

Johnson, Barbara J. (CDC/IOID/NCEZID)

From:

Sent:

To:

Durland Fish [Durland.Fish@yale.edu]

Sunday, October 07, 2007 7:24 AM

'Phillip Baker'; 'Edward McSweeney'; 'AgueroRosenfeld, Maria'; 'Dattwyler, Raymond'; 'Leasure, Mark'; 'McKenna, Donna'; 'Munoz, Jose'; 'Nadelman, Robert'; 'Nowakowski, John'; 'Schwartz, Ira'; 'Wormser, Gary'; 'allen steere'; 'arthur weinstein'; 'bettina wilske'; 'eugene shapiro'; 'franc strle'; 'gerold stanek'; 'hank feder'; 'harvey artsob'; 'jerry green'; 'johan bakken'; 'john halperin'; 'Juan Salazar'; 'Justin Radolf'; 'Lawrence Zemel'; 'linda bockenstedt'; 'mark klempner'; 'muhammad morshed'; 'paul auwaerter'; 'peter krause'; 'Richard Porwancher'; 'robert smith'; 'Rosalie Trevejo'; 'steve dumler'; 'sue o'connell'; 'sunil sood'; 'susan wong'; 'tom draper'; 'volker fingerle'; 'william agger'; Johnson, Barbara J. (CDC/IOID/NCEZID); Mead, Paul (CDC/IOID/NCEZID)

Cc:

Subject:

RE: Lyme rally in front of the University of CT Health Center

This battle cannot be won on a scientific front. We need to mount a socio-political offensive, but we are out numbered and out gunned. We need reinforcements from outside our field.

Durland Fish, Ph.D.

Professor of Epidemiology and Public Health

Professor of Forestry and Environmental Studies

203 785-3525

<http://publichealth.yale.edu/faculty/fish.html>

From: Phillip Baker (b)(6)

Sent: Saturday, October 06, 2007 9:50 PM

To: Edward McSweeney; AgueroRosenfeld, Maria; Dattwyler, Raymond; Leasure, Mark; McKenna, Donna; Munoz, Jose; Nadelman, Robert; Nowakowski, John; Schwartz, Ira; Wormser, Gary; allen steere; arthur weinstein; bettina wilske; durland fish; eugene shapiro; franc strle; gerold stanek; hank feder; harvey artsob; jerry green; johan bakken; john halperin; Juan Salazar; Justin Radolf; Lawrence Zemel; linda bockenstedt; mark klempner; muhammad morshed; paul auwaerter; peter krause; Richard Porwancher; robert smith; Rosalie Trevejo; steve dumler; sue o'connell; sunil sood; susan wong; tom draper; volker fingerle; william agger; barbara johnson; paul mead

Subject: Re: Lyme rally in front of the University of CT Health Center

Why not take this as an opportunity to challenge them to provide unequivocal evidence to show that those who believe they have late or chronic Lyme disease actually have a persistent *Borrelia burgdorferi* infection, and to demonstrate -- from the results of a published, randomized, placebo-controlled trial-- that extended antibiotic therapy is beneficial?

Phillip J. Baker

(b)(6)

Demanding answers

Next Friday, the 12Th, from 11 to 1 pm we will hold a rally in front of the University of CT Health Center on Rt 4, 263 Farmington Ave. Farmington CT. All are welcome to attend.

Dr. Hank Feder from the University of CT has made it clear that Lyme is easy to cure.

We will be requesting that they make public the method they use to determine that the Lyme Bacteria, Borrelia Burgdorferi is eradicated after the IDSA treatment guidelines.

We demand that UCONN show us the test that is being used to prove that the lyme spirochete has been eradicated. Many of us in the lyme community have been suffering for many years with active infection.

It's time for Dr. Feder and others to back up there claim of short term cure. All we have seen so far are papers published by these same people that demonstrate that even after long term treatment the spirochete can survive.

See our \$20,000 reward at www.ctlymedisease.org

More to follow on this event over the weekend. Please forward this to anyone you know that may be able to attend.

Contact Randy Sykes if you have any questions - Great Hartford Lyme Disease Support & Action Group 1-860-685-9938

For sick people they certainly have a lot of energy. Not to mention a lot of signs and placards.

Ed

Edward McSweeney, PhD
Crofton, MD
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Johnson, Barbara J. (CDC/IOID/NCEZID)

From: Wormser, Gary [GARY_WORMSER@NYMC.EDU]

Sent: Sunday, June 10, 2007 2:57 PM

To: Steere, Allen C., M.D. (b)(6)

Cc: Olson, Diana; Leasure, Mark; hmasur@mail.cc.nih.gov; steve dumler; Johnson, Barbara J. (CDC/IOID/NCEZID); eugene shapiro; franc strie; gerold stanek; johan bakken; john halperin; mark klempner; Mead, Paul (CDC/CCID/NCEZID); peter krause; ray datwyler; robert nadelman; william agger; arthur weinstein; Johnson, Barbara J. (CDC/CCID/NCEZID); bettina wilske; donna mckenna; durland fish; hank feder; harvey artsob; ira schwartz; jerry green; john nowakowski; Munoz, Jose; Juan Salazar; Justin Radolf; Lawrence Zemel; linda bockenstedt; maria aguero; muhammad morshed; paul auwaerter; phil baker; Richard Porwancher; robert smith; Rosalie Trevejo; sue o'connell; sunil sood; susan wong; tom draper; volker fingerle

Subject: RE: Letter to UCS

Please include me as well. gary

-----Original Message-----

From: Steere, Allen C., M.D. [mailto:ASTEERE@PARTNERS.ORG]

Sent: Friday, June 08, 2007 9:32 AM

To: (b)(6)

Cc: Wormser, Gary

Subject: Letter to UCS

Ed,

I have been meaning to write to you about the UCS letter, and have not had a chance to do so. There is one point that I would like to emphasize. In untreated patients, there is a chronic form of Lyme disease that commonly results in Lyme arthritis or, in rare cases, Lyme encephalopathy or polyneuropathy. Our point is that subjective pain, neurocognitive or fatigue symptoms following IDSA-recommended courses of antibiotic therapy for Lyme disease are not caused by chronic infection. Moreover, there is no peer-reviewed medical evidence that shows that months or years of antibiotic therapy is beneficial for the treatment of such symptoms. However, I think that we need to be careful not to say that there is no chronic form of Lyme disease. Such language has been largely removed from the current draft of the letter. However, I have made a few suggestions (with track changes) for care in these statements.

I would be willing to sign the letter as long as a number of other members of the Ad Hoc International Lyme Disease Study Group do so.

Thanks for taking on this important task.

Allen

<<UCS Letter4.doc>>

Bacterial Diseases Branch
Division of Vector-Borne Infectious Diseases Centers for Disease Control and Prevention
Tel: 970-221-6463
Fax: 970-225-4257

-----Original Message-----

From: Steere, Allen C., M.D. [mailto:ASTEERE@PARTNERS.ORG]
Sent: Wednesday, October 24, 2007 1:01 PM
To: Johnson, Barbara J. (CDC/CCID/NCZVED)
Subject: Serology manuscript

Dear Barbara,

It was good to see you and have the opportunity to talk at the recent Banbury conference. It has taken me this long to have a free moment to write to you afterwards. Immediately following the Banbury conference, I was consult attending for two weeks. Then came the IDSA meeting, and I have been in Europe for the last two weeks.

I have attached two tables. One gives summary data about the results of the prospective serologic study based on our data (Table 1) and the other (Table 1a) gives the summary results of your data. Now that I have looked at this again, I see why we were previously concerned about reporting these results together.

Although the biggest discrepancy is in IgM testing, the frequency of positive results in every category is less in your testing than in ours.

I think that this is particularly problematic as it relates to the early disseminated infection (neurologic and cardiac disease) and late disseminated

(arthritis) groups. In your testing, the frequency of IgG positivity is on the low side in each of these groups. In contrast, in our prospective testing, these patients had positive results. We have postulated that this may have resulted from some degrading of the sera with shipping and with time. However, this is only one explanation that one would have to give in a manuscript. I am worried that some people would conclude that two-tier testing is not that reliable, which is not the message that we would want to give. Therefore, I would propose that we go back to the plan in which we simply report the prospective study results from my laboratory.

Please let me know what you think.

Allen

<<SerologyCDCMIGHsummary.doc>>

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Johnson, Barbara J. (CDC/OID/NCEZID)

From: Feder, Henry M. [FEDER@NSO2.UCHC.EDU]
Sent: Friday, June 29, 2007 8:05 AM
To: Wormser, Gary
Cc: Johnson, Barbara J. (CDC/OID/NCEZID); Eugene.Shapiro@yale.edu; asteere@partners.org; Susan O'Connell
Subject: RE: what do you think of this revised section?

I think the key is not to debate the CLD scientific evidence with the patient. We cannot prove the patient does not have CLD. Instead the clinician should be sympathetic, and focus on treating the patient's symptoms. Here is the revision I struggled over and it has a low word count.

Advice to Clinicians

How should a clinician handle the referral of a symptomatic patient who has been purportedly diagnosed with and often treated for CLD? The patient should be thoroughly evaluated for medical conditions that could explain their symptoms. If a specific diagnosis cannot be made, the goal should be managing their symptoms without antibiotics. The physician should not debate the diagnosis of CLD but instead acknowledge that the symptoms are real and need to be treated [54-56]. Realistic goals should be agreed upon by the patient and clinician and careful follow-up should be provided.

From: Wormser, Gary [mailto:GARY_WORMSER@NYMC.EDU]

Sent: Thursday, June 28, 2007 9:00 PM

To: steve dumler; allen steere; barbara johnson; eugene shapiro; franc strle; gerald stanek; johan bakken; john halperin; mark klempner; paul mead; peter krause; ray dattwyler; robert nadelman; william agger; arthur weinstein; barbara johnson; bettina wilke; donna mckenna; durland fish; Edward McSweagan; Feder, Henry M.; harvey artsob; ira schwartz; jerry green; john nowakowski; Munoz, Jose; Juan Salazar; Justin Radolf; Lawrence Zemel; linda bockenstedt; maria aguero; muhammad morshed; paul auwaerter; phil baker; Richard Porwancher; robert smith; Rosalie Trevejo; sue o'connell; sunil sood; susan wong; tom draper; volker fingerle

Subject: what do you think of this revised section?

Justin offered suggestions that has led to this potential revision of the advice section.

Advice to Clinicians