




When Social Media Is Your Friend

Using Social Media To Find What You Need

Mary Anne (Mimi) Razim-FitzSimons

MARF995@aol.com / 612-239-6747

1



How can social media help people who have compromised immunity (and their families) navigate an era of both pandemics and rapid changes?

- ❖ Access to a whole lot of information is available with a few mouse clicks
- ❖ A support network is available with a few mouse clicks
- ❖ General questions can be answered fairly quickly and, if you choose your sources carefully, usually fairly accurately

2

Drawbacks?

- ❖ Accuracy - ALWAYS evaluate sources of information, even if you've gotten the information from a group you trust. Why do you trust this information?
- ❖ Temptation to substitute what someone in your Internet support group tells you for what your own physician tells you – don't do that.
 - ❖ Social media groups CAN help you frame questions in support of productive conversations with your own physician.
- ❖ Privacy issues inherent in social media use. Be careful out there!

3

Facebook Groups

- ❖ These are valuable because they are specific-interest groups populated by individuals who understand your situation and many of your concerns
- ❖ **Transplant Vaccine Study Group**
 - ❖ Information, support, and advocacy for people who are immunocompromised
 - ❖ Anyone who has a compromised immune system, or whose family member has a compromised immune system, is welcome.
 - ❖ LOTS of helpful, accurate information, including information about where to find COVID vaccines and therapies, enroll in clinical trials, how to construct a Corsi-Rosenthal box, how the guidance on use of rapid antigen tests has changed, and HOW TO NAVIGATE A WORLD THAT DOES NOT SHARE OUR DAY TO DAY HEALTH CONCERNS.
 - ❖ Very serious about the accuracy of information shared. Information that is false or misleading is removed.
 - ❖ We are friendly and polite! Politics and arguing is strongly discouraged.

4

Transplant Vaccine Study Group

- ❖ To join, go to the search bar in Facebook and type in "Transplant Vaccine Study Group," click the "join" button, and answer the questions. If you are asked who invited you to join the group, enter "Mimi Razim-FitzSimons."
- ❖ Once you've joined the group, PLEASE review the rules (right column, under "**About**." We are a collegial group. We work hard to leave politics and argument at the door.
- ❖ If you look under "**Featured**" you'll see what our hot topics are, and if you look under "**Files**" you'll find PDFs and some Word documents that we've uploaded since the group was created.
 - ❖ The files cover a variety of topics and we add to them when we receive information of general interest.
- ❖ If you join the group, you don't have to post anything at all, but please do introduce yourself! And if you have questions, just ask – did I mention that we're friendly? We're friendly.

5

Substack

- ❖ Substack is a new(er) kid on the Internet block! It's been around for about 6 years.
 - ❖ Paid and unpaid subscriptions.
 - ❖ Blogs and newsletters cover a WIDE variety of topics. If you look around you'll probably find a Substack that matches your interest or meets your needs.
 - ❖ Many of its writers have well established expertise. Dr. Eric Topol writes a newsletter on Substack.
- ❖ **Dr. Joe's COVID and Science Newsletter**
 - ❖ Dr. Joe Eastman compiles, summarizes, and explains relevant information from a variety of high quality sources. Summarizes information that is behind paywalls and may be inaccessible without paid subscriptions to other publications/newsletters.
 - ❖ Subscriptions are free! Paid and nonpaid subscribers receive the same information.
 - ❖ Shares his political views, but the information he provides is valuable and worth scrolling past any political position you disagree with.

6



Other Interesting Substack Newsletters

- ❖ **Ground Truths**, written by Eric Topol, M.D. Dr. Topol is a cardiologist and the director of the Scripps Research and Translational Institute in La Jolla, CA. His focus is much broader than COVID and matters specifically affecting people who are immunocompromised, but this newsletter is very interesting and covers topics ranging from infectious disease to pharmaceutical WOW moments to artificial intelligence. Free, with proceeds from any paid subscriptions directed to Scripps.
- ❖ **Your Local Epidemiologist**, written by Katelyn Jetelina, Ph.D., Assistant Professor of Epidemiology, University of Texas Health Science Center, Houston, TX. Her focus is on public health science generally, with a lot of attention to COVID and easily communicable diseases. Paid subscriptions with some free posts.
- ❖ **Immunocompromised Times**, written by Susanna Speier, a journalist who is immunocompromised. She writes primarily about improving safety and accessibility in shared spaces. COVID focus, but applicable to easily communicable pathogens generally. Paid subscriptions with some free posts.