



Name: \_\_\_\_\_ Age \_\_\_\_\_  
Gender \_\_\_\_\_ Height \_\_\_\_\_ Weight \_\_\_\_\_ Date \_\_\_\_\_

### HEALTH CHECK

DETAIL	HOW OFTEN	DATE CHECKED	APPOINTMENT	COMPLETE
Bone Density Test			5/28/2018	100%
Blood Test			4/28/2018	100%
Dentist			5/5/2018	10%
Eye Test			5/13/2018	20%
General Cpt			5/23/2018	3%
Spinal Fluid			5/18/2018	10%
Thyroid/Glucose			6/7/2018	10%
Stem Cell/ur Screening			6/14/2018	20%

# Improving access to care and treatment for Huntington's Disease patients and families







New treatments in sight....



NDC 64406-058-01

# Spinraza<sup>™</sup>

(nusinersen)  
Injection

**12 mg / 5 mL**  
(2.4 mg/mL)

A situation we don't want to copy

Sterile solution for  
Intrathecal Use Only  
Rx Only

Dose Vial  
Content

to 46°F). Use contents within  
vial from the vial.  
Freeze. Store in carton until use.  
Protect from light.





## The European HD umbrella

---

- **30.000+** people
- **45 organisations**
- **30 countries**





Leadership and coordination



**Knowlegde is power**







Learning - a dynamic and teambuilding process





VIRTUAL ROUNDTABLE - Improving Access to Care for Huntington Fa...



Se senere

Donna Walsh



**EFNA**

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS



VIRTUAL ROUNDTABLE

**IMPROVING ACCESS  
TO CARE AND TREATMENT  
FOR HD PATIENTS AND FAMILIES:  
WHAT ROLE FOR POLICYMAKERS?**

Hosted by the European Huntington Association (EHA) and  
European Federation of Neurological Associations (EFNA)

Thursday 3 December 2020  
14:00 – 16:00 CET

E VIDEOER

*This roundtable meeting is organised with support provided by Roche*

Roche



1:38 / 2:07:31



YouTube

# CONSENSUS STATEMENT



## Improving access to care and treatment for Huntington's Disease patients and families

Following a virtual policy roundtable held on 3 December 2020, organised by the European Huntington Association (EHA) and the European Federation of Neurological Associations (EFNA) with financial support from Roche, the following organisations and stakeholders call for further EU and national action to improve the quality of care and treatment for people living with Huntington's Disease.

Support from policymakers at national and international levels is crucial to enable the necessary steps to be taken to improve the quality of life of those affected by Huntington's Disease.

This Consensus Statement sets out a number of recommendations where multi-stakeholder action could help overcome some of the key challenges faced by those affected by Huntington's Disease.



## About Huntington's Disease



[Petition details](#)[Comments](#)[Updates](#)

# Improving access to care and treatment for Huntington's Disease patients and families

## CONSENSUS STATEMENT

### IMPROVING ACCESS TO CARE AND TREATMENT FOR HUNTINGTON'S DISEASE PATIENTS AND FAMILIES



[European Huntington Association EHA](#) started this petition to Members of European Parliament and [5 others](#)

181 have signed. Let's get to 200!



European Huntington Association EHA  
signed this petition

- Yes! Tell me if this petition wins, and how I can help other relevant petitions
- No. I do not want to hear about this petition's progress or other relevant petitions.

 [Sign this petition](#)



WEB DESIGN SKETCH #2

COMPANY

Logo

category x5

5000 px

ABOUT US

responsive design for mobile





# A Snapshot of IPF Care in Europe





# The European Scorecard

INDICATORS	COUNTRIES												
	Austria	Belgium	Bulgaria	France	Germany	Greece	Hungary	Ireland	Italy	The Netherlands	Poland	Spain	United Kingdom
GUIDELINES													
Availability of IPF guidelines (national and international)	Green	Green	Yellow	Green	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green
Implementation of IPF guidelines	Green	Green	Yellow	Yellow	Green	Red	Green	Green	Yellow	Green	Green	Red	Yellow
Assessment of IPF care pathways	Red	Yellow	Green	Grey	Red	Red	Green	Green	Yellow	Grey	Red	Red	Red
DIAGNOSIS AND ACCESS TO SPECIALISED CARE													
Assessment of diagnostic procedure	Green	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green
Assessment of standardisation of IPF diagnosis	Green	Green	Grey	Grey	Green	Red	Yellow	Grey	Green	Grey	Green	Green	Green
Availability of information materials	Yellow	Yellow	Green	Green	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow	Yellow
Assessment of self-management education tools	Red	Red	Yellow	Yellow	Yellow	Red	Red	Green	Yellow	Yellow	Yellow	Red	Yellow
Assessment of distribution and activities of specialised centres	Green	Green	Yellow	Green	Green	Yellow	Grey	Green	Yellow	Green	Green	Yellow	Green
Availability of and access to multidisciplinary team	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Green	Yellow	Red	Green
ACCESS TO PHARMACOLOGICAL TREATMENT													
Availability of pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
Reimbursement of pharmacological treatment	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green	Green
Assessment of distribution of prescription centres	Green	Yellow	Green	Green	Green	Yellow	Green	Yellow	Yellow	Green	Yellow	Yellow	Yellow
Assessment of distribution of dispensation centres	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green	Green
ACCESS TO NON PHARMACOLOGICAL TREATMENT													
Availability of and access to oxygen therapy in the hospital	Green	Green	Yellow	Green	Green	Yellow	Green	Green	Green	Green	Yellow	Green	Green
Reimbursement of oxygen therapy in the hospital	Green	Green	Green	Green	Green	Green	Green	Yellow	Green	Green	Green	Green	Green
Availability of and access to oxygen therapy at home	Green	Green	Green	Green	Green	Red	Green	Green	Green	Green	Yellow	Green	Green
Reimbursement of oxygen therapy at home	Green	Green	Red	Green	Green	Red	Yellow	Green	Green	Green	Red	Green	Green
Availability of and access to pulmonary rehabilitation programmes	Green	Green	Yellow	Green	Green	Red	Green	Green	Green	Green	Green	Yellow	Green
Coverage of pulmonary rehabilitation programme	Green	Yellow	Green	Green	Green	Red	Green	Green	Green	Green	Green	Yellow	Green
Availability of lung transplants	Green	Green	Red	Green	Green	Red	Green	Green	Green	Green	Yellow	Green	Green
Availability of and accessibility to information on clinical trials	Green	Green	Green	Green	Green	Red	Green	Green	Yellow	Green	Green	Green	Green
ACCESS TO PALLIATIVE CARE AND END-OF-LIFE CARE													
Availability of and access to palliative care	Green	Green	Green	Green	Green	Red	Red	Green	Yellow	Green	Yellow	Yellow	Green
Coverage of palliative care	Green	Green	Red	Green	Green	Red	Red	Green	Yellow	Green	Yellow	Yellow	Green
Availability of palliative care centres and mobile teams	Green	Green	Grey	Green	Green	Red	Grey	Green	Red	Green	Green	Yellow	Green
Inclusivity of decision-making process for patients and families in palliative care	Green	Green	Grey	Green	Green	Red	Red	Green	Yellow	Green	Green	Yellow	Green
Availability of and access to home hospice	Yellow	Yellow	Yellow	Yellow	Green	Red	Red	Yellow	Red	Green	Red	Yellow	Green





Huntingtonians United – a dreamteam!