The landscape of lung cancer treatment is changing. Research is enabling people with lung cancer to live longer and with a better quality of life. The Bonnie J. Addario Lung Cancer Foundation (ALCF) recognized the value of patient input and worked to create the Lung Cancer Registry in 2016, thus adding a voice to research and paving the way for patients to have an even more active role in improving the care continuum. ALCF joined forces with the American Lung Association and then the International Association for the Study of Lung Cancer to work in collaboration to expand the registry. We sat down with Sandra Shaw, Director of the Lung Cancer Registry at ALCF, to learn more about it.

What is the Lung Cancer Registry?
The Lung Cancer Registry is a database of patient information that is donated by patients themselves or by a loved one of a person who has passed due to lung cancer. It is a direct way they can affect the future of lung cancer treatment by simply sharing their insights and experiences.

Today, we have more than 1,300 participants in the community, and our goal is to add many more. We have a lot of progress to make in terms of better screening and diagnostic tools and more effective treatments. The more information we collect, the closer we get to the next advance that could save lives.

What’s in it for the patient?
People with lung cancer are encouraged early on to know as much as they can about their diagnosis, including the exact type, stage and molecular status, because that helps them make more educated decisions about their care. Generally, the more they learn, the more engaged they are in helping promote the research that leads to lifesaving treatments. The Lung Cancer Registry offers the opportunity for people with lung cancer to be an integral part of that research. To know that they’re having a direct effect on the future of lung cancer treatment is empowering. It’s also uplifting to be connected to a community of like-minded people living with lung cancer.

An added bonus is that they can be involved from the comfort of their own homes. We need data, and they can provide it by simply answering questions about themselves from a home computer or mobile device, such as a phone or tablet. We don’t ask for biopsies or specimens, and there are no required medical visits to be part of the Registry. Another important fact is that it’s free. It doesn’t cost anything to be in the Registry.

What happens to the information that is donated?
Once the data is input, it is de-identified, which means each participant’s name and any other identifying information are removed. Personal security is a top priority. No one, aside from our Lung Cancer Registry coordinators, can connect an individual to the information provided. The data is then aggregated, or summarized, and made available to everyone in the patient community as well as the medical community, including other nonprofit organizations, doctors, research scientists, medical investigators, regulatory agencies, and pharmaceutical, biotechnology and biomedical companies.

Patients may be interested in seeing the summarized information from other people who have the same mutation or are on the same type of therapy. It may provide insights into their own treatment path and options, and it can provide hope to see how other people experience their journeys. Scientists can access the data to add it to ongoing research. Medical professionals learn the patients’ point of view on how they are being diagnosed, tested and treated and may then adapt their current strategies accordingly.

How does someone get involved?
2. Register to be a member. Or, a caregiver or a designated representative can register for the patient.
3. Click the permissions box. In addition to reading the terms and conditions described on the site, keep in mind that privacy is a top priority to the Registry. By clicking the permissions box, a person opts in to participate and share information. Anyone may change his or her mind and opt out at any time without having to provide any explanation.
4. Click “Create account” to join the more than 1,300 participants already in the patient community.
5. The first and only required activity is to take a baseline survey about their lung cancer diagnosis. It takes 20 minutes or less, and asks questions about things such as symptoms, type and stage of lung cancer, testing, current and past treatments, and family history.

What happens next?
As a member of the patient community, each registrant receives a monthly newsletter that provides updates about new developments within the Registry. People may receive targeted emails with news or information about new clinical trials or other research projects that apply specifically to them based on the information shared. For example, those with a certain biomarker or who are on a specific treatment may be asked to consider a clinical trial or participate in a survey that will help researchers learn more. However, no one will be inundated with a lot of unnecessary emails. We value our participants’ involvement and send them only the most beneficial information.

We also encourage patients to update their data throughout the year as changes occur in their diagnosis and treatment to ensure everyone is viewing the most current information.

What advice would you personally want to share with someone who is newly diagnosed with lung cancer?
Receiving this diagnosis is devastating, but knowledge is power. Taking advantage of the valuable, valid resources that are available is a great first step.

Then, after having a chance to absorb the diagnosis and moving forward with your treatment plan, consider joining the Registry. Many people find comfort in knowing they’re able to help others. It makes them feel good to contribute to research that could improve the outcomes of future cancer patients.