Director’s Overview:  A Team that Works

D. Ross Camidge, MD, PhD

It’s been quite a year for lung cancer and for the CU lung cancer program. Until recently, although many drugs were being explored in clinical trials, only a handful of drugs had ever been licensed by the FDA for the treatment of advanced lung cancer. However all that changed in 2015, when not one but SEVEN new FDA licenses were granted. Importantly, CU was involved in the development of almost all of the new drugs and continues to explore many more new agents and approaches. Is every one of this batch of newly licensed drugs a game-changer? Maybe not, but some are, and some of them are opening up wide, new areas for us to research into how best to understand, prevent and treat lung and other thoracic cancers in the future.

As you will see in this newsletter, your support of the Lung Cancer Colorado Fund (LCCF), continues to help us build one of the best thoracic oncology programs in the world. You will see how LCCF support has helped expand advanced symptom control by the palliative care team into the outpatient setting; funded innovative research projects; continues to build an endowment to allow us to support the training of the next generation of scientific and clinical leaders and generally created a highly productive philanthropic environment. This year we have been very fortunate to be able to tell the stories of some major donors to the program, as well as appreciating the power that comes from using donations of all sizes for organized goals. Alongside the news of clinical and laboratory developments, you will see pictures and stories of real people dealing with their cancer diagnosis (complete with hyperlinks to videos for those reading electronically and URLs to explore for those looking at a hard copy version), and team photos of many of the people who help to make the CU program what it is. Any way you look at it, the message is clear: We are better together.

To see an archive of previous newsletters and of media stories related to the CU Program, visit the LCCF website:

http://uch.thankyou4caring.org/lungcancercolorado

CU Thoracic Surgery: Life at the cutting edge
International Association for the Study of Lung Cancer makes case to Congress for Increased Lung Cancer Funding

Garth Sundem

In October 2015, Fred R. Hirsch, MD, PhD, CU Lung Cancer Investigator and CEO of the International Association for the Study of Lung Cancer (the largest professional organization devoted to lung cancer) was invited to speak in Washington D.C. at a congressional briefing on lung cancer. Members of a newly formed Congressional Lung Cancer Caucus learned from Hirsch about progress in lung cancer therapy with special focus on molecularly targeted therapies and immunotherapy.

“Much of this information was new for most if not all of the representatives in the lung cancer caucus. I think this hearing and the continuing briefings in this series will bring much more attention to problems surrounding lung cancer,” Hirsch says.

The Congressional Lung Cancer Caucus is a bipartisan group headed by Rick Dolan (D-MN), Frank LoBiondo (R-NJ) and Lois Capps (D-CA) with the mission of educating members of Congress on issues surrounding the disease. Briefings are designed in partnership with the Lung Cancer Alliance, a nonprofit dedicated to saving lives and advancing research by empowering those living with or at risk for lung cancer.

Afterwards, Hirsch met privately with staffers for Senators Michael Bennet (D-CO) and Cory Gardener (R-CO) and Congressman Mike Coffman (R-CO), the last of whom represents Colorado’s 6th congressional district that includes the Aurora campus of the University of Colorado Cancer Center.

“It is a very exciting time to be part of the lung cancer research community,” Hirsch says. “New tools and ideas allow us to understand and treat the disease as never before. The fact of this newly established caucus demonstrates awareness of this unique time in the history of lung cancer research and could eventually influence funding for this disease.”

According to the National Cancer Institute, as of August 1, 2015, research grants for lung cancer totaled $51 million, making it the third most-funded cancer behind colorectal cancer ($56m) and breast cancer ($110m). Unfortunately, this year in the USA about 158,000 people will die from lung cancer in the United States, compared with 50,000 deaths from colorectal cancer and 40,000 from breast cancer.

“This caucus is a great opportunity to show the need for and promise of increased attention to lung cancer,” Hirsch says.

“We’re just going to take each day as a step, and know that each day is a gift.”

Dawn Kelsey is a mother of three boys with a great sense of humor, a love of fun, and a scary disease. Luckily, she also has a motivated son in Connor—who organized an incredibly successful Relay for Life event in Highlands Ranch, Colorado—and a will to fight.

See the video at: http://catchitintime.org/story/every-day-gift#sthash.brRGfA7cd.dpuf
Studies over the past 10 years have allowed lung cancer to be subdivided according to oncogenic drivers. This has resulted in the successful use of targeted therapies in clinical trials using patient selection based on identifying the dominant drivers. However, patients develop resistance to these therapies, underscoring the need for novel approaches. Cancer progression and metastasis require interactions between the cancer cells and the tumor microenvironment (TME), which includes vascular, inflammatory, and immune cells.

Exciting recent successes of so-called “checkpoint inhibitors” targeting the interactions between cancer cells and CD8+ T cells has resulted in the recent FDA approval of nivolumab and pembrolizumab, both PD-1 inhibitors, for patients with metastatic squamous and non-squamous cell lung cancer. However, the clinical response rates for this class of agents is only approximately 20% in unselected patients.

To develop a better understanding of criteria for patient selection, as well as to test novel combination therapies will require preclinical models that reproduce the human disease. In particular, there is little information on how specific oncogenic drivers interact with the TME. Studying this has been problematic as most laboratory cancer models involve growing human tumors in mice with abnormal immune systems (to prevent rejection of a tumor from a different species).

Therefore to move the field on we require different laboratory models to be developed, that would, for example, allow mouse lung cancers to grow in immunocompetent mice. While panels of human lung cancer cells with distinct oncogenic drivers have been developed, there are no comparable panels of driver-specific cell lines for murine (mouse) lung cancer. The goal of this project is to develop these pre-clinical models to allow an assessment of these interactions. We will establish spontaneous models of lung cancer under the control of activating EGFR mutants, as well as fusion kinases such as ALK or ROS1. Cell lines will be derived from these tumors. Completion of these studies will then allow our team of investigators to more effectively assess therapies targeting the microenvironment and develop preclinical data encompassing combinations of immunotherapy and targeted therapies.
Sleep is vital to human functioning and allows the brain and body to effectively maintain health. Unfortunately, between 50 and 75% of patients with a cancer diagnosis experience significant difficulty getting enough sleep. Chronic insomnia has also been shown to cause poor wound healing, increased chances of cardiovascular disease including risk for heart attack and stroke and can prevent the body from developing appropriate immune responses (reduces the development of cellular immunity). Sleep deprivation can also cause increased symptoms of depression, anxiety and other mental health concerns that are more prevalent in the population that has cancer. Other sleep-related problems thought to occur at a higher rate in cancer patients include sleep apnea (breathing difficulty that interferes with sleep) and sleep-related movement disorder, such as restless leg syndrome.

While increased insomnia appears prevalent across all cancer diagnoses, research has highlighted specific concerns for various types of cancers. Those with lung cancer report the greatest difficulty with insomnia and the lowest sleep efficiency (time spent in bed compared to time asleep in bed) as well as the most difficulty with initial sleep onset (falling asleep). This finding has been confirmed by numerous studies and appears to apply to those in active treatment and also to those who are through active treatment and in remission from lung cancer.

The most effective treatments for insomnia in cancer patients involve cognitive behavioral therapy for insomnia, which is focused on changing behavior in ways that improve sleep and managing unhelpful thoughts related to sleep. Medications can be helpful for the occasional night of poor sleep but often have undesirable side effects and the benefits are not maintained well over time.

Many patients with cancer are encouraged to “get rest” by friends and family but this can also negatively impact the normal routine of sleeping. They may spend more time in bed, add naps during daylight hours and spend less time in bright light during the morning- all of which are known to contribute to insomnia at night. Paradoxically, by attempting to sleep more, many patients find that their sleep becomes disrupted. Once insomnia begins, concern about getting a good night sleep and worry about not sleeping often serve as a secondary process that can maintain insomnia by maintaining alertness and physiologic arousal at night. For these patients the bed often becomes a place of worry about sleep instead of a safe and restful area.

Do I have insomnia?

Insomnia is defined as: Significant difficulty falling or staying asleep more than three nights a week and significant daytime impairment or distress from lack of sleep.

Each person has different needs for sleep, the average sleep amount in the United States is 6.5-7 hours a night and recommendations for a healthy night sleep are 7-9 hours for adults and 7-8 hours for older adults (65+). Some people
sleep less but feel rested during the next day and this does not represent insomnia.

If you think you might have a problem with sleep, the recommendations below may help, but intervention by a trained psychologist in the cancer center may help better tailor treatment to your specific situation. Certain sleep problems (sleep apnea, sleep movement problems and others) should be diagnosed in a sleep lab by a sleep medicine specialist and referrals for this workup can be arranged as needed by your treatment team.

**Tools to Treat Cancer Related Insomnia:**

1. **Stimulus Control**
   - The goal of stimulus control is to re-align sleep with circadian cues (day/night) and to re-train the brain to sleep well in bed.
   - To do this only use the bed for sleep (no TV, meals, phone/tablet)
   - Refrain from sleeping anywhere else (couch, chair…)
   - If you can't fall asleep in about 20 minutes get up out of bed and sit somewhere else to relax - then try to sleep in bed again when you feel sleepy

2. **Sleep Restriction**
   - We all have a built in drive to sleep that increases the longer we are awake
   - Mild sleep restriction involves restricting time in bed to the actual amount of sleep a person gets each night – this has the effect of improving sleep onset and quality
   - If you have insomnia try restriction to 6 hours for one week and use firm in bed and out of bed times
   - After sleep quality improves sleep can be expanded out to 7-9 hours

3. **Addressing unhelpful thoughts about sleep (cognitive therapy)**
   - Worrying thoughts about sleep will keep you awake at night
   - Learn to challenge the veracity of unhelpful beliefs about sleep (e.g. “If I don’t sleep 6 hours I will be a mess tomorrow” or “I just know I am going to have a hard time falling asleep tonight”)
   - Address these automatic thoughts to reframe them to be more accurate and less distressing
   - Relaxation techniques such as diaphragmatic breathing, muscle relaxation and guided imagery help to calm the body and can be a better focus then distressing thoughts

4. **Good ‘Sleep Hygiene’**
   - Sleep hygiene are behaviors known to promote sleep, many of these behaviors are described above, additional recommendations include:
   - Keep the bedroom cool and very dark and quiet
   - Pets or children in bed can disrupt sleep
   - Don’t go to bed hungry or too full (finish eating at least 1.5 hours before going to bed)
   - Avoid caffeine, exercise and intense activities before bed (including watching action movies…)
   - Maintain a schedule with ‘bed time’ and ‘out of bed time’ even when you did not sleep well the night before
   - Use a 30-60 minute “wind down period” before bed each night
   - Dim lights 30 minutes prior to bedtime: avoid TV, tablet, phone
   - Bright light in the morning (sit near a window) helps to ‘set the clock’ so that you become sleepy in the evening

For additional questions email Dr. Ben Brewer, Clinical Psychologist at the University of Colorado Cancer Center: Benjamin.brewer@ucdenver.edu
Non-small cell lung cancer frequently spreads to the central nervous system (CNS), but patients with CNS metastases may be excluded from clinical trials of new drugs. A University of Colorado Cancer Center study presented at the 16th World Conference on Lung Cancer revealed the full extent to which the CNS may be under-explored in clinical research. The study combed the website ClinicalTrials.gov to identify 413 open lung cancer clinical trials. Overall, 41 percent of trials only included patients if their CNS disease was previously treated. Twenty-six percent allowed in patients with CNS involvement and no previous treatment. Fourteen percent excluded all patients with a history of brain spread and nineteen percent of trials did not comment on any criteria related to CNS disease at all.

When multiple different subcategories of clinical trial were considered, only the sponsor of the trial was significantly associated with strict CNS exclusion, with university-sponsored trials being significantly less likely to exclude such patients than industry-sponsored trials (Hazard Ratio 0.442, p=0.0342).

“On one hand, if a new drug works great in the rest of the body but somehow doesn’t get into the brain, including patients with untreated brain metastases could put the patients at increased risk as well as lower the initial estimates of the drug’s activity,” says Caroline McCoach, MD, PhD, thoracic fellow and investigator at the CU Cancer Center and the presenting author of the study. “But on the other hand, if we fail to include patients on the trial of a drug that does work in the brain, we may not discover the drug’s activity for a long time and patients who may benefit would be inappropriately excluded.”

“The fact that the only dominant factor affecting strict exclusion was the sponsor of the trial suggests that some of our current practice may be based more on habit, than perhaps universally agreed upon scientific rationale,” says D. Ross Camidge, MD, PhD, Joyce Zeff Chair in Lung Cancer Research at the CU Cancer Center and senior author of the study.

Indeed, in the last two years, the Response Assessment in Neuro-Oncology (RANO) group, an assembly of international experts, have been driving a series of publications that have started to build a more rational approach to addressing brain metastases in clinical trials. “Dr. McCoach’s presentation really defines the status quo for how lung cancer patients with CNS disease are being treated in clinical trials and has already started a lot of debate within the RANO group,” Camidge says.

“What we really want to see are sensible clinical trial designs, with CNS inclusion and exclusion criteria that are logical and appropriate given both what is or isn’t known about the drug’s activity in the brain and how far advanced an experimental drug is in development at the time,” says Camidge. “In an ideal world that might well involve dedicated clinical trial sub-studies looking at patients with untreated CNS disease very early in drug development, trying to see if there is a CNS signal to explore further, or modify later trials to more appropriately manage risks if the drug is unlikely to work in the CNS.”

“Sometimes, we may have to learn by mistakes,” says McCoach explaining that many trials of the new class of immunotherapy drugs completely excluded patients with brain metastases yet newer data seems to show that CNS responses can safely occur and this early caution and denial of trial access to such patients may not have been warranted.

“The brain is an important battleground for treatment right now, and you can’t really force the issue of wanting better trial designs until you show people the lack of consensus in how we are currently doing things. The goal of this study was to highlight the full extent of current practice and open up the field for more informed debate,” she says.
New Faces: Chad Rusthoven, MD
Radiation Oncologist

Where did you grow up?
Rusthoven: Sarasota, Florida

What is your educational background?
Rusthoven: I gained a Bachelors in Psychology at the University of Florida, then I got my MD at the University of South Florida College of Medicine. I did my Internship in Internal Medicine at Georgetown University/Washington Hospital Center, and then my Radiation Oncology Residency at the University of Colorado School of Medicine.

What are your clinical interests?
Rusthoven: Radiation treatment of Thoracic and Central Nervous System malignancies, Stereotactic Body Radiation Therapy (SBRT), and Stereotactic Radiosurgery (SRS)

What are you research interests?
Rusthoven: The same as my clinical interests - Thoracic and CNS malignancies, including population-based research using large national cancer registries, and the integration of precision high-dose radiation therapy with stereotactic body radiation therapy (SBRT) and stereotactic radiosurgery (SRS) in the treatment of a variety of malignancies

How did you become interested in treating lung cancer?
Rusthoven: Lung cancer remains the leading cause of cancer death in the United States and worldwide. I view efforts toward improving the cure rates, survival outcomes, and tolerability of oncologic therapy for patients diagnosed with this disease as my most important goals.

What are your interests/hobbies?
Rusthoven: Skiing, Hiking, Music, Writing, and cheering for the Denver Broncos.

How are you enjoying Colorado?
Rusthoven: Denver, Colorado is without a doubt my favorite place that I have ever lived

Raising Awareness: “Anyone can get lung cancer”.

This was part of the lung cancer awareness message from our friends at the Bonnie Addario Lung Cancer Foundation. Anyone can get lung cancer. Even you. Regardless of age, race, gender, family history; even if you’ve never smoked. Watch the video and share the message.

See the video at: https://vimeo.com/144304524?ref=tw-shareLets
By October 2015, when the LCCF committee met to review the distribution of the funds raised for the LCCF through both the Hospital and University mechanisms that year, the annual amount raised had exceeded $108,000. The preceding year we had given $20,000 to help get the outpatient palliative care program off the ground quicker (see article on: ‘New Clinic Aims to Close Palliative Care Gap’ in this newsletter), but this time no immediate infrastructural improvements were considered pressing by the group. We gave $10,000 to support patient welfare through our social work department and $30,000 to fund another pilot grant to be awarded by the CU Lung Cancer SPORE scientific review process (see article on last year’s beneficiary: ‘Modelling the interaction between molecular subtypes of lung cancer and the immune system’ in this newsletter). Finally, we continued to build towards our medium term goal by contributing the remainder (~$68,000) into a growing training fellowship endowment to help support the salary of trainees in any aspect of the program in the future.

Help Support Us:

Overseen by the physicians and scientists of the University of Colorado’s Lung Cancer Program, the Lung Cancer Colorado Fund is used to support the many different needs of the University and UCH’s combined fight against lung cancer ranging from basic science, clinical and translational research, through to patient support and infrastructural improvements.

Contributions to the Lung Cancer Colorado Fund may be via the hospital or university to allow the most efficient use of any fund matching schemes. All donations, regardless of whether given via the Hospital or University are overseen by the same committee, for the same purposes.

Giving via the: The University of Colorado Hospital Foundation

You can write a check payable to the Lung Cancer Colorado Fund and please be sure to write “UCH Foundation” on the memo line. Mail your donations to: University of Colorado Hospital Foundation, Mail Stop F485, 12401 East 17th Avenue, Aurora, CO 80045

Or you can give on line at: http://uch.thankyou4caring.org/lungcancercolorado

Giving via the: The University of Colorado Foundation

(which may help for some fund matching schemes, if, for example, a center for higher education is required to be listed)

You can write a check payable to the CU Foundation and please be sure to write “Lung Cancer CO Fund” in the memo line. Mail your donations to: CU Foundation, Mail Stop A065, 13001 E. 17th Place, Aurora, CO 80045 Or you can give on line at:

https://giving.cu.edu/fund/lung-cancer-colorado
 Soon after a cancer diagnosis, or at any point in their cancer journey, many patients would like to have a second opinion. Maybe it is to see if there are options not available in their own center, maybe it’s just to reassure their friends, relatives or themselves that they are doing the right thing, or, if necessary, to point them in a different, better, direction. However, the hassles of traveling, extra expenses, and even child care may sometimes make it seem impossible to seek out advice from an expert that is not local. The University of Colorado Cancer Center’s Remote Second Opinion Program (RSO) is now helping to change the way patients and cancer experts can interact, so that patients can benefit from the center’s world class faculty without having to leave the comforts of their home.

Ross Camidge, MD, PhD, Joyce Zeff Chair in Lung Cancer Research at the CU Cancer Center, started the RSO program in late 2011 after a series of high profile lung cancer treatment breakthroughs led to patients or their relatives emailing him for advice from all round the USA and the world.

“While I would try and help each person, a quick email isn’t the same as a real consultation. Also we weren’t capturing the information on their cases in a way that would let us refer back to it, as and when any new developments occurred,” he says. “However, it also felt wrong to drag a patient half-way across the country or the world just to sit in the same room as a physician. Something new was needed.”

Several other academic institutions or third party vendors had already established programs that allowed cancer patients to have their records sent in and then receive a second opinion letter back, but Camidge wanted something different.

“Looking at the existing programs, they were a little formulaic. Some of them were clearly based on cutting and pasting blocks of text that was appropriate if you had just been diagnosed or wanted advice on routine first or second line approaches, but it wasn’t cutting edge. The people who seek out second opinions are often very savvy and have explored the standard options already,” says Camidge. “In addition, the best medicine involves really effective communication and just getting a letter may not be the optimal way to do that. Conversational to and fro counts for a lot.”

In the CU Cancer Center’s program, a patient’s notes and scans are gathered in advance and then the patient is scheduled with the physician at a particular date and time, just like a regular doctor’s appointment. However, in the RSO the new patient spends an hour on the phone with the doctor rather than sitting in the same room as them.

“The call is very personal, very tailored to whatever that person needs to discuss,” says Camidge. “The expert is there with them in their living room, talking through their scans, making sure they understand what is going on and what their treatment and trial options are, wherever they are.”

Payment for CU’s RSOs is currently only via credit card and not reimbursable by insurance, but for any out-of-state patient the cost would usually be significantly less than the cost of travel, taxis, meals and accommodation for an in-person trip.

“The CU Cancer Center has one of the widest arrays of new treatments available, together with the expertise to direct patients to the therapies that will have the greatest chance of success,” notes Wells Messersmith, MD, Division Chief for Medical Oncology and a prominent expert in the care of gastro-intestinal cancers. “For the RSO program, though, we took things to an even higher level. The doctors participating in this program are some of the best-of-the-best. Given what our RSO users are looking for, we make sure the doctors involved really know their field inside out, and can advise patients on all the options out there, including clinical trials and the best care located in other places around the country and the world.”

Phil (back, middle) and Andy (back, right) Trahan from Louisiana have made good use of the CU Remote Second Opinion Program. “We can consult a world expert on Monday afternoon and still be in the Superdome for Monday night kickoff.” Also pictured (front row) Andy’s sister Jennifer, mom Karen, wife Leslie and brother Joey (back, left)
Because of Dr. Camidge’s involvement, the initial pilot program for RSOs at CU focused on thoracic oncology, covering lung cancer, mesothelioma and thymic cancers. To date, the thoracic oncology RSO program has now allowed over a hundred people all over the United States, as well as the world, to get a second opinion from the experts at the CU Cancer Center. Phil and his son, Andy Trahan, both living in Louisiana, decided to utilize the thoracic oncology RSO program in 2013 after Andy was diagnosed with stage IV lung cancer.

“Dr. Camidge’s reputation is what brought us to CU Cancer Center and he is the reason we chose to do RSOs there,” explains Phil. “Our personal experience with the RSO program has been very good. Dr. Camidge always calls exactly on time and we never feel that we are being rushed through. We have made several important decisions on the basis of these consultations.”

The Trahan’s feel they have benefitted greatly from the program, particularly when it came to being more educated about the disease and feeling more confident about their treatment decisions.

“As opposed to having a local oncologist consult a specialist for a second opinion, I feel better when I can hear the specialist myself. Follow-up questions, clarifications and “what ifs” are very important and can get lost in the translation when three parties are involved,” says Andy. “I think RSOs are particularly helpful to patients and caregivers who have educated themselves on their disease, as they will have some idea of the issues and can get more value out of the time.”
In addition to helping patients across more than half the states in the USA, the RSO program has reached out internationally. Paul Rosenberg, an American living in Manila in the Philippines, had initially received treatment for his lung cancer both in New York and locally. After recurrence, he felt he needed a second opinion from a recognized expert doctor in lung cancer but a meeting in-person was difficult. He inquired from the Bonnie Addario Lung Cancer Foundation about this including the names of some possible doctors including Ross Camidge. He was told that the University of Colorado Cancer Center had exactly what he was looking for with its RSO program. He immediately applied for the RSO program and had all his records sent to Camidge.

“I was very satisfied with the initial RSO,” explains Rosenberg. “I had a very detailed phone call for almost an hour with Dr. Camidge at which we discussed my situation in great depth including opportunities in the new immunotherapy area. We agreed to have my tumor sample tested to see if I would qualify for a drug trial. The test results came back positive.”

“Doing the trial in Colorado was not workable and they helped me get accepted for the trial at a site in Singapore, closer to my home in the Philippines. I responded very well to the trial for over a year and when it stopped working, the first place I went back to for my next plan was CU,” he says. As only a few small areas of his cancer had started to grow, after Dr Camidge spoke with the clinical trials staff in Singapore, he opted to pursue stereotactic radiation at CU with Dr Brian Kavanagh and continue his immunotherapy treatment when he returned home. ‘Kavanagh is one of the foremost radiation oncology experts in the world when it comes to the stereotactic treatment of oligoprogressive disease,’ said Camidge. ‘His expertise was exactly what Mr Rosenberg needed.’

After the success of the thoracic oncology pilot, RSOs have now become an option for many different programs in the Cancer Center. Virginia Borges, MD, director of the young woman’s breast cancer program at CU recently completed an RSO on a breast cancer patient from Kansas who was pregnant at the time and so could not travel for an in-person visit.

Following the RSO call, the patient sent the following email to the colleague who had referred her: “I wanted to take a minute to thank you for referring me to Dr. Borges. She truly is wonderful and provided a lot of great insight. I ended up switching oncologists and treatment plans all while remaining under the care of my original hospital. I am feeling so much better about things now!”

“The RSO program has really extended who we can help,” says Borges. “Our limits are no longer being set just by the four walls of the Cancer Center. Having a real, detailed, conversation with a patient, even if they live many miles away, is what allows me to give them the best advice. There are things that a review of somebody’s case records and a letter without the personal contact just cannot cover.”
Philanthropy in Action: The Christine Burge Endowment

Chris and I were married in July 1970 between our Junior and Senior year at CU Boulder. From that time until her untimely death in January 2007 we forged a beautiful life together raising two children and I had the good fortune of a successful career as a veterinarian and business owner.

The diagnosis of Chris with stage IV lung cancer as a woman who was super healthy and never smoked was a shock. Fortunately we were referred to Paul Bunn at the University of Colorado and that was the beginning of my understanding of how prevalent lung cancer was and that 10-15% of lung cancer patients never smoked. Further I learned that Chris fit the profile of the fastest growing group of lung cancer patients: nonsmoking females in their 50s. I also knew that lung cancer carried the stigma of a cancer someone brought on themselves, had very few survivors and was thus tremendously underfunded.

During the initial period of loss I felt I could best honor her life by helping fund research with a focus on nonsmoking lung cancer. Initially we created the Christine Burge Endowment at the University of Colorado with $42,000, $25,000 to establish the endowment and the balance as a distribution fund. As Chris was an avid tennis player, in 2007 we started the annual Chris Burge Classic Tennis Tournament in Fort Collins to raise funds for this research. Each year we raised more funds than the previous year. In 2012 in an effort to expand the scope of our fund raising our tennis tournament became part of a bigger concept where we expanded the events to be more than just a tennis tournament and named the new concept “Colorado Moves to End Cancer”. We now raise far more funds and split the funds with 50% going to the Burge Endowment at the University and 50% going to the new CU Cancer treatment Center in Fort Collins.

With guidance from Dr Bunn, in the last few years we have directed the distribution of this modest ‘innovation’ fund to study genetic mutations in lung cancer patients as part of the nationwide Lung Cancer Mutation Consortium. We have also directed funds for CU’s Dr Antonio Jimeno to establish tumors growing in mice directly from lung cancer patients who had never smoked to help study the genetic abnormalities those cancers may possess. Currently we are helping to fund CU’s Dr Doebele complete a project looking at early changes in response to targeted therapies that may explain how a proportion of cancer cells can survive even when the initial response is dramatic, as those early surviving cells may act as the seeds from which later, more obvious, treatment resistance later emerges.

Making a difference through our philanthropy has been very important to us as a family. It has been a great way to honor Chris, to keep her memory alive and to help us do some more good in the world. If lung cancer has touched your life, please think about supporting the Lung Cancer Colorado Fund or speaking to your physician directly about how you can help change things for the better.

What are you grateful for?

In November 2015, for Lung Cancer Awareness Month, our friends at the Global Resource for Advancing Cancer Education (GRACE), asked a series of patients and physicians to describe what they were grateful for and they captured it all on this inspiring video:

“I have a Future Again”: New Drug Horizons

Chris Casey

Tears stream from behind Nichol Miller’s glasses as she studies the latest CAT scan of her torso. Where just four months ago tumors covered both lungs, now only a few tiny dots appear.

“It’s a dramatic change,” Robert Doebele, MD, PhD, Associate professor of medicine, CU School of Medicine, says to his patient, who wears a beaming smile.

Miller, a 42-year-old wife and mother of three, has grown accustomed to seeing improvement during her monthly visits to the University of Colorado Cancer Center, but this scan is especially stunning. “Ah, that’s music to my ears. … Dramatic is such an understatement,” she says, reaching for a tissue. “There needs to be a bigger word for the transformation of me (in March) and me now. I kind of always sit around waiting for the other shoe to drop — is it going to continue to work? We’re in uncharted waters.”

Nichol Miller’s before and after lung scans

‘They need their mom’

Miller is one of the first patients in a clinical trial of LOXO-101, a targeted-therapy drug developed in a short period of time — just three years — through the work of Doebele and his research team at the CU Cancer Center. The drug inhibits a gene, NTRK1 (neurotrophic tyrosine kinase receptor), that, by fusing to a different gene, results in a mutation that causes tumors.

So far, in Miller’s case, the results couldn’t be much better.

From week one, Miller has shown improvement on the drug; she currently takes the pill orally twice a day. Just like the shrinking tumors in her lungs, Doebele says, tumor markers in her blood continue to show dramatic declines. Miller updates Doebele on her recent activity: She walked six miles in a Relay-for-Life event and enjoyed a camping trip with her family. “I walked all over — never felt out of breath.”

As Doebele elaborates on the test results, Miller’s eyes well up again. “It’s amazing. It’s given me back my future,” she says. “I have three kids. They’re young — 14, 12 and 10. They need their mom; I need them. I wasn’t ready to be done.”

‘Gave me hope’

Early last March, Miller and her husband drove from their home in Portland, Ore., to Aurora. Miller knew she was dying: Her lungs were filled with tumors, pain radiated through her chest, and breathing was almost impossible without five liters of oxygen a minute.

Lara Davis, MD, an oncologist at OHSU, recommended that Miller participate in the clinical trial at the CU Cancer Center. “Coming here was our hail Mary,” Miller said. “Everyone here — doctors, nurses, the entire staff — has been amazing. Through the whole process they gave me hope.”
As test results kept coming out positive, it dawned on Miller that she could start to make plans again with friends and family. “I can make plans for two, three years down the road, it feels like,” she said. “It’s not the inevitable like it was in March.”

A mother’s legacy to another

The medical journey that has given Miller hope actually began three years ago.

In 2012, Doebele was treating a 46-year-old never-smoker, also a mother of three children, who had metastatic lung cancer and whose disease had progressed through all available treatments. Before she died, the patient agreed to Doebele getting a sample of her tumor to grow an immortal cell line that could be used for further research and to test drugs against this type of cancer.

In a broad search of hundreds of potential oncogenes his team found the abnormal gene NTRK1 in her cancer. “That really accelerated the development of drugs that can treat this type of tumor, because that was the initial proof we needed to convince companies to pursue these drugs in clinical trials,” Doebele said. “We’re really grateful that this patient’s allowance to use her cells has really helped another young mother treat her cancer better, and hopefully will help many, many patients in the future.”

A local pharmaceutical company — Array Biopharma in Boulder — produced a drug that showed promise in blocking the activity of this gene. Loxo Oncology, Inc., subsequently acquired the license to conduct clinical trials using the drug; the trial began in 2014, with the CU Cancer Center being the closest trial site to Miller’s home in the Pacific Northwest.

Targeted cancer therapies give physicians confidence of their effectiveness, while offering the added benefit of reduced side effects, Doebele said. “We’re actually matching the drug to the patient’s tumor, and when we use this strategy, we can expect that patients have probably a 60 to 70 percent chance of a dramatic tumor shrinkage and probably about a 90 percent chance of having control of their tumor in some ways,” he says. “Whereas with chemotherapy, the percentages range from 10 to 20 to 40 percent at most.”

Doebele said other patients with the NTRK1 gene, which is present in about 1% of lung cancers and a range of other types of cancer as well, are starting to enroll in the clinical trial (clinicaltrials.gov NCT02122913). He is hopeful that within a couple years the current clinical trial of LOXO-101 will lead to a drug physicians can prescribe.

Genetic testing is critical

Miller underwent extensive genetic testing which allowed physicians to identify the abnormal gene in her tumor. The NTRK1 mutation occurs in a small percentage of many different cancers, Doebele said.

“It speaks to the issue of the importance of getting broad genetic testing because it may be that a sarcoma, lung or breast cancer — or any type of cancer — can probably have this type of alteration. And we won’t know unless we’re testing,” he said. “The old paradigm was that a mutation in a particular gene would only happen in one type of cancer, but that’s not really true anymore.”

Through it all — including the grim period just four months ago — Miller has maintained a positive outlook. “I believe being positive has a lot to do with how things pan out.” She now has her sights on taking her children to Disneyland, traveling to see family members in the Midwest, and going on a cruise with her husband to celebrate their 15th wedding anniversary next year. “We never had a honeymoon.”

Also high on the list is a plan to finish her training become a licensed lactation consultant.

‘I have a future’

Miller is currently enjoying relatively smooth sailing — albeit in the “uncharted waters” of a clinical trial. Doebele says solid tumors remain difficult to cure unless they are caught at a very early stage. Long-term control of these types of cancers is becoming increasingly feasible through multi-drug treatments.

The medical journey that has given Miller hope actually began three years ago.

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whose disease had progressed through all available treatments. Before she died, the patient agreed to Doebele getting a sample of her tumor to grow an immortal cell line that could be used for further research and to test drugs against this type of cancer.

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“This is a rapidly emerging field that allows us to test patients’ tumors and perhaps identify this gene or other genes that may allow them either FDA-approved therapies or clinical trials that are very likely to help them control their cancer,” Doebele says. “I think a lot of us think about HIV as a model. Although we’re not typically curing HIV with multi-drug regimens, we are controlling it for decades so that people can live a relatively normal life. So I think that might be a closer goal.”

After her most recent clinical update, an elated Miller steps into a CU Cancer Center hallway to call family members with the good news. She tells her ecstatic husband about the tumors that are now barely visible on the CAT scan. “They’re like specks,” she says.

As the dots shrink in her lungs, Miller sees more life unfolding on her horizon. “It was during these last couple months when we started to see this dramatic change — this amazing change — that’s when it really hit home: I have a future again.”
Denver hosted the 16th World Conference on Lung Cancer (WCLC), which was held at the Denver Convention Center over 4 days in the Fall of 2015. About 6000 delegates, ranging from clinicians, scientists, nurses to patient advocates, from 84 different countries participated in this very successful conference. The WCLC is arranged by the International Association for the Study of Lung Cancer (IASLC), which is headquartered in Denver at the University campus in Aurora. The location of the conference rotates between Asia/Pacific, European and American geographical locations and in 2016 the WCLC will be held in Vienna, Austria.

The local multidisciplinary lung cancer group at CU took several years to organize the Denver conference. The content of the meeting reflected the significant increase in both scientific and therapeutic developments that have occurred in the lung cancer field in the last few years. Many different clinical trial and clinical research results were presented as well as promising scientific discoveries which may lead to future clinical developments. The Denver conference included several new educational innovations including programs specifically planned for patient advocates and nurses as well as a specific program for community based practices. A new program designed to improve the training of young investigators from developing countries was also implemented; 13 young investigators were invited to Denver under a special mentorship program through which, in addition to attendance at the conference, they were also able to spend a further week at an academic institution in the US. The lung cancer group at CU was proud to host 6 young investigators from China, Egypt, India and Argentina, several of whom described it as a “life-changing” event to be mentored by world experts in so many different disciplines of lung cancer management.

Fred R. Hirsch, IASLC CEO

World Conference on Lung Cancer held in Denver, Colorado, September 6-9, 2015

Packed Audiences at the World Conference on Lung Cancer in Denver
Many cancers include increased copies of the gene MET. But in which cases is MET driving the cancer and in which do these increased copies happen to “ride along” with other molecular abnormalities that are the true cause of the disease? The answer influences whether a tumor will respond to drugs that inhibit MET, like crizotinib. A University of Colorado Cancer Center study presented at the 16th World Conference on Lung Cancer in Denver, Colorado shed light on the best method to determine the threshold at which MET amplification becomes clinically relevant.

“Generally, there are two ways that the number of copies of the MET gene can be increased: The tumor can make multiple copies of the entire chromosome on which it sits – chromosome 7 – or it can amplify just the MET region. In the first case, MET is unlikely to be the specific driver of the cancer’s biology, it may just be a ride along. But if the MET region is amplified separate from the rest of the chromosome, this would suggest that the MET gene is indeed the area of specific importance to the cancer,” says Sinead Noonan, MD, investigator at the CU Cancer Center, senior thoracic oncology fellow at the CU School of Medicine, and the study’s first author.

The goal of the current study was to find evidence supporting the above hypothesis and to identify a group of MET-driven patients in which crizotinib would be effective.

To do so, Noonan worked with Marileila Garcia, PhD, CU Cancer Center investigator and professor of Oncology at the CU School of Medicine, who assessed the genetics of over 1,000 lung cancer patients. Using the low level criteria commonly used for defining an increase in MET copy number, independent of whether it was increased by increasing the overall number of copies of the chromosome or just that region of the chromosome, 14.4 percent of these samples were positive for MET copy number gain. The group then looked at another measure, comparing MET copy number to the number of chromosome 7 centromeres – the center point of the chromosome – which allowed them to see how specifically MET was amplified in comparison with the chromosome as a whole. When the low level criteria for defining an increase in MET copy number using the ratio of MET to centromere 7 was used, only 4.5 percent of these cases were positive.

Now the question was what ratio of MET to centromere 7, exactly, defined patients whose tumors were driven by this gene amplification and so would be most susceptible to MET inhibition via crizotinib.

“There is almost always only one driver abnormality in any given tumor,” Noonan says. But in 47 percent of the tumors defined by the minimal MET-to-centromere-7 ratio criteria, the group was able to identify other known genetic drivers, including mutations or gene rearrangements in EGFR, KRAS, BRAF, ALK, ERBB2, RET or ROS1.
“Strikingly, as we looked at cases with higher and higher MET positivity, the degree of overlap with other known drivers decreased,” Noonan says. In other words, as the MET-to-centromere-7 ratio increased, the group was less likely to find any other candidates for the cause of the cancer.

A group completely free from overlap with other known cancer drivers was only found in the group in which MET overbalanced centromere 7 by 5 times. Using the other common method of simply counting MET, independent of the ratio, it was impossible to find a group without additional known genetic driver.

“I think these data really help to solidify MET-to-centromere ratio as the better measure for defining a lung cancer driven by MET copy number,” says D. Ross Camidge, MD, PhD, Joyce Zeff Chair in Lung Cancer Research at the CU Cancer Center and the senior author of the study. “While the highest ratio only occurs in 0.34 percent of cases, it has clearly been associated with responses to crizotinib approaching 70 percent. However, responses have also been seen at lower ratios. Overall, if we look across all levels of MET-ratio positive cases but exclude those with other identifiable drivers we can identify a group representing 2.4 percent of adenocarcinomas which is ripe for further investigation as potential MET-sensitive subtypes of lung cancer.”

The drug company Pfizer has an ongoing clinical trial program to evaluate the usefulness of crizotinib against a range of drivers, including MET copy number-driven lung cancer. The drug has already been shown to be useful against lung cancer driven by ALK and ROS1 gene rearrangements.

“There’s definitely a population of patients with cancers sensitive to MET inhibition that can be identified by MET copy number increase. The challenge is finding these people accurately so they can get the best, most personalized approach to treatment possible,” says Noonan.

‘Happy’ Flash Mob: Watch it and try not to smile

Jane Grifasi, from Parker, Colorado, has stage IV lung cancer but that doesn’t get her down. She is one of those incredibly positive people who goes out of their way to make everyone feel better around her. So when Jane Grifasi’s daughters wanted to show their support for their mom and her fight against lung cancer, they knew just what to do. Watch the look of surprise on her face as her family made a flashmob suddenly appear at a community event who then all began dancing to Jane’s favorite song, Pharrell William’s ‘Happy.’

See the video at:  https://www.youtube.com/watch?v=4cGWR4UjDiY

Rockies Rockpile

CU’s Thoracic Oncology Clinical Research Coordinators and Data Managers (the people who do all the work behind the scenes on clinical trials) enjoying a team trip to the Rockies Rockpile
The Denver Broncos meet the Denver Oncos

For those of you who have seen the commercials for UCHealth, you will know there is already a mutual appreciation of the effort it takes to succeed between the CU Cancer Center and the Denver Broncos.

Watch the video: https://www.youtube.com/watch?v=drV6tIe4yJQ

What you may not know is that Broncos quarterback Peyton Manning felt that if he was going to endorse something like a Cancer Center, he wanted to get to know it better. So without a fanfare or an entourage, one day he just turned up, walked around the infusion center with our own Dr Tom Purcell, (Executive Director for Clinical Services and an Attending within the Thoracic Oncology Program) and said ‘hi’ to some folks getting treatment, just to make their day a little brighter. Now that’s a class act.

*Star Players: Peyton and Purcell*
On January 3rd 2016, Jonathan Gonzalez from 9NEWS ran with the following story:

DENVER -- A 38-year-old Denver woman battling lung cancer has put herself into position to win a trip to the Super Bowl on Feb. 7 in Santa Clara, Calif. So far, Kim Ringen has raised more funds for lung cancer research than any person in the country -- as part of a contest sponsored by the Chris Draft Family Foundation, named after the former NFL linebacker who lost his wife to lung cancer.

Ringen was diagnosed in June of 2013 and has battled the disease ever since at the University of Colorado Cancer Center. “50 percent of what I raise goes to the Chris Draft Family Foundation, which supports research, survivorship and their program. The other 50 percent goes to the winner’s choice. ... So mine is going to go to the CU Cancer Center, but within that, specifically the Lung Cancer Colorado Fund,” she said. “Because it’s specifically looking at the research that tries to figure out what are driving these lung cancers.”

Ringen said she is looking for her “miracle” cure, but that she has a terminal diagnosis. A huge Denver Broncos fan, she jumped at the chance to cross ‘Super Bowl’ off of her bucket list. “I started the kickoff from my hospital bed, because I just got out of the hospital just a couple of weeks ago. And so I was doing all of this social media campaign from my phone. In and out of surgery, telling all the surgeons, telling everyone about it,” said Ringen, who is $10,000 ahead of the next highest fund-raisers. “I don’t want to be overly confident because that doesn’t get anyone, anywhere, in case there’s a sleeper. Another Denver person is second, which is good. Go Denver. We’re taking first and second. She has a lovely family and so she deserves to go to either one, as well.”

A second place finish isn’t “too shabby,” Ringen said, because they win a trip to the Pro Bowl in Hawaii.

Ringen says if she’s lucky enough to remain the leader through Sunday night and win that Super Bowl trip, she hopes she gets to see her beloved Broncos on the field. “I’m going to the Super Bowl -- you guys need to go with me!” she said. “The thing about football, especially after my diagnosis, is it gives me something to cheer for other than myself.”


On January 4th 2016 Kim sent us the following email. It was all over:

“It’s official!! We’re the winner! Donations are still coming in but the competition is closed - right now we’re at $22,385. And 50 % goes to Lung Cancer Cancer Fund! “ smiles Kim.
How Do You Decide?  A Research Study

Please consider taking the web survey about Decision Making by Lung Cancer Patients: https://www.surveymonkey.com/r/lungcancerdecisions

This is a survey that can be taken by lung cancer patients or their significant others or caregivers. It was designed by Dr Laurie Gaspar, a Professor in Radiation Oncology, at the University of Colorado. Dr Gaspar is gathering information that might improve the way that physicians and patients work together to make difficult decisions. The survey takes approximately 15 minutes or less to complete and plans to set the stage for further decision making studies in the future.

The Joyce Zeff Chair in Lung Cancer Research

In July 2015, the Joyce Zeff Endowed Chair in Lung Cancer Research was established in the Cancer Center at the University of Colorado Anschutz Medical Campus, through a generous outright gift from Joyce Zeff. With her support, the Cancer Center will be able to provide valuable long-term resources to attract, reward and retain some of the world’s foremost experts in lung cancer research and care, and to improve outcomes for countless patients and families battling the disease.

Mrs. Zeff and the Zeff family established the chair in gratitude for the high-quality, personalized care they received here as Mrs. Zeff battled stage IV lung cancer. By establishing this named chair, the Zeffs are leaving an important legacy in perpetuity, and helping to ensure that no one fighting the disease need look any further than the CU Anschutz Medical Campus for the absolute best care informed by the latest research.

Professor Ross Camidge, MD, PhD, Director of the Thoracic Oncology Program at CU, has been appointed the first Joyce Zeff Endowed Chair in Lung Cancer Research for all that he has accomplished for thousands of patients and families like the Zeffs.
## Philanthropy in Action: The Joyce Zeff Legacy

In August 2015, The Intermountain Jewish News posted the following obituary for Joyce Zeff, whose generous legacy, after her battle with lung cancer, enabled the creation of a new chair in lung cancer research at CU.

JOYCE ZEFF, an unpretentious, humble woman whose financial gifts to Denver’s Jewish community will sustain it for many years to come, passed away Aug. 5, 2015. She was 84.

Diagnosed with Stage 4 lung cancer in September 2014, her dedication to organizations and individuals alike never faltered.

Mrs. Zeff gave an unprecedented $5 million total endowment gift to Israel Study Tour (IST) ($3 million), JEWISHcolorado ($1 million) and Jewish Family Service ($1 million) in January, 2015. Along with her late husband Kal Zeff, Mrs. Zeff received countless tributes. Buildings bear the couple’s name.

But a single motive propelled their generosity — sharing their blessings with those less fortunate.

Mrs. Zeff “was a fighter, and we were awed by the way she handled the difficulties in life,” the family told the IJN. “She appreciated what she had and just did what needed to be done.

“Her highest priority was being there for us, and for others.”

Rabbi Joe Black and Cantors Joel Lichterman and Elizabeth Sacks officiated at Mrs. Zeff’s service Aug. 7 at Temple Emanuel, which was filled to capacity.

“Joyce understood the importance not only of giving thanks for the goodness of her life but in giving back to the community — of building a better world and sharing the many blessings with which she lived,” Rabbi Black eulogized.

Mrs. Zeff “cared deeply about people,” he said. “She was the kind of person who wanted to know everybody’s story. Relationships were the driving force of her personality.

“And yet she was a private person. There were very few people, other than family, who knew her well. She listened, often far more than she spoke. And when you were in her presence you felt grateful that you were able to share with her.

“But Joyce was not the kind of person who wore her heart on her sleeve,” he said. “She was a giver, not a taker, all her life.”

Yana Vishnitsky, president and CEO of JFS (the building on Tamarac is named for the Zeffs) was visibly shaken.

“When I think about Joyce, I think about a wise, kind, compassionate person,” she said at the service. “She was intelligent and modest. She was comforting and unassuming.

“I think about her always doing the right thing. She didn’t participate in community politics. She was true to who she was. She was fair, non-judgmental and genuine.

“I think about an incredible human being who provided a sense of safety and security to those around her.

“And I think about a friend whose friendship changed my life, and the life of Jewish Family Service.”

One of Mrs. Zeff’s grandchildren also spoke, as did Celeste Grynberg.

Mrs. Zeff, who never smoked, recently endowed a chair in lung cancer research at CU’s Anschutz Center.

JOYCE ABELSON was born May 14, 1931, in Altoona, Pa., and grew up in Tucson, Ariz. She attended Stanford University and graduated UCLA.

Not long after moving to Denver, she married developer Kal Zeff on Dec. 31, 1958. Mr. Zeff passed away in 2005.

“Our home was always open,” Mrs. Zeff’s family said. “You could totally relax. When we were young, everyone else’s house had strict rules, but you could be yourself at our home. That’s what our friends always said.”

An active participant at her children’s schools, her passions encompassed Israel, Hadassah, JFS, JEWISHcolorado, National Jewish, the Joint Distribution Committee, JCC, ADL, AIPAC, the Denver Art Museum and the Gathering Place.

Elected to the JFS board in 1990, Mrs. Zeff served as vice president, 1993-1996; chair, 1997-1998; and past chair, 1999-2001. She was instrumental in helping JFS and SHALOM Denver obtain permanent homes.

Mrs. Zeff was on the national boards of JDC, the Assn. of Jewish Family and Children’s Agencies, and served on DU’s Center for Judaic Studies board.

She also started the Right to Read program in the Cherry Creek public schools, was Hadassah’s Netanya president and belonged to BMH-BJ’s board.

Mrs. Zeff, the first recipient of the JCC’s Hineni Award in 2011, received JFS’ Jack Shapiro Community Service Award and was honored by National Jewish, among others.
“Mom liked to lunch,” her family said. “And she loved doing everything with us.”

She played tennis in her youth; belonged to a discussion group that examined a Jewish-related topic of the day; and loved the beach and swimming.

Mrs. Zeff enjoyed sports — “watching them, not playing them,” the family said.

She regularly attended the Boston Music Festival and was fascinated by politics and current affairs.

“But more than anything, she was just a great and devoted mother,” her loved ones said.

Mrs. Zeff is survived by her children Diana Zeff Anderson of Denver, Ron Zeff of California, Michael Zeff of California and Dana (Julie) Zeff of California; 13 grandchildren; and one great-grandchild.

A Patient Empowerment, Social-Media, Advocacy Force-of-Nature

Janet Freeman-Daily is a cancer patient advocate who used her own battle against lung cancer as a platform to help other patients better understand their own disease and better advocate for their own health. Diagnosed in May 2011, her cancer metastasized a year later. In between, she educated herself on treatment protocols and research developments. After learning her cancer had spread to other parts of her body, she took matters into her own hands and visited CU Cancer Center to enroll in a clinical trial which has put her cancer into remission ever since.

“I am alive today thanks to precision medicine and other patients I came in contact with through online support groups and communities,” she said. Her lessons helped fuel her new life’s passion as a cancer patient advocate, internet and social media expert, spreading her message of empowerment and hope during talks with cancer patients, physicians and regulators. ‘She is a Force-of-Nature,’ says CU oncologist, Ross Camidge. ‘Her positive impact on the wider lung cancer community has been immeasurable in the last few years.’

Read her award-winning lung cancer blog at: http://grayconnections.net

Three Qs and As with Janet Freeman-Daily:

Why travel from Seattle for a clinical trial in Denver?

Originally, I came to Denver because CU was one of a handful of hospitals worldwide offering the one clinical trial available for my rare type of lung cancer. My cancer had progressed after chemo and radiation, and the trial drug looked like my best chance for staying alive. Denver was the closest trial site to Seattle, and I was able to stay with my nephew and his wife in Highlands Ranch. Over the next few years, as I got to know the people at CU and the research they were doing, I realized CU was a world class lung cancer research center, and one of the best sources for information and treatment for lung cancer.

What is the CU Lung Cancer SPORE and what is your role in it?

The CU Lung Cancer SPORE (Specialized Program of Research Excellence) is one of four National Cancer Institute (NCI)-funded research programs that aim to accelerate the process of moving basic science research into lung cancer treatments for patients. I am a patient advocate for the CU SPORE, which means I attend monthly meetings, serve as a patient voice regarding research programs
and priorities, and learn a lot about cutting-edge research in the process. In addition to CU SPORE meetings, I attended the NCI Lung SPORE meeting in Washington DC and heard about the work other NCI Lung Cancer SPOREs were doing. It’s very exciting to see the early stages of new research that might one day cure my disease. I also initiated a project that works with families of deceased lung cancer patients to move their loved ones’ tissue samples from community hospitals into the CU biobank, where they can be used for research. If you are interested in this then email me directly: jfreeman.wa@gmail.com

What websites would you recommend for lung cancer patients and why?

There are many reliable online resources that offer accurate information and support to lung cancer patients. I actually learned about molecular testing for lung cancer and my CU clinical trial from other patients in an online patient community. Below are some websites I use.

**Online Patient Communities:** Good places to find people who have the same diagnosis, questions, treatments, and side effects as you, and are willing to share their experiences:

- Inspire’s Lung Cancer Survivor Support Community [www.inspire.com](http://www.inspire.com) -- lots of survivors and caregivers willing to share their experience and support, with discussions about specific treatments and clinical trials (I quickly learned which patients to trust and which not to)
- Smart Patients [www.smartpatients.com](http://www.smartpatients.com) -- a well-moderated forum with tags that allow exploring and tracking types of lung cancer, treatments, and research across cancer types
- “Lung Cancer Awareness” closed group on Facebook -- a more familiar format for some, and moderated by LUNGevity staffers (ask to join)
- “ROS1 Positive (ROS1+) Cancer” closed group on Facebook -- for patients and caregivers dealing with my type of cancer anywhere in the body (ask to join)
- Lung Cancer Social Media feed on Twitter (tweets containing “#LCSM”) – info and breaking news about treatments, research, resources, advocacy, survivorship, patient/caregiver support and the biweekly #LCSM Chat on Twitter

**Other Useful Websites:**

- Lung Cancer Alliance [www.lungcanceralliance.org](http://www.lungcanceralliance.org) and LUNGevity [www.lungevity.org](http://www.lungevity.org) - both offer info on lung cancer diagnosis and treatment, questions to ask your doctor, support services, clinical trial finders, and ways to become involved in advocating for lung cancer patients and research
- National Cancer Institute [www.cancer.gov](http://www.cancer.gov) - comprehensive overview of types of cancer, diagnosis, and treatment, plus a glossary and list of cancer drugs
- ASCO (American Society for Clinical Oncology) patient site [www.cancer.net](http://www.cancer.net) - tips for navigating cancer care, coping with cancer, and survivorship

**Purrfectly Gigi - Cat with a Cause**

Gigi is a tabby that likes to accessorize. She blends beauty and style purrfectly. Through the sales of her cards and images, Reagan Hudgens continues to support lung cancer research through the LCCF, giving over $3000 last year. (Ok, we know the pictures are a little over the top and we can’t believe Gigi puts up with accessorizing either...but she does and it’s just a little way to have fun while supporting a good cause). Please think about how you might be able to raise funds for the LCCF: golf tournaments, runs, even dressed up cats – we’ll be grateful every time!

New Clinic Aims to Close Palliative Care Gap

A decade after launching its inpatient palliative care service, University of Colorado Hospital has expanded the care it provides patients with serious illnesses.

The Palliative Care Outpatient Clinic officially opened July 15 on the second floor of the University of Colorado Cancer Center. For now, palliative care specialists will see patients with serious illness referred by University of Colorado Hospital providers two to three mornings a week, said Jeanie Youngwerth, MD, the clinic’s medical director.

Plans are to expand the number of clinic mornings to five in September after an additional physician and a nurse practitioner come on board, Youngwerth said.

Youngwerth also directs the Palliative Care Consult Service (PCCS), which works with hospitalized palliative care patients and their caregivers to identify their goals of care, manage pain and symptoms, plan advance care directives, and so on. The general goal is to improve quality of life and ensure patients’ decisions about their care are based on their personal values and those of their loved ones.

Growing need. The hospital’s inpatient palliative care volume has increased significantly since the PCCS formalized as an interdisciplinary team in 2005. The service, which earned Joint Commission advanced certification in 2013, now handles about 80 consults a month, up from 11 the first year. The hospital also designated four floating beds for palliative care patients when the Oncology Unit expanded to Anschutz Inpatient Pavilion 2 in June 2013.

In general, hospital-based palliative care is becoming well established, but outpatient services are sparse, Youngwerth said. Hospice care serves patients who are in the last six months of their lives, but many patients with cancer and other serious conditions need help well before hospice as they cope with disease, the therapies that treat it, and symptoms such as fatigue and depression.

“Palliative care doesn’t have a prognosis stamp on it,” Youngwerth said. “There are a huge number of patients with serious illnesses who are not at end-of-life. There is a major gap in care for those patients and their caregivers. We want to establish a more seamless transition for patients when they are discharged from the hospital.”

Another goal of the new clinic is to move palliative care “upstream,” so that patients get help with complex pain and symptom management to avoid hospital admissions or make emergency department visits, Youngwerth said. “The goal is to keep patients at home and feeling the best they can so they can do the things they want to do,” she said.

Room to grow. The new Palliative Care Clinic is one step UCH is making toward changing the present care system, Youngwerth said. Two board-certified palliative care physicians, David Nowels, MD, MPH, and Simon Schrick-Senasac, DO, MS, now see patients. New consult appointments are scheduled for 90 minutes, with follow-ups scheduled for 30. Family meetings last an hour. For patients with urgent issues, such as difficulty tolerating their treatment plan or making complex decisions about their care, the clinic will schedule same-day appointments, Youngwerth said.

In September, Carolyn Lefkowitz, MD, a gynecologic oncologist and palliative care specialist from the University of Pittsburgh, and Debra Davis, a nurse practitioner who was previously operations manager for the palliative care consult service at University of Florida Health, will join the clinic. With Lefkowitz and Davis aboard, the clinic will expand operations to five half-days per week, Youngwerth said.

The Palliative Care Clinic received strong support from Cancer Center providers and leadership, including Executive Medical Director of Cancer Services Tom Purcell, MD, MBA, and Executive Director of Oncology Services Jamie Bachman, Youngwerth noted. With the support of Ross Camidge, MD, PhD, director of the Thoracic Oncology Clinical Program and associate director for clinical research at the Cancer Center, the Lung Cancer Colorado Fund also contributed $20,000 to help fund staff salaries and clinic operations.

“Having access to expert palliative care in the outpatient setting has been a dream of mine since I started in Colorado,” Camidge wrote in an email. “Lung cancer patients, along with many other cancer patients, are often highly symptomatic. Getting a team behind every patient to manage the cancer, the symptoms caused by the cancer, or by the treatment is the best way to support every patient on their cancer journey.”
The First Annual Colorado Cancer Wellness Conference was a Huge Success

How do you know a conference is going to be good? When the keynote speaker starts off with the question, “When is the best time to have a cupcake?” The answer: Before someone else does!

On September 19, 2015 more than 140 cancer patients, cancer survivors, caregivers, and members of the community attended the first annual Colorado Cancer Wellness Conference (CCWC). The University of Colorado Cancer Center, experts from UCHealth, University of Colorado Hospital Center for Integrative Medicine, and the University of Colorado Anschutz Health and Wellness Center partnered to host the event.

Formally known as Colorado Cancer Day, CCWC has expanded to be all-inclusive. “In the past Colorado Cancer Day was disease specific so it only reached certain members of the cancer community,” explains Darcy Sypolt, MSW, LCSW, OSW-C, psychosocial oncology program coordinator and lead planner of the event. “This time we wanted the conference to be all-encompassing of any cancer patient, survivor, or caregiver.”

After an initial welcome and presentation about personalized cancer care, conference goers split in to two Colorado-themed groups: Maroon Bells and Collegiate Peaks. The Maroon Bells group had the chance to travel down the street to visit the CU Anschutz Health and Wellness Center. Once there, three breakout sessions were available: ‘Culinary Comforts’, ‘Exercise and Cancer Treatment’, and a course on survivorship. In the ‘Culinary Comforts’ session Lisa Wingrove, RD, demonstrated how to make food taste better and make it easier to swallow for people going through radiation and chemotherapy (see her article for more detail later in this newsletter).

Personal trainers from the wellness center taught simple stretches that cancer patients can do during their treatment. It may seem counter-intuitive but light exercise can battle fatigue that often comes with a cancer diagnosis. The survivorship class focused on the most recent clinical advancements as well as tips for survivors.

The Collegiate Peaks group had five breakout sessions to choose from. Classes included: ‘Coping with difficult emotions through cancer’, ‘Filling your tank caregiver class’, ‘Chemobrain’, ‘Relationships and sexual intimacy’, and ‘Healthcare navigation and advocacy’. “I loved the variety of topics,” says a conference attendee. “I wanted to go to every breakout session. It was hard for me to choose!”

“This conference was a great learning opportunity for us, and I am so glad to have gotten such positive feedback,” says Sypolt. “In the future we hope to continue to make the event bigger and better.”

For information on additional Wellness events please contact Darcy Sypolt: Darcey.Sypolt@uchealth.org

Personal trainers from the wellness center taught simple stretches that cancer patients can do during their treatment. It may seem counter-intuitive but light exercise can battle fatigue that often comes with a cancer diagnosis. The survivorship class focused on the most recent clinical advancements as well as tips for survivors.

Salmon was the main dish at ‘Culinary Comforts.’

Personal trainers show how to do simple stretches.
Please check out the videos below of various talks from the Wellness Conference:

Ross Camidge, MD, PhD - Personalized cancer care:  https://www.youtube.com/watch?v=LDhD3w9-vP0
Reid Hayward, PhD - Exercise and cancer:  https://www.youtube.com/watch?v=fRx6jJQmrl0&feature=youtu.be
Lavanya Kondapalli, MD - Cardiac oncology:  https://www.youtube.com/watch?v=9k4tGPmeO98&feature=youtu.be
James Hill, PhD - Closing remarks:  https://www.youtube.com/watch?v=2wYEOqfKuko&feature=youtu.be

Preventing lung cancer: An ongoing trial

“An ounce of prevention is worth a pound of cure” is highly applicable to lung cancer. Other than smoking cessation, which results in a gradual decrease in risk over years, we do not yet have proven ways to reduce the risk for either a first lung cancer or a new primary in a lung cancer survivor. A number of vitamins, natural products, and mineral supplements have been assessed and found to be ineffective. Researchers at the University of Colorado Cancer Center, including Robert Keith, Raphael Nemenoff and myself (York Miller), are following promising leads on compounds related to prostacyclin (a signaling molecule in the body, whose production is affected by aspirin and other non-steroidal anti-inflammatory drugs). Prostacyclin overproduction in mice makes them resistant to the development of lung cancer triggered by tobacco smoke and other carcinogens.

Previously, a multi-institutional National Cancer Institute funded clinical trial led by two of us (Drs. Keith and Miller) demonstrated that a tablet which could increase prostacyclin production (iloprost) led to an improvement in premalignant changes in the airways of former smokers, but not current smokers. This reinforced the importance of smoking cessation as a critical first step in lung cancer prevention. A follow up National Cancer Institute funded trial of an inhaled version of the same drug is now underway in former smokers. Subjects must have at least a 20 pack-year smoking history (ie at least one pack a day for 20 years or 2 packs for 10 years, etc), have quit smoking for at least 12 months, and not have undergone chemotherapy or radiation within the past 6 months. Survivors of previous lung or head and neck cancers are eligible. The trial includes a bronchoscopy before and after treatment, assessment of lung function changes, and exploratory investigation of ways to identify those most likely to benefit from the treatment, similar to the personalized treatment approaches now available for lung cancer.

For further information, contact Brandi Bagwell in the University of Colorado Cancer Center at 303-724-1657

Left to Right: Bob Keith, MD, Brandi Bagwell and York Miller, MD
Image: Response of bronchial epithelium to oral iloprost. Left panel demonstrates severe dysplasia and right represents normal epithelium at the same location in the same patient after six months of iloprost. The normal epithelium exhibits cilia (the hair-like projections on the right surface) and goblet cells (the cells with clear contents), which are all missing in the dysplasia in the left panel.

Personalizing lung cancer radiation therapy

Dr. Yevgeniy (Jenia) Vinogradskiy, PhD, Assistant Professor of Radiation Oncology at CU, has been recently awarded an R01 grant from the National Institute of Health to support a project entitled, “Clinical trial personalizing radiation therapy through a novel lung function imaging modality”.

Dr. Vinogradskiy received his PhD in Medical Physics from the UT MD Anderson Cancer Center before joining the University of Colorado faculty. The current project represents an evolution of his doctoral and faculty research work, which has involved the study of 4-dimensonal CT imaging (3-dimensions plus the effect of time in terms of breathing movements) as a tool to characterize lung function and facilitate planning for radiotherapy in the treatment of lung cancer.

“The multi-institutional clinical trial by Dr. Vinogradskiy holds great promise for advancing the utility of a novel functional imaging modality in radiation therapy to reduce lung treatment complications,” says Moyed Miften, PhD, Professor and Chief of Medical Physics at CU.

“I am thrilled that we will be able to move forward with this clinical trial. The techniques we will be using should help us reduce treatment side effects and improve quality of life and perhaps even lengthen survival as a result,” says Dr. Vinogradskiy.
Brian D. Kavanagh, voted President-elect of The American Society for Radiation Oncology (ASTRO)

Dr. Kavanagh MD, MPH, FASTRO is Professor and Chair of the Department of Radiation Oncology at the University of Colorado School of Medicine, Denver, and an attending physician at the University of Colorado Hospital. He was recently elected to serve for 1 year as President-elect, 1 year as President, and 1 year as Chair of ASTRO.

Q: What is ASTRO and what does it do?

A: Kavanagh: The American Society for Radiation Oncology (ASTRO) is a 10,000 member organization comprised of medical professionals practicing at hospitals and cancer centers in the United States and around the globe. ASTRO members form the radiation therapy teams that are helpful in the fight against cancer. These teams include radiation oncologists, medical physicists, medical dosimetrists, radiation therapists, oncology nurses, nutritionists and social workers. More than one million cancer patients are treated with radiation therapy each year. ASTRO's highest priority is improving the quality of care given to cancer patients. The organization achieves this goal by offering educational programs for doctors and others, publishing scientific journals, overseeing a practice accreditation program, and advocating to government agencies on behalf of cancer patients, among other things.

Q: What will being President mean for you?

A: Kavanagh: I have been serving on the ASTRO Board of Directors for the last 4 years, and I am hopeful that some of the projects that I helped launch during that time will come to fruition during the next year or two. My favorite among them is a national registry of patients undergoing stereotactic radiosurgery (SRS) for a brain tumor or certain type of blood vessel malformation in the brain. In this project, ASTRO has partnered with the AANS, a leading society of neurosurgeons. The goal is to improve the quality of SRS treatments by studying up to 30,000 patients treated with SRS in the next 3 years. The registry will be open at 30 leading centers of SRS excellence across the US, and I am happy to say that the University of Colorado Hospital was the first institution to begin enrolling patients.

It is a very exciting time to work in the field of radiation oncology. We are learning so much each year about how we can continue to improve upon how well cancer patients do after treatment, both in terms of how long they live and how good their quality of life can be. One of my tasks as president will be to supervise the educational program at our annual meeting in 2017, and it will be lots of fun to select the best of the latest scientific news and clinical trial results to be showcased in that forum.
Eating to Support Wellness

Like exercise and stress management, healthy nutrition promotes wellness and can improve quality of life. Patients being treated for lung cancer may face changes in their nutrition that makes eating more difficult. Taste changes, lack of appetite, and fatigue can all impact the way we feel about food, and mealtime may become a chore or something to avoid. Eating well during treatment can help improve your tolerance of therapy, as well as give you the energy to do your normal activities. Good nutrition throughout your treatment helps your immune function as it provides vitamins, minerals and proteins – all essential parts of your body’s defense system.

So, how can you find satisfying foods if you have taste changes? Depending upon your treatment, you might have a metallic or bitter taste, or sweet foods are too sweet; patients share that foods may be salty or have no taste at all. When foods taste poorly, the desire to eat is limited and this can be frustrating to both patient and caregiver. Here are some ideas to help improve flavor:

- Choose plastic, wood or bamboo flatware instead of metal
- If a food is too sweet, consider adding some tart or acid tastes. Lemon or lime juice, balsamic vinegar or soy sauce can often balance sweetness
- Adding salt can unlock flavor and make taste more pronounced
- Fresh herbs add both aroma and heighten taste
- Using a marinade with beef, chicken and fish can soften the protein and add flavor

Adding healthy fats can also bring more flavor and enjoyment to your meals as fats coat the mouth and bring a richness to mouthfeel. Fats have taste and flavor molecules that ‘switch on’ receptors in the mouth and nose: These then relay pleasure to the brain. Healthy fats that can create this feeling include avocado, olive oil and nuts. In addition, foods rich in omega-3 fatty acids have flavor and are a heart healthy choice. Omega-3’s boost the immune system, reduce inflammation, decrease blood clotting and can also reduce high blood pressure. Studies suggest that eating from 1g-3g/day can lower blood triglyceride levels and reduce the incidence of stroke. Fish high in omega-3 fatty acids include salmon, tuna, trout, mackerel, sardines and herring. Plant sources of omega-3’s include flaxseed, walnuts and sunflower seeds. While these are healthy diet choices, the body does not convert or use this form as well as it does the animal form.

Flavor and healthy fats combine in this recipe for Salmon with a Citrus Dressing. Baking the salmon in parchment allows the juices to form, and keeps the salmon soft and easy to chew and swallow. The liquid of the dressing helps to move the food around a dry mouth.

Salmon with a Citrus Dressing

12 oz. salmon filet
Slices of lemon
Salt and pepper
Parchment paper

Dressing
3 T lemon juice
2 T lime juice
1/3 cup orange juice
1 teaspoon of sugar
3 tablespoons olive oil

Preheat oven to 350 deg.
Lay salmon piece in middle of parchment paper, grind salt and pepper to taste and arrange lemon slices along the fish. Fold edges of parchment paper over the fish several times, to seal into an airtight packet. Bake salmon for 20-25 minutes. Carefully open the package – salmon is cooked when the flesh flakes easily and has a light pink tinge.

Prepare the dressing: Place the juices and sugar into saucepan and bring to the boil, simmer until sauce is reduced by around 1/3. Whisk in the olive oil until mixed.

Spoon the dressing on the salmon and serve.

Culinary Comforts is a cooking/nutrition class to help with common problems that patient’s face that impact their interest in food and eating and is intended for both patients and caregivers. Led by Lisa Wingrove RD CSO, topics include ways to enhance flavor, foods to help with swallowing, and how to bring healthful cancer fighting nutrients to your plate. Class is held monthly on a Tuesday from 5.30-6 pm.

Register at: www.anschutzwellness.com/cooking
You Wanna Write?

Our ‘YOU WANNA FIGHT?’ media campaign provoked strong reactions. Love it or hate it, it got people off the couch and talking about lung cancer, firing them up one way or another.

Watch the video: https://www.youtube.com/watch?v=lr1iVM8I8JY

Well, now we have another challenge for you. As the LCCF grows and its newsletter and stories expand, we’re going to need to grow our newsletter support group too. If you’re interested in helping to collect and collate stories, interview people, and generally make the next newsletter happen (all for the fun of it, no payment involved), please email: ross.camidge@ucdenver.edu

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 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@ucdenver.edu and each newsletter going forward we’ll aim to show others what ‘hope’ really looks like.

To see additional stories of hope, view the online newsletter at:
To contribute:

Lung Cancer Colorado Fund
University of Colorado Hospital Foundation
Mail Stop F485
12401 East 17th Avenue
Aurora, CO 80045

or online at: https://uch.thankyou4caring.org/

then choose Lung Cancer Colorado Fund from Drop down box, enter your donation amount, donation type and complete the general information requested.