




BSBMTCT REGISTRY NEWSLETTER

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Welcome to our first BSBMTCT Registry Newsletter  The Registry Team will be sending quarterly newsletters to keep our centres updated on up and coming events and what's happening within the Registry. We are always here to help and support

The BSBMTCT Registry Team pictured opposite from left to right Clementina Abamba, Rachel Pearce, Julia Lee, Ruth Paul and Marie Wilson

We have a **NEW PRESIDENT** **Professor John Snowden** is a Consultant Haematologist & Director of BMT at Sheffield Teaching Hospital and will remain our President until end of December 2022



INDUCTION MANUAL DEVELOPMENT

- Due to Covid 19 restrictions, funding and other difficulties the Registry have decided to focus on an Induction Manual which be available to BMT staff along with our DM Training days
- Incorporated will be a multitude of online learning modules covering many areas involved in BMT
- The Registry Team are busy writing these modules and working through ideas
- We will be in touch with our "Focus Group" from our centres who volunteered to help and attended our previous meeting
- If your centre wishes to contribute their own items/resources we welcome your ideas

A reminder the deadline for the **12th Commissioners Report** for Registrations and follow up between **2014 to 2019** data is **1st April 2021**

PATIENT CONSENT remains essential. Any transplants where patients have **NOT** given consent for their data to be used must be sent to BSBMTCT. There are specific procedures in place for these patients; centres **MUST NOT** enter this data to remain GDPR compliant. Thank you!

Please use your **NHS.NET** secure email which is **GDPR** compliant to send patient data to our generic email gst-tr.bsbmtregistry@nhs.net

The BSBMTCT have updated their **COVID guidelines** please use the links below [BSBMTCT recommendations for COVID Adults](#) and [BSBMTCT SARS-CoV-2 Vaccination Statement](#)

All BSBMTCT COVID guidelines can be found here:
[BSBMTCT and COVID](#)

The BSBMTCT paper on NICE COVID 19 guidelines has now been published online: [NICE COVID19 Guidelines paper](#)

Follow us on
Twitter:
@BSBMTCT
Look at our **website**
for future events:
bsbmtct.org

Another **DATA MANAGER TRAINING DAY** will hopefully take place around September, time and resources allowing. This year an all virtual event is planned and will remain **Free of Charge** as in previous years. Included will be the soft launch of our Induction Manual for BMT staff. Please send us your ideas and let us know if you would like to give a presentation on our generic email:

gst-tr.bsbmtregistry@nhs.net

**DATA
MANAGER
SURVEY 2019** is
in the process of
being written up
and should be
published later
this year

Please register and use the **DM Discussion Board** on our website. As well as chat and advice from colleagues there is also a contact list of all our centre DMs:

<https://bsbmtct.org/data-managers/>

The BSBMTCT CTC committee is still very much active, and we plan to hold the next CTC meeting in April 2021. We will be discussing retrospective study and survey updates as well as asking for new proposals.

- **CTCR 19-01 PET FL Study** – This study is now closed data is being sent for analysis
- **CTCR 20-01 AN cryopreservation study** – will be closing this month
- **CTCS 20-01 UK Physicians Perspectives on Palliative Care** – This survey has been circulated and a response gathered. A presentation of the findings will be presented at the BSBMTCT CTC meeting in April.
- **CTCR 19-02 PD1/PDL1 Inhibitors in Hodgkin's Lymphoma** – This study should be starting in March

The Asymptomatic staff survey, which was circulated last year, has now been published in BJHaem [SARS-CoV-2 screening for asymptomatic health care workers in UK stem cell transplant units](#)

If you have a **SHARED PATIENT** with another centre, HSCT and follow up are happening at different centres and your centre needs access to their record contact BSBMTCT and we can do this for you

In June 2020 Julia Lee (Registry Head) sent a **FAILED DONATIONS PROFORMA** form to all our Allo centres. This refers to the donating donor contracting a confirmed diagnosis of COVID 19 thus rendering the donation unusable. Data collection, which is for all **RELATED DONORS ONLY**, has been extended until April. Please complete the proforma for all related donations, not just failed ones.

Anthony Nolan is collecting information on unrelated donors

We still offer support for **HLA data entry**
Please send it securely to gst-tr.bsbmtregistry@nhs.net

Global Registration Identifier for Donors (GRID) is now being used in the UK and Europe wide. There is a field being added into ProMISe for this information when entering donor information for **ALLO TRANSPLANTS**. We will let you know when this has been implemented. For those wanting to know more about the GRID please see the link to the WMDA website which gives a helpful guide:
<https://wmda.info/professionals/optimising-search-match-connect/why-global-identifier/>

Under new EBMT Registry rules, both the HSCT and Cellular Therapies such as CAR-T must both be followed up individually, and not just the last treatment.
This is because the data collected will be different for each treatment.

Please remember the **EBMT FOLLOW UP GUIDELINES** and submit follow ups:

- Every year if the patient was transplanted less than 10 years ago
- Every 2 years if the patient was transplanted 10 - 20 years ago
- Every 5 years if the patient was transplanted more than 20 years ago

EBMT UPDATE

- **EBMT BENCHMARKING REPORTS**
 - ❖ These are available please contact: benchmarking@ebmt.org
- **EBMT VIRTUAL ANNUAL MEETING 2021**
 - ❖ The Early bird registration offer will now remain in place as of this year so no price increase.
 - ❖ There are free DM places for member centres (check the website)
 - ❖ The DM day this year is on Wednesday 17th March 2021
 - ❖ Last year's congress was a great success so do have a look at this year's schedule.
- **MACRO**
 - ❖ Unfortunately there are still some issues with the MACRO database and the EBMT team are working hard to resolve these.
 - ❖ A launch date is still to be confirmed
 - ❖ Training/refresher training will be available nearer the time from EBMT
- **ProMISe**
 - ❖ The helpdesk is always available for any ProMISe technical issues
registryhelpdesk@ebmt.org
 - ❖ Please notify EBMT if one of your patients contracts Covid-19:
<https://www.ebmt.org/ebmt/news/prospective-survey-impact-covid-19-stem-cell-transplant-recipients-and-patients-treated>

Thank you for reading I hope you found it interesting
Look out for Issue 2 in the Spring