



EMBARGOED UNTIL MONDAY, MARCH 23, 2015 @ 6:00 A.M. EDT

PROFOUND, DEBILIATING FATIGUE FOUND TO BE A MAJOR ISSUE FOR AUTOIMMUNE DISEASE PATIENTS IN NEW NATIONAL SURVEY

AARDA Calls on “Fuzzy,” Largely Ignored Symptom to Become a New Focus of Research

WASHINGTON, D.C., March 23, 2015 -- Fatigue described as “profound,” “debilitating,” and “preventing them from doing the simplest everyday tasks,” is a major issue for autoimmune disease (AD) patients, impacting nearly every aspect of their lives. It affects their mental and emotional well-being and their ability to work. And while most AD patients have discussed their fatigue with their physicians, many have not been prescribed treatment for their fatigue.

Those are among the major findings of a new online survey of autoimmune disease patients conducted by the American Autoimmune Disease Related Diseases Association (AARDA), the nation’s only not-for-profit autoimmune disease patient advocacy organization, to examine the connection between autoimmune disease and fatigue. AARDA released the findings of the survey of 7,838 AD patients at a national summit held to commemorate National Autoimmune Disease Awareness Month at the National Press Club in Washington, D.C.

Major findings include:

- Almost all (98 percent) AD patients surveyed report they suffer from fatigue.
- Nine-in-10 (89 percent) say it is a “major issue” for them and six-in-10 (59 percent) say it is “probably the most debilitating symptom of having an AD.”
- More than two-thirds (68 percent) say their “fatigue is anything but normal. It is profound and prevents [them] from doing the simplest everyday tasks.”
- While nearly nine-in-10 (87 percent) report they have discussed their fatigue with their doctor, six-in-10 (59 percent) say they have not been prescribed or suggested treatment by their doctors.
- Seven-in-10 (70 percent) believe others judge them negatively because of their fatigue.
- Three-quarters (75 percent) say their fatigue has impacted their ability to work; nearly four-in-10 (37 percent) say they are in financial distress because of it; one-in-five (21 percent) say it has caused them to lose their jobs; while the same number (21 percent) report they have filed for disability as a result of their fatigue.

- Fatigue impacts nearly every aspect of AD patients' lives including overall quality of life (89 percent), career/ability to work (78 percent), romantic (78 percent), family (74 percent) and professional relationships (65 percent) and their self esteem (69 percent), among others.

"In this busy, busy world, it's normal to be tired, but the kind of fatigue autoimmune disease patients suffer from is anything but normal," said Virginia T. Ladd, President and Executive Director of AARDA.

"The overwhelming response AARDA received to this survey shows without a shadow of doubt that fatigue is not a 'fuzzy' symptom, it's real. Yet, for too long, it has been ignored and/or misunderstood by the medical community and the public at large. It's time we bring more research funding to this issue to advance understanding and effective treatments for fatigue."

The survey revealed that fatigue has a significant impact on AD patients' mental and emotional well-being. They say it has resulted in increased emotional distress (88 percent), a sense of isolation (76 percent), anxiety (72 percent) and depression (69 percent).

According to one AD patient, "It's difficult for other people to understand our ongoing fatigue when it can't be seen by them. It's so hard just trying to get others to really, really understand how very tired you are sometimes – even our own doctors don't understand. One wonders if even our doctors may think we are for the most part just mental cases and/or whiners."

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About the Survey

AARDA conducted the survey online using Survey Monkey and promoted the link through its Facebook page, the Autoimmune Awareness and Education Forum Facebook group and via email to the National Coalition of Autoimmune Patient Groups. The survey was in the field for roughly four weeks from Saturday, February 7, 2015 – Monday, March 2, 2015.

A total of 7,874 responses were received. The less than .5 percent reporting having only Chronic Fatigue Syndrome and/or Fibromyalgia, neither of which are considered autoimmune diseases, were removed for a final total sample audience of 7,838.

About AARDA

American Autoimmune Related Diseases Association (AARDA) is the nation's only non-profit organization dedicated to bringing a national focus to autoimmunity as a category of disease and a major women's health issue, and promoting a collaborative research effort in order to find better treatments and a cure for all autoimmune diseases. For more information, please visit www.aarda.org.

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