

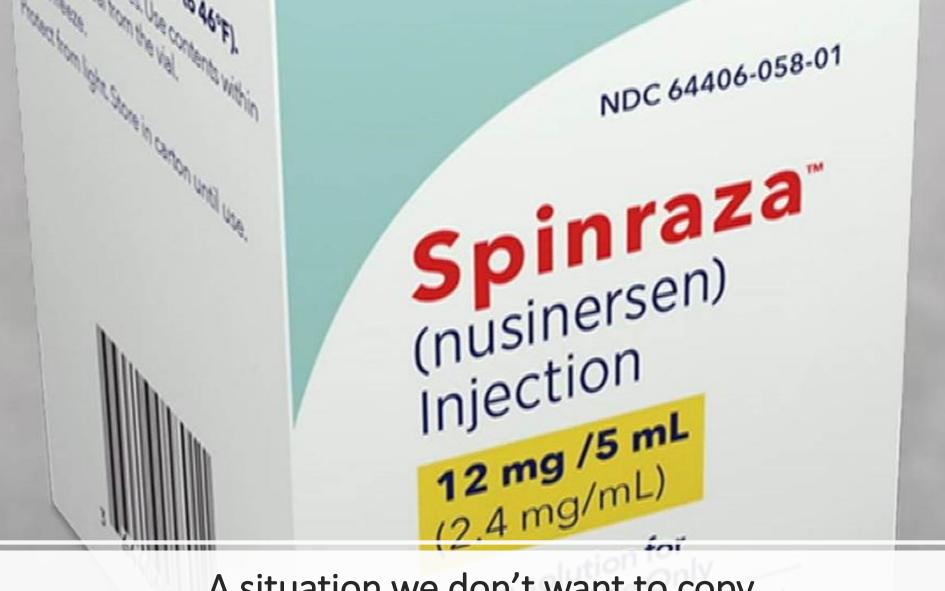
Improving access to care and treatment for Huntington's Disease patients and families







New treatments in sight....



A situation we don't want to copy

Dose Vial





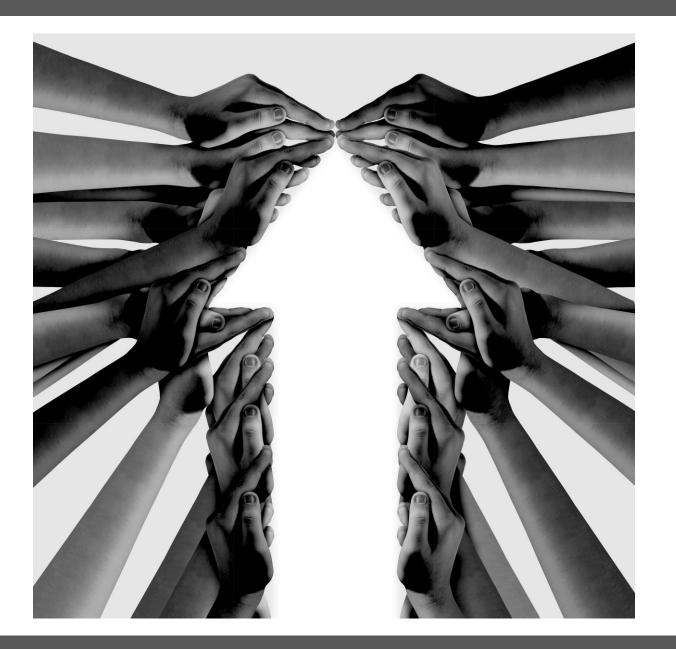


**Knowlegde** is power





Learning - a dynamic and teambuilding process



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







#### 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









#### **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.



Petition details

Comments

Updates

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

### CONSENSUS STATEMENT

TREATMENT FOR HUNTINGTON'S DISEASE
PATIENTS AND FAMILIES





181 have signed. Let's get to 200!



European Huntington Association EHA signed this petition

First name

Last name

Email

- 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.

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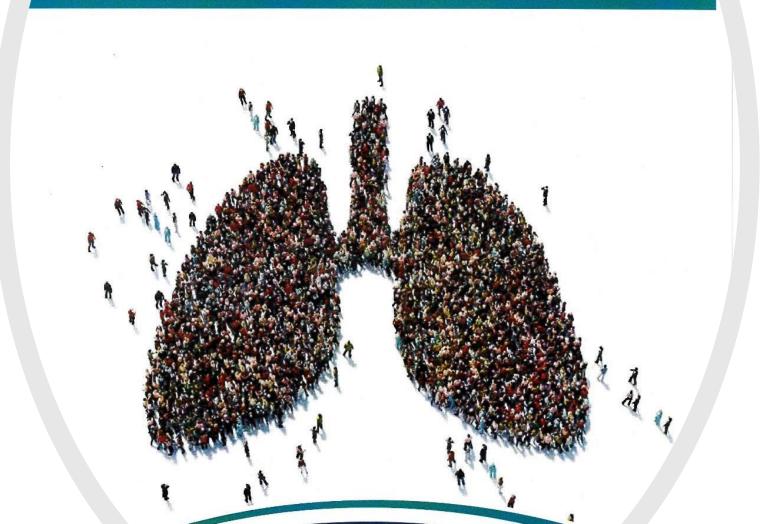
<u>European Huntington Association EHA</u> started this petition to Members of European Parliament and 5 others







## 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)													
Implementation of IPF guidelines													
Assessment of IPF care pathways													
						NAGNOSIS ANI	ACCESS TO SPI	ECIALISED CARE					
Assessment of diagnostic procedure						NOT TO							
Assessment of standardisation of IPF diagnosis													
Availability of information materials													
Assessment of self-management education tools													
Assessment of distribution and activities of specialised centres													
Availability of and access to multidisciplinary team											Name of the Owner		
						ACCESS TO PI	HARMACOLOGIC	AL TREATMENT	(Ministration Access to Unite				
Reimburgement of pharmacological treatment													
Assessment of distribution of prescription centres													annionus seno
Assessment of distribution of dispensation centres									WILLIAM CALIFORN			ANTERCONNO DEL SONE, DIRE	
		home blood water on		Mark Vision (Vision Indiana)	A Markatan da kalandari	CESS TO NON	PHARMACOLOG	ICAL TREATMEN				reconstruction of the second	
Availability of and access to oxygen therapy in the hospital			NAMES OF STREET										
Reimbursement of oxygen therapy in the hospital													
Availability of and access to oxygen therapy at home													
Reimbursement of oxygen therapy at home													
Availability of and access to pulmonary rehabilitation programmes													
Coverage of pulmonary rehabilitation programme													
Availability of lung transplants													
Availability of and accessibility to information on clinical trials													Bergerani
				Total State Control	ACI	CESS TO PALLI	ATIVE CARE AND	END-OF-LIFE CA	RE				10.000
Availability of and access to palliative care													
Coverage of pulliative care													
Availability of palliative care centres and mobile teams													
Inclusivity of decision-making process for patients and families in palliative care													
Availability of and access to home hospice													

