ROS1derings

A newsletter by and for the ROS1 cancer community

Issue 4

In this issue

As if navigating ROS1 lung cancer wasn't enough we are now faced with additional burdens from COVID-19. In this issue, we explore topics related to the virus. Are we at additional risk? How do we handle treatment options now? How can we stay safe during a scan? What is our new normal?

In addition, Janet Freeman Daily and Lisa Buonomo share news from the field, including research about pulmonary hypertension in ROS1+ patients, and an update from the National Lung Cancer Roundtable.

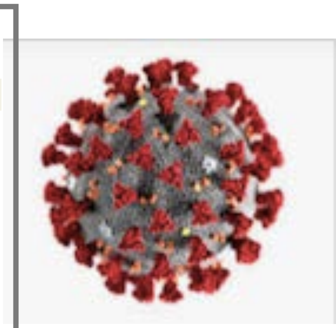
ROS1der risk and COVID-19

At the ASCO 2020 conference, two registries reported on efforts to track cancer patient outcomes. The research suggests that lung cancer patients infected with COVID-19 have worse outcomes.

COVID-19 and Cancer Consortium found that patients with actively progressing cancer were five times more likely to die within 30 days of a COVID-19 diagnosis compared to patients who were in remission or had no evidence of disease. (Read finding.)

A second registry effort, *Thoracic cancERs international coVid 19 cOLlaboraTion* reported that patients receiving chemotherapy within three months of a diagnosis of COVID-19, either alone or in combination, fared the worst, with a significantly increased risk of dying (64%) compared to those who did not receive chemotherapy.

Read more, a GO2 Foundation update on COVID-19 and an IASLC Guide to COVID-19 here and here.



Should we delay scans and appointments?

By Jeff Wynne

Every 3 or 4 months, my wife Joyce and I made a 90 minute trip to the Mayo Clinic for a "day of cancer." First stop: blood tests — a 20-minute wait alongside at least 50 other people. Three more crowded waiting rooms awaited us through the day, and then finally an appointment with our oncologist. As all of you know, this is an extremely stressful day. With the advent of the virus, the prospect seemed overwhelming.

The post-COVID dilemma: Should we go to the scans as scheduled, or delay them for a couple months to reduce the risk? What if this meant missing early detection of progression?

Our solution was to keep our scheduled scans, but do them at a local small hospital, avoiding the crowds at the Mayo. Then, we scheduled a video appointment with a doctor there. We can still contact our Mayo doctor if we need his opinion on any findings.

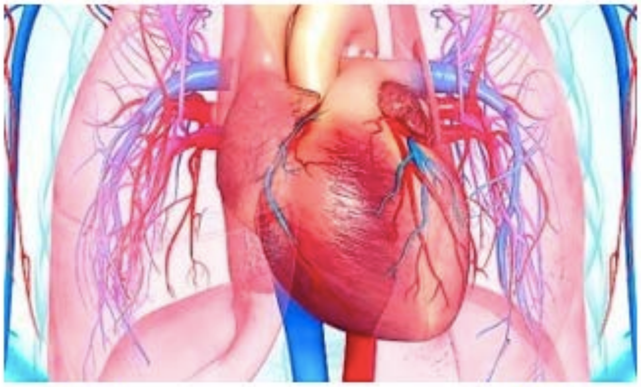
I found this experience safe and easy, and it points to the importance of problem-solving, as well as the benefits of finding health care providers who will work with you to keep you safe.

Want tips for staying safe on scan day? You'll find five on page 5.

Tips on safely doing scans cont page 5

Pulmonary hypertension in ROS1+ patients on TKIs

By Janet Freeman-Daily



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Two independent studies have found that ROS1+ lung cancer patients are more likely to develop blood clots than patients who have other lung cancers. Pulmonary embolisms are not uncommon in the ROS1ders. Pulmonary embolisms are a type of blood clot that can eventually result in pulmonary hypertension, because they increase pressure on the heart. Pulmonary embolisms can sometimes be caused by deep vein thrombosis (DVT), which occurs when a blood clot (thrombus) forms in one or more of the deep veins in your body usually in your legs.

Symptoms and what to do

According to the Mayo Clinic, symptoms of a DVT — which occurs when blood clots form — include: 1). pain, cramping or soreness, usually in a leg; 2) discolored skin; or 3) a feeling of warmth on the skin. Symptoms of a pulmonary embolism include: 1) sudden shortness of breath upon exertion, 2) chest pain that worsens when you take a breath; 3) cough, which may produce blood; 4) feeling lightheaded or dizzy, or 5) a rapid pulse.

Because ROS1+ patients are more likely to develop blood clots, patients should see a doctor as soon as possible when symptoms arise. An ultrasound can quickly determine whether treatment is needed.

Read more

The appearance of a blood clot in a patient taking a tyrosine kinase inhibitor (TKI) may indicate that the TKI is not entirely effective, that progression is happening, or that anticoagulation treatment needs tweaking. There isn't data about this other than a few case studies, however there is a new letter to the editor discussing pulmonary hypertension and ALK TKIs in the Journal of Thoracic Oncology.

Other research describes the relationship between ROS1+ cancer and blood clots:
ROS1-rearranged Non–small-cell Lung Cancer is Associated With a High Rate of Venous Thromboembolism: Analysis From a Phase II, Prospective, Multicenter, Two-arms Trial (METROS)

ROS1-Rearranged Non–Small-Cell Lung Cancer, Factor V Leiden, and Recurrent Venous Thromboses

NLCRT Stigma Summit Summary

By Lysa Buonanno

The National Lung Cancer Roundtable (NLCRT) is a national coalition of voluntary organizations and individuals dedicated to reducing the incidence of, and mortality from, lung cancer in the United States.

The Roundtable recently held its first Stigma Summit in Atlanta, Georgia. Sixty-five attendees from across the U.S. came together to identify issues affected by the stigma of lung cancer and strategize about how to eliminate it. The group included ten patients and caregivers.

We had excellent speakers, including medical oncologists, pulmonologists, primary care physicians, researchers, and survivors. After seeing the results of studies on stigma and hearing how survivors were personally impacted, we broke out into small groups to tackle six main issues we had identified.

After brainstorming, we identified tactics to address the stigma and challenges we may encounter along the way. Each group shared the features and benefits of each strategy; then the whole group gave feedback. I really feel this was a great way to get a lot of minds together to tackle each aspect of the stigma.

The goal of this meeting was not to walk out with all the answers but to start the process. As far as next steps, the NLCRT chairs are working on a statement that will be shared with all attendees so we can put out a unified message surrounding the stigma associated with lung cancer.

I feel optimistic about this summit and was encouraged to see the passion and commitment in the room. I was pleased they not only gave survivors a seat at the table, but truly listened to, and asked for, our input. As we all know, actions speak louder than words. I hope to see action taken on this in the near future. especially from the larger organizations involved that have the most influence. We must change the conversation around lung cancer and ensure that every single patient is treated with empathy and has access to treatments regardless of their smoking history.

Frequently Asked Question:

How often should I be scanned?

(A summary of Facebook responses)

- Most ROS1 patients get chest and abdomen CT scans every 3 – 4 months. Brain scans happen less often – 6 months to a year in frequency.
- It’s important to note that individual concerns may require more frequent scans. For example, if brain metastasis has occurred, oncologists may do brain MRIs more frequently.
- Those who are in drug trials often have scans more frequently to adhere to trial protocols.
- PET scans are different than CT scans. Typically, PET scans are used at diagnosis and initial assessments, and CT scans are used regularly after that. ROS1der Mark Baran aptly describes the difference this way: “PET scans track radioactive sugar to find spots in the body with higher metabolic processing that may indicate cancer. A CAT scan is essentially a 3D x-ray.”

Hacker hits ROS1 website

On June 30, a Vietnamese hacker gained access to our website at ROS1cancer.com. His access has since been terminated. In the process of restoring site content, a barrage of emails were automatically sent to everyone who subscribes to our blog. Some subscribers also received spam emails that might have been associated with this hack. We apologize for any inconvenience, and assure you no personal health information was compromised.

The ROS1der Drivers

Scan safety tips

1. Check with your cancer center. Ask what addition precautions they are taking, such as pre-screening patients for COVID-related symptoms before appointments, allowing for physical distancing between patients, longer appointment times if needed, cleaning equipment and surfaces after each patient visit, and having staff wear personal protective equipment.

2. Ask if visitors or family members can accompany you for the scans and blood tests.

3. Many doctors are turning to telemedicine to limit cancer patients' trips to the hospital. Check with your oncologist if this is an option.

4. Mask up.

5. If you feel your clinic is unsafe, look into other nearby clinics you could go to.

Getting back to our next normal

By Jeff Wynne

A diagnosis of stage 4 lung cancer changes life forever. The future that once seemed so clear now looks like a bank of fog. That was how I saw things four and a half years ago when I was diagnosed. I was six months into my retirement, and had a clear picture of how I wanted to spend this next chapter in my life.

Cancer changed my outlook from one of long-term planning and delayed experiences to one of short-term planning and living out my dreams **now —** while I felt healthy enough to enjoy them. With each successful scan, I planned a new travel adventure, trips to see the grandkids, and excursions to new golf courses across Minnesota. I am so fortunate that Xalkori has worked well for me. I have been able to enjoy these many experiences, and I was looking forward to more.

Then the virus hit, and all planning came to a halt. Trips were canceled. Dinner with friends was out. Even walking to the local pub with my wife was too dangerous. Visiting and hugging the grandkids was put on indefinite hold.

Every one of us is asking the same question: When are things going to get back to normal? My first instinct is, of course, to do everything possible to keep myself safe. Studies indicate lung cancer patients run a much higher rate of mortality if they contract the virus. (See page 1.)

I should put off my planned experiences for a future day, but this runs counter to my desire to experience as much as I can now, knowing that I am just one scan away from not being able to do so. This is especially tough when I think about all the hugs from my grandkids I might lose.

I don't have answers to the questions, but my wife and I have decided to focus on a balance of risk and reward. If I live for today, how much risk am I willing to take? What can I do to minimize the risks so that I can experience just a little more? As a mathematician, I wish I could assign number values to each of these risks and each of these rewards, but for now I'll have to rely on my intuition and any available research.

In this next normal, I wish all of you as many experiences as you can create, and many safe and healthy days.

About this newsletter...

ROS1derings is a newsletter of The ROS1ders patient advocacy group. The ROS1ders is a group of patients and caregivers dealing with ROS1+ cancer. We strive for better outcomes for all ROS1 cancers by supporting patients and caregivers, increasing awareness and education, accelerating research, and improving access to effective diagnosis and treatment.

We will use this space to share updates about our progress, to feature questions frequently asked by the ROS1 community, and to invite all ROS1 patients to join us in our mission. Learn about the ROS1ders.