

Dear Member

There are now almost 1500 of you registered with MDS UK, which means you are part of the largest support group for MDS in the UK. Many thanks for your continued readership, membership, and invaluable support.

We hope most of you had a reasonably good Christmas and start to the New Year. We heard that some people have had difficult times, so please know we are here for you, and the entire MDS community is thinking of you in support. If you do need support but are not online, please remember you can always call us on our Helpline on **02077337558**

We don't have an email address for you, so if you are now online and have an email address, please send your details to our Membership Officer on this email membership@mdspatientsupport.org.uk

Since the beginning of Covid-19 pandemic we have produced a monthly newsletter which is e-mailed to members, and I have printed some extracts of the last three months' issues for you to have a look over.

We are also scheduling many online 'virtual' meetings with speakers, using a platform called Zoom. This has proven very popular with members and can be accessed even via a standard smart phone or tablet. We have many 'beginners' at every meeting. These meetings provide patient to patient contact and the latest advice and information. We would love for you to join us.

Once again if you have an email address - or perhaps a family member does - we can include you on this list.

In terms of the COVID-19 risks – please take very good care, as the new Omicron variant is even more contagious than previous Covid-19 mutations.

As the government has now decided to lift all COVID restrictions – it is even more important for MDS patients and other vulnerable people to maintain all the usual precautions - social distancing, hand washing, wearing of masks, avoiding any crowds or visitors with any cold symptoms.

Please see the latest important Covid instructions on the back of this letter – and follow them to increase your protection. We are aware that not all MDS patients have received this information from the NHS – so please keep this letter carefully – and show it to your GP if necessary.

We are working to resolve issues with the NHS to ensure all patients receive all necessary official letters.

Please note: as Lateral Flow Tests may not remain free of charge after the 1st April 2022 – we recommend you and your family to order extra packs now.

Best wishes,

Caroline Mc Govern – Office Manager
Chaudian Morgan – Membership Officer
Sophie Wintrich – CEO

Covid Vaccines and Covid Treatments – 21st February 2022 status

Some MDS patients have had problems getting access to their fourth dose of the covid vaccine and may not have been made aware of the four new COVID treatments available to MDS patients, both of which they are entitled to. This is the result of the NHS Digital having omitted to include several types of blood cancers, and due to the overwhelming pressure of work at many GP surgeries. Some of you will have received all the relevant information, but for those who have not, here are some tips put together by fellow MDS patients who had missed out on information from NHS centrally, or their GP.

All MDS patients are urged to ensure that they receive their 4th vaccine, and that they are aware of the priority COVID treatments and how to obtain them if they develop COVID symptoms.

4th Dose of COVID Vaccine

MDS patients should receive a 1st, 2nd, and 3rd 'Primary' dose, and then a 4th dose (the 'Booster') at least 91 days after the 3rd Primary dose. Experience of many of our members has found that, at some GP surgeries, MDS patients have had their 3rd dose recorded as a 'booster' in error - which has then led to them not being invited back for their 4th dose (their real 'booster').

If that has happened to you:

- Contact your GP surgery and ask for your 4th dose of the covid vaccine.
- If necessary, remind your GP surgery that an MDS diagnosis puts you in the highly vulnerable group (with MDS being a rare condition, the Admin Staff at GP surgeries can often not be aware of this).
- You can also get your 4th dose at a Walk-In Centre, but you may need a letter from your consultant.
- Contact your MDS clinical care team (via your specialist hospital nurse or Consultant's office) if you haven't already had a letter which states that you needed a 3rd Primary dose / 4th Booster dose.

Access to Urgent Treatments Should You Catch Covid

All MDS patients are also entitled to be assessed to receive one of four different covid treatments, two of which are given intravenously on a day-visit to a local hospital, and two which are dispensed in tablet form. These medicines are called *Sotrovimab*, *Paxlovid*, *Remdesivir* and *Molnupiravir*.

These drug treatments must be started within 5 days of symptoms starting – so speedy access is crucial.

Priority PCR Test Kits are available to MDS patients to have on 'stand-by' at home to help speed up the process. If you haven't already been sent one then you should telephone the NHS 119, see below.

Do this straightaway, and don't wait until you develop symptoms, the idea is to have one on hand at home in case you need one. These priority PCR test kits are labelled differently to ordinary PCR test kits, so that when they are received at the laboratory and they are confirmed as positive for COVID, you are 'flagged' for priority access to the treatments through what is known as a CMDU (Covid Medicines Delivery Unit).

- **Dial 119** (be prepared to have to make up to 7 or 8 'option' choices). You need to speak with someone about PCR tests, to obtain a '**Priority PCR Test Kit.**' You may need to be gently persistent and ask to be put through to the **Elective Care Team**. They will be able to take your details and send you the Priority Kit.
- If you develop covid symptoms use this Priority PCR Kit and send it off URGENTLY.
- It is not absolutely necessary to use the Priority PCR Kit if you haven't received one. It is also now possible to use an LFT (Lateral Flow Test) but if you do, **it is important that you register the result by phoning 119** (or if you are able, online at <https://www.gov.uk/report-covid19-result>).

Because of the urgency required in receiving these treatments if you catch covid, it is also recommended that if you test positive on a Lateral Flow Test at home, or through a PCR test that you have sent away, you should also contact your hospital MDS care team as soon as possible to advise them, as they may also be able to arrange for you to receive one of the urgent treatments.

This 'belt & braces' approach is recommended, to reduce the risk of any delay in receiving one of the treatments. **Remember that the COVID treatments must be started within 5 days of symptoms appearing.**