

making a
difference

By MMR Resident Jill Gollinger

DEALING WITH CHRONIC LYMPHOCYTIC LEUKEMIA

In 2016 I was diagnosed with CLL (Chronic Lymphocytic Leukemia). Imagine my surprise as I felt perfectly fine. I found out there is no cure – that's why it is called 'chronic'. However, people can live a long time with this cancer and may not need treatment ever or at least right away – called 'watch and wait'. Interesting is I eventually needed treatment four years later. Many new drugs and drug combos are now available and people are living longer and fuller lives.

In the meantime, I discovered this incredible group founded by Dr. Brian Koffman, a retired physician and a CLL patient as well. He started CLL Society and I luckily joined this amazing organization. The main thrust is to educate, support and be on top of all the latest treatments, and there are plenty. The website is CLLSociety.org. Dr. Koffman reminds us that if we see a CLL specialist doctor, numbers show we can live longer.



antibodies test is the only sure way to be checked. So, we've had to rely on vaccinated people around us and now that is changing with this newest Delta variant. There are only a few articles out there delivering the facts regarding the high-risk group who can only be protected by the safety of people around them.

There is a glimmer of hope. Recently through lots of research, I found the only non-clinical trial program from Regeneron giving out therapeutic treatments. They recently were FDA approved for Emergency Use Authorization (EUA) so high-risk people can get the Regen-Cov drug if they have COVID or been exposed to a COVID person. Great news. However, what so few know about is Regeneron has a Compassionate Use Program where a patient's doctor can fill out forms requesting the use for their high-risk patient to use Regen-Cov as a prophylaxis treatment. I was recently accepted into this program. Pretty exciting news. I am going for it and my date is at the end of this month.

After almost two years of feeling confined, I cannot wait for this newfound freedom. I am planning my first flight in almost two years to go visit my grandchildren on the East Coast and then abroad. It would be so amazing to get the word out and I thank Cary Frumes for giving me this platform for starters. We are not studied well or rarely even talked about. We are vaccinated up but we might as well not be in many cases like myself. We need more drug treatments, not just vaccines. Both will give everyone better choices.

So, back to my story. Just in the nick of time, my prognosis went from 'watch and wait' to 'treatment is needed now,' all during this crazy horrific pandemic world. We soon learned that out of all cancers, our blood cancer has the worst odds reported with COVID and making it. Think of it as our blood runs through our whole body. It is pretty tough to decipher what, when and how to treat our illness during these times. I actually stopped my CLL treatment for a couple of months when vaccines were not yet available from the fear of running into a medical person, patient or friend with COVID, or of being in a store where one can easily be near an asymptomatic person with COVID. This is simply dangerous to us. Add to that the Delta variant, where people with vaccines can now contract the virus without warning signs.

Statistically speaking, there are over nine million of an immunocompromised forgotten group of people. Twenty percent of blood disorders and transplant patients or people on specific drugs for any autoimmune deficiency do not know the vaccines might not be protecting them. They feel safe and that may not be true. My concern is getting the word out to the immunocompromised. We cannot totally rely on a vaccine for covid protection. In fact, I received negative protection from all three vaccines. The

Looking for the **Right** vehicle at the **Right Price**?

Make the Right Choice



The **Right Choice** for Sales, Leasing, Service and Parts

Right Toyota

7701 E. Frank Lloyd Wright Blvd. | 480-778-2200 | RightToyota.com
On Frank Lloyd Wright, 1/2 mile east of Scottsdale Rd.

TOYOTA
Let's Go Places