

# Hydroxychloroquine, Rheumatic Diseases amidst the Covid-19 Pandemic: *Overcoming checkpoints & roadblocks*

By:

*Annabel Yap, Gerald B. Natanauan, Dominic Dela Cruz*

**Introduction:** Covid pandemic has led to an acute shortage of hydroxychloroquine (HCQ) for our patients. Here and around the world, concerns of HCQ supply shortages for patients with rheumatic disease are increasing due in part to the interest of the scientific community for HCQ as potential therapy for Covid-19.

Clinical trials testing HCQ to treat Covid-19 have started as early as March paving the way for further researches. In our country, chloroquine (CQ) and HCQ are being used as compassionate care for Covid-19 in hospitals like the Lung Center of the Philippines. Meanwhile, its use in lupus include prevention of flare-ups while also improving cholesterol levels, the skin, joints and even prevention of blood clots. Hence, its impact on the over-all survival of these group of patients is significant. Similarly, its use in other rheumatic diseases like Rheumatoid arthritis (RA) as a disease modifying anti-rheumatic drug (DMARD) had long been recognized thereby preventing joint damage and reducing the risk of long-term disability.

Filipino rheumatologists recognized and anticipated the dire consequences of this shortage in supply of HCQ, and kept in close touch with their patients and pharmacies to be continually updated on availability of stocks.

The enduring capacity of the Bayanihan Act and the people behind its implementation to be translated into real-time action had moved every sector of the government to respond to the call of these challenging times. In so manner, Lupus Inspired Advocacy (LUISA) of the Rheumatology

Educational Trust Foundation Inc. (RETFI) under its Chief Executive Officer (CEO) Dr. Sandra V. Navarra and patient liaison Ms. Robelle Tanangunan, partnered with Cancer Warriors Foundation headed by Ms Carmen Auste, and Psoriasis Philippines (PsorPhil) headed by Sir Josef de Guzman, in a feverish rush to deliver donated HCQ from the Department of Health for lupus and RA patients all throughout the country, undeterred by checkpoints and roadblocks. It was truly heartwarming and gratifying to have a surge of volunteers working round-the-clock to ensure that lupus and RA patients receive the donated HCQ tablets. As of May 31, 2020, a total of 985 patients all over the Philippines received free HCQ amidst the COVID19 pandemic (see figure)!

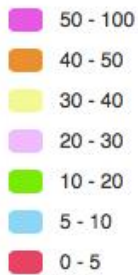
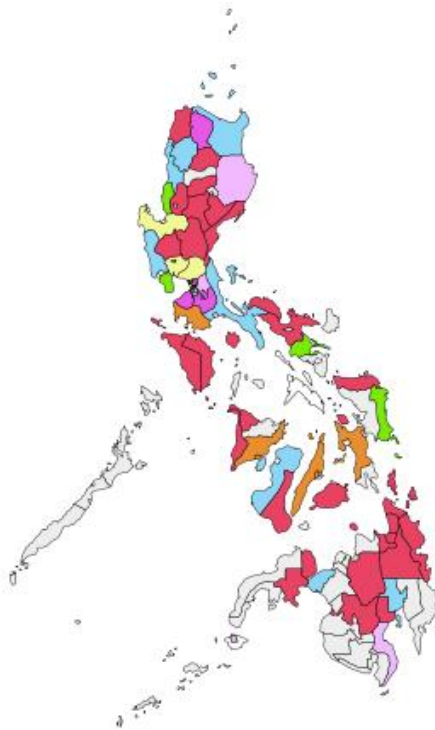
***Postscript 15 June 2020:***

**”HCQ No Longer Approved Even a Little for COVID-19”**

— Study after study showed no benefit, and now the FDA has had enough

Finally on June 15, FDA rescinded its emergency use authorization (EUA) of HCQ to treat COVID-19 patients, citing HCQ as **“unlikely to be effective”** at treating COVID-19”.

Nonetheless, the HCQ ‘direct delivery’ experience to rheumatic disease patients in the last 3 months has been an eye-opener to the plight of our patients at a time of pandemic and a uniquely gratifying learning experience for patients, physicians and drug delivery services alike!



Created with paintmaps.com

**NCR (271)**

- Manila – 39
- Pasay – 6
- Quezon City – 78
- Pasig – 18
- Paranaque – 17
- Muntinlupa – 8
- Las Pinas – 13
- Caloocan – 25
- Malabon – 6
- Valenzuela – 11
- Marikina – 14
- San Juan – 4
- Mandaluyong – 7
- Makati – 5
- Taguig – 12
- Valenzuela – 13
- Pateros – 1
- Navotas - 5

**Region 1 (61)**

- Pangasinan – 31
- Ilocos norte – 1
- Ilocos sur – 10
- La Union – 19

**CAR (14)**

- Abra – 6
- Benguet – 5
- Ifugao – 2
- Kalinga - 1

**Region 2 (38)**

- Cagayan – 6
- Isabela – 27
- Quirino – 3
- Nueva Vizcaya – 2

**Region 3 (119)**

- Bulacan – 34
- Pampanga – 38
- Nueva Ecija – 15
- Bataan – 18
- Aurora – 1
- Zambales – 10
- Tarlac – 3

**Region 4A (209)**

- Rizal – 28
- Cavite – 66
- Batangas – 46
- Laguna – 61
- Quezon – 8

**Region 4B (7)**

- Occidental Mindoro – 2
- Oriental Mindoro – 3
- Marinduque – 2

**Region 5 (3)**

- Camarines norte - 1
- Camarines sur - 2

**Visayas (178)**

- Iloilo – 47

- Negros occidental – 7
- Negros oriental - 1
- Cebu – 41
- Bohol – 1
- Akian – 4
- Antique – 1
- Guimaras – 10
- Leyte – 46
- Northern Samar – 2
- Eastern Samar – 13
- Biliran - 5

**Mindanao (85)**

- North Cotabato - 5
- South Cotabato – 3
- Butuan – 1
- Surigao City – 1
- Zamboanga del sur – 5
- Bukidnon – 2
- Lanao del norte – 10
- Misamis occidental – 2
- Misamis oriental – 14
- Agusan del norte – 2
- Agusan del sur – 2
- Surigao del norte – 3
- Surigao del sur – 1
- Cotabato city – de oro – 1
- Davao oriental – 1
- Davao del norte – 6
- Davao del sur – 25
- Camiguin - 1

**Total Number – 985**

## Some thank you messages from doctors and patients:

When I started getting text messages from patients telling me they could not find hydroxychloroquine, there was this sense of panic in me. Summer heat was at its peak in our province and I knew that these months were the flare season for lupus patients. I have seen patients losing hope and parents giving up on their children when they get hospitalized with bad flares or infections. Just putting myself into their shoes, the feeling was really scary. Witnessing their course of deterioration all the more weighs me down emotionally and mentally. So I always do my best in helping them and give extra effort especially in these difficult times.



I am SUPER GRATEFUL for the free hydroxychloroquine being given by DOH thru Lupus Inspired Advocacy (LUISA) who are handling the shipping. Thank you very much Dr. Sandra Navarra, Mam Robelle Tanangunan and all the staff who are making all these possible. I am more confident that my patients will get through and adapt in this "new normal" as we all battle this pandemic.

- Dr. Vivian Santos,

Rheumatologist, Region 2

Non una hind pa me nahihirapan makabili ng hcqs bago declare ni pangulo Rodrigo Duterte ang ecq. Nakabili pa me ng one box. Non nakita ko ang post ni Robelle magkakaubosan na sa manila ng hcqs. Agad me pumunta sa pharmacy na akin binibinhan don ko na pag alaman na talaga wala na daw na dumadating na supply sa kanila halos lahat na pharmacy natawagan dto sa quezon halos araw araw na me natawag sa mga pharmacy na kung san me nakakabili laging ang sagot sakín wala pa daw ng dedelivery na mga supplier nila. Nagpost na me sa FB kung san mayron Hcqs na mabibilhan na pharmacy kasi na tatakot me flare lalo na sa panahon ngayon na may pandemic. May nakapagsabi sakín na mayron sa tayabas community hospital pharmacy agad me tumawag sa nasabing hospital. Nag makaawa na me na pagbilhan ako kahit 3 tablet lang para may, mainom ako sa araw na iyon. Pero ang sagot sakín hind sila pwd mg binta sa outpatient kasi may pasyente din sila na kailanga uminom un at isa isang box na daw ang sock nila at wala pang nadating na delivery nila. Sa kakaisip kung saan ako nakakabili ng gamot naisip ko si Robelle. Agad naman ng reply si robelle sakín. Pagkalipas ng ilan linggo nag txt sakín ang ust na, may hcqs daw me na matatanggap at agad ko naman ibinigay ang aking address at buong pangalan at contract no. Subra me natuwa talaga ako. Ung una na dismaya ako kasi hind ako matawag kasi, napakahirap talaga ng signal namin lalot na, katatapos lang ng bagyong nawala pa ang internet connection namin kasi 2 days kami walang kuryente. Hind ko na nga inaasahan na makakakuha pa me ng libre gamot at hind na me natawagan. Tinawag me ng aking pamangkin na may maghahanap daw sakín naka motor tinanong ko kung sino hind daw nila kilala. Laking gulat ko na may delivery para sakín sabi pa sakín ng delivery boy wala daw me babayaran. Laking gulat ko pagbukas ko sa package ung gamot subrang natuwa talaga me halos 3mos me hind makakabili ng gamot na hcqs. malaking tulong na dito sakín sa panahon ngayon. Salamat sa lahat ng doc. ko sa UST lalo na kay Doctora Navarra at sayo Robelle, God bless all ang keep safe.

- Aileen Manago from Quezon Province

*From Genelyn, member of LSGP:*



*Morning everyone! Sa ngayon panahon nang crisis sobrang hirap mgghanap nang hydroxychloroquine, khit anong brand, lhat nang pharmacy wlang stock, if ever mtuloy yng pg sponsor nng DOH ang hcqs nmin lhat nang my lupus, sbrang laking tlong yn sming lahat. God bless us all.*

From Ruthell Moreno, Lupus support group of Panay president

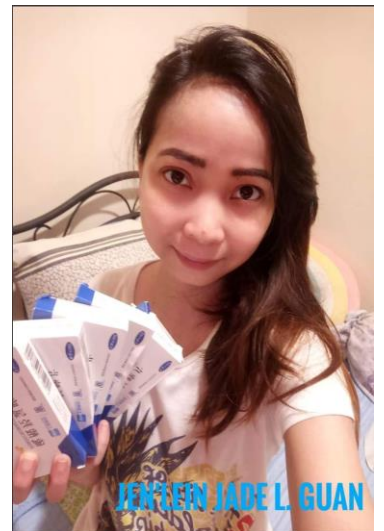
Ang Lupus Support Group of Panay (LSGP) ay isang organisasyon ng mga taong na diagnose ng lupus. Layunin ang organisasyon na tumulong at magbigay impormasyon sa mga pasyenteng may lupus upang mas mapagtagumpayan nila ang kanilang laban kontra sa kanilang sakit. Mahirap para sa karamihan ng myembrong may lupus ang araw araw na pagsustento sa kanilang mga gamot, at mas lalong naging mahirap ng dumating ang pandemyang covid19. Ang lahat ng myembrong may lupus at umiinom ng hydroxychloroquine o mas kilala sa brand names na plaquenil, heqs at hyquin, ay nanawagan upang sila'y dinggin at huwag ipagdamot sa kanila ang kanilang gamot. Dahil ginagamit ang heqs sa paggamot ng mga taong nagkakasakit ng covid19, naubusan ng gamot na heqs sa mga botika. Ang gamot na heqs, kasama ng iba pang gamot, ay tumutulong upang maiwasan ang pag active ng sakit ng isang taong may lupus. Kaya naman laking kasiyahan at pasasalamat ng mga myembrong may lupus nang malaman nila na may libreng heqs na ipamimigay. Ito ay katuparan sa kanilang panalangin. Sa lahat ng tumutulong, maraming salamat.

Noong nag-announce ng ECQ, I was able to buy supply pa ng HCQS. Kampante pa ako that time kase sabi nung pharmacist hindi naman daw sila nawawalan ng stock. Hindi ko inexpect na mag eextend pa yung quarantine period tapos yun nga nagkakaubusan ng supply ng HCQS sa mga drugstores at napabalita nga na ginagamit ito pang-gamot sa mga covid-19 patients. Allegedly, may mga reports din na may mga bumibili din daw nito to use it as prophylaxis drug against covid-19. Before maubos yung HCQS ko, palagi na akong tumatawag sa mga Mercury branches na malapit sa area namin pero palaging walang stocks. I started na mag-worry kung anong magiging effect kung hindi ako makainom ng gamot. November pa yung last visit ko sa Rheuma ko at laboratory tests so wala akong idea kung kumusta ngayon ang overall health condition ko. Andun yung mga negative thoughts na pwedeng mangyari saken sa hindi pag-inom ng HCQS. Pero eventually naisip ko na hindi yun makakatulong sa health ko. I lean on this verse instead:

“Do not be anxious about anything, but in every situation, by prayer and petition, with thanksgiving, present your requests to God.” Philipians 4:6 NIV

Then, nalaman ko yung about sa binibigay na free HCQS ng LUISA. Nag sign up agad ako, hoping na makatanggap ako. Hindi ako nakareceived ng call galing sa kanila hindi tulad ng mga kasamahan ko sa Lupus Society of Batangas. But then, I put my trust na lang na si Lord ang bahala saken. He will provide for me. At yun nga, May 20 nakatanggap ako ng call from J&T informing me na nasa labas siya ng gate ng subdivision namin. When I opened the package, 6 boxes of HCQS ang laman. Natuwa ako kase talagang gumagawa ng way si Lord. Thankful ako sa mga taong behind ng project na ito ng free HCQS para sa mga lupus patients na katulad ko na hirap makakuha ng supply. I hope and pray na madami pa silang matulungan. Again, thank you so much po and God bless your team.

-Jen'Lein Jade L. Guan, Lupus Support group of Batangas member

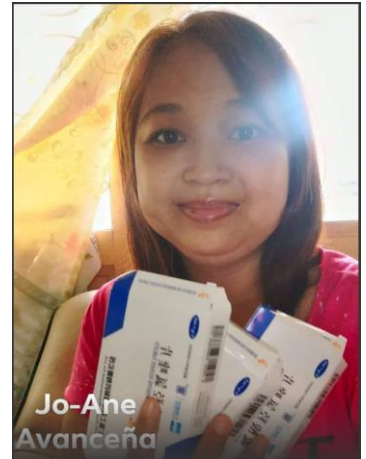


I never thought that buying hcqs would never be a problem cause of 3years being a lupus patient i never encounter out of stock medicines. But Pandemic came and its like a roller coaster ride experience. Suddenly it became out of stock and nowhere to found. Its very stressing moment for us patients that we rely our life to that medicine. How can we avail that if the hospitals uses it for covid19 patients as prophylaxis. How can we react to that? Life vs life. God really do miracles. Someone told me from the Lupus group of Batangas that we had to fill out the form that offered free medicine which is HCQS. After how many days of waiting.

Hooooorraahhhh this is it. My heart is full. I cannot contain my happiness. Search for the HCQS is over. ITS ALL FREE 6boxes is worth the wait.

Thanks so much to Ms. Abigail Lim, Cancer Warriors Foundation Inc and Ms. @Rosalyn Esguerra for doing this great and noble job for us. Salute to all the people behind this project! Godspeed!♡♡♡

-Jo-Ane Avanceña, Lupus Supper group of Batangas member



Hcqs. Yung gamot na pagnawala sadyang ramdam koy maghahina ako...nang nagkaroon nang covid19...malaking dagok dahil sa kawalan nang stock, kinabahan na ako, post dini post doon nagbabakasaling may tutulong. Hanggang sa group nang lupus society ay nagkaroon nang post si President Rosalyn Esguerra na Kung sinong kailangan Ang hcqs, agad agad. Kung inilagay information ko sa group, at ipinasa, after 3 to 4 days may tumawag akin para I confirm Ang address ko, I aki kong pasasalamat Kay Mam Rose Ann alvaro, sa lahat nang bumubuo nang "cancer warriors foundation Inc, Lupus inspired advocacy, at Psoriasis Philippines . Thank you...

- Marcela V. Manimtim



From Nora Nava, one of LSGP members:

Pareho aming mga taga GUIMARAS, may mga botika dito pero walang bumibenta ng HCQS . So kailangan pa naming sumakay ng bangka papuntang ILOILO para lang makabili ng gamot. Ok lang kung may extra money ako to buy meds for 1month . Isa pa mahirap magtravel going Iloilo City especially specialy kung masama ang panahon dahil hinihinto ang byahe ng pumpboat. So para sa amin na taga guimaras, mas mahirap ngayon dahil may

crisis pa tayo. Kung merong gamot na hcqs na maibibigay, malaking tulong ito sa lahat ng may lupus

From Thydess, LSGP member:

Having a LUPUS is already hard to handle, how much more difficulties accessing hydroxychloroquine? We lupians do understand how hard it is not to take this maintenance on time. Specially now a days, covid19 is everywhere. Kahit madali kaming mahawaan ng sakit, nag rrisk kaming isa isahin ang mga pharmacy just to try our luck of it's availability. But sad to say, lahat ng pharmacist sinasabi "wala po kaming stocks ma'am". So uuwi nalang kami sa kanya kanya naming bahay na bagsak ang balikat. Yung feeling na iniinda mu ang init at ulan, Plus pa ung pagod ng katawan na parang nilibot mu na buong ciudad. Then one day fellow lupian informed me na merong nagpoprovide nga HCQS. naisip ko finally may tutulong na sa amin. Binigyan uli kami ng pag-asa,HCQS is life for us. And we are hoping isa kami sa matutulongan. And yes, No more pharmacy hopping! 😊

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From Ellen of LSGP:

Good morning everyone.

Sa loob ng 20 taon na may Lupus ako, ngayon ko lang naranasan na magpanic dahil sa out of stock ang maintenance ko na gamot specifically ang HCQS (plaquenil). Dumagdag pa sa stress ko dahil nga sa pandemic na naranasan natin ngayon, wala ka na sa isipin na, wala kang trabaho, na kung anong mangyayari sa pamilya mo. Hindi naman ako makalabas sa takot na baka mahawaan ka. Pray, pray, pray yun ang lagi kung sandata. Not until, one morning na ang pinsan ko who is working in one of the mercury branch called me na may dumating na daw na stocks ng plaquenil. Thank you Lord, pero ang sabi limited lang daw ang pwedeng ibigay ng drugstore kasi may order na regulated na ang drug. But still God is good kasi habang nagpapahinga ako staring no where nag pop up sa celfone ko na may invitation sa akin sa group chat ng mga lupus, informing me to send my personal info kasi daw tutulongan kami ng DOH to avail HCQS. Thank you Lord again, another answered prayer. And also thank you to Ms Ruthell kasi sya ang angel na pinadala ni Lord to facilitate everything. And now I'm hoping na sana ma materialize ang HCQS para sa aming mga lupus patients.

Thank you in advance and God bless.

Ako po si Lois Gomez taga-Cagayan De Oro City, 25 years old, 15 years SLE patient.

Plaquenil/HCQS/Hydroxychloroquine has always been one of my maintenance since I was diagnosed with SLE. Kaya noong nagsimula ang pandemic na covid at naisama nila ito as one of the effective treatments daw ng virus, nahirapan akong maghanap sa mga pharmacy. At sa mercury drug ko lng ito nabibili dahil wala ito sa ibang pharmacy.

May time na nag every other day ako as per prescribed by my doctor para lang po ma extend yung remaining stock ko ng gamot. Pero kapag hindi ako nakaka inom,

iba talaga ang pakiramdam ko compared sa nakaka inom ako. Minsan pagod and katawan, or naglalabasan ang rashes ko, o kaya naman ay nanakit ang joints ko. Kaya ang saya ko noong sinabi sa akin ng doctor ko na meron daw ipapamigay ang LUISA na libreng hcqs.

Financially, malaki ng tulong yan dahil sobrang mahal ng gamot na yan at syempre, ilang araw din na meron akong sure na maiinom habang naghahanap ako ng mabibilhan ko para sa future days. Sa totoo lang, hindi ako nag expect na may dadating sa akin bilang nasa mindanao area pa ako. Pero on May 30, na surprised ako dahil may delivery na dumating. Akala ko nung una online na order. Yun pala ang gamot ko.

Maraming salamat po sa lahat ng nag initiate na kami ay mabigyan ng gamot na ito (LUISA, Cancer Warriors Foundation, Psorphil, etc), especially sa panahon na ito na mahirap ito mahanap. Malaki ng tulong po talaga ito sa amin lalo na sa aking budget sa gamot at nagkakahirapan pa makabili. Salamat po.

**Acknowledgements:** Ms. Carmen Auste of Cancer Warriors Foundation who led the volunteers and facilitating the donation from International partners and from the Philippine Department of Health. Ms. Robelle Tanangunon (LUISA of RETFI), who triaged patients in need of medications, coordinated with drivers and with doctors who wrote out the prescriptions.



**Others:**

- Lupus Inspired Advocacy - for shouldering courier services to provincial patients and checking each patient information and prescription
- Mr. Josef De Guzman of Psoriasis Philippines
- Ms. Abigail Tan Lim – for initiating the survey for patient list
- Ms. Roseann Alvaro of Cancer Warriors Foundation and Team from Philippine Cancer Society – for taking time to call and validate each patient and their addresses

**Metro Manila deliveries by:**

- Mr. and Mrs. Joaquin and Imelda Kua from Lupus Inspired Advocacy
- Mr. Paul Cleofas from Psoriasis Philippines
- Dr. Claire and driver from Cancer Coalition
- Dr. Rachel Rosario and driver from Philippine Cancer Society
- Former Congressman Roger Sarmiento and driver