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Dear Healthcare Professional,

Cystinuria is an hereditary disease, which leads to the loss of cystine in the urine. Cystine is poorly soluble and causes large recurrent kidney stones. Cystinuria is significantly worse than run-of-the-mill kidney stone disease, because the size of the stones is much greater and the rate of recurrence makes it particularly hard to manage.

I have one of the largest cystinuria populations in the United States and, as part of the Rare Kidney Stone Consortium (www.rarekidneystones.org) I am funded by the National Institutes of Health and the Office of Rare Disease Research to study cystinuria. The disease is extremely variable and affects quality of life in a way that is can be quite difficult and unfortunate. It may be difficult to manage even with the best intentions and adherence to prescriptions. Our work demonstrates that cystinuria leads to significantly worse quality of life than common kidney stones.

Many patients have recurrent stones and require visits to Emergency Rooms. The diagnosis of renal colic in a patient with cystinuria is usually obvious. Failure of stone passage despite NSAIDs and Tamsulosin might warrant an ultrasound. CT scans can be reserved for more persistent renal colic as the young average age of onset leads to excessive radiation exposure over the course of a lifetime.

The most important means of prevention of stones is drinking lots of fluids. The result is the need to urinate frequently as well. People with cystinuria should be permitted to have liquids with them at all times and have liberal bathroom privileges as well.

Pain medications are often necessary on a chronic basis. While physicians usually claim that patients who do not have obstructing stones on imaging do not experience pain, this has not been supported by my clinical practice. Many patients have chronic pain syndromes that require chronic use of NSAIDs, opiates such as Percocet and Vicodin or methadone. Many patients with these chronic pain syndromes are able to

attend school and work if properly medicated. On the other hand, disability may result and some people simply cannot work or attend school for large periods of time.

I am happy to help take care of patients with cystinuria at a distance. If you have questions or comments regarding the management of cystinuria, you are welcome to email or call me any time. I appreciate your empathetic care of this deserving group of beleaguered patients.

Yours truly,

David

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