BE THE VOICE

PARTNER TOOL KIT

TOGETHER, WE CAN BUILD THE KNOWLEDGE TO IDENTIFY AND UNDERSTAND THE COMPLEXITIES OF LUNG CANCER

LUNGCANCERREGISTRY.ORG
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Lung Cancer Registry Invites Patients to Be Part of the Solution to End Lung Cancer

People living with any type or stage of lung cancer are invited to be part of the search for new and better treatments by joining the Lung Cancer Registry (LungCancerRegistry.org). Sponsored by registry members Bonnie J. Addario Lung Cancer Foundation, the American Lung Association and the International Association for the Study of Lung Cancer, the Registry is a global database designed to help researchers understand the disease and provides a forum for lung cancer patients to access information about their type of cancer.

“Because patient experiences are a critically important tool in developing new therapies, signing up for the registry lets patients participate in the global search for treatments and provides researchers with the broad data they need to improve patient care,” said Bonnie J. Addario, 14-year lung cancer survivor and founder of the ALCF.

The Registry, which assures patient privacy, provides data-driven information to:

- Support and facilitate improved disease management and standard of care;
- Allow collaboration and information sharing among researchers and health care providers;
- Evaluate the effectiveness of different treatments and services;
- Measure patient outcomes to assess the quality and effectiveness of treatment; and
- Use aggregate data as a tool to find patterns that could better predict outcomes and quality of life for patients, both individually and as a group, over time.

“When we look at disease communities that have found new treatments, they have one thing in common – patient registries,” added Addario. “The Registry holds that same promise of facilitating treatment solutions for all people living with lung cancer and for the 1.8 million people diagnosed with some form of lung cancer every year.”

Once patients join the Lung Cancer Registry they can decide if they want to be contacted about research or clinical trials, and whether they would like to receive information relevant to them about their specific type of cancer. Patients can also access the Registry to see what their disease looks like compared to others in the registry.

Though there has been progress in lung cancer treatment, more work is needed. By joining the Lung Cancer Registry, patients will help facilitate that important work by providing the information needed to better understand and treat cancer.

Interested patients with any form or stage of lung cancer can be part of the solution to end lung cancer by joining The Lung Cancer Registry at LungCancerRegistry.org
THE LUNG CANCER REGISTRY

• Sponsored by member organizations the Bonnie J. Addario Lung Cancer Foundation, the American Lung Association and the International Association for the Study of Lung Cancer

EMPOWERING PATIENTS AND RESEARCHERS

• Patients with any type or stage of lung cancer
• Patient privacy assured
• Global database provides data for identifying patterns/treatments
• Empowers patients with information

KNOWLEDGE IS POWER

The Lung Cancer Registry is designed to:
• Support and facilitate improved disease management and standard of care
• Allow collaboration and information sharing among researchers
• Evaluate the effectiveness of treatments and services
• Measure patient outcomes, assess quality and effectiveness of treatment
• Develop data to find patterns that could better predict outcomes, quality of life

KNOWLEDGE IS POWER

Once signed up, patients can opt for information about:
• Research and clinical trials
• Information relevant to them and their lung cancer journey
• How their disease compares to others in the registry

JOINING THE REGISTRY

Lung cancer patients:
• Anyone diagnosed with lung cancer can join
• Information can be submitted by a caregiver on behalf of the patient

Researchers and clinicians:
• Access, view and search de-identified data with a professional account
• It is a research tool for YOU!

Log into and sign up at www.lungcancerregistry.org

BE THE VOICE

Be part of the solution to end lung cancer - sign up for The Lung Cancer Registry today
Social media is an excellent tool to help notify lung cancer patients about how they can be part of the solution to end the disease by signing up for the Lung Cancer Registry. By posting content similar to the sample content below on your Facebook and Twitter feeds, you can help inform potential participants about the Registry and its benefits.

- Lung cancer patients: be part of the solution to end #lungcancer! Join the Lung Cancer Registry today. lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- The key to discovery lies within the patient themselves. Join the Lung Cancer Registry today! lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- Knowledge is power. Bring power to the fight against #lungcancer – join the Lung Cancer Registry today! lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- Your patient experience is critical to uncovering treatments and cures. Sign up for the Lung Cancer Registry today! lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- We are in this together. Let’s find solutions together. Join the Lung Cancer Registry today. lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- Lung cancer patients of all types can participate in uncovering solutions to their disease. Join them! lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- The Lung Cancer Registry empowers patients with information and helps find solutions. Join today! lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
- The life you help save could be your own. Join the Lung Cancer Registry today. lungcancerregistry.org #beatlungcancer #lungcancerregistry #lcsm
Can You Help? Lung Cancer Registry Invites Patients to Be Part of the Solution to End Lung Cancer

People living with any type of lung cancer are invited to be part of the search for new and better treatments by joining the Lung Cancer Registry (LungCancerRegistry.org). Sponsored by registry members Bonnie J. Addario Lung Cancer Foundation, the American Lung Association and the International Association for the Study of Lung Cancer, the Registry is a global database designed to help researchers collaborate and understand the disease and provides a forum for lung cancer patients to access information about their type of cancer.

It is easy to sign up for the Registry and patient privacy is assured. Once patients join, they can decide if they want to be contacted about research or clinical trials, and whether they would like to receive information about their specific type of cancer. Patients can also access the Registry to see what their disease looks like compared to others.

Though there has been progress in lung cancer treatment, more work is needed. By joining the Lung Cancer Registry, patients will help facilitate that important work by providing the information needed to better understand and treat cancer.

Interested patients with any form or stage of lung cancer can be part of the solution to end lung cancer by joining The Lung Cancer Registry at LungCancerRegistry.org.
Your organization can help inform lung cancer patients how they can contribute to a global database designed to help researchers understand the disease and uncover better treatments.

Simply add the HTML code for the badge to your website and link lung cancer patients to the Lung Cancer Registry where they can sign up to be part of the solution to end the disease.

Download the badge at lungcancerfoundation.org/LCRtoolkit.
06 DOWNLOADABLE MATERIALS

The following materials can be downloaded at lungcancerfoundation.org/LCRtoolkit.

FOR PATIENTS

**Rack Cards**

Calling All Patients & Caregivers!
Have you joined the lung cancer registry yet?

Patients and caregivers are providing patient data to help researchers better understand the disease and move lung cancer developments forward.

Join the lung cancer registry at www.lungcancerregistry.org.

**Immunotherapy Study**

Calling All Lung Cancer Patients!
Patient-Friendly Lung Cancer Registry Launches National Enrollment Study!

Share your results and be a part of advancing this science.

Log in or sign up at www.lungcancerregistry.org. Only sign up if you register to be a mentor.

Why Patient Feedback is Critical

- There is increasing awareness of the importance of collecting patient-reported outcomes (PRO) data in clinical trials.
- PROs are collected at the time of treatment or follow-up.
- Up to date, relevant information will be shared only with unwieldy patient organizations.

How do I sign up!

www.lungcancerregistry.org

FOR RESEARCHERS

**Rack Cards**

Calling All Physicians & Researchers!
Access the Lung Cancer Registry!

Omit your professional account at www.lungcancerregistry.org.

Patients are providing data to help researchers better understand the disease and move lung cancer developments forward.

As a researcher, you can access the data from hundreds of patients worldwide...and contribute, setting research in motion.

www.lungcancerregistry.org

**Immunotherapy Study**

Calling All Clinicians and Researchers!
LUNG CANCER REGISTRY LAUNCHES IMMUNOTHERAPY STUDY!

Get a researcher professional account for the Lung Cancer Registry and help to collect and share the data on side effects.

The Lung Cancer Registry (www.lungcancerregistry.org) is a national platform for patients on an immunotherapy treatment.

- Patient-Reported Outcomes (PRO) for the use of immunotherapies, the PR3 and PR4 for these, and others.
- The registry can be published for quality improvement, research, and disease registry.

How do I sign up!

www.lungcancerregistry.org

To learn more, visit the Lung Cancer Registry and sign up on your account.

Proposals for research studies can be submitted to the Lung Cancer Registry at research@lungcancerregistry.org.