

# DANISH DEMENTIA RESEARCH CENTRE

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



DANISH DEMENTIA  
RESEARCH CENTRE



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The seahorse in the DDRC's logo resembles an area of the brain shaped like a seahorse, which is why it is called the hippocampus (Latin for seahorse). This area of the brain plays an important role in memory.



DANISH DEMENTIA  
RESEARCH CENTRE



Rigshospitalet

# PREFACE

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It is a pleasure to present the 2016 DDRC annual report, which describes our research and provides a general overview of our clinical services and national educational services over the past year.

The number of people with dementia will continue to increase, and the growing cost of medical care and associated societal burden threaten to rise to an overwhelming level as more people live into old age. The past decade has seen remarkable improvements in the quality of care. However, no treatments are yet available to modify or cure the severe brain disorders causing dementia, and knowledge on the best methods of care need to be disseminated.

In 2016 the first comprehensive 2025 national dementia strategy and action plan was completed after an impressive effort by the Ministry of Health and the Elderly and the National Board of Health, with a wide range of health care professionals and institutions in Denmark also contributing. The Minister of Health, the Minister of the Elderly and the political parties behind the pool of public funds earmarked for disadvantaged groups all agreed to allocate a total of DKK 470 million to 23 initiatives in the 2016-2019 action plan. Part of the strategy involves permanently financing DDRC as of 2017, a step we are extremely grateful for, also as an acknowledgment of our work, after working for a decade on time-limited grants.

We were very pleased to receive an official visit from the former Minister of Health and the Elderly, Sophie Løhde, in August 2016 during her preparations for the national plan. We are looking forward to contributing to the implementation of the 23 initiatives in the national dementia strategy during the next three years.

An important hallmark of the collaborative activities in addition to national networking with health care professionals and interacting with society, is our ability to translate science to clinical evidence and then implement best practice in the care of people with dementia. Thus, our educational activities attracted more than 5,100 participants in 2016 and we also launched a new e-learning module, ABC Dementia for doc-

tors, while ABC Dementia for professional carers now has more than 17,000 users. Both programmes are available for free on our website.

Meeting patients with dementia and their caregivers serves as a constant source of inspiration for our research and educational activities. Our memory clinic has extended its activities and, after a planned merger, will soon comprise out-patient clinics at three DDRC locations: Blegdamsvej at Rigshospitalet, Glostrup and on the Island of Bornholm, all of which are served by highly professional multidisciplinary staff.

Among the highlights of 2016 were two major annual international conferences hosted in Copenhagen by the European Academy of Neurology and Alzheimer Europe. We also hosted the annual meetings of two international dementia research networks, Interdem and the European Alzheimer's Disease Consortium. All of these events contributed to drawing attention to Danish research in dementia. Two research leaders, Jørgen Nielsen and Asmus Vogel, have been named associate professors in clinical neurogenetics and neuropsychology, respectively, effectively boosting our translational and cognitive research.

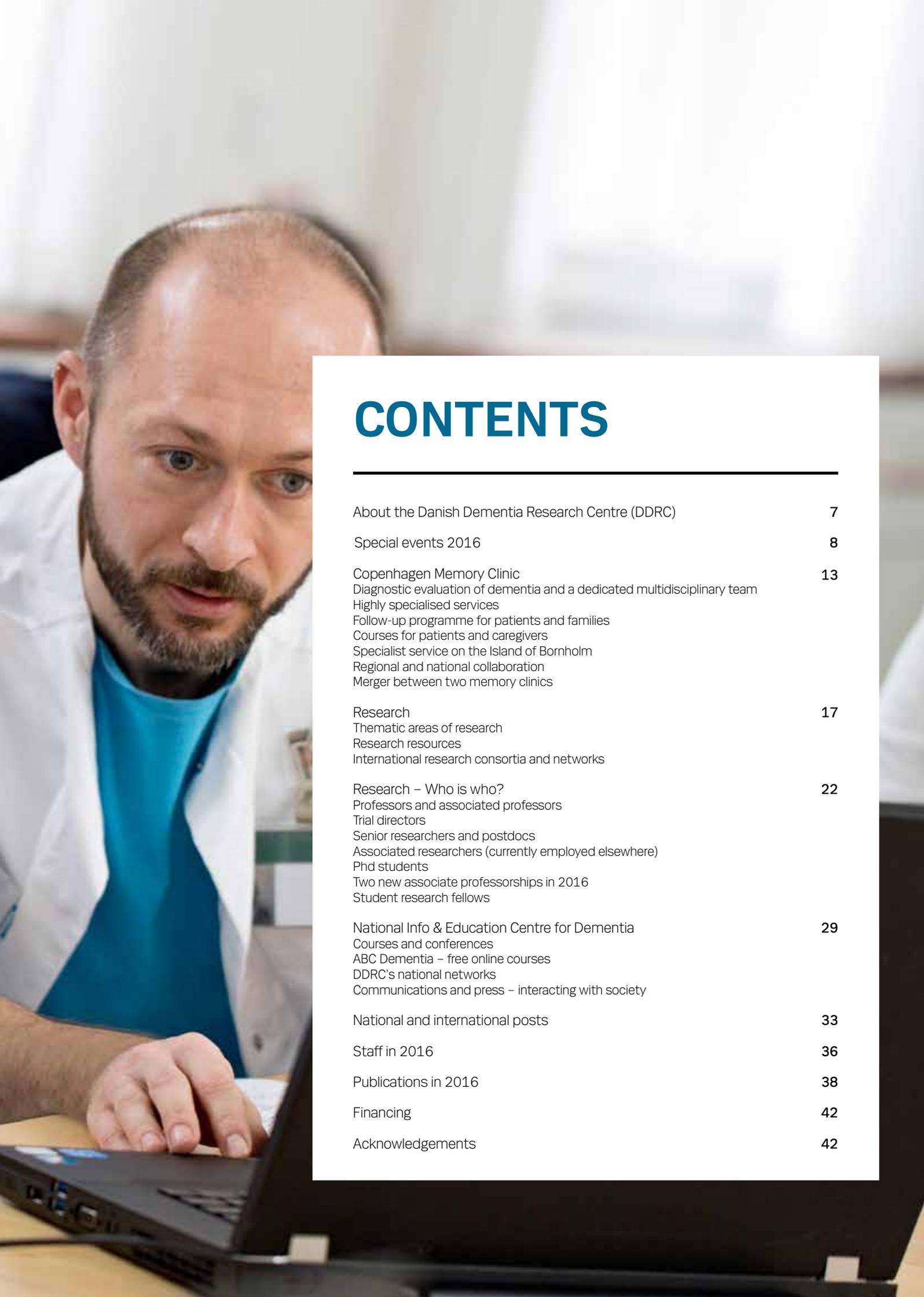
With this 2016 annual report we would like to thank our national and international collaborators and our external scientific and educational advisors. We would also like to extend a special thanks to the private and public foundations that support our work financially.



A handwritten signature in black ink that reads "G. Waldemar".

Gunhild Waldemar  
Professor, Director of the DDRC



A man with a beard and short hair, wearing a white lab coat over a blue t-shirt, is looking intently at a laptop screen. The background is a blurred clinical or office setting.

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# ABOUT THE DANISH DEMENTIA RESEARCH CENTRE

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## ORGANISATION

Located at Rigshospitalet and based in the Department of Neurology, the Danish Dementia Research Centre (DDRC) comprises three sections:

- Copenhagen Memory Clinic
- Dementia and Neurogenetics Research Unit
- National Info & Education Centre

The Copenhagen Memory Clinic is a secondary and tertiary referral-based multidisciplinary out-patient clinic offering diagnostic evaluation and treatment of patients with cognitive disorders and dementia.

The Research Unit comprises clinical research groups as well as a neurogenetic research laboratory and the Danish Dementia BioBank.

Initiated and funded by the Danish Ministry of Health and the Elderly, the National Info & Education Centre for Dementia has a steering committee and a scientific advisory board.

With representatives from the Ministry of Health and the Elderly, Danish Regions, Local Government Denmark and the Danish Health Foundation, the steering committee monitors the strategic development and performance of the National Info & Education Centre according to predefined objectives and milestones. A new strategy for 2016-2020 was implemented in 2016.

The scientific advisory board reviews and contributes with advice on major educational and scientific activities. The members of the advisory board represent the Danish Health and Medicines Authority, municipalities in Local Government Denmark, Danish Regions, the Danish Medical Association, the Danish Alzheimer's Association, the Danish Huntington's Disease Association and the DaneAge Association.

For an updated list of members for the steering and advisory committees see [videnscenterfordemens.dk](http://videnscenterfordemens.dk).

## VISION

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

## VALUES

Our four key values serve to guide our priorities as well as our organisational decisions.

**Professionalism:** Highly ambitious, we constantly strive to reach the highest professional standards, professionalism and innovation with regard to the development of our services.

**Commitment:** Our commitment is reflected in our work and our dedication to the goal of preventing dementia and improving the quality of life for patients with dementia and their caregivers.

**Respect:** We show respect for patients, caregivers, professionals and groups. We show respect for the ethical challenges related to caring for people with dementia. We are dedicated to understand, include and meet their needs.

**Transparency:** We assure transparency with regard to our activities and in our professional relationships.

# SPECIAL EVENTS 2016

## Dementia strategy meeting with the Danish prime minister

In May 2016 Gunhild Waldemar gave a presentation to Danish Prime Minister Lars Løkke Rasmussen and Minister of Health and the Elderly Sophie Løhde at a political meeting at Marienborg, the official home of the prime minister, in order to discuss development of the national dementia strategy.

## European Academy of Neurology (EAN) in Copenhagen

Hosted in Copenhagen in 2016, EAN attracted more than 5,500 attendees and a wide range of presentations on dementia and other neurological disorders.



## Master class with Peter Nestor

In March, sixty neurologists, psychiatrists and neuropsychologists from across the country benefitted from Professor Peter Nestor's knowledge and experience at the DDRC master class in diagnostic evaluation of dementia. Nestor, who works at the German Center for Neurodegenerative Diseases (DZNE) in Madeburg, Germany, began the class with a lecture on: "Interpreting Clinical Neuropsychology in Suspected Dementia".

## Research conference on medicine and dementia

In November 2016 DDRC organised its annual research conference at Rigshospitalet with 200 attendees. The topic was medication and dementia. Among the international speakers were Professor Sube Banerjee from Trafford Centre for Medical Research, University of Sussex, UK and Professor Johan Fastbom from the Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Sweden.



### Dementia Days

In May DDRC held its annual Dementia Days conference. The main topic was “A Healthy life for all”. The event was attended by more than 900 participants from across the nation, and Minister of Health and the Elderly Sophie Løhde talked at the official opening of the conference. Professor Miia Kivipelto from Karolinska Institute in Stockholm and brain researcher Peter Vuust from Centre for Music In the Brain at Aarhus University were among the invited guest speakers.



### New National Dementia Strategy 2025

In 2015 Danish Minister for Health and the Elderly Sophie Løhde, together with the political parties behind a pool of public funds earmarked for disadvantaged groups, launched an ambitious plan for developing a national dementia strategy up to 2025, allocating DKK 470M toward its development and activities in 2016-2019.

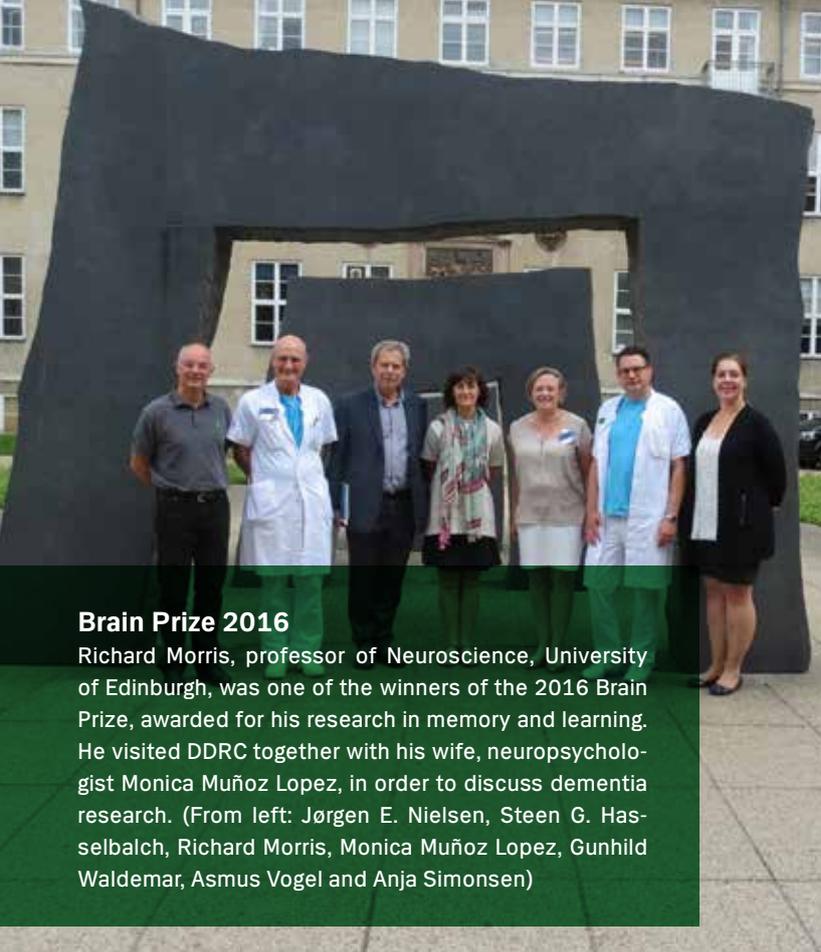
The aims of National Dementia Strategy 2025 will focus on:

- Denmark being a dementia friendly country, where people with dementia can live a safe life with dignity
- Treatment and care based on the needs and values of the individual person with dementia; organisation of treatment and care into coordinated plans focusing on prevention, early diagnosis and support, best available evidence and more research
- Active involvement of and more support for family caregivers

In 2016 the draft version of the strategy, containing 23 initiatives, was developed by the Ministry of Health and the Elderly to prepare for the official launch in January 2017.

With permanent funding for our National Info & Education Centre, DDRC is pleased to contribute with knowledge, research, dissemination of evidence, educational activities and with networking spanning the primary and secondary health care sectors and other relevant sectors.





### Brain Prize 2016

Richard Morris, professor of Neuroscience, University of Edinburgh, was one of the winners of the 2016 Brain Prize, awarded for his research in memory and learning. He visited DDRC together with his wife, neuropsychologist Monica Muñoz Lopez, in order to discuss dementia research. (From left: Jørgen E. Nielsen, Steen G. Haselbalch, Richard Morris, Monica Muñoz Lopez, Gunhild Waldemar, Asmus Vogel and Anja Simonsen)



### Taiwan visits DDRC

In August 2016 politicians and executives from Taiwan visited DDRC to learn about the organisation of health care for people with dementia in Denmark.



### Ida Unmack Larsen's PhD defence

Ida Unmack Larsen, MSc, was awarded a PhD after defending her thesis: "Personality traits and cognitive impairment in Huntington's disease" in October 2016.

From left: Randi Starrfelt (evaluation committee), Anders Gade (supervisor), Julie Snowden (evaluation committee), Asmus Vogel (supervisor), Ida Unmack Larsen, Palle Møller Pedersen (evaluation committee). Jørgen Erik Nielsen (supervisor) is not pictured.





### Minister of Health and the Elderly visits DDRC

In August 2016, while preparing for the national dementia strategy, Minister of Health and the Elderly Sophie Løhde and chair of the Regional Council of the Capital Region of Denmark Sophie Hæstorp Andersen visited the DDRC to learn more about DDRC activities and strategy. They also had the opportunity to talk with patients and caregivers in the memory clinic.



### International Alzheimer Europe conference hosted in Copenhagen

Professor Gunhild Waldemar presented the keynote lecture on "Improving quality of health care for people with dementia" at the Alzheimer Europe conference in Copenhagen in October 2016. More than 1,500 representatives from patient organisations, patients, caregivers, politicians, scientists and professional carers gathered to discuss important topics related to the theme of the conference: "Excellence in dementia research and care". HRH Princess Benedicte opened the conference. (From left in the small picture: Gunhild Waldemar, Birgitte Vølund and HRH Princess Benedicte)



# COPENHAGEN MEMORY CLINIC

## DIAGNOSTIC EVALUATION OF DEMENTIA AND A DEDICATED MULTIDISCIPLINARY TEAM

The Copenhagen Memory Clinic at Rigshospitalet (Blegdamsvej site) is a combined secondary and tertiary referral-based multidisciplinary out-patient clinic. Offering diagnostic evaluation and treatment of patients with cognitive disorders and dementia, the clinic receives referrals from general practitioners, private practice neurologists, psychiatrists and other hospitals. Patients may also be referred from other memory clinics for second opinion evaluations.

New patients are referred for diagnostic evaluation of cognitive, behavioural or other symptoms suggestive for a neurodegenerative condition. Patients with rare, complex or familial disorders may be referred for treatment and follow-up, and genetic counselling is also offered for healthy at-risk family members.

Diagnostic evaluation and treatment are managed by a multi-disciplinary team of consultant neurologists, a consultant psychiatrist, clinical geneticist, neuropsychologists, specialist nurses, a social counsellor, medical secretaries and a laboratory technician.

The large majority of patients undergo the standard set of examinations and procedures, beginning with a detailed medical history. Cognitive functions are then assessed with the Mini-Mental State Examination and the Danish version of Addenbrooke's Cognitive Examination. Physical and neurological examination, routine laboratory tests, ECG and structural CT or MRI of the brain are also performed. Other supplemental investigations are performed if clinically relevant, for example: fludeoxyglucose positron emission tomography (18FDG-PET), routine and biomarker examination of cerebrospinal fluid (CSF), EEG, psychiatric evaluation and neuropsychological assessment.

After completion of the initial examinations and procedures, the multidisciplinary team prepares a standardised consensus report containing a classification of the cognitive profile, the primary underlying cause, concomitant conditions and a treatment plan. After the consensus meeting, the patient (and caregivers) is invited to meet with the neurologist and specialist nurse, where information is given on diagnosis and on the plan for treatment and care. A short summary is subsequently sent to the patient's general practitioner. A monthly clinical conference is held with specialists from the imaging (MR and

### KEY FIGURES 2007-2016

	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016
<b>New patient referrals</b>	737	709	726	842	778	920	953	1021	965	1009
<b>Number of visits</b>	4,638	4,192	4,811	5,807	5,700	6,052	6,311	6,920	6,318	5,558
<b>Patients in follow-up programme</b>	1,516	1,487	1,648	1,766	1,892	2,038	2,088	2,044	2,117	2,183

The table below lists the number of new patients who completed a diagnostic evaluation programme in 2016 and how they were classified.

SYNDROME	DIAGNOSIS	NUMBER
Dementia		408
	• Alzheimer's disease	182
	• Vascular or mixed dementia	80
	• Dementia with Lewy bodies, Parkinson's disease with dementia, Parkinsons-plus syndromes	33
	• Frontotemporal dementia	22
	• Normal pressure hydrocephalus	35
	• Other specific conditions, including Huntington's disease	18
	• Dementia of uncertain aetiology and alcohol	38
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	233
No cognitive impairment	Patients with subjective symptoms and no significant pathology	96
Genetic counselling	Family members of patients with familial neurodegenerative conditions referred for genetic counselling	169

PET) departments and four annual conferences are held with the Movement Disorders Clinic at Bispebjerg Hospital.

## HIGHLY SPECIALISED SERVICES

In accordance with guidelines for local, regional and highly specialised medical services from the Danish Health and Medicines Authority, the Copenhagen Memory Clinic has been approved as a highly specialised centre in the fields of dementia and neurogenetics. Its services include:

- Second opinion evaluation of patients with possible dementia/dementia with uncertain aetiology
- Diagnosing and treating rare dementia diseases
- Diagnosing and treating hereditary neurodegenerative diseases, for instance: Alzheimer's disease (AD), frontotemporal dementia (FTD), spinocerebellar ataxias (SCA), Huntington's disease (HD)
- Clinical evaluation and lumbar perfusion tests for patients with suspected normal pressure hydrocephalus (NPH)
- Diagnostic evaluation of patients where brain biopsy is considered

These 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).

### NPH

Diagnostic evaluation of NPH is a complex task. The patients often have multimorbidity and characteristic symptoms such as: gait disturbance, urinary incontinence and cognitive decline, which are also common to various other diseases. Most patients are referred for possible NPH because their CT or MRI has demonstrated a dilated ventricular system. In 2016 there were 210 patients referred for a clinical evaluation of NPH, 107 of whom had a lumbar perfusion 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 cerebrospinal fluid from the brain, may reverse some of the symptoms and restore functioning.

### Genetic counselling

The Copenhagen Memory Clinic also offers a programme for healthy at-risk family members from families with confirmed or suspected late-onset familial neurodegenerative diseases referred for clinical

genetic evaluation and counselling. This service is executed in collaboration with Department of Clinical Genetics at Rigshospitalet and includes an evaluation by our specialist in clinical genetics, as well as a consultation with a trained psychologist before genetic testing is considered. The clinic also offers post-genetic test counselling when needed.

## FOLLOW-UP PROGRAMME FOR PATIENTS AND FAMILIES

The follow-up programme currently monitors 2,183 patients. All patients with mild cognitive impairment (MCI), dementia or specific neurodegenerative disorders are offered counselling and follow-up in collaboration with primary health care. Patients with conditions of uncertain aetiology and healthy mutation carriers may also be offered follow-up in the memory clinic. The majority of patients in the follow-up programme have MCI, AD, Dementia with Lewy bodies (DLB), FTD, HD, SCA, NPH, Down's syndrome with dementia or other neurodegenerative/neurogenetic conditions. Most patients are accompanied by their family caregivers when visiting the clinic, and the social counsellor, specialist nurses, psychologists and medical doctors also offer counselling for the caregivers as an integral part of the follow-up programme.

## COURSES FOR PATIENTS AND CAREGIVERS

As part of its services the clinic offers courses for patients and caregivers.

- Early-phase AD patients are offered a course run by a neuropsychologist focusing on the maintenance of cognitive functions as well as an introduction to compensatory techniques related to cognitive deficits.
- A two-session course run by multi-disciplinary staff with weekly meetings is offered four times a year for family caregivers and includes information on symptoms and treatment; legal issues and social services; and treatment, care, communication and practical daily-life issues.

## SPECIALIST SERVICE ON THE ISLAND OF BORNHOLM

Every other week, for one day, a team of one consultant neurologist and one neuropsychologist from the Copenhagen Memory Clinic sees patients on Bornholm. Patients with possible dementia and other cognitive disorders are managed in close collaboration with the staff at the local psychiatric department. Consultants from the Copenhagen Memory Clinic have also contributed to educational services for health care professionals on Bornholm.

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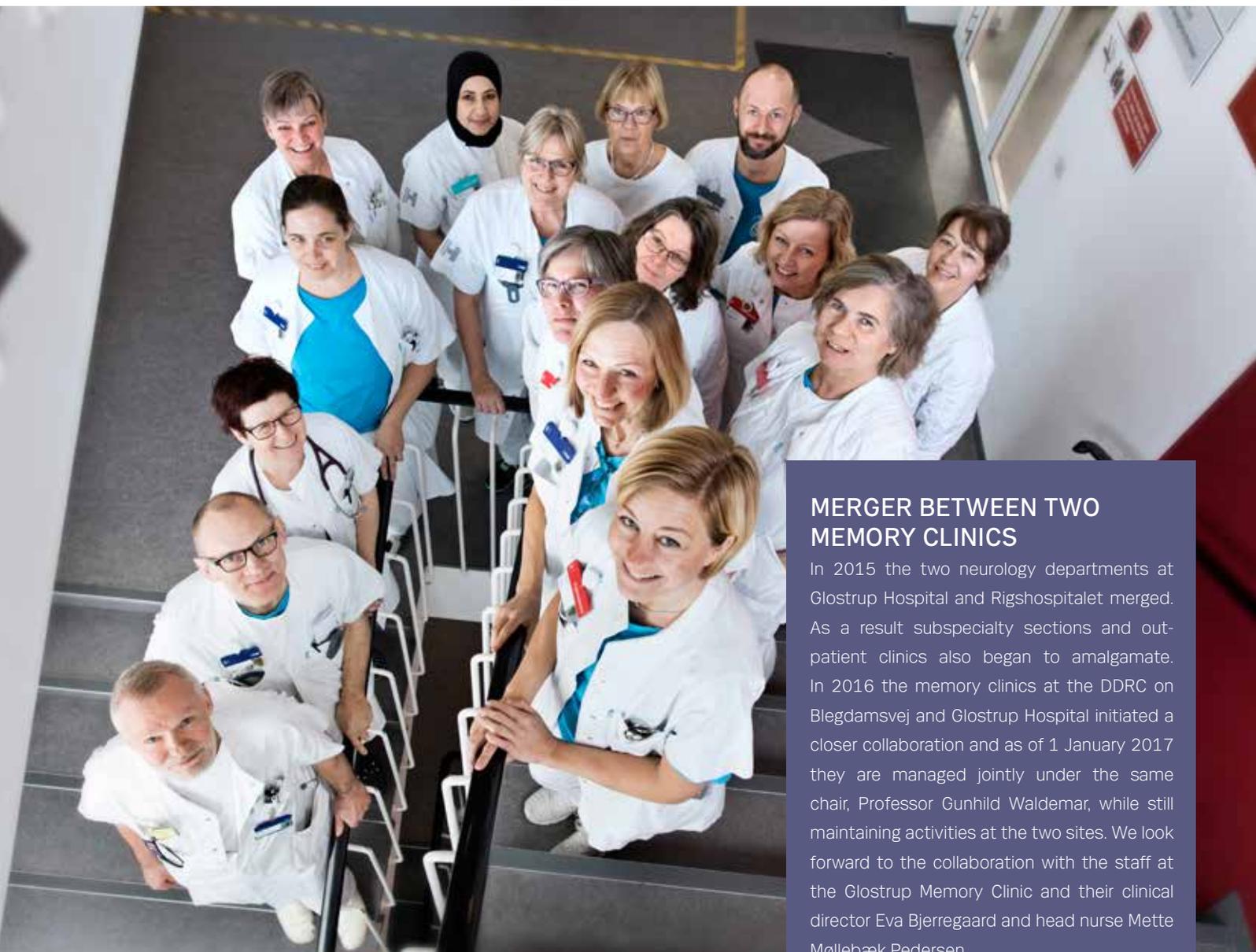
## REGIONAL AND NATIONAL COLLABORATION

In 2006 the Capital Region of Denmark established a quality registry for the diagnostic evaluation of dementia. The registry, which includes data from all five memory clinics (and the specialist service on Bornholm), is monitored by the region's Scientific Dementia Council and coordinated by the Copenhagen Memory Clinic. In 2014 the registry was adjusted to accommodate quality indicators for a national database, which was launched in 2016.

The Capital Region of Denmark established guidelines for coordinating patient care pathways between hospital-based memory clinics,

mental health centres, other hospital departments, general practitioners and primary health care in its 29 municipalities.

For patients from the City of Copenhagen, the Copenhagen Memory Clinic at Rigshospitalet has specific collaboration programmes with the Departments of Geriatrics at Bispebjerg Hospital, the Mental Health Centre Copenhagen, the Mental Health Centre Frederiksberg, general practitioners, and the care institutions and home care in the City of Copenhagen and the City of Frederiksberg. The Copenhagen Memory Clinic is an active member of the Network of Danish Memory Clinics.



### MERGER BETWEEN TWO MEMORY CLINICS

In 2015 the two neurology departments at Glostrup Hospital and Rigshospitalet merged. As a result subspecialty sections and outpatient clinics also began to amalgamate. In 2016 the memory clinics at the DDRC on Blegdamsvej and Glostrup Hospital initiated a closer collaboration and as of 1 January 2017 they are managed jointly under the same chair, Professor Gunhild Waldemar, while still maintaining activities at the two sites. We look forward to the collaboration with the staff at the Glostrup Memory Clinic and their clinical director Eva Bjerregaard and head nurse Mette Møllebæk Pedersen.



# RESEARCH

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DDRC research programmes cover a wide spectrum of clinical and translational research, including studies on epidemiology, biofluid markers, brain imaging, neurogenetics, genotype-phenotype correlations, patient-specific stem cells, disease course, neuropsychology, drug trials, non-pharmacological interventions and health service research. Our research is funded by external grants and donations from public and private foundations (see Acknowledgements). The health service and intervention research programmes with direct relevance to improving the quality of dementia care in Denmark are funded in part by the Danish Ministry of Health as an integral part of the National Info & Education Centre.

In 2016 one PhD thesis was completed and DDRC published 60 papers in peer-reviewed journals and four book chapters (see Publications). At the end of 2016 professors and clinical trial directors (with shared clinical and research positions), postdocs/senior researchers, PhD students, associated researchers and student research fellows, counting a total of 34, were employed on our research team. In addition, most consultant neurologists and neuropsychologists in the clinical team contributed significantly to our research. Three research nurses (study coordinators), two research administrators and one administrative assistant took care of the coordination and financial aspects of our many research programmes.

The next four sections of the annual report describe:

- Thematic areas of research
- Research resources
- International research consortia and networks
- DDRC researchers – who is who?

## THEMATIC AREAS OF RESEARCH

### Early diagnosis: Neuropsychology and biomarkers

Discovery and validation of disease markers for AD and other neurodegenerative disorders are key research areas in DDRC, which include new biofluid markers, brain imaging and neuropsychology. The biomarker research aims to discover and validate new biofluid markers for the early diagnosis of AD and for the prediction of disease progression using proteomics and genomics technologies. DDRC conducts and participates in several brain imaging studies on early diagnosis of dementia that include both structural and functional brain imaging, including studies with amyloid-specific PET tracers.

Many biomarker studies are carried out in collaboration with other Danish centres, as well as a wide range of European centres. Neuropsychological research mainly focuses on characterisation of cognitive deficits in the early phase of dementia diseases and MCI. In recent years se-

veral studies on cognitive processes in aging have been published, with changes in personality traits and social cognition in manifest and pre-manifest Huntington gene-expansion carriers gathering a great deal of attention.

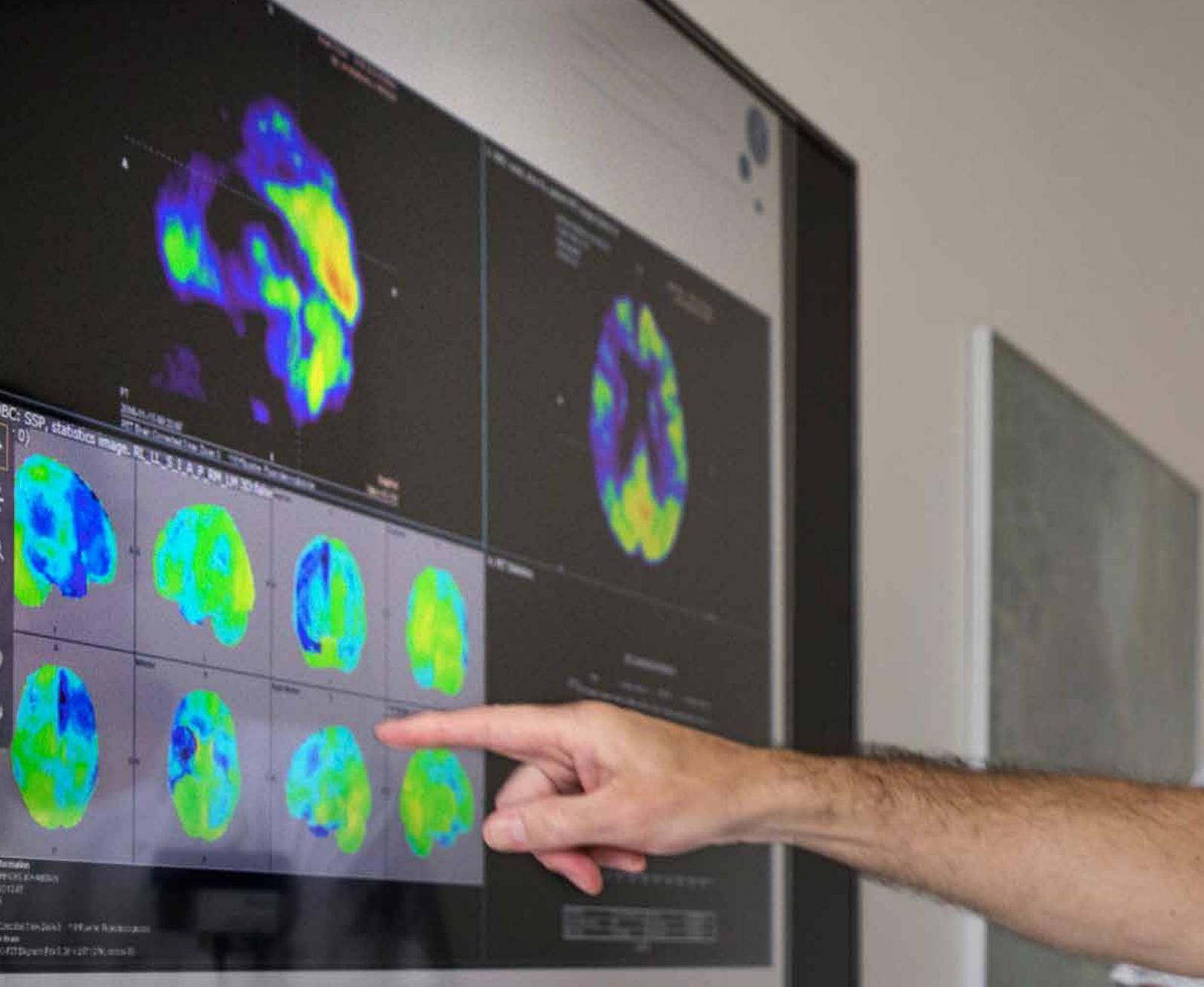
### Familial neurodegenerative disorders

Neurogenetic research focuses on clinical characteristics, ancillary investigations and basic research into gene function and therapy. Many neurodegenerative disorders, including AD, FTD and ataxias manifest with progressive loss of specific subsets of neurons in the brain. In some diseases genetic mechanisms are involved. Different diseases have different genetic backgrounds, but evidence shows that common mechanisms of neurodegeneration may exist. Some of our research focuses on the identification of common molecular mechanisms in neurodegeneration, e.g. in FTD linked to chromosome 3 (FTD3) and spinocerebellar ataxia type 2 (SCA2).

We are also exploring the cellular environment in patient-derived cell cultures to pinpoint therapeutic targets. The FReJA Consortium investigates FTD linked to FTD3, which occurs in a large FTD family in western Jutland. Research in this disease focuses on the molecular disease mechanism, with neuronal cell lines now derived using stem cell technology to further explore the potential of gene therapy. The Copenhagen Memory Clinic's neurogenetics section is a significant international contributor to research in HD, and our large cohorts of patients are assessed with detailed clinical and neuropsychological evaluations, genetic markers and CSF profiles.

### Medication and health services

Using nationwide registry data we investigate the quality of diagnostic evaluation, access to health services and the use of medication in patients with dementia as compared to the general Danish population. Using nationwide registry data allows us to study time trends concerning the use of medication among patients with dementia in Denmark. The research is carried out in cooperation with the National Centre for Register-based Research at Aarhus University. Recently, projects investigating patterns of use of opioids, other analgetics, psychotropics and anti-dementia medication were conducted. One important recent result is that, despite a decrease in prevalence of antipsychotic drug use over the past decade, there is a pronounced geographical variation in use. The results of ongoing studies aimed at identifying and defining the consequences and background for the high level of use are incorporated into the national dementia plan, where reduction of antipsychotic use is one of several goals. Our research will help provide evidence for creating new guidelines and for DDRC teaching materials.



# RESEARCH

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## **Rehabilitation and psychosocial support**

We have extensive experience in carrying out large-scale multi-centre intervention studies investigating non-pharmacological treatment in neurodegenerative diseases, some of which examine the effects of psychosocial education programmes or cognitive stimulation. The recently completed ADEX study demonstrated a positive effect of physical exercise on neuropsychiatric symptoms in early AD. This project was initiated to establish a platform for future collaboration on dementia research in Danish memory clinics. In parallel with the physical exercise study, a platform was established creating a research alliance between Danish memory clinics with benchmarking to Swedish and Dutch networks.

The ongoing ReACT project develops a software programme that meets some of the cognitive support needs of people with dementia. An iterative user-driven innovation process was used to design and develop the software, resulting in an innovative adaptive application devised to support memory, structuring and communication. ReACT validated the tool, which is one of the first of its kind in the development of personalised systems for cognitive rehabilitation.

## **Global health and cross-cultural aspects of dementia**

DDRC is conducting various studies on cross-cultural aspects of dementia. For some years the centre has studied cognitive functions in



different ethnic groups in Denmark and in other European countries in an effort to improve diagnostic evaluation and care of European ethnic minorities with dementia. A special interest is the development and validation of cross-cultural cognitive tests and screening instruments for use in low and middle-income populations. Population-based studies have been conducted in Lebanon and a new research project in the Philippines focuses on the attributable risk of vascular risk factors for dementia. Greater knowledge about these factors will aid in designing public health programmes with the ultimate goal of reducing the incidence and prevalence of dementia.

**Pharmacological treatments: From first in man to proof-of-concept and large scale clinical trials**

DDRC has extensive experience in the conduction of phase 1-3 clinical pharmacological trials in patients with AD, MCI and HD and as advisors for trial design and safety monitoring. The collaboration between Danish memory clinics (ADEX network) represents a platform for Den-

mark's contribution to international trials. On average, DDRC's track record shows that the inclusion of patients is more than 30% above the intended number. The clinical trials are conducted with state-of-the-art imaging techniques in collaboration with the Danish Research Centre for Magnetic Resonance, Hvidovre Hospital and the PET and Cyclotron Unit, Rigshospitalet.

## RESEARCH RESOURCES

### Translational Neurogenetics Laboratory

In order to investigate the molecular mechanisms underlying neurodegenerative disorders we work with a variety of techniques within molecular and cellular biology. Our facility is fully equipped to perform all aspects of cellular biological research and has biosafety class I and II laboratories. Using skin biopsies from patients in our memory clinic we establish patient-specific cell cultures to dissect the molecular mechanisms of disease. These patient cells have also been used to induce

# RESEARCH

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pluripotent stem cells. These cell models form the basis of our work in combination with additional advanced techniques such as image cytometry, fluorescence microscopy, viral vector generation and RNA interference.

## **Danish Dementia BioBank (DDBB)**

DDBB was established in 2008 with the aim of collecting biological fluids for biomarker research in neurodegenerative diseases. DDBB contains samples from patients referred to the Copenhagen Memory Clinic at Rigshospitalet and the Zealand University Hospital Memory Clinic. As of 31 December 2016 DDBB contained samples from more than 5,000 patients with a wide range of neurodegenerative and psychiatric disorders. Whole blood, buffy coat, EDTA plasma and serum are stored for all patients, and CSF from approximately 25% of the patients. The samples, handled and stored according to international biobank guidelines, have contributed to multiple international biomarker and stability studies.

## **Clinical cohorts and intervention studies**

To investigate how different neurodegenerative processes arise and become manifest, specific patient cohorts, representing a wide range of diagnostic entities, cohorts of healthy controls and gene mutation carriers, are the foundation of many DDRC research programmes. These patient cohorts make up an essential basis for most of our clinical studies, with the aim of improving diagnostic evaluation, treatment and care for patients with dementia and neurodegenerative disorders. Often, intervention studies require a large number of patients, demanding multi-centre collaboration with national and international partners/memory clinics. DDRC coordinated two large-scale multi-centre intervention studies (DAISY and ADEX), with more than 200 AD

patients in each, resulting in two cohorts for future studies. A formalised platform for future collaboration on dementia research in Danish memory clinics has been established in the ADEX network.

## **Danish national registries**

Access to nationwide health care registries allows for very large population-based studies on health service, risk factors, medication and outcome in neurodegenerative disorders. All Danish in and out-patients who have had contact with a Danish hospital are registered in national registries with basic information on clinical diagnoses and procedures. In some of the earliest epidemiological studies, our group examined the validity of dementia diagnoses. Since then, the unique national registries have been the basis for several studies on the use of medication in patients with dementia and on the quality of diagnostic evaluation in various patient groups.

## **INTERNATIONAL RESEARCH CONSORTIA AND NETWORKS**

### **PredictND**

PredictND is a four-year, €4.2 m European project focusing on developing tools and means for earlier, evidence-based diagnosis of a range of neurodegenerative diseases. PredictND consortium members include 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), VTT Technical Research Centre of Finland Ltd. (Finland) (coordinator) and VU/VUmc (the Netherlands).

## **Global Excellence – In Health award**

Established in 2010 in close cooperation with the University of Copenhagen and the Technical University of Denmark, The Global Excellence award is given to hospital and university environments in the Capital Region of Denmark that perform first-rate international level research leading to the development and implementation of new, pioneering healthcare services, treatment methods and products for the benefit of patients.

The awardees are characterised by their unique efforts within one or more areas, such as the extent and quality of

their research and development, teaching, patientcare, innovation and dissemination of knowledge.

DDRC received the Global Excellence – In Health award in 2010 and again in 2014 for its outstanding contributions to the development of world class health care services in the Capital Region of Denmark.



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### **BrainStem – Stem Cell Center of Excellence in Neurology**

BrainStem – Stem Cell Center of Excellence in Neurology is supported by Innovation Fund Denmark. The project coordinator is Professor Poul Hyttel, University of Copenhagen and its primary partners are the University of Copenhagen, Lund University (Sweden), DDRC at Rigshospitalet, University of Southern Denmark, Aarhus University (Denmark), Bioneer (Denmark), Lundbeck A/S (Denmark) and Innovative Concepts in Drug Development (France). Advanced stem cell technologies are used to re-programme skin cells from patients with AD and Parkinson's disease to diseased neurons to investigate the molecular mechanisms, to develop better diagnostics and to test new drugs.

### **Frontotemporal Dementia Research in Jutland Association (FReJA)**

FReJA is an international multidisciplinary consortium established more than a decade ago to investigate a unique, large FTD-3 family in western Jutland. Basic and clinical scientists in Denmark, Sweden and the UK have made major progress over the years in identifying the disease gene and in understanding the disease mechanisms and their wider relevance for neurodegeneration in general.

### **European Alzheimer's Disease Consortium (EADC)**

EADC is a network of more than 50 European academic centres of excellence working in the field of AD and other dementias. It provides a forum for expanding scientific understanding and development of ways to prevent, delay, slow or ameliorate the primary and secondary symptoms of AD. The European Commission provided initial funding for EADC and supports working towards standardisation of diagnostic criteria, assessment tools and data collection methods, with a view to this being followed by a trial period involving the testing and practical application of the tools agreed upon (see [eadc.info/sito/pagine/home.php](http://eadc.info/sito/pagine/home.php)). The only Danish EADC member, DDRC has contributed to or directed studies on assessment tools, health economics, biomarkers and cross-cultural aspects of dementia care. DDRC hosted the bi-annual EADC meeting in Copenhagen in November 2016.

### **Interdem**

DDRC takes part in Interdem, a pan-European network of researchers collaborating in research on and dissemination of early, timely and quality psychosocial interventions aimed at improving the quality of life across Europe for people with dementia and their supporters. Members of the network include academic and clinical researchers from 23 nations. DDRC hosted the annual Interdem meeting in Copenhagen in November 2016.

### **Nordic Network in Dementia Diagnostics (NIDD)**

NIDD is funded by the Nordic Council and comprises eight academic memory clinics in the Nordic countries and Lithuania. As the name indicates, the main objective of the network is to examine various aspects of diagnostic procedures in dementia. DDRC and the memory clinic at Roskilde Hospital are the network's Danish partners.

### **European Huntington's Disease Network (EHDN) and Enroll HD**

DDRC is part of EHDN, which provides a platform for professionals and people affected by HD and their relatives to facilitate collaboration throughout Europe. DDRC's staff and patients with 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. The study is designed as a clinical research platform that will enable healthcare professionals, scientists and families affected by HD to work together towards an improved understanding of HD and better care and treatments. At the close of 2016, DDRC's Enroll-HD cohort comprised 206 participants.

### **National dementia research and education centres in Scandinavia**

Norway, Sweden and Denmark have national non-profit dementia research and education centres commissioned and funded by the national boards or ministries of health. DDRC, the Norwegian Centre for Dementia Research and the Swedish Dementia Centre collaborate and meet annually to share ideas and exchange programmes for the benefit of professional care staff, persons with dementia and family caregivers throughout Scandinavia. A sizeable conference on leadership in dementia care is one of the larger outcomes of this Scandinavian collaboration. The conference is held every other year.

### **North Sea Dementia Group**

The North Sea Dementia Group is an association of interested persons from dementia care practice and research. The theme of this year's meeting in Scotland was Dementia Aware Societies. The meeting included visits to care homes and day care centres.

### **Joint Programming on Neurodegenerative Diseases (JPND)**

Funded by Horizon 2020 and EU member states the JPND is an innovative collaborative research initiative established to tackle neurodegenerative diseases. DDRC has taken part in three JPND funded research consortia on biomarkers in Alzheimer's and Parkinson's diseases (BIOMARKAPD), on definition of outcome measures in dementia and on harmonization of assessment methods.

# RESEARCH – WHO IS WHO?

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## PROFESSORS AND ASSOCIATED 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 multicentre trial on physical exercise in AD.



### **JØRGEN E. NIELSEN – FAMILIAR NEURODEGENERATIVE DISORDERS**

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



### **ASMUS VOGEL – COGNITION AND NEUROPSYCHOLOGICAL DEFICITS**

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



### **GUNHILD WALDEMAR – INTERVENTION STUDIES, EPIDEMIOLOGY, GLOBAL HEALTH**

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

## TRIAL DIRECTORS



### **LENA ELISABETH HJERMIND – CLINICAL TRIALS – HD**

Consultant neurologist, PhD. Directs DDRC's participation in the Enroll-HD cohort study and clinical trials in HD. She also contributes to other studies in familial neurodegenerative diseases.



### **PETER JOHANNSEN – CLINICAL TRIALS – AD**

Consultant neurologist, PhD. Directs DDRC's clinical AD trials, including prodromal-Alzheimer and phase 1-3 trials. He is also involved in studies on familial FTD.

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## SENIOR RESEARCHERS AND POSTDOCS



### **ANNE SIGGAARD BIE – SCA2 AT THE CELLULAR LEVEL**

Postdoctoral fellow. Is exploring the cellular environment in patient-derived cell cultures to pinpoint therapeutic targets. By examining SCA2 assisted by large-scale techniques, such as mass spectrometry and RNA sequencing, the aim is to identify the function of ataxin-2 and its cellular milieu.



### **ADELE MARTHALER – MODELING SCA2 USING PATIENT-DERIVED INDUCED PLURIPOTENT STEM CELLS (IPSCS)**

Postdoctoral fellow. Has generated patient-derived iPSCs that were subsequently gene corrected using CRISPR/Cas9 gene technology. Patient iPSCs and gene-corrected controls will be differentiated into neurons to study the disease phenotype and the role of ATXN2 in the cell type predominantly affected by SCA2. Studies will include electrophysiological assays, global RNA sequencing and functional assays related to autophagy and apoptosis.



### **T. RUNE NIELSEN – CROSS-CULTURAL ASSESSMENT AND DEMENTIA IN ETHNIC MINORITIES**

Neuropsychologist. Main research focus is cross-cultural assessment of cognitive deficits and ethnic differences in dementia diagnostics, treatment and care. He is initiating and coordinating national and international studies on the development and validation of cross-cultural cognitive tests.



### **TROELS TOLSTRUP NIELSEN – MOLECULAR MECHANISMS IN NEURODEGENERATION**

Senior researcher. Research focus is on multiple neurodegenerative disorders, including AD, FTD and ataxias manifest in progressive loss of specific subsets of neurons in the brain. His research centres on finding molecular mechanisms in neurodegeneration using two monogenic disorders as models, namely FTD linked to FTD3 and SCA2.



### **KIEU PHUNG – CROSS-CULTURAL DEMENTIA EPIDEMIOLOGY AND PUBLIC HEALTH INTERVENTIONS**

MD, neuroepidemiologist and visiting professor at the University of Santo Tomas and University of the Philippines. Main research focus is dementia frequency, risk factors and risk modification across different cultures and ethnic groups. She has conducted population-based studies in Denmark and Lebanon and is currently working on a research project in the Philippines that studies the attributable risk of vascular risk factors for dementia.



### **ANJA HVIID SIMONSEN – BIOMARKERS AND BIOBANK**

Senior researcher and director of the Danish Dementia BioBank. Main research focus is molecular and genetic biomarkers for diagnosis and prognosis of neurodegenerative diseases as well as for response to interventions. Coordinator of the Danish Dementia BioBank's participation in international collaborative biomarker projects and projects related to sample quality.



### **JONATHAN WARDMAN – SCA2 AT THE CELLULAR LEVEL**

Postdoctoral fellow. Is investigating the second-order dysfunction caused by aggregation and interaction of the mutant protein with various aspects of the proteostatic system. Studying the differential responses of SCA2 patient fibroblasts versus controls will make it possible to determine what specific aspects of the proteostatic system are disrupted in SCA2 and to find specific (potentially druggable) cellular targets.

# RESEARCH – WHO IS WHO?

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## ASSOCIATED RESEARCHERS (CURRENTLY EMPLOYED ELSEWHERE)



### **KRISTIAN STEEN FREDERIKSEN – PHYSICAL EXERCISE AND CLINICAL APPLICATION OF AD BIOMARKERS**

MD, PhD. Main research areas are physical exercise in neurodegenerative dementias with regard to treatment and primary prevention. A second area of interest is the application of biomarkers of AD and other neurodegenerative diseases in the clinic, with a special focus on brain imaging techniques.



### **CHRISTINA JENSEN-DAHM – EPIDEMIOLOGY AND REGISTER-BASED RESEARCH**

MD, PhD. Major research focus is epidemiological studies based on registry data. Current research focuses on medication use (analgesics, anti-dementia drugs, psychotropic medication and polypharmacy) in elderly with dementia, diagnosis of dementia and ethnicity.



### **IDA UNMACK LARSEN – COGNITION AND PERSONALITY IN HUNTINGTONS DISEASE**

Neuropsychologist, PhD. This PhD project investigates neuropsychological impairments in executive functions and social cognition in the premanifest and early manifest stages of HD. Also conducted were exploratory studies investigating whether carrying the HD gene or growing up in an HD family will affect personality traits.



### **MALENE SCHJØNNING NIELSEN – MILD COGNITIVE IMPAIRMENT**

MD. Her PhD project examines the diagnostic and prognostic value of three simple, inexpensive and widely available methods in the assessment of patients with MCI and AD.



### **LISE CRONBERG SALEM – DEMENTIA IN PEOPLE WITH DOWN SYNDROME**

MD, PhD. Main research focus is studying diagnostic tools (e.g. quantitative EEG) to improve the diagnostic evaluation of dementia in patients with intellectual disabilities, which may be a difficult task due to their impaired ability to cooperate with regard to common diagnostic methods, such as lumbal puncture and advanced scans of the brain.



### **TUA VINTER-JENSEN – CLINICAL SYMPTOMS IN HUNTINGTON'S DISEASE AND POSSIBLE BIOMARKERS PREDICTING DISEASE COURSE**

MD, PhD. Studied a cohort of manifest and premanifest HD gene-expansion carriers with neurological, psychiatric and cognitive examination, together with blood and CSF analysis and MR/PET-FDG and will offer follow-up to identify biomarker predictors.

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## PHD STUDENTS



### **MARIE BRUUN – DIFFERENTIAL DIAGNOSTICS OF NEURODEGENERATIVE DISEASES**

MD. Her PhD project explores the potentials of and validates the PredictND tool, a data-driven diagnostic decision support system designed to assist in differential diagnostics of dementia diseases. Is also studying the properties of quantitative measurements of motor signs as diagnostic or prognostic biomarkers.



### **ANETTE NØRGAARD CHRISTENSEN – USE OF PSYCHOTROPIC DRUGS IN PATIENTS WITH DEMENTIA**

MD. Using nationwide registry data, her PhD project investigates time trends in the use of antipsychotics and other psychotropic drugs as well as the extent of the use of antipsychotics in combination with other psychotropic drugs (psychotropic polypharmacy) among patients with dementia in Denmark.



### **LE GJERUM – OPTIMISING 18F-FDG-PET IN THE DIAGNOSIS OF DEMENTIA DISORDERS**

MD. Her PhD project will optimise and evaluate a visual 18F-FDG-PET rating scale for cingulate island sign as a biomarker for DLB.



### **CAMILLA STEEN JENSEN – BIOMARKERS AND EXERCISE IN PATIENTS WITH ALZHEIMER'S DISEASE**

MSc. Her PhD project investigates the beneficial effect of physical exercise on patients with AD measures in CSF. Various aspects are being studied of the biochemical parts of AD, among others the diagnostic biomarkers amyloid-beta and tau.



### **MARIE NATHALIE NICKELSEN HELLEM – HUNTINGTON'S DISEASE**

MD. Her coming PhD project will investigate 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.



### **PETER ROOS – CLINICAL AND MOLECULAR ASPECTS OF FTD LINKED TO FTD-3**

MD. In the search for early markers and for modifiers of FTD-3, his PhD project examines clinically affected and presymptomatic CHM P2B gene mutation carriers from the Danish FTD-3 family.

# RESEARCH – WHO IS WHO?

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## **NINA ROSTGAARD – CSF BIOMARKERS AND MOLECULAR MECHANISMS IN INHERITED FTD-3**

MSc. Her PhD project studies biomarkers in CSF to elucidate if there is a clear FTD-3 profile. The aim is also to understand the underlying disease mechanisms of the disease fibroblasts from FTD-3 patients.



## **LÆRKE TAUDORF – DEMENTIA AND MORTALITY: A REGISTER-BASED STUDY**

MD. Her coming PhD project will investigate life expectancy from the time of dementia diagnosis and whether life expectancy has changed over time. It will also investigate whether certain comorbidities are associated with higher mortality. Finally, the project will review the registered causes of death in individuals with dementia.



## **LAILA ØKSNEBJERG – ASSISTIVE TECHNOLOGY AND COGNITIVE REHABILITATION**

Neuropsychologist. Her project (ReACT), which examines rehabilitation in AD using cognitive support technology, involves the design of tailor-made software to support the cognitive functions of people with dementia through a user-involvement innovation process. Technology implementation methods are also under study, with a main emphasis on cognitive rehabilitation. .

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## **TWO NEW ASSOCIATE PROFESSORSHIPS IN 2016**

In 2016 the Institute of Clinical Medicine, Faculty of Medicine and Health Sciences, University of Copenhagen awarded consultant neurologist Jørgen Erik Nielsen, PhD, a five-year clinical research associate professorship. As an associate professor with a shared clinical and research position at DDRC, Nielsen will have the opportunity to strengthen his research in the neurogenetic aspects of neurodegenerative diseases and to serve as a main supervisor for PhD students. He will also teach undergraduate medical students in clinical neurology and supervise bachelor and master's students.

In 2016 neuropsychologist, phd., Asmus Vogel, was employed as associate professor at the Department of Psychology, University of Copenhagen. As an associate professor with a shared clinical and research position at DDRC, Vogel will have the opportunity to strengthen his research in clinical neuropsychology. He will also train and supervise under- and postgraduate neuropsychologists.

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## STUDENT RESEARCH FELLOWS (MASTER STUDENTS)



**FREDERIKKE JEPPESEN KRAGH – QUANTITATIVE MEASUREMENTS OF MOTOR SIGNS IN DEMENTIA**

Her study investigates if a quantitative motor assessment provides a more objective, sensitive and standardised measurement of motor dysfunction in AD, FTD and DLB.



**RACHEL UNDERLIEN KRISTENSEN – REGISTER-BASED RESEARCH ON POLYPHARMACY IN DEMENTIA**

Using nationwide data, her project investigates the frequency and time trends of polypharmacy among people with and without dementia to examine potential disparities.



**CHRISTINA STRAND-HOLM MANNICHE – CSF BIOMARKERS IN NPH, VASCULAR DEMENTIA AND AD**

Her project investigates the ability of specific biomarkers in CSF to distinguish NPH from SIVD and AD.



**CHRISTIAN SANDØE MUSAEUS – EPILEPTIC SEIZURES IN AD**

His coming PhD project aims to assess subclinical epileptiform activity with continuous EEG monitoring using novel ear EEG registration and to correlate findings with MRI hippocampal blood flow assessments.



**LEA STEVNSBORG – REGISTER-BASED RESEARCH ON DEMENTIA IN IMMIGRANT POPULATIONS**

Her project investigates the use of anti-depressants and anti-psychotics in immigrant populations with dementia in order to identify possible disparities in access to treatment in immigrant populations.



**JOHANNE KØBSTRUP ZAKARIAS – EPIDEMIOLOGY AND ANTIPSYCHOTIC USE IN DEMENTIA**

Using nationwide registry data, this project investigated potential geographical variation in use of antipsychotics in people with dementia to determine possible factors contributing to the high prevalence of usage.



# NATIONAL INFO & EDUCATION CENTRE FOR DEMENTIA

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Established in 2007 and funded by the Ministry of Health and the Elderly the National Info & Education Centre provides research, nationwide education and the dissemination of information about dementia, primarily to health care professionals and care staff in Denmark. DDRC communicates to a variety of professionals and societies on a range of platforms via, for example the DDRC website, training courses, networks, e-learning, public media, apps, publications and conferences.

## COURSES AND CONFERENCES

The National Info & Education Centre offers a wide range of courses throughout the country, in addition to two annual conferences.

The 2016 course catalogue offered a variety of activities (courses, thematic events and conferences with more than 5,000 participants) on a wide range of subjects, such as dental care, behavioural symptoms, diagnostic evaluation of dementia in patients with minority language or cultural background, physical exercise, medication, sexuality, conveying a difficult message, and leadership in dementia care.

In 2016 DDRC organised more than 60 courses and conferences tailored to the needs of specific groups per request by local authorities and regional institutions. Designed to meet a specific purpose or cover a certain subject, customised courses were attended by a broad range of professionals. With 138 participants, blended learning was popular in 2016 and required that participants complete ABC Dementia (our free, online course) before attending a customised course.

### Dementia Days – a national conference

Every year DDRC organises Dementia Days, a national two-day conference for dementia specialists and practitioners. As Denmark's largest conference on dementia, it provides a valuable educational opportunity for management and staff working in the social services and health care sector. The Minister for Health and the Elderly, Sophie Løhde, opened the conference on 19 May 2016, which revolved around the theme "A healthy life for all" and had 930 participants. Thirty-three invited speakers presented their reviews and data within a extensive range of topics. During the conference, participants had the opportunity to present results from their own research.

### Scandinavian conference for leaders in dementia care

Every other year DDRC organises a two-day conference for leaders in care in collaboration with the Norwegian and Swedish national research and education centres. In 2016 the conference was held in Oslo, Norway on the topic "Management in the gap between ideology and practice". The conference attracted 281 leaders from Sweden, Norway and

Denmark and a number of internationally recognised speakers were invited.

### Annual research conference

Every year a full-day national conference primarily devoted to the latest scientific news within a specific topic of interest related to dementia takes place in November at Rigshospitalet. The conference attracts scientists and practitioners from across Denmark. On 25 November 2016 more than 188 professionals attended the annual research conference on "Pharmacological treatment and dementia" to update their knowledge.

## ABC DEMENTIA – FREE ONLINE COURSES

Offering free e-learning is one way of providing easy-access knowledge about dementia to different target groups across the nation. The practice-oriented nature of the topics and the variety of educational approaches used make the courses especially user friendly. "ABC Dementia – care" involves e-learning for professional caregivers, with each module designed to cover a specific topic, such as dementia disorders, behavioural symptoms or communication. At the close of 2016 all ten modules and a final online test had been produced.

When launched in 2013 ABC Dementia targeted basic care staff (home care and nursing homes) and was a new approach designed to reach beyond traditional courses and conferences. By the end of 2016 ABC Dementia had more than 16,000 users and more users join weekly. In October 2016 ABC Dementia for physicians was launched targeting physicians in training, primarily within geriatrics, neurology, psychiatry and general practice. The content was developed based on a variety of cases and touches on topics such as disease progression, assessment/diagnostics, occurrence and treatment. By the end of 2016 ABC Dementia for physicians had more than 300 users.

## DDRC'S NATIONAL NETWORKS

In order to foster an exchange of knowledge, education and quality programmes, DDRC and its National Info & Education Centre coordinates national networks across regional, municipal and professional boundaries.

### Network of Danish Memory Clinics

Set up by DDRC, the Network of Danish Memory Clinics serves as a platform for dissemination and exchange of information, for harmonising and standardising assessment and treatment methods and for strengthening local and national collaboration. Its members, which comprise multidisciplinary staff such as nurses, medical doctors and



neuropsychologists, are mainly based in hospital psychiatric, geriatric or neurological departments and receive referrals from local general practitioners for diagnostic evaluation of dementia. Network members meet once a year to maintain and further develop national cooperation.

In October 2016 DDRC held its 9th annual network conference for memory clinics in Denmark, which attracted representatives from more than 30 memory clinics nationwide. The 151 participants included physicians, nurses, psychologists, secretaries and therapists. The main topics presented at the conference were the national dementia plan 2025; the Malmo dementia clinic and organisation of health care in dementia in Region Skåne, Sweden; the national quality registry for diagnostic evaluation of dementia; and ABC Dementia for physicians.



Network of Danish Memory Clinics:

- Memory clinics
- ADEX Memory clinics
- ADEX affiliates

# NATIONAL INFO & EDUCATION CENTRE

## National network of municipality-based dementia ambassadors

Each of the 98 Danish municipalities have appointed a dementia ambassador to disseminate information about DDRC activities and news from other municipalities to local professionals and to monitor local needs for educational activities. Special newsletters sent six times a year and an annual meeting for the ambassadors ensure contact between DDRC and the ambassadors.

## Psycho-social Research Network

For multidisciplinary researchers interested in psychosocial interventions, such as cognitive rehabilitation, music therapy and personalised care, the Psycho-social Research Network is the Danish counterpart of the pan-European network Interdem. The network meets at least once a year with the aim of improving psychosocial dementia research in Denmark.

## Network for teachers in schools, colleges and continuing education services focused on health care

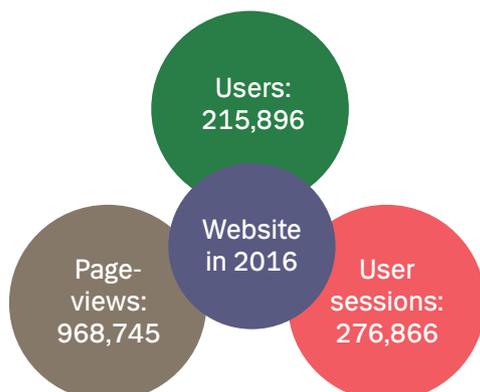
Teachers who are involved in the education of nurses, nurse assistants, occupational therapists and physical therapists use the network to exchange ideas and educational material on teaching about dementia.

## COMMUNICATIONS AND PRESS – INTERACTING WITH SOCIETY

All of our platforms have seen a high level of activity and we have a growing number of followers on social media. This is due to an ongoing strategic approach to public relations and a focused effort in reaching out to our stakeholders and the press in general. In 2016 we continued implementing our new visual identity to give our digital and printed materials a more uniform appearance.

### Website

Our website, videnscenterfordemens.dk, provides information about dementia diseases, risk factors and statistics for people who work with the assessment, treatment and care of individuals with dementia.



Materials and tools useful in clinical practice can be downloaded or ordered on the site. The press, patients and caregivers also use our website extensively.

### Newsletter

Our newsletter is published 6-8 times per year and contains information about the latest research and current courses and conferences.

THE DDRC NEWSLETTER				
	2013	2014	2015	2016
Subscribers	3,976	4,288	4,400	5,259

### 'About Dementia' app

The app "About Dementia" is a widely used observation tool for professional caregivers. In 2016 the app was used 52,550 times (user sessions) and had 15,575 unique users. In 2016 the Norwegian centre Norwegian National Advisory Unit on Ageing and Health translated the app into Norwegian with the name "Knowledge about Dementia".

### Social media

Facebook is a useful way to create and maintain a relationship with the public and to disseminate knowledge about dementia and DDRC, e.g. activities, courses, conferences, while Twitter is valuable for spreading news about research and building relationships with relevant journalists. Facebook inquiries in particular draw traffic to our website.

FOLLOWERS ON SOCIAL MEDIAS				
	2013	2014	2015	2016
Facebook	120	508	1,150	3,000
Twitter	30	290	474	693

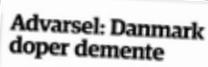
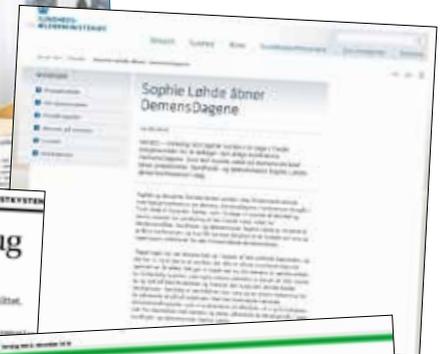
### DDRC conference booth

DDRC participated with its conference booth in events in 2016, e.g. Dementia Days. The booth is instrumental in promoting direct contact with our target groups, allowing us to generate new contacts and disseminate information about our products to professionals and stakeholders, as well as general knowledge about dementia to the public.

**DDRC in the press**

DDRC takes pride in offering comments, articles and statements on dementia-related issues to the public media. As shown in the statistics DDRC is present in the press on an almost daily basis.

DDRC IN THE PRESS					
	2012	2013	2014	2015	2016
Print	108	173	315	313	425
Online	122	166	301	384	638
Radio/TV	21	38	72	40	65



# NATIONAL AND INTERNATIONAL POSTS

**Birgitte Bo Andersen**, inspector for the Danish Health and Medicines Authority (appointed by the Danish Neurological Society); appointed member of the Dementia Council of the Capital Region of Denmark.

**Marie Bruun**, board member of the Danish Neurological Society; member of the local organising committee for the 2<sup>nd</sup> Congress of the European Academy of Neurology (EAN) in 2016 in Copenhagen.

**Kristian Steen Frederiksen**, member of EAN Scientific Panel on Dementia and Cognitive Disorders; member of representatives, Danish Alzheimer Association; board member, Young neurologist, neurosurgeons and neurophysiologists (YNNN).

**Steen G. Hasselbalch**, board member, Danish Alzheimer Association; chair of the Alzheimer Research Committee under the Danish Alzheimer Association; member of the Scientific Panel on Dementia and Cognitive Disorders, EAN.

**Lena Hjermand**, PI of the global observational study on HD, Enroll-HD; CPI and PI of the phase 2 trial "Pride" for treatment of HD; adviser for European Huntington's Disease Network (EHDN) and member of the working groups "Genetic testing and counselling" and "Symptomatic Treatment and Research" in EHDN; vice-president of the Danish Huntington's Disease Association; member of the working group "Genetics" in the COST Grant work plan, BM1101 European Network for the Study of Dystonia Syndromes.

**Peter Johannsen**, chair, Danish National Dementia Registry; advisor on anti-dementia drugs, the Danish Medicines Agency, representing the Danish Neurological Society; Danish national coordinator (and PI) on six clinical trials on AD; scientific adviser for Nasjonalforeningen for Folkehelse, Oslo, Norway; member of the editorial board for Dementia and Geriatric Cognitive Disorders.

**Kasper Jørgensen**, neuropsychology consultant for the Danish Patient Safety Authority; board member, Dansk Psykologisk Forlag.

**Ida Unmack Larsen**, member of the behavioural working group in EHDN.

**Jørgen Nielsen**, Danish national coordinator (and PI) of the international SPATAX network on cerebellar ataxias and spastic paraplegias; advisor for EHDN and member of the REGISTRY steering committee of EHDN; appointed member of the Research Committee at Rigshospitalet; appointed member of European Academy of Neurology, scientific panel in neurogenetics.

**T. Rune Nielsen**, co-founder and member of Nordic Research Network on Dementia and Ethnicity; member of advisory group on dementia in ethnic minorities in the Nordic Dementia Network coordinated by the Nordic Welfare Centre.; international coordinator and PI of the European multinational CNTB study on validation of a cross-cultural neuropsychological test battery; local PI on the multinational CLEARLY study on culturally adapted versions of the ADCS-PACC.

**Jette Stokholm**, neuropsychology consultant for the Danish Patient Safety Authority.

**Tua Vinther-Jensen**, member of EHDN biomarker working group and behavioural working group; board member, YNNN.

**Asmus Vogel**, section editor, *Scandinavian Journal of Psychology*.

**Gunhild Waldemar**, board member, Alliance for Biomedical Research in Europe; committee member of Liaison Committee and member of Management Committee for Scientific Panel of Dementia of European Academy of Neurology (EAN); member of the Medical and Scientific Advisory Panel (MSAP) of Alzheimer's Disease International; member of Expert Advisory Panel, Alzheimer Europe; member of the Board of Trustees and chair of the research committee, the Lundbeck Foundation; advisor, the National Legal Medicine Council, the Danish Ministry of Justice; vice-chair, Dementia Council, Capital Region of Denmark; member of executive committee of the Neurology Council, Capital Region of Denmark; president, the Medical Society of Copenhagen; member of the psychiatry committee, the Danish Health and Medicines Authority.

**Laila Øksnebjerg**, co-lead of pan-European working group "Dementia outcome measures: Charting new territory", which is supported by the EU Joint Programme – Neurodegenerative Disease Research.







# STAFF IN 2016

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## MANAGEMENT



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



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



**Head nurse  
Copenhagen Memory Clinic**  
Hanne I. Sørensen, RN



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



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



**Educational director**  
Karen Tannebæk,  
occupational therapist  
(gerontology)



**Research administrator**  
Jette Rasmussen



**Director of communications  
and press**  
Mette Tandrup Hansen, MA

## ADMINISTRATION

Benedikte Andersen, MSc, research secretary  
Jette Gotlieb Iversen, course administrator  
Ditte Majgaard Jensen, course administrator  
Jette Rasmussen, research administrator

## NATIONAL INFO & EDUCATION CENTRE

Helle Akselbo, RN, educational advisor  
Tove-Marie Buk, RN, educational advisor  
Marie Ejlersen, MA, communication officer  
Mette Tandrup Hansen, MA, director of communications and press  
Kasper Jørgensen, MSc, neuropsychologist  
Christina Aagrén Nielsen, MA, communication officer  
Elsebeth Refsgaard, RN, educational advisor, project manager  
Karen Tannebæk, OT, educational director  
Gunhild Waldemar, MD, DMSc, professor and chair

## RESEARCH

Anne Siggaard Bie, PhD, postdoc  
Kathrine Bjarnø, medical laboratory technician  
Marie Bruun, MD, PhD student (maternity leave)  
Ane Nørgaard Christensen, MD, PhD student (maternity leave)  
Tina Elberling, MD, project director  
Le Gjerum, MD, PhD student  
Christina Vangsted Hansen, RN, research nurse  
Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist, research director  
Anne-Mette Hejl, MD, PhD, senior neurologist, associate professor  
Marie Nickelsen Hellum, MD, PhD student  
Lena Elisabeth Hjermand, MD, PhD, senior neurologist  
Oda Jakobsen, RN, research nurse  
Peter Johannsen, MD, PhD, senior neurologist  
Ida Unmack Larsen, MSc, PhD, neuropsychologist  
Jørgen E. Nielsen, MD, PhD, associate professor, senior neurologist, research director  
Troels Tolstrup Nielsen, MSc, PhD, laboratory leader, senior researcher  
T. Rune Nielsen, MSc, PhD, neuropsychologist  
Mikkel Nif Rasmussen, medical laboratory technician  
Peter Roos, MD, PhD student  
Nina Rostgaard, MSc, PhD student  
Anja H. Simonsen, MSc, PhD, senior researcher  
Camilla Steen-Jensen, PhD student  
Jette Stokholm, MSc, neuropsychologist  
Asmus Vogel, MSc, PhD, neuropsychologist, associate professor  
Gunhild Waldemar, MD, DMSc, professor, senior neurologist  
Jonathan Wardman, PhD, post.doc.  
Laila Øksnebjerg, MSc, neuropsychologist, PhD student

### Associated researchers (excluding students)

Kristian Steen Frederiksen, MD, PhD  
Christina Jensen-Dahm, MD, PhD  
Ida Unmack Larsen, MSc, PhD, neuropsychologist  
Adele Marthaler, PhD, post.doc.  
Tien Kieu Phung, MD, PhD Lise Cronberg Salem, MD, PhD  
Malene Schønning, MD, PhD  
Tua Vinther-Jensen, MD, PhD

## COPENHAGEN MEMORY CLINIC

### Medical doctors

Birgitte Bo Andersen, MD, DMSc, senior neurologist  
Nanna Winther Dombrowsky, MD, resident in neurology  
Ghazaleh Doroudian, MD, junior physician (maternity leave)  
Elsebeth Steno Hansen, MD phd, senior psychiatrist  
Steen G. Hasselbalch, MD, DMSc, professor, senior neurologist  
Anne-Mette Hejl, MD, PhD, associate professor, senior neurologist  
Lena Elisabeth Hjermand, MD, PhD, senior neurologist  
Peter Johannsen, MD, PhD, senior neurologist  
Christina Rørvig-Løppenthien, MD, staff neurologist  
Susanne Lindquist, MD, PhD, clinical geneticist  
Jørgen E. Nielsen, MD, PhD, associate professor, senior neurologist, research director  
Lisbeth Regeur, MD, senior neurologist  
Lise Cronberg Salem, MD, PhD, resident in neurology  
Sarah Taudorf, MD, PhD, staff neurologist  
Gunhild Waldemar, MD, DMSc, professor, senior neurologist

### Nurses

Nicole Cordes, RN  
Christina Vangsted Hansen, RN  
Lene Iben Hvidkjær, RN  
Oda Jakobsen, RN  
Hanne Rygaard Jensen, RN  
Annette Lauridsen, RN  
Hanne Inge Sørensen, RN  
Sanne Voss, RN  
Naomi Wakabayashi, RN  
Sara Wendel Winther, RN

### Clinical neuropsychologists

Rune Nielsen, MSc, PhD  
Selma Nielsen, MSc  
Jette Stokholm, MSc  
Asmus Vogel, MSc, PhD, associate professor  
Nadia Falcon Bærnthsen, MSc

### Medical secretaries

Benthe Friedman  
Dorte Hansen  
Susanne Lindstrøm  
Pernille Munch-Christensen  
Ulla Thranow

### Social counsellor

Pernille Starnø

### Medical laboratory technologist

Kathrine Bjarnø

### Receptionists

Anne-Mette Pedersen  
Joan Rysgaard

# PUBLICATIONS IN 2016

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## PHD DISSERTATION

Larsen, IU, *Personality traits and cognitive impairment in Huntington's disease*. University of Copenhagen, 2016.

## SCIENTIFIC PAPERS

Bertelsen, B, Nazaryan, L, Sun, W, Mehrjouy, MM, Xie, G, Chen, W, Hjer-mind, LE, Taschner, PEM & Tümer, Z. A germline chromothripsis event stably segregating in 11 individuals through three generations. *Genetics in medicine* 2016; nr. 18: 494-500.

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## CONTRIBUTIONS TO MULTICENTRE STUDIES (European Huntington's Disease Network)

Cubo, E, Ramos-Arroyo, MA, Martínez-Horta, S, Martínez-Descalls, A, Calvo, S, Gil-Polo, C, European HD Network. Clinical manifestations of intermediate allele carriers in Huntington disease. *Neurology* 2016; 87: 571-8.

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## BOOK CHAPTERS AND BOOKS

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# FINANCING

The total annual budget of the DDRRC amounts to approximately DKK 43 m, distributed almost evenly between internal funding (DKK 20,7m for memory clinic services) and external grants for research and educational activities. In 2014 operation of the National Info & Education

Centre was extended with a DKK 19.2 m grant from the Danish Ministry of Health (2016-2018). In 2016 the governmental funding for the National Info & Education Centre was extended to DKK 8 m/y and made permanent from 2017.

External funding for research and education activities 2016 (DKK Million)	
New grants recieved	4,7
New grants accumulated 2007-2016	127,9
External grants spent on specific programmes	
• The National Info & Education Centre from the Danish Ministry of Health and the Elderly	6,5
• Other external grants for research	9,3
Total	15,8
Conferences, educational courses and products	3,8
Research contracts	3,0
Staff 2016	
Number of employees	75
Full-time equivalent employees with funding from	
• Internal sources	29,0
• External sources	31,4
Total	60,4

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Fonden for Neurologisk Forskning	Aase and Ejnar Danielsen Foundation
Gangstedfonden	

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