

Blastocystis Research Foundation

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FAX/VM: 815-572-9701
www.bhomcenter.org

May 12, 2008

Dr. Anthony S. Fauci, MD, Director NIAID
31 Center Drive
Bethesda, MD 20892-2520

Dear Dr. Fauci,

I am following up on Representative Neal's letter (attached) and Representative Tauscher's communication (attached) concerning *Blastocystis* infection.

We've contacted your office previously for assistance in addressing this problem. Since then, we've raised money from private sources to duplicate the types of *Blastocystis* studies being published in the Middle East [6-8], Asia [9-10] and Europe [11-12]. But we shouldn't have address infectious diseases with bake sales and volunteer microbiologists, especially for a protozoan that inexplicably start showing up in 23% of samples from West Coast labs in a time when most other protozoal infections have declined [4-5,13].

Many of the countries currently publishing studies (Iran, Egypt, Turkey) have small biomedical research budgets but are able to get resources to scientists, so I'm more hopeful than Rep. Tauscher. We will be petitioning the NIH for a Funding Opportunity Announcement to support University and clinical researchers in the development of reliable diagnostics and treatments for *Blastocystis* infection. The amount will be proportional to that spent in the Middle East and Asia.

The evolution of case reports since 1989 is consistent with a pandemic infection which was first reported from Saudi Arabia in 1989 [1]. Persian Gulf War veterans may have been first large group of US citizens impacted [32]. At least one disease causing type of *Blastocystis* is now endemic in communities in California and Oregon [3-5]. Our diagnostics may detect less than half of the infections [12,14-15] and the treatments used by physicians are unlikely to be effective in many cases [16-17]. This has a substantial impact on patient care, especially on the West Coast, and returning international travelers, such as veterans from the Middle East.

Blastocystosis is not a trivial disease, and because our diagnostics aren't reliable, many patients don't even know why they are sick. My case took two years to diagnose, and put me on medical disability for months, and doctors still don't know how to treat it. Similar accounts can be found in testimony presented to the Oregon State Legislature last year by doctors and patients [18].

I hope I can count on your support in our upcoming petition. A copy of this letter along with a bibliography of over 100 studies identifying *Blastocystis* as disease causing, will be available on the web site, <http://www.KeepAmericaHealthy.org>

Best Regards,

Ken Boorum
Director, Blastocystis Research Foundation

cc: Dr. Griffin P. Rodgers, MD, Director NIDDK; Dr. Elias A. Zerhouni, MD, Director NIH;
Representatives Richard E. Neal (D-Mass); Representative Ellen Tauscher (D-California)

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May 12, 2008

The Honorable Richard E. Neal
2208 Rayburn House Office Building
Washington, DC 20515
FAX: 202 225-8112

Dear Representative Neal,

I wanted to thank you for contacting the NIH, and listening to your constituent who wrote you concerning *Blastocystis* infection contracted overseas.

Listening is important, and we're trying to get the NIH to listen to researchers in the Middle East and Asia who have been reporting severe illness with this since the early 1990's. The primary type of *Blastocystis* that returning travelers carry back from these areas may be different from what was in the United States in the 1980's, and this may have caused confusion at the NIH.

As noted in the attached letter, this issue has gotten to State Legislature in Oregon, but you are the first Congressional Representative at the Federal level to take action.

This is a new pathogen with a new name (*Blastocystis* sp. subtypes 3 and 1), and we need our scientists to coordinate with researchers in the rest of the world to address it. One recent article (see attached letter) identified a source that indicated that 50% of the Persian Gulf War veterans returned with *Blastocystis* infection, but we've been so sure of opinions in the United States, we've never investigated this as a cause for illness.

Blastocystis was researched for years by an NIH scientist, Dr. Charles Zierdt, who concluded it could cause serious disability, and produced a huge volume of research published in peer reviewed medical journals. He produced the bulk of scientific research on *Blastocystis* published before 1992. Unfortunately, Dr. Zierdt retired shortly after Gulf War veterans returned, and the NIH has not been as active in addressing this since then.

Many thanks for your support.

Best Regards,

Ken Boorum
Director, Blastocystis Research Foundation
director@bhomcenter.org

cc: Dr. Anthony Fauci, MD, Director NIAID
Dr. Griffin P. Rodgers, MD, Director NIDDK
Dr. Elias A. Zerhouni, MD, Director NIH
Representative Ellen Tauscher (D-California)

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May 12, 2008

The Honorable Ellen Tauscher
2459 Rayburn HOB
Washington, DC 20515
FAX: (202) 225-5914

Dear Representative Tauscher,

I wanted to thank you for following up on your constituent's letter (attached), and to copy you on the attached letters to Representative Neal and NIAID Director Anthony Fauci.

Blastocystis is a gastrointestinal protozoa that produces symptoms of skin rash, severe fatigue and gastrointestinal distress in immunocompetent (not AIDS infected) humans. Multiple types infect humans, and the most prevalent type from the Middle East does not show up reliably on our diagnostics, and would not be easily treatable with drugs used in this country.

Infectious diseases are relatively inexpensive to address once they are identified. In the United States, lack of *Blastocystis* funding is a cultural phenomenon, not an economic one. Today, many countries with small biomedical research budgets like Iran, Turkey, Jordan, Egypt, Greece, Malaysia, Mexico, Italy, Denmark, Singapore, and China all have active programs. In fact, the Gross Domestic Budget in some of those countries is of the same order of magnitude as the NIH budget, so it's not a question of money. In the United States, *Blastocystis* research isn't being pursued out of principle and cultural belief.

When we are willing to admit the possibility of error, we can understand why people coming back from the Middle East are sick, and why US citizens are getting sick with symptoms of Gulf War illness without ever leaving the country.

Perception of *Blastocystis* varies with geographical prevalence. In the Middle East, it is viewed as a serious problem, and we've had communication concerning at least one immunocompetent patient (9-year old female) ending up on life support. In the United States, the problem is present in all states, but West Coast states seem to be particularly impacted. In Maryland, where the NIH's offices are located, *Blastocystis* infection is somewhat rare, so scientists there may not perceive it as problematic.

But if we speak clearly and persistently, I think the NIH will hear us all the way on the East Coast.

A list of other Representatives that have contacted by their constituents is on the reverse side of this letter.

Best Regards,

Ken Boorum
Director, Blastocystis Research Foundation
director@bhomcenter.org

Patients in the following constituencies have contacted the Representatives:

California – Representatives Lungren (R-3), Matsui (D-5), Tauscher (D-10), Capps (D-23), McKeon (R-25), Schiff (D-29), Watson (D-33), Lewis (R-41), Rohrabacher (R-46)

Oregon – Representatives DeFazio (D-4) (multiple constituents), Hooley (D-5) (multiple constituents)

Washington State – Representatives Dicks (D-6), McDermott (D-7)

Nevada – Representative Porter (R-3)

Texas – Representative Johnson (D-30)

North Dakota – Representative Pomroy (D)

Ohio – Representatives Ryan (D-17) (multiple constituents), Sutton (D-13), Jones (D-11),

Florida – Representative Brown-Waite (R-5)

Massachusetts – Representative Neal (D-2) (multiple constituents)

New York – Representative Rangel (D-15)

West Virginia – Representative Mollohan (D-1)

RICHARD E. NEAL
SECOND DISTRICT, MASSACHUSETTS

AT-LARGE WHIP



COMMITTEE ON WAYS AND MEANS
CHAIRMAN,
SUBCOMMITTEE ON SELECT
REVENUE MEASURES
CHAIRMAN, FRIENDS OF IRELAND

Congress of the United States
House of Representatives
Washington, DC 20515

February 29, 2008

Dear Mr. [REDACTED],

Thank you for your letter regarding *Blastocystis* infection.

Your letter may help end needless suffering due to lack of medical research into this infection. As a concerned representative of my constituents, I felt that it was necessary to get involved in convincing the NIAID to make a Funding Opportunity Announcement. This is a very important issue for individuals such as yourself, as well as our troops in the Middle East.

I sent a letter to the NIAID on your behalf, requesting that *Blastocystis* be placed on their Category B Biodefense pathogen list, as well as asking them to issue a FOA for clinically directed research on this infection.

Thank you very much for taking the time to contact my office. If I can be of help in the future, please do not hesitate to contact me.

Sincerely,

Richard E. Neal,
Member of Congress

REN/yc

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