The EndBrainCancer Initiative Urges Immediate ACTION so Brain Cancer Patients are Not Excluded from Medicare Coverage for Genetic Profiling (Next Generation Sequencing-NGS)

Seattle, WA - May 28, 2019 - In 2018, the Centers for Medicaid and Medicare Services (CMS) approved funding for specific diagnostic tests associated with genomic profiling, both for predictive usages and for analysis for cancer patients with recurrent, relapsed, refractory, metastatic, and/or advanced Stages III and IV cancers. The EndBrainCancer Initiative (EBCI) urgently seeks amendment or clarification of this regulation (Transmittal 215) to ensure that brain cancer patients are covered by the new medicare provision, and not excluded. Public comment closes on May 29.

Two critical changes are needed.

First, the rules as stated approve funding for patients with “Stage III or Stage IV” cancer. Brain Cancer is not designated in “stages” but is designated in “grades.” Grade III and Grade IV are comparable to Stage III and Stage IV with other cancers. We therefore advocate for change in language or confirmation in the explanatory memo so that brain cancer patients with the highest grade tumors—Grade III Anaplastic Astrocytoma (AA) and Grade IV Glioblastoma (GBM)—are covered for this testing.

The second change pertains to recurrent brain tumors. A high percentage of Grade III and Grade IV brain cancer patients will experience recurrent tumors. We ask that CMS provide coverage for repeat testing for patients' specific disease states because the genetic profiles of recurrent tumors often diverge from the original profiles. It is therefore medically necessary to get new profiles to identify variations to assist with treating patients with a corresponding therapeutic product or to place the patients in appropriate clinical trials that match the profiles.

Genetic profiling, as in many other cancers, has become very significant in the analysis, treatment, and research of brain cancer. The EndBrainCancer Initiative has historically advocated for inclusion of Next Generation Sequencing (NGS) as part of Standard of Care and for coverage via

May is National Brain Cancer Awareness Month
Medicare / Medicaid and private insurance entities. May is National Brain Cancer Awareness month.

If you are a patient and/or caregiver, health professional, researcher or other type of brain cancer advocate, you can comment directly requesting these changes at this link: https://go.cms.gov/2WdD5Y7. The close for public comment is May 29th at 5:00 PM eastern. We urge ACTION and comment immediately. Here is the explanatory overview for this: https://go.cms.gov/2KaBhaW.

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