

Rt Hon Steve Barclay MP
Secretary of State for Health and Social Care
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU

27th June 2023

Dear Secretary of State,

RE: Urgent concerns regarding delivery of post-exposure treatments for COVID-19

We write to you regarding our concerns about the planning and implementation of changes to the system for the delivery of post-exposure treatments for COVID-19 for the most vulnerable patients.

As you are aware, post-exposure treatments including Paxlovid and Sotrovimab are treatments used to help prevent hospitalisation and death due to severe COVID-19 and are made available to all those considered to be vulnerable and at the highest risk. This cohort of approximately 2 million people includes a wide range of conditions, including those with blood cancers and disorders, lupus, transplant recipients, kidney diseases, respiratory diseases, among others. You are no doubt aware that the timely delivery of these drugs is critical in order to ensure their effectiveness in avoiding severe outcomes for these patients.

The planning for the change in delivery of these drugs, from the dedicated Covid Medicine Delivery Units (CMDU's) to Integrated Care Boards (ICB's), has been ongoing since we first raised it, in December of 2022. In March 2023 it was announced by NHS England that responsibility would pass to ICB's on 27th June. In mid-June patients were individually made aware of this change by email from NHSE, but no details were provided on the system being put in place.

We now find ourselves in the position that with only a few days to go until this change is implemented, most ICB's have still not confirmed or published plans as to what the system will be in their areas and what process patients will be required to go through in order to be able to access COVID-19 treatments.

We have spoken to ICB's across the country, and we are deeply concerned that some ICB's are still unaware of this change and many others have not been able to publish details of their plans. We know many frontline GP's and clinicians are totally unaware of this change in access too. This leaves the most vulnerable patients in the position of not knowing who to turn to, in order to receive time-critical and essential medication. This leaves them exposed to the dangers of COVID-19, made all the more worse when many in this group have little or no protection from vaccinations, especially as the current Spring Booster Vaccination Programme has had such a low uptake, in part due to issues we have previously raised around poor communications.

Patient groups have repeatedly raised the issue regarding the changeover and planning and made it clear that there needs to be a coherent working system in place before the switch to the new system occurs. This system must ensure that there is provision for 24 hours access, in place before the changeover is implemented, and that no patients are put into a position of inequality of care due to their location. Despite continually raising our concerns with those carrying out the planning, implementation, and communication of this, we now find that we are in exactly the position we warned against. The failure to effectively manage this migration to the new system in a seamless manner will result in patients being placed at potentially high risk, along with the accompanying anxiety this will cause for those that contract COVID-19 and are unable to easily access the drugs in the time sensitive period required.

We have made concerted efforts to communicate our concerns and attempts to clarify the situations with both NHSE and ICB's. Despite these efforts, as charities and patient groups supporting the most vulnerable, we will be left in the position on Tuesday 27th June of having no timely information to be able to pass on to those most in need. This situation undermines our ability to care and advise our patients at times of their most need.

We therefore urge you to look into this situation as a matter of urgency. Without a swift resolution many high-risk patients may be unable to access the drugs that are provided as part of the much-heralded safety net by your government, placing them at undue risk. The situation cannot be allowed to continue and needs to be resolved and communicated to ensure the quality of care for these 2 million patients continues without any interruption.

We are asking you to provide reassurance that fail-safes are in place in case individual ICB's are not adequately prepared on Tuesday 27th June or to consider postponing the transition of responsibility to ICB's and maintain the current CMDU's until we can be given much needed reassurance that the ICB's have systems and protocols in place.

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

Signed for and on behalf of: -

Forgotten Lives UK - Prof Martin Eve, Nikola Brigden, Mark Oakley

Action for Pulmonary Fibrosis - Louise Wright, CEO

Immunodeficiency UK - Dr Susan Walsh, CEO

Blood Cancer UK - Helen Rowntree, Chief Executive

LUPUS UK - Debbie Kinsey, Health Information Officer

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

Kidney Care UK - Fiona Loud, Director of Policy

National Kidney Federation - Andrea Brown, Chief Executive

National Rheumatoid Arthritis Society (NRAS) - Claire Jacklin, Chief Executive

Anthony Nolan - Yasmin Sheikh, Head of Policy and Public Affairs

Leukaemia Care - Zack Pemberton-Whiteley, CEO

Cardiothoracic Transplant Patient Group, NHS Blood and Transplant - Robbie Burns, Chair

Shine Cancer Support - Ceinwen Giles, Co-CEO

Myaware - Sarah Cuthell, CEO

Sarcoidosis UK - Leo Cassimo, Senior Executive

Vasculitis UK - Dorothy Ireland, Chair

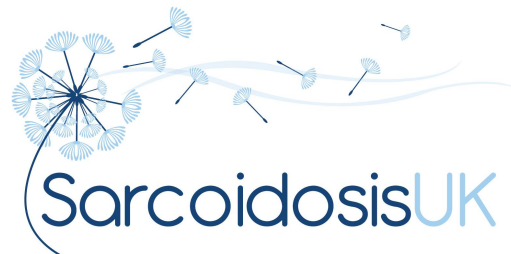
Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) Sue Farrington, Co-Chair of and CEO of Scleroderma and Raynaud's UK (SRUK)

British Liver Trust - Pamela Healy OBE, Chief Executive

UK PIPS - Sue Dimmock, Trustee

Leukaemia UK - Fiona Hazel, CEO





Leukaemia^{UK}

Please could you urgently reply to nikolabrigden@icloud.com, hilary.webb@bloodcancer.org.uk, policy@bloodcancer.org.uk and by post to:

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