

Sally Callow

Influencer Award

Describe the work of the individual being nominated

Sally has been working tirelessly for over five years, despite being an ME sufferer for 13 years herself and able to function for limited periods of time, to raise awareness of this debilitating and crippling illness, which affects many thousands of patients and which is subject to many myths and prejudices. Sally has been an advocate for five and half years, and fought to gain recognition of the disease and to correct the misinformation that has had detrimental impact on the lives of sufferers throughout the UK and internationally (through using websites, text and video blogs, twitter, LinkedIn and other social media platforms). Sally runs and generates content for the advocacy and fundraising website (www.mefoggydog.org). She is also Managing Director of an online training provider, (www.stripylightbulb.com) that delivers educational material, which she developed and authored herself, to improve knowledge of the condition, its effect on patients and ways in which professionals with a duty of care for sufferers can accommodate their needs better. Sally is highly active across a variety of platforms and has been extremely successful in representing the voice of the M.E. or C.F.S. patient community to achieve real and lasting change in the education, healthcare and employment sectors.

What was the change that was required? Help us understand the vision, aims, and objectives

M.E. or C.F.S. is a condition that has been subject to misdiagnosis and inappropriate clinical management for many years, despite being appropriately categorised by the WHO as far back as 1969. Misunderstanding, prejudice and bias amongst the medical community, worldwide, continue to see the condition being treated inappropriately. Sufferers are also subjected to inappropriate adjustments and workplace expectations by employers. As a condition with no outward, visible signs, the condition is not generally understood or accommodated by the general public or service sectors, leading to sufferers not being given the same consideration and help as other, more visible disabilities. The advocacy which Sally undertakes, seeks to address the inappropriate categorisation and mistreatment by clinical professions, to educate employers, teaching professionals and healthcare workers on the adjustments that could be made to improve the lives of M.E. or C.F.S. sufferers and, where appropriate, allow them to contribute to the workforce, and to raise general awareness of M.E. or C.F.S., specifically, and other invisible disabilities amongst the general public and service industries. Sally's vision is to generate real, tangible benefit to M.E. or C.F.S. sufferers through education and social action and to influence government and corporate policy across a wide range of sectors in order to allow for a more inclusive and understanding treatment of individuals within the community.

How did you use your influence? Who you influenced, what methods you used to influence them, what resources you used and how you overcame the problem etc.

Sally has been active across a spectrum of social platforms. These include – but are not limited to – websites, Twitter, Facebook, and LinkedIn. She has engaged directly with government policy institutions, including the Department for Health and Department for Education. She has been actively engaged with Public Health England, and the Cure M.E. team at the M.E./C.F.S. Biobank, located at the London School of Hygiene and Tropical Medicine – a world-renowned research facility and influential body in policy formulation. She has engaged with the National Institutes for Clinical

Excellence, Members of Parliament and members of groups which represent employers, including NHS Employers and the professional bodies that represent HR practitioners and teachers. As well as social media, she has generated countless written letters and other mail documents – directed to individuals and corporations – to address specific aspects of the advocacy strategy. She also, when her illness allows, is a frequent public speaker and regularly delivers presentations to groups who may be willing to her message.

What changed? Outline the result of your work and its impact, with specific examples

Through Sally's efforts, the lives of many M.E. or C.F.S. patients have benefitted. Awareness is growing as individual employers improve their management of sufferers. Although public health policy remains disadvantageous to sufferers, with inappropriate treatment recommendations, NICE have committed to review the relevant policy in 2020 and it is hoped that the ground work carried out by Sally has paved the way for a major policy shift, which should ensure more appropriate treatment and management of the condition. The public health community, represented by the London School of Hygiene and Tropical Medicine are supportive of the change and have started campaigning for the appropriate changes to the public policy environment.

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