

#BrainLifeGoals

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INTRODUCTION

#BrainLifeGoals is a social media awareness campaign from the European Federation of Neurological Associations (EFNA), which was presented at EAN this year.¹ EFNA represent 18 neurology patient associations across Europe and further afield. Their slogan represents their mission: “Empowering neurology patient groups.” They use four pillars to structure their work to ensure they make strides towards this goal.

EUROPEAN FEDERATION OF NEUROLOGICAL ASSOCIATIONS¹

Advocacy

EFNA want to raise awareness of the different neurological diseases and be a voice for the patients that these associations represent. They want to generate more evidence to help shine a spotlight on the burden and impact of these diseases. Also, there is a drive towards improving the level of priority that neurology is given by the decision makers in healthcare.

Empowerment

This pillar ensures that the 18 patient associations feel both empowered and supported in order to take an active role in being an advocate for the neurological diseases they focus on. EFNA also work towards providing these organisations with the platforms and opportunities to be advocates for their patients.

Awareness

The third pillar focusses on the promotion of neurological conditions: making the public both more aware of the diseases that exist and aiding

them in better understanding them. There is also a strong drive around destigmatising these conditions and removing any prejudice.

Engagement

Finally, EFNA want to fully engage their stakeholders, including working closely with their partners. This enables them to ensure that neurology patients’ voices are heard and that their preferences and perspectives are represented. This creates a patient-led, multi-stakeholder approach.

THE CREATION OF #BRAINLIFEGOALS

Initial EFNA Survey

In 2018, EFNA, in working on their pillar of awareness, focussed their attentions on 18 to 35-year-olds to give this underrepresented audience amongst their organisation a voice. The issues that affect young people who are living with neurological disorders are not getting public or political attention, as they face additional burdens in education, employment, and socially.

EFNA produced a survey with 1,368 responders from 21 European countries,¹ made up of 80% females and 20% males. Participants in the survey had a range of neurological conditions, most commonly including multiple sclerosis (MS), migraine, chronic pain, and myalgic encephalomyelitis (ME). From these results, EFNA recognised the biggest issues that young people were facing:

1. Access to medication and treatment.
2. Isolation.
3. Stigma.

4. Depression and anxiety.
5. Access to employment.
6. Relationships and sexual health.
7. Medication and treatment costs.
8. Access to education.

They also looked at understanding of brain disorders and found that the participants ranked the public understanding of brain disorders as 2.5/10, family understanding as 5.7/10, and friend understanding as 4.3/10. When asked how comfortable they felt discussing their brain disorder with their employer, respondents gave the score 3.4/10.¹

Highlighting the lack of public understanding and the frustrations that can coincide with neurological conditions, one survey participant said: “I am behind peers by years as far as education and employment goes, due to the inability to do many things most people take for granted and struggling just to deal with what little I do try to accomplish.”

Another participant said: “I can’t stand the stigma, no matter how hard I try to explain, it seems that they don’t understand any better. Because I look ‘healthy’ I feel like it’s hard to get the help I need.”

#LifeGoals

EFNA recognised the severe need to improve understanding of these conditions. They came up with the idea to communicate something unknown using something familiar. The hashtag #LifeGoals is a common term on social media to portray people’s ambitions, often in a tongue-in-cheek manner. While these often refer to superficial or luxury items, EFNA outlined how there are some people who have goals such as better treatment for their condition and employment opportunities. With 1 in 3 people living with a brain disorder, EFNA decided to put a spin on #LifeGoals, encouraging people to share their #BrainLifeGoals.

Aims of #BrainLifeGoals

- To increase awareness of the impact neurological conditions have on patients.
- To engage those living with brain disorders to advocate for better awareness.
- To showcase patient examples and show what

is important to them and how this should steer decision-making and research and development.

- To identify and communicate unmet patient needs.

CAMPAIGN ENGAGEMENT AND PLANS FOR THE FUTURE OF #BRAINLIFEGOALS

EFNA are utilising the huge audience that social media offers and encouraging people living with brain disorders to get involved. Patients starting using the hashtag, sharing goals such as “Drive a car without pain #BrainLifeGoals” and “To live one day without thinking about my illness #BrainLifeGoals”.¹ This method is helping to bring some public understanding to the neurological diseases these patients live with, as well as heightening awareness.

Some of EFNA’s affiliated organisations also made use of the campaign, such as the International ME conference held in London, UK, in May 2019, which brought the campaign to attendees and encouraged them to share their #BrainLifeGoals.

The social media campaign is growing and on World Brain Day, EFNA will hold events in Brussels, Bucharest, Dublin, and Warsaw, where they will partner with patient organisation to raise awareness on the issues that are important to patients. They will also be working towards what can be done surrounding policy at both National and European Union (EU) levels to increase awareness of neurological disorders and get better results for patients.

EFNA are also offering grants to five projects to further the reach of this campaign, in which entrants must reflect the campaign themes, raise awareness of the neurological disorders, and improve understanding surrounding these in European countries.²

References

1. EAN Neurotank. #BrainLifeGoals: An awareness campaign. 2019. Available at: <https://www.ean-neurotank.org/#!/resources/brainlifegoals-an-awareness-campaign>. Last accessed: 29 July 2019.
2. EFNA. #BrainLifeGoals. 2019. Available at: <https://www.efna.net/brainlifegoals/>. Last accessed: 29 July 2019.