Is Patient Advocacy Making Us Sick?
BRF Publishes Blastocystis Collections

BRF cross-references hundreds of Pubmed-indexed Blastocystis studies to help researchers and public health officials determine what research has already been performed.

One of BRF’s most frequent requests from researchers is a list of studies already performed in a particular area, such as culturing Blastocystis, or human immune response to the infection.

And to BRF, one of the most frustrating things is to hear a public official claim there is no information about a specific aspect of Blastocystis, even when there are a dozen studies already published about that topic.

To address both issues, BRF has cross-referenced all Pubmed-indexed studies (about 850) by study category, and posted the results online at BRF’s web site. The collections index directly into the NIH’s Pubmed database. Users can click on any topic and be taken to Pubmed’s search page, pre-loaded with a list of studies on that topic.

Unlike bibliographies, the lists are comprehensive – they include all the applicable studies indexed on the NIH’s Pubmed server at a point in time.

BRF’s Collections Page is designed to help researchers in different areas build on each other’s work. That’s especially valuable in Blastocystis infection, because research is being conducted in at least in 14 different countries today.

Fact or Fiction?

Here are a few ways BRF’s Blastocystis Collections can be used to verify claims that suggest no information is available about the disease:

“This study showed no correlation between infection and symptoms, so Blastocystis must be harmless” Enteric protozoal infections are often (but not always) asymptomatic in young children. We include a dozen studies from the US showing absolutely no correlation between symptoms and infection with Giardia, along with papers from CDC and NIH experts urging that Giardia not be treated based on a lack of correlation between patients (usually children) and symptoms.

“We can’t do anything because nobody knows how Blastocystis infection is transmitted” All 13 studies which investigated transmission concluded that the infection is transmitted through the fecal-oral route by consumption of food and water contaminated by Blastocystis cysts in fecal material.

“Blastocystis has never been shown to cause illness in an animal study” Ten (10) studies from four (4) countries report that animals get sick with the same symptoms seen in humans when experimentally infected. Blastocystis infection killed mice in two studies.

“The drug metronidazole will cure all Blastocystis infections.” All three recent in vitro studies have shown a high degree of metronidazole resistance in Blastocystis. Clinical studies also report resistance.

“It is impossible to tell if symptoms in a Blastocystis patient are due to Blastocystis or to a viral or bacterial disease” Sixteen studies described laboratory methods used to exclude other causes.

“Blastocystis comes and goes from stool samples, proving it is not a source of illness” All of the 15 studies investigating methods used in clinical labs for Blastocystis detection found them to be unreliable.

To view BRF’s Blastocystis Collections Page, goto http://www.bhomcenter.org/ and click on Collections under Resources for Researchers.

Doctors prescribe medicine of which they know little, to cure diseases of which they know less, in human beings of which they know nothing - Voltaire
Evidence-based Decision Making: Bringing emotions into decisions about infectious diseases produces outcomes that aren’t the best for anyone, and may even make the problem worse. BRF is proposing legislation to require federal infectious disease decisions based on facts like the number of people who are sick, whether the treatments are working.

Nothing New Under the Sun: The current epidemic of Blastocystis is similar to what happened with Entamoeba histolytica infection in the United States from the 1900’s to the 1970’s. Yes, finding Blastocystis at 10-20% in specific geographic areas counts as an epidemic. We dig up studies to see what we should expect, and what to do about it.

Blastocystis and Pregnancy: The spike in US Blastocystis rates comes at a bad time for women in their 30’s who wanted to have a family. Some patients are so sick, they can’t imagine carrying a child to term. Others have had repeated miscarriages. With their biological clocks ticking, will the NIH and CDC make up their minds about Blastocystis in time?

Single Nucleotide Polymorphisms in Infectious Disease Susceptibility: Small changes to your DNA can make a huge difference in the symptoms seen in infectious diseases. But sometimes the changes that reduce the severity of symptoms cause other diseases, like cystic fibrosis. We look at research the University of Texas is doing to explain why some people get sicker than others with infectious diseases.

Nice Microbes Finish Last: The same properties that make protozoal diseases prevalent and long lasting also may cause them to produce symptoms in patients. Nice protozoa get chewed by their hosts, while robust protozoa shut down host immune functions.

Can Tea Party Republicans Fix the NIH? Is it a good idea to manage all US infectious disease spending from Bethesda, Maryland? Is the NIH ignoring diseases that are dominant on the West Coast, while favoring East Coast diseases like Lyme Disease? This year, President Obama handed the NIH $10 billion in extra Recovery Act funding. Much of that funding appears to have missed real-world diseases, going instead to shiny toys. The NIH handed out almost $100 million to its favorite researchers to pay off their student loans. BRF puts out some ideas for refocusing the NIH back on patients, like sending some of the NIH’s grant money back to states, and letting state-run science boards decide where to spend it.

(1) To get a list of studies on a particular topic, go to BRF’s Web site at http://www.bhomcenter.org, find the collections under “Resources for Researchers” and click on the appropriate topic, such as “How is Blastocystis transmitted?”

(2) You will be taken directly to the NIH’s Pubmed server which will provide a list of relevant studies
UC San Francisco Team Identifies Source of Neurological Symptoms in Patients with Chronic GI Disease

A trypsin-like protease makes patients look crazy and leaves no evidence in blood tests

Hands turning blue. Muscles twitching. Widespread pain. Skin burning. A feeling like somebody is running an electric current through your head. An inability to stand or walk for more than a few minutes. “Mind fog”.

Both Blastocystis and irritable bowel syndrome (IBS) patients report a host of neurological symptoms. But blood tests fail to show any abnormalities commonly associated with infectious diseases, like an elevated white blood cell count. So some researchers have concluded that the patients are mentally disturbed.

But this is problematic, as between 10 and 20% of the population in many developed countries now report these symptoms. Additionally, a study found that a third of returning Mormon missionaries had acquired ‘IBS’ while travelling abroad. Is insanity contagious?

Science to the Rescue

Researchers working independently in both North America and France may have found the missing piece to the puzzle, which links all of these symptoms together. Over the last two years, the results from their studies have been published in a group of leading medical journals, including Clinical Gastroenterology and Hepatology (May 2007), the Journal of Clinical Investigation (March 2007), and the American Journal of Gastroenterology.

The scientists investigated a phenomenon known as “widespread pain syndrome” in which patients report generalized pain and “alldynia,” the perception of harmless sensor stimuli as painful.

The experiment was deceptively simple. The researchers obtained biopsies from the intestines of IBS patients and introduced them into mice, and then showed the mice experienced widespread pain and hypersensitivity, while mice exposed to biopsies from healthy patients did not. This experiment flies in the face of what most US experts have been writing about IBS, mainly that the diarrhea and illness is due to bad parenting and unresolved emotional conflicts.

The teams performed additional work to isolate a specific chemical – a serine protease similar to trypsin – as the culprit. All biopsies from IBS patient produced high levels of this compound. Additional study in a culture dish using nerve cells isolated from mice showed that the protease levels in IBS patients would cause those nerves to fire, while the levels produced from colonic biopsies of healthy adults did not produce the high levels of protease.

Not Viral, Not Bacterial

Researchers have suggested that viral and bacterial infections may underlie IBS, but the an examination of stool samples from patients with viral and bacterial enteritis, and found that these individuals did not contain high levels of the protease. The protease is unique to IBS and inflammatory bowel disease (IBD) patients.

The protease triggers receptors on human cells known as “Protease Activated 2” or PAR2 receptors, which are present in humans and mice. The research team showed that knockout mice which are genetically engineered to lack PAR2 did not show symptoms when exposed to the IBS biopsies. PAR2 receptors are widespread throughout the body, and control functions as varied as gastrointestinal contractions, pain, immune responses, learning, and the constriction of blood vessels. In fact, the group of bodily functions previously reported to be associated with PAR2 receptors is a remarkable match to the symptoms reported by patients with IBS and Blastocystis infection.

Trypsin produces neurological effects at very low concentrations. About 50 mg (1/20th of a gram) of trypsin would be sufficient to cause physiological symptoms in a human, based on research done in mice.

BRF investigated potential sources for trypsin production in Blastocystis patients in a recently published paper (page 7).

PAR2 receptors are a member of a larger family of receptors known as G-protein coupled receptors. About 30% of modern drugs are based on triggering or inhibiting these receptors. As such, symptoms reported by Blastocystis and IBS patients may appear more like side effects of drug use, rather than those commonly associated with infections. At this time, there is no widely available diagnostic that can assess trypsin levels, but the researchers have suggested that such a test would be of value in diagnosing patients.

References


The researchers enrolled a total of 330 patients in the study, with 171 IBS patients and 159 healthy controls. Stool samples were obtained from all patients and a combination of stool culture and DNA extraction was used to analyze the samples. Researchers found that 53% of IBS patients were positive for Blastocystis infection, compared to 16% of the healthy controls, a statistically significant result (p=0.001). Additionally, more IBS patients than healthy controls were positive for Dientamoeba fragilis (0.6% vs. 3.5%), but that result did not reach statistical significance (p=0.123).

The study also compared several methods for identifying the infection, mainly direct microscopy, culture, and polymerase chain reaction (PCR) testing. Direct microscopy involves looking for the organism in a stool sample with a microscope, and is the only method commonly used in clinical laboratories worldwide at this time. The culture technique involves placing the stool sample in a vial with a growth medium for several days, and then examining the result with a microscope. PCR involves using a series of chemical methods to extract DNA directly from the stool sample, and then searching for DNA sequences associated with the organisms using detection methods similar to those used by police at crime scenes to analyze DNA. The culture technique was found to be more sensitive than either the PCR technique or direct microscopy. A number of other studies have previously reported that direct microscopy will identify only about a third of samples that are positive by stool culture. In this study, the researchers had considerably better success, and were able to identify 83 samples as Blastocystis-positive with direct microscopy, compared to 90 with stool culture. They were able to identify 6 samples as Dientamoeba fragilis-positive with direct microscopy, compared to 7 with stool culture. The findings from this study are similar to those reported in an earlier 2004 study published in the American Journal of Medicine and Tropical Hygiene by some of the same researchers.

IBS is the seventh most common diagnosis made by physicians in the United States, and the annual US costs of the disease in the US have been estimated at over US $30 billion, mostly due to lower productivity and lost work days. IBS patients experience abdominal pain, diarrhea, nausea, vomiting, bloody stools, and other symptoms. Symptoms are permanent in most patients. In surveys, between 5% and 20% of various populations in developed countries are found to have IBS. About 30% of returning international travelers experience the illness.

The dominant focus of US research has been on the idea of “conversion”, namely that such patients are mentally disturbed. Many researchers outside of the US report the patients have infectious diseases that would not be detected by US labs. Researchers in the Middle East, Asia and Europe have noted that the group of symptoms is identical to those experienced by patients with intestinal protozoal infections, and have suggested that the disease may be largely due to the presence of such an infection in developed countries.

This would suggest that “IBS” can be addressed the way earlier infectious diseases have been addressed, through antimicrobial therapy, better sanitation, and possibly vaccination.

References
Yakoob J, et al. (2010) Blastocystis hominis and Dientamoeba fragilis in patients fulfilling irritable bowel syndrome criteria. Parasitol Res. 8.0(8):293-1038
In BRF’s first PLOS-one paper, we showed that patients in Turkey, like those in the United States, have been sick for a long time with Blastocystis, and methods in use in clinics in the US and Europe will not detect the infection.

This November, the peer reviewed scientific journal, PLOS-one published one of the largest studies to investigate Blastocystis infection in patients diagnosed with irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD). The study, co-authored by BRF, compared different methods of identifying Blastocystis infection in patients, and also investigated the possibility that the neurologically active “trypsin” identified by UC/San Francisco researchers is being produced by Blastocystis cells.

The first part of the study analyzed stool samples from 105 IBS and IBD patients using different detection techniques, such as stool culture (growing the organism), examination under a microscope with a conventional stain, and the use of a newer commercially available immunofluorescence staining product, Blastocystis WorldFluor.

Researchers have described more sensitive methods for detecting Blastocystis for years, but so far none have been adopted widely by clinical laboratories. Most of the methods won’t work with the formaldehyde preservative from the stool collection vials that are commonly used in the US and Europe.

With stool culture used as a gold standard, the study showed that trichrome staining, the method used in the US, had a sensitivity of 50%. The IFA stain came in at 86%. Using all methods combined, the study showed that 76% (16/21) of the IBS patients were infected with Blastocystis. If trichrome staining had been used for detection, the infection would have only been detected in 29% (6/21) of the patients.

The study also collected demographic data, and reported that patients had been sick an average of 4.9 years, which contradicts the suggestion that Blastocystis infection is only associated with short-term illness. Most of the patients in the study were 40 or older, raising the possibility that Blastocystis infection may be more likely to be symptomatic in middle-aged patients, although a number of patients were in their 20’s.

How does Blastocystis cause disease?

An additional objective of the study was to understand how Blastocystis is distributed in the large intestine, and whether it might be producing the neurologically active trypsin previously found in IBS patients. To do this, researchers obtained biopsies from IBS and IBD patients, and the biopsies were tested for Blastocystis along with the stool samples.

Using the stool and colonic biopsies, the study showed that Blastocystis could be consistently found in IBS patients, but that few of the patients had large quantities of the organism in their intestine or stool samples. In fact, most of the biopsies from stool-positive patients were negative. As such, Blastocystis is not “overgrowing” in those patients. Instead, it is exerting an influence at relatively low concentrations, at least after the patients has undergone the colon cleansing process for the biopsy procedure.

A ‘miserable minority’ of Blastocystis patients report neurological symptoms which produce abundant guffawing and eye rolling by disbelieving physicians.

Because we did not find Blastocystis consistently in the stool samples, the study concluded that it is unlikely that Blastocystis is producing the trypsin directly. An alternate possibility was suggested based on existing literature, namely that Blastocystis produces a compound that interferes with immune cell communication, down-regulating production of IgA and leaving enteric cells unprotected against certain kinds of enteric flora. The cells may then switch on a more primitive type of immune response in which trypsin is produced.

The study was co-authored by researchers from Gazi School of Medicine (GSM), who performed the clinical laboratory work, and from Yildirim Beyazit Education and Research Hospital, where the biopsies were performed. This is the second paper BRF has co-authored with researchers from GSM’s lab.

References

Reader Feedback: Can Experimental Human Infection be Used to End the Disagreement About Blastocystis?

I am a Christian, so I would never do it myself, but after reading the article [by Dr. Markell], I almost wish that someone would do to those doctors what Erin Brokovich did to those company executives in her movie.

-FED UP in California

Dear FED UP,

You are of course, referring to the scene where Erin Brokovich serves executives water drawn from the wells of families who have gotten sick from hexavalent chromium, which they insist is harmless.

Dr. Markell, a physician who worked at a health maintenance organization (HMO) in Oakland in the 1980’s, published two studies that suggested Blastocystis was harmless. His work developed a following at the US Center for Disease Control, which continues to list all the Markell on their information sheet since the early 1990’s, and included no studies from scientists who contradict Markell’s findings. The question of whether specific organisms cause illness has been contentious on a number of occasions. Here are five cases where people have infected themselves or others to find the answers.

#1 CHOLERA: On October 7, 1892 German biologist Max von Pettenkofer publicly drank a culture of Vibrio cholerae, the bacterium that causes cholera, to support his belief that cholera was due to "many causes", and the bacteria alone could not cause the disease. He got slightly ill, but did not develop cholera, so he considered his point to be proven. Over 100 years later, researchers learned that some people have a genetic trait which controls chlorine ion flow, and makes them immune to the chemical produced by Vibrio cholerae that causes diarrhea. That trait was discovered by the current director of the NIH, Dr. Francis Collins.

#2 STOMACH ULCERS: Contrary to popular belief, most stomach ulcers are not caused by stress but by an infection with a bacterium called Helicobacter pylori, which can be cured in a few weeks with antibiotics, but will cause lifelong misery if left untreated. Dr. Barry Marshall shared the Nobel Prize in 2005 for this discovery. To convince researchers that H. pylori really caused ulcers, he infected himself with H. pylori and had one of his fellow gastroenterologists at the Royal Perth Hospital in Australia perform an endoscopy before and after infection to demonstrate the results.

#3 THE NORWALK VIRUS: In the 1970’s, when nobody could figure out what was causing “winter vomiting disease” (WVS), NIH scientists stepped in and filtered stool samples from sick people through a fine sieve to exclude all bacteria. Volunteers who swallowed the result developed illness, showing a virus was responsible for WVS, and not some kind of novel geophysical phenomenon. Ah, the good old days. Today, IRB boards would block such a study. College professors would tap into an endless supply of grant money to argue the disease was caused by their favorite research topic.

#4 GIARDIA: Giardia is a gastrointestinal protozoan discovered in 1681, but not fully accepted as a cause of diarrhea until the 1980’s. Robert Rendtroff infected 40 volunteer prisoners with Giardia in 1957. All of them cleared the infection and none developed illness. He got similar results in an experiment with the potentially deadly parasite Entamoeba histolytica. Why? We can’t be sure, but many years later, researchers found that prior exposure to these organisms can make people immune. The prisoners, who come from a disadvantaged background, may already been exposed.

References
For references, see our online version at http://www.bhomcenter.org

Three researchers who infected themselves or others to prove a point. Left to right, Max von Pettenkofer infected himself and students with V. Cholerae, Barry Marshall infected himself with H. pylori, and Herbert Dupont infected NIH volunteers with the Norwalk virus to determine an epidemic was caused by a virus, not a syndrome.
Reader Feedback: My doctor said there are millions of different microbes in the human body, and it doesn’t make sense to treat Blastocystis

I’ve been sick for about 4 months since I returned from a trip to India. I’ve had four stool tests, and the only thing they found was Blastocystis, but my doctor won’t treat it. He said there are millions of different kinds of microbes in the gut, and you can’t worry about all of them.

-CONFUSED in California

Dear CONFUSED,

There are also lots of microbes in the world, but the list of ones that cause disease in humans is thankfully short. A paper from the head of the US National Institute for Infectious and Allergic Diseases puts the number at around 200. If you find one of these in a patient with symptoms of the infection, history has shown that eradicating the organism will eliminate the symptoms.

Six is much less than millions. Although hospitals have been treating Blastocystis patients since the 1980’s, a number of individuals (mostly those who have been telling people not to treat Blastocystis) have suggested the sky will fall, the earth will implode if we add a sixth protozoan to the list.

We do, in fact, know these organism will cause disease by themselves because in all cases (except for D. fragilis), researchers in many different countries have infected animals with the organisms and shown they get sick. If you infect animals with other members of the “millions” of microbes, the don’t get sick.

-Ken

Blastocystis wasn’t a pathogen. He said I should try yoga.

-MISTREATED in California

Dear MISTREATED:

Our web site has a list of studies that show metronidazole won’t work for many infections, along with a limited number of studies looking at other options. I’d love to ask your doctor why he prescribed metronidazole in the first place if he thought Blastocystis was non-pathogenic.

Your physician has an intriguing approach to dealing with antimicrobial resistance. Perhaps we can diagnose patients with drug-resistant TB infection as having irritable lung syndrome (ILS). Trichomas vaginalis, a sexually transmitted protozoal infection has also developed resistance to metronidazole. Irritable Vagina Syndrome (IVS) anybody?

-Ken

When IBS Becomes a Diagnosis of Convenience

Dear BRF,

…my test was positive for many Blastocystis hominis. They treated me with a round of flagyl [metronidazole], and I was still sick. So I went back and my doctor said I had irritable bowel syndrome, and
BRF Turns 4

By Ken Boorom
Founder, BRF

What’s the first thing every patients needs to know about medical research in the United States today?

It’s not about curing diseases in patients. It’s about earning as much money as possible to pay the high salaries needed to attract quality professors to teach in the schools.

When I started BRF in April 2006, I greatly underestimated the difficulty of addressing this infection within the context of the country’s medical research system. US labs have remarkably little interest in a disease that causes permanent diarrhea, but otherwise isn’t a really good topic for NIH funding or new drug development.

And while I overestimated Washington DC’s responsiveness, I underestimated the extent of the problem, and also how well-qualified medical researchers are in other countries. The same problems we were having in Corvallis, Oregon were being seen and researched in a dozen countries around the world. It soon became obvious that the path to solving the problem lay in networking with existing Blastocystis research groups and developing ways to share skills and experience.

Besides coordinating research, BRF has provided a phone line, e-mail address, and physical office for four years. Patients with symptoms of Blastocystis infection are three times more likely to attempt suicide, and the hopelessness of having a disease that federal authorities won’t do anything about compounds that problem. Patients report that they derive reassurance from knowing someone is working on the problem, and that there may be a cure someday.

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BRF: The First Four Years by the Numbers

- Number of peer-reviewed NIH Pubmed-indexed medical papers co-authored by BRF: 8
- Number of times BRF co-authored review on Blastocystis in BMC Parasites+Vectors: 6383
- Number of countries represented by BRF co-authors: 10 (US, UK, France, Greece, Turkey, Egypt, Jordan, China, Thailand, Japan)
- Number of times other researchers have referenced BRF’s studies in their papers: 25
- Number of patients in examined in BRF’s published studies and studies in progress: >450
- Average cost to BRF (excluding volunteered time) to complete a study: $400
- Number of US studies on Blastocystis NIH has approved for funding since 1995: 0
- Number of times Congressional Representatives have contacted the NIH and CDC about Blastocystis: 3

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BRF Firsts

- First standardized subtyping of Blastocystis from patients in United States (and France and Egypt) Jan ‘09, Aug ’09, Jan ‘10
- First study to genotype Blastocystis from IBS patients Aug ’09
- First study to genotype Blastocystis from IBD patients Aug ‘09
- First study to identify Blastocystis infection in a “Gulf War Syndrome” patient Jan ‘09
- First study to identify PAR2 activation as likely cause for neurological symptoms in Blastocystis infection Oct ‘08
- First review of a commercially available assay for Blastocystis Nov’10
- First collaborative international review of Blastocystis literature Oct’08

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St. Vincent’s Hospital Researchers in Australia Report 94% Cure Rate by Treating D. fragilis Infection in Patients with Chronic Gastrointestinal Illness

Once we get a reliable treatment for Blastocystis infection, what percentage of patients will be cured by eradicating the microbe? Research into a similar infection suggests the number may approach 100%.

Here are the facts. Blastocystis now infects 10-20% of the population in some areas of affluent countries, and over 30% of the population in many developing countries. Most adults with the infection (>50%) will have symptoms that include abdominal pain, diarrhea, fatigue, nausea, and neurological symptoms. Infecting animals with Blastocystis taken from sick people will make the animals sick. And there is no treatment in common use today that eradicates the infection reliably.

As researchers start the task of identifying a treatment, the big question for patients is, “Will eradicating the microbe eliminate my symptoms?”

The answer to this question depends on who you ask. Researchers who make their living promoting their new ideas about chronic gastrointestinal illness downplay the role of infectious disease in such patients, and suggest that the illness is actually caused by everything from bad parenting to unresolved subconscious conflicts. These researchers suggest that Blastocystis infection is just a symptom of the disease, since some people don’t show symptoms when infected with Blastocystis.

On the other hand, scientists have noted that all infectious diseases have asymptomatic carriers. Despite that, when patients with the disease and symptoms are treated with a therapy that eradicates the infection, almost all of the patients recover with no symptoms. Such infections include gastrointestinal infections like Giardia lamblia and Entamoeba histolytica as well as diseases like chlamydia.

Researchers at St. Vincent’s Hospital in Sydney, Australia have reported that 93.4% (33/35) of their patients with gastrointestinal symptoms and Dientamoeba fragilis infection were cured of symptoms with antimicrobial therapy designed to eradicate the infection. All patients were immunocompetent.

To identify all Dientamoeba fragilis infections, researchers used PCR analysis of DNA extracted from stool samples. When all 33 cases are considered, researchers used six different drugs, primarily to address treatment failure with metronidazole. Most physicians are not aware of the need for second-line treatment in enteric protozoa.

BRF founder Ken Boorom commented, “It looks like Australia is way ahead of the United States in solving the problem of chronic gastrointestinal illness by doing what everyone knows should be done – updating diagnostic methods to properly diagnose patients. In the US, these patients are told they have IBS, and given inappropriate procedures like MRI’s and endoscopies/colonoscopies.”

The majority of infections (28/35) were treated with metronidazole, however in 21.4% of those cases, the organism was still found in patients by PCR analysis at the end of treatment. All patients (3/3) treated with iodoquinol reported cessation of symptoms, and PCR analysis showed the infection was cleared. Paromycin was used in five patients, all of whom reported cessation of symptoms and clearance. Combination therapy with nitazoxanide, paromycin, and/or doxycycline was used in other patients.

References


If you’re not a part of the solution, there’s good money to be made in prolonging the problem.

- E.L. Kersten
Better Than Wiki-leaks

BRF discovers the NIH’s own MESH dictionary echoes what we’ve been saying for four years: Blastocystis infection will make some healthy people very sick.

In November of 2010, Wiki-leaks released over 250,000 classified communications from the US Federal government, provoking a lot of discussion about topics which had remained secret for years.

We think we found something even better.

The NIH ended all US-directed Blastocystis research in 1995, and today points to “disagreement” between researchers for failure to allocate a single dollar toward the infection in every year since then. In 2007, BRF presented a petition with close to 100 signatures from Gulf War Veterans, patients, physicians, and scientists asking that the NIH resume research for Blastocystis, which has become the country’s #1 protozoal infection.

In our Spring 2010 newsletter, we reprinted the response from NIAID Deputy Directory Secretary Auchinleck, who called a commitment of funding to Blastocystis research “infeasible.” This is the NIH’s position, despite the number of labs in Europe, Asia, China, and Mexico treating and researching Blastocystis.

But what is this we find? The NIH’s own online medical terms dictionary defines Blastocystis as a pathogen (see below). The directory entry says exactly what BRF has reported for the last four years – Blastocystis is disabling people and they won’t get any better until a reliable treatment is found.

You can look at the web page for yourself. But look quickly, before someone takes it down.

*   *   *   *   *   *   *   *   *   *   *

Potentially Disabling Symptoms: To see for yourself, logon to the NIH’s MESH database, type Blastocystis, and follow the entry for B01.046.500.100.200.200.375, or follow the link from the online copy of this newsletter at http://WhenDidYouGetSick.org
Is Advocacy-Based Management of Infectious Diseases Making You Sick?

Patients shouldn’t have to sew quilts to convince researchers to use public funds to support public health

In today’s world, federal regulators to protect consumers can be found everywhere. There are regulations on the amount of lead that can be used in children’s toys. Other regulations control the fuel economy requirements on cars that manufacturers sell. There are even regulations on the amount of time that an airline can keep passengers stuck in an airplane on the runway. The safety and efficacy of drugs is also regulated. The FDA rules on 100-200 drug applications every year.

With all this attention to consumer safety, you might be surprised how little attention gets placed on medical practice in diagnosing and treating infectious diseases.

For example, MRSA now kills more people in the United States than HIV infection, around 12,000 per year. And 85% of serious MRSA infections are occurring in hospitals, and could be reduced with better hand washing. But those institutions have successfully blocked legislation requiring them to disclose MRSA death rates, or even change hospital practices.

How is it that airlines have to count the minutes for airplanes on the runway, but hospitals don’t have to count their body bags?

MRSA Survivor Network

Jeanine Thomas found out about MRSA the hard way. She was infected by a hospital, which then failed to diagnose the infection for days. To make matters worse, they then gave her the wrong antibiotics and the infection sent her into multiple organ failure.

After the experience, she was surprised that doctors shrugged off the entire thing, and didn’t see any need to change the procedures that had nearly killed her, and are in fact killing tens of thousands, and maiming many more.

She also found that the CDC favored the hospital’s side of the story, declining to take any action on the disease.

Since then, she’s formed a non-profit organization to get hospitals to do things which most other corporations in the US do without being asked – manage their affairs so as not to kill their customers.

The United States medical system consumes 17.3% of the gross national product, and pays its specialists over $300K/year, ten times the average wage of many of their patients.

Why should patients have to bear the burden of managing quality systems for the healthcare industry?

Jeanine’s experience is becoming surprisingly common in the United States. And that’s not a good thing.

Patients who have already been damaged by the medical system are being saddled with the additional burden of correcting the problems that, in some cases, bankrupted or maimed them to begin with.

Federal regulatory agencies - largely staffed by medical doctors with close ties to the industry – usually decline to take any action to address the problems.

Yes, this has created the odd situation where United Airlines can get in trouble for keeping you on the tarmac for too long, but if the local hospital kills you first, there’s no burdensome paperwork to fill out.

Blastocystis Diagnostics

BRF has been working to address the problem of diagnostics for Blastocystis infection, which currently only detect 30% of the positive patients in many studies. Remarkably, not one US commercial microbiology laboratory has offered any assistance, although many of them will privately acknowledge the problem with diagnostic reliability. Diagnostic failure for enteric protozoal infections has been a repeated topic of papers from infectious disease labs over the past several years.

Although they have not provided assistance, labs have wished BRF luck with “raising awareness about Blastocystis infection.”

Why is the medical industry exempt from modern quality standards?
Almost every modern business in the United States, Europe, and more recently Asia needs to comply with sets of basic quality standards. These govern financial accounting, and more recently, ISO standards that require basic procedures be in place for quality management and customer responsiveness.

However, large regions of medical practice feel they should be exempt from any such standard. The result is that a minor problem with Apple Computer’s I-Phone’s antenna makes front-page news. But Apple employees visiting their local medical provider will be subject to expensive, faulty diagnostics that haven’t improved much since the 16th century.

Where are we now

Patient-run infectious disease organizations now occupy the watchdog role for the medical community that federal organizations perform for other industries.

For example, MRSA is now one of the top three killers in the United States, yet there is virtually no action from the CDC and NIH to address this. Who is doing the work? MRSA Survivors Network, a group founded and funded by patients.

_Blastocystis_ is now the number one protozoal infection in the United States, but the NIH has refused to approve a single grant to study the disease in US patients for the last 15 years. BRF, a patient-founded and funded organization is now the only group regularly publishing studies in the United States.

This is a new trend. We used to have professional who worried about things like TB, mumps, measles, chickenpox, polio, and other diseases. Today, the trend is to abandon the disease at the federal level, and dump the problem on physicians who then dump it onto patients.

National Disgrace

But do we really want to rely on patient groups to manage all of the 200+ infectious diseases that federal officials are too busy to think about.

And why are other federal agencies like the FAA or FBI able to manage multiple projects, without requiring the situation to deteriorate to the point that volunteers have to step in to perform basic agency functions.

The FAA modernized their aircraft tracking system all by itself. How cool is that. We didn’t have to buy wrist bands or “raise awareness” or have a fundraiser for the FAA.

The FCC made a decision about digital broadcasting and converted the country without so much as a single quilt being knit and sent to Washington.

The Department of Transportation is able to routinely test new vehicles using a scientific process without so much as a single “fun run” needed to raise awareness of the need for us to open our checkbooks up and send them money.

This level of organization seems to escape the CDC and NIH when it comes to infectious diseases.

Is this really about something so important that we all have to help?

Or is another way to rip off patients?

Robin Hood….In Reverse

Let’s look at some of the figures. The medical industry in the US consumes 17.3% of the gross national product, and pays its specialists over $300K/year, ten times the average wage of many of their patients.

Patient Advocacy presumes it is OK for federal agencies to perform at such a low level that patients must organize and fund infectious disease work. But this is like a regressive tax, since the patients also have to pay for the treatment. And it requires that the people least able to afford the research – those who are sick – pay for it.

HIV Began the Precedent

According to a detailed study presented to the National Academy of Sciences in 2009. It wasn’t widely recognized until the 1980’s. Before then, doctors told their patients they had cancer or an auto-immune disease.

If gay men hadn’t been having promiscuous sex in the 1980’s, doctors might still be telling people they were dying from an auto-immune disorder.

I’m sure someone would be blaming vaccines.

The emergence of HIV was a watershed event in infectious diseases, the way Love Canal was a pivotal development in regulation of toxins. But HIV infection produced a large amount of funding for a specific disease, but did not bring about institutional reforms that were seen in the EPA and other institutions following Love Canal.

Leaving infectious disease management to chance is bad news for patients, and the economy. It means that diseases that could be stopped for about $100 plus a doctor’s appointment will bankrupt families.

There are more diseases than we have patient groups. Respiratory infections and diarrheal diseases are the number 1 and 3 infectious killer’s world wide. Diarrheal diseases are much less expensive to diagnose and treat, yet federal agencies have given up this area, and surrendered it to alternative medicine.

HIV patients and everyone else aren’t getting reliable treatments and diagnostics for commonplace infections. Federal agencies have ignored the rise of Cryptosporidium, the number 2 enteric protozoal infection in the US. HIV groups also managed to get some action with the approval of the first new drugs to treat the disease in decades.

_Blastocystis_ Research News
http://WhenDidYouGetSick.org
Don’t Test, Don’t Tell

Should physicians be required to disclose positive test results for Blastocystis infection to patients?

The CDC doesn’t think so

BRF has been working for several years to identify reliable diagnostics for Blastocystis infection, and bring those to patients. But many patients have told us their physicians did not disclose positive test results for Blastocystis infection to them.

This was true even though they were being tested to determine the cause of chronic diarrhea, abdominal pain, and other symptoms. Patients were told they had IBS, or were given additional medical tests and told they had microscopic colitis. The patients discovered the test results when they switched doctors, or when they asked for copies of their medical records.

President Obama just started a national inquiry into medical ethics following the revelation that the US funded studies to use prostitutes to infect prisoners in Guatemala with syphilis without their knowledge in 1940’s. This comes in addition to the Tuskegee study where doctors failed to disclose positive syphilis test results to patients.

BRF argued that patients need to give informed consent to procedures and treatments. Hiding positive Blastocystis test results from patients means that patients are not informed, thus informed consent is impossible.

Because Blastocystis is a communicable infection, patients should be told about positive test results so they can avoid transmitting the infection to family members, or customers if they work in the food service industry or at a school cafeteria, for example.

Unfortunately, the CDC did not agree with BRF.

While BRF understands that some medical philosophies don’t fully accept the germ theory of illness, we believe that failure to disclose infectious disease test results to patients is a poor precedent to set.

BRF will also be raising concern regarding the current practice of recruiting patients for ‘IBS’ studies without testing them for infectious diseases first. Most US-funded studies are currently conducted by physician trying to prove their thesis that diarrhea and other symptoms are produced by bad parenting and unresolved subconscious conflicts.

Patients involved in those studies may be in the same position of the Tuskegee patients, mainly they may have an infectious disease for a long period of time that could be treated, but is not being addressed because of their involvement in the study.

BRF will be contacting IRB boards for federally funded ‘IBS’ studies to determine if patients have been told that ‘IBS’ symptoms can be caused by infectious diseases, and have been given the opportunity to be tested for such infections.
New NIH ‘STAR’ Objectives Omit Any Reference to Curing Diseases or Helping Patients

The NIH’s new STAR guidelines emphasize making a lot of money and getting lots of attention.

June 1, 2010. The National Institutes of Health announced its new STAR metrics this week. The metrics describe a set of criteria the NIH will use to judge the success of its grants.

Based on the new STAR metrics, grants will now be judged on economic considerations, like generating patents and business spinoffs.

But there’s something missing from the new National Institutes of Health guidelines? Although Congress chartered the NIH, its new objectives make no reference to curing diseases, improving medical practice, or improving health of human beings. Will patients with chronic and terminal diseases be happy to know that researchers are thinking about patents and business spinoffs?

At BRF, we’ve been concerned that letting Universities have too much influence on federally funded medical research is bad for patients, because projects stop focusing on health and instead become oriented toward making money for colleges, or getting college professors published in prestigious magazines like Science.

The focus on using medical research grants to generate cash is relatively new. In 1980, Congress passed the Bayh-Dole act which allowed Universities to make money off federal research dollars by patenting things and starting businesses. What’s the impact? NIH-funded researchers used to do things like find the bacteria that caused Lyme disease, and find out which existing antibiotics would treat it. A researcher who was thinking about patents and businesses wouldn’t be interested in identifying a bacteria that is treatable with existing drugs.

Additionally, researchers rarely get everything right when they first investigate a disease, and they need the freedom to modify their ideas as new information comes in.

The researcher’s ego is already an impediment to progress in medical research. When you add to that a financial interest in defending a scientific viewpoint that supports a patent, you are creating a situation where researchers are bound to be less useful or even counterproductive to the fact finding process.

Which looks better under the STAR guidelines – Salk’s Polio Vaccine or a Methamphetamine Lab

The NIH’s STAR guidelines judge research based on economic and pedagogical criteria. Whatever happened to curing diseases? Using the new criteria, we took a look at how Dr. Jonas Salk’s polio vaccine would compare to a meth lab.

References: We looked up some of Dr. Salk’s papers on the NIH’s Pubmed web site. Let’s just say Salk was better are preventing diseases than getting people to reference his papers. Some of Salk’s papers have been referenced only 3 or 4 times.

Patents: Salk didn’t patent the polio vaccine – he gave it to the world freely. He’s a real schmuck by the NIH STAR guideline standards!

Jobs/Businesses: Salk’s polio vaccine eliminated businesses instead of starting them. Iron lung companies went out of businesses. Rehabilitation centers had to close because nobody was getting polio. On the other hand, meth labs create jobs for policemen, emergency room workers, decontamination crews, etc.

The Verdict: A meth lab fares better under the new NIH STAR guidelines than the Salk polio vaccine.

TRY THIS AT HOME: Which fares better under STAR? Viagra® or insulin therapy.
Where does Blastocystis come from?

1. BRF’s 2007 review on Blastocystis (BMC P&V, 1:1(41)) showed that Blastocystis detection rates on the US West Coast increased from 1985 (2 to 3%) to 2000 (over 23%), then decreased. What is going on?

2. A second intriguing phenomenon is that Blastocystis in the US is more common in specific states. For example, patients from California and Oregon are three times more likely to be infected than those from Virginia, where most federal employees call home. The study’s author thought there might be something about coastal states that produced a higher rate of infection.

3. BRF follows Blastocystis in Taiwan and Singapore, because those countries have the lowest Blastocystis infection rates in the world today, less than 3%. They also have a low rate of chronic gastrointestinal illness (permanent diarrhea). However, nearby countries like Malaysia and the Philippines have rates that are much higher.

   What are those countries doing? Both of them screen incoming workers for gastrointestinal parasitic infections, and require that they be treated if they are found. Workers are given free treatment, and government follow-ups help make sure they have been treated properly.

4. We obtained immigration figures from a study done by Pew Research Center, which exhibits a pattern similar to the Blastocystis infection rate. The pattern may be related to economic growth in the US, which drives demand for foreign workers.

5. What about the geographic variation? We obtained the below plot which shows the percentage of foreign-born workers in different states. Blastocystis appears to be most common in many states with the highest immigrant populations.

6. Other explanations are possible for the changes in Blastocystis infection - cyclical behavior is seen in viral diseases.

   What’s happening here are home? Some US federal officials keep promoting the idea that Blastocystis is harmless. Some US citizens even travel to Mexico now for treatment.

   And Mexican researchers are doing most of the research in North America on protozoal diseases like Blastocystis since US federal officials promote the idea the infection is harmless. Maybe we could help Mexican researchers. Providing diagnosis and treatment to people has worked in Taiwan and Singapore.
Welcome to the Future:
Toilets on Wheels

Blastocystis and Dientamoeba fragilis are now found in 10-20% of the population in specific geographic areas of developed countries, but patients aren’t getting diagnosed or treated. How are communities adapting to the high rate of chronic diarrhea?

When you think the future, and of how people will get around, what images come to mind?
Fuel efficient hybrid vehicles? Computerized mass transit? Flying cars?
How about toilets on wheels?
Probably not, but they may be coming to a town near you. In developing countries, around 10-20% of the population has diarrhea at any time. In the United States we may have had statistics like that in the 1800’s. Acceptance of the germ theory of illness allowed countries to develop their medical infrastructure and economy. The two things go hand in hand, and eventually put countries in the United States and Europe where they are today.

That trend has reversed itself in the last 10-15 years, as national research policies started shutting down clinical infectious disease work in common illnesses to focus on HIV infection, as well as “new paradigms” that supposedly will replace germ theory.

Heavily promoted by college professors receiving grants, these are variously referred to in the literature as “wholistic therapy”, multi-determinism, and brain-gut axis theory, and “biome” studies. The new thinking ditches the idea of finding specific microbes that cause illness using animal models and an understanding of cellular physiology. Instead, researchers rely on literature, mysticism, and lots of hand waiving to explain how just about anything can be shown to cause disease.

Overall, some may argue the “New Medicine” looks a lot like the “Old Medicine” that scientists stamped out in the early 20th century.

The loss of emphasis on diagnosing and treating infectious diseases has produced a predictable rise in morbidity due to unexplainable causes. The rate of inflammatory bowel disease rose by a factor of 10 in some areas of Europe, especially in young people, reaching levels as high as 1% in some areas.

In the United States, the expansion of Blastocystis may be the most significant driver in the rise of chronic gastrointestinal illness, simply because of the numbers. Blastocystis was found in 2-3% of patients on the West Coast of the US in the mid-1980’s. By 2000, labs were recovering the organism at a rate of 23%.

Every 40 minutes, a new bowel movement
A study from Vancouver, BC on Canada’s West Coast noted that patients with Blastocystis infection may have up to 20 bowel movements per day. And as BRF has reported in multiple studies, the symptoms may continue indefinitely in some patients.

What kind of job can patients get who have to use the toilet every 30 or 40 minutes? Travel can be problematic as well – airplane travel may be out of the question, and car travel can be problematic.

Ingenuity to the Rescue
Although the scientists have been out-to-lunch on Blastocystis treatment, patients have been thinking about the toilet problem. One innovation coming from the United Kingdom is the Mobile-Let.

Designed by a patient with chronic diarrhea, this is a portable toilet that is towed behind a car.

As Blastocystis infection spreads, and medical agencies opt to take the easy route of telling patients they have IBS, the need to innovations like this will grow. Patients can purchase Mobile-Lets and attach them to their cars so they can travel to work, pick up children, or even go on vacation and still accommodate frequent bowel movements.
BRF visits the American Association for Clinical Chemistry Conference, July 27-29 in Anaheim, CA

We need reliable, low-cost, and available diagnostics for Blastocystis and other infections to get patients identified, treated, and out of the medical system.

In the 15th century, scientists identified microbes in stool specimens by poking around at samples using a microscope. Six centuries later, we have robotic and laser surgery, magnetic resonance imaging and pacemakers. But lab techs are still poking at bits of stool samples to try to find organisms.

The problem? Cells from pathogens don’t look much different from harmless cells, or fat cells. Once the cells have gone through the digestive tract, and been shaken up in the formaldehyde preservative used in stool collection vials, they look like a piece of roadkill on a super highway after a few days.

That’s a problem in the United States and around the world, and BRF’s first focus was getting the diagnostics right. In addition to needing reliable diagnostics for finding patients, you need them to determine which drugs actually eradicated the infection.

With 30-60 million US citizens infected, and more in the Americas, Europe, Asia, and Middle East, we need a fast way and inexpensive way to find the infection.

BRF Founder Ken Boo-rom visited vendors at the AACC. Ken noted that “I had an opportunity to visit reps from the two largest clinical labs in the US – Labcorp and Quest. “The AACC brings together hundreds of clinical laboratory vendors in a single site, so I’m able to handout a lot of literature at a low cost to BRF.” Ken paid for the AACC trip and declined to be reimbursed by BRF.

The diagnostics methods used in many clinical laboratories only identify a third of many kinds of infections. The industry itself has not been inclined to address this quality problem. Newer methods are both more reliable and even less expensive. Ultimately, the issue with testing boils down to one thing:

Do you want to be served food by someone who got a clean bill of health based on a diagnostic that only works a third of the time?

Innovations in the electronics industry improving health diagnostics. QBC’s portable $700 fluorescence microscope replaces older $20,000 systems that used xenon tubes that explode sometimes. Over 1000 units have been deployed world-wide for malaria diagnosis. They can be reconfigured for diagnosing GI protozoa.
Some Federal Officials Say Blastocystis is Harmless

That has us seeing red

Twenty years ago, some physicians published studies suggesting Blastocystis could not cause illness. Once infectious disease labs began working on the problem, they developed better methods and have universally concluded the Blastocystis will cause disease. In fact, in the last 15 years, over 96% of NIH-indexed medical studies identify Blastocystis as disease causing. And in 2008, a panel of 11 experts from 9 countries examined the problem, and concluded that, based on published literature, Blastocystis behaves no differently in humans than from Giardia and Entamoeba histolytica (BMC P&V 1(1) 40) in most patients. The panel consisted of scientists from the US Center for Disease Control, China's Center for Disease Control, a WHO Collaborating Center for the Molecular Epidemiology of Parasitological Infections, the US Air Force, the Pasteur Institute., and parasitologists from national universities in Greece, Turkey, and Thailand.

US physicians don’t always get infectious diseases right the first time. It’s time to admit the rest of the world is right, and move onto the problem of finding treatments for the large population of chronically infected patients. If you’d like to be part of the solution, contact us at http://WhenDidYouGetSick.org e-mail director@bhomcenter.org