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THE FUTURE CHARITY – FOR YOUR CONSIDERATION

The ME/CFS ICD.10 G93.3 community UK badly needs a national adult patient focussed organisation to represent our interests.

What we had hoped subsequent to the Myalgic ‘Encephalopathy’ Association (MEA) Annual General Meeting in December 2003 is that the MEA would be it. That they would deliver their strategy vision of what we need in the UK. That there would be clear blue water evinced between the roundly discredited psychosocial charity Action for ME (AfME) and the MEA. Not only has this strategic vision failed to be delivered by the MEA, but also double-dealings behind the scenes are clearly as rampant as ever. As a community we need to focus on our needs, what we require and what we are prepared to pay for.

Here is an agenda that we set out for your consideration. We would ask other members of the ME/CFS community to make comment. To add items that you consider to be important. To delete others that you consider not relevant. Here are our suggestions in no particular order of importance.

We need a charity that:

- Adheres to and promotes the term and classification of Myalgic Encephalomyelitis /Chronic Fatigue Syndrome as a neurological disease as classified under ICD-10 G93.3 by the World Health Organisation, Geneva.
- Adopts the Canadian Guidelines, Treatments and Protocols as produced by an international expert panel of eleven physicians that have between them treated/diagnosed over 20,000 sufferers worldwide.
- Produces a sustained and orchestrated campaign to deliver the message to the Government, to the Department of Health, to the National Health Service, to the Medical Research Council, to the psychiatric lobby, to Social Services, to the Education Authorities, to the media and all opinion formers that ME/CFS is not a mental disorder/somatization disorder or erroneous belief system as propounded by the psychiatric lobby for years on end, but a neurological illness.
- Prioritises the need for aetiological and biomedical research to be undertaken in regard to this disease; research to attempt to ascertain the multi-factoral causes thus leading to diagnostic bio- markers, a soundly researched care path to follow and in time, we hope, a cure.
- Lobbies the Government in relation to ease of provision of the Benefits that so many sufferers of this neurological illness need to survive and provides practical help to sufferers in relation to the obtaining of same.
- Refuses to collude with the psychiatric lobby that has done so much harm to sufferers of the neurological disease ME/CFS for years without number.
- Works towards the provision of domiciliary care and support for sufferers.

- Mounts a sustained information campaign regarding this disease such that diagnosis is definitively obtained within three months for children and within six months for adults. (NB. For my son who contracted ME at the age of 10, this process took eighteen months and it was sheer agony to obtain that diagnosis. If I had obtained that diagnosis in the first three months of the onset of this disease, I would have done things differently and things might not be as they are with us today).
- Focuses on those sufferers most severely afflicted by ME/CFS and attempts to meet their needs that are so often ridiculed and ignored by the very professionals charged with a duty of care for them; and ensures that those most severely afflicted are included as a matter of priority into all research studies of this disease.
- Works with other organisations in the field so that the incidences of children being forcibly removed from their families because they have the neurological illness ME/CFS are completely eradicated.
- Conducts a strategic, proactive, co-ordinated and targeted media campaign that highlights the suffering caused by the neurological illness ME/CFS and what needs to be done for sufferers in terms of care, research and understanding; and is swift in cogent rebuttal of damaging stories on this disease as and when they occur; a media campaign that speaks with one voice and changes hearts and minds.
- Liaises with government and the health service at the highest levels to promote the interests of ME/CFS sufferers.
- Works closely with Local ME Groups around the UK and provides support in terms of collaboration, information and, in time, possibly finance.
- Liaises with other charities and organisations in the field such as Tymes Trust, MERGE, RiME, the 25% Group et al such that common cause is made for sufferers of all ages, nationwide.
- Liaises with international organisations worldwide in terms of research being undertaken in other countries and treatment programmes.
- Retains a Medical Adviser/Advisers who adhere to the core beliefs of this organisation and act and behave accordingly.
- Is accountable and transparent in all its dealing with its members and the ME/CFS community in general.

CONCLUSION

Doubtless there are items that could be added and we leave it up to you as the ME/CFS community to comment.

This is the type of charity activity that we would like to see. The above is not rocket science. It is pure common sense. Moreover, this is the way in which reputable disease charities generally strive to work.

It is a complete and utter scandal that selected of the charities that currently take the money of adult sufferers in the UK have not adhered to the principles set out above. That secrecy, lack of transparency and double-dealings have been their watchwords.

THE ME/CFS COMMUNITY UK NEEDS TO FIND ITS VOICE AND USE IT!

Jane Bryant

THE ONE CLICK GROUP

<http://health.groups.yahoo.com/group/THEONECLICKPROTEST/>

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