

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." <lcarravi@yahoo.com>, "Gerald Natzke, Jr., D.O." <GDN2@aol.com>, "Deborah Duncan, M.D." <drdehd@fentonmedical.com>
Cc: Pete Levine <plevine@gcms.org>
Subject: Drafted Letter to Gastroenterologists (for input/approval)

Good afternoon!

At the request of Peter Levine, please find a draft letter attached for your review.

After you have taken a moment to review this letter, please respond with your comments regarding additions/edits, or with your approval.

Thank you in advance for your attention and response.

Respectfully,

Sherry Smith

Executive Secretary

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 Please note: GCMS is closed every Friday.

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