Dementia diagnostics. DDRC and the Zealand University Hospital Memory Clinic in Roskilde are the network's Danish partners.

EUROPEAN CONSORTIUM ON CROSS-CULTURAL NEUROPSYCHOLOGY (ECCRON)

ECCroN was founded in late 2019 and comprises neuropsychologists, neurologists and psychiatrists working with cross-cultural neuropsychological assessment in several European countries, and the 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 and recommendations for interpreter-mediated neuropsychological assessment, and research on dementia epidemiology in minority ethnic groups and validation of cross-cultural cognitive tests for assessment of dementia.

NATIONAL DEMENTIA RESEARCH AND EDUCATION CENTRES IN SCANDINAVIA

Norway, Sweden and Denmark have national non-profit dementia research and education centres commissioned and funded by the national boards or ministries of health. DDRC, the Norwegian National Centre for Ageing and Health ("Aldring og Helse"), and the Swedish Dementia Centre ("Svenskt Demenscentrum") collaborate to share ideas and have exchanged programs for the benefit of professional care staff, people with dementia, and family caregivers throughout Scandinavia.

DYSTONIA EUROPE

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

EUROPEAN DLB

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


DemensDagene
– årets tværfaglige konference



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

National Information and Education Centre for Dementia

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

PROJECTS

DDRC was commissioned by the Danish Ministry of Health to conduct three new projects in 2024-2027:

- Developing new models for diagnostic evaluation of dementia in Denmark
- Reducing prescriptions of anti-psychotic medication to people with dementia in general practice – in collaboration with KiAP (*Quality in General Practice)*.
- Further development and maintainance of the e-learning concept *ABC Dementia*.

Planning and development of these projects have been the main focus in 2024. The first project aims at optimizing dementia diagnostic pathways by developing digital tools for use across general practice, hospital-based dementia services, and municipalities that contribute to harmonizing and improving quali-

ty of diagnostic evaluation. One tool supports diagnosis of frail patients with severe dementia, which can be carried out in primary care, with (virtual) support from the hospital-based dementia services if needed. The other tool supports diagnosis of patients with mild or uncertain cognitive symptoms by novel self-administered, remote, digital assessment, that 1) determines the need for further assessment, and 2) contributes to more efficient workflows in hospital-based dementia services. Both tools will be validated in 2025-2026.

The second project about reducing prescriptions of anti-psychotic medicine aims at making clinically relevant data about antipsychotic prescriptions available for quality assurance purposes to all general practitioners. Furthermore, the aim is to provide knowledge of best practice available to the general practitioner especially knowledge of non-pharmacological alternatives to antipsychotics.

The third project is an extension of our existing *ABC Dementia* concept, where we have developed and launched three new courses in 2024.

E-LEARNING – Number of participants with completed course i 2024

ABC Dementia Care addresses dementia from a broader perspective and targets a wide range of professional caregivers	3311
ABC Dementia for Physicians – Diagnostic Evaluation targets medical doctors in specialist training for geriatrics, neurology, psychiatry or general medicine, and other professionals who work with dementia assessments	209
ABC Dementia for Hospitals targets care staff at hospitals who need basic knowledge about dementia.	733
ABC Dementia-friendly Hospitals targets all hospital staff and adresses the challenges when a person with dementia is admitted to hospital.	2192
ABC Dementia Challenging Behaviour targets care staff in municipalities (adds to ABC Dementia Care).	1568
ABC Dementia for Physicians in Hospitals targets physicians working in internal medicin and surgical hospital departments.	166
ABC Dementia – pain targets professional caregivers in primary care.	1136
ABC Dementia – infection targets professional caregivers in primary care.	1558
ABC Dementia – delirium targets professional caregivers in primary care.	1834
Total	12707

Since 2013 offering free access to e-learning has been one way of providing easy access nationwide education on dementia to various target groups. The e-learning courses are user friendly, due to the practice-oriented nature of the topics and the wide range of educational approaches used in the programs.

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

COURSES AND CONFERENCES

National Information and Education Centre on Dementia offers a wide range of courses (both nationwide and local tailored courses) and annual conferences, e.g. the Dementia Days conference. A total of 2,984 professionals participated in one of NVD's planned course and conference activities, in-house courses, lectures, or learning programs in 2024.

There continues to be great interest in Cognitive Stimulation Therapy (CST) in Denmark. To run evidence-based group sessions for people with dementia, a course in the method and group leadership is required. These courses are in demand both as registration courses and as in-house courses for municipalities. In 2024, five registration courses and five in-house courses were conducted, and we trained 231 new group leaders.

In collaboration with the Norwegian Natioal Centre for Ageing and Health (Aldring og Helse), we developed and tested a follow-up course targeted at CST group leaders. The knowledge bank for CST has been developed and is widely used by the network.

During the last four years we have educated more than 600 group leaders and have created a national network for CST leaders to support implementation.

In 2024 we have continued a fruitful collaboration with the Danish Society for Patient Safety (PSImprove). Organized by the Danish Health Authority, this collaborative project aims to implement and teach new strategies for managing behavioural disturbances in people with dementia in a wide range of Danish municipalities. DDRC delivers part of the educational task.

Our annual two-day conference Dementia Days (DemensDagene) has been organized

	Teaching courses and thematic conferences with open registration	Tailored courses or lectures by requistion	Implementation and learning processes for municipalities
Face-to-face/online activities	20	16	23
Number of participants	1892	605	575

since 1999 and is the largest conference on dementia in Denmark. Every year we convene professionals who work with dementia in a wide range of settings, e.g. staff working in the social or health care services, physicians, leaders in health care, researchers, national authorities in health care, and stakeholder organisations, for this national conference.

DemensDagene 2024 was held at the Tivoli Congress Center in Copenhagen with the theme 'Equality in Health.' The program featured various symposia with a wide range of themes, as well as debates and participant engagement both in discussions and with questions to dementia experts. Additionally, participants could apply to present their development or research projects as posters or free presentations. A total of 1,012 people attended.

COMMUNICATION AND PRESS

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

In 2024, the website had a total of 1,659,889 page views and 478,494 unique visitors. The most popular pages, besides the homepage, were '10 Warning Signs of Dementia,' the ABC Dementia entry page, and 'Symptoms and Progression of Alzheimer's Disease.'

Among significant web projects were:

- Update of accessibility on the main site (videnscenterfordemens.dk)
- A mini-universe with articles related to the popular DR's series *The Dementia Choir* (Demenskoret) with DDRC-experts participating ind the series.
- A major revision of *The Toolbox*-subsite ("Værktøjskassen") and a new theme on art and dementia on the subsite hverdagslivetmeddemens.dk.

In 2024, we have continued to strengthen our dissemination of information about dementia and DDRC's activities through two selected social media (Facebook and LinkedIn) and DDRC's newsletter.

By the end of 2024, DDRC had 5,208 followers on LinkedIn, a total annual increase of 875 followers, and 6,989 followers on Facebook, a total annual increase of 336 followers.

14 issues of the DDRC newsletter was published in 2024.

In 2024, there was a significant increase in media appearances during the period around the TV broadcast of Demenskoret (late August and for the following 6 weeks). According to Hypefactors, we had a total of 863 media appearences in 2024.

About our networks

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

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 collaboration across hospitals.

National network for CST group leaders in Denmark

The purpose is to enable CST group leaders to stay updated on the latest CST research, receive professional support, gain inspiration, and exchange experiences with each other. Furthermore, the network aims to support the implementation of CST in Denmark and to strengthen the professional quality of CST practice. Members of the CST network are invited to participate in meetings twice a year, held either in person or online.

Network of Danish Memory Clinics

Serves as a platform for dissemination and exchange of information, for harmonising and standardizing assessment and treatment methods, and for strengthening local and national collaboration on dementia. Members are multidisciplinary staff such as nurses, medical doctors and neuropsychologists, who work in hospital-based memory clinics in psychiatric, geriatric or neurological departments. Network members meet once a year to maintain and further develop national cooperation.

Danish Research Network on Psychosocial Methods in Dementia

Was formed to promote psychosocial research in dementia in Denmark. The network was inspired by the pan-European network for dementia researchers, Interdem. The aim of the network is to provide researchers with the opportunity to meet and exchange knowledge on various psychosocial methods and research topics, and to promote collaboration and more activity within this field of research. The network has two annual meetings.

National network of municipality-based dementia ambassadors

Each of the 98 Danish municipalities has appointed a 'dementia ambassador', who participates in the network that disseminates information about DDRC's activities, and monitors local needs for education activities in primary care.

The network also forms an important setting for exchanging knowledge and information among local dementia professionals. The network has two annual meetings, and in addition a special newsletter is published six times a year.

Artworks from Ny Carslberg Foundation, above from left: 'Untitled' (2007) by John Kørner, 'Chimney, Iceland' (2004) by Henrik Saxgren, 'Stillness in the air' (2023) by Ida Sønder Thorhauge and 'Fruits on a carpenter's bench' (1999) by Johannes Carstensen. Page 34: 'Flowers, Rome' (2012) by Erik A. Frandsen.

ART DONATION IN DDRC

In 2004, the Ny Carlsberg Foundation donated a series of artworks to the The National Information and Education Centre for Dementia. The artworks are displayed, among other places, in the demonstration environment *Everyday Life with Dementia*, where one can see examples of dementia-friendly design.

With the theme we seek to inspire professionals to actively use art and other decorations to promote the well-being of people with dementia and meet the special needs for adapted sensory stimuli that come with a dementia diagnosis.

In the Memory Clinic at Rigshospitalet, large photographs of well-known places or nature in Denmark, make it easier to find the specific examination room where the conversation with the doctor and nurse will take place. Furthermore the photos in the memory clinic are easy to talk about because the motive evokes memory and are easy to recognize.

Thanks to the Ny Carlsberg Foundation for the donation of 14 artworks, which have made it possible to decorate, among other things, the demonstration environment – *Everyday Life with Dementia* – in a truly unique way.

User involvement

DDRC has established a nationwide user panel to ensure that initiatives and activities reflect the needs and perspectives of people living with dementia and their family caregivers.

Anyone over the age of 18 who has been diagnosed with dementia, provides care for a family member or friend with dementia, or has lost someone to dementia within the past three years is eligible to be a part of the panel.

The majority of the current panel members are caregivers. The members come from all five regions of Denmark, and various dementia diagnoses are represented with Alzheimer's and Lewy Body dementia being the most common.

Panel members are invited to participate in phone interviews or surveys several times a year, where they provide valuable input on various aspects of dementia. The members contribute to specific initiatives as well as the development or evaluation of research projects.

Furthermore, DDRC has a user involvement group with eight members selected from the user panel, who meet in person with professionals from DDRC approximately four times a year. The meetings focus on new initiatives, projects, and other relevant topics for DDRC.

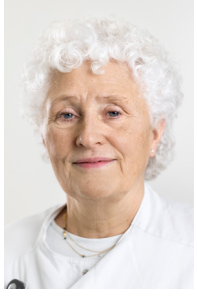
The user panel consists of about 80 members. Examples of activities in 2024 include interviews where members provided feedback on surveys for a research project about doctors' communication with MCI patients in the memory clinic, as well as workshops on art in the dementia-friendly garden.

Management

MANAGEMENT GROUP (per 31/12/2024)

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 Trials
Kristian Steen Frederiksen, MD, PhD, clinical research associate professor, senior neurologist

Educational director
Karen Tannebæk, MPG, occupational therapy specialist

Director of communications and press
Marie Ejlersen, MA

Program director
Ann Nielsen, MScPH, PhD

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

Head of administration
Brit Mouritsen

National and international posts

Birgitte Bo Andersen, appointed member, Dementia Council of the Capital Region of Denmark and chair of the Committee of Quality in the Dementia Council; consultant in cognitive disorders, Danish Patient Safety Authority.

Kristian Steen Frederiksen, co-chair, EAN Guideline Production Group; board member, Alzheimer Research Committee under the Danish Alzheimer Association; National coordinator and Principal investigator on a number of phase 2 and 3 trials in Alzheimer's disease; member, Expert Advisory Panel member, Alzheimer Europe, Editor-in-Chief, Alzheimer's Research and Therapy, chair, Danish National Treatment Guidelines – Neurodegenerative diseases, Editorial Board member, European Journal of Neurology.

Steen G. Hasselbalch, board member, Danish Alzheimer Association; board member, Danish Alzheimer Research Foundation; chair, Alzheimer Research Committee under the Danish Alzheimer Association; member of Scientific Board, Alzheimerfonden, Sweden; appointed member, EAN Scientific Panel on Dementia and Cognitive Disorders; appointed member, Dementia Council of the Capital Region of Denmark.

Lena Hjermind, national coordinator and Principal investigator on intervention trials phase I, II and III and of the global observational study on HD, Enroll-HD; appointed member of the program committee of the European Huntington's Disease Network (EHDN)/Enroll-HD Conferences; member of two EHDN working groups "Genetic testing and counselling" and "Symptomatic treatment and research"; board member, European Dystonia Network; appointed member "Tvangsbehandlingsnævnet", the Danish Patient Safety Authority; appointed member, working group for clinical application of WGS, and national network for neurogenetics, Danish National Genome Center; board member, European Reference Network – Rare Neurological Diseases.

Kasper Jørgensen, neuropsychology consultant, Danish Patient Safety Authority; neuropsychology consultant, National Legal Medicine Council.

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

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

Jørgen E. Nielsen, Danish national coordinator and sub investigator of the global observational study on HD, En-roll-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; column speaker: Neurodegenerative Diseases, Neuroscience Academy Denmark.

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

Christina Rørvig-Løppenthien, member, Steering committee for Danish Dementia Quality Registry (DanDem).

Jette Stokholm, neuropsychology consultant, Danish Patient Safety Authority.

Hanne Sørensen, appointed member, Dementia Council of the Capital Region of Denmark; appointed member, steering committee for revision of patient care pathway programme and education for dementia, Capital Region of Denmark.

Karen Tannebæk, member, Nordic Dementia Network established by Nordic Welfare Centre; coordinator, Danish Network on Psychosocial Methods in Dementia (DaneDem); member, reference group Knowledge Center on dignified elderly care; member, follow-up group on national dementia action plan, Danish Health Authority; member follow-up group on Action plan to prevent and deal with extroverted behavior in elderly care; Danish Health Authority. Member of the Occupational Therapist Association's specialist board.

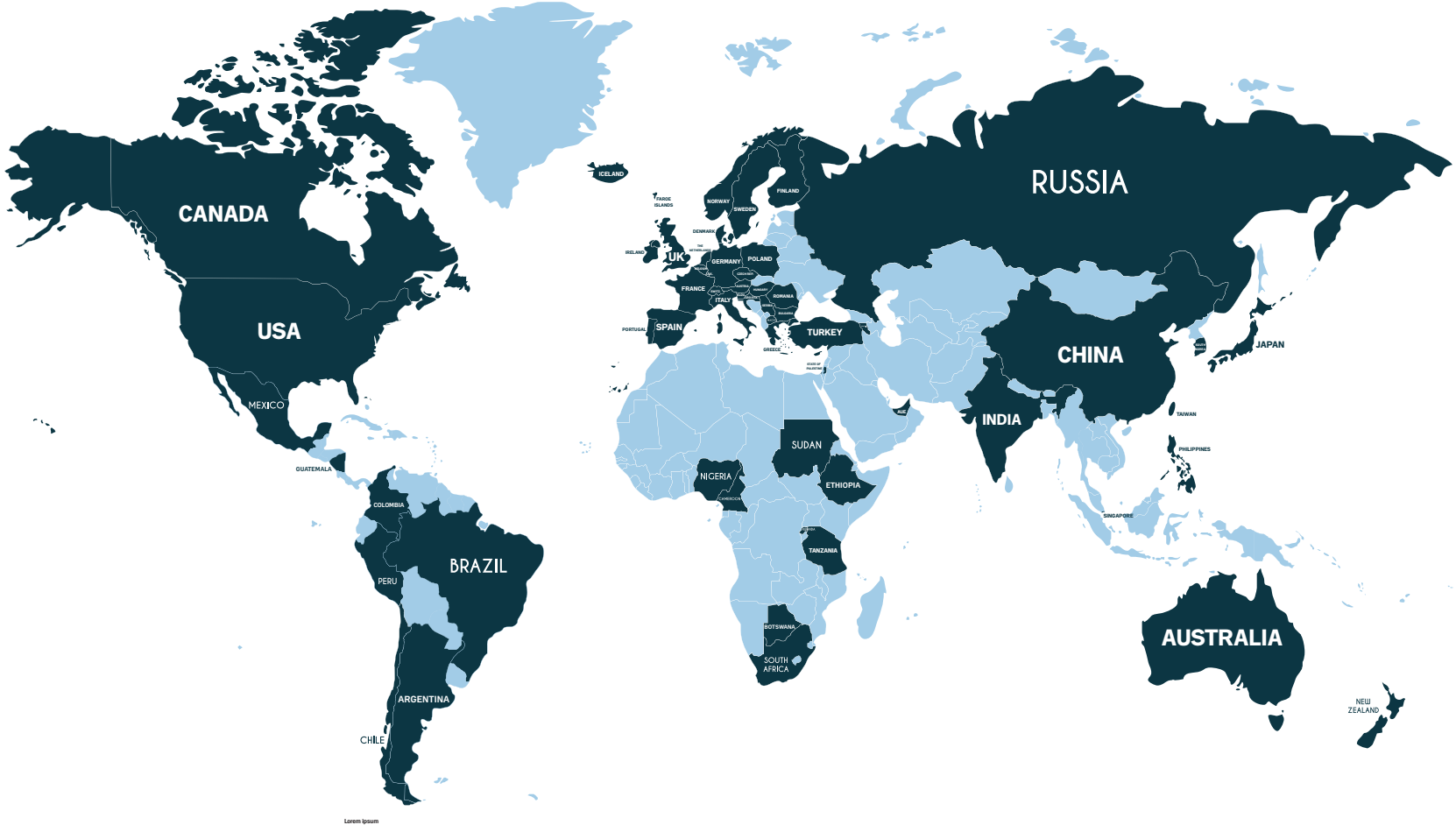
Tua Vinter-Jensen, appointed member, European Academy of Neurology, scientific panel in neurogenetics.

Asmus Vogel, member, European research network Brain Involvement in Dystrophinopathies.

Gunhild Waldemar, board member (past-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; advisor, National Legal Medicine Council, Danish Ministry of Justice; chair, Dementia Council, Capital Region of Denmark; executive committee member, Neurology Council, Capital Region of Denmark; medical lead, Trial Nation Denmark Dementia Centre; chairman, KFJ clinical research prize committee, University of Copenhagen; member, Steering committee for Danish Dementia Quality Registry (DanDem)

Publications

Graphic illustration of DDRC international collaboration. In 2020-2024 DDRC has published scientific papers in collaboration with institutions in countries marked with dark blue color.



PHD DISSERTATIONS

1. Henriksen, EE. Advancing SCA2 Research: *Proteomic Characterization, Autophagy Modulation and Cerebellar Organiod Model Development*. University of Copenhagen 2024.

2. Toft, A. *CHMP2B-mediated Frontotemporal Dementia: Markers, Models and Mechanisms*. University of Copenhagen 2024.

3. Musaeus, CM. *Long-term outpatient ear-EEG monitoring for detection of epileptiform discharges in patients with Alzheimer's disease and Lewy body dementia*. University of Copenhagen 2024

MASTER'S THESIS

1. Andersen, LSN. *Demographics, comorbidities and cognitive performance of amyloid negative, p-tau positive patients in memory clinic cohort*. Master's Thesis 2024.

2. Højte, EB. *Sociodemografiske faktorers effekt på screeningsbatteriet The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) – En gennemgang af den neuropsykologiske testlitteratur og en empirisk undersøgelse baseret på et dansk sample*. Master's Thesis 2024.

3. Meshki, M. *Diagnostik af kronisk traumatisk encefalopati (KTE) ante-mortem*. Master's Thesis 2024.

4. Thomas, FB. *Apathy and impulsivity on the FTD-MND continuum*. Master's Thesis 2024.

5. Wang, MC & Raben-levetzau, FN. *Behandling af Alzheimers sygdom med brug af monoklonale antistoffer rettet mod beta-amyloid*. Master's Thesis 2024.

SCIENTIFIC PAPERS

1. Appel, AM, Janbek, J, Jensen-Dahm, C, Laursen, TM & Waldemar, G. The effect of influenza vaccination on the rate of dementia amongst older adults. *European Journal of Neurology* 2024;31(12):e16489.

2. Axelsen, TM, Høgh, P, Bihlet, AR, Karsdal, MA, Henriksen, K, Hasselbalch, SG & Simonsen, AH. Serum Tau-A and Tau-C Levels and Their Association with Cognitive Impairment and Dementia Progression in a Memory Clinic Derived Cohort. *The journal of prevention of Alzheimer's disease* 2024;11(3):730-738.

3. Barbosa, A, Ferreira, AR, Smits, C, Hegerath, F-M, Vollmar, H, Fernandes, L, Craven, MP, Innes, A, Casey, D, Sezgin, D, Hopper, L & Øksnebjerg, L. Use and uptake of technology by people with dementia and their supporters during the COVID-19 pandemic. *Aging & Mental Health* 2024;28(1):83-94.

4. Clemmensen, FK, Areskeviciute, A, Lund, EL & Roos, P. Variably protease-sensitive prionopathy with methionine homozygosity at codon 129 in the prion protein gene. *BMJ Case Reports* 2024;17(2):e258199.

5. Damsgaard, L, Janbek, J, Laursen, TM, Høgh, P, Vestergaard, K, Gottrup, H, Jensen-Dahm, C & Waldemar, G. Mapping morbidity 10 years prior to a diagnosis of young onset Alzheimer's disease. *Alzheimer's & dementia* 2024;20(4):2373-2383.

6. Damsgaard, L, Janbek, J, Laursen, TM, Vestergaard, K, Gottrup, H, Jensen-Dahm, C & Waldemar, G. Prescription medication use in the 10 years prior to diagnosis of young onset Alzheimer's disease: a nationwide nested case-control study. *Alzheimer's research & therapy* 2024;16(1):150.

7. Delgado-Álvarez, A, Hernández-Lorenzo, L, Nielsen, TR, Díez-Cirarda, M, Cuevas, C, Montero-Escribano, P, Delgado-Alonso, C, Valles-Salgado, M, Gil-Moreno, MJ, Matias-Guiu, J & Matias-Guiu, JA. European cross-cultural neuropsychological test battery (CNTB) for the assessment of cognitive impairment in multiple sclerosis: Cognitive phenotyping and classification supported by machine learning techniques. *Multiple Sclerosis and Related Disorders* 2024;91:105907.

8. Dubois, B, Villain, N, Schneider, L, Fox, N, Campbell, N, Galasko, D, Kivipelto, M, Jessen, F, Hanseeuw, B, Boada, M, Barkhof, F, Nordberg, A, Froelich, L, Waldemar, G, Frederiksen, KS, Padovani, A, Planche, V, Rowe, C, Bejanin, A, Ibanez, A, Cappa, S, Caramelli, P, Nitrini, R, Allegri, R, Slachevsky, A, de Souza, LC, Bozoki, A, Widera, E, Blennow, K, Ritchie, C, Agronin, M, Lopera, F, Delano-Wood, L, Bombois, S,

Levy, R, Thambisetty, M, Georges, J, Jones, DT, Lavretsky, H, Schott, J, Gatchel, J, Swantek, S, Newhouse, P, Feldman, HH & Frisoni, GB. Alzheimer Disease as a Clinical-Biological Construct-An International Working Group Recommendation. *JAMA Neurology* 2024;81(12):1304-1311

9. Feng, LR, Waldemar, G, Hasselbalch, SG, Vogel, A, Henriksen, OM, Law, I & Frederiksen, KS. The cingulate island sign in a mixed memory clinical cohort: Prevalence and diagnostic accuracy. *Parkinsonism & related disorders*, 2024;122:106062.

10. Frederiksen, KS, Morató, X, Zetterberg, H, Gauthier, S, Boada, M, Pytel, V & Mattke, S. Focusing on Earlier Management of Alzheimer Disease: Expert Opinion Based on a Modified Nominal Group Technique. *Alzheimer Disease and Associated Disorders* 2024;38(1):1-7.

11. Frisoni, GB, Festari, C, Massa, F, Cotta Ramusino, M, Orini, S, Aarsland, D, Agosta, F, Babiloni, C, Borroni, B, Cappa, SF, Frederiksen, KS, Froelich, L, Garibotto, V, Haliassos, A, Jessen, F, Kamondi, A, Kessels, RP, Morbelli, SD, O'Brien, JT, Otto, M, Perret-Liaudet, A, Pizzini, FB, Vandenbulcke, M, Vanninen, R, Verhey, F, Vernooij, MW, Yousry, T, Boada Rovira, M, Dubois, B, Georges, J, Hansson, O, Ritchie, CW, Scheltens, P, van der Flier, WM & Nobili, F. European intersocietal recommendations for the biomarker-based diagnosis of neurocognitive disorders. *The Lancet Neurology* 2024;23(3):302-312.

12. Gramkow, MH, Clemmensen, FK, Sjælland, NS, Waldemar, G, Hasselbalch, SG & Frederiksen, KS. Diagnostic performance of light reflex pupillometry in Alzheimer's disease. *Alzheimer's & dementia* 2024;16(3):e12628.

13. Gramkow, MH, Clemmensen, FK, Waldemar, G, Hasselbalch, SG & Frederiksen, KS. Test-retest reliability and short-term variability of quantitative light reflex pupillometry in a mixed memory clinic cohort. *Journal of the Neurological Sciences* 2024;456:122856.

14. Gramkow, MH, Waldemar, G & Frederiksen, KS. The Digitized Memory Clinic. Nature reviews. *Neurology* 2024;20(12):738-746.

15. Hendel, RK, Hellem, MNN, Larsen, IU, Vinther-Jensen, T, Hjermind, LE, Nielsen, JE & Vogel, A. Impairments of social cognition significantly predict the progression of functional decline in Huntington's disease: A 6-year follow-up study. Applied neuropsychology. *Adult* 2024;31(5):777-786.

16. Hooshmand, K, Xu, J, Simonsen, AH, Wretlind, A, de Zawadzki, A, Sulek, K, Hasselbalch, SG & Legido-Quigley, C. Human Cerebrospinal Fluid Sample Preparation and Annotation for Integrated Lipidomics and Metabolomics Profiling Studies. *Molecular Neurobiology* 2024;61(4):2021-2032.

17. Ishtiak-Ahmed, K, Jensen-Dahm, C, Christensen, KS, Waldemar, G & Gasse, C. Association of Psychotropic Prescriptions With NonRegistered Indications and the Risk of Mortality in Older Adults: A Danish Nationwide Cohort Study. *International Journal of Geriatric Psychiatry* 2024;39(11):e70014.

18. Ivosevic, M, Overbeck, G, Holm, A, Waldemar, G & Janbek, J. Detection and management of suspected infections in people with dementia – a scoping review of current practices. *Ageing Research Reviews* 2024;101:102520.

19. Janbek, J, Laursen, TM, Frimodt-Møller, N, Magyari, M, Haas, JG, Lathe, R & Waldemar, G. Risk of Major Types of Dementias Following HospitalDiagnosed Infections and Autoimmune Diseases. *Journal of Alzheimer's Disease* 2024;98(4):1503-1514.

20. Jonsgaard Larsen, L, Hjermind, LE & Birk Møller, L. Generation of induced pluripotent stem cells, KCi005-A derived from a female with Parkinsońs disease and homozygous for the PINK1 variant c.1366C > T, p.Gln456. *Stem Cell Research* 2024;74:103279.

21. Jørgensen, K, Nielsen, TR, Nielsen, A, Oxbøll, A-B, Gerner, SD, Waldorff, FB & Waldemar, G. Diagnostic accuracy of the Brief Assessment of Impaired Cognition case-finding instrument in a general practice setting and comparison with other widely used brief cognitive tests—a cross-validation study. *European Journal of Neurology*. 2024;31(10):e16418.

22. Knecht, L, Dalsbøl, K, Simonsen, AH, Pilchner, F, Ross, JA, Winge, K, Salvesen, L, Bech, S, Hejl, A-M, Løkkegaard, A, Hasselbalch, SG, Dodel, R, Aznar, S, Waldemar, G, Brudek, T & Folke, J. Autoantibody profiles in Alzheimer´s, Parkinson´s, and dementia with Lewy bodies: altered IgG affinity and IgG/IgM/IgA responses to alpha-synuclein, amyloid-beta, and tau in disease-specific pathological patterns. *Journal of Neuroinflammation* 2024;21(1):317.

23. Knorr, U, Simonsen, AH, Zetterberg, H, Blennow, K, Willkan, M, Forman, J, Miskowiak, K, Hasselbalch, SG & Kessing, LV. Biomarkers for neurodegeneration impact cognitive function: a longitudinal 1-year case-control study of patients with bipolar disorder and healthy control individuals. *International Journal of Bipolar Disorders* 2024;12(1):2.

24. Knorr, U, Simonsen, AH, Nilsson, J, Brinkmalm, A, Zetterberg, H, Blennow, K, Knudsen, MB, Forman, J, Hasselbalch, SG & Kessing, LV. Cerebrospinal fluid synaptic biomarker changes in bipolar disorder - A longitudinal case-control study. *Journal of Affective Disorders* 2024;358:250-259.

25. Lindskov, FO, Karlsson, WK, Skovbølling, SL, Nielsen, EN, Dunø, M, Stokholm, J, Henriksen, OM, Langkilde, AR & Nielsen, JE. Expanding the Spectrum of Stress-Induced Childhood-Onset Neurodegeneration with Variable Ataxia and Seizures (CONDSIAS). *Cerebellum* 2024;23(2):861-871.

26. Manzoni, C, Kia, DA, Ferrari, R, Leonenko, G, Costa, B, Saba, V, Jabbari, E, Tan, MM, Albani, D, Alvarez, V, Alvarez, I, Andreassen, OA, Angiolillo, A, Arighi, A, Baker, M, Benussi, L, Bessi, V, Binetti, G, Blackburn, DJ, Boada, M, Boeve, BF, Borrego-Ecija, S, Borroni, B, Bråthen, G, Brooks, WS, Bruni, AC, Caroppo, P, Bandres-Ciga, S, Clarimon, J, Colao, R, Cruchaga, C, Danek, A, de Boer, SC, de Rojas, I, di Costanzo, A, Dickson, DW, Diehl-Schmid, J, Dobson-Stone, C, Dols-Icardo, O, Donizetti, A, Dopper, E, Durante, E, Ferrari, C, Forloni, G, Frangipane, F, Fratiglioni, L, Kramberger, MG, Galimberti, D, Gallucci, M, García-González, P, Ghidoni, R, Giaccone, G, Graff, C, Graff-Radford, NR, Grafman, J, Halliday, GM, Hernandez, DG, Hjermind, LE, Hodges, JR, Holloway, G, Huey, ED, Illán-Gala, I, Josephs, KA, Knopman, DS, Kristiansen, M, Kwok, JB, Leber, I, Leonard, HL, Libri, I, Lleo, A, Mackenzie, IR, Madhan, GK, Maletta, R, Marquié, M, Maver, A, Menendez-Gonzalez, M, Milan, G, Miller, BL, Morris, CM, Morris, HR, Nacmias, B, Newton, J, Nielsen, JE, Nilsson, C, Novelli, V, Padovani, A, Pal, S, Pasquier, F, Pastor, P, Perneczky, R, Peterlin, B, Petersen, RC, Piguet, O, Pijnenburg, YA, Puca, AA, Rademakers, R, Rainero, I, Reus, LM, Richardson, AM, Riemenschneider, M, Rogaeva, E, Rogelj, B, Rollinson, S, Rosen, H, Rossi, G, Rowe, JB, Rubino, E, Ruiz, A, Salvi, E, Sanchez-Valle, R, Sando, SB, Santillo, AF, Saxon, JA, Schlachetzki, JC, Scholz, SW, Seelaar, H, Seeley, WW, Serpente, M, Sorbi, S, Sordon, S, St George-Hyslop, P, Thompson, JC, Van Broeckhoven, C, Van Deerlin, VM, Van der Lee, SJ, Van Swieten, J, Tagliavini, F, van der Zee, J, Veronesi, A, Vitale, E, Waldo, ML, Yokoyama, JS, Nalls, MA, Momeni, P, Singleton, AB, Hardy, J & Escott-Price, V. Genome-wide analyses reveal a potential role for the MAPT, MOBP, and APOE loci in sporadic frontotemporal dementia. *American Journal of Human Genetics* 2024;111(7):1316-1329.

27. McWilliam, O, Gramkow, MH, Blaabjerg, M, Clemmensen, FK, Hasselbalch, SG & Frederiksen, KS. Differentiating anti-IgLON5 disease and Lewy body dementia: a systematic review. *Journal of Neurology* 2024;271(4):1707-1716.

28. Musaeus, CS, Kjaer, TW, Lindberg, U, Vestergaard, MB, Bo, H, Press, DZ, Andersen, BB, Høgh, P, Kidmose, P, Hemmsen, MC, Rank, ML, Hasselbalch, SG, Waldemar, G & Frederiksen, KS. Subclinical epileptiform discharges in Alzheimer's disease are associated with increased hippocampal blood flow. *Alzheimer's research & therapy* 2024;16(1):80.

29. Nguyen, CM, Rampa, S, Staios, M, Nielsen, TR, Zapparoli, B, Zhou, XE, Mbakile-Mahlanza, L, Colon, J, Hammond, A, Hendriks, M, Kgolo, T, Serrano, Y, Marquine, MJ, Dutt, A, Evans, J & Judd, T. Neuropsychological application of the International Test Commission Guidelines for Translation and Adapting of Tests. *Journal of the International Neuropsychological Society* 2024;30(7):621-634.

30. Niazi, S, Gnesin, F, Thein, A-S, Andreasen, JR, Horwitz, A, Mouhammad, ZA, Jawad, BN, Niazi, Z, Pourhadi, N, Zareini, B, Meaidi, A, Torp-Pedersen, C & Kolko, M. Association between Glucagon-like Peptide-1 Receptor Agonists and the Risk of Glaucoma in Individuals with Type 2 Diabetes. *Ophthalmology* 2024;131(9):1056-1063.

31. Nielsen, TR, Franzen, S, Watermeyer, T, Jiang, J, Calia, C, Kjærgaard, D, Bothe, S & Mukadam, N. Interpreter-mediated neuropsychological assessment: Clin-

ical considerations and recommendations from the European Consortium on Cross-Cultural Neuropsychology (ECCroN). Neuropsychology, Development and Cognition. Section D: *The Clinical Neuropsychologist* 2024;38(8):1775-1805.

32. Nielsen, TR, de Mendonça, A, Frölich, L, Engelborghs, S, Gove, D, Lamirel, D, Calia, C & Waldemar, G. Assessment of Dementia in Minority Ethnic Groups in Europe: A 14-Year Follow-Up Survey. *International Journal of Geriatric Psychiatry* 2024;39(12):e70034.

33. Nuytemans, K, Franzen, S, Broce, IJ, Caramelli, P, Ellajosyula, R, Finger, E, Gupta, V, Gupta, V, Illán-Gala, I, Loi, SM, Morhardt, D, Pijnenburg, Y, Rascovsky, K, Williams, MM, Yokoyama, JS, Acosta-Uribe, J, Akinyemi, R, Alladi, S, Ayele, BA, Ayhan, Y, Bourdage, R, Castro-Suarez, S, de Souza, LC, Dacks, P, de Boer, SCM, de Leon, J, Dodge, S, Grasso, S, Ghoshal, N, Kamath, V, Kumfor, F, Matias-Guiu, JA, Narme, P, Nielsen, TR, Okhuevbie, D, Piña-Escudero, S, Ruiz-Garcia, R, Ryan, B, Scarioni, M, Slachevsky, A, Suarez-Gonzalez, A, Tee, BL, Tsoy, E, Ulugut, H, Onyike, CU, Babulal, GM & ISTAART Frontotemporal Dementia and Related Disorders PIA, ISTAART Diversity and Disparities PIA. Gaps in biomedical research in frontotemporal dementia: A call for diversity and disparities focused research. *Alzheimer's & dementia* 2024;20(12):9014-9036.

34. Okkels, N, Grothe, MJ, Taylor, J-P, Hasselbalch, SG, Fedorova, TD, Knudsen, K, van der Zee, S, van Laar, T, Bohnen, NI, Borghammer, P & Horsager, J. Cholinergic changes in Lewy body disease: implications for presentation, progression and subtypes. *Brain* 2024;147(7):2308-2324.

35. Oxbøll, A-B, Jørgensen, K, Nielsen, TR, Christiansen, SD, Nielsen, A, Waldorff, FB & Waldemar, G. Diagnostic accuracy of BASIC-Q for detection of cognitive impairment in a primary care setting - a cross-validation study. *BMC Geriatrics* 2024;24(1):53.

36. Pourhadi, N, Janbek, J, Gasse, C, Laursen, TM, Waldemar, G & Jensen-Dahm, C. Opioids and Dementia in the Danish Population. *JAMA network open* 2024;7(11):e2445904.

37. Pourhadi, N, Janbek, J, Jensen-Dahm, C, Gasse, C, Laursen, TM & Waldemar, G. Proton pump inhibitors and dementia: A nationwide population-based study. *Alzheimer's & dementia* 2024;20(2):837-845.

38. Pourhadi, N, Mørch, LS, Holm, EA, Torp-Pedersen, C & Meaidi, A. Dementia in Women Using Estrogen-Only Therapy. *JAMA – Journal of the American Medical Association* 2024;331(2):160-162.

39. Sjaelland, NS, Gramkow, MH, Hasselbalch, SG & Frederiksen, KS. Digital Biomarkers for the Assessment of Non-Cognitive Symptoms in Patients with Dementia with Lewy Bodies: A Systematic Review. *Journal of Alzheimer's Disease* 2024;100(2):431-451.

40. Stefansson, H, Walters, GB, Sveinbjornsson, G, Tragante, V, Einarsson, G, Helgason, H, Sigurðsson, A, Beyter, D, Snaebjarnarson, AS, Ivarsdottir, EV, Thorleifsson, G, Halldorsson, BV, Norddahl, G, Styrkarsdottir, U, Sturluson, A, Holm, H, Helgason, A, Moore, K, Eggertsson, HP, Oddsson, AH, Jonsdottir, GA, Gunnarsson, AF, Bjornsdottir, G, Gisladottir, RS, Thorgeirsson, TE, Skuladottir, A, Gudbjartsson, DF, Sulem, P, Jonsson, P, Thordardottir, S, Snaedal, J, Eyjolfsdottir, H, Creese, B, Ballard, C, Corbett, A, Vasconcelos Da Silva, M, Aarsland, D, Andreassen, OA, Werge, T, Banasik, K, Brunak, S, Ullum, H, Frikke-Schmidt, R, Ostrowski, SR, Didriksen, M, Sørensen, E, Simonsen, AH, Nielsen, JE, Waldemar, G, Pedersen, OB & DemGen Study Group. Homozygosity for R47H in TREM2 and the Risk of Alzheimer's Disease. *The New England journal of medicine* 2024;390(23):2217-2219.

41. Svart, K, Korsbæk, JJ, Jensen, RH, Parkner, T, Knudsen, CS, Hasselbalch, SG, Hagen, SM, Wibroe, EA, Molander, LD & Beier, D. Neurofilament light chain is elevated in patients with newly diagnosed idiopathic intracranial hypertension: A prospective study. *Cephalalgia: an international journal of headache* 2024;44(5):3331024241248203.

42. Toft-Bertelsen, TL, Andreassen, SN, Norager, NH, Simonsen, AH, Hasselbalch, SG, Juhler, M & MacAulay, N. Differential Lipid Signatures of Lumbar and Cisternal Cerebrospinal Fluid. *Biomolecules* 2024;14(11):1431.

43. Toft-Bertelsen, TL, Andreassen, SN, Simonsen, AH, Hasselbalch, SG & MacAulay, N. The CSF lipid profile in patients with probable idiopathic normal pressure hydrocephalus differs from control but does not differ between shunt responders and non-responders. *Brain communications* 2024;6(6):fcae388.

44. Torkpoor, R, Frolich, K, Londos, E & Nielsen, TR. Diagnostic Accuracy of the Swedish Version of the Multicultural Cognitive Examination for Cognitive Assessment in Swedish Memory Clinics. *Journal of Alzheimer's Disease* 2024;97(2):715-726.

45. Tsai, S, Ma, S, Nielsen, TR & Calia, C. Assessment of Dementia in Minority Ethnic Groups in Scotland: Results of a Survey of Cognitive Specialists. *Alzheimer Disease and Associated Disorders* 2024;38(1):85-90.

46. van Gils, AM, Tolonen, A, van Harten, AC, Vigneswaran, S, Barkhof, F, Visser, LNC, Koikkalainen, J, Herukka, S-K, Hasselbalch, SG, Mecocci, P, Remes, AM, Soininen, H, Lemstra, AW, Teunissen, CE, Jönsson, L, Lötjönen, J, van der Flier, WM & Rhodius-Meester, HFM. Computerized decision support to optimally funnel patients through the diagnostic pathway for dementia. *Alzheimer's research & therapy* 2024;16(1):256.

47. Vogel, A, Bruus, AE & Waldemar, G. Developing a Danish version of the LASSI-L test - reliability and predictive value in patients with mild cognitive impairment, mild dementia due to AD and subjective cognitive decline. Aging, *Neuropsychology, and Cognition* 2024;31(1):174-186.

48. Vogel, A, Mellergaard, C, Waldemar, G & Frederiksen, KS. Impaired performances on the category cued memory test in mild Alzheimer's disease and dementia with Lewy bodies: A comparative validity study. *Applied neuropsychology. Adult* 2024;31(4):323-328.

49. Wittebrood, C, Boban, M, Cagnin, A, Capellari, S, De Winter, F-L, Djamshidian, A, González, MM, Hjermind, LE, Krajcovicova, L, Krüger, J, Levin, J, Reetz, K, Rodriguez, ER, Rohrer, J, Van Langenhove, T, Reinhard, C, Graessner, H, Rusina, R, Saracino, D, Houot, M, Seelar, H & Vandenberghe, R. Pharmacotherapy for behavioural manifestations in frontotemporal dementia: An expert consensus from the European Reference Network for Rare Neurological Diseases (ERN-RND). *European Journal of Neurology* 2024;31(12):e16446.

BOOK CHAPTERS

1. Andersen, H, Ashina, M, Bjarkam, CR, Blaabjerg, M, Christensen, H, Danielsen, EH, Hasselbalch, SG, Jeppesen, TD, Juhler, M, Korshoej, AR, Kondziella, D, Larsen, VA, Løkkegaard, A, Simonsen, CZ, Nielsen, JE, Sabers, A, Sellebjerg, FT, Tankisi, H, Vissing, J & Waldemar, G. In E-M Hauge, MA Ainsworth & SD Poulsen (ED), *Medicinsk Kompendium: Neurologiske Sygdomme*. 20 udg. Munksgaard Forlag, København, 2024: 211-350.

OTHER PUBLICATIONS

1. Delgado-Peraza, F, Nogueras-Ortiz, C, Simonsen, AH, Knight, DLD, Yao, PJ, Goetzl, EJ, Jensen, CS, Høgh, P, Gottrup, H, Vestergaard, K, Hasselbalch, SG & Kapogiannis, D. Correction: Neuron-derived extracellular vesicles in blood reveal effects of exercise in Alzheimer's disease. *Alzheimer's Research & Therapy* 2024;16(1).

2. Juhler, M, Waldemar, G, Meling, T & Mathiesen, T. *Flemming Gjerris 1936-1924*. 2024.

3. Nielsen, TR & Kjaergaard, D. Primary Progressive Aphasia Across Languages: Prevalence and Presentation of Phenotypes Are Shaped by Language-Specific Features. *Neurology* 2024;103(12):e210165.

4. Pourhadi, N, Mørch, LS & Meaidi, A. Estrogen-Only Hormone Therapy and Dementia-Reply. *JAMA – Journal of the American Medical Association* 2024;331(18):1594-1596.

5. Pourhadi, N, Janbek, J, Jensen-Dahm, C, Gasse, C, Laursen, TM & Waldemar, G. Response to "Comment on 'Proton pump inhibitors and dementia: A nationwide population-based study'". *Alzheimer's & dementia* 2024;20(3):2287-2288.

Finance

The DDRC's total expenditures budget for 2024 was DKK 70.2 m, distributed almost evenly between internal funding (DKK 32.7 m for memory clinic services) and external grants (DKK 37.5 m for research, projects, 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, PROJECTS AND EDUCATION ACTIVITIES 2024 (DKK M)	
New grants received*	**38.0**
External grants spent on specific programs and projects • National Information and Education Centre for Dementia from the Danish Ministry of Health, including projects • Other external grants for research	**24.8** 13.9 10.9
Grant to Danish Memory Clinics*	**5.0**
Conferences, educational courses and products	**4.1**
Research contracts	**3.6**

* 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 2024	
No. of employees/full-time equivalents	**106/96**

Acknowledgements

We are grateful for generous support from grants and donations from private and public foundations and institutions for projects and research:

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

Beckett Fonden

Danish Arts Foundation (Statens Kunstfond)

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

Danish Ministry of Health

Danish Neurological Society

The Danish Order of Freemasons

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

GN Foundation

Grosserer L. F. Foghts Fond

Harboe Fonden

Helsefonden

H. Lundbeck

Huntington's National Association

Innovation Fund Denmark

Jascha Foundation

KID Fonden

Kong Christian den Tiendes Fond

Kronprins Frederik og Kronprinsesse Marys Fond

Lundbeck Foundation

M. L. Jørgensen og Gunnar Hansens Fond

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

Neuroscience Academy Denmark

New Carlsberg Foundations (Ny Carlsberg Fondet)

Nordic Autophagy Society

Novo Nordisk Foundation

Overretssagfører L. Zeuthens Mindelegat

Parkinson Association

P.A. Messerschmidt & Hustrus Fond

Rigshospitalet Scientific Committee

Toyota Foundation

Trial Nation Denmark

TrygFonden

UNEEG Medical

Vera og Carl Johan Michaelsens Legat

VELUX FOUNDATION

Aase and Ejnar Danielsen Foundation

DANISH DEMENTIA
RESEARCH CENTRE