23rd March 2023

Rt Hon Rishi Sunak MP

Prime Minister

10, Downing Street

London

SW1 2AA

Dear Prime Minister,

Continued Protection of Immunocompromised Patients

Today, 23rd March 2023, marks the third anniversary of the first national lockdown in the United Kingdom. For many, this is now a distant memory, but for a large group of immunocompromised patients (recently identified as 1.2 million people by NICE) the continued effects of Covid-19 are still very much at the forefront of their lives. Due to their conditions or medication, they have little or no protection from the vaccines available and as highlighted in numerous studies, such as the recently published WHO ISARIC CCP-UK study by Birmingham University. Consequently, they are at a proven higher risk of more severe outcomes from the virus. They have no choice but to live restricted lives, with many now entering a fourth year of shielding while they await the availability of protective drugs on the NHS.

Many of those affected have seen the chance to use a protective drug, Evusheld, squandered by an unnecessarily elongated process. The Government should give the same priority to developing and implementing protection for this at-risk group as it did for the vaccine development, procurement and roll out. The decision and process for Evusheld was concluded, by NICE themselves, in their draft guidance dated 16th February 2023, to have failed in its objective and is in need of urgent replacement with a rapid system of appraisal for such drugs. This would then meet the urgent and currently unmet need to protect this vulnerable patient group from a potentially life-threatening disease; to reduce admissions to hospital; and to alleviate the stress and misery of life away from society, family and friends.

Those in this position are now reliant on protecting themselves as precautionary measures have been removed throughout society, including in healthcare settings. It is wrong that vulnerable patients, often those who have been the recipients of expensive treatments such as transplants, are now forced to risk contracting Covid-19 in healthcare settings. The already difficult position of self-reliance is soon to be compounded by the decision by the Office of National Statistics to suspend the Covid-19 Survey Data publication. This decision

will further endanger the large number of immunocompromised and clinically extremely vulnerable patients who will have no reliable data upon which to assess their level of risk.

Furthermore, many of the most vulnerable are still cared for and protected by their family members. Yet the new spring booster vaccine programme has failed to include family members or carers of the most vulnerable, removing another important layer of protection from those most in need.

The many who remain in this position have already endured three years of trying to live with this virus, some in isolation from friends and family, with restrictions on their ability to work, study and socialise. Many now suffer from long-term effects on their physical and mental health, whilst receiving no financial support and no communication on plans to protect them in the future. Family members have the huge pressure of trying hard to protect their loved ones, which has taken its toll, especially on their children. Many in this group wish to return to work, to study and to contribute to society, but are denied re-entry into the economy at a time when they are needed most.

We urge you, Prime Minister, to act to ensure that policies are put in place to protect the vulnerable. As representatives of the concerned patient group, charities and with support of many concerned parliamentarians across the House we ask you to: -

- 1: Ensure that a rapid system of evaluating new protective/prophylactic Covid-19 drugs and treatments is developed and implemented as a priority.
- 2: Reverse the decision to suspend the ONS Covid-19 Survey Data publication
- 3: Ensure immunocompromised household members are included as eligible for the spring Covid-19 vaccine booster programme.
- 4: Ensure better communication with patients, including direct ministerial consultation with concerned charities and patient representative groups and parliamentary colleagues to ensure transparent decision making.
- 5: To appoint a minister with specific responsibility for the clinically vulnerable and immunocompromised.

As Prime Minister, you have stated that this Government will look after its most vulnerable. We now hold you to this and ask that you prioritise action that will protect and change their lives, allowing them the freedom that the rest of society has gained. They too deserve the protection to enable them to live their lives with Covid, which has been sadly lacking to date.

On behalf of all those we represent we look forward to your reply.

Signed for and on behalf of: -

Evusheld for the UK - Prof Martin Eve, Nikola Brigden, Mark Oakley

LUPUS UK - Paul Howard, CEO

Kidney Research UK - Alison Railton, Head of Policy and External Affairs

Action for Pulmonary Fibrosis - Steve Jones, Chair of Trustees

National Kidney Federation – Andrea Brown, Chief Executive

Shine Cancer Support - Ceinwen Giles, Co-CEO

Immunodeficiency UK - Dr Susan Walsh, CEO

Sarcoidosis UK - Leo Casimo, Senior Executive

Crohn's and Colitis UK - Sarah Sleet, CEO

Kidney Care UK - Fiona Loud, Policy Director

CLL Support - Marc Auckland, Chair of Trustees

CLL Ireland - Jan Rynne, Chair

Cardiomyopathy - Joel Rose, Chief Executive

Follicular Lymphoma Foundation - Kate Rogers, CEO

MDS Patient Support - Sophie Wintrich

Arthritis and Musculoskeletal Alliance (ARMA) - Sue Brown, CEO

Myeloma UK - Dr. Sophie Castell, Chief Executive

MS Society - Jonathan Blades, Head of Campaigns and External Relations

Myaware UK - Sarah Cuthell, CEO

WMUK - Jane Nicholson, CEO

Due to the large number of signatories on this letter, we will appreciate your reply being sent to nikolabrigden@icloud.com at Evusheld for the UK. We will then disseminate this to the other signatories.









CROHN'S& Colitis UK

















Supporting families affected by primary and secondary immunodeficiency













