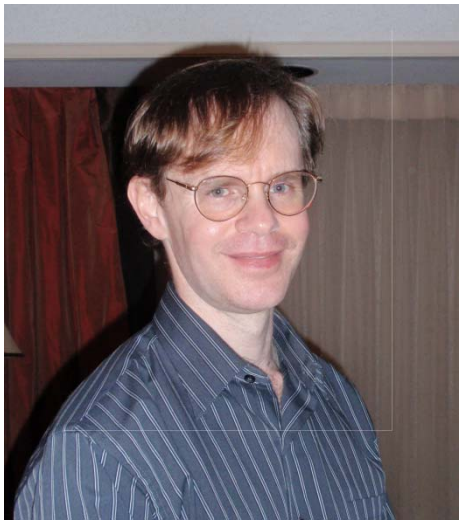
Blastocystis Research News Spring 2010

Gulf War Illness Issue



Blastocystis Research News is the newsletter of the Blastocystis Research Foundation (BRF). Opinions expressed are those of the authors, and may not necessarily reflect those of BRF or its collaborating researchers. Names of patients may be changed to protect their privacy.

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http://www.bhomcenter.org
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Founders Corner

This April, the *Blastocystis* Research Foundation turned four. When I started BRF, I imagined that we would document the long-term cases in the United States. We would link them with international research. Then the Center for Disease Control would help by getting patients diagnosed and treated.

I never imagined that officials at the CDC and NIH would oppose or ignore the work for 4 years. I didn't know about the politics behind infectious diseases, or appreciate the number of professionals who have staked their reputations on *Blastocystis* being harmless. For a good description of the politics of infectious diseases, read "Betrayal of Trust" by Laurie Garrett, or any of the papers by Dr. Fran Collyer.

I also didn't realize that *Blastocystis* is a strongly regional problem, and I was living in a state with one of the highest rates in the country (Oregon). *Blastocystis* infection rates are relatively low in the states that host the CDC (Georgia) and the NIH (Maryland). The physicians who run those organizations aren't likely to get infected, or to have family or staff members infected. If the CDC and NIH were headquartered in a state where the disease is epidemic (California, Oregon, Texas, Florida, New York, and Ohio), their kids would be getting sick, and we would have treatments by now.

The final complexity is that the United States has shut down most of its infectious disease labs, except for those studying HIV, which now comsume 60% of the country's infectious disease budget. Most US medical research into chronic gastrointestinal illness is performed by medical doctors who are generalists. They aren't technically oriented, and they aren't microbiologists. Bright students in the United States aren't going into infectious disease microbiology – they go into finance and engineering (that's what I did). Five scientists have received Nobel Prizes since 2005 for relating a microbe to a disease. None of them were from the United States. In trying to setup collaborative relationships between US and overseas groups, we've run into a brick wall when US researchers can't read or understand the medical papers being written in Asia, Europe, and the Middle East.

To give you an idea of the extent of the neglect, *Blastocystis* has grown to be the most prevalent protozoal infection in most of the the US and the Middle East. I am now the United State's leading researcher on *Blastocystis*, as measured by the number of peer reviewed publications published in the last 10 years. All my work has been done on a volunteer basis on nights and weekends, using my family's savings and donations from patients. You simply can't do this in any field of science unless it is being aggressively neglected.

But the United States is not the world. Research is moving forward thanks to bright scientists in Europe, Asia, Australia, and the Middle East, all of whom are reporting similar findings. Repeatability is what science is all about. We will stop this epidemic. And we will work to pass laws to make sure the NIH and CDC can't abandon another of the country's infectious diseases for political reasons.

Researchers Identify Split Between *Blastocystis* and *D. fragilis* in IBS patients

Think IBS is no big deal? Rapper Cam'ron (upper left) wrote a song about his case. Jamie-Lee Curtis, another sufferer, sells Activia on TV. Camille Grammar reportedly had her youngest child carried by a surrogate mother because her case was so severe. Women like Camille with *Blastocystis* frequently write BRF, often describing multiple miscarriages and severe diarrheal illness.

What do Jamie Lee Curtis, rapper Cam'ron, and Camille Grammar have in common? All three have 'irritable bowel syndrome' or IBS.

What is IBS? Vomiting. Constant diarrhea. Food sensitivities. Abdominal pain. Widespread pain. Headaches. Night sweats. With symptoms like that, you would think that IBS patients have an infectious disease.

And you wouldn't be the only one. Since the 1990's, researchers in the Middle East and Europe have reported that IBS patients carry a protozoal disease called *Blastocystis* at a very high rate. They've also found another protozoal disease called Dientamoeba fragilis (DF) in IBS patients. Both are gastrointestinal infections transmitted by contaminated food or water. Unlike bacteria, these diseases can stay with patients for a lifetime unless they are treated.

But which infection is most important in IBS patients? Researchers at the Department of Medicine of Aga Khan Medical School in Karachi Pakistan have published the first combined *Blastocystis*-DF study of IBS patients.

The study was performed on 330 patients: 171 with diarrhea predominant IBS, and 159 healthy controls. By culturing stool specimens, the researchers found *Blastocystis* in 53% (90/171) of the IBS patients, and DF in 4% (7/171) of that group. *Blastocystis* and DF were present in 16% (25/159) and 1.3% (2/159) of the healthy controls. Both findings are statistically significant. Researchers tested for a half dozen other protozoa and bacteria in patients, and showed that *Blastocystis* and DF were the only ones present. They also used two methods for detecting *Blastocystis* – PCR and stool culture – which are not generally available in the United States.

IBS was a concept created in the United States to explain away patients with gastrointestinal illness who didn't seem to be infected with anything. Physicians in the Middle East have had a particularly difficult time swallowing the idea of IBS. At Aga Khan medical school in Pakistan, about a third of their medical class is now sick with the symptoms. And those symptoms are identical to symptoms seen in other parasitic diseases that doctors treat frequently in that region. Middle East researchers have contributed many of the close to 100 studies which report *Blastocystis* is making people sick. They've also performed many studies that show it causes disease in animals.

For the most part, these studies are ignored in the United States. *Blastocystis* has become a "hot button" among physicians because of the implication that IBS is being caused by a problem in the medical system. The prevalence of *Blastocystis* has skyrocketed in the US in the last 15 years, rising from a rate of 2.5% in the 1980's to its current rate of 12-15% in many studies. Drugs that used to work against the infection are now ineffective.

The issue has become so controversial that many doctors won't inform US patients of positive results in testing. The CDC declined to support initiative by BRF to recommend that patients be informed of positive test results, so they can take action to avoid spreading the infection. New York State laboratory microbiologists are instructed NOT to report *Blastocystis* on patient records unless the physician specifies the special code-word "All Parasites" on the requisition form. Techs who report *Blastocystis* when the physician asks for "All Protozoa" will actually lose points on their proficiency exam, even when the organism is present in the patient sample.

References

Yakoob J, et al.(2010) *Blastocystis* hominis and Dientamoeba fragilis in patients fulfilling irritable bowel syndrome criteria. Parasitol Res. Jun 8.

Yakoob J, et al. (2010) Irritable bowel syndrome: is it associated with genotypes of *Blastocystis* hominis. Parasitol Res 106:1033–1038

Yakoob et al. (2004) Irritable bowel syndrome: in search of an etiology: role of *Blastocystis* hominis. Am J Trop Med Hyg. 2004 Apr;70(4):383-5.

Stensvold CR, Arendrup MC, Mølbak K, Nielsen HV (2007) The prevalence of DF in patients with suspected enteroparasitic disease in a metropolitan area in Denmark. Clin Microbiol Infect 13:839–842

Brody TJ, et al. (2002) Eradication of DF can resolve IBS-like symptoms. J Gastroenterol Hepatol 17:A103

Hussain R, et al. (1997) Significantly increased IgG2 subclass antibody levels to *Blastocystis* hominis in patients with irritable bowel syndrome.Am J Trop Med Hyg 56:301–306

Parasitology Proficiency Testing Program, Wadsworth Center, New York Dept of Health. http://www.wadsworth.org/parasitology/critiquesFeb06.htm

Research Roundup
October 2009 – June 2010

To view the abstract of any paper in this list, go to the NIH's PubMed database (Google Pubmed), and type in the 7-digit PubMed ID which appears in parenthesis at the end of the description.

BRF Co-Authored Studies

 United States: *Blastocystis* sp. subtypes 1,2,3,4 and 8 were found in individuals with long-term gastrointestinal illness associated with *Blastocystis* or of unknown cause in Oregon. (20127113)

 Egypt, France, United States: *Blastocystis* isolates from symptomatic Egyptian patients belong mainly to subtypes 3, 1 and 2. (19953268)

Asia/Pacific

 China: *Blastocystis* cells implanted into the abdominal cavity of immunocompetent mice were still viable six months later, suggesting that the organism can survive in immunocompetent animals for a long period of time. (20306208)

 Taiwan: Patients in a long-term care facility who tested positive for *Blastocystis* were three times more likely to require an in-place tracheotomy than those who were *Blastocystis* negative. (19488784)

 Malaysia: *Blastocystis* sp. subtype 3 is the most frequently found type of *Blastocystis* in cancer and AIDS patients. (19603182)

 Malaysia: The soluble portion of *Blastocystis*' antigens promotes the growth of cancer cells and shuts off expression of many genes in humans cells that produce immunological factors. (20165878)

 Malaysia: Humans naturally infected, and rats experimentally infected with *Blastocystis* exhibit high levels of oxidative stress, as determined by urinary hydrogen peroxide and lipid hydroperoxide concentration. (19961647)

 Malaysia: Rats experimentally infected with *Blastocystis* exhibited high levels of hyaluronidase activity, which has previously been identified as a factor associated with invasive infection in E. histolytica. (20358228)

 Singapore: Cyclosporine A and iodoacetamide both inhibit apoptosis in *Blastocystis* cells exposed to cytotoxic monoclonal antibodies. (20056704)

 Singapore: The target of a mouse monoclonal antibody that is cytotoxic to *Blastocystis* was found to be a legumain present on the surface of *Blastocystis*. The mAB produces programmed cell death in *Blastocystis* cells.(19915007)

 Australia: *Blastocystis* genotyping from zookeepers and their animals suggests zookeepers are being infected by their animals. Stool samples from zookeepers from 4 zoos were examined by PCR. All zookeepers who were positive for *Blastocystis* reported gastrointestinal symptoms, even though *Blastocystis* was the only organism found in their stool samples. (20089360)

 Indonesia: A study found that 96% of immunocompromised children with diarrhea carried *Blastocystis*. (20539063)

Middle East

 Pakistan: Stool samples from 171 diarrhea-predominant IBD patients and 159 healthy controls were exampled for *Blastocystis* and Dientamoeba fragilis direct microscopy, stool culture, and PCR analysis. *Blastocystis* and D. fragilis were found in 53% (90/171) of IBS-d patients, compared to 16% (25/159) of the controls. D. fragilis was found in 4% (7/171) of IBS-d patients compared to 1.3% (2/159) of controls. (20532564)

 Egypt: Researchers genotyped *Blastocystis* from humans, their pets, and their water sources. *Blastocystis* was found in most pets owned by *Blastocystis*-positive humans. *Blastocystis* was also found in tap water at some homes. (20544220)

 Egypt: Researchers identified the minimum quantity of *Blastocystis* cysts needed to reliably orally infect albino mice as 40 million cysts. Two weeks after infection, the mice were examined. Vacuolar *Blastocystis* cells infiltrated the lamina propria, submucosa, and muscle layers of the gastrointestinal tract, producing severe inflammation.

 Egypt, France, United States: *Blastocystis* isolates from symptomatic Egyptian patients

belong mainly to subtypes 3, 1 and 2. (19953268)

Pakistan: Researchers genotyped *Blastocystis* from 158 patients with IBS, and *Blastocystis* from 157 patients without gastrointestinal symptoms. (20177906)

Europe

Germany: A returning German tourist with chronic skin rash and IBS underwent extensive testing and *Blastocystis* was the only infection found. Two anti-protozoal treatments produced temporary remission in symptoms, followed by relapse, and positive *Blastocystis* results. A combined anti-protozoal treatment eliminated both the infection and *Blastocystis*. (20363362)

Turkey: Researchers genotyped *Blastocystis* isolates from 32 symptomatic patients and 12 asymptomatic individuals. (19685075)

Greece: Researchers genotyped and examined *Blastocystis* from 51 symptomatic and asymptomatic individuals to understand the relationship between morphological forms of *Blastocystis* and symptomatic status (20093234)

Denmark: In a study of 92 *Blastocystis*-positive patients, symptoms reported include skin rashes, fever, joint pain, and bloody stools. Patients with *Blastocystis-Dientmoeba. fragilis* co-infections were no more likely to have symptoms than those with 'pure' *Blastocystis* infections. *Blastocystis* was strongly correlated with animal contact. Also, 69% of patients taking metronidazole reported continuation of symptoms, and all were still positive for *Blastocystis* on follow-up. (19393117)

Denmark, UK, Australia: Researchers suggest that none of the treatments being used for *Blastocystis* reliably eradicate the infection in a review for the *Journal of Clinical Gastroenterology*. (19834337)

Spain: Symptomatic *Blastocystis* patients in Valencia are infected primarily with *Blastocystis* sp. subtype 4. (19471964)

Philippines: In mice infected with *Blastocystis*, IgM antibodies form the initial serological immune reaction, while IgA antibodies form the dominant reaction in intestinal secretion. Serum antibodies detect *Blastocystis* proteins of weight 28.2 kDa to 77.6 kDa, while secretory antibodies detect proteins of weight 15.1 to 117.5 kDa. Serum antibodies primarily detect two antigens of weight 39.8 and 77.6 kDa, while secretory antibodies detect antigens of weight 55.0 and 56.2kDa.(19597843)

North America

United States: The Center for Disease Control declined a request from BRF to recommend that patients be informed of *Blastocystis* infection status by their physicians. The CDC indicated they will take no action on *Blastocystis* because "experts disagree" as to whether it causes disease.

The NIH continues to reject all *Blastocystis* research proposals.

BRF began recruiting patients for the Gulf War Illness study.

United States: *Blastocystis* sp. subtypes 1,2,3,4 and 8 were found in individuals with long-term gastrointestinal illness associated with *Blastocystis* or of unknown cause in Oregon. (20127113)

Mexico: Ulcerative colitis patients who have infections with *Blastocystis* are more likely to experience relapsing illness. (20145404)

Use Google Maps to Plot Research Trends for *Blastocystis* – Flags labeled "P" show studies identifying *Blastocystis* as disease causing in otherwise healthy, immunocompetent humans. To use this tool yourself, go to our web site (http://WhenDidYouGetSick.org) and click on "Use Google Maps"

UK physicians narrowly avert…..

World War II Syndrome

The United States is nearing the half-billion dollar mark on spending for Gulf War Syndrome studies, with no discernable progress in site. Can these physicians from the United Kingdom teach their American counterparts a thing-or-two about medicine?

In the United Kingdom, hospitals treating World War II veterans were seeing some disturbing symptoms. Vets who were imprisoned as POW's in South-East Asia were developing an unexplained multi-symptom disease.

Fever. Respiratory problems. Skin rashes. Gastrointestinal complaints. And chronic obstructive pulmonary disease (COPD).

If this sounds familiar, it should be. Many US veterans who served in the Middle East experienced similar problems. Researchers coined the term "Gulf War Syndrome," called it a multi-symptom disease, immediately blamed toxins, and started raking in cash to prove their thesis.

What followed in the US was a $350 million, two-decades long government-funded boondoggle. Suddenly, anything could produce chronic diarrhea, fatigue, headaches, and other symptoms. Jet fuel. Vaccines. Pesticides. DEET, the active ingredient in the insect repellent OFF. Nerve gas from those Weapons of Mass Destruction Sadaam had, or didn't have as the case turned out. Pyridostigmine bromide, a drug that doctors have been giving to frail seniors with myasthenia gravis.

Almost twenty years later, none of the Gulf War veterans have been cured by this research. And not one researcher outside of the United States is echoing the accusations we're hearing about insect repellent. One member of the Veterans Administration's Committee on Gulf War Illness has admitted that that the veterans may die of old age before the cause is known.

But the UK doctors, lead by Dr. Geoffrey Gill, took a different approach. They didn't have millions in government funding, but they had a knowledge of infectious diseases seen overseas, and they didn't assume that the veterans had been properly tested. Using more reliable tests, they found that 10-20% of the UK POW's from the Far East were carrying *Strongyloides stercoralis* a parasitic gastrointestinal infection common in Southeast Asia.

Yes, these vets, now in their 70's and 80's had been walking around for 40 years with an infection they picked up half a world away. By treating them with the proper anti-parasitic drugs, physicians are able to cure the vets.

A Learning Experience

In some areas of Southeast Asia, almost 20% of the male population is infected with *Strongyloides stercoralis.* Not all people with the infection have symptoms, and the gastrointestinal symptoms can be vague. *Blastocystis* has *Strongyloides* beat. It's present in 50% of food handlers in Egypt, and produces skin rashes, joint pain, gastrointestinal symptoms, and neurological symptoms.

Have Gulf War Veterans been carefully tested for any of these infections? Probably not. Researchers are still trying to figure out reliable ways to test for these infections, and most of the leading labs are in the Middle East and Asia. Unfortunately, the investigators for Gulf War Illness have shown no interest in working with BRF or Middle East labs to look for routine causes of these symptoms in the patients under their care.

Dr. Geoffrey Gill lead the study that showed the "multi-symptom" disease in World War II veterans was caused by a common, undiagnosed infection.

Legislation

To help US researchers learn from the UK's experience, BRF has proposed the Patient Protection Act. This legislation would require that researchers receiving federal funding to investigate novel "syndromes" ensure that human subjects in their studies receive the same level of care they would get if they were being seen by a physician outside of the study. Researchers investigating symptoms acquired overseas would be required to review medical reports from overseas physicians to ensure those infections were excluded before looking for "novel" causes.

References

Gill GV, Welch E, Bailey JW, Bell DR, Beeching NJ. Chronic Strongyloides stercoralis infection in former British Far East prisoners of war. QJM. 2004 Dec;97(12):789-95.PMID: 15569810

Blastocystis Shuts Down Immune Processes in Human Cells

…and promotes growth of cancer cells.

Doctors treating patients with immunological problems often find *Blastocystis*. But is it the cause of illness? Or the result?

Researchers at the University of Malaysia may have answered the question in a paper published in the March 2010 issue of *Parasitology Research*. By exposing cultures of human cells to antigens produced by *Blastocystis*, the researchers determined that *Blastocystis* can shut off immunological responses in the host.

The researchers used peripheral mononuclear blood cells (PMBC's) and human cancer cells in their study. PMBC's play a role in orchestrating the body's immune response to both infectious diseases and cancer. The researchers found that when PMBC's were exposed to the *Blastocystis* antigen, the production of many of chemicals the body uses to coordinate immunological responses was reduced.

Production of interferon-gamma, interleukin 6 (IL-6), and IL-8 were reduced by a factor of 2, 2.5, and 3.6 respectively. Additionally, the expression of two genes which play a role in the body's defense against cancer were reduced. Expression of the tumor suppressor gene p53 was reduced by a factor of 1.3. Production of TNF-alpha was relatively unaffected.

In addition to down-regulating immunological factors, the *Blastocystis* antigen promoted the growth of cancer cells. The *Blastocystis* antigen was able to produce these effects at a concentration of just 1 microgram/milliliter. This would be equivalent to a dosage of about 70 milligrams in a 150 pound adult, making it nearly as potent as many immunosuppressant drugs.

This study examined the effect of the water soluble antigen present in *Blastocystis*, suggesting that the antigen may be able to circulate in the host's bloodstream, producing symptoms in parts of the body distant from the site of the *Blastocystis* infection.

Dr. Suresh Kumar, the head of the lab which performed the research, has been publishing papers on *Blastocystis* since the early 1990's, making Malaysia's *Blastocystis* lab one of the longest-running continuous efforts in *Blastocystis* research. The group has previously published papers on *Blastocystis* in cancer patients, but in those studies it was not clear whether *Blastocystis* was the result of the cancer or whether it might be contributing to it. This study suggests *Blastocystis* may speed the progression of cancer by shutting off host immunological functions.

Immunomodulatory properties of *Blastocystis* have been reported by researchers in Germany. Chinese researchers have suggested that *Blastocystis* suppresses CD4 cell production based on patient studies. This was the first study to partially refine an antigen and quantify its impact.

Parasitic organisms commonly exhibit immunosuppressive properties, which are believed to contribute to the survival of the organism by turning off host immune responses. A 2002 review, authored by research scientists at the US National Institutes of Allergies and Infectious Diseases identified over a dozen compounds produced by parasitic protozoa which turn off host immunological functions. Compounds that interfere with host immune responses have also been identified in *Giardia* and *E. histolytica*. Even larger parasitic organisms can get into the act: the tick that carries Lyme disease produces a compound in its saliva which "turns off" the ability of white blood cells to act on invading organisms.

Dr. Suresh G. Kumar, Professor of Medicine at University of Malaysia, heads one of the world's longest running *Blastocystis* research labs

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Chandramathi S, Suresh K, Kuppusamy UR. Solubilized antigen of *Blastocystis* hominis facilitates the growth of human colorectal cancer cells, HCT116. Parasitol Res. 2010 Mar;106(4):941-5. Epub 2010 Feb 18.PMID: 20165878\

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Kamda JD, Singer SM. Phosphoinositide 3-kinase-dependent inhibition of dendritic cell interleukin-12 production by Giardia lamblia. Infect Immun. 2009 Feb;77(2):685-93. Epub 2008 Dec 1.PMID: 19047410

Survival of the Richest: Fruitless Search for 'Other Cause' Bankrupts US Patients

If you or a family member has been diagnosed with *Blastocystis* infection, you already know this is not a typical disease.

What are the clues? Maybe the number of times your doctor re-ran tests. Or the muffled tone in which the diagnosis was given. Or the reluctance to give any firm diagnosis despite repeated testing.

Like many other gastrointestinal protozoal infections, *Blastocystis* will produce gastrointestinal illness, abdominal pain, and fatigue in healthy adults. Unlike other infections, the disease is permanent in over half of the patients unless treated.

In the United States, a National Institutes of Health Lab performed most of the early work to establish *Blastocystis* as pathogenic. The lab published over 20 studies from 1976 to 1993. But a small number of US physicians didn't want scientists sticking their nose into medicine. They opposed this work, and started a scientific knife fight that contributed to the shutdown of all *Blastocystis* study in the US in 1995. Since then the NIH hasn't approved any US study that hints of *Blastocystis* investigation.

Rallying Cry: "Other Cause"

The US physicians who shut down *Blastocystis* research in the mid-1990's insisted that some other cause could always be found in patients with the disease. Doctors who treated *Blastocystis* infection were lazy and irresponsible. The search for the "Other Cause" became a rallying cry for their movement.

The timing of the shutdown was poorly planned. In the early 1990's, the prevalence of *Blastocystis* in the US population was less than 3% in most studies. By 2000, stool samples from California and Oregon were testing positive over 20% of the time in one lab which serves patients in that region.

What happened? There are almost a dozen different species of *Blastocystis* found in humans today. The increase may have been caused by the introduction of a more persistent, and virulent, type of *Blastocystis*, possibly from Asia or South America.

Another possibility is that before the 1980's, doctors did not have reliable diagnostics for an infection that produces similar symptoms, *Entamoeba histolytica*. Patients with symptoms were treated with a barrage of potent anti-protozoals at the time, which have since been restricted by US officials. *Blastocystis* patients may have been getting the wrong diagnosis, but the right treatment.

Cashing in on an Epidemic

While *Blastocystis* has become a disaster for US families, it's a bonanza for groups offering exotic gastrointestinal tests, as doctors still search for the elusive "other cause." *Blastocystis* patients usually get stool tests, then an endoscopy/colonoscopy. And they may go on to get CT scans, multiple blood tests, a "Nuclear medicine heptobiliary function with HIDA scan", more stool tests, and more colonoscopies.

Blastocystis has become a problem in over a dozen countries now. Finding a patient with *Blastocystis* infection is about as unusual as finding a patient with malaria or *Strongyloides* infection in many parts of the world. Overseas researchers with limited budgets may be amused that anyone would spend $25,000 for just one patient to diagnose something this prevalent.

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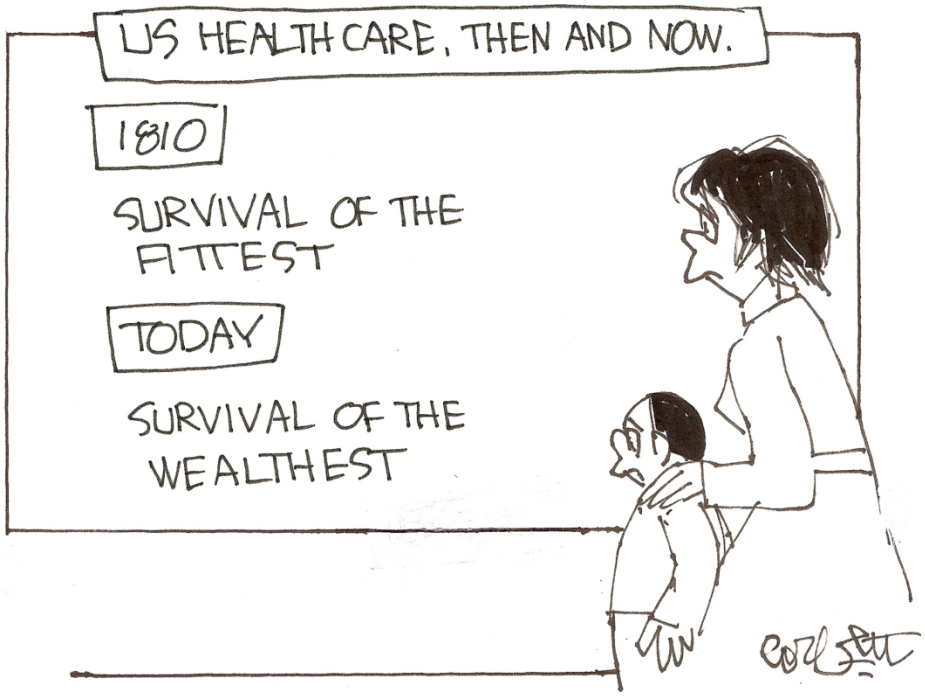
FACTOID

The cost of providing medical care for a Medicaid patient who has developed IBS is $5908/year, compared to $2191/year for a non-IBS patient, in North Carolina. (Martin, B, et al. Utilization patterns and net direct costs to Medicaid of IBS. Curr Med Res Opinion, 2003)



BRF's "SEND US YOUR BILLS" Project

Date of Service	Provider	Total Billed	Total Paid
2-May-08	Primary Care Physician	$137.00	$86.93
5-May-08	Lab1	$344.83	$83.00
5-May-08	Lab1	$513.50	$114.00
5-May-08	Lab1	$81.00	$20.00
8-May-08	Gastroenterologist	$170.00	$165.00
12-May-08	Lab1	$308.54	$132.23
14-May-08	Lab2	$1,011.00	$909.90
14-May-08	Other Specialist	$194.00	$194.00
19-May-08	Primary Care Physician	$137.00	$87.10
21-May-08	Lab1	$69.27	$8.00
22-May-08	Gastroenterologist	$118.00	$87.00
23-May-08	Primary Care Physician	$197.00	$121.73
23-May-08	Lab2	$1,042.00	$937.80
24-May-08	Other Specialist	$1,015.00	$1,015.00
27-May-08	Other Specialist	$420.00	$330.00
27-May-08	Gastroenterologist	$960.00	$709.20
27-May-08	Gastroenterologist	$325.00	$325.00
27-May-08	Endoscopy Center	$990.00	$603.90
28-May-08	Other Specialist	$437.00	$437.00
28-May-08	Lab2	$3,126.85	$2,814.17
29-May-08	Lab2	$392.00	$352.80
29-May-08	Other Specialist	$31.00	$31.00
30-May-08	Lab2	$276.00	$248.40
30-May-08	Primary Care Physician	$137.00	$87.10
30-May-08	Other Specialist	$110.00	$79.00
3-Jun-08	Lab2	$546.00	$491.40
3-Jun-08	Other Specialist	$79.00	$79.00
4-Jun-08	Gastroenterologist	$118.00	$0.00
10-Jun-08	Lab2	$1,192.00	$1,065.60
10-Jun-08	Lab1	$137.00	$96.23
12-Jun-08	Gastroenterologist	$118.00	$1.60
25-Jun-08	Primary Care Physician	$137.00	$87.10
3-Jul-08	Gastroenterologist	$118.00	$72.00
3-Jul-08	Primary Care Physician	$137.00	$87.10
9-Jul-08	Lab1	$137.00	$96.23
10-Jul-08	Gastroenterologist	$118.00	$72.00
23-Jul-08	Gastroenterologist	$118.00	$72.00
24-Jul-08	Primary Care Physician	$137.00	$87.10
25-Jul-08	Lab2	$247.00	$186.30
28-Jul-08	Gastroenterologist	$500.00	$400.00
28-Jul-08	Endoscopy Center	$990.00	$603.90
28-Jul-08	Gastroenterologist	$300.00	$269.20
28-Jul-08	Other Specialist	$255.00	$255.00
5-Aug-08	Gastroenterologist	$118.00	$72.00
19-Aug-08	Gastroenterologist	$118.00	$90.00
20-Aug-08	Primary Care Physician	$137.00	$87.10
26-Aug-08	Primary Care Physician	$220.00	$135.64
8-Sep-08	Lab1	$137.00	$96.23
8-Sep-08	Other Specialist	$131.00	$131.00
8-Sep-08	Lab2	$321.00	$288.90
9-Sep-08	Gastroenterologist	$118.00	$90.00
9-Sep-08	Other Pysician	$1,458.00	$552.53
10-Sep-08	Primary Care Physician	$137.00	$87.10
18-Sep-08	Lab2	$77.00	$69.30
1-Oct-08	Lab1	$137.00	$96.23
2-Oct-08	Gastroenterologist	$118.00	$90.00
6-Oct-08	Primary Care Physician	$93.00	$54.46
7-Oct-08	Lab1	$115.50	$33.00
	TOTALS:	$21,362	$15,974

$21,362 to diagnose the United States' most prevalent parasitic infection !!! Joanie from California developed chronic gastrointestinal illness and other symptoms overseas. Upon returning home to California, she tested positive for *Blastocystis*, but physicians billed her over $21,000, mostly to run tests to exclude the "other cause."

Testing Patients to Death

in Search of the "Other Cause"

1. Stool test. Showed no enteric campylobacter, no C. Difficile, no salmonella or shigella. ***Showed moderate Blastocystis hominis***.
2. Abdominal sonogram was normal.
3. Test for chagas. "Nonreactive"
4. Endoscopy rules out H pylori, metaplastic goblet cells, and fungal organisms. No pathologic findings. Showed some moderate chronic gastritis/antritis.
5. CT abdomen without and with contrast and CT pelvis with contrast. Showed "possibility of an infiltrating process, either neoplastic of inflammatory." "There is thickening of the gastric antrum and pyloric region, with a narrowing of the gastric lumen on all image sequences." Otherwise, nothing significant in the abdomen or pelvis.
6. XR-KUB. Nothing of interest.
7. Blood test. No Trypanosoma or other parasites observed. Did malaria smear and thick and thin blood smear.
8. Small bowel follow-through. "Nonspecific bowel gas pattern. Retained constrast in colon."
9. Nuclear medicine heptobiliary function with HIDA scan. Everything normal, gall bladder ejection fraction is 83%.
10. Stool test. ***Few Blastocystis hominis seen.*** *This is post-Flagyl.*
11. Stool test. No ova or parasites seen.
12. Stool test. Fecal WBC negative. No ova or parasites seen, pancreatic elastase normal
13. Colonoscopy showed mild chronic colitis, but no submucosal collagenous bands, fibrosis, or organisms.
14. Stool test. No ova or parasites seen.
15. ***Few Blastocystis hominis*** (concentration and trichrome)
16. No acid-fast bacilli, no enteric campylobacter isolated, no cryptosporidium oocysts seen, ***many Blastocystis hominis*** (concentration), few *Blastocystis* hominis (trichrome), no salmonella or shigella isolated.
17. Stool test. ***Many Blastocystis hominis***.
18. Stool test. ***Many Blastocystis hominis***.

Blastocystis? or Gulf War Syndrome?

Descriptions of illness from *Blastocystis* patients are remarkably similar to those reported by veterans with Gulf War Illness. Researchers still don't know what's making vets sick. With infection rates running at 25-50% in the Middle East, *Blastocystis* may be a good bet. Can you tell the difference? About half of the below descriptions are from *Blastocystis* patients posted to BRF's web site. The others are widely circulated descriptions from Gulf War Illness patients. Answers on page 13.

(1) Arthritis and abdominal pain: The combination of "arthritis" and abdominal pain is a nightmare when both are flaring at the same time. I used to be a very physically active 49 year old (regularly biking up and down alpine passes where we live), but this has been physically debilitating. I have been following a low carb, no wheat, high-protein diet for some time (though prone to lapses when I see a bag of tortilla crisps lying around!)….with lots of fresh vegetables and very little fruit (due to sugar).

(2) 6-year old with Splatter Poop: (My daughter) gets rashes for no reason. She is allergic to chocolate, meat- all meat even fish, broth anything, Penicillin, amoxil, zithromax, ceclor, augmentin and she used to be lactose intolerant. When she has too many milk products she has problems but we limit her. Her allergies were so bad that her school had a mold problem that affected her so badly that we are now home schooling her. Not what I had planned but when she was on clarinex, singular and they wanted her on allergy shots in order to breathe I couldn't let her stay there. We have to watch everything she eats, if she has stuffing that has turkey broth in it she will have such terrible stomach cramps and pains and diarrhea it is awful to watch**. She is 6 and calls it "splatter poop**. So, my child can't have chocolate chip cookies, a hot dog or any normal food. We have to get her "fake" corn dogs and chicken, all soy protein. It's expensive shopping for her.

(3) My husband became ill ..... he has spent the last 2 years in and out of hospitals, wracking up numerous medical bills, thinking we have diagnosed. [He's been] given medicine that makes him more ill, lots of side effects …. and we are still battling. ….This is .. for the purpose of helping Representative Schrader make a case to these organizations.

(4) I never believed ….. my daughter and Brian can't have red meat. I always ate meat, loved it. It never made me ill. I loved my BBQ ribs and steak. Now, only the slightest juice from meat dripped on my food leaves me sick for days. I began getting ovarian cysts that when some ruptured the first time I went the ER thinking my appendix burst. I get weird rashes and still have female problems. We desperately want another child…

(5) No Modesty: He no longer has normal functioning bowels. On bad days when he has numerous bouts he has to use a bucket in the back of his work truck to "bag" one because he can't make it to a bathroom. We've lost our modesty by now so excuse my harsh way of describing our situations! LOL

(6) Can't Walk: those symptoms got progressively worse to the point where I couldn't go for a 15 minute walk without feeling extremely fatigued and tired ...

(7) Fatigue: The single constant is debilitating fatigue, the symptom that irritates me more than all others put together because most people think it is the same as "tired". Debilitating fatigue means fatigue beyond consciousness and functionality. I have passed out from fatigue.

(8) Dog: I'd had that dog for 5 years with no medical problems. He started getting sick about a year after I did with bumps under his skin. At first he would just lie down and wimper. When I tried to pat him on the head he would recoil in pain. Then he got this kind of intermittent diarrhea like I had – like mustard. When I'd try to take him for a run, he'd stop in the middle because of the pain. The vet couldn't find anything the first few times, then they said there was some kind of thing growing inside his abdomen.. We finally had to put the poor thing down, and the kids wouldn't stop crying. The vets report is enclosed.

(9) Pets: I also had 3 dogs and 2 cats that are ill. We already lost one cat to a kidney infection that our veterinarian seemed very puzzled about because the cat wasn't that old and was very healthy. Both of the larger dogs have strange knots all over their bodies, different sizes and shapes. One dog (who recently died this past Easter am.) has had four surgeries removing these knots but they kept returning. They all have kidney infections at least once a month. They all have rectal bleeding at times. They all have severe arthritis and all but one are sensitive to loud noises and that's because she is completely deaf. They hide all the time as if they're scared. ….. All of them are very sensitive on the top of their heads like they're in severe pain. They all get diarrhea periodically and run fevers for no reason. Our pets didn't act or hurt like this before.

More Than Skin Deep:

In Infectious Diseases, Racial Heritage Makes a Difference.

Is US policy on *Blastocystis* based on a 20-year old study of *Blastocystis* in young, gay African-American men?

Your genetic heritage can determine how sick you get with many infectious diseases.

Let's make one thing clear. *Blastocystis* makes people in all countries sick. Researchers in Asia and the Middle East are doing most of the research work into *Blastocystis*. Severe cases show up in every culture.

But there is some evidence that suggests gastrointestinal protozoal infections like *Blastocystis* may be more severe more often in European Americans. In a 1956 study, researchers infected 42 prisoners in Mississippi with a variant of *E. histolytica* which was proven to be virulent in experimental animal infections [1]. None of the prisoners developed illness, although they tested positive for infection. While the study did not report the race of prisoners, today's prison population in Mississippi is more than 80% black and Hispanic. A similar study to infect prisoners with Giardia produced no symptomatic cases [2].

Malaria, Smallpox

Genetic immunity to protozoal diseases like malaria has been known for decades. Blood cells from all Europeans carry a series of chemical tags called Duffy blood group antigens. *Plasmodium vivax*, the organism that causes one type of malaria, uses Duffy antigens to invade host cells. West Africans lack these antigen, likely due to the process of natural selection over thousands of years.

But mutations to provide resistance to infections don't make an individual "fitter." Africans also carry the sickle-cell trait that makes it more likely for children to survive the severe stage of malaria infection, but produces the genetic disease sickle cell anemia. Researchers at the NIH's National Institute of Allergies and Infectious Diseases have also suggested the high rate of diabetes and high blood pressure in African Americans is related to mutations to survive malaria [3].

While protozoal diseases shaped Africans, cholera and smallpox were rearranging the European genome. Descendents of European Jews often carry genetic traits which reduce the severity of cholera infection. But if too many of those traits accumulate in one person, they produce the genetic disease Cystic Fibrosis [4]. Smallpox emerged in the African Rift valley over 10,000 years ago, and spread to Europe, where it caused devastation for centuries. In the 1700's, it was still a problem in Europe, but it nearly exterminated the Native American population, who hadn't experienced the generations of natural selection seen in Europe.

Blastocystis

When researchers began identifying *Blastocystis* as disease causing in the United States, the biggest complaint came from an HMO physician located in Oakland California, California's city with the highest African American population. Markell's earlier research showed gay men from his region who were infected with *Giardia* and *E. histolytica* were no more likely to have symptoms than those who were uninfected. Markell omitted information about the age or race of his subjects in his studies. Was he observing a genetic link?

Today, the NIH takes great care to make sure that studies consider the age and race of subjects, because different ages and races will respond differently to medications and infectious diseases. A researcher can't recruit white male college students to test a high-blood pressure drug that might be used in elderly black women.

But those safeguards did not exist in 1988. As such, US policy on our most prevalent infectious disease may be based on a 20-year old study of young gay African-American men. That study may have no relevance to what's going on in other populations.

References

1. Beaver, P et al. Experimental Entamoeba histolytica Infections in Man. Am. J. Trop. Med. Hyg., 5(6), 1956, pp. 1000-1009

2. Rendtorff, RC. The experimental transmission of human intestinal protozoan parasites. II. Giardia lamblia cysts given in capsules. Am J Hyg. 1954 Mar;59(2):209-20.

3. Miller, *Impact of malaria on genetic polymorphism and genetic diseases in Africans and African Americans*, Proc. Natl. Acad. Sci. USA 91 (1994).

4. Bijman J, De Jonge H, Wine J. Cystic fibrosis advantage. Nature. 1988 Dec 1;336(6198):430.

CORRESPONDENCE

Cleaning House

My 3 children and I have been struggling with *Blastocystis* infections for over 12 months and having tried various treatments and have had varying amounts of success. I am writing to you to try and find out some info regarding the amount of time *Blastocystis* can survive outside of a host, as I am trying to get rid of sites around my home that would be likely to be contaminated e.g., the chickens and their cage, the vegetable garden which has been fertilized with contaminated chicken manure. For the past twelve months we have carted water from town (we live on a farm). We are also trying to find a way of sterilizing our water. Can you please provide any info that might help me make informed decisions to rid our home of possible sites of re-infection?

- FARM-FAMILY in Australia

The treatments used for Blastocystis are unreliable, which gives the impression patients are being re-infected. That said, Blastocystis outbreaks are almost always associated with contaminated water or food, so it would be unlikely that clean, dry surfaces in your home are a problem. If you are drinking untreated well water, use a water filter that is NSF certified to remove Cryptosporidium.

Applause

I just wanted to applaud your efforts to bring this parasite out into the light. As a victim of *Blastocystis* for 2 years myself, I feel that so many people are suffering such a great deal; and it is really sad because their suffering goes unrecognized by the medical community due to the supposed 'controversial' nature of this pathogen….So I just wanted to thank you for all of your hard work, and I hope that an effective treatment for this infection can be found sooner than later. -Oregon

Thanks for the kind words!

.SwimVictim

I suspect I caught Blasto from swimming & kayaking in the Willamette River last summer. Last fall I had all of the classic symptoms of a parasite infection. I went through a round of unsuccessful doctor visits & tests. I then stumbled across parasite information on the internet and pursued a natural herbal treatment in December. This worked wonders for the first month following. Now, it's like all the crummy symptoms are back. Major bloating after eating, stomach pain, nerve/muscle spasms in my intestinal area, food intolerances to dairy, wheat & sugar.

-AP in Portland OR

Sorry to hear you've had a difficult time of things.

My Patient was Close to death

I am currently treating a woman with a possible 20 year history of *Blastocystis*. She reported she was close to death with it at one stage. She recently tried a course of Flagyl and has just tested 3+ for the *Blastocystis*. I am extremely interested in the work you are doing.

Many of the patients who write to us have been hospitalized, or rushed to the emergency room with unexplained symptoms.. How sick you get can depend on how old you are, and your genetics (none of which can be controlled by the patient).

Kaiser Still Does Not Like *Blastocystis*

After extensive efforts to obtain an accurate diagnosis of my chronic constipation, bloating, abdominal pain, skin rashes, fatigue, joint pain, and depression, I have finally been referred to an Infectious Disease specialist within Kaiser, Dr. ------, MD, who apparently believes that *Blastocystis* is not a pathogen. When pressed, she concedes that only in rare cases does it cause gastro problems, and then it ONLY causes diarrhea. She said she performed an extensive literature search and showed me four articles, one from Saudi Arabia, and another one from Romania. Can you give me any information to help me get treated, or to get referred outside of Kaiser? - California

Quoting directly from p. 76 of a 1991 NIH review on Blastocystis by Dr. Charles Zierdt, "Diarrhea is not common and constipation is frequent." BRF's 2008 review, published in the open access journal BMC Parasites and Vectors, included a bar-chart showing the breakdown between diarrhea and constipation in Blastocystis patients reported from studies. A number of parasitic infections will produce constipation in patients, such as Entamoeba histolytica, Strongyloides stercoralis, and Dientamoeba fragilis.

It was the work of two Kaiser physicians that contributed to the shut down of Blastocystis research in the US in the mid-1990's. They diagnosed their Blastocystis patients with IBS. Kaiser may be trying to reduce their costs by telling patients they have IBS. This is one reason why we have petitioned Congress to pass a law requiring an open, public process be used to determine which organisms are identified as disease causing.

References:

Zierdt CH. Blastocystis hominis--past and future. Clin Microbiol Rev. 1991 Jan;4(1):61-79. Review.PMID: 2004348

Boorom KF, Smith H, Nimri L, Viscogliosi E, Spanakos G, Parkar U, Li LH, Zhou XN, Ok UZ, Leelayoova S, Jones MS. Oh my aching gut: irritable bowel syndrome, Blastocystis, and asymptomatic infection. Parasit Vectors. 2008 Oct 21;1(1):40.PMID: 18937874

Help for our Son

Our 27-year old son has been diagnosed with *Blastocystis*. He lives in Oregon and has had intestinal pain, joint pain and lethargy for several months. He has been treated with a course of Flagyl but his symptoms did not improve. He has seen five different doctors, two of whom are gastroenterologists, but has not been successfully treated. Either the doctors believe *Blastocystis* is asymptomatic or they are not aware of any treatment protocol. His symptoms seem to be getting worse. We don't know where to turn and so I'm e-mailing you to ask for two things: a referral to a physician in Oregon who is familiar with (and can treat) *Blastocystis* or, failing that, some literature explaining the treatment which we can hopefully convince a doctor to prescribe and monitor.

I wish people at the Center for Disease Control could understand the kind of damage they are doing by doing nothing. Your doctors should be getting more information from the CDC, such as this paper from the Journal of Clinical Gastroenterology, which I am forwarding to you

Blastocystis-Bankruptcy

I commend you for your efforts to have this condition be taken seriously, and would like to help in any way I can. I am not in a position to contribute financially (having had to file for bankruptcy 4 years ago in the wake of the devastation of this disease, and currently being unable to work), but if an interview can help, I am willing to do it.

– Berkeley, California

Sorry to hear you have had such a difficult time with this. We've gotten many e-mails from patients who lost their jobs after they got sick, as well as others who are on social security disability or partial disability from the military. Some physicians say Blastocystis is "not serious" but if you lose your job, that's serious.

* * * * * * * * * *

BRF News welcomes reader comments. To contact BRF, you can e-mail us at director@bhomcenter.org, or use the form on our web site at http://WhenDidYouGetSick.org

Answers to Gulf War or *Blastocystis* : Accounts 1,3,6,7 and 8 are *Blastocystis* patients. Accounts 2,4,5, and 9 are from Gulf War Syndrome patients and their families

* * * * * * * * * *

FACTOID

Doctors in Thailand were the first to report using stool culture for clinical diagnosis of *Blastocystis* infection. In 2003, they used the method to help test over three hundred soldiers in the Thai Royal Army following exposure to contaminated water. According to their study, about two-thirds of the cases would not have been detectable with the methods for diagnosing *Blastocystis* in the United States.

Legislative Communication

For much of the 20th Century, the US led the world in identifying microbes that were causing diseases. This included the discovery of the bacteria that caused Lyme disease. The early work on *Blastocystis* was done by NIH scientist Charles Zierdt. Even when US scientists did not identify a microbe, US policy was often copied by countries around the world. *Cryptosporidium* was identified as important when over 250,000 people in Milwaukee were sickened when the city's water supply was contaminated. The "controversy" around *Giardia lamblia* being pathogenic was resolved when Congress passed the Clean Water Act which specifically required that *Giardia* and *Cryptosporidium* be removed from municipal water sources. Enterotoxic E. coli was known to medical researchers as a threat for over a decade before CDC scientists finally reported on the outbreak that brought the bug to world attention.

But in the last 15 years, the US has given up this role. Since 2005, five Nobel Prizes were awarded to researchers for identifying pathogens that cause stomach ulcers, AIDS, and cervical cancer. None went to US scientists.

The next page shows BRF's communication to the CDC, and the CDC's response to Representative Kurt Schrader. The original questions were not about *Blastocystis*. We were asking process-related questions which could apply to any pathogen, be it *Blastocystis*, HIV, or Mad Cow Disease. Does the CDC believe that it has a responsibility to identify pathogens? Has the CDC defined the process by which they will perform that task? How long should that process take? If the CDC fails to do this in a timely fashion, are officials held accountable? None of these questions were answered.

The CDC's response was so general, it could have been written by anyone who read the Wikipedia entry on *Blastocystis*. It's becoming apparent that the CDC doesn't know the answers to these questions which we asked.

BRF is proposing legislation that will clarify the issue for them. The **Patient Protection Act** will require the CDC to perform a yearly review of published medical literature on all common pathogens and suspected pathogens, and report the results in a standardized form similar to a Materials Data Safety Sheet which can be used by physicians, Congress, and other policymakers in the United States. The CDC will be required to use the most recently published studies in this review which will prevent the agency from being pressured to "cherry pick" specific studies for political reasons.

Many agencies in the Federal Government have to make unpopular decisions. Removing lead from gasoline and house paint; identifying contaminants in Chinese drywall; reporting data that showed asbestos was causing lung cancer; identifying cigarettes as carcinogenic are just a few examples of scientific decisions that have broad consequences. If it is possible for Federal agencies to make decisions about chemicals that harm human health, we believe it should also be possible to make timely decisions about infectious diseases as well.

From: *Blastocystis* Research Foundation [mailto:director@bhomcenter.org]
Sent: Sunday, September 27, 2009 2:00 PM
To: Christensen, Meagan
Subject: Meagan - Could you help us with the CDC and NIH?

Dear Ms. Christensen,

I wanted to thank you for your help earlier in the year and ask if Representative Schrader's staff may be able to help in an additional area. …Our request, or possibly the legal question we are asking is, "What responsibility do the CDC and NIH have for completing a timely investigation into an infectious disease, and subsequently developing a policy to control it and make sure patients have reliable treatments?" …..
The legislative questions would be as follows:

1. Do these organizations have a responsibility to make a timely decision as to whether an organism will cause symptoms in otherwise healthy (immunocompetent) patients?

2. Are public officials accountable if they fail to make a timely decision? That is, can they simply keep saying, "We can not make a decision, so we are not going to do anything."

3. Is there a court patients can use to get a hearing? If these agencies refuse to support research themselves, can studies from international agencies like Pasteur Institute, China's Center for Disease Control, and national universities in Malaysia and Singapore be used as evidence to overturn a policy of inaction?

4. In toxicological studies, showing a chemical causes disease in animals is sufficient. *Blastocystis* has been shown to cause disease in animal experimentation since 1997, and reports in the last several years show it will kill laboratory animals, even if some humans can carry it asymptomatically (this is true in many infectious diseases - nothing makes everybody sick). Is this sufficient to cause an organism to be designated as a pathogen?

5. If the Federal Government has made a mistake and allowed a large number of people to be infected with a chronic disease, what responsibility does it have to redress this? Is there a watchdog agency for these groups? That is, if they have refused to provide any funding for 15 consecutive years, do they have a responsibility to develop an "emergency program" to recruit researchers and develop a treatment?

In testimony in 2007, a state of Oregon DHS employee indicated there were over a million cases of *Blastocystis* in Oregon. Given the numbers we are seeing in studies, about half of these people will have chronic gastrointestinal illness, and about a third will have severe symptoms which may put them in surgery or on disability.

In the case of *Blastocystis*, the NIH and CDC appear to have latched onto a small number of studies done by a doctor at a health maintenance organization in Oakland, California in the 1990's. These were used by officials to, in my opinion, evade their professional responsibility. When my family got sick in 2003, 8 years had lapsed since the last NIH funded work, which ended in 1995. That should have been an adequate amount of time to do the studies that are now being done in the Middle East and Asia which show *Blastocystis* is virulent enough to kill laboratory animals.

In general, the request of my family, and those of other families, is that the CDC and NIH take positive action to identify drugs that will treat these diseases, and make sure those are available to patients.

Thank you for your attention.

Best Regards,

Ken Boorom
Corvallis, Oregon

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

NOV 25 2009

The Honorable Kurt Schrader
House of Representatives
Washington, D.C. 20515

Dear Mr. Schrader:

I am responding to your letter to Ms. Barbara Clark, Acting Assistant Secretary for Legislation of the Department of Health and Human Services, on behalf of your constituent, Mr. Kenneth Boorom, regarding *Blastocystis hominis* infection. Ms. Clark has asked me to respond directly to you. Please excuse the delay of this response.

Mr. Boorom, who represents the Blastocystis Research Foundation, previously raised his concerns regarding *Blastocystis hominis* infection with the former and acting directors of the National Center for Zoonotic, Vector-Borne, and Enteric Diseases at the Centers for Disease Control and Prevention (CDC).

CDC recognizes that *B. hominis* is a common microscopic organism, now believed to represent an unusual fungal form, found throughout the world. However, experts disagree on whether *B. hominis* is a pathogen, and as such, the primary cause of symptoms, because it is often found with other parasitic organisms, bacteria, or viruses. Drugs are available by prescription to treat *B. hominis* infection, although medication is not always effective in relieving symptoms.

We will continue to follow with great interest the growing body of peer-reviewed literature on both the pathogenicity and treatment options for this organism. Our advice to public health laboratories and physicians will continue to evolve as more data and information is available from published studies that can help guide our messages.

We appreciate your interest in this important public health matter and hope this information is helpful in responding to Mr. Boorom.

Sincerely,

Thomas R. Frieden, M.D., M.P.H.
Director, CDC, and
Administrator, Agency for Toxic
Substances and Disease Registry

BRF's Longest Running Case – 23 years and counting

In 2009, BRF co-authored the first paper that identified *Blastocystis* infection as a cause of long-term "Gulf War Illness" in a Gulf War Veteran (Jones, et. al. *Association of Blastocystis subtypes 3 and 1 with chronic gastrointestinal illness in an Oregon Community*, Parasitology Research, 2009 Jan;104(2):341-5). Our vet had been sick since 1991, for a total of 18 years.

But Ben has this record beat. He got sick in 1987 while visiting a Kibbutz in Israel. Twenty-three years and many treatments later, he still tests positive, and has had to deal with multiple health problems for most of his life. Remarkably, he still has his test results from 1989 which showed the infection.