

NEWS RELEASE - EMBARGOED UNTIL 22nd JULY 2020

Results of EFNA's Survey on Stigma and Neurological Disorder

In celebration of World Brain Day 2020, the European Federation of Neurological Associations (EFNA) has published the results of its recent [survey on stigma and neurological disorder](#).

According to the World Health Organisation, stigma is a major cause of discrimination and exclusion: it affects people's self-esteem, helps disrupt their family relationships and limits their ability to socialise and obtain housing and jobs. EFNA has chosen to examine the stigma suffered by those with neurological disorders by commissioning this survey into its causes and effects.

1373 responses to the survey were received from 37 countries. Responses came from a diverse range of neurological conditions, with the greatest numbers coming from the areas of Myalgic Encephalomyelitis (ME), dystonia, migraine or headache and chronic pain.

92% of respondents report feeling affected by stigma on account of the neurological disorder they live with. Lack of understanding is seen as the biggest cause of this, followed by myths/misconceptions about these disorders and their invisible nature.

The issue of stigma has proved most problematic during interactions with medical professionals. 74% felt that a medical professional did not believe the extent or severity of their symptoms and the same percentage feel they did not receive adequate or appropriate treatment because a medical professional did not take them seriously.

Stigma is also prevalent within families and in social situations. 49% say their families sometimes make them feel that they exaggerate their condition and, sadly, 32% of respondents with children have been made to feel that they are inadequate parents. Almost half of respondents who lived with a neurological disorder during childhood found it difficult to make friends or maintain friendships at school, and a similar number were excluded from school events on account of their condition.

EFNA President, Joke Jaarsma, said

"We hope that EFNA, together with our member organisations, can use these findings to work to develop strategies that will combat stigma where it arises, thereby improving the quality of life of people living with neurological disorder".

The report contains overall results, disease-specific results and a comparison of disease areas. The complete findings of the survey are available from EFNA's website at <https://www.efna.net/survey2020>

Please help to disseminate the results of this survey by sharing it with your network - via email, newsletters and social media - and encourage others to do the same!

[Suggested social media messages and graphics below...](#)

SUGGESTED TWEETS / SOCIAL MEDIA MESSAGES

1. To mark #WorldBrainDay, @EUneurology has published the results of their recent survey on #stigma and neurological disorder. Read the report here: <https://buff.ly/2Bcy8VZ> #WBD2020
2. 92% of respondents to @EUneurology's recent survey on stigma and neurological disorder feel affected by stigma on account of their illness. Read the report: <https://buff.ly/2Bcy8VZ> #WorldBrainDay #WBD2020 #BrainLifeGoals
3. 'Lack of understanding of the condition' is seen as the biggest cause of stigma toward those living with a neurological disorder, followed by myths/misconceptions around the conditions and their frequently invisible nature. <https://buff.ly/2Bcy8VZ> #WorldBrainDay #BrainLifeGoals
4. 74% of those affected by a neurological disorder feel they did not receive adequate medical treatment because a medical professional did not believe the severity of their symptoms. Let's work together to address this! <https://buff.ly/2Bcy8VZ> #WorldBrainDay #WBD2020 #BrainLifeGoals @wfneurology



[Download the graphics pack here.](#)

ABOUT THE EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS (EFNA):

EFNA is an umbrella body of pan-European, disease-specific, neurology (and related) patient groups. We cover epilepsy, Parkinson's disease, multiple sclerosis, migraine and other headache disorders, brain tumour, chronic pain, neuromuscular disorders –including Charcot Marie Tooth, ADHD, ataxia, Huntington's disease, restless legs syndrome, dystonia, myasthenia gravis, post-polio syndrome, myalgic encephalomyelitis, retinal diseases and stroke. We feel that in sharing EFNA's vision and mission, we are ideally placed to tackle the challenges together and optimise the opportunities outlined above.

EFNA's mission is:

- To be a voice for neurology patients across Europe.
- To raise awareness of the prevalence and impact of neurological disorders; leading to reduced stigma, isolation and discrimination for neurological patients and their carers.
- To ensure policy makers, opinion leaders and decision makers in Europe –and worldwide –recognize the increasing socio-economic and healthcare burden of neurological disorders and allocate resources for prevention, treatment, services and support.
- To communicate and collaborate with our members to achieve positive change and ensure our actions add value to their own concerns and activities.
- To motivate, inspire and empower those living with neurological disorders, leading to more meaningful involvement and engagement of patient advocates in policy and decision making, and in research and development.
- To establish strong partnerships and alliances with key stakeholders in the scientific, clinical, political and corporate arenas to help achieve our strategic objectives.

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