



THE UNIVERSITY OF KANSAS HEALTH SYSTEM

Rebecca Moburg
Director of Patient Experience

July 17, 2023

Nicole Henry and Aaron Clary


Dear Ms. Henry and Mr. Clary,

I am writing in response to the complaints Mr. Clary brought to our attention through email communication and during our May 12, 2023 conversation regarding the care and treatment of Ms. Nicole Henry, from The University of Kansas Health System (TUKHS). I appreciate your patience as we have reviewed Mr. Clary's feedback, allegations and observations and apologize for the length of time it has taken to provide you with a final written response.

A thorough evaluation of your concerns was conducted, which included a review of Ms. Henry's TUKHS electronic medical record (EMR), feedback from members of her care team and input from other specialists. Our review concluded on July 12, 2023. It should be noted that several of the concerns you expressed were related to actions or inactions of outside organizations, and those concerns should be addressed directly with those agencies. We will only address the concerns specific to TUKHS.

Mr. Clary alleges Ms. Henry has a diagnosis that has been hidden, first by an outside organization and now by TUKHS providers. Although not since 2021, Ms. Henry has been seen by several TUKHS providers, all of whom have provided their recommendations for treatment and testing based upon their assessment and testing results. We have found no evidence that any diagnosis has been concealed by TUKHS providers and our review indicates care and treatment recommendations provided to Ms. Henry has been appropriate.

Mr. Clary indicated that on September 10, 2019, Ms. Henry had an MRCP at another hospital and page 2 of the report showed an "adrenal adenoma" and indicated her liver measured "19.8cm with a prominent lobe." According to Mr. Clary, her liver wasn't enlarged 8 days prior, and this finding was concerning to him. Upon establishing care with Dr. Safavi on November 12, 2019, the physician referenced record review from the outside hospital in her notes and referred to the MRCP which demonstrated a possible small stone. There was no reference to an adrenal adenoma.

Dr. Safavi ordered tests including an ASMA titer and ANA which resulted on November 12, 2019 as 160 and <80 respectively. Mr. Clary was adamant in his belief this indicated Ms. Henry's liver was "being attacked" by something" and during Ms. Henry's November 25, 2019 visit with Dr. Safavi, it was noted that Ms. Henry shared her concern of a rheumatologic condition that was going undiagnosed. Notes indicate her ANA was negative and a rheumatology referral was made. During Ms. Henry's November 25, 2019 visit with Dr. Safavi, more tests were ordered but there was not another ASMA level tested, which Mr. Clary found unusual and believes this is part of the alleged "cover up." He also indicated his perception there is a large proportion of patients with autoimmune hepatitis who have a positive ASMA titer without a positive ANA. Mr. Clary also shared that although she was not diagnosed



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officially, Ms. Henry was treated for autoimmune hepatitis with a Z-pack and prednisone by a provider at an outside hospital in December of 2019 who simply indicated the medications were for something that “hadn’t reared its ugly head.” There has been no evidence of autoimmune hepatitis in her EMR or on biopsy which is considered the gold standard for diagnosis.

Ms. Henry was subsequently seen by rheumatology for her initial visit on January 17, 2020 and a review of her EMR was performed by the rheumatologist who noted evaluation of her previous lab work including confirmation of appropriate work-up with immunoglobulins, hepatitis C, ANA and rheumatoid factor, all of which resulted negative, and verification of a positive ASMA of unknown significance with no prior history of liver disease or recently elevated liver enzymes. Rheumatology’s assessment was classic fibromyalgia syndrome which would explain most of Ms. Henry’s symptoms, but this specialty also suggested further screening.

Mr. Clary has explicitly shared his belief that Ms. Henry was intentionally kept sick by multiple physicians under TUKHS’s supervision and has voiced that his wife is literally “dying of adrenal cancer and liver cirrhosis that was caused by physicians working for The University of Kansas Health System.” Mr. Clary was clear in his belief that Dr. Safavi relocated because she found out about Ms. Henry’s alleged adrenal adenoma and this is also part of the cover up, although we were unable to substantiate this allegation. He also indicated Ms. Henry experienced ataxia which evolved to an encephalopathic coma and believes this is because of a delay in Dr. Safavi finding a diagnosis. At no point was Ms. Henry treated for an encephalopathic coma at TUKHS, nor is there evidence of either confirmation or suspicion of an adrenal adenoma or adrenal cortical carcinoma in her EMR. In fact, Ms. Henry’s May 20, 2020 CT scan of her abdomen and pelvis indicated unremarkable adrenal glands.

In April of 2023, Ms. Henry apparently underwent imaging in Las Vegas, Nevada to prove she has an adrenal cortical carcinoma. According to Mr. Clary, Ms. Henry underwent a full body scan which showed a growth 23mm x 9mm on the adrenal gland. Ms. Henry has not been seen by TUKHS providers since 2021, and when records pertaining to the April 2023 scans were requested to aid in our review, and Mr. Clary denied this request.

Following our in-person conversation, Mr. Clary later indicated his belief that Dr. Safavi “almost killed” Ms. Henry by prescribing her valproic acid while she suspected Ms. Henry had autoimmune hepatitis and further went on to state this put her into a hepatic encephalopathic coma within 8 days of starting the medication. Our review showed that valproic acid was prescribed on November 25, 2019 for intractable chronic migraine without aura and without status migrainosus. There was no evidence or suspicion of autoimmune hepatitis noted in the EMR at the time this medication was prescribed or after. While valproic acid can potentially cause fatty liver changes, those are typically of a specific type which were not reported on Ms. Henry’s biopsy. Her liver blood tests in May, 2020 were normal and her liver biopsy in August, 2020 was nearly normal with only very mild fatty liver disease changes. There was no significant fibrosis which means no significant scarring therefore she did not have evidence of cirrhosis at the time of the biopsy. In fact, it was the exact opposite with no evidence of scarring.



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Ms. Henry requested testing for porphyria during her visit with Dr. Safavi on April 23, 2020. Labs were ordered and a referral was placed for gastroenterology (GI) to evaluate. Notes from Ms. Henry's last visit with GI, on February 2, 2021, indicate her last endoscopy ultrasound did not reveal any neuroendocrine tumor in pancreas and no further GI evaluation was warranted at the time until all other metabolic/endocrinology issues had been addressed. Ms. Henry was being evaluated by endocrinology at an outside hospital at the time but had expressed a desire to transfer her care to TUKHS and a referral to TUKHS endocrinology was placed February 2, 2021. Another referral to TUKHS endocrinology was placed by neurology on March 26, 2021, but no visits with endocrinology were noted in the EMR. The hepatology specialty was also engaged by GI on May 22, 2020 to follow up on CT results indicating mild hepatomegaly with mild diffuse hepatic steatosis and recommendations, including follow-up in three years, were made.

Additionally, Mr. Clary shared that on January 15, 2020, TUKHS received a fax, 57 pages in total, from an outside hospital with records and these went to Dr. Safavi's office. He indicated a portion of these pages were uploaded to Ms. Clary's "My Documents," section of MyChart, and under "outside lab reports" in MyChart, a paragraph from a psychiatrist at an outside hospital was immediately visible. According to Mr. Clary, the paragraph insinuated Ms. Henry was "crazy, wouldn't accept her diagnosis and would continue to look for answers." He believes this information condemns his wife's mental health and has created bias among healthcare providers. It is important to note that physicians and staff do not access patients' EMRs through MyChart other than the use of the messaging functionality. Members of the healthcare team access patient information through a different view. Nevertheless, we are truly sorry this created any concern or anxiety on the part of either of you and wish to reassure you that TUKHS providers and staff are committed to providing world class care to everyone who seeks our expertise regardless of race, gender, socioeconomic status or any other factor.

Again, we have found no evidence that any diagnosis has been concealed by TUKHS providers and our review indicates care and treatment recommendations provided to Ms. Henry has been appropriate. We are truly sorry for the health concerns Ms. Henry continues to experience and for the resulting stress that accompanies these concerns. Thorough attention has been given to the complex nature of Ms. Henry's illness and numerous recommendations and appropriate referrals made in an effort to assist.

Sincerely,

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***Please note: This letter mailed on 7/17/23 and sent via secured email as well**