

Potential Damage to Vision from an Anti-Malarial Drug Used to Treat Inflammatory Arthritis

What are Hydroxychloroquine & Chloroquine, and why are they used to treat some types of arthritis?

- Systemic lupus erythematosus (SLE) and rheumatoid arthritis (RA) are rheumatic diseases that require long-term treatment.
- Hydroxychloroquine (HCQ), also known as Plaquenil, and Chloroquine (CQ), are inexpensive anti-malarial drugs commonly used to manage symptoms of SLE and RA because it has been shown to prevent ‘flares’ (episodes when symptoms worsen), prevent disease progression, and help people live longer.

Damage to vision related to taking HCQ and CQ

NEW TESTS DONE BY OPHTHALMOLOGISTS ALLOW DETECTION OF EARLY DAMAGE TO VISION DUE TO HCQ AND CQ USE

- Most drugs have some unwanted ‘side-effects’, such as causing nausea. Although many people have few or no side-effects when taking HCQ or CQ, research showed that taking HCQ or CQ for long period of time can affect vision, and if not detected on time, it may lead to vision loss¹.
- As a result, it is recommended that people taking HCQ or CQ for 5 years or more should have their vision tested by an ophthalmologist every year using new technology that detects early changes before they are irreversible².

References:

1. Melles RB, Marmor MF. The Risk of Toxic Retinopathy in Patients on Long-term Hydroxychloroquine Therapy. *JAMA Ophthalmol.* 2014;132(12):1453-1460. doi:10.1001/jamaophthalmol.2014.3459.
2. Marmor MF, Kellner U, Lai TYY, Melles RB, Mieler WF. Recommendations on Screening for Chloroquine and Hydroxychloroquine Retinopathy (2016 Revision). *Ophthalmology.* 2016;123(6):1386-1394. doi:10.1016/j.ophtha.2016.01.058.

- There isn't any information about how many Canadian patients taking HCQ for more than 5 years have vision loss.
- More importantly, a recent study by Arthritis Research Canada (ARC), found that about 40% of those who should have had their vision tested had not had the test within the past 5 years³ – it was even worse (almost 70% didn't have their vision tested) if they were not being cared for by a rheumatologist³.

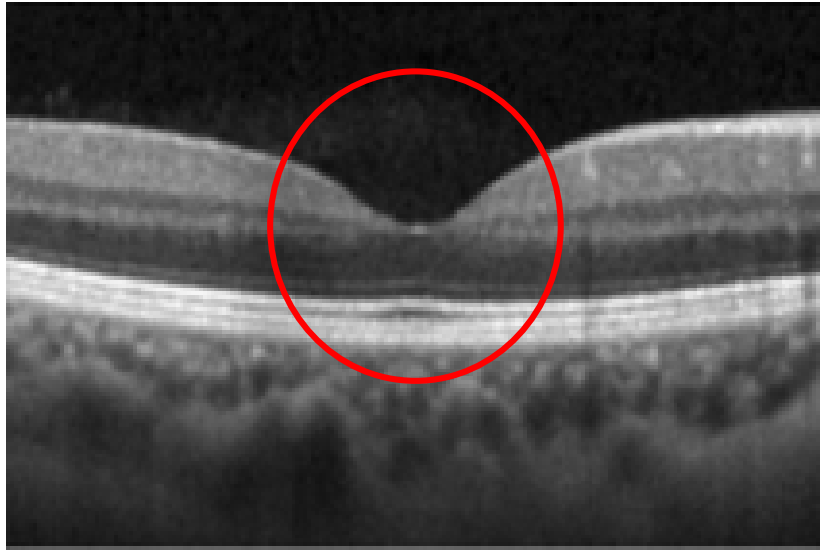
Reference:

3. Kazem M, Maberley D, Tavakoli H, et al. Gaps in screening for retinal toxicity in patients with systemic lupus erythematosus and rheumatoid arthritis exposed to antimalarials: A population based-study. Submitted to Canadian Rheumatology Association (CRA) Scientific Meeting, 2018.

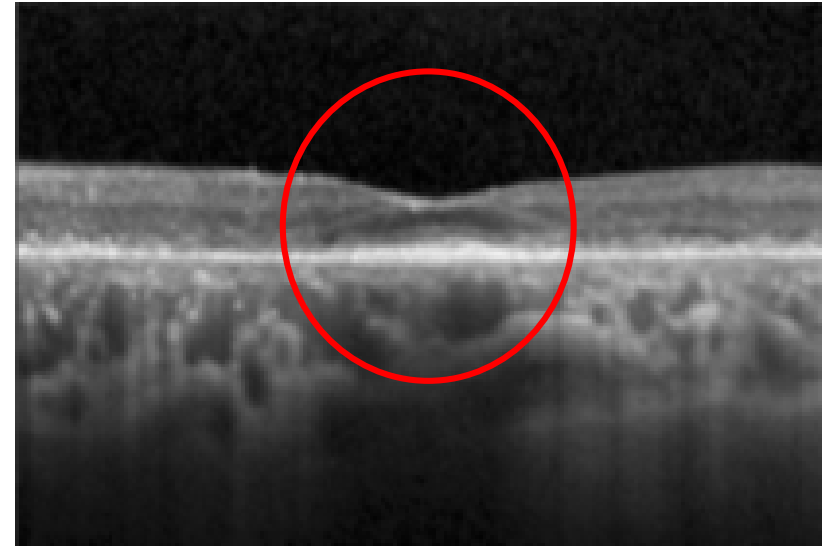
DAMAGE TO VISION DUE TO HCQ or CQ

The pictures below are photos obtained using the new technology that will be used in this research project

A. Normal Eye



B. Severely Damaged Eye



Reference:

Images modified from: Melles RB, Marmor MF. The Risk of Toxic Retinopathy in Patients on Long-term Hydroxychloroquine Therapy. *JAMA Ophthalmol.* 2014;132(12):1453-1460

**What we want to do
and
how you can help**

Our team wants to do research to:

1. accurately determine the risk of vision loss related to taking HCQ or CQ in Canadians living with SLE and RA
2. provide annual vision testing to approximately 3,000 patients with SLE or RA who have been taking HCQ or CQ for more than 5 years.

We will use a state-of-the-art vision testing method that can detect any signs of vision loss at an earlier stage before the damage is irreversible.

- Our research team understands that patients are experts in their own health and recognizes that your voices are essential in ensuring high-quality research. Consequently, we invite you to help us design this research project.
- We need your help to determine the best way to invite patients to participate in the study. There are two options.

**Your opinion about the best way to
invite patients to participate in this
research project**

OPTION 1

The research team will send a letter to the patients who have SLE or RA and have been taking HCQ or CQ for more than 5 years. **The letter will ask the patient to ask their doctor** (family doctor or rheumatologist) **to send a referral to see an ophthalmologist** for the vision tests.

OPTION 2

The research team contacts the family doctor or rheumatologist directly and requests that the doctor tells their patients with SLE and RA about the study and sends a referral to the ophthalmologist.

YOUR OPINION

Select either option #1 or option #2 – whichever one you feel would be the ‘best way’ for patients to be invited to participate in the study. To select your preferred option, click on the survey link below:

<https://freeonlinesurveys.com/s/HmmG7mHb>

We sincerely appreciate the time you take to provide your input.

THANK YOU!

