Blue Faery Helps Liver Cancer Patients Spread Their Wings

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Abstract (300 word limit)

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 nonprofit in the United States specifically devoted to fighting primary liver cancer, specifically 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 — 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 nonprofits 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.

Conclusion & Significance: When patient advocacy groups serve patients and caregivers, they can make a major impact on not only the quality of life for patients and caregivers, but also on the visibility, funding, research and awareness of the disease.

Recent Publications (minimum 5)

Britt Jim, Lutes Jim, **Wilson Woods, Andrea.** *The Change 12: Insights Into Self-Empowerment*. Amazon 2016.

Gill Jennifer, Baicean Andrei, Bee Julianah, Latiff Abdul, Clark Paul, Langford Andrew, **Wilson Andrea**, Yang Pei-Ming, Yoshida Eric, Kanavos Panos. "Understanding the hepatocellular carcinoma (HCC) patient landscape: Results of the first global survey of people living with HCC." *Annals of Oncology*, Volume 28.Oxford University Press. 1 June 2017.

Biography (150-word limit)



Andrea J. Wilson founded Blue Faery: The Adrienne Wilson Liver Cancer Association after losing her 15-year-old sister Adrienne, whom she raised for seven years, to stage IV liver cancer. Blue Faery's mission is to prevent, treat and cure primary liver cancer, specifically hepatocellular carcinoma (HCC), through research, education and advocacy. As a patient advocate, Andrea serves on many committees and advisory boards including the NCI Hepatobiliary Task Force and Target Pharma Solutions HCC Advisory Board. She is the only American to serve on CCSN's Liver Cancer Advisory Council. Andrea represents Blue Faery as a member of AASLD, ASCO, Deadliest Cancers Coalition, GI Cancers Alliance, etc. Andrea's goal is to see a cure for HCC in her lifetime.

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