

Mattie Stepanek Peace Foundation

402 King Farm Blvd. #125, Rockville, MD 20850 www.MattiesPeaceFoundation.org - INFO@MattiesPeaceFoundation.org Peace. Purpose. Play.

Sen. Cheryl C. Kagan State Senator, District 17

February 3, 2025

Dear Sen. Kagan:

This letter is my show of support for the "Right to Repair – Powered Wheelchairs (SB382) proposed bill.

After enjoying three decades of life as an athlete, I was diagnosed with a rare and progressive adult-onset neuromuscular disease in 1992 when I was turning 33 years old. Within two years, I was relying on a power wheelchair for mobility as my strength declined. Across the years, my need for more specialized and adaptive wheelchair supports increased as the condition continued to progress. Since 2007, I have also required non-invasive ventilation to support my breathing and to slow the progression of cardiac challenges. The ventilator and power sources are mounted on my wheelchair, which now has more than 10 actuators that control functions such as tilt, recline, headrest, footrest, and more – all of which are critical to preventing pressure sores and to supporting activities of daily living.

Indeed, I am quite a "complex care patient. However, I am also an active member of my community who handles a fulltime workload and also volunteers to serve others. I am able to continue my role as a senior faculty specialist at the University of Maryland and my appointment as President of the Mattie Stepanek Peace Foundation because of my highly adapted power wheelchair. That said, when there is a problem with the chair – when a part breaks, when a control malfunctions, when any of the actuators do not work as designed – I am not only unable to work, but I am also at risk of medical complications that are prevented by the support of my wheelchair.

I have been blessed to have a dedicated "wheelchair guru" who has tended to my needs in a timely and professional and compassionate way for the past 15 or so years. Before he was taking care of my chair, there were times I was quite literally bedridden without my chair, when I had to wait for replacement parts or service calls. In addition, I have occasions when I work out of the state; when I have had wheelchair challenges and malfunctions during travel, there is no organized way for me to have even easily remedied malfunctions tended to.

For these reasons, it is with gratitude and enthusiasm that I support the Consumer Protections – Right to Repair – Powered Wheelchairs SB0382 proposed legislation. Such legislation would be beneficial to countless individuals – who like me – rely on adaptive equipment to work, to live, and to enjoy life.

With gratitude and peace,

Jeni Stepanek, PhD

President & Founding Chair

Mattie Stepanek Peace Foundation,

MamaPeace@MattiesPeaceFoundation.org