



Director's Overview And the world changes...

By: D. Ross Camidge, MD, PhD



Members of the CU Thoracic Medical Oncology Team get all masked up for the first time at the start of the new COVID normal in March 2020.

To some extent everything pre-COVID feels like a dream – a time of togetherness, of less stress and of greater innocence - and everything during-COVID feels like waking up from that dream to a much harsher reality. Yet for those affected by thoracic cancers – lung cancer, mesothelioma and thymic cancers – living with harsh realities is nothing new. Indeed, COVID is just another thing to address with when you are already coping with cancer. Take a number, COVID, I'll deal with you later!

Yet there are incredibly important things that everyone touched by cancer can and should learn from how we have all adapted to pandemic life. Positive things.

For example, despite travel limitations, the world has gotten smaller. Not just because 'to Zoom' has become a new verb for our everyday communication. But because now, wherever you live in the world, whatever you have going on in your life, we all have something immediately in common. Through the shared fear and loss of

the pandemic, our empathy for others has also increased, including, perhaps, a greater understanding of the stresses of a cancer patient's life. So, if you are affected by cancer, and there are people you have not spoken to about it, it has never been easier to connect with people, literally and emotionally, than it is now.

On a scientific level too, we can also take something positive from COVID. If the world has learned that through resilience and grit and science and research, we can make progress with COVID, we should also recognize that the same qualities lead to progress in dealing with cancer. If the world can adapt and adjust and still find a way to thrive, despite massive upheavals, we can do the same with cancer.

The CU program remains one of the world leaders in changing how we think about thoracic cancers, developing new breakthroughs and celebrating our patients as the pioneers that they are. In this newsletter you will see multiple examples of cancer patients and cancer professionals working together to push their versions of resilience and grit and science and research. And changing the world for the better as a result. In this newsletter we are also taking the opportunity to highlight some of the transformative research we do that goes beyond the lab and the latest drug trial including imaging, radiation therapy, and supportive care.

Help us to deliver the resources to keep CU at the cutting edge, through COVID times and beyond. If you are reading this and you or someone you know has a thoracic cancer - please support the LCCF and help change the world for the better. Our LCCF website includes an archive of all the past newsletters and details of where every dollar has gone. What will the future hold for those affected by thoracic cancers?

You get to decide.

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Variation in how side effects are reported leaves first impressions of new anti-cancer drugs open to manipulation

by Garth Sundem



Emily Simons, MD, MPH

An important goal of early-phase clinical trials is to discover a drug's possible side effects. But despite FDA guidelines seeking to standardize this reporting, a University of Colorado Cancer Center study published in the *Journal of Thoracic Oncology* finds significant variation in how drug side effects are reported, potentially making some drugs seem safer or less safe than they really are.

"Without standardizing how we present such data, there is the potential for misinformation about these side effects," says Emily Simons, MD, MPH, senior resident at University of Colorado School of Medicine and the first author of the study.

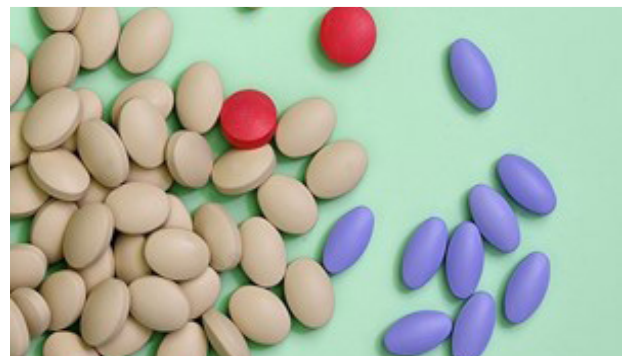
The group including senior author D. Ross Camidge, MD, PhD, got interested in the topic after seeing how differently the side effects of new drugs for treating lung cancer were being presented – and realizing that differences in reporting methods could over- or under-estimate the apparent safety of such drugs.

"Sometimes you only report an adverse event that happens in, say, 10 percent or more of

patients on a trial. However, if you split related side-effects into lots of little sub-groups, perhaps no one event reaches this 10 percent threshold and nothing gets reported," Simons says. "In contrast, if you combine rationally grouped events – like confusion and memory issues – then this group passes 10 percent and you could clearly see the side effects as, for example, very broadly affecting higher functions of the brain."

These observations led Simons to look into all phase I and II clinical trials involving lung cancer patients reported at the American Society for Clinical Oncology (ASCO) annual meetings from 2017-2019, the major outlet for early-phase trial results, finding 209 trials in all. What the group found was wide-ranging variation in the ways trial investigators report drug side effects.

For example, the study found six different thresholds used to decide when a side effect should be reported. Simons and colleagues also found that when patients were treated with multiple doses of a trial drug, side effects were sometimes reported only across all drug dosages. Combining side effect data across dosages could make a drug look more toxic due to the inclusion of side effects that occur only at very high doses. On the



other hand, including side effects from especially low doses of a drug could make the drug seem more benign than it is at the recommended dose.

Additionally, patients are supposed to report all symptoms when they are on a clinical trial and then it's up to trial investigators to decide, in their opinion, whether a symptom is likely due to the drug or just happens to be another symptom the

patient is experiencing at the time.

“Determining if a side effect is treatment-related or not is subjective. If you rely on this, you get rid of some of the background noise of coincidental symptoms. However, you can also miss more subtle side effects,” Simons says.

Simon’s study found that the reasons patients in some clinical trials stop taking study drugs or reduce the doses are also usually not documented. Similarly, some patients received blood tests to evaluate possible side effects, but it was often not documented whether everyone on a trial received these tests, or if only those patients already identified to be at risk were tested.

“If you don’t know if everyone or only a fraction of people got a specific blood test, you don’t know if the ten people with an abnormal result should be documented as 100 percent or 10 percent of the trial population. Some trials require patients to reduce the dose of a drug after an abnormal blood tests, even without other symptoms. Without knowing the details of why dose changes occurred leaves a lot open to speculation,” Simons says.

Simons suggests there is a tremendous opportunity for conferences and academic journals to standardize their requirements for the reporting of side effects to help accurately communicate risk.

“Given the increased speed of drug licensing, early phase trial data is essential in helping us form accurate impressions of a new drug. Recognizing and addressing the variation in how side effects are reported would improve the accuracy of these impressions in the future,” Simons says.

The new LCCF Main Page URL is:
<https://medschool.cuanschutz.edu/lccf>

Includes:

- **Newsletter Archive**
- **Estate Planning Special Edition**

Hometown Hero: Danielle James of Moore, Oklahoma

<https://stories.whataburger.com/whataburger-heroes>



Danielle James. Abraham Farrar Photography

It looked like Danielle James might not see her 26th birthday.

In 2013, the registered nurse was diagnosed with stage four lung cancer and given six months to live despite having never smoked. Her particular diagnosis had about a 7 percent survival rate. “In the scan, all of the cancer in my chest lit up like a Christmas tree,” James says.

Despite the grim prognosis, James started fighting. She began chemotherapy. When that didn’t work, doctors prescribed a targeted medication for her specific cancer cells. The medicine was successful, and by July 2013 James’ tumors were barely visible.

In January 2015, she married.

But cancer wasn’t finished with James. Eight months after her wedding her lung cancer had spread, and she had five tumors in her brain.

The targeted medication had stopped working. “I went to Denver and got on a clinical trial for a drug that was supposed to work better,” she says.

Three years later, James is alive thanks to that drug. Now, the survivor is using her experience to help others do the same.

Fighting for a voice

James works with the American Lung Association’s LUNG FORCE initiative, which creates a network for survivors and advocates for more research.

In April, James met with legislators in Washington, D.C., about increasing spending on cancer research.

“I want to share my story because I know I can help or inspire someone,” she says. “People need to know that there is life after diagnosis.”

Paying it forward

Terri Bailey, the executive director of the American Lung Association, Oklahoma, is so appreciative of the support James has given to the organization. “She is instrumental in spreading our message in Oklahoma, and her impact can be felt by so many.” Bailey tells the story of a woman who recently moved to Oklahoma and was diagnosed with stage four lung cancer. “It took her three months before she even came to our support groups,” Bailey says. “She began to open up, but she always talked about, ‘why would I want to buy a new car or buy a new house or anything?’ But through the help of the support group, specifically Danielle, she learned living with stage four lung cancer can be done.” Bailey says that woman has since bought a house and is decorating it with her husband. And she gives the credit to James who lives an inspirational life and shares her powerful story with others.

A new chapter

James recently started a new adventure: motherhood. With her nursing experience, she and her husband fostered infants born with drug addictions. They have since adopted one of those infants, naming her JoyAnna.

She says they plan to foster again, but teens. “There is a huge need for families that are willing to foster older kids,” she says. “Many of them age out of the system, which puts them at a huge risk for homelessness.”

Until then, their focus is on their daughter. “Joy-Anna is my little best friend,” James says. “She is the reason that I get out of bed every morning. She brings so much joy to my life and she is my hope for the future.”

African Americans, Hispanics less likely to receive recommended lung cancer imaging

by Garth Sundem

The use of PET-CT imaging gives doctors the best possible picture of non-small cell lung cancer (NSCLC), and this accurate imaging helps to match patients with the best treatments. Unfortunately, not every NSCLC patient gets the recommended PET-CT imaging. Now a University of Colorado Cancer Center study published in the Journal of the National Cancer Institute shows an important predictor of PET-CT use: African American patients were only about half as likely as non-Hispanic whites to receive this important imaging; Hispanics received this imaging about 70 percent as frequently as non-Hispanic whites.



“We started from the perspective of outcomes: we know that Black and Hispanic lung cancer patients tend to not do as well as non-Hispanic whites. We wondered if there could also be dif-

ferences in how these groups are imaged at diagnosis,” says Rustain Morgan, MD, CU Cancer Center investigator and assistant professor in the CU School of Medicine Department of Radiology. The study, with co-authors Sana Karam, MD, PhD, and Cathy Bradley, PhD, looked at PET-CT use and outcomes of 28,881 non-Hispanic Whites, 3,123 African Americans, and 1,907 Hispanics diagnosed with NSCLC between 2007 and 2015. To focus on potential ethnic/racial differences, the study controlled for factors including education level and socioeconomics.

“Our study showed a couple things,” Morgan says. “First, it reaffirmed that patients who are imaged with PET-CT at diagnosis have better cancer-specific survival. Second, it showed there is a significant difference in who gets the recommended PET-CT at diagnosis. And third, it leads to more questions, like what is driving this difference and are these disparities in adherence to imaging guidelines present in other cancers.”

In cancer treatment, more advanced cancers generally require more aggressive treatments. Some earlier imaging strategies including chest radiography may identify a primary lung tumor but may not be sensitive enough to see smaller deposits of the disease, leading doctors and patients to underestimate a cancer’s stage. Misidentifying a cancer’s stage can lead to under-treating the disease, and possibly to worse outcomes.

“If African Americans and Hispanics aren’t getting the best imaging, this could be a piece of the puzzle explaining why these patients with lung cancer tend to have worse outcomes than white patients,” Morgan says.

He points to a couple possible explanations for these disparities. First, PET-CT machines are relatively specialized and expensive, meaning that not all hospitals have the capability to offer this imaging.

“For example, our safety net hospital, Denver Health, doesn’t have a PET-CT machine. It is also rare for rural hospitals to have this equipment, which means patients would have to travel several hours to have their imaging,” Morgan says. In fact, in addition to racial/ethnic disparities, Morgan’s study also shows differences in

PET-CT use based on the type of treatment facility: Patients treated at NCI-designated cancer centers were more likely than those treated at teaching hospitals and especially those treated at community cancer centers to receive PET-CT imaging.

“Another, and potentially even more problematic factor, could be unconscious bias is a driver of the differences we found,” Morgan says. Future studies hope to answer some of these questions. For example, Morgan is working with CU Cancer Center colleagues to plan a project examining the financial cost of inappropriate cancer staging. And, of course, now that a clearer picture of these disparities is starting to emerge, Morgan and colleagues hope to explore ways to ensure that all NSCLC patients receive the recommended imaging during the process of diagnosis.

“Now that we know more about this problem, we must find ways to address it,” Morgan says.



Rustain Morgan, MD, CU Cancer Center investigator and assistant professor in the CU School of Medicine Department of Radiology

Radiation Oncologist wins major Research Award

In 2020, Dr Chad Rusthoven, UC Radiation Oncologist won the prestigious Dr. Charles Coltman Fellowship from The Hope Foundation for Cancer Research, which is aligned with the Southwest Oncology Group (SWOG). The grant will provide research support for two years as he serves as national Principal Investigator for the SWOG S1827 “MAVERICK” clinical trial – a randomized trial comparing standard prophylactic cranial irradiation versus brain surveillance imaging alone for small cell lung cancer patients.

“Small cell lung cancer can spread to the brain at higher rates than some other cancers and, in response to this observation, prophylactic (aka, preventative) brain irradiation has been used as a strategy to reduce these events and improve disease control outcomes. However, we have also found that this approach can be associated with noticeable side effects for some patients.

This trial is evaluating a strategy of avoiding the prophylactic approach in favor of close surveillance with brain MRIs, and then only treating with brain radiation if brain metastases occur,” Rusthoven says.



Chad Rusthoven, MD

“I am so grateful and honored to be a recipient of the Coltman Fellowship. This award will provide essential protected time during the week to allow me to focus on the trial in our efforts to improve outcomes and quality of life for patients with lung cancer.”

The reach of Open Access Science

When a scientific article gets published, sometimes you can only read it on-line if you, or your institution, pays for a subscription to that journal. Without that, the only other way is to utilize a pay-per-view option for each individual article, which can rapidly become very expensive. However, some journals now adopt an Open Access policy, making the article available for free as soon as it is published. With library costs escalating, the importance of this approach is now being studied.

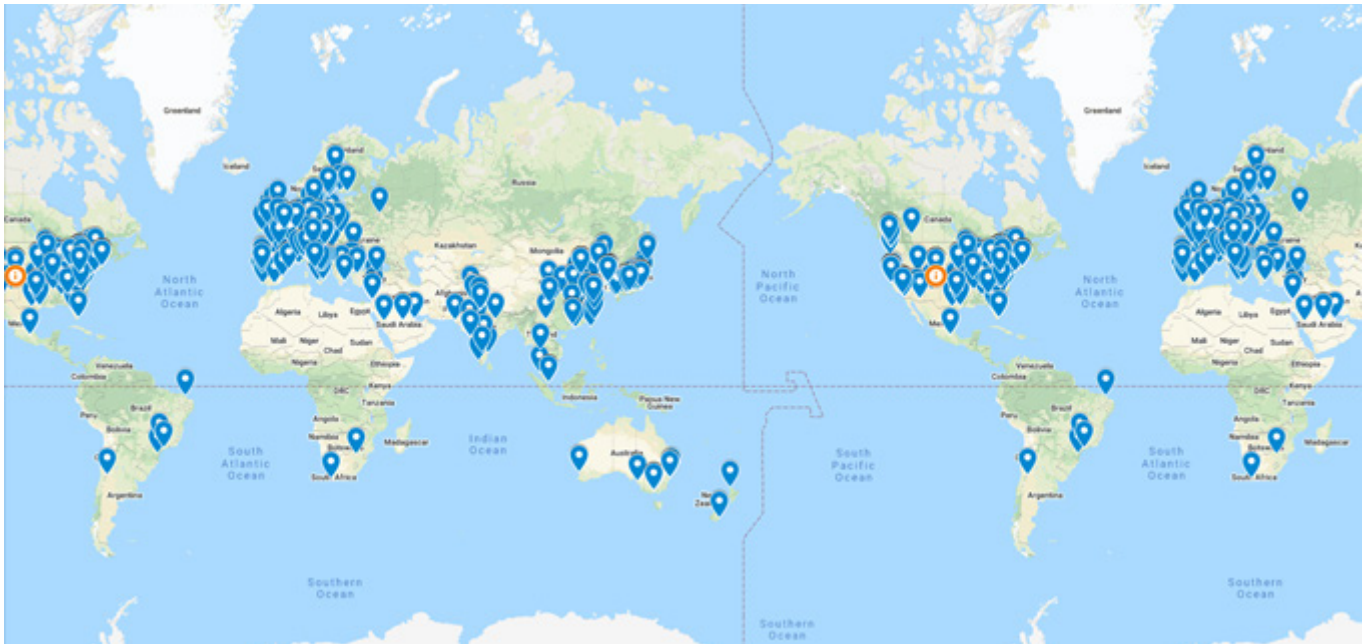


Danielle L. Ostendorf

As one example of how this may dramatically increase the impact of a scientific breakthrough, Danielle Ostendorf, the Electronic Resources Librarian at the Strauss Health Sciences Library on the Anschutz medical Campus generated the map below. Each pin shows the location of other authors who cited the original article on

“Anaplastic Lymphoma Kinase Inhibition in Non-Small-Cell Lung Cancer” published in the Open

Access New England Journal of Medicine from 2010.



Closing the mental health care gap for cancer patients

By Tyler Smith

Miguel and Bonita (Bonnie) Birge first met in high school, when Bonnie’s brother introduced them.



A boa constrictor (he has two) offers Miguel solace as he battles cancer. Photo courtesy of Miguel Birge.

The casual start became a lifetime commitment: they celebrated their 20th wedding anniversary in late June 2019. Many others share their Aurora home, including four dogs, four cats and two snakes, which Miguel says are just as companionable and worthy of affection as the furry four-legged friends.

“If you love an animal, care for it and show it love, it will in turn respond,” said Miguel, 46. But for much of their time together, the Birges have had another unwelcome companion – the physical and mental stress caused by disease and injury. Diagnosed at 23 with Hodgkin’s disease, Miguel endured a grueling four-drug combination chemotherapy regimen that goes by the acronym MOPP. He emerged from the exhausting six-month ordeal haggard but cancer-free. Miguel worked steadily through 2008 in window and door sales and contracting. But then a drunk driver plowed into his car, severely injuring his back, ending his work career and ushering in a decade of physical and emotional challenges. Around 2012, severe abdominal pain he com-

pared to “beating the hell out of you with a baseball bat” required surgery to remove the tail of his pancreas, along with his spleen and gallbladder. In April 2019, pain in his upper stomach sent Miguel to the emergency department at UCHealth University of Colorado Hospital on the Anschutz Medical Campus, where a CT scan revealed nodes in his right lung. He was diagnosed with stage 4 non-small cell lung cancer (NSCLC).

Miguel underwent genetic testing to see if he could be treated with drugs that inhibit cancer cell growth driven by a genetic mutation, but he tested negative for these and chemotherapy and immunotherapy were his initial options for keeping the disease at bay. He began thrice-weekly treatments at the end of May 2019.



Miguel, who is pictured with his wife Bonnie Birge, receives counseling services as part of his treatment for lung cancer. Photo by UCHealth.

His medical oncologist, however, had another treatment suggestion for the Birges. He pointed them to a study sponsored by the University of Colorado Denver (UCD) that tests the effectiveness of providing mental health support to relieve stress, depression and anxiety among underserved patients with lung and head and neck cancers and their caregivers. Patients at UCH, National Jewish Health, Denver Health, Saint Joseph Hospital and St. Mary's Hospital and Regional Medical Center in Grand Junction

were to be enrolled in the trial.

The randomized study ultimately enrolled 440 patients. Half received “stepped” mental health services: the amount and intensity of counseling increases with the severity of their assessment for emotional stress and depression. The control group received a list of local and national counseling resources.

The Patient-Centered Outcomes Research Institute (PCORI), which investigates the effectiveness of treatment options, funded the \$1.9 million study, which concluded in 2020. The Birges qualified for the trial and began counseling sessions in June 2019.

Mental health support for cancer patients a needed service

The physical effects of head and neck and lung cancer treatments – difficulty swallowing and breathing, pain, nausea, coughing, weight loss and fatigue, for example – can be tightly intertwined with emotional distress, said Dr. David Raben, a radiation oncologist at UCHealth TomoTherapy Cancer Care Clinic – Lone Tree.

“All of these side effects can lead to symptoms of depression and feeling helpless,” said Raben, who is a co-investigator in the study. During an interview in late June, Miguel put that observation in down-to-earth terms.

“I have trouble dealing with the end-of-life thoughts,” he said. “How do I address the end of my life and how do I prepare for that? I’ve been dealt some hard cards.”



One of the Birges' four dogs. Their animals are reliable stress relievers. Photo courtesy of Miguel Birge.

Filling a gap in mental health support

The PCORI trial built on the findings of two earlier studies, noted principal investigator Dr. Evelinn Borrayo, associate director of the CU Colorado Cancer Center and associate director of research with the Latino Research and Policy Center at the Colorado School of Public Health.

A small study in 2013 at Denver Health, dubbed EASE, led by Dr. Kristin Kilbourn, a licensed clinical psychologist with UCD, suggested that phone counseling for patients with head and neck cancers could help to “buffer” the physical and emotional challenges of treatment. In 2016, another study at Denver Health concluded that a lack of mental health services and access to them contributed to delays in medical treatment for underserved patients with head and neck and lung cancers.

“What was clear is that these patients need a lot of mental health support, but there is very little for [that] aspect of their treatment,” Borrayo said.

The EASE study, Borrayo added, indicated that it would be important to tailor counseling interventions to the mental health needs of each patient – some may experience few or no symptoms while others may be affected severely – and that patients could benefit from face-to-face meetings with counselors (although phone contact is still an option for patients who have trouble arranging transportation).

Counseling that relieves depression and anxiety among patients and caregivers is important simply to improve their quality of life. But it can also play a vital role in keeping a patient’s treatment regimen on track, Raben noted.

“The worry of whether the treatment is going to work, compounded with the symptoms they experience during treatment, can really wear a patient out and make them lose their desire and passion for life every day,” he said.

Raben’s words echo those of Miguel as he contemplates a battle he said is worth fighting but he also concedes will be very difficult to win.

“The issue is that you get so beat down physically that it converts to mental stress,” he said. “Eventually you get tired of fighting that. It wears

on you. Some people just get so tired that they want it to stop.”



UCHealth radiation oncologist Dr. David Raben sees mental health as an essential part of his patients’ medical treatment. Photo by UCHealth.

The PCORI study’s emphasis on including mental health services as an integral part of care for head and neck and lung cancer patients addresses a fundamental health care problem, Raben added.

“It’s an area that warrants further research and support because many times patients who are underserved don’t have access to health care that others do and many do not get the best or optimized, proactive care while they undergoing treatment or after treatment for these types of cancer,” he said.

Staying on track

Feelings of depression and anxiety must be addressed if a patient is to benefit fully from treatment, said Alejandra Solis, a licensed treatment therapist with Denver Health who is working with both Miguel and Bonnie.

“We try to help people think of ways to adjust to the unknown,” Solis said. “If they are feeling depressed, they might stop taking their medications or engage in unhealthy behaviors. We know that everything is connected, so if one piece is not functioning properly, everything is affected.”

Caregivers are a key part of that connection, so the trial focuses on also helping them to find ways to cope, Solis added.

“It’s very important for caregivers to take care of themselves,” she said. “I ask them, ‘What do you do for yourself?’ If we’re not taking care of ourselves, how can we be expected to take care of others?”

Bonnie helped Miguel through his previous bouts with disease and injury but acknowledged his lung cancer diagnosis has created new pressures. There is financial stress – Bonnie’s job as a mechanical engineer is the couple’s primary source of income – but fear of what lies ahead is a greater source of anxiety, she said.

“My biggest concern is looking at the future and not knowing,” she said. “It feels like I won’t have Miguel around when I retire. When I first found out that he had cancer, that was all I could think about. I dwelled on it.”

Solis said she helps Bonnie and others in similar situations cope by focusing on things they can control rather than things they can’t – the fact that a loved one has a serious disease being the primary example of that.

“They can learn to decrease the symptoms of depression and anxiety by having information and power,” Solis said. “For things they can’t control, we talk about how to alleviate those feelings by going for a walk, calling a friend, writing in a journal, joining a group or identifying a passion.”

Sources of support for cancer patients



Treatment therapist Alejandra Solis provides coping strategies to both Miguel and Bonnie. Photo courtesy of Alejandra Solis.

For both Miguel and Bonnie, their animals provide welcome distraction and comfort. Bonnie said she’s also learning to focus on the present rather than obsess about the future.

“We have talked about instead of thinking so far out, living in today,” she said. “When I start thinking about the future now, I just remind myself that we’re not there yet and that I need to take one day at a time and think about what I have today. I tell myself I have Miguel now and I need to enjoy the time I have with him now.”

Miguel said he’s found help with coping strategies he learned and friends he made through Alcoholics Anonymous (AA). He’s been sober for seven years. He wants to extend those support skills to patients with cancer, a choice he said Solis encourages.

“AA is another tool that I use to help me deal with the cancer issue, and I hope to use it to help others,” he said. “Life is not easy for everybody. Helping others to get through hard days helps me as well.”

At the same time, Miguel has also needed what Borrayo calls “problem-focused support” for pain and nausea caused by his cancer and chemotherapy. In those instances, he’s turned to the CARE (Clinical Assessment & Rapid Evaluation) Clinic at the CU Cancer Center, which helps to stabilize patients struggling with acute symptoms. The Birges said the clinic’s providers – nurses, physicians and pharmacists – have so far prevented emergency department visits and hospitalizations for Miguel.

Toward holistic treatment

The study results will ultimately be used to evaluate how well counseling helps to lessen symptoms of depression and anxiety and perceived stress, improve quality of life and strengthen coping skills, Borrayo said. She would also like to see mental health support for cancer patients continue beyond treatment.

“As time goes by and people survive, the support doesn’t tend to be as available,” she said. “I honestly think we are focused on patients and not looking enough at survivorship as a long-term issue. Many [patients and caregivers] will continue to struggle with anxiety and depression for the rest of their lives.”

In Raben's view, mental health support for cancer patients should be part of an overall symptom management strategy that includes nutritional support, exercise and software programs that connect patients and providers on a regular basis to address issues.

"The more we can holistically approach patients and proactively manage them, the better our care will be," Raben said.

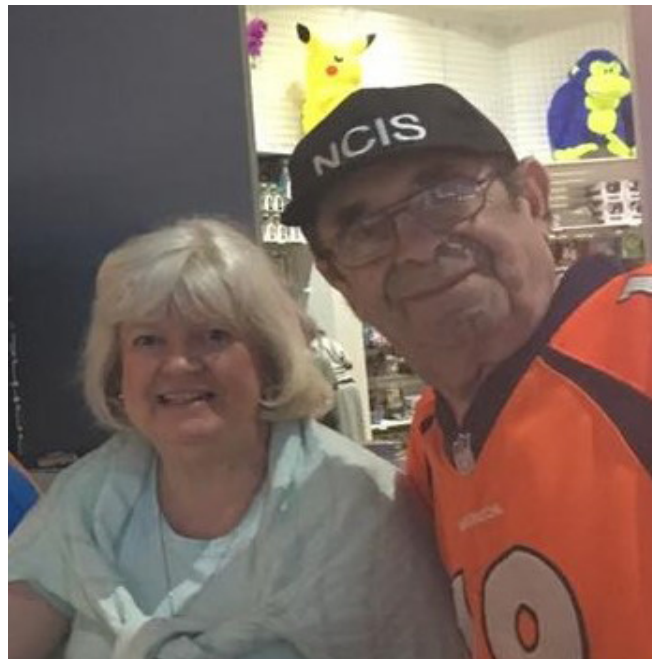
Colorado C-stories: Images of life after a cancer diagnosis.

Receiving the news of any cancer diagnosis can be devastating. Patients may feel like their lives are coming to an end, that they will not be able to accomplish many goals they had. Yet time and again the human spirit (with a little advanced medical care) prevails and people remember to be the people they were before they became patients – not just living with a cancer diagnosis but thriving. At CU, we see patients from all over the country and the world. Here are a selection of the CU's finest showing that life remains about living, even, or perhaps especially, after a cancer diagnosis.

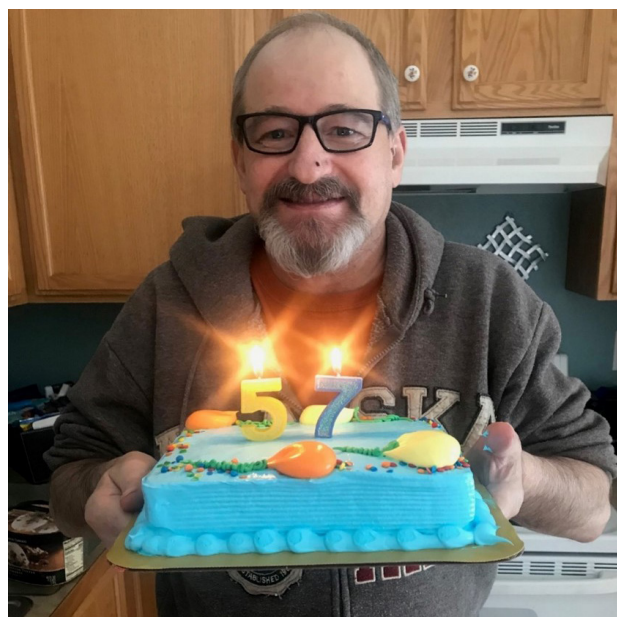
Send your pictures and a line or two to ross.camidge@cuanschutz.edu and each newsletter going forward we'll aim to show others what 'hope' really looks like. Look for more images scattered throughout this newsletter.



Daryl Nickel, 6-year lung cancer survivor. "Half a lung short and still singing!"



Terry and Marvin Romer. "Still smiling after 6-years of Marv as a lung cancer patient and 49 years of marriage."



Charlene Martin, surprised her husband Mick, an eight-year stage IV lung cancer survivor, with family, friends and a big cake for his 57th birthday!

Coronavirus Diaries: I Have Lung Cancer and a Cough. I Can't Get a Test - I'm worried about whom I might have exposed.

By Janet Freeman-Daily

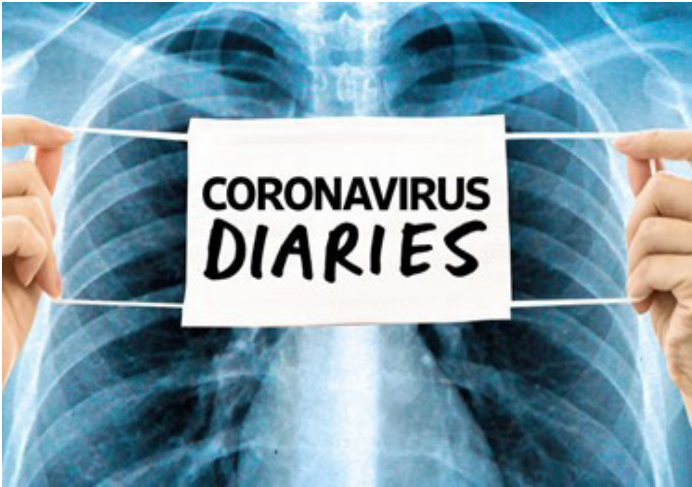


Photo illustration by Slate. Photo by Getty Images Plus.

Author's Note: I have metastatic lung cancer. I live in the greater Seattle area, ground zero for COVID-19 in the United States. I've had a cough for well over a month. I haven't been able to get tested to check whether I have the coronavirus.

Here's my log of how things unfolded.

When the cough starts in January, COVID-19 feels like something happening on another continent. Coughing is not uncommon for me this time of year, but it's always cause for some concern because I tend to get pneumonia. My lungs, which have twice been radiated to treat my cancer, have trouble clearing gunk out. There's scar tissue, and one left lobe—the left lung has two lobes—is shriveled. By mid-February the cough is accompanied by headaches, fatigue, and shortness of breath. (there's a blood clot in the main artery feeding my lungs—cancer patients are prone to get blood clots).

Given that most patients who take the oral targeted therapy cancer drug I take eventually see their cancer grow again, I'm used to living with uncertainty. Life doesn't stop just because I don't feel well.

Cough in tow, I fly to Los Angeles for a conference on lung cancer research, and a training session with fellow lung cancer patient advocates. I'm a retired Boeing engineer, and now in my work as an advocate, I write about the science of lung cancer for patients and provide a patient's perspective for researchers.

At the conference, I chat with researchers from several countries about my cancer patient group's activities. I shake a lot of hands and share a lot of hugs. When I return home, my chest feels congested like I can't get a deep breath. I feel like I have the flu. I spend a couple of days in bed and binge Star Trek reruns with my cat, Admiral Dufus, on my lap.

Two days later I start coughing up thick green gunk, like I have when previously diagnosed with pneumonia.

The news of the coronavirus where I live worsens with my symptoms—which, though I don't have a fever, sound a lot like those of COVID-19.

On Feb. 28, there's a report of a young man near Seattle who tested positive for the coronavirus but did not have any travel or exposure to confirmed cases of the virus. The virus is spreading in the community.

On Feb. 29, the Centers for Disease Control and Prevention report the first U.S. death from COVID-19 in Kirkland, about 35 miles north of my home.

On March 1, there's another death near Seattle. A postal worker at the bulk mail facility less than five miles from me tests positive. A researcher in Seattle says the virus has likely been circulating in our area for several weeks. I begin to really worry.

I email my oncologist. He doesn't know if they have a protocol to test for the virus but will order my usual blood draws—I'm due for a checkup soon anyway—and will add a chest X-ray to check for pneumonia. I head to the clinic, wearing my N95 respirator to cover anything my cough expels.

I ask the lab receptionist if a COVID-19 test is on the lab order. She says no, and offers no further comment. Back home, I check the CDC website

and discover I do not fit the testing criteria. The only people who can be tested are those who have symptoms and traveled from countries having outbreaks, were exposed to someone who tested positive, or are hospitalized with severe COVID-19 symptoms.

Soon after, the nurse calls me with my test results: no pneumonia. However, she suggests I stay home for two weeks just to be cautious. This is not a big inconvenience, as I'm retired from corporate life and now work from home doing advocacy-related activities and writing. We have perhaps a month's worth of food stocked up, a large yard, and exercise equipment in the basement. But I would really like to know if the coronavirus was going around those conferences so I can warn others.

The lung cancer community is getting anxious about COVID-19. Article after article repeats World Health Organization statistics that most people will have only mild symptoms, except for those who are over 60 and have underlying health conditions. We have so many questions: Which aspect of lung cancer or its treatments qualifies as an "underlying condition"? Are all patients at high risk, even if they are young and on targeted therapy? So far, there's little data. I share the facts we do have on my blog, and on social media. I keep hoping I can figure out if I've exposed anyone to the virus myself, if my cough is evidence that I might have been sick with it while at meetings in Los Angeles.

There are promises of widely available tests.

On March 3, Vice President Mike Pence says, "We will issue new guidance from the CDC that will make it clear that any American can be tested with no restrictions, subject to doctor's orders." The University of Washington announces that it will begin testing for the virus. One of my social media contacts says two commercial labs will start testing soon. But clinics like mine still don't have testing guidelines.

I am stuck in a loop: My clinic's website refers testing questions to the state Department of Health. But the DOH website says, "If you have symptoms, call your healthcare provider." It recommends that people without severe symptoms

(like me) just stay home.

Risk reduction might be my best play, test or not, since we don't have a vaccine or treatment. But understanding the true spread of the disease is important for containing and mitigating it, especially for high-risk groups like lung cancer patients. Even as my symptoms subside, I am still concerned that I've made others ill. I want to be able to warn people, with accurate information.

This week, the New York Times reported that regulators squashed efforts in Seattle to add testing for COVID-19 into a large flu study. Politico reported a "looming shortage" in the materials needed for tests. On the local news, people are being asked to call their doctor rather than go into a clinic or hospital. Doctors on Twitter are talking about contacting cancer patients and suggesting they postpone coming into the clinic for follow-up appointments. I've emailed my oncologist to ask if he has the bandwidth to help me get tested, but he hasn't responded. I imagine he's swamped.

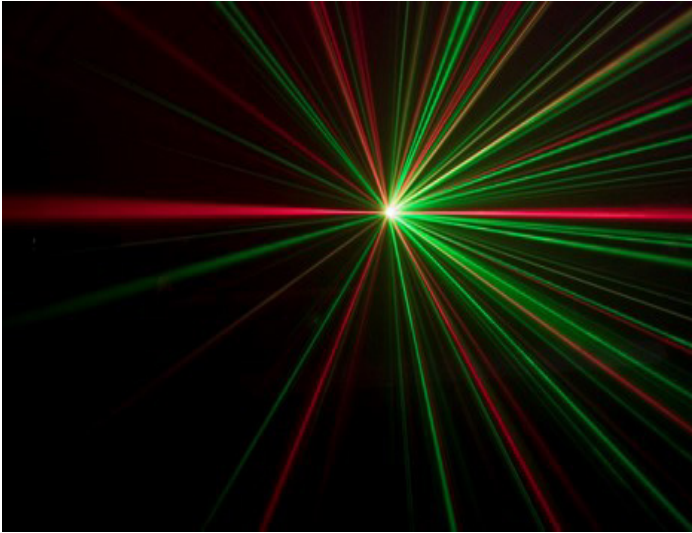
Originally published in SLATE magazine, March 12th, 2020. <https://slate.com/technology/2020/03/coronavirus-diaries-lung-cough-test.html>



Melissa Turner (left), 3-year stage IV lung cancer survivor, enjoying goat yoga in Loveland, Colorado with her husband and daughter.

FIRE-SCLC analysis: Largest ever study of first-line radiosurgery for brain metastases from small cell lung cancer

by Garth Sundem



The international First-line Radiosurgery for Small-Cell Lung Cancer (FIRE-SCLC) analysis led by University of Colorado Cancer Center researchers and published in JAMA Oncology details clinical outcomes for 710 patients with brain metastases from small cell lung cancer treated with first-line stereotactic radiosurgery (SRS), without prior treatment with whole-brain radiation (WBRT) or prophylactic cranial irradiation (PCI).

The study represented a substantial research effort including international collaborators from 28 individual centers and one prospective clinical trial from Asia, North America, and Europe. Following first-line SRS, the outcomes were encouraging overall with a median time to brain progression of 8.1 months and a median overall survival of 8.5 months.

The investigators also compared these SRS results with a control group of 219 patients treated with first-line WBRT for brain metastases, which is the current standard of care for small cell lung cancer. Importantly, no overall survival benefit was observed with WBRT compared to SRS. In fact, the survival outcomes were slightly better with SRS even after matching for baseline char-

acteristics. The authors were careful to note, however, that the observed differences in survival in favor of SRS could be related to uncontrolled treatment selection factors in the setting of a retrospective analysis.

“As expected, whole brain radiation was superior to focused treatment with radiosurgery in lengthening the time to disease progression in the brain. However, the improvement in brain control with whole brain radiation did not appear to translate into an improvement in overall survival,” says Chad Rusthoven, MD, assistant professor in Radiation Oncology at the University of Colorado Cancer Center, the paper’s lead author.

The study, with senior author Tyler Robin, MD, is the largest analysis of outcomes with first-line SRS for brain metastases from small cell lung cancer, offering important descriptive and comparative data on this potential treatment paradigm.



Tyler Robin, MD

“Although SRS has become the preferred treatment strategy for limited numbers of brain metastases arising from many cancer types due to improved quality of life and cognitive preservation compared to WBRT, small cell lung cancer remains an important exception where WBRT has remained the standard of care for limited and even solitary brain metastases. The primary reason for this is that small cell lung cancer pa-

tients were excluded from the randomized trials that established SRS,” Robin says.

Because small cell lung cancer patients were excluded from the landmark prospective trials evaluating SRS, understanding of SRS for small cell lung cancer has lagged behind other cancers, including non-small cell lung cancer.

“Small cell lung cancer is known to have an increased propensity for spread to the brain compared to many other cancers. Historical caution regarding first-line SRS for small cell lung cancer has generally been related to concerns that omission of WBRT could result in rapid disease progression and decreased survival times. Thus, it is an important observation that, in this large international study, the omission of WBRT in favor of first-line SRS did not result in diminished overall survival,” Rusthoven says.

This analysis, which may represent the strongest data reported thus far in support of first-line SRS for small cell lung cancer, comes at a dynamic time in the evolution of small cell lung cancer management.

“Paradigms for the treatment of small cell lung cancer are evolving. In recent years, we have seen the integration of immunotherapy into small cell lung cancer management, a decrease in the administration of WBRT, and national guideline updates recommending routine brain MRI surveillance for all patients. These changes may be expected to increase the identification of small cell lung cancer patients with limited brain metastases who may be candidates for first-line SRS,” Robin says.

The study also provided detailed analyses of outcomes with SRS by the number of brain lesions treated. Patients treated with SRS for a single brain metastasis experienced the best brain control and overall survival outcomes. After that, the clinical outcomes for patients with 2-4 vs 5-10 brain metastases were very similar, whereas patients with 11 or more metastases were seen to have the shortest time to brain progression and overall survival.

The authors note that prospective trials evaluating the role of first line SRS for small cell lung

cancer patients are needed to confirm the encouraging results observed in this retrospective study. In the meantime, this large international analysis provides important descriptive and comparative data on first-line SRS as a potential emerging treatment option for brain metastases in carefully selected small cell lung cancer patients.



Anne Phillips, 5-year stage IV lung cancer survivor, rocking those Fall colors.



Linda Rengel (middle), 6-year stage IV lung cancer survivor.

“Thank you to the wonderful nurses and doctors at UCHHealth for helping me live long enough to give and receive these very cherished hugs.”



Les Shapiro and Vic Lombardi's new "Unstoppable" podcast celebrates personal triumphs in face of adversity

By Sean Keeler, The Denver Post

When Les Shapiro initially birthed the notion of a podcast about overcoming adversity, he had no idea truly how much adversity was coming in 2020. For all of us.

"We wanted to do something unique," the long-time Denver-area talk-show host told The Denver Post. "There are a lot of podcasts out there now." And yet, from a timing perspective, the theme of "We Are Unstoppable," Shapiro and Vic Lombardi's new podcast, feels more apropos than ever during a global coronavirus pandemic.

"Unstoppable," which launched in partnership with BurstMarketing and sponsorship from the University of Colorado Anschutz Medical Center, features interviews with sports and entertainment figures reflecting on how they overcame a specific challenge in their personal lives.

Olympic swimmer Missy Franklin in a recent episode opened up on her struggles with depression and anxiety. Legendary ESPN broadcaster Dick Vitale discusses being bullied as a youngster after a childhood injury gave him a drifting left eye. Former Rockies manager Clint Hurdle talks about overcoming alcoholism and bladder cancer, the latter of which was diagnosed in 2015.

"It was never made public," Shapiro said of the former Colorado and Pittsburgh skipper. "At the time, he was the manager with the Pirates and he didn't feel it was necessary for everybody to know this. They got it taken care of and he's

been clean ever since."

The podcast's title and mantra were inspired by the personal experiences of Shapiro and Lombardi, Emmy-winning broadcasters who both have battled cancer in recent years. Shapiro is under treatment for stage IV lung cancer and Lombardi has been treated for stage III prostate cancer. The podcast format includes a segment with a medical expert from Anschutz discussing the clinical side of whatever crisis the celebrity on the podcast has navigated.

"Unstoppable" is slated to drop two episodes per month and is available via all major podcast providers and at unstoppablepodcasts.com.

"When it comes to athletics, athletes, coaches and front office people don't always want to talk about their vulnerabilities," said Shapiro, who left Mile High Sports radio in February and moved to Scottsdale, Ariz. "But Vic and I have been able to extract that ... to get them to open up about it. "And you find out they're not all that bashful about it. I think a lot of it has to do with them wanting to help other people."

Check the podcasts out here: <https://unstoppablepodcasts.com/>



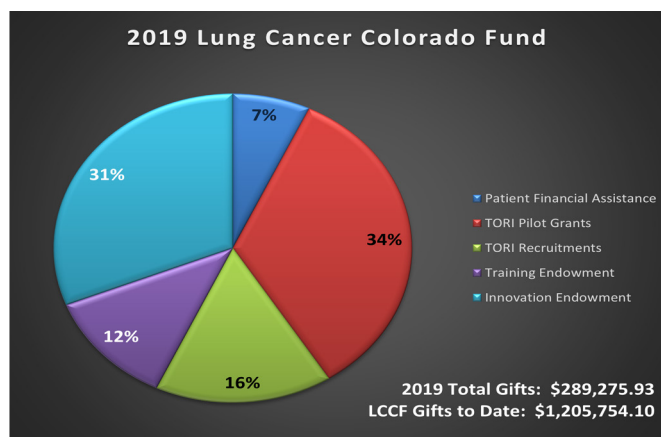
Halloween fun with a radiation oncology mask by Kelly Dignan

LCCF Expenditures 2019:

By D. Ross Camidge, MD, PhD

By December 2019, when the LCCF committee met to review the distribution of the funds raised for the LCCF in the year, the annual amount raised from the last meeting in 2018 was \$289,275.93.

- We have given \$20,000 to support patient welfare through our social work department.
- We have given \$100,000 to fund research pilot projects within the CU Thoracic Oncology Research Initiative (TORI).
- We gave an additional \$45,000 to TORI to contribute to the recruitment of new faculty's start-up packages.
- We contributed \$35,000 to our first permanent quasi-endowment (to help support the salary of trainees in any aspect of the program in the future). We hope that a single donor/group will now match or exceed this amount to complete this permanent Fellowship fund to approximately \$500K total and have the Fellowship named by them if they so wish. Contact ross.camidge@cuanschutz.edu if interested.
- Finally, we continued to crowd-source our new Thoracic Oncology Program Support 'Innovation Fund' with \$89,275.93, with the same goal re a single donor/group matching/exceeding the amount to take it over to complete the donation to approximately \$1M total. Contact ross.camidge@cuanschutz.edu if interested

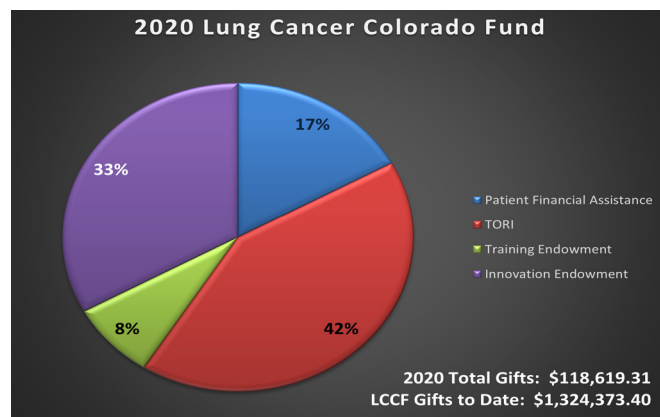


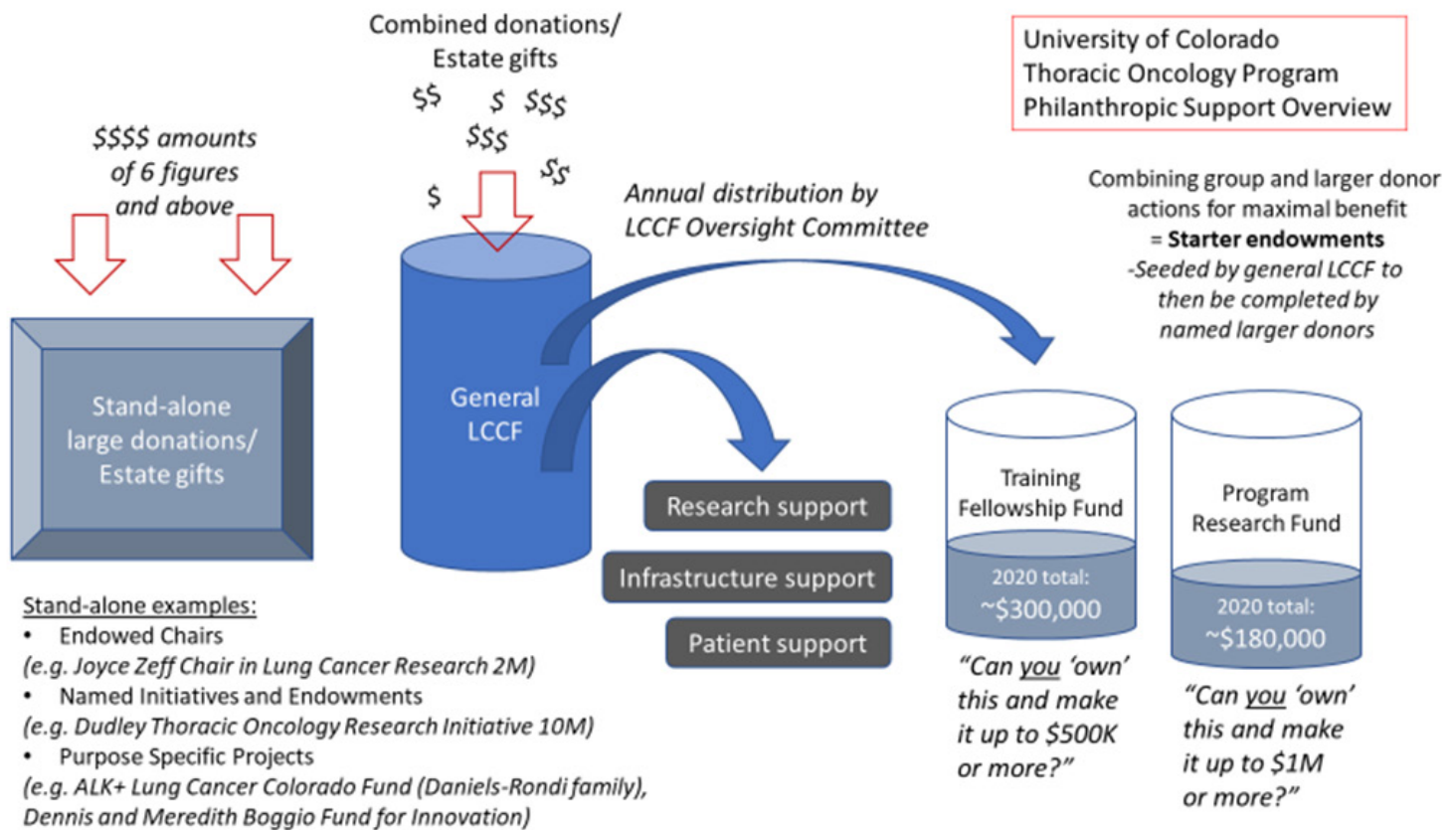
LCCF Expenditures 2020:

By D. Ross Camidge, MD, PhD

By November 2020, when the LCCF committee met to review the distribution of the funds raised for the LCCF in the year, the annual amount raised from the last meeting in 2019 was \$118,619.31.

- We have given \$20,000 to support patient welfare through our social work department.
- We have given \$50,000 to fund research within the CU Thoracic Oncology Research Initiative (TORI).
- We contributed \$10,000 to our first permanent quasi-endowment (to help support the salary of trainees in any aspect of the program in the future). We hope that a single donor/group will now match or exceed the total amount to complete this permanent Fellowship fund to approx. \$500,000 or more and have the Fellowship named by them if they so wish. Contact ross.camidge@cuanschutz.edu if interested.
- Finally, we continued to crowd-source our new Thoracic Oncology Program Support 'Innovation Fund' with \$38,619.31 with the same goal re a single donor/group matching/exceeding the total amount to take it over to complete the donation to approximately \$1M total and have the fund named by them if they so wish. Contact ross.camidge@cuan-schutz.edu if interested





Quasi-endowments, current monies, endowments and all that jazz:

Beyond the immediate use of funds that the LCCF committee distributes annually as already described, larger donations can sometimes have defined purposes all by themselves.

The Office of Advancement at CU (contactable through 303-724-8227 or <https://medschool.cuanschutz.edu/lccf>) can help with such plans, and these are especially helpful when you work with your physician and/or the LCCF to craft something that the program and donor are really passionate about together.

Sometimes the monies are for immediate use, sometimes they are permanent funds where the principal gift cannot be touched but the interest

can be (endowments), or a mix of the two (quasi-endowments, that generate interest but the principal amount can also be used).

The LCCF has had a vision to prime the pump on several quasi-endowments in the hope that each fund, addressing a specific need of the program will then be matched/exceeded and completed to the tune of at least \$1M total by a larger donor/group who would also be able to name the fund, if they so wish. Please speak to your MD or ross.camidge@cuanschutz.edu if you are interested in these opportunities.

Five+ Year Cancer Survivors' party – The second year



A few years ago this picture would have been impossible... That's progress

In 2018, for the first time, the CU Thoracic Oncology Program made a decision to invite all those who were at least 5 years out from their initial diagnosis of a thoracic cancer to come and celebrate. Partly, it was to have an excuse to eat birthday cake. However, it was mostly to photograph the group and to be able to show to those earlier in their diagnosis that hope had a face and that that face could look like any one of us. The second decision was to make this an annual event and so in the Fall of 2019 the second Five+ Year Survivor celebration took place on campus, with ESPN broadcaster Les Shapiro as the guest speaker. Each year we get better at figuring out the logistics and the plan is to ask all those who cannot attend (and there are many of you) to at least send a photograph so we can share your inspiration too. In 2020, of course, COVID, got in the way, but the celebration will continue.

If you would like to help sponsor any aspect of the Survivor's Event at some point in the future – if you have space, ideas or the potential to help with catering please contact: ronni.miller@uchealth.org.

New faces and other changes

Samantha Mossman, RD, CSO, CNSC



Sam Mossman

Samantha Mossman is a registered dietitian for the thoracic oncology clinic at the University of Colorado Hospital. She holds a specialty certificate in oncology nutrition. Originally from Massachusetts, she moved to Denver in 2019 and enjoys all of the outdoor activities Colorado has to offer. Her favorite part about being a dietitian is speaking with patients and helping them find foods that are both appealing and nourishing during cancer treatment.

Tejas Patil, MD

Dr. Tejas Patil has recently joined the Thoracic Malignancies program at the University of Colorado as an Assistant Professor in Medical Oncology. He obtained his undergraduate education at the University of Pennsylvania with a degree in piano performance and psychology. He obtained his medical education at the University of Southern California. He continued his medical residency and fellowship at the University of Colorado.

He was awarded the John Fisher Legacy Award at the 2019 International Association for the Study of Lung Cancer (IASLC) World Conference held in Barcelona, Spain for his research focusing on early detection of oncogene-driven lung cancer. His main research interests are in

developing targeted therapies for oncogene-driven lung cancer (such as ALK and EGFR) and understanding mechanisms of acquired resistance. Outside of work, Dr. Patil enjoys film, skiing and learning new repertoire for the piano.



Tejas Patil

Erin Schenk, MD PhD

Dr. Erin Schenk is an Assistant Professor of Medicine in the Division of Medical Oncology at the University of Colorado Anschutz Medical Campus. She joined the Thoracic Oncology group in 2018.



Erin Schenk

Dr. Schenk received her MD and PhD from the Mayo Clinic Medical Scientist Training Program in Rochester, Minnesota. Her thesis work focused on the adaptive immune response to cancer antigens. She completed her internal medicine residency and fellowship at Mayo Clinic with a continued focus in tumor immunology through the Clinician-Investigator Training Program. The Schenk Lab is part of the

Thoracic Oncology Research Initiative at the University of Colorado and investigates the lung cancer tumor microenvironment as a contributor to lung cancer progression and treatment resistance.

Outside of work, Dr. Schenk and her family enjoy exploring the mountains and frequenting their local coffee shop.

Nina Thomas, MD

Dr. Nina Thomas recently joined the Thoracic Malignancy program at University of Colorado as an Assistant Professor in the Division of Pulmonary and Critical Care and is primarily based in the Lung Nodule Clinic. She is originally from Chicago, IL

and obtained her undergraduate degree in Biomedical Engineering at Case Western Reserve University in Cleveland, OH. She then returned to Chicago for her medical degree at Rush University. She completed her residency in Internal Medicine at Tulane University in New Orleans, LA followed by fellowship in Pulmonary and Critical Care at Medical University of South Carolina in Charleston, SC.



Nina Thomas

Dr. Thomas has a focus in evaluation, diagnosis and staging of known or suspected lung cancer with a special interest in pulmonary nodules and lung cancer screening. She performs advanced bronchoscopy including endobronchial ultrasound (EBUS). Additionally, Dr. Thomas is actively involved in clinical research related to lung cancer screening, tobacco cessation, diagnostic bronchoscopy and implementation of lung cancer screening. Outside the hospital, she enjoys hiking and camping with her pup, Huckleberry,

listening and playing music on the piano, ukulele or drums, and painting with watercolors.



Homemade masks modelled by Candice Rossi, NP and Ross Camidge, MD made by Peggy Dennis a 4-year stage IV lung cancer survivor (right).



Jean Landsverk, 6-year lung cancer survivor. "Thanks to Dr. Doebele and his wonderful Staff!!"



'Pay attention to the details' photograph by Melissa Turner, 3-year stage IV survivor

Departure of Robert 'Bob' Doebele, MD PhD

After 12 years at CU, Dr Bob Doebele transitioned in September 2020 from seeing patients as a Medical Oncologist and Director of the Thoracic Oncology Research Initiative (TORI) to a new role as the Chief Scientific Officer of Rain Therapeutics. Rain is a small drug company that Bob co-founded back in 2017.



Bob Doebele

He still plans to maintain a presence at CU; keeping his academic lab running for a while to finish off some projects. His patients will be transitioned to other faculty members of their choosing. The whole team will miss his brilliance, compassion and thoughtfulness and the amazing care he gave to his patients. We wish him the best of luck in his new career direction. An international search for his replacement as TORI Director is underway.



Lisa Moran (middle), a five-year stage IV lung cancer survivor, enjoying the first taste of a craft beer named after her: Lisa's Luck Amber Ale.



Heather Smith (right), 4-year stage IV lung cancer survivor, celebrating Lung Cancer Awareness Month (November) with her wife, Kayla.



Hazel Senz, 6-year lung cancer survivor. “Only dead fishes go with the flow.”



Reagan Hudgens sells cards and other products decorated with her cat, Gigi, to raise funds for the LCCF in honor of her mother, Dorothy Hudgens, who was diagnosed with advanced lung cancer.

Estate Planning

- Consider including the Lung Cancer Colorado Fund in your estate plans
- – It makes a huge difference and is not that complicated. Please review
- the Special Estate Planning LCCF Newsletter Edition (‘Ben and Ellen’s
- Adventures in Estate Planning’) available in the clinic rooms or on-line at:
- <https://medschool.cuanschutz.edu/lccf> or call The Office of Advancement
- at CU on 303-724-8227.



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To Contribute:

If you would like to add additional names to our newsletter distribution list or if you wish to opt out of receiving this newsletter, please contact Shana Spears at 720-848-5455 or shana.spears@cuanschutz.edu

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