
From: Wells, Eden (DHHS)
Sent: Thursday, October 22, 2015 10:39 AM
To: Laura Carravallah
Cc: Mark Valacak; Kay Doerr
Subject: Re: Drafted Letter to Gastroenterologists (for input/approval)

This is great- thank you!!!

Sent from my iPhone

On Oct 22, 2015, at 10:35 AM, Laura Carravallah <Laura.Carravallah@hc.msu.edu> wrote:

Dear Eden, Mark and Kay,

I am attaching a draft letter from the medical society that will likely go out today and also my commentary relating to the conversations I have had with the liver services at Henry Ford and UM Ann Arbor.

I think the letter is good. I would suggest adding a paragraph - see below.

I was able to talk to a Dr. Segovia with Henry Ford hepatology (recommended by Dr. Kim Brown, Director of their Liver Transplant service), and also the nurse of Dr. Askari at UM, the Director of the Wilson Disease clinic there.

Dr. Segovia did not have any specific suggestions - they just tell their patients to get their water tested and act accordingly. She was interested in what we find. Dr. Askari's nurse said they tell their patients to use either DISTILLED water (not bottled - for instance they said Dasani actually has rather high levels of copper) OR get a reverse osmosis system. I found some of these systems online and they ranged in price with some around \$150 or so. I don't know which ones are good.

Dr. Segovia said they may have 1-2 patients with Wilson Disease at the most. Dr. Askari's nurse thought there may be 10 or less in the clinic at UM (they ask them back for annual checks when stable). She said all of their patients get the above advice.

I would propose that we add a paragraph that says:

"The UM Wilson Disease clinic director, Dr. Askari, recommends that all Wilson Disease patients use either specifically distilled water (not all bottled water is

distilled), or a reverse osmosis system. We are hoping to get a reasonably accurate number of patients who may be affected so that we can get the information to them (through you, or through an outside referral clinic) and also see if it is possible to get funding for those who may have difficulty obtaining the necessary water or system, particularly during the next year when the water is still considered more corrosive than average. It is also important to note that copper pipes tend to be more common in newer homes, so the distribution of high concentrations of copper in water may be different than that for lead."

I am also going to send this information to Eden Wells at MDHHS at her request.

When I spoke to Dr. Marc Edwards on the phone, he did send a list of all the other metals for which he tested and none were over the action limit. As may have been mentioned earlier, he also said that there were no samples which had copper over the action limit, but that is not the appropriate limit for patients with copper storage disease. This problem is clearly much less widespread than the lead problem, but after being surprised once, I don't want for us to leave anything else out this time around.

Laura

Begin forwarded message:

From: Laura Carravallah <lcarrav1@yahoo.com>
Date: October 22, 2015 at 10:24:21 AM EDT
To: Laura Carravallah <laura.carravallah@hc.msu.edu>
Subject: Fwd: Drafted Letter to Gastroenterologists (for input/approval)

Begin forwarded message:

From: Sherry Smith <ssmith@gcms.org>
Date: October 21, 2015 at 2:02:10 PM EDT
To: "Laura Carravallah M.D." <lcarrav1@yahoo.com>, "Gerald Natzke, Jr., D.O." <GDN2@aol.com>, "Deborah Duncan, M.D." <drdebd@fentonmedical.com>
Cc: Pete Levine <plevine@gcms.org>
Subject: Drafted Letter to Gastroenterologists (for input/approval)

Good afternoon!