Periodical
The American Legion

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NATIONAL VETERANS AFFAIRS AND REHABILITATION COMMISSION
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For God and Country

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Amyotrophic Lateral Sclerosis (ALS)
"Lou Gehrig's Disease"
Nationwide Study

You may already be aware of the VA and DoD study to investigate ALS in Gulf War Veterans. However, if you are not or have not passed on this valuable information please read this immediately.

The study will seek to identify each Gulf War veteran who has become disabled with ALS. Our role is to encourage these individuals to enroll in the study, or have a family member speak on their behalf. **The study hopes to have the majority of veterans with ALS enrolled by August 1, 2000.** It is critical that we assist people in reaching out and being counted. The findings of this study may significantly impact VA and DoD policy.

What is ALS?
ALS is a non-contagious disease that affects adults by destroying the brain and spinal cord cells that control movement. Severe paralysis will occur within a few short years (often 3-5). The mental functioning and sharp mind of these victims remains well intact; it is only the muscles that are injured.

What will the study do for veterans?
This nationwide study will attempt to locate each Gulf War veteran who has contracted the disease so that they can determine if veterans are getting it more than other populations. Also, the study will attempt to understand if particular exposures during the war period could have caused ALS.

Initially, 28 Gulf War veterans with ALS were identified by VA and DoD clinicians.

Who is eligible to participate?
Gulf War veterans who were on active duty, to include Reserve and Guard units, between August 2, 1990 and July 31, 1991 are eligible. It does not matter if the veteran was

deployed to the Gulf region or not. The veteran will need to have a medical diagnosis of ALS during or after their service.

If the veteran is deceased or cannot speak for him or herself, a family member can enroll on the individual's behalf.

What will veterans need to do as a participant?
First, make the call to enroll. The study has a toll-free number 1-877-DIAL-ALS (1-877-342-5257) which is a recording asking you to leave your name and number. Someone will call you back.

Second, there will be an in-home interview by a nurse researcher, which will be to ask and answer questions.

Third, an expert physician at a local hospital will conduct a neurological exam.

*This study will not involve drugs.

Where can I get more information?
Contact Lisa Spahr of The American Legion at (202) 861-2700, LSPAHR@legion.org, for more information.

The ALS Association, a non-profit, non-governmental agency dedicated to assisting ALS patients can be reached by calling 1-800-782-4747 or emailing Mary Lyons, mary@alsa-national.org. The ALSA has been in full support of this study moving forward to identify victims of ALS.

The study investigators can be reached at 1-877-DIAL-ALS (1-877-342-5257) or dawnhoward@mindspring.com. Their address is ALS Study (152), VA Medical Center, 508 Fulton Street, Durham, NC 27705. The study website is http://hsrd.durham.med.va.gov/eric/als/als.htm

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