

Cancer Science & Pediatrics 2019: Blue Faery helps liver cancer patients spread their wings - Andrea J Wilson - The Adrienne Wilson Liver Cancer Association, USA

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According to the European Respiratory Society, patient advocacy organizations serve three roles: support and advise others; make changes happen and provide the patient's perspective. Blue Faery is the only non-profit corporation in the United States that specifically devoted to fighting primary liver cancer, especially Hepatocellular Carcinoma (HCC), the second most common cause of cancer deaths worldwide. Blue Faery's mission is to prevent, treat and cure primary liver cancer through research, education and advocacy. Blue Faery has five key values that drive the organization: commitment to outstanding service to patients and caregivers; competence with high quality products; cost effectiveness and efficiency; conscientious collaboration and communication and transparency.

These values ensure that the organization always puts its end users i.e. patients and caregivers above funders. Blue Faery supports and advises patients and caregivers through its educational materials, online community, one-on-one peer support program and website that translates into nine languages specifically targeted at the HCC patient population. As a member of the Deadliest Cancers Coalition (DCC), Blue Faery works with other non-profits to make changes happen at the federal level.

Most recently, the efforts of the DCC resulted in \$2 billion increase for the National Institutes of Health (NIH) for FY2019. Blue Faery works with its partners in a number of ways to provide the patient's perspective. From online surveys to in-person meetings, Blue Faery brings HCC patients, caregivers and survivors together to facilitate discussions about improving outcomes and increasing access to clinical trials. When patient advocacy groups serve patients and caregivers, they can make a major impact on the quality of life for patients and caregivers as well as on the visibility, funding, research and awareness of the disease. Surgery is the recommended first-line treatment for patients with early-stage hepatocellular carcinoma, although most tumors reoccur, which is hypothesized to be a result of

micro metastases (small collection of cancer cells that shed from an original tumor and spread to another part of the body) after surgery. Neoadjuvant therapies such as Libtayo could potentially improve these outcomes, although there is no recommended treatment in this setting. "The pathological response data support larger trials to identify optimal clinical end points that correlate with improvement in survival and to establish the utility and safety of perioperative PD-1 in patients with respectable (hepatocellular carcinoma)," said Dr. Thomas Urban Marron, assistant director of immunotherapy and early phase trials at The Tisch Cancer Institute and assistant professor at the Icahn School of Medicine at Mount Sinai, in the oral presentation on the data.

Twenty-one patients (median age, 68 years, 85.7% men) with hepatocellular carcinoma received 350 milligrams of Libtayo every three weeks for two cycles prior to the surgery, and then the same dosing regimen for eight cycles following the procedure for an additional eight cycles. Significant tumor necrosis was defined as greater than 70% necrosis of the resected tumor and was reported in four out of 20 patients after treatment with Libtayo. Three patients (15%) achieved complete tumor necrosis and seven patients (35%) achieved at least 50% tumor necrosis. There were 90.5% of patients who experienced at least one treatment-emergent side effect of any severity, and 28.6% of patients reported a side effect that was severe or worse.

The most common any-grade side effect was increased aspartate aminotransferase (which may indicate liver disease, heart issues or pancreatitis; 28.6%), increased alanine aminotransferase (potentially indicating liver diseases; 14.3%), increased blood creatine phosphokinase (injury or stress to the muscle tissue, heart or brain; 14.3%), constipation (14.3%) and fatigue (14.3%). Most common severe or worse side effects included elevated blood creatine phosphokinase (9.5%), increased aspartate aminotransferase (4.8%) and hypoalbuminemia (low level of albumin in the blood; 4.8%).