

DATA SUPPLEMENT

- A. Gout Self-Management Examination
- B. Gout Curriculum

SUPPLEMENTARY DATA “A”:

Gout Self-Management Examination - Before First Visit and at 6 and 12 Months

Please circle the letter that corresponds to your answer for each question.

1. If you have been taking a maintenance (long-term) gout medication (such as allopurinol) for 6 months and are not having any gout flares:
 - a. You should still avoid triggers of gout
 - b. You are probably cured of gout
 - c. It is OK to skip some doses of medicine
 - d. Your uric acid level is high
 - e. I don't know
2. If you take your long-term (maintenance) gout medication regularly for 2 years, you will most likely:
 - a. Have fewer flare-ups
 - b. Learn to live with pain
 - c. Stop your gout attacks
 - d. Learn the best medications for pain
 - e. I don't know
3. Triggers of gout can include which of the following:
 - a. Alcohol intake
 - b. Dehydration
 - c. Meat gravies
 - d. Running on a foot with a gout attack already started
 - e. All of the above
 - f. I don't know
4. If you avoid all possible triggers of gout, and follow a careful diet, you will:
 - a. Control your gout
 - b. Control your gout, (but only) if you also take your medicines
 - c. Likely get your uric acid to goal
 - d. I don't know
5. If you have been taking allopurinol or febuxostat and your gout is under control you should:
 - a. stop the allopurinol or febuxostat
 - b. continue taking the medication
 - c. continue the medication until you run out of all the pills
 - d. try taking the medication every other day
 - e. I don't know
6. When you start your maintenance (long-term) medication for gout, such as allopurinol, and a bridge medication, such as colchicine, your doctor is likely to advise you to:
 - a. Stop the bridge medication, such as colchicine, in 3 months

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- b. Stop your maintenance medication in 3 months, unless you have more attacks
 - c. Stay on the bridge medication for the first six months, then stop, but continue the maintenance medication
 - d. Take your maintenance medication every other day.
 - e. I don't know
7. If you are having a gout flare (attack) your doctor is likely to advise you to:
 - a. Take a rescue (attack) medication such as a non-steroidal anti-inflammatory medication (such as naproxen), corticosteroids (such as prednisone), or colchicine
 - b. Increase impact exercise to the joint in order to relieve the inflammation (swelling)
 - c. Not add any other medicines, as no additional gout medicines are necessary.
 - d. Stop your maintenance medication (such as allopurinol)
 - e. I don't know
8. If you have been given a 4 day plan for rescue medications (such as prednisone) and at the end of the 4 days the joint is still swollen, you should:
 - a. Take more of the rescue medications
 - b. Call your doctor to discuss the next step
 - c. Start exercising
 - d. Double your maintenance (long-term) medication
 - e. I don't know
9. What is the most important difference between people who get gout and people who don't?
 - a. Their weight
 - b. Their diet
 - c. Their genetic makeup (their genes)
 - d. How much and what type of alcohol they drink
 - e. I don't know
10. Bridge medications for gout (taken for a specific period of time to prevent problems with another medication) include:
 - a. Colchicine
 - b. Allopurinol
 - c. Febuxostat
 - d. All of the above
 - e. I don't know
11. Lab draws of your blood:
 - a. Will be used to monitor your blood uric acid level
 - b. Are not needed if you are not having gout flares
 - c. Cannot tell us anything about your gout
 - d. Are not important for finding side-effects of medication
 - e. I don't know
12. The most important factor in how your gout does over time is:
 - a. What you eat
 - b. Whether you drink alcohol
 - c. Whether your uric acid is kept below 6
 - d. How well you learn to live with pain
 - e. I don't know

Questionnaire given to subjects at entry, 6 and 12 months.

Answer key: 1) a, 2) c, 3) e, 4) b, 5) b, 6) c, 7) a, 8) b, 9) c, 10) a, 11) a, 12) c.

SUPPLEMENTARY DATA “B”:

GOUT SELF-MANAGEMENT EDUCATIONAL CURRICULUM: WHAT DO YOU NEED TO KNOW TO HAVE THE BEST GOUT OUTCOME?

What is Gout?

Gout is a painful form of arthritis in which high levels of uric acid build up in the blood. The uric acid **is deposited in the joint** as needle-shaped crystals, causing inflammation, with swelling, pain, and redness. The most common joint to be affected is the big toe, but other joints like the ankles, knees, hands, wrist, and elbows can also be affected.

What does a gout attack look like?

A gout attack usually develops suddenly, with a swollen, red, tender and warm joint. It often is in just one joint, but may be in more than one joint at a time. Common locations are mentioned above.

Why do I have Gout?

- Genes: Gout is genetic – even if you can’t recall a family history of gout.
- Gender: Gout is more common in men, but a number of women get gout, especially after menopause.
- Weight: Being overweight increases uric acid and the risk of developing gout
- Diet: Eating a diet rich in purines can set off gout (details below).
- Alcohol: increases uric acid level.
- Medications: most diuretics can increase uric acid level.

Can Gout Attacks be stopped? What’s the long-term picture?

Gout attacks can be very successfully treated, but more importantly they can be prevented by the right medications and changes in diet. The success rate of preventing gout is excellent if the treatment plan is followed carefully. Close to 95% of gout patients can be gout-free, essentially “cured” of gout with 1-3 years, sometimes sooner, if they stay on their medication. Without treatment, gout is known to get steadily worse over the years, with more frequent attacks.

Understanding Medications for Gout:

What are the 3 groups of medications taken for gout?

- **Rescue medications:** taken for attacks. They help calm swelling and pain. These include NSAID’s (non-steroidal anti-inflammatory agents) such as naproxen, anti-inflammatory steroids (such as prednisone or methylprednisolone), colchicine and local steroid injections.
- **Maintenance medications:** taken to lower uric acid to prevent future attacks. These medicines need to be taken long-term, indefinitely. These include allopurinol, febuxostat and probenecid.
- **Bridge medications:** Temporary gout medications, most often taken during the first 6 months of the use of maintenance medications (sometimes longer) to prevent flares. This is because flares (attacks of gout) can sometimes increase when you start a maintenance medication. Colchicine is the most studied bridge medication, and sometimes a non-steroidal anti-inflammatory agent (such as naproxen) or low-dose prednisone is used.

Medications for Gout – Fast Facts on the most common gout medications

See above for definitions of maintenance, bridge and rescue medication. It’s very important for gout patients to know which type each of their medications is. For example, a maintenance medication (such as allopurinol) that can completely prevent gout attacks in the future, will not help treat an attack you are having right now. Gout patients need to know each type of gout medications, as each of them work in different ways!

1. Allopurinol

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- a. Which type of gout medication: Maintenance/ “long-term”
- b. Why to take: lowers uric acid, for long-term prevention of attacks
- c. How it works: decreases body’s production of uric acid
- d. How to take: once a day, with or without food
- e. For how long to take: indefinitely
- f. What side-effects to watch out for: skin rash. Get labs tests to check liver.

2. Febuxostat

- a. Which type of gout medication : Maintenance / “long-term”
- b. Why to take: lowers uric acid, for long-term prevention for attacks
- c. How it works: decreases body’s production of uric acid
- d. How to take: once a day, with or without food
- e. For how long to take: indefinitely
- f. What side-effects to watch out for: skin rash. Get labs to check liver.

3. Colchicine

- a. Which type of gout medication: Bridge. (Can also be used as Rescue)
- b. Why to take: decreases ability of uric acid crystals to cause inflammation (helps to prevent gout attacks and to make any attacks you get milder).
- c. How it works: makes uric acid crystals less active in causing inflammation
- d. How to take: with food.
- e. For how long to take: as Bridge medication, usually 6 months. As Rescue, 2 pills at onset of attack and one pill an hour later in most cases.
- f. What side-effects to watch out for: diarrhea. Blood counts will be followed.

4. Corticosteroids (prednisone, methylprednisolone)

- a. What type of gout medication? Rescue (for attacks of gout).
- b. Why to take: Stops the inflammation caused by uric acid crystals. Calms pain and swelling
- c. How it works: Anti-inflammatory
- d. How to take: with food, following specific instructions you’ll be given
- e. For how long to take: until attack fully gone, or until end the course your doctor prescribes (then call if not improved)
- f. What side-effects to watch out for: if diabetic, rise in blood sugar. Agitation or insomnia, rise in blood pressure, ankle swelling.

5. NSAID’s (non-steroidal anti-inflammatory drugs (e.g. naproxen, indomethacin, celecoxib)

- a. What type of gout medication: Rescue (for attacks of gout).
- b. Why to take: Stops the inflammation caused by uric acid crystals. Calms pain and swelling
- c. How it works: Anti-inflammatory
- d. How to take: with food, as directed
- e. For how long to take: until the attack is fully gone, or until end of the course your doctor prescribes (then call if not improved)
- f. What side-effects to watch out for: stomach upset, ankle swelling, rise in blood pressure.

Lifestyle/Dietary Issues and Gout

In addition to taking your medication as prescribed, there are many steps you can take to stay healthy and reduce the effects of gout. **Avoid or decrease foods that are high in purines:** organ meats: liver, kidney, brain, sweetbreads, game meats, anchovies and sardines, meat extracts and gravies and shellfish.

1. **Avoid foods high in high fructose corn syrup** (such as regularly sweetened sodas) – these raise uric acid.
2. **Limit alcohol** as much as you can, especially when you are first starting a maintenance medication. Beer seems to be the worst type of alcohol for gout, but *all types of alcohol*, including wine and spirits, are associated with increased risk of gout attacks.

3. No limits on dairy products. Vegetables, even those which have mildly high purine content (such as asparagus) do *not* seem to be a problem with gout and don't need to be limited.
4. **Exercise regularly**, and try to lose weight if you are overweight: maintaining an ideal weight is especially important because obesity increases uric acid.
5. **Drink good amounts of fluid** (trying to avoid using regularly sweetened sodas, since they have a lot of high fructose corn syrup and can raise uric acid), since dehydration can set off gout, and a good fluid intake can help prevent gout-related kidney stone.
6. If you get a gout attack in your foot, stay off your feet as much as you can since this can help the attack get better.

What can trigger a gout attack and what should be done about it?

Alcohol, high purine foods (such as red meats and shellfish), high impact on the foot, as in running or injury, dehydration, or adding a medication such as a diuretic that increases uric acid—all can set off a gout attack. Often, though, an attack can come on without an obvious trigger.

If an attack of gout seems to be coming on:

- **Rest the joint** – especially avoid high impact on that joint. Local ice to the joint can help,
- Most important is to start your “rescue” medication as soon as possible after the attack starts. If you don't already have a plan with your doctor for which rescue medication to take, call your doctor as soon as possible and get started. Early treatment is very important for gout attacks. Make sure you talk to your doctor about making a plan for what to do when you feel attack coming on.

Importance of Keeping Lab and Doctor Appointments

Lab appointments: Uric acid levels in your blood are directly related to how your gout does, in the long term. Gout maintenance medications are extremely effective at lowering uric acid, but the dose needs to be adjusted to the right level for you, to bring your uric acid below 6. Lab testing can also pick up certain side-effects of gout medication. *It is not enough to take a gout maintenance medication—you need to have the medication adjusted to a dose right for you.*

Doctor's appointments: Even if you feel you are generally doing well, doctor's visits early in gout management are very important, to make sure you are at the right dose of your maintenance medication, that you are tolerating your bridge medication, and that you are using your rescue medication appropriately.

Summary: What are the most important things in controlling gout?

- **The uric acid must be brought below 6** (for some patients below 5).
- Certain foods and medications can increase uric acid (discussed above). It's important to follow a careful diet and check with your doctor about other medications you are taking.
- Increased body weight increases uric acid; losing weight and staying at a healthy weight helps.
- We have medications that very successfully lower uric acid, and most people can't get to their goal of below 6 without medication. It's important to stay with the dose of medication you are given, since the dose is chosen to get the uric acid to the right level.
- Gout attacks can be very successfully treated, and future attacks can be prevented. Proper treatment with medication, diet and lifestyle changes, can help most patients be “gout free” within 1- 3 years, and often much sooner.