



PRESS PACK
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NEURODEGENERATIVE DISEASES PLAN 2014-2019

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Foreword

Neurodegenerative diseases are a challenge for our health system and research policies both in France and abroad.

In France, there are currently over 850,000 people suffering from Alzheimer's or a related disease, over 150,000 suffer from Parkinson's and over 85,000 suffer from multiple sclerosis.

The prevalence of over a million sufferers in France and the seriousness of the impact of these diseases on the quality of life of both the sufferers and their caregivers requires us to take action.

At a time of structural reforms and serious constraints to the public purse, it is now more important than ever to clearly define our priorities.

We must collaborate closely with the representatives of sufferers and their caregivers to improve our health system in order to ensure quality healthcare is available throughout their time living with the disease, equitable access to healthcare and an adequate support system throughout the country, as well as the coordination of all research professionals.

The directions and measures put forward in the Neurodegenerative Diseases Plan – NGDP - are part of wider national health and research strategies. These are partly based on previous research on disability and on improvements ushered in by the bill on adapting society to accommodate ageing and the Health bill.

The government has been particularly proactive, by extending this commitment to quality care, so that it also covers other diseases that require similar treatments to protect braincells, and similar care that provides a good quality of life for sufferers.

These aside, it is essential that we also address the specificities of each disease. This cross-disciplinary approach has posed a real challenge for us, halfway between a targeted plan focusing on one specific disease, and a global strategy. This additional drive forward pushed by the French President since 2012 heralds a new international and European dynamic for care and treatment for neurodegenerative diseases.

Marisol TOURAINE, Minister for Social Affairs, Health and Women's Rights

Laurence ROSSIGNOL, Minister for Families, the Elderly and Autonomy

Geneviève FIORASO, Minister for Higher Education and Research



THE FOUR STRATEGIC FOCUS AREAS

1. Life-long, country-wide care and support
2. Encouraging societal adaptation to the issues surrounding neurodegenerative diseases and reducing the social and personal consequences on everyday life
3. Developing and coordinating research on neurodegenerative diseases
4. Turning the governance of the plan into a real tool for innovation and management of public policies and health democracy

AN INTEGRATED APPROACH

- Integrating associations for sufferers, their families and caregivers into the implementation and follow-up of the process
 - Integrating the diagnosis, expertise, care and life-long support, regardless of age and location
 - Integrating health and medico-social services for a global assessment of the healthcare and support needs of the sufferers and their relatives
 - Integrating more research, health and social dimensions, as part of a drive to improve conditions for sufferers of neurodegenerative diseases
 - Integrating France's input in the creation and implementation of research and health policies carried out on an international and European level
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A COMMON PLAN AND THE CONSIDERATION OF THE SPECIFICITIES OF EACH DISEASE AND EACH LIFESTYLE

PARKINSON'S

Parkinson's disease is a chronic condition, slowly progressive, whose causes remain largely unknown.

It primarily affects an area situated a few millimetres from the base of the brain, made up of neurones, which progressively disappear. The purpose of these cells is to make and release dopamine, a neurotransmitter that plays a crucial role in the way our brain controls movement. Parkinson's disease has a huge impact on the quality of life of sufferers, due to its motor symptoms (walking disorders, postural instability), vegetative (digestive, urinary, cardio-vascular...) and psychic disorders (anxiety, depression...). Intellectual faculties remain intact, except in old age.

Aside from support with loss of autonomy and healthcare, we must also consider the issue of social and professional integration for younger sufferers.

Very rare in those under 45 years old, Parkinson's disease tends to affect older people: 1% of people over 65 are concerned, with a peak in frequency at around 70 years old. We currently estimate that there are over 150,000 people affected in France.

MULTIPLE SCLEROSIS

Multiple sclerosis (MS) is an inflammatory condition that affects the central nervous system (brain and spinal cord) that is relatively little-known amongst the general public. Its cause is yet unknown.

MS evolves with time and in an unpredictable manner. It manifests itself in very different ways amongst sufferers. Its main symptoms are for example optic neuritis, sensitive disorders (burning sensation, electric discharge) or loss of sense perception, motor disorders (functional weakness, balance disorders), physical fatigue, and even focusing and memory problems.

Improvements in therapy in the last few years don't as yet allow us to cure multiple sclerosis. And for certain forms of MS (primary progressive), there is as yet no treatment that has any influence over the course of the disease. However, a number of treatments can delay its evolution and reduce the symptoms, thereby improving the quality of life of sufferers (long-term treatment, treating relapses, symptomatic treatment).

It affects around 85,000 people in France, including 700 children. $\frac{3}{4}$ of sufferers are women. Most of the people diagnosed with MS are aged 25 to 35.

ALZHEIMER'S

When it comes to Alzheimer's, neurones, which control muscle movement, either die or degenerate, which in turn impairs cognitive faculties. Memory disorder is the most constant and perceptible symptom. But it's not the only one. Executive function disorders (for example, the sufferer might not be able to use their phone or remember a previously very familiar recipe), as well as loss of sense of time and space are also revealing. Alzheimer's disease manifests itself through progressive disorders that affect speech (aphasia), handwriting (dysgraphia), recognition (agnosia) associated with behavioural disorders (anxiety, depression, irritability).

Although the frequency of the disease is strongly linked to age, affecting 2 to 4% of people aged 65 and over and 15% of people aged 80 and over, it can nevertheless occur in much younger people. There are currently 32,000 sufferers in France aged 65 and under and between 15,000 and 25,000 sufferers aged 60 and under.

There are currently over 850,000 people suffering from Alzheimer's disease in France. In reality, over 3 million people are affected, in the sense that constant support has to be given by carers.



4 FOCUS AREAS, 12 CHALLENGES AND 96 MEASURES

FOCUS AREA 1: Life-long, country-wide care and support

Challenge 1: encouraging quality diagnoses and preventing misdiagnosis

Challenge 2: encouraging a shared and global assessment of each situation and guaranteeing access to a personalised healthcare plan

Challenge 3: improving access to quality healthcare over the period of life with the condition

Challenge 4: adapting training for professionals to improve the quality of the response to the needs of sufferers

FOCUS AREA 2: Encouraging societal adaptation to the issues surrounding neurodegenerative diseases and reducing the social and personal consequences on everyday life

Challenge 5: improving the sufferers' quality of life as part of a respectful and inclusive society that is proactive in adapting to their needs

Challenge 6: encouraging social and community relations and social innovation, and tackling isolation

Challenge 7: supporting caregivers, including relatives that provide care

Challenge 8: reducing the economic consequences of the disease and providing support for professional development for young sufferers

Challenge 9: ensuring that civil rights and ethical considerations serve to drive social change



FOCUS AREA 3: Developing and coordinating research on neurodegenerative diseases

Challenge 10: boosting and improving the coordination of research on NDD

Challenge 11: improving our understanding and knowledge of NDD to better prevent them and slow down their evolution

FOCUS AREA 4: Turning the governance of the plan into a real tool for innovation and management of public policies and health democracy

Challenge 12: improving the effectiveness of health democracy and structure of governance as part of the implementation of the NDD Plan



FLAGSHIP ACTIONS FOR FOCUS AREA 1

Life-long, country-wide care and support

CHALLENGE 1: encouraging quality diagnoses and preventing misdiagnosis

- Discussing the benefits of early treatment and care with patients and their families
- Making sure the conditions are in place for a fast referral to a neurologist and a post-diagnosis follow-up by said neurologist, regardless of whether they work in town or in a hospital, in coordination with the sufferer's GP

CHALLENGE 2: encouraging a shared and global assessment of each situation and guaranteeing access to a personalised healthcare plan

- Giving the patient a personalised healthcare programme, which includes all the details of the various professionals that they will deal with and all the information on their treatment
- Implementing and improving assessment practices by professionals (local GPs, medico-social professionals, staff from the *maisons départementales des personnes handicapées* (regional centres for disabled people), case workers...) and building closer relationships between health professionals, patients and their representatives

CHALLENGE 3: improving access to quality healthcare over the period of life with the condition

1. Improving prevention and reinforcing the role of the sufferer and their relatives in the management of the disease through therapy and future support programmes

- Encouraging the development of therapy and support programmes that take into account the sufferers' and their relatives' needs
- Developing innovative solutions (text alerts, mobile or tablet apps...) that keep the patient informed about prevention and improve the treatment follow-up



2. Guaranteeing access to adapted healthcare all over the country namely through the use of expert centres and networks

- Encouraging necessary cross-disciplinary healthcare to improve the quality of support for MDD sufferers; “the right type of care, at the right time, by the right professional” by developing teamwork in care centres, and medical hubs and nursing homes, collaborative work tools, resources directories and improving relationships between cities and hospitals...
- Encouraging existing centres of expertise (Alzheimer's, Parkinson's, MS) to work together, and sharing expertise on neurodegenerative diseases
- Improving the facilities and services provided by the National Reference Centre for Young Alzheimer's Patients (CNR-MAJ), overseeing Alzheimer's and related diseases
- Improving the functioning of the 25 centres of expertise on Parkinson's and supporting their establishment throughout the country
- Continuing funding of MS networks according to the government's own operating conditions and creating 24 MS centres of expertise
- Creating a “Parkinson's” database to help improve our knowledge of all the professionals, and to use as a useful tool for research and public policy management

3. Improving the quality and safety of healthcare

- Making sure we inform the sufferers and their relatives, as soon as the treatment starts, of all side-effects of the treatment and of the ways in which they can identify warning signs
- Improving the ways in which organisations operate to secure the continuity and relevance of treatments, especially when it comes to highly complex anti-Parkinson's treatments
- Carrying out an iatrogenic risk prevention policy
- Improving neurostimulation practices in the treatment of Parkinson's disease and related diseases
- Encouraging access to medical care at home ('HAD et Equipes Mobiles' (Home Care) for sufferers regardless of their location
- Improving the National Alzheimer's Data Bank and ensuring they can operate in the long-term
- Developing 20 to 30 new Unités Cognitivo-Comportementales (cognitive-behavioural units)
- Improving awareness of any psychological problems and access to specialised care whenever necessary, namely, as part of the regional health service planned under the Health Bill.



4. Improving services to better meet support needs

Ensuring sufferers are supported at home (alongside new measures introduced by the future bill on adapting society to accommodate ageing : (Personalised Autonomy Allowance (APA) reforms and a right to respite for carers)

- Identifying and empowering “reference” services in each region (SAAD and SSIAD (health services at home)) helping sufferers and their relatives find adequate support when they most need it
- Improving the identification of specific daily needs and the involvement of care and support services at home (SAAD) in preventing the increasing loss of autonomy, continuing efforts to improve training and professionalisation of these services
- Creating 74 new 'Equipes Spécialisées Alzheimer' (ESA- specialised Alzheimer's teams), which amounts to 740 places and 2,220 people that benefit from support in order to ensure ESA country-wide coverage
- Testing interventions by specialised teams, following the model of the ESA in order to better meet the needs of people suffering from another NDD
- Experimenting with and assessing the services of a psychologist via an analysis of activity and home care provision strategy (SSIAD)

Ensuring access to support and adapted healthcare in a socio-medical establishment

- Identifying, as part of the regional diagnosis conducted by the ARS, 'resources' establishments that help sufferers and their relatives find the appropriate support according to their specific needs and improve the quality of the response
- Adapting the various projects conducted by medical establishments to the support required by elderly people suffering from a NDD and ensuring the continuity of subsidies for a number of medical products
- Continuing the deployment of Pôles d'accompagnement et de soins adaptés (PASA – Adapted Activity and Care Centres) and the Unités d'Hébergement Renforcé (UHR-Reinforced Housing Units) within establishments of accommodation for elderly dependent people (EHPAD)
- Creating 65 extra support and respite platforms to benefit sufferers and their carers
- Improving and continuing to develop day-care centres and temporary housing to diversify the types of support we can offer in terms of home care

5. Improving end of life care and support

- Kick-starting a strategy to address end of life support and palliative care as part of a personalised approach to care and support at home or in a medical establishment
- Training professionals to better deal with the specific requirements of end of life care for people suffering from a neurodegenerative disease, and have a better grasp of communication and ethics in that sector, and of the specific night-time needs of sufferers



6. Supporting treatments especially in complex situations

- Adapting the requirements of regional health services to neurodegenerative diseases: regional diagnoses, implementation of regional platforms that provide support for health professionals, supporting pilot projects (this measure is part of the Health Bill)
- Ensuring country-wide coverage through the creation of 100 new MAIA set-ups (Méthode d'Action pour l'Intégration des services d'aides et de soins dans le champ de l'Autonomie (integrated and coordinated care for autonomy))
- Improving training for MAIA managers and equipping case workers with a unique tool for multidimensional assessment

CHALLENGE 4: adapting training for professionals to improve the quality of care to meet the needs of sufferers

- Improving the quality of initial training for professionals, namely by developing multi-professional training programmes and by involving patients and their representatives, in order to increase the sharing of expertise
- Improving ongoing training by relying on centres of expertise and using digital learning tools
- Improving training and highlighting the role and actions of neuropsychologists working in the field of NDD.



FLAGSHIP ACTIONS FOR FOCUS AREA 2

Encouraging societal adaptation to the issues surrounding neurodegenerative diseases and reducing the social and personal consequences on everyday life

CHALLENGE 5: improving the sufferers' quality of life as part of a respectful and inclusive society that is proactive in adapting to their needs

Understanding and raising awareness of the reality of living with a neurodegenerative disease for sufferers and their relatives

- Creating and supporting communication campaigns, designed in collaboration with associations for sufferers and their relatives
- Using the web and open data to create new forms of expression for users, new services for the general public, sufferers and their relatives, and professionals
- Updating the current website used as part of the Alzheimer's Plan 2008-2012

Creating the right conditions for an easier, more autonomous life at home and outside

- Using technical means and the use of new technologies (with simple, explicit interfaces, adapted to the real needs of users)
- After an assessment of the service provided, evaluating the possibility of including measures that improve autonomy in the list of refundable medical tools
- Encouraging autonomy policies to fully utilise digital tools; ensuring this is done as part of a wider ethical discussion and with respect to everyone's civic rights

CHALLENGE 6: Encouraging social and community relations and social innovation, and tackling isolation

- Promoting and extending existing remarkable initiatives (identifying, evaluating, conceptualising, outlining the extension process)
- Encouraging and promoting new forms of solidarity (mutual aid, support for digital solidarity tools and campaigns, volunteer and twinning networks...)
- Highlighting and rewarding projects that encourage social innovation
- Including France's approach in terms of social innovation to help sufferers and their carers in a more international dynamic



CHALLENGE 7: Supporting caregivers, including relatives that provide care

- Ensuring a better assessment of the needs of carers both by themselves and by professionals to tailor each intervention to the sufferer's condition and environment
- Improving training for carers and developing support strategies
- Targeting the various impediments to the support provided by carers, especially the problems they have taking any leave (the 'right to respite' measure, part of the Bill for society's adaptation to ageing)
- Developing adequate support initiatives that meets the expectations of both carers and patients, in order to make them more successful
- Encouraging a discussion around access to psychological support for carers

CHALLENGE 8: Reducing the economic consequences of the disease and providing support for professional development for young sufferers

- Prioritising job retention (alongside tailoring their career plan, role, working conditions etc.)
- Supporting the sufferer with the help of their GP, and were required, the centre of expertise (or network), which oversees the follow-up of their treatment and professional development with their employers, occupational medicine services and the Departmental Office for People with Disabilities (MDPH).
- Encouraging the company to take all appropriate measures to retain employees suffering from a NDD or help them return to work
- Improving access to financial compensation in case of sick leave
- Improving access to the system in place and specific benefits involved in the retirement process
- Improving fair and equitable access to insurance and credit: standardising health questionnaires according to illness, clarifying the role of GPs, developing informative actions and raising awareness for everyone involved

CHALLENGE 9: Ensuring that civil rights and ethical considerations serve to drive social change

- Encouraging the National Reference Centre on Ethics about Alzheimer's (EREMA) to target other neurodegenerative diseases
- Continuing to develop ethics, social and human sciences resources, at both regional and inter-regional levels and throughout the EREMA network



FLAGSHIP ACTIONS FOR FOCUS AREA 3

Developing and coordinating research on neurodegenerative diseases

CHALLENGE 10: boosting and improving the coordination of research on NDD

- Giving the Multi-organism Thematic Institute (ITMO) of Neuroscience, Cognitive Sciences, Neurology and Psychiatry the presidency of a 'trans-alliance' management committee for the coordination of the research on NDD
- Improving translational and clinical research on neurodegenerative diseases
- Identifying and endorsing regional teaching and research centres of excellence that ensure continuum of research to treat neurodegenerative diseases and progressively promote them as European centres of excellence as part of the CoEN (International Network of Centres of Excellence in Neurodegeneration)
- Maintaining France's involvement in the JPND (Joint Programming to combat neurodegenerative diseases)
- Involving all actors of research to improve public understanding of the NDD

CHALLENGE 11: Improving our understanding and knowledge of NDD to better prevent them and slow down their evolution

- Reinforcing the dedicated cohorts to better understand NDD (developing and improving the support network and initiatives available to these cohorts in order to better understand NDD)
- Improving our understanding of social breakdown
- Coordinating and encouraging research to identify new biomarkers of NDD in the fields of 'omics', high res imagery, cognition and behaviour
- Understanding the NDD within model systems in order to better identify the biological targets and initiate innovative clinical trials
- Testing the efficiency of non-medicinal interventions
- Allowing the patients affected by NDD to benefit from major technological innovations



FLAGSHIP ACTIONS FOR FOCUS AREA 4

Turning the governance of the plan into a real tool for innovation and management of public policies and health democracy

CHALLENGE 12: improving the effectiveness of health democracy and structure of governance as part of the implementation of the NDD Plan

Making health democracy work

- Developing agreements with associations for sufferers and/or their carers and public authority representatives at both local and national levels
- Asking the National Conference on Health (CNS) to produce a diagnosis and make proposals on how to better involve representatives of NDD sufferers and their carers on both an individual level and a collective level
- Encouraging collaboration amongst associations through the work of regional foundations developed as part of the NDD Plan, under the aegis of the ARS

Outlining the governance of the plan

- Improving the evaluative dimensions of the plan
- At a national level, setting up a follow-up committee for the NDDP presided over by a qualified professional and including all stakeholders, especially associations for sufferers and their carers, the representatives of health professionals, and medical establishment and health and medico-social services managers
- Putting together a national team in charge of overseeing the project and the relations with the various partners
- Improving the role of the ARS in the implementation of the plan throughout the various regions (this measure is part of the Health Bill)
- Encouraging the integration of research, healthcare and support issues, including those that come up as part of the governance of the plan
- Building a reputation as a major innovator at a European level in terms of public policy (sharing practices and experiences in line with such projects as the G7 Dementia's Alcove)



THE KEY STEPS IN THE DEVELOPMENT OF THE NEURODEGENERATIVE DISEASES PLAN

- **21 September 2012:** The Alzheimer's Assessment Plan 2008-2012 and its expansion to include other neurodegenerative diseases are announced by the French President
- **23 November 2012:** Joël Ankri, geriatrician at the Hôpital Sainte Périne - Chardon Lagache – Rossini (AP-HP) and Dr Christine Van Broeckhoven, Director of the Department of Molecular Genetics at the University of Antwerp in Belgium are asked to oversee the Alzheimer's Assessment Plan 2008-2012
- **26 June 2013:** The Alzheimer's Assessment Plan 2008-2012 is presented to the Ministers for Health and Social Affairs; Higher Education and Research and the Elderly and Autonomy
- **Starting in September 2013,** the various ministers carry out the preliminary work for the development of the neurodegenerative diseases plan, with the help of qualified professionals
- **30 October 2014:** The neurodegenerative diseases plan is launched and the documents are accessible on the Ministries' websites.

The implementation of the plan will cover the period from 2014 to 2019



THE GOVERNANCE OF THE PLAN

The governance of the plan relies on:

- The involvement of well-known personalities to represent and showcase the implementation of an ambitious health and research policy.
 - Professor Michel Clanet, President of the follow-up committee
 - Professor Joël Ankri, Vice-President of the follow-up committee
 - Professor Etienne Hirsch, President of the management committee for research
- The creation of a follow-up committee whose members are:
 - Associations for users and their carers
 - Representatives of medical professionals
 - Representatives of health and medico-social establishments and services
 - Representatives of local authorities
 - Representatives for research
 - 3 qualified professionals
 - Partners
 - Representatives of the State through a project team and the involvement of the managers of relevant public departments and benefits offices



LIST OF THE MEASURES OF THE NDDP

Measure 1: encouraging quality diagnoses and preventing misdiagnosis

Measure 2: developing and improving assessment practices

Measure 3: providing professionals carrying out assessments with specific tools to help them carry out their work, namely as part of the MAIA services

Measure 4: making sure all patients affected by a chronic NDD have access to a personalised care programme to support them throughout their treatment

Measure 5: developing therapy, as part of the HAS recommendations, whilst taking into account the needs of patients and their relatives

Measure 6: addressing risk factors for any deterioration in the patient's health

Measure 7: improving health services to provide equal access to quality local healthcare for all

Measure 8: developing a global expertise that covers all neurodegenerative diseases throughout the country

Measure 9: furthering the progress made regarding Alzheimer's and related diseases regardless of the age of the sufferers

Measure 10: continuing with and expanding the work done around centres of expertise on Parkinson's and related diseases

Measure 11: acknowledging centres of expertise on MS and improving the support-care-research strategy

Measure 12: ensuring full country-wide coverage for the centres expertise for amyotrophic lateral sclerosis (ALS)

Measure 13: improving the quality and consistency of medicinal care tailored to the needs of each patient and preventing the risks of side-effects

Measure 14: improving neurostimulation services: a complex treatment for Parkinson's disease and related diseases

Measure 15: removing the impediments to access to home medical care for persons affected by NDD regardless of where they live: 'Hospitalisation à domicile (HAD) et Equipes Mobiles' (Home Care and mobile medical teams)

Measure 16: improving and perpetuating the work of the National Alzheimer's Data Bank

Measure 17: continuing efforts to develop cognitive-behavioural units (UCC) and integrating them as part of the full treatment

Measure 18: improving our consideration of psychological problems and access to specialised healthcare whenever necessary

Measure 19: contributing to the diversification of housing options suitable for disabled people or those suffering from a loss of autonomy



Measure 20: improving the involvement of home care and support services, as part of the wider support policies for sufferers and their overall treatment

Measure 21: reinforcing and tailoring the work of the nursing care services (SSIAD), multifunctional home care and support services (SPASAD)

Measure 22: continuing our efforts to develop specialised 'ESA' teams (Alzheimer's care teams) to cover the whole country, defining and experimenting with new protocols

Measure 23: tailoring institutional projects to the support needs of all elderly people affected by a NDD and reviewing the specifications for the support available in the various specialised units for Alzheimer patients (units created within the EPHAD following the Alzheimer Plan 2008-2012)

Measure 24: including in the current reforms of the pricing system of the EHPAD the issues brought up by residents affected by a neurodegenerative disease

Measure 25: ensuring the continuity of care and/or access to treatment tailored to EHPAD residents affected by a neurodegenerative disease by removing the financial impediments to their access to a number of treatments (medical and medicinal)

Measure 26: continuing to develop and open Adaptive Treatment and Activity Centres (PASA) and including them as part of existing "ordinary" care and support systems

Measure 27: continuing – and improving – the development of Reinforced Housing Units (UHR) within the EHPAD and including them as part of existing "ordinary" care and support systems

Measure 28: continuing the development of specific platforms to support carers and helpers

Measure 29: improving and adapting existing day-care and temporary housing services to diversify the types of home care and support services available

Measure 30: improving end-of-life care

Measure 31: tailoring the requirements of the regional health services to the field of neurodegenerative diseases

Measure 32: developing medico-social support on the basis of a range of integrated services put forward by calls for cross-sector proposals

Measure 33: identifying the resources that are most adapted to the specific needs of sufferers, as part of the support given in medico-social establishments

Measure 34: continuing our efforts and improving the integration of care and support services for elderly people experiencing loss of autonomy thanks to the deployment of the MAIA

Measure 35: continuously improving the quality of initial training for professionals

Measure 36: improving ongoing training by relying on centres of expertise and using digital educational tools

Measure 37: kick-starting discussions on advanced practice in the field of NDD (drawing from the approach initiated in the field of cancerology)

Measure 38: improving training and highlighting the role of neuropsychologists working in the field of NDD



- Measure 39:** promoting cooperative protocols between professionals
- Measure 40:** creating a Master's Degree in International Partnerships
- Measure 41:** introducing an efficient and tested information and communication policy to raise awareness and change people's outlook on neurodegenerative diseases
- Measure 42:** increasing our use of technical aids and new technologies
- Measure 43:** highlighting the progress made by current adapted housing policies directed at people living with a disability or experiencing a loss of autonomy
- Measure 44:** integrating a "mobility" dimension to the follow-up of the neurodegenerative diseases plan
- Measure 45:** committing to engaging in a discussion on rights and ethics whenever home intervention is required
- Measure 46:** encouraging and promoting new forms of solidarity
- Measure 47:** putting together a process of observation, validation and conceptualisation of remarkable initiatives
- Measure 48:** encouraging and promoting social innovation
- Measure 49:** identifying this issue as a national priority when it comes to the allocation of government subsidies
- Measure 50:** creating and implementing an active policy to support carers, including relatives that provide care
- Measure 51:** kick-starting a discussion on access to psychological support tailored to the needs of carers
- Measure 52:** making job retention a priority (including tailoring careers goals, position, working conditions etc.)
- Measure 53:** supporting the sufferer with the help of their GP, or if needs be the centre of expertise (or network), who oversees, the follow-up of their treatment and professional development with their employer and occupational medicine services and the MDPH
- Measure 54:** improving the relevance and reactivity of the occupational medicine services' response
- Measure 55:** improving access to rights at work for sufferers and boosting existing services to avoid them losing opportunities at work
- Measure 56:** encouraging companies and businesses to take the necessary steps for job retention and return to work
- Measure 57:** reducing the economic consequences of the disease
- Measure 58:** improving access to insurance and credit
- Measure 59:** increasing the involvement of "spaces for ethical reflection" nationally and regionally
- Measure 60:** creating a management committee for research on NDD
- Measure 61:** improving transnational and clinical research on neurodegenerative diseases thanks to the implementation of shared calls for proposals from the Directorate-General for Research and Innovation (DGRI) and General Directorate for Healthcare Provision (DGOS)
- Measure 62:** identifying and approving regional centres of excellence ensuring a health-research continuum



Measure 63: ensuring the involvement of platforms, cohorts and tools dedicated to research on neurodegenerative diseases and coordinating their actions

Measure 64: progressively promoting the acknowledgement of national centres of excellence as European centres of excellence as part of the CoEN (International Network of Centres of Excellence in Neurodegeneration)

Measure 65: continuing France's involvement in the JPND (Joint Programming to combat neurodegenerative diseases)

Measure 66: ensuring France's involvement in the international initiative "Global action against dementia"

Measure 67: circulating a positive image of the science involved amongst the general public and improving their understanding of NDD

Measure 68: encouraging sufferers and their families to consider the opportunity of taking part in a clinical trial

Measure 69: creating a "story bank"

Measure 70: privileging the quality and originality of the variables studied

Measure 71: developing large e-cohorts of sufferers and online patient communities in conjunction with sufferers and associations that represent them

Measure 72: facilitating the inter-operability of databases and their opening

Measure 73: promoting brain donation

Measure 74: identifying risk factors for NDD in population studies

Measure 75: increasing our understanding of the causes of social exclusion

Measure 76: organising the collection and analysis of biomarkers

Measure 77: improving and coordinating research on imaging in NDD conducted by the Centre for Image Acquisition and Processing (CATI)

Measure 78: improving and developing cognitive and behavioural treatment follow-up tools for NDD

Measure 79: creating a discussion group on "big data" for NDD

Measure 80: national and international censuses of experimental models and targets

Measure 81: coordinating research on therapy for neurodegenerative diseases

Measure 82: developing innovative and efficient methods of assessment for the efficiency of therapies in real life

Measure 83: testing the efficiency of non-medicinal interventions

Measure 84 : promoting a multimodal approach in pain management

Measure 85: enabling patients affected by NDD to benefit from technological innovations

Measure 86: developing or sustaining existing agreements with associations for sufferers and/or their carers at national and local levels

Measure 87: asking the National Conference on Health to create a diagnosis and to make proposals to better integrate issues around collective and individual representation for representatives of people suffering from NDD and their carers



Measure 88: encouraging collaboration amongst associations thanks to the organisation of regional centres, developed as part of the NDDP, under the aegis of the ARS

Measure 89: improving the evaluative dimension of the plan

Measure 90: putting in place a system of governance for the plan on both national and regional levels, getting the representatives of sufferers and their carers together

Measure 91: encouraging the integration of research, health and support issues, including as part of the governance of the plan

Measure 92: Building a reputation as a major innovator at a European and international level in terms of public policy (sharing practices and experiences in line with such projects as the G8 Dementia's Alcove)

Measure 93: improving our understanding of the roles and input of the various national and regional levels to ensure a better quality of support for sufferers locally, whilst maintaining an ambitious objective of equal access to treatment across the country

Measure 94: improving and/or developing robust steering and follow-up tools for the public policy implemented as part of the Plan

Measure 95: including the NDDP in the Open Data strategy, whilst respecting confidentiality requirements for personal data

Measure 96: continuing the annual activity surveys, and adding a “network” dimension, supporting and circulating the studies (including those conducted by the government) in order to increase our understanding of neurodegenerative diseases