

Sharing the Latest on ALK-Positive Lung Cancer Research and Survivorship

Members of the ALK-positive lung cancer community gathered at a summit to learn new developments and nurture support.

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Until 2007, about 1 in 20 [lung cancer](#) patients all had the same thing in common but did not know it.

In 2007, however, researchers discovered that molecular alterations in the anaplastic lymphoma kinase (ALK) gene were present in 4-5% of lung cancer cases. Since then, scientists, clinicians, and patients have united to understand and seek increasingly effective treatments for what would become known as ALK positive lung cancer.

This ongoing work was a focus of ALK Positive Summit 2022, held Saturday and Sunday, July 30 and 31, in Denver. About 800 clinicians, researchers, and people living with an ALK positive diagnosis gathered in person and virtually to learn about promising research developments, highlight survivorship, and nurture communities of support that span the globe.

“Because of the discoveries we’ve made and the treatments that have been developed for ALK positive lung cancer, we’re seeing a lot more long-term survivors who are young and motivated,” says University of Colorado [Cancer Center](#) member [Ross Camidge, MD, PhD](#), keynote speaker at ALK Positive Summit 2022 and a professor of [medical oncology](#) in the CU [School of Medicine](#).

“Because of the internet and Facebook, they know each other and form communities around the world, and are one of the driving forces in the progress we’re making in research and treatment.”

Improving Treatment for More Patients

For Nancee Pronsati, chair of ALK Positive Summit 2022, the summit’s aim was not only to share information and updates on ongoing research, “but to drive hope,” says Pronsati, who lives in Golden and received her ALK positive diagnosis more than six years ago. “It’s a chance to hear patient stories and learn how people are coping, and to create these networks of support that are so important when you have this diagnosis.”

An important summit focus for both clinicians and patients was learning about research and clinical trials happening around the world that are showing great progress in treating ALK positive lung cancer.

“At the University of Colorado, our clinical trials have really been working to improve targeted therapy for patients with ALK positive lung cancer,” says [Erin Schenk, MD](#), a CU Cancer Center member and featured speaker at the summit. “We’ve been involved in a number of major clinical trials focusing on certain targeted therapies that are helping patients live for a number of years following diagnosis.”

Several ongoing studies either being led by or involving CU Cancer Center researchers are focused on the next generation of tyrosine kinase inhibitors (TKI) that are showing fewer side-effects, increased efficacy, and are more easily tolerated by patients.

“Targeted therapies are fantastic and a mainstay of treatment for patients with ALK positive lung cancer, but they eventually stop being effective,” Schenk says. “One of the things we’re really interested in trying to understand is how we can augment those therapies specifically through the immune system. My laboratory is really interested in the ways immune cells can inhibit the effectiveness of these targeted therapies, and we’re asking fundamental questions about how the immune system interacts with this cancer. We’re trying to target these interactions or alter them in some way to make TKI therapy work even better for a broader range of patients.”

Defining Long-Term Survivorship

A certain urgency has driven ALK positive lung cancer research since the ALK alteration was identified. “It frequently occurs in young people who were never smokers, but we don’t know what causes it, and it has a high propensity to spread to the brain,” says Camidge, who has been at the forefront of global ALK positive research since the acquired genetic change was identified.

Early research demonstrated that patients who received the TKI crizotinib showed progression-free survival of more than twice the number of months as that experienced by patients who received chemotherapy.

“What became really exciting is suddenly we have patients who could be on a treatment which worked incredibly well with very few side effects,” Camidge says. “We are now seeing patients with advanced lung cancer who are 10 years, 15 years out from diagnosis. I think the ALK positive patient population have really come to define long-term survivorship.”

Even though about half of all ALK positive lung cancer diagnoses are made in people younger than 50, the continually lengthening survivorship has begun to incorporate issues and questions not often associated with cancer treatment: “If you’re a young woman of child-bearing age, you start asking whether you can have kids,” Camidge says. “The idea of long-term survivorship, even with advanced cancer, is allowing people to bring back their future planning. People are getting

married, they're starting families, they're seeking promotions in their jobs."

As with all cancer treatment, the foundational goal in treatment for ALK positive lung cancer is "perfect control of the cancer and perfect quality of life," Camidge says. "Maybe we don't always achieve that, but with better treatments and everything that's happening in research, people with an ALK positive diagnosis can expect more from life than just being alive."

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