

AN INTRODUCTION TO FOP AND KIDNEY STONES



Individuals with FOP have an approximately threefold greater prevalence of kidney stones than the general population. In a 2017 study, 7.9–9.2% of all FOP participants reported at least one kidney stone, with a stronger prevalence in males. More than 50% of those with kidney stones had multiple stones. This study also found that greater immobility may be associated with an increased likelihood of kidney stones, an issue for individuals with FOP as they age (Gupta et al, 2018). Learning about how to prevent, identify, and treat a kidney stone is important for all individuals with FOP and their caregivers.

WHAT IS A KIDNEY STONE?

Kidney stones are hard, pebble-like masses that form in one or both kidneys when high levels of certain minerals are present in the urine. If treated, kidney stones rarely cause permanent damage. Kidney stones vary in size and shape. They may be as small as a grain of sand or as large as a pea. Rarely, some kidney stones are as big as golf balls. Kidney stones may be smooth or jagged and are usually yellow or brown. A small kidney stone may pass through the urinary tract on its own, causing little or no pain. A larger kidney stone that gets stuck can block the flow of urine, causing severe pain or bleeding. If no blood is present in the urine, passing a first kidney stone can sometimes mimic flare-up-like symptoms. Calcium stones, including calcium oxalate stones and calcium phosphate stones, are the most common types of kidney stones. Despite their name, kidney stones may form anywhere in the urinary tract.

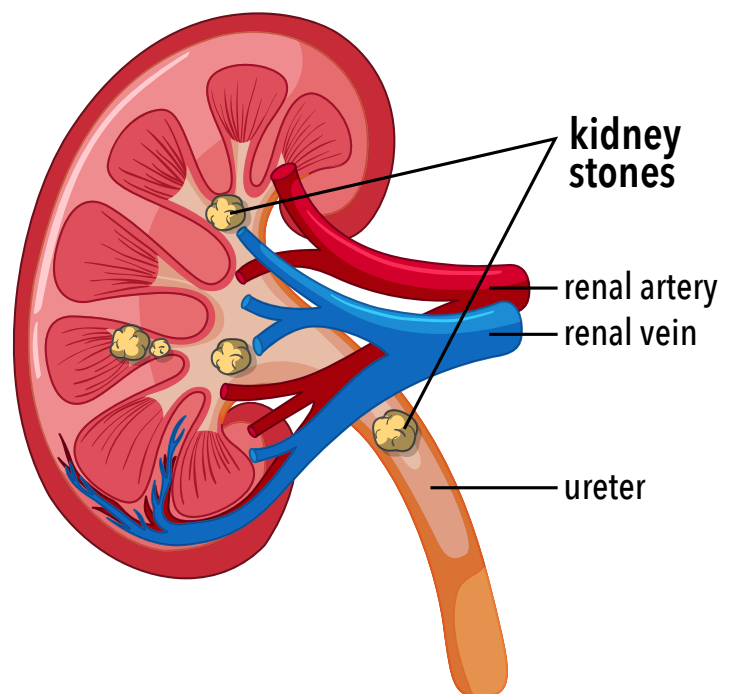
WHAT ARE THE RISK FACTORS FOR KIDNEY STONES?

» Immobilization caused by growth of heterotopic bone

is a significant risk factor in the development of kidney stones for people with FOP.

» Other risk factors include:

- Blockage of the urinary tract
- Certain kidney diseases
- Chronic bowel inflammation
- Digestive problems or a history of gastrointestinal tract surgery
- Gout
- Hypercalciuria or hyperoxaluria (i.e., high levels of calcium or oxalate in the urine)
- Hyperparathyroidism
- Hyperuricosuria (high levels of uric acid in the urine)
- Obesity
- Recurrent urinary tract infections (UTIs)
- Medications including some diuretics, calcium-based antacids, indinavir, and topiramate



WHY ARE KIDNEY STONES DANGEROUS?

Complications associated with kidney stones include hematuria (i.e., blood in the urine), severe pain, UTIs (including kidney infections), and loss of kidney function.

ARE THERE DIETARY MODIFICATIONS THAT CAN REDUCE THE LIKELIHOOD OF KIDNEY STONES?

Given the high prevalence of kidney stones in FOP, preventative measures are extremely important. These measures include eating a high-fiber diet, limiting the intake of animal proteins and oxalate-rich foods, avoiding vitamin C supplements and refraining from adding salt to food.



IS CALCIUM INTAKE SAFE?

It is a misconception that calcium intake can worsen heterotopic ossification. It is recommended that patients obtain the recommended dietary allowance (RDA) of calcium as per the Institute of Medicine 2011 guidelines, which is 1,000 mg of elemental calcium daily for adults aged 18–50 years old. It is recommended that calcium intake be obtained from diet (for example, milk, cheese, yogurt, or calcium-fortified foods like orange juice and almond milk), and that calcium supplements be limited. Excessive calcium intake, especially from supplements, can increase the risk of kidney stones.

HOW MUCH WATER SHOULD I DRINK?

Drinking adequate amounts of water, between 1.5 and 2.0 liters per day, is recommended.

HOW IS A KIDNEY STONE TREATED?

In the absence of being able to pass a kidney stone, a urologic surgical procedure may be necessary. These procedures are generally safe in FOP, but like other procedures, expert anesthesia assistance (since the jaw and neck may be completely or partially locked) and consultation with an FOP expert is required.



REFERENCES

- » Gupta RR, Delai PLR, Glaser DL, Rocke DM, Al Mukaddam M, Pignolo RJ, Kaplan FS. Prevalence and risk factors for kidney stones in fibrodysplasia ossificans progressiva. *Bone* 109: 120-123, 2018.

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Access additional resources for navigating care related to kidney stones by visiting ifopa.org/fop-and-kidney-stones. These resources include links to the most current FOP Treatment Guidelines and videos of presentations on the topic.

This information is provided for educational and informational purposes only and does not constitute providing medical advice, training, or professional services. The information provided should not be used for diagnosing or treating a health problem or disease, and those seeking personal medical advice should consult with a licensed physician. Always seek the advice of your doctor or other qualified healthcare provider regarding your medical condition.

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