

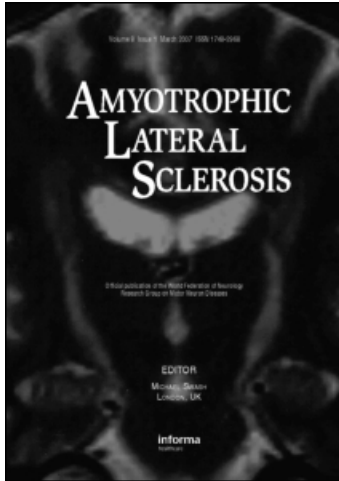
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EDITORIAL

ALSUntangled (ALSU): A Scientific Approach to Off-Label Treatment Options for People with ALS Using Tweets and Twitters

RICHARD BEDLACK & ORLA HARDIMAN

People with ALS often consider alternative and off-label treatments (AOTs), based on information gleaned from the internet (1,2). Such AOTs can be expensive and some are potentially harmful. Moreover, the evidence presented for the efficacy and safety of these is often sketchy and frequently inaccurate (3). Pursuit of more invasive treatments such as injection of stem cells into the nervous system is usually undertaken in unregulated parts of the world, and for many people with ALS, is in place of participation in a properly governed clinical trial.

A forum for easily accessible scientific information for the informed lay person on these treatment options is urgently required ALS Clinician Scientists have always had the interest and training to provide an informed opinion about AOTs, about which they are frequently asked by those attending their clinics. Indeed, some clinicians have undertaken detailed investigations of suspect AOTs on behalf of their patients. In 2007, Neurologist Dr. Leonard van den Berg, working on behalf of Dutch people with ALS, investigated the Institute of Neuro-Regeneration, Repair and Functional Recovery in Beijing. This included a detailed review of the facility, the cost of attending and the scientific validity and ethics of the “treatment” approach. He then systematically assessed 12 people with ALS who had travelled there for this AOT. The Dutch work was discussed at an International ALS Symposium, and received appropriately wide coverage (4). As a result, people with ALS now have a much clearer view of both the costs and the risks of what is being offered. Another group recently performed an investigation of the AOT called IPLEX (4). This included a critical review of the rationale for IPLEX, and an account of a cohort of people with ALS in Italy taking the drug provided by Italian Neurologist Dr. Vincenzo Silani. The Journal has made this IPLEX investigation freely accessible online –thus generating considerable and appropriate discussion about this unproven therapy. They Journal has also published a scientific review, discussing the role of the IGFs as potential therapeutics in ALS (5)

A more formalized approach by which ALS Clinician Scientists can continue to contribute con-

structively to the ongoing debates on AOTs has now been launched. This initiative uses new internet tools, and is called ALSU (ALSUntangled). There are three parts to ALSU: learning about the AOTs that people with ALS might consider; a “war room” in which these AOTs are investigated by ALS Clinician Scientists; and finally, public release of the results of the investigations both online, and in a summarized form in the Journal.

The learning phase will use the website Twitter (6). Free and simple to join, people with ALS and / or their caregivers can use this site to introduce an AOT, simply by putting it into a short text message (called a “tweet”) along with the term ALSUntangled. The ALSU group can then use the Twitter Search application (6), which is now part of the World Federation of Neurology ALS Research Group (WFN-ALS) website (7) to find such “tweets”. Once AOTs have been identified, the ALSU group will import them into a separate page within a website called NING (9), also now linked to the WFN-ALS website (8). NING is a social networking site similar to Facebook (10). The site allows the creation of a discussion forum for ALS Clinician Scientists. The forum can support not only text, but photos and imported data that can be analyzed for each AOT. Goals for each investigation will be to clarify exactly what is on offer, how much it costs, the scientific and ethical basis of the “treatment”, and the potential benefits and risks. Individual ALS Clinician Scientists will contribute not only opinion, but first-hand knowledge of specific AOT site, its infrastructure, and additional de-identified patient outcomes (as Dr. van den Berg did with the Institute of Neuro-Regeneration Repair and Functional Recovery). Once sufficient information about an AOT has been collected, a summary of the investigation will be released to the public. This will occur via presentations at ALS-relevant meeting and in a summarized form in this Journal, with free online access.

ALS-U is a new and exciting initiative. It should be welcomed by clinicians and people with ALS alike. Driven from the “ground up” it will provide a timely, accurate and scientifically valid analysis of

AOTs. And this in turn will help people with ALS and their families to make informed decisions in an increasingly noisy environment.

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