

Amyotrophic Lateral Sclerosis

ISSN: 1748-2968 (Print) 1471-180X (Online) Journal homepage: informahealthcare.com/journals/iafd19

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To cite this article: (2011) ALSUntangled No. 12: Dean Kraft, Energy Healer, Amyotrophic Lateral Sclerosis, 12:5, 389-391, DOI: 10.3109/17482968.2011.609309

To link to this article: https://doi.org/10.3109/17482968.2011.609309

Published online: 10 Oct 2011.

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Amyotrophic Lateral Sclerosis, 2011; 12: 389–391

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REPORT

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The ALSUntangled Group

Active for 29 months, ALSUntangled (www.alsuntangled.org) investigates alternative and off-label ALS treatment options using social networking tools. Our twitter and NING memberships continue to grow, as do our collaborations. In addition to Quackwatch (www.quackwatch.org), PatientsLikeMe (www.patientslikeme.com) and ALS Worldwide (www.alsworldwide.org) we are pleased to announce a new collaboration with the Motor Neurone Disease Association (www.mndassociation.org). We have thus far published 11 investigations on 12 different alternative and off-label treatment options, and have 34 other open investigations. We now present our investigation of Dean Kraft's energy healing, which was undertaken at the request of patients with ALS (PALS).

Dean Kraft is perhaps the best known of a group that calls themselves 'energy healers'. These practitioners place their hands either on or just above various body regions, directing their 'energy' into patients. Kraft, who has been engaged in this for 39 years, states that this procedure can "unblock and balance the patient's natural energy fields in order to catalyse their own healing system to start to correct itself, to function properly" (1). He goes on to say "As I try to help someone with a health problem, I visualize the area or areas that are diseased. For example, if a person has liver tumors that medical science has deemed 'hopeless', I would then 'see' or 'imagine' the tumors shrinking – and most of the time, this action actually creates a physical change" (1). The technique is not the same in every patient, says Kraft: "There is a very intuitive process to my energy healing work" (1). Apparently one can either be born with the ability to perform energy healing (as Kraft was) or can learn it (Kraft reports being asked to join the faculty at Lincoln Hospital in South Bronx, New York, in order to teach his techniques to physicians there). Kraft admits that he is not a medical doctor, says he is a strong believer in science-based or standard medicine, and says he prefers to work as "an adjunct alongside the physicians in a complementive manner" (1).

Kraft's website states that he 'is the only non-religious laying-on-of-hands energy healer that works successfully with most forms of cancer. In many cases he has been the catalyst of full remissions and complete cures for people suffering with the worst types of malignant metastatic cancers known to mankind' (1). Kraft's website also reports that he has helped patients suffering from stroke, 'paraplegia and quadriplegia due to various causes', neuropathy, multiple sclerosis, various orthopedic maladies, scoliosis, ankylosing spondylitis, rheumatoid arthritis, deafness, shingles, scleroderma and 'many ALS patients to all varying degrees' (1).

Kraft's website calls him 'the most documented healer of our time' (1). Along these lines, it includes brief testimonials from physicians and/or patients; for example, "Mrs. Howard observed her husband, Abe, substantially improve with the life-threatening disease Lou Gehrig's disease (ALS), after Dean's energy healing treatments" (1). There is also a section of the website entitled 'research'. This details various experiments including one in which Kraft reportedly moved a pendulum placed under a glass belljar using only his mind, and another in which he was able to dislodge HeLa cells from a cultured monolayer (1). None of these experiments was apparently ever published in a peer-reviewed journal; a PubMed search identified no papers by or about Dean Kraft. His website does list published articles; again, none appear to be in peer-reviewed journals but rather in lay press such as the National Enquirer, National Tattler, London Daily Mail and Penthouse-Forum.

Kraft's website also includes case histories: one of these is the striking and widely publicized case of Nelda Buss, who reportedly had advanced ALS completely reverse while under Kraft's care. ALSUntangled had the pleasure of interviewing Nelda Buss for this article and with her assistance obtained her medical records. In November 1984, at age 43 years, she experienced gradual onset difficulty writing and walking. Over time, her arms and legs gradually worsened until, six months into her illness, she was unable to walk or accomplish any activities of daily living. She was seen at Roanoke Memorial Hospital, and later at the University of Virginia (UVa). At UVa, Frederick Wooten documented normal mental status including speech. Motor exam showed normal bulk and tone. Power testing showed fairly diffuse, symmetric upper greater than lower extremity weakness.

ISSN 1748-2968 print/ISSN 1471-180X online © 2011 Informa Healthcare
DOI: 10.3109/17482968.2011.609309

Sensory and coordination examinations were normal. Reflex examination showed a jaw jerk, brisk triceps jerks, pathologically brisk knee and ankle jerks with sustained clonus. There were no Hoffman or Babinski signs. Work-up included CT scan of the neck, and myelogram, which were reportedly unremarkable. She had two sets of nerve conductions with needle EMGs. Neither study showed sensory neuropathy or motor conduction block. The first study showed denervation and reinnervation restricted to the cervical myotomes; the second (performed by Robert Pascuzzi and Lawrence Phillips) showed fibrillations, fasciculations and large motor unit potentials with reduced recruitment in multiple cervical myotomes, and large motor unit potentials with reduced recruitment in multiple lumbosacral myotomes. Bloodwork included normal ESR, RPR, TSH, and PT/PTT. Spinal fluid testing included normal cell counts, glucose, and protein. Her UVa team concluded that she had amyotrophic lateral sclerosis. Although there were some atypical features (young age, rapid progression, lack of muscle atrophy), based upon the information provided, ALSUntangled agrees with this diagnosis. Following her visit to UVa, she tried physical therapy and a variety of 'alternative' therapies for her condition including carrot juice and a holistic chiropractor. Despite these, she reports that she progressed, eventually becoming quadriplegic and developing breathing dysfunction. Indeed, she appears quadriplegic in videos (2); no further medical records were available to quantify her progression or her nadir. Under Dean Kraft she states that she had energy treatments lasting 1–2 hours, roughly every other week for 1–2 years. During this time she continued physical therapy. By her reports and in various videos (2) she gradually improved, eventually recovering back to her pre-ALS baseline in terms of bulbar and upper extremity function, and regaining the ability to walk but not run. Dean Kraft's website refers to this case as "unequivocal proof that the laying on of hands can indeed reverse terminal illnesses that had no treatment, no cure, and no hope". This is inaccurate. While spontaneous remissions in ALS are very rare, they have been observed by ALSUntangled clinicians, and reported multiple times in peer-reviewed literature (3–6). Thus, a single case report of ALS reversal cannot be regarded as proof of a treatment's effectiveness.

ALSUntangled searched for other patients treated by Dean Kraft. In an e-mail exchange with his wife Rochelle, we asked for the total number of patients with ALS that have been treated by Kraft, and the overall success rate; we were told via e-mail that we would not be able to obtain this information anytime soon because "all of our files and case histories are in storage on the West Coast". Within the PatientsLikeMe community, no patients with ALS reported treatment by Dean Kraft.

In terms of costs, Nelda Buss reported spending approximately $75 per session, and $25,000 overall. Dean Kraft's website does not list current prices, and our request for these via e-mails to him has gone unanswered. Two patients with ALS in the PatientsLikeMe community reported Dean Kraft's current prices to be $800 per session. When asked about side-effects, Rochelle Kraft reports that in 39 years of treatment "there has never been a negative side-effect".

Recommendations

In our opinion, Dean Kraft's energy healing lacks a plausible scientific rationale. The experiments listed on his website as proof of his being able to emit some sort of energy have never been published in a peer-reviewed journal and thus cannot be properly validated. The strongest evidence for his being able to heal ALS comes from the case report of Nelda Buss who appeared to have ALS, and while under the care of Dean Kraft and a physical therapist, recovered nearly completely. Spontaneous remissions in ALS are very rare, but certainly have been reported before. One case cannot be considered proof of a specific treatment effect. At a minimum, a small well-designed case series would be necessary. We would be happy to work with Dean Kraft to design such a study if he is interested. Without more evidence, ALSUntangled cannot support this expensive alternative treatment for ALS.

The ALSUntangled Group currently consists of the following members: Richard Bedlack, Orla Hardiman, Tulio Bertorini, Tahseen Mozaffar, Peter Andersen, Jeff Dietz, Josep Gamez, Mazen Dimachkie, Yunxia Wang, Paul Wicks, James Heywood, Steven Novella, L.P. Rowland, Eric Pioro, Lisa Kinsley, Kathy Mitchell, Jonathan Glass, Sith Sathornsumetee, Hubert Kwiecinski, Jon Baker, Nazem Atassi, Dallas Forshew, John Ravits, Robin Conwit, Carlayne Jackson, Alex Sherman, Kate Dalton, Katherine Tindall, Ginna Gonzalez, Janice Robertson, Larry Phillips, Michael Benatar, Eric Sorenson, Christen Shoesmith, Steven Nash, Nicholas Marigakis, Dan Moore, James Caress, Kevin Boylan, Carmel Armon, Megan Grosso, Bonnie Gerecke, Jim Wymer, Bjorn Oskarsson, Robert Bowser, Vivian Drory, Jeremy Shefner, Terry Heiman-Patterson, Noah Lechtzin, Melanie Leitner, Robert Miller, Hiroshi Mitsumoto, Todd Levine, James Russell, Khema Sharma, David Saperstein, Leo McClusky, Daniel MacGowan, Jonathan Licht, Ashok Verma, Michael Strong, Catherine Lomen-Hoerth, Rup Tandan, Michael Rivner, Steve Kolb, Meraida Polak, Stacy Rudnicki, Pamela Kittrell, Muddasir Quereshi, George Sachs, Gary Pattee, Michael Weiss, John Kissel, Jonathan Goldstein, Jeffrey Rothstein, Dan Pastula.

Note: This paper represents a consensus of those weighing in. The opinions expressed in this paper are not necessarily shared by every investigator in this group.

Declaration of interest: ALSUntangled is sponsored by the Packard Center, the Virginia Gentlemen Foundation and the Motor Neurone Disease Association.

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