Testimony of David Hysong

Founder & CEO

SHEPHERD Therapeutics and SHEPHERD Foundation

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I am honored to provide testimony before the House Veterans Affairs Committee with my family's deep connection to the military and my professional and personal experience developing therapeutics for rare cancers that require advancements in precision medicine.

My father attended Embry Riddle Aeronautical University and commissioned in the United States Air Force as a helicopter pilot. He flew Hueys, served as the Special Air Mission Aircraft Commander of the Presidential Airlift Wing, received the Air Force Meritorious Service Medal for hazardous rescue, and twice received the Air Force Commendation Medal.

I too have my own connection with the military. While completing graduate school at Harvard University, I was selected for the Navy's SEAL Officer Selection process four years ago. After successfully completing the process, my military experience was cut short by my diagnosis of adenoid cystic carcinoma, or ACC, at 27 years old. While my cancer was successfully resected, if it returns there will be no approved modern therapies with which to treat it. If it returns, it will likely metastasize to areas including my bones and brain. I'm not one to go down without a fight. I am determined to not just beat this but help millions of others do the same.

Unfortunately, over 60 cancers may disproportionately affect our nation's veterans and service members. Sixty-seven percent are rare and only 25 of these rare cancers have an FDA approved targeted therapy. Many of those cancers are potentially caused by service-related exposures such as asbestos, burn pits, radiation and Agent Orange. Even children of veterans who were exposed to Agent Orange have an increased risk of certain cancers, according to a 2018 National Academy of Sciences study. In addition, rare cancers occur more frequently among Hispanics, Asians and Pacific Islanders compared with non-Hispanic blacks and whites. These populations frequently suffer from worse outcomes and shorter survival times, and African American cancer patients have a lower 5-year survival rate than white patients. Regardless of ethnicity, age or exposures, the vast majority of new cancer patients – over 80% – who lack even one FDA-approved targeted therapy for their cancer are rare cancer patients.

SHEPHERD's research has shown that at least 380 forms of cancer meet the most conservative estimate of what constitutes a rare cancer, the American Cancer Society's metric of fewer than 6 new diagnoses per 100,000 people per year. Those 380 forms compose 95 percent of all forms of cancer, which collectively will afflict over 550,000 new patients this year. As more diagnostic testing is provided for all cancer patients, the molecular subtyping will enable precision diagnosis and hopefully, one day, precision treatment. This means the number of "rare" cancers will continue to rise as a greater proportion of all cancer types, which makes precision medicine and targeted therapeutics critical to saving lives.

Yet, current clinical trials – often a cancer patient's best option for treatment – lack rare cancer patients. Our analysis of all clinical trials between 2012 and 2016 showed that 74.89 percent of all trials did not include even one rare cancer. Only around 13 percent of all rare cancers were specifically named as a focus of a phase 3 clinical trial in those five years. More than four times as much money in that time frame was spent on non-rare cancer trials than on trials which included a rare cancer. For minorities, those discrepancies are amplified, as minorities are less likely than Caucasians to be included in clinical trials, which can lead to underrepresentation of key biological variables that make drugs less effective among those populations. As data presented at a recent MIT conference showed, only three percent of the U.S. population is represented in clinical trials. These trials fail to capture the genetic diversity present in the population as well as in many forms of cancer.

This is why I encourage the Department of Veterans Affairs to explore ways to improve how the VA engages with investigators. At SHEPHERD Therapeutics, I have built a team of researchers in rare disease and oncology who are developing therapies which can tackle multiple rare cancers by leveraging shared biology. This approach will enable targeted therapeutic development for many rare cancer patients who are currently neglected by a drug development market that favors common cancers because they produce the greatest financial rewards.

As of February 2019, 182 cancers lacked an FDA-approved targeted therapy and 181 of them were rare cancers. That means that in 2019 almost 200,000 new rare cancer patients will face their diagnosis without a modern treatment, and current reimbursement policies contribute to this failure. While CMS decided in March 2018 to ensure that Medicare and Medicaid patients whose cancer recurs after treatment can receive molecular diagnostics, patients ideally should receive molecular diagnostics when they are first diagnosed to best inform treatment decisions. Diagnostics are especially important for cancers without good treatment protocols, as the tests may identify genetic drivers that can be addressed with existing therapies. Many patients do not know to request molecular diagnostics, and cannot afford to pay for testing. Even at large NCI care centers, molecular diagnostics is frequently covered only by donations and internal hospital funding and policy. This increases the gap between the quality of care afforded to those who have access to large NCI care centers, and the care provided to the majority of cancer patients who are treated at community hospitals. In addition to supporting patient care, this data can be vital to NIH, DoD and the VA by advancing scientific understanding of what causes a disease, the types of therapies which may work on it, and the appropriate patient population for molecularly-targeted clinical trials.

With approximately 20 million veterans, plus the millions more in their families and those who are currently serving in the military today, the gap in rare cancer therapeutic options is disturbing. Millions of lives are touched by rare cancers for which there are no treatment options. This must end. As a patient and CEO of a therapeutic company working hard to change the current paradigm for drug development to advance targeted treatments, I urge you to make the necessary changes in a collaborative fashion with the VA, DoD and NIH to ensure patients are no longer neglected. The VA can take a critical role in collaborating with researchers to share data, cell lines and discoveries to advance the development of targeted therapeutics. Our veterans deserve this care. Thank you.