**Top Tips on Taking Hydroxychloroquine for Lupus**

(Practical Guidance for Patients)

Full article online for patients at:

**lupusencyclopedia.com/top-tips-on-taking-hydroxychloroquine-for-lupus**

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The Lupus Encyclopedia

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Taking hydroxychloroquine for systemic lupus erythematosus (SLE) is considered the most important drug for lupus. It is the only drug proven to prolong survival and is one of just a few drugs shown to reduce organ damage from SLE. The [SLE management guidelines](https://linkinghub.elsevier.com/retrieve/pii/S0003496724003868) recommend that all SLE patients should be taking hydroxychloroquine (or chloroquine).

This article goes over how to take hydroxychloroquine in the best ways to be most effective while also reducing the risk of side effects.

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**NOTE: Johns Hopkins University Press, publisher of**[**The Lupus Encyclopedia**](https://www.amazon.com/Lupus-Encyclopedia-Comprehensive-Patients-Providers/dp/1421446847/ref=sr_1_1_sspa?crid=2KXJSAWLKWZCH&dib=eyJ2IjoiMSJ9.R8Xi4J2PMKmKzBxylmGbtunJG2FbM-5-AsjnRMVO5c6y2CGWcFEuZCGHMKJ9a_ewS3vTPvv00GsKNOa8kMkmCoXwniitiqfnd2f7Q6neocgV3ttr6ERmu9cvAZ4YXvofpaTWI8_YgWXldsTDQ-axCn6HTzWrAaNOiNqbReaiQJ11kKenHZSkwBhDVRsitSfDWnhA9TGYql3sIBrxaL-wq8BOHq7QpPKMGxz9duF5go7sFcp_wKszxpciN61ttfY_mUt6nG7FoJ8FPiDQ1n1GI4rbBN4XcGk_jOOgAW3CZNY.fIdB2N4PbyHZ98godCLWxERb8_9xPGj-lINBcEerVbo&dib_tag=se&keywords=lupus&qid=1736102348&sprefix=lupus%2Caps%2C110&sr=8-1-spons&sp_csd=d2lkZ2V0TmFtZT1zcF9hdGY&psc=1)**, is a nonprofit publisher. If you purchase JHUP books, like The Lupus Encyclopedia, you support projects like**[**Project MUSE**](https://en.wikipedia.org/wiki/Project_Muse)**.**

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PREVIOUS UPDATES

**May 2025**: Added that the ACR “[**SLE Treatment Guidelines**](https://rheumatology.org/lupus-guideline)” recommended that we consider [***higher doses when first using HCQ (called using loading doses)***](https://www.lupusencyclopedia.com/top-tips-on-taking-hydroxychloroquine-for-lupus/#load) and during flares so it works better and faster (up to 6.5 mg/kg/day)

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A study by Dr. Shivani Garg suggests that [aiming for a hydroxychloroquine level of 750 to 1200 ng/mL is optimal for most patients](https://acrjournals.onlinelibrary.wiley.com/doi/10.1002/acr.25228). (For high-risk patients, I prefer 1000 to 1200 ng/mL)

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[A nicely done study by Melles RB et al, FEB 2023](https://www.lupusencyclopedia.com/top-tips-on-taking-hydroxychloroquine-for-lupus/#dosing), **Hydroxychloroquine Dose and Risk for Incident Retinopathy A Cohort Study**, resulted in this nice quote: “[**our findings suggest that, under current screening recommendations and dosing patterns, loss of visual acuity from hydroxychloroquine retinopathy should be rare**](https://www.acpjournals.org/doi/10.7326/M22-2453)“

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[**Update (DEC 2022): Harvard study showing that using hydroxychloroquine doses of 5mg/kg/day or less (as recommended by the American Academy of Ophthalmology) are associated with high risk of flares compared to using higher doses. Click here to jump to that section of the page.**](https://www.lupusencyclopedia.com/top-tips-on-taking-hydroxychloroquine-for-lupus/#5mg)

**A simpler desensitization technique for hypersensitivity rashes is linked to (DEC 2022)**

**Addition in August 2023**: Do not smoke cigarettes. Discussed below

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[**Brand name Plaquenil is more tolerable and works better than generics for some people**](https://www.lupusencyclopedia.com/top-tips-on-taking-hydroxychloroquine-for-lupus/#plaquenil)

**Never smoke when taking hydroxychloroquine**

Smoking cigarettes decreases the effectiveness of antimalarial drugs like hydroxychloroquine. If you smoke, you are keeping the most important drug for treating lupus from working properly. This puts you at high risk for needing stronger drugs that suppress the immune system (like steroids). If you require immunosuppressant drugs, then smoking also greatly increases your risk for life-threatening infections, especially pneumonia.

**Smoking cigarettes as a lupus patient is equivalent to having an early death wish.**

**The benefits of taking hydroxychloroquine for lupus**

As recommended by “[The Lupus](https://www.lupusencyclopedia.com/lupus-secrets/)[Secrets](https://www.lupusencyclopedia.com/lupus-secrets/),” taking hydroxychloroquine (Plaquenil) for lupus is incredibly important. In addition to being the only drug proven to prolong survival in lupus patients, the [benefits of hydroxychloroquine](https://link.springer.com/article/10.1007/s40674-016-0036-9) are many:

* [**Greatly increases the chances of living longer for lupus patients**](https://www.lupusencyclopedia.com/hydroxychloroquine-decreases-deaths/)
* Reduces the need for steroids (for example, prednisone). Allows lower doses to be used, therefore decreasing steroid side effects.
* Lowers the chances for organ involvement (such as the kidneys and lungs)
* [Reduces the chances of heart attacks](https://www.sciencedirect.com/science/article/pii/S2052297520300998), blood clots, and strokes
* Decreases the chances for organ damage (such as in the kidneys and lungs)
* Lessens the possibility of developing diabetes, and [it improves glucose sugar control in those with diabetes](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4206615/)
* [Lowers bad cholesterol levels](https://journals.sagepub.com/doi/abs/10.1177/09612033221090127)
* [Increases healthy birth outcomes](https://www.lupusencyclopedia.com/successful-lupus-pregnancy/) and reduces the chances of a baby getting neonatal lupus or congenital heart block due to [anti-SSA](https://www.lupusencyclopedia.com/know-your-lupus-labs-anti-ssa/) (anti-Ro) antibodies
* [Increases the chances for lupus remission](https://journals.sagepub.com/doi/10.1191/0961203306lu2313oa)

To understand why antimalarial drugs help lupus patients, see my previous blog on  
“[How does hydroxychloroquine work for lupus?](https://www.lupusencyclopedia.com/how-do-antimalarial-drugs-work-for-lupus/)”

**Do I have to take hydroxychloroquine with food?**

**No**. You do not have to take hydroxychloroquine with food.

Many patients have lupus flares due to missing doses of hydroxychloroquine due to stickers on the bottle saying, “take with food.” However, this does not apply to most people.

The main reason to take hydroxychloroquine with food is if it bothers your stomach. In some people, hydroxychloroquine causes stomach upset, nausea, bloating, heartburn, or loose stools. If any of these happen, take it with food or milk.

Taking smaller amounts at a time (as discussed below) is also helpful.

Also, taking something like **bismuth subsalicylate** (like **Pepto Bismol**) with your hydroxychloroquine can reduce gastrointestinal issues.

**Can I cut my hydroxychloroquine pills in half?**

Some patients are told by pharmacists not to cut their pills in half. We often prescribe 300 mg of hydroxychloroquine daily, and the typical recommendation is to cut some of the pills in half ([using a pill splitter](https://www.amazon.com/Multiple-Splitter-Alignment-Splitting-Quartering/dp/B00JMHZ5BG/ref=sr_1_22_sspa?crid=3LY5YCSNIKN3V&dib=eyJ2IjoiMSJ9.9Hb3qGsoDb7NpOX4yxYYWwBBKNMP5QCW3VcoS3D6Mtjq9Gq5IbwgLeICWhdvINX1eqonRd6PkL7XSAhe2fBC1NPPuGcQ9tD9-AeE9J0EW4FBgSPlQFABEBRl3FbTWqBofla9PXEPNVBVEkv4oXvwNzUZL_MiRngNSWDaAt7ddDlUbXyM69Tv07n7JypNb6QSaxrolo36oUasM9zldPCv9H2PHt4XucW7QJp8mJX9l68JJoJIXu0HB0hjm8RD684PkthcCaT0wRz2RUhtTdLcW_nQw5t-gQD_hr7JJAkjvyw.aqVnQYiO2lgE5wmUt5olhI_ojWBSHy2avXO5gMgWqHI&dib_tag=se&keywords=pill+splitter+blue+oval+shaped&qid=1716917745&sprefix=pill+splitter+blue+oval+shaped%2Caps%2C125&sr=8-22-spons&sp_csd=d2lkZ2V0TmFtZT1zcF9tdGY&psc=1)) and take 1 1/2 tablets daily of the 200 mg tablets.

The manufacturer put in the package insert not to cut the pills in half for two reasons: First, the cut pill can have an unpleasant taste. However, I’ve had no patients complain of this. The second reason is that the tablets are not scored for cutting. However, we rarely have patients complain of the taste.

Regarding not being scored, this is OK. If someone doesn’t cut the pill exactly in two equal-sized pieces, this does not interfere with how well it works. In pharmaceutical terms, hydroxychloroquine has a very long half-life (very slow to get out of the body’s system, but also very slow to work). Therefore, having more on one day and less on the next day does not interfere with how well it works.

Some patients prefer to take 300 mg a day (on average) by taking 2 tablets, alternating with 3 tablets every other day. Taking 400 mg on one day (2 tablets) and 200 mg on the alternate day (1 tablet) averages out to 300 mg a day and works just as well as taking 1 1/2 tablet a day. People who do not like the taste or who do not like cutting tablets usually prefer this method.

**What should I do if you miss doses of hydroxychloroquine?**

Missing doses of hydroxychloroquine is a common cause of lupus flares. However, there are things you can do to decrease the chances of missed doses:

If you miss a dose of hydroxychloroquine, you can **make up for the missed dose on the next day** (if you tolerate doing this without stomach upset or other problems from taking a higher amount). Again, ask your doctor first before you do this. However, this does very well for most people.

For example, if you take two tablets at the same time once daily and realize you forgot your dose yesterday, you can make up for this missed dose by doubling the amount today. Take two tablets in the morning and two in the evening on the day after you forgot your dose. This is possible because hydroxychloroquine has a long “half-life.”

This is one of the most important things you can learn to do with lupus. Having the correct hydroxychloroquine drug level (discussed below) by not missing doses is important for decreasing the risk of lupus flares.

How to keep from missing hydroxychloroquine doses

There are other things you can do to decrease the chances of missed doses:

* Take all the pills at once daily. When doctors put “take two tablets daily” on the medication bottle label, some people interpret that as taking one at a time twice daily. However, it means to take both at the same time once a day. Taking medications all simultaneously once a day makes it much easier not to miss doses of medications. Double-check with your doctor what medicines should not be taken with other drugs.
* Use a medicine **dosing and packaging pharmacy** (like [Pill Pack](http://pillpack.com/)). They prepackage your medicines by date and time. For example, if you take five different pills in the morning and just two at night, they are packaged that way instead of the usual method (all of the same drug in the same bottle). This makes it easy. You do not have to arrange the pills yourself, and it is easy to notice if you are late or forgot to take a dose of medication.
* In addition to the usual 200 mg tablets, hydroxychloroquine is also available in 100 mg, 300 mg, and 400 mg tablets.

**Why consider alternative tablet strengths?**

* + These could help with compliance and tolerability.
  + For example, if you take 1 ½ of the 200 mg tablets daily, taking one 300 mg tablet a day may be better if you sometimes forget to cut up the pills.
  + You can also do this if you cannot tolerate the cut-up pills due to their [bad taste](https://jamanetwork.com/journals/jama/article-abstract/393453).
  + If you do not tolerate ½ of a 200 mg tablet at a time (100 mg), you may want to try taking ½ of the 100 mg tablet at a time. If someone is extremely sensitive to hydroxychloroquine, taking ½ of a 100 mg tablet three times daily may be as much as they can tolerate. This is only 150 mg daily, but it is better than not taking it at all.

**What should I do if I get side effects from hydroxychloroquine?**

Most side effects from hydroxychloroquine are what we consider “nuisance-type” and not severe reactions. They are also typically “dose-related,” meaning that they are more likely to occur at higher doses and less likely at lower doses.

I will address rashes and eye problems in a separate section below.

**Nuisance-type side effects** include nausea, diarrhea, stomach upset, feeling wired, anxious, having bad dreams, insomnia, dizziness, headaches, and others.

How to take hydroxychloroquine without side effects

If these occur, I recommend that my patients do the following (ask your doctor first, but the vast majority will agree with this approach):

* Stop your hydroxychloroquine until the side effect disappears and you return to your normal self.
* Then start again at a very low dose, such as ½ tablet once daily.
* Taking it with food or milk in the evening improves tolerability. However, if you have trouble sleeping or get nightmares from hydroxychloroquine, take it in the morning instead of the evening.
* After three to seven days, increase your dose by a tiny amount, such as taking ½ tablet in the morning with food and ½ tablet in the evening.
* Three to seven days later, increase the dose again by a small amount (unless the above is already at your total quantity), such as taking ½ tablets three times daily with food.
* Three to seven days later, see if you can combine any of your doses, such as ½ tablet in the morning and a full tablet in the evening
* Three to seven days later, if your full dose is 400 mg daily, take a full 200 mg tablet in the morning and a full 200 mg tablet in the evening. Some people may do best by taking ½ pill in the morning, ½ tablet midday, and one full tablet in the evening.
* **Very Important**: At any point, if you get any of the side effects at all (for example, even just a slightly upset stomach), DO NOT CONTINUE THAT DOSE. We do not want you to feel bad. Instead, go down to the previous dose that you tolerated well. Figure out the highest amount you can handle that does not give you any side effects.

**Can I still take hydroxychloroquine for lupus if I get an allergic rash from it?**

If your rash was not severe, you could often get your body to tolerate it through a dosing technique called “desensitization.”

(Examples of severe rashes, after which you do NOT want to try taking hydroxychloroquine again, include things like Stevens-Johnson syndrome and toxic epidermal necrosis. Ask your doctor first).

With 100 mg tablets now available, desensitization has become much easier.

You first need to stop the hydroxychloroquine until the rash has completely disappeared. Then, I recommend the following, which is not too different from a published [hydroxychloroquine desensitization technique](https://ard.bmj.com/content/annrheumdis/77/Suppl_2/696.1.full.pdf). Do NOT do this without your doctor’s permission:

**How to take hydroxychloroquine after having a rash (desensitization)**

* Take ¼ of a 100 mg hydroxychloroquine tablet once daily. NOTE: This does not need to be exact. A little smaller or a little bigger than a ¼ tablet is fine.
* After three days, take ¼ tablet two times a day.
* Three days later, take ¼ tablet three times a day.
* Three days later, take ½ tablet in the morning and ½ tablet at night
* Keep following a similar pattern, increasing by ¼ tablet every three days until you reach the total target dosage. Your doctor can then give you larger tablets (such as 200 mg) at that time.
* If you get a rash, immediately stop taking hydroxychloroquine until the rash disappears.
* Write down the previous dose of hydroxychloroquine that you took before the rash occurred. That will be your largest tolerable dose for you.
* After the rash disappears, restart the desensitization at ¼ of a 100 mg tablet daily and slowly increase it per the above instructions.
* When you reach the maximum dose you wrote down above, stop there and stay on that dose.

**What can I do if hydroxychloroquine is too expensive for me?**

Go to a **prescription coupon source** (such as [GoodRX](http://goodrx.com/" \t "_blank)) and download the coupon. Take it to your pharmacy to pay for the prescription. For example, today (September 2022), you can get 180 of the 200 mg tablets for $42 ($14 a month if you take two pills a day or 400 mg daily).

**What is the best dose of hydroxychloroquine to take?**

Dosing HCQ by Body Weight and Its Flaws

Most rheumatologists dose hydroxychloroquine at a dose of no more than **5 mg per kilogram of actual body weight per day**.

An uncomplicated way to remember the amounts is that someone who weighs 135 pounds to 170 pounds would take 300 mg daily. Someone less than 135 pounds would take 200 mg daily, and someone more than 170 would take 400 mg daily.

However, this dosing recommendation is controversial and has many critics (including myself). This is the 2016 recommended dosing by the American Academy of Ophthalmology (AAO). However, it is based on only one study that looked at dosing to prevent eye complications (retinopathy). It did not look at the effectiveness of this dosing recommendation, and the way it looked for eye complications did not use the best research methods.

A 2022 Harvard study supports this view. Their [**systemic lupus patients who were taking HCQ at the AAO recommended dose of no more than 5mg/kg/d were twice as likely to have lupus flares**](https://jamanetwork.com/journals/jama/fullarticle/2796634) compared to those taking higher doses. Even worse: They were six times more likely to have moderate to severe flares, which are associated with a high risk of increasing permanent organ damage. This should be a call to arms by all rheumatologists to start using HCQ drug levels as described below to manage their lupus patients optimally.

*Jorge AM, Mancini C, Zhou B, Ho G, Zhang Y, Costenbader K, Choi HK. Hydroxychloroquine Dose per Ophthalmology Guidelines and the Risk of Systemic Lupus Erythematosus Flares. JAMA. 2022 Oct 11;328(14):1458-1460. doi: 10.1001/jama.2022.13591. PMID: 36112387.*

**Dr. Thomas Recommends Using Hydroxychloroquine Drug Levels to Adjust Doses**

Since hydroxychloroquine drug levels have become available, many of us find that [some patients need higher doses than recommended](https://lupus.bmj.com/content/6/1/e000335), while others need lower doses.

**HCQ Has a Wide Range of Absorption and Bioavailability**

Many to most rheumatologists dose HCQ by body weight (5 mg/kg/day or lower). The problem with this, is that this recommendation is not based on good science at all. [HCQ has a wide bioavailability (eg absorption) of 50% – 91%](https://bpspubs.onlinelibrary.wiley.com/doi/10.1111/j.1365-2125.1993.tb00388.x). Dr. SE Tett and his colleagues (pharmaceutical kinetic experts) did the most thorough studies on this topic and made the statement (on [*page 410 of their 3rd hydroxychloroquine absorption study*](https://bpspubs.onlinelibrary.wiley.com/doi/10.1111/j.1365-2125.1993.tb00388.x)) that many patients will be underrated:

***“This variability in fraction absorbed is likely to be of clinical significance as subjects with lower bioavailability may be under-treated.”***

In fact, this has now been proven in several studies where SLE patients dosed by body weight below 5 mg/kg/d often have subtherapeutic HCQ drug levels and have significantly higher rates of disease activity, disease flares, and hospitalization rates.

It is simply ridiculous to dose a drug by body weight with such a wide range of absorption. Testing drug levels is much more accurate and makes much more sense in order to reduce flares by ensuring the HCQ drug level is at least 75 ng/mL and to ensure a lower risk for eye problems by ensuring the level is below 1200 ng/mL. This is truly precision medicine.

In addition, the American College of Rheumatology’s “SLE Treatment Guidelines” specifically mention using 5 mg/gk/d to 6.5 mg/kg/d

**Consider High-Dose HCQ Initially (Loading-Doses) to Work Faster and During Flares**

Kudos to the American College of Rheumatology for their 2025 “[***SLE Treatment Guidelines***](https://rheumatology.org/lupus-guideline).” They include that health care providers should consider:

***5.0 – 6.5 mg/kg/day initially when initiating HCQ and also temporarily during disease flares.***

For over 2 decades, I have “loaded” HCQ with 200 mg three times daily for the first 1-2 months. It works faster this way. Otherwise, it is too slow. When it works faster, we can reduce disease activity quicker and reduce the need for steroids.

**Ask Your Rheumatologist to Measure HCQ Drug Levels**

I recommend asking your rheumatologist (or other doctors) to check a “whole blood hydroxychloroquine drug level” every time you have labs done. Make sure it says “whole blood.” There are other methods for hydroxychloroquine drug levels that are unhelpful. Quest and LabCorp (the two most common commercial labs in the United States) do this test. In addition, most insurances cover the test.

The **best timing for the drug level is right before your scheduled dose (called a trough level).** However, this is not always practical. The second best alternative is to not take your hydroxychloroquine on the day of your blood tests until after your labs are done. If you take hydroxychloroquine and then get your labs done a few hours later, your level can end up being artificially much too high (an inaccurate result).

**Target Levels and Why They Matter**

“Regularly measuring hydroxychloroquine drug levels should become the standard of care in the management of all patients who have lupus”

*Dr. Michelle Petri, Medical Director, Johns Hopkins Lupus Center*

The perfect “sweet spot” goal would be to have a trough, whole-blood [**hydroxychloroquine drug level of 750ng/mL to 1200 ng/mL for most patients**](https://acrjournals.onlinelibrary.wiley.com/doi/10.1002/acr.25228). However, for high-risk patients, patients with severe disease, and patients who flare, I prefer 1000 to 1200 ng/mL. [Studies by Dr. Nathalie Costedoat-Chalumeau show that patients with levels less than 1000 ng/mL are four times more likely to flare](https://pubmed.ncbi.nlm.nih.gov/17009263/) than those with higher levels.

When my patient has been faithfully taking their medication regularly, then I know this level is accurate. If the level is too low, I increase their dose. If the level is too high, then I lower the dose.

If a patient just started taking hydroxychloroquine for lupus, it is important to wait at least 1 1/2 months before checking their drug level. After adjusting a dose in someone who has been on it for a while, the level can be checked a month after the dose change. If the drug level is not above the target level, I adjust the dose.

However, it is not easy to get it exactly at this level. A level of 750 to 1500 is more realistic for many patients. A few patients may need a level as high as 2000 ng/mL to keep their lupus under control. I do not allow levels greater than 2000 in my patients to reduce their risk for hydroxychloroquine retinopathy.

The reasoning for keeping it above 1000 ng/ml is that this has been shown to [lower lupus flares](https://onlinelibrary.wiley.com/doi/epdf/10.1002/art.22156), decrease overall disease activity, and [decrease the risk of strokes, blood clots, and heart attacks](https://onlinelibrary.wiley.com/doi/10.1002/art.41621).

The reasoning for keeping it less than 1200 ng/mL (up to 2000 ng/mL max) is to decrease the risk for side effects, such as [eye problems (retinopathy)](https://onlinelibrary.wiley.com/doi/10.1002/art.41121), [stomach upset, and dark skin pigmentation (hyperpigmentation)](https://www.sciencedirect.com/science/article/abs/pii/S0248866316304660?via%3Dihub).

**Skin Pigmentation when Taking Hydroxychloroquine for Lupus**

As mentioned in the previous paragraph, hydroxychloroquine (and chloroquine) can cause increased pigmentation of the skin. We call this “[***anti-malarial hyperpigmentation***](https://www.lupusencyclopedia.com/book-photos/#pigment).”

It most commonly occurs after years of use, but can occur after just months in someone who is on blood thinners like aspirin. The lesions are typically brownish, bluish, or black and most commonly occur around the shins, tops of the hands, neck, face, nails, the gums and the upper palate in the mouth. It appears that this pigmentation occurs most commonly in areas of bruising, trauma, pressure, and in those who take blood thinners (even turmeric or ginger supplements).

Reducing the dose of the medication can help decrease worsening and occasionally help the pigmentation decrease in severity. However, it is permanent in most patients.

Quinacrine can  cause a yellowish discoloration. When this occurs in the whites of the eyes (sclerae) it can be mistaken for jaundice and patients sometimes end up undergoing an unneeded liver workup.

**When Hydroxychloroquine Causes Skin Itching**

An underrecognized problem when patients take hydroxychloroquine (HCQ) for lupus is a problem called “aquagenic pruritis.” [Aquagenic pruritis occurs in approximately one out of every 20 patients taking HCQ](https://pubmed.ncbi.nlm.nih.gov/11243651/). Typical symptoms are intense itching after taking a warm shower or bath. It is not an allergic reaction; histamine receptors do not play a role. Therefore, anti-histamines do not work. Instead, it is due to irritation of special small-fiber “itch nerves” from the HCQ.

**Methods of reducing the itching from hydroxychloroquine-induced aquagenic pruritis:**

* take cooler showers and baths
* take HCQ immediately after your shower (therefore drug levels are at their lowest when you shower or bathe)
* sometimes, the HCQ dose may need to be reduced (but we try not to do this if we do not need to)
* medications that reduce itch nerve activity (like gabapentin and pregabalin) can be helpful

**How can I prevent eye problems from hydroxychloroquine?**

As described above, one method is to ask for a **drug level**every visit.

It is also important to have your **eyes tested** regularly as per the advice below.

**What eye tests should I get while taking hydroxychloroquine?**

Ensure you get two eye tests yearly (if you do not have Asian ancestry, discussed below). The best tests are to get a **visual field 10-2 (VF 10-2)** and a **spectral domain optical coherence tomography (SD-OCT)**. You must ensure they are exactly these tests. Most eye exam places can perform a VF 24-2 or VF 30-2 (commonly used for glaucoma), but many cannot do a VF 10-2. It is an expensive machine.

If your location does not have both tests mentioned above, then a **fundus autofluorescence (FAF)** test or a **multifocal electroencephalogram (mf-ERG)** can be substituted.

Always make sure you get two different tests done each year. Getting only one test is not sufficient. Eye problems can show up on one test first and not the other.

**Eye tests recommended for Asians**

Around half of the people with Asian ancestry can get eye problems missed by the VF 10-2. They need either a VF 24-2 or 30-2. However, these two tests can miss retinopathy in those Asians who develop the more common type of hydroxychloroquine retinopathy (so Asians also need to get a VF 10-2 test as well).

Therefore, Asian patients need **three yearly tests** instead of two. They should get a VF 10-2, SD-OCT, and a VF 24-2 (or a VF 30-2).

**How often should I get eye exams for hydroxychloroquine?**

Everyone should get a VF 10-2 and an SD-OCT soon after starting their medicine. **Most people can then wait five years before doing both tests yearly.**

However, people at [increased risk for retinopathy](https://www.ncbi.nlm.nih.gov/books/NBK537086/) should get both tests yearly immediately after starting hydroxychloroquine. This includes those with decreased kidney function, preexisting retina and macula problems, and those taking tamoxifen. If your eye doctor recommends yearly exams after your first tests, you should also get them done. For example, diabetes can cause retinopathy, and some eye doctors in my area recommend yearly tests for diabetics. Some doctors may recommend yearly tests immediately if you are [short, obese, over 60 years old, or have severe liver disease](https://onlinelibrary.wiley.com/doi/10.1002/art.41121).

Good news from a 2023 study…

“**our findings suggest that, under current screening recommendations and dosing patterns, loss of visual acuity from hydroxychloroquine retinopathy should be rare**“

[*Melles RB, et al. Hydroxychloroquine Dose and Risk for Incident Retinopathy: A Cohort Study*](https://www.acpjournals.org/doi/10.7326/M22-2453)

**What if my eye doctor tells me that my eye tests are abnormal and that I should stop my hydroxychloroquine?**

The eye tests mentioned above often have abnormalities due to [eye problems unrelated to hydroxychloroquine](https://www.lupusencyclopedia.com/important-advice-for-rheumatologists/) and can be misinterpreted by eye doctors who do not specialize in hydroxychloroquine retinopathy.

I always ask my patients to see a hydroxychloroquine retinopathy expert who can do the **mf-ERG test**. Therefore, I would recommend that you do the same.

These machines are expensive, and properly interpreting them requires a lot of special training. In the Washington DC area, where I practice, I recommend seeing [Dr. Reshma Katira](https://www.rgw.com/retina-specialists-doctors/reshma-katira-md/). She is in Silver Spring, Maryland, and Alexandria, Virginia. The Johns Hopkins Wilmer Eye Clinic in Baltimore, Maryland, is also reputable. Dr. Michael Marmor at Sanford in Palo Alto, California, is a well-known expert with mfERG. I am not familiar with experts in other areas. You would need to ask your ophthalmologist.

If your ophthalmologist is unsure who to send you to, look for the best retinologist in your area. Someone at a major medical school teaching institution is usually an excellent choice.

Suppose the abnormality is due to an eye problem unrelated to hydroxychloroquine (which is most of the time in my experience). In that case, the mfERG test should be done yearly while taking your medicine.

**What if I am allergic to or cannot tolerate hydroxychloroquine? Is there an alternative to hydroxychloroquine for lupus?**

If you are truly allergic to hydroxychloroquine, absolutely cannot tolerate even low doses, have had a severe reaction to it, or have hydroxychloroquine retinopathy, there is an alternative. You can ask your doctor to prescribe the antimalarial drug [quinacrine](https://www.lupusencyclopedia.com/patient-education/). It is again available (as of 2022) after a period of not being available.

**Ask for Brand Name Plaquenil**

For some people, brand (also called trade) name Plaquenil works better or is easier to tolerate than generics. If you have tried the advice above and still have problems, ask your doctor if the brand name Plaquenil is an option for you. If so, make sure your doctor puts “brand only” on the prescription.