

## Legislation Text

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**File #:** 190624, **Version:** 0

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A resolution recognizing July 23, 2019 as World Castleman Disease Day and recognizing the continued efforts of Dr. David Fajgenbaum and the Castleman Disease Collaborative Network (CDCN) in searching for a cure for Castleman's Disease.

WHEREAS, Castleman Disease is a rare disease of the lymph nodes and other related tissues, which causes abnormal overgrowth of cells in the lymph system. Roughly 6,500 to 7,700 new cases are diagnosed annually; and

WHEREAS, Castleman Disease is a grouping of 3 heterogeneous autoimmune diseases and is primarily classified by the number of enlarged lymph nodes a patient exhibits. Patients that exhibit only one or one region of enlarged lymph nodes have Unicentric Castleman Disease, while having multiple regions or nodes enlarged would diagnose a patient with Multicentric Castleman Disease; and

WHEREAS, Multicentric Castleman Disease can be broken down into two subgroups, individuals infected with Human Herpes Virus-8 (HHV-8). These patients are typically infected with HIV, but that is not a guarantee. Patients who are not infected with HHV-8 or HIV are diagnosed with idiopathic Multicentric Castleman Disease; and

WHEREAS, While Castleman's Disease is not officially considered cancer, it can lead to patients developing lymphoma and is just as deadly as cancer. Multicentric Castleman disease has a nearly identical 5-year mortality rate as colon cancer (35%) and a worse mortality rate than prostate cancer, breast cancer, non-Hodgkin lymphoma, and Hodgkin lymphoma; and

WHEREAS, More often than not, Castleman Disease is misdiagnosed, as its rarity often leads physicians to diagnose a patient with some form of cancer before recognizing the mistake. As noted, only 6,500 to 7,700 new cases are diagnosed annually, as compared to lung cancer (224,390) or diabetes (22,000,000) in 2016; and

WHEREAS, In order to increase awareness of the disease and to accelerate research for a cure, Dr. David Fajgenbaum and Dr. Frits van Rhee co-founded The Castleman Disease Collaborative Network (CDCN) in 2012; and

WHEREAS, The mission of the CDCN is to accelerate CD research, treatment, and patient care through global collaboration, strategic investments in research, and supportive resources for patients and their loved ones; and

WHEREAS, By holding events such as the Annual Patient and Loved One Summit, the Quest for a Cure Gala, and the Million Dollar Bike Ride fundraiser, for Castleman Disease patients, the CDCN is able to raise awareness as well as offer support and hope to patients and their families; and

WHEREAS, Through the CDCN, the First Annual World Castleman Disease Day took place on July 23, 2018,

which was used by advocates to raise awareness worldwide on social media; and

WHEREAS, The CDCN will hold the 2nd Annual World Castleman Disease Day on July 23, 2019; and

WHEREAS, Before Dr. Fajgenbaum graduated from medical school, Castleman Disease put him in the hospital and on his deathbed, almost preventing him from graduating the Perelman School of Medicine at Penn. But he survived and is dedicating the rest of his life to finding the cure to the rare disease; and

WHEREAS, Dr. David Fajgenbaum is the Assistant Professor of Medicine in the Division of Translational Medicine & Human Genetics at the University of Pennsylvania and leads the Castleman Research Program at Penn as the PI of 18 translational research studies and the first- ever NIH R01-funded research of idiopathic Multicentric Castleman disease; now, therefore, be it

RESOLVED, BY THE COUNCIL OF THE CITY OF PHILADELPHIA, That we hereby recognize July 23, 2019 as World Castleman Disease Day and recognize the continued efforts of Dr. David Fajgenbaum and the Castleman Disease Collaborative Network.

FURTHER RESOLVED, That an Engrossed copy of this resolution be presented to the Castleman Disease Collaborative Network as evidence of the sincere sentiments of this legislative body.