

ALTERNATIVE TREATMENTS

There has been ongoing interest in alternative and unproven therapies within our community. In Philadelphia at the Annual Meeting (2005), discussions in the corridors highlighted the need for a statement from the Alliance on alternative or unproven treatments. This need was further highlighted by the reports of people investing in treatments in China using Olfactory Ensheathing Glia.

Significant work has been undertaken to produce a statement on alternative treatments.

For the purposes of this document, the term 'Alternative' used here refers to treatments or interventions that are not part of mainstream (conventional or Western) medicine and generally have not been scientifically documented and/or may not be recognised as being safe and effective for ALS/MND.

Background

Those with ALS/MND have always been interested in alternative treatments. It is understandable that when you have been informed that you have a terminal illness and conventional medicine cannot provide a cure, that you will look to other alternatives which may provide you with some hope.

With the rise in the use of the internet and the ease of mass communications, the promotion and marketing of such alternative treatments has never been easier.

Over the years there have been a number of alternative treatments which have come to the attention of those with ALS/MND and purport to offer improvements in symptoms and/or delays in progression of the disease. Such alternative treatments include snake venom, goat serum and more recently Olfactory Ensheathing Glia (OEG) transplantation.

People with ALS/MND are frequently taking a more proactive approach to their condition and actively seek out different or alternative forms of treatments and as such the International Alliance has, as an umbrella organisation, been approached on a number of occasions to provide advice and guidance on such treatments.

While the Alliance has neither the resources nor expertise to act as guardians or police on such treatments, it would be beneficial if some statement could be issued on such occasions that would serve to state the International Alliance's position on such matters whilst providing some form of positive guidance for the enquirers.

When a person with ALS/MND wishes to try an alternative treatment, it is not the Alliance's responsibility to be a policeman, to block such a wish or to shatter their hopes. Rather our aim should be to raise the awareness of people with ALS/MND so that they can be properly informed and able to make appropriate decisions. The Alliance wants to empower people with ALS/MND, allowing them to make informed choices about their health care.

The International Alliance's position should be weighted towards the use of rigorous scientific testing and clinical trials, the results of which can offer reliable information to guide doctors, health care professionals and the general public. This in turn helps to improve the ability of those affected by ALS/MND to make informed choices in the use of

treatments. However, there is always the possibility that an alternative treatment may provide some lasting benefit without having undergone the rigors of scientific testing and any statement needs to take this into consideration.

The destruction of a family's financial resources should be considered as much a risk as some of the medical ones.

The following Statement, and guidance principles, was adopted by the Board of Directors of the International Alliance of ALS/MND Associations at its meeting on 15 July 2005. It is recommended to you by the Board of Directors.

STATEMENT ON ALTERNATIVE TREATMENTS

The International Alliance of ALS/MND Associations recognises the interest that people affected by ALS/MND can have in seeking alternative forms of treatments.

The International Alliance of ALS/MND Associations supports the individual's right to choose what treatment they wish to undertake but would strongly encourage anyone considering any treatment to fully discuss the issues around such treatment with their doctor, health care professional and family before making a final decision.

The International Alliance of ALS/MND Associations believe that treatments for, and research into, ALS/MND should be legal, have a sound scientific rationale and have the potential to bring us closer to the cause, treatment or cure for the condition.

The International Alliance of ALS/MND Associations only recommends treatments that have been proven through thorough scientific testing and clinical trials to be safe and effective.

The International Alliance of ALS/MND Associations recommends all providers of non-proven and/or alternative treatments for those affected by ALS/MND to conduct scientific research and submit papers to the appropriately recognised journals so that peer review can be undertaken and the information can be shared amongst the whole ALS/MND community.

Guidance Principles

When looking at alternative treatments, the International Alliance would recommend that you give careful consideration to the following questions to help you think through the issues and to make an informed decision:-

What claims are being made for the treatment?

Often there will be claims of stopping the progression of the disease or of a reversal/improvement in symptoms. Check who it is that is making these claims and what evidence there is to back them up. If the claims are genuine then they will have been published in recognised scientific journals and there will be published results of clinical trials. Often there will be testimonials from people with ALS/MND of the improvements they have experienced. It is important to find out how long the improvements lasted for as there is a recognised phenomenon called the 'placebo' effect which occurs when individuals experience beneficial effects only because they believe that they're receiving

beneficial treatment. Does their doctor agree that there has been a benefit in undergoing the treatment?

How are people finding out about the treatment?

Is it mainly being promoted through the mass media i.e. newspapers, magazines, the Internet etc. Any genuinely safe and effective treatment will be promoted and recommended by your doctor and the ALS/MND Associations.

Who is offering the treatment?

Is the treatment being offered by an appropriately recognised institution? Is it being offered by a number of different institutions or just one? If it's just one then why are others not following and doing the same? Do you have to travel to another country to receive the treatment and if so why is it not available in your own country?

What are the risks involved?

Is it clearly stated what risks are involved in undergoing the treatment? Are there any side effects and how long may they last? Has the treatment been proved to be safe and effective and if so how was this done? Don't forget that there can be financial risks associated with treatment particularly if it is expensive and involves overseas travel.

What follow-up monitoring is carried out after the treatment?

Follow-up monitoring is extremely important not just for you but for all those with ALS/MND. For you it is important to know that you will be monitored so that any adverse effects can be picked up as soon as they occur. For all those with ALS/MND they need to know if the treatment is successful and that they can rely on the claims being made.

International Alliance of ALS/MND Associations