



CLL SOCIETY

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International COVID-19 Blood Cancer Coalition Launches Campaign Highlighting the Need to Prioritize Protections of Immunocompromised Blood Cancer Patients

Chula Vista, CA — On June 20th, 2022, the International COVID-19 Blood Cancer Coalition (ICBCC) launched its worldwide campaign to help raise awareness about the vulnerability and needs of the immunocompromised blood cancer community pertaining to COVID-19 prevention and treatment. The ICBCC is working to address the specific impact of the pandemic on immunocompromised blood cancer patients and to recommend solutions and actions to mitigate those risks. Coalition partners from almost every continent are synchronizing their voices to inform others that people living with blood cancers, who are also moderately to severely immunocompromised, need protection too. Approximately 237 million people worldwide are estimated to be immunocompromised or immunosuppressed. That number equates to approximately two to three percent of the global population and includes over seven million people in the US.

"As more and more people are now protected from the worst of the pandemic and moving away from preventive measures such as masking and social distancing, the immunocompromised have become even more at risk for contracting COVID-19 and suffering from severe disease and even death," states Brian Koffman, Co-Founder, Executive VP, and Chief Medical Officer at CLL Society, who is also a CLL patient himself. "Societal awareness and compassion towards the vulnerable would go a long way towards ending the ongoing risks for those who can't make antibodies after vaccinations and would help speed the end of the pandemic."

Approximately half of the people with CLL/SLL do not make antibodies when given COVID-19 vaccines. Therefore, it is crucial that policymakers know that more monoclonal antibody preventatives and treatments, as well as antiviral treatments, are essential and must be easily accessible for everyone who is immunocompromised.

The CDC's current definition of those with cancer who should be considered immunocompromised only includes but is not limited to "those who have been receiving *active cancer treatment* for tumors or cancers of the blood." Since the beginning of the pandemic, this CDC definition has not specifically included patients diagnosed with certain blood cancers who are not undergoing active cancer treatment but still are moderate to severely immunocompromised. Examples of this would be those with chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL), who have a chronic cancer of the immune system. Most of the time, they do not need to undergo active cancer treatment right away, and sometimes never at all. However, patients diagnosed with CLL/SLL are moderate to severely immunocompromised even when they are not undergoing treatment because they have cancer that impairs their immune system's ability to produce antibodies in response to vaccines or to fight off infection.

"Inclusion of the immunocompromised in the pandemic response is a matter of equity and good public health policy" said Janet Handal, President, and Co-Founder of TRAIAPAG (Transplant Recipients and Immunocompromised Patient Advocacy Group). "When lifesaving scarce resources are allocated, it is critical that the definitions used to prioritize them reflect known scientific data."

Still, many immunocompromised blood cancer patients have not been understood as meeting the CDC's definition of being immunocompromised. As a result, they were not prioritized when lifesaving COVID-19 vaccinations were first



released, many were told they did not qualify to receive recommended booster doses per the CDC's recommendations for the immunocompromised, and individuals are still being told they are ineligible for preventative COVID-19 therapies and treatments. This has created multiple gaps in equitable access throughout the pandemic for this population and has even prompted some to refer to themselves as the forgotten "prisoners of the pandemic."

"Individuals who are immunocompromised, including those with certain blood cancers, remain at increased risk of COVID-19 infection despite taking measures such as social distancing, masking, and receiving all appropriate vaccinations to decrease their risk. These individuals warrant additional steps to decrease their risk of life-threatening infection," says Dr. S. Shahzad Mustafa, Chief of Allergy, Immunology, and Rheumatology at Rochester Regional Health. In the United States, crucial preventative COVID-19 medications such as Evusheld (a Pre-Exposure Prophylaxis preventative monoclonal antibody authorized for the immunocompromised), and monoclonal antibodies used for treatment after infection, are either in short supply or are inaccessible in many parts of the country.

Mustafa goes on to say, "Beyond vaccination, these additional steps include using medications such as Evusheld, as well as prompt treatment of COVID-19 infection with oral antiviral medications or monoclonal antibody infusions for these patients. As these therapies become increasingly available, it is imperative for clinicians to be aware of these therapies and know how to access them in a timely fashion in hopes of leveling the playing field for the immunocompromised population." Many immunocompromised patients have had difficulty obtaining Evusheld, in part due to a general lack of awareness amongst both patients and healthcare providers as to who is eligible to receive Evusheld. Further compounding the problem, healthcare providers often refer to the CDC's definition of who should be considered immunocompromised to determine eligibility for Evusheld, which does not specifically include blood cancer patients who are not actively undergoing treatment.

Lynn Albizo, Vice President of Public Policy at the Immune Deficiency Foundation, shares, "Since founding the Immunocompromised Collaborative in 2020, we at the Immune Deficiency Foundation and our partner organizations have learned that while there are many patient advocacy coalitions, the collective voice for immunocompromised individuals needs to be heard."

As the global focus seems to be shifting towards 'learning to live with COVID-19,' the health of the immunocompromised must be prioritized now more than ever. Blood cancer patients who are immunocompromised, regardless of treatment status, remain at high-risk of developing severe COVID-19 disease and death. Making sure that the CDC definition of who is considered immunocompromised is inclusive of those with certain blood cancers of the immune system is critical. Doing so will help ensure these at-risk individuals are prioritized in the future to receive additional COVID-19 vaccine doses and preventative therapies as recommended and allow for quick access to lifesaving treatments when they are needed. Society must provide adequate resources to protect those at high risk and make appropriate accommodations so all can enjoy the benefits of the world opening up. Learning to live with COVID-19 must include remembering the needs of the vulnerable individuals who also live among us.

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CLL Society is an inclusive, patient-centric, physician-curated nonprofit organization that addresses the unmet needs of the chronic lymphocytic leukemia and small lymphocytic lymphoma (CLL/SLL) community through patient education, advocacy, support, and research. Learn more at www.cllsociety.org.