Charlene York, Volunteer State Ambassador

Senate General Government and Agency Review Committee

Senate Bill 164-Witness Testimony

Monday, October 7, 2019

Chairman Schuring, Vice Chair Rulli, Ranking Member O’Brien and Members of the Senate Government and Agency Review Committee, thank you for the opportunity to present written testimony on Senate Bill 164.

As the Volunteer Ohio State Ambassador for the National Organization for Rare Disorders’ (NORD) Rare Action Network, I support Senate Bill 164, that would designate July as the Hank Kabel Sarcoma Awareness Month. A rare disease (of which there are over 7,000 types) is defined as a disease with fewer than 200,000 diagnosed patients. The majority of rare diseases have no cure or treatment.

Among rare diseases, over 30 rare diseases are sarcoma cancer related. Some of these forms of sarcoma cancer affect both humans and canines. Researchers of both canine and human forms frequently turn to each other seeking new information that could potentially leading to clinical trials to find a cure or treatment. For this reason it would be useful to raise awareness regarding one of these diseases so the future can be bright for those that suffer with sarcoma related diseases.