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It's not Freedom Day but Forgotten Day for some says UK Charity

Tuesday 22 February, 2022

Following the PM's announcement of 'Freedom Day', a UK charity is asking the Government to establish a clear path to Covid preventative treatment for the estimated 500,000* vulnerable people who are immunocompromised or have an immune deficiency who feel "isolated", "forgotten" and "discriminated against". These adults and children have not been able to live a 'normal' life for 2 years and have no idea when they will be able to live a normal life again.

The charity - <u>UKPIPS (UK Primary Immune-deficiency Patient Support)</u> – is questioning Government claims that the vulnerable are protected by following the JCVI vaccination advice and targeted testing.

Sue Dimmock, charity member, says: "The fear everyone felt on the first day of Covid with no innate protection is the fear that people with an immune deficiency feel every day."

She continues: "After three Covid vaccinations and a booster, most people with an immune deficiency will have the same antibody level they had before any vaccination. Immunity is high in most of the general population but not in this population.

"Adults and children living with immune deficiency have no (or very limited) ability to produce antibodies in response to Covid (or any other) vaccination. The condition is due to full or partial impairment of the immune system, affects both children and adults and means they are unable to effectively resolve infections or disease.

"Targeted testing detects those already infected – the aim for this vulnerable group is to *prevent* infection. Many people have been shielding for 2 years with no clear route out of this. Removing the legislative requirement to self-isolate increases the risks, as there is now no way to avoid Covid, particularly for those in the workplace. Every contact is a potential Covid carrier and therefore a high-risk contact for this forgotten community."

Lynda Rhodes, a Trustee from UKPIPS, adds: "Levels of anxiety and stress increase with every restriction that is removed. People feel discriminated against since neither they, nor their families, can safely enjoy the same freedoms as everyone else. Members say they feel 'neglected' and 'thrown on the rubbish pile'. Relying on people's personal responsibility to protect them does not help and just creates more anguish."

UKPIPS wrote to the Secretary of State for Health and Social Care on 29th January 2022 and followed up on 14th

February 2022 with several requests for those with immune deficiency including:

- a clear plan for access to prophylactic neutralising monoclonal antibodies treatments such as Evushield, which has already been approved in six countries for those with immune deficiency. This treatment has the potential to provide a 'preventative' level of antibody protection that most of the rest of the population already enjoy from the vaccination programme.
- children under twelve are given access to Covid treatments if they catch Covid. At the moment they are expected to attend school but have no treatment options available if they catch Covid.
- Access to free lateral flow tests for families and carers as well as those with immune deficiency.

The Charity is awaiting a response.

Ms. Dimmock summarises: "As we 'learn to live with Covid', it is not clear how those with immune deficiency can do this. Immunology teams are doing their best to support these people but (aside from post-infection treatments) consultants currently they have very little to offer their patients".

ENDS

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