Consistent Testing Terminology

Use Cases Workshop

March 11, 2021
Consistent Testing Terminology Working Group

PATIENT ADVOCACY GROUPS

PROFESSIONAL SOCIETIES

INDUSTRY PARTNERS
Use Case – Lymphoma and Chronic Lymphocytic Leukemia (CLL)

Presented by Kinya Harte, Director of Communications and Marketing, Lymphoma Research Foundation
Use Case: Lymphoma and CLL
Presenter: Lymphoma Research Foundation

• More than 111,600 new cases of lymphoma and CLL are expected to be diagnosed in 2021

• There are many different types of lymphoma, with over 85 types of NHL alone according to the World Health Organization

• Treatments for these cancers vary greatly, and a number of indolent lymphoma subtypes do not require immediate treatment
Use Case: Lymphoma and CLL

• Biomarker testing is still in its infancy in the blood cancer space, but we expect it to become increasingly important
  • CLL- 17p del
  • DLBCL- MYC, BCL 2, BCL 6 (Double or triple hit lymphomas)
  • ALCL- ALK+/-
  • Although treatments may not necessarily target these biomarkers, we know that testing for them is critical due to treatment implications
  • Right now, “NGS sequencing” or “genomic testing” are terms that some patients may hear from their HCPs to refer to biomarker testing for genomic mutations
Use Case: Lymphoma and CLL

- At this time, there is no guideline-recommended genetic testing for inherited cancer risk or inherited mutations in lymphoma/CLL.
Use Case: Lymphoma and CLL

• The Summer 2020 issue of LRF’s premier publication, PULSE, featured an article on biomarker testing terms with quotes from Nikki Martin

• LRF has promoted the work of the CTTWG through its social media channels

• Patient education programs will now include breakout sessions on biomarker testing, and discussions are underway on the development of factsheets discussing biomarker testing

• LRF remains committed to consistent use of the “biomarker testing” term in education materials and programming
Use Case: Lymphoma and CLL

• Limited knowledge and use of biomarker testing in lymphoma and CLL remain a challenge among many in the medical community

• Example: Medical reviewers for a recent update of one of our disease guides did not incorporate suggestions to include the term “biomarker testing” in the diagnostics section, likely due to a lack of awareness of the term
Use Case: Lymphoma and CLL

• The medical community, including HCPs and researchers, need to be engaged for their buy-in

• A potential opportunity is to have a discussion about the term “biomarker testing” in LRF’s professional education program/CME, Lymphoma Rounds