EveryLife Foundation Annual Scientific Workshop

Integrating the Patient Experience into Lung Cancer Policy, Treatment and Research
FDA FY2013 meetings

- Myalgic encephalomyelitis/chronic fatigue syndrome – April 25, 2013
- HIV – June 28, 2013
- Lung Cancer – June 28, 2013
- Narcolepsy – September 24, 2013
Goals

- Understand disease symptoms and daily impacts that matter most to patients
- The patient perspective on treatment of this condition

Audience

- ~15 lung cancer patients and 15 patient representatives
- ~25 patients via live webcast
In-person participants represented a higher proportion of:

- Women
- Patients diagnosed more than 5 years ago
- Patients whose cancer is currently in remission

In actuality, the lung cancer population is closer to 50/50 split between men and women and there is only a small % of the overall patient population whose lung cancer is in remission.
WHAT’S CHANGED?

• The approval of targeted therapies

• Immunotherapy

• Explosion of drugs in development

• More visible and active survivor community
• An initiative to integrate the patient experience into lung cancer policy, treatment and research.

• Includes multi-stakeholder external advisory committees, patient preference studies, benefit-risk tradeoff studies and understanding and addressing barriers to access that a patient experiences.
An initiative to integrate the patient experience into lung cancer policy, treatment and research.
Change the paradigm in lung cancer

• From assumptions - to evidence-based conclusions about patient desires

• Ensure that patient’s preferences are recognized, their voices are valued, and that living well with lung cancer can ultimately become the norm
• Patient preference studies

• Benefit-risk tradeoff studies

• Understanding and addressing barriers to access that a patient experiences.
Where are we to-date?

- Collaborating with researchers at John’s Hopkins on a pilot study to measure the stated preferences of people diagnosed with lung cancer.

- Pilot study will demonstrate the value of stated-preference methods to document the experience of patients and other stakeholders and will build capacity for future research focused on lung cancer.
Follow-on studies

- Inform a larger, amplified, patient preference study to drill down on the most significant issues of concern to patients

- Patient preference will be collected in a systematic way which can be used in collaboration with the FDA and industry partners to ensure patients help drive discovery and delivery as well as can meaningfully inform treatment options and interventions.
Thank you