

Breadcrumb

1. Home

Entity Print

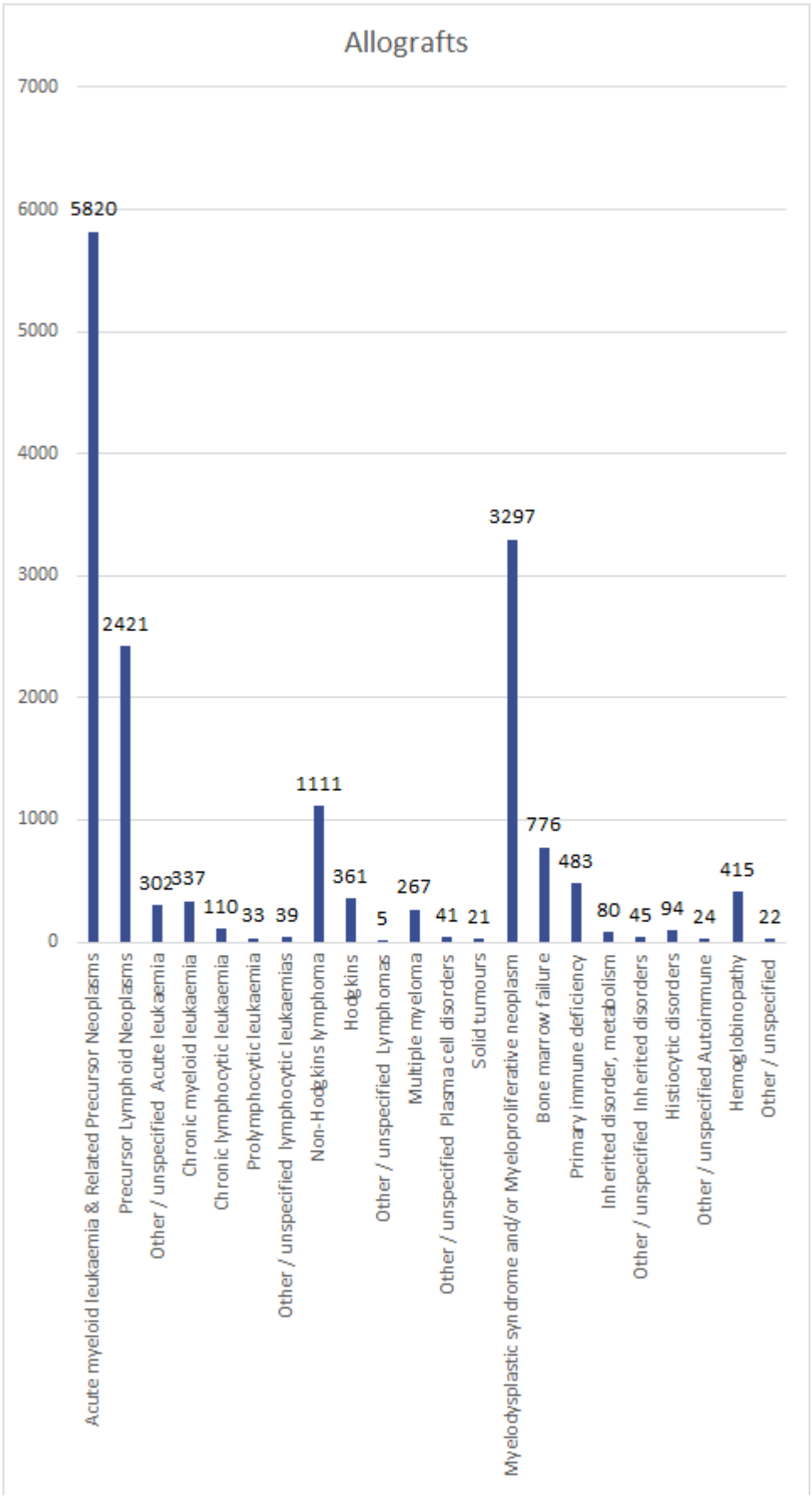


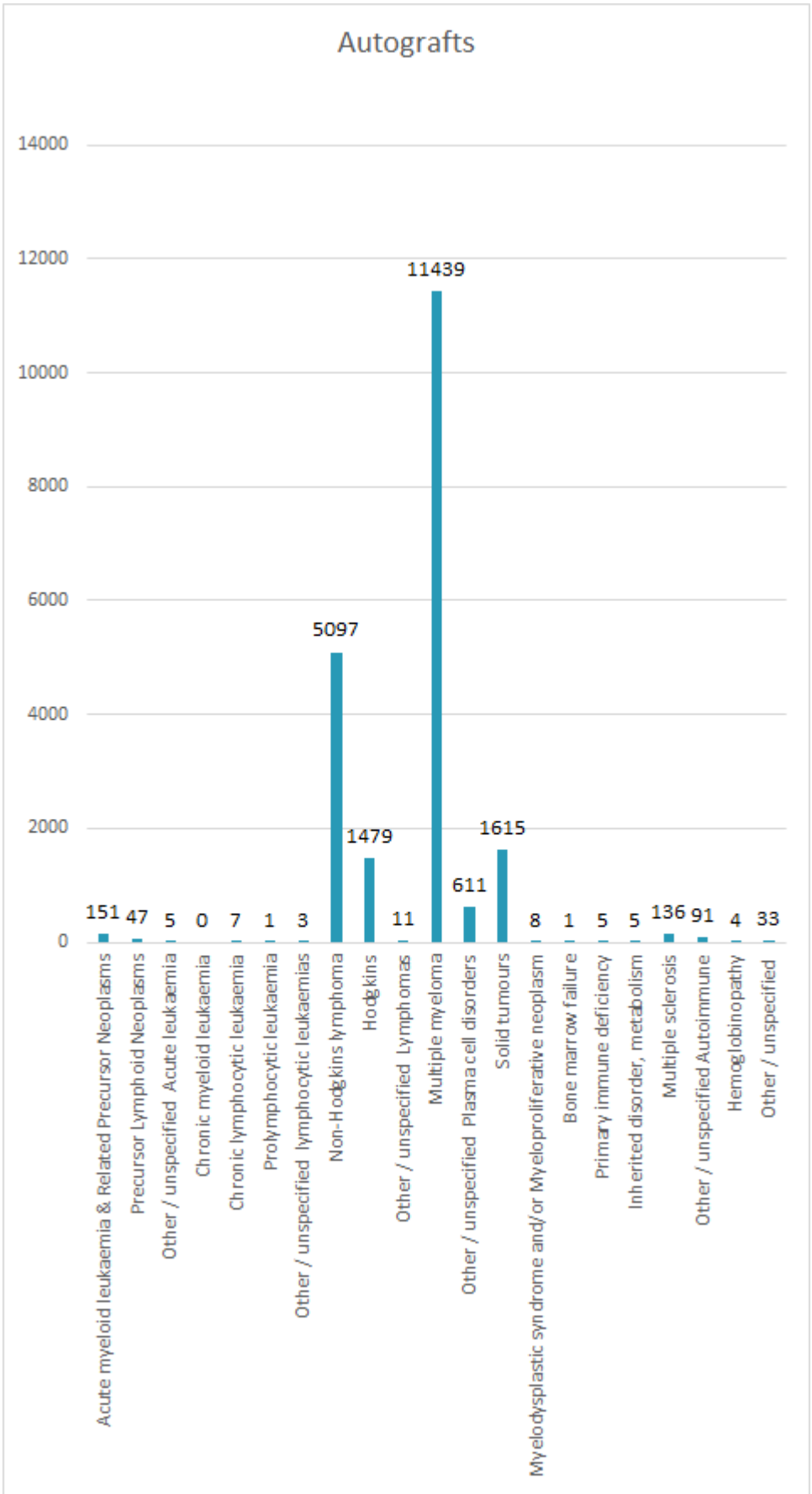
Bas Middelkoop
Registry Director
Netherlands

New Registrations for HSCT in 2020

By the end of 2020, the entire Registry included at least 740,000 transplant registrations in total. New registrations during 2020 were around 10% lower than the previous year. We include the charts below. A probable reason for this is the impact of Covid 19.

16105 allografts and 20758 autografts were registered during 2020. Note that these numbers also include some transplants performed during earlier years.


Allografts
7000
6000
5000
4000
3000
2000
1000
0
5820
2421
302
337
110
33
39
1111
361
5
267
41
21
3297
776
483
80
45
94
24
415
22
Acute myeloid leukaemia & Related Precursor Neoplasms
Precursor Lymphoid Neoplasms
Other / unspecified Acute leukaemia
Chronic myeloid leukaemia
Chronic lymphocytic leukaemia
Prolymphocytic leukaemia
Other / unspecified lymphocytic leukaemias
Non-Hodgkins lymphoma
Hodgkins
Other / unspecified Lymphomas
Multiple myeloma
Other / unspecified Plasma cell disorders
Solid tumours
Myelodysplastic syndrome and/or Myeloproliferative neoplasm
Bone marrow failure
Primary immune deficiency
Inherited disorder, metabolism
Other / unspecified Inherited disorders
Histiocytic disorders
Other / unspecified Autoimmune
Hemoglobinopathy
Other / unspecified

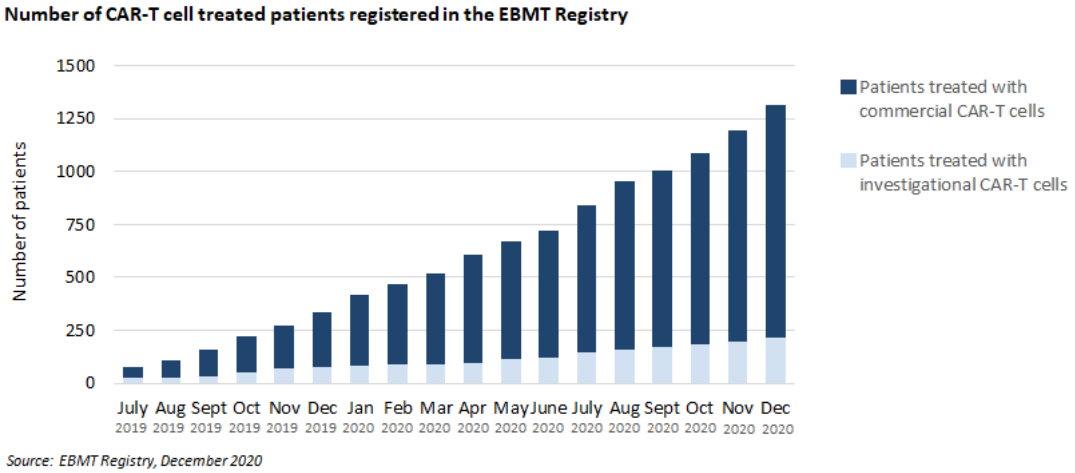


Graphs: Logarithmic scale

New Registrations for Cellular Therapy in 2020

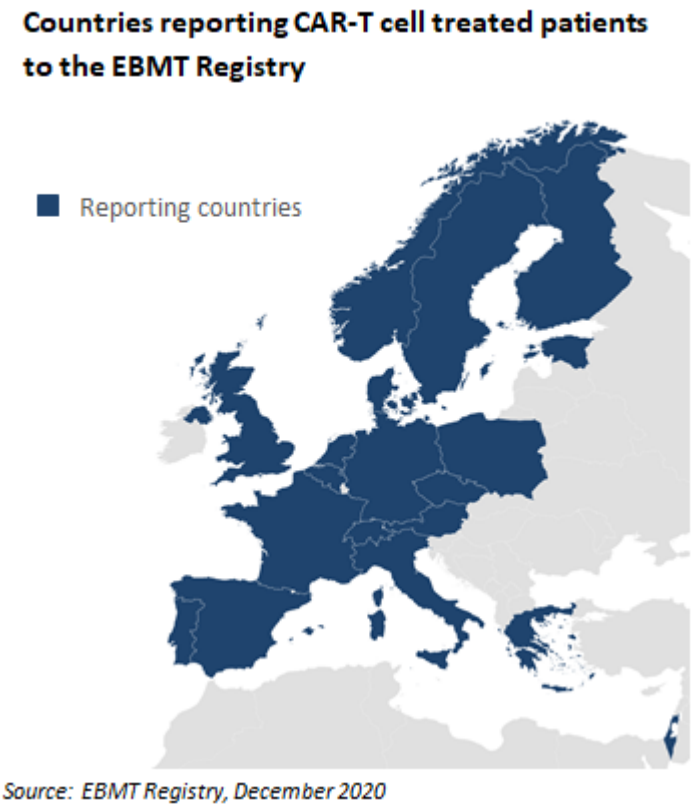
Through the network of our EBMT newsletter the Registy has actively encouraged centres to report on all cases involved in the treatment of patients using a CAR-T product whether commercial or investigational. The 1st graph below illustrates the steady growth of new reported cases into the EBMT Registry during 2020 and the reflected number of centres.

All centres should continue to complete the current Cell Therapy Form outlined in ProMISe on a timely basis to create an accurate patient representation.



Source: EBMT Registry, December 2020

The 2nd graph represents a geographical approach in blue of all our reporting countries who are continually submitting data to the EBMT Registry. We look forward to welcoming more countries in 2021 as the number of CAR-T products on the market steadily increase.



Source: EBMT Registry, December 2020

Registry Upgrade

The Registry upgrade project has faced several challenges during the course of 2020, and these caused a complete halt of the data migration mid-year. Due to the high priority of this project, a thorough analysis on behalf of the EBMT was carried out. Looking at several technical as well as functional issues, this has resulted in a comprehensive Test plan created by the vendor. Together with the vendor, an approach was defined in order to address all the identified issues, find solutions and build towards a strong foundation to continue the project as a whole.

Outcomes of these tests are expected in the Q1 of 2021, whereafter new Validation and Test plans will be developed by the Registry in order to complete the data migration.

Registry Resource

In 2020 the Registry has transitioned form the previous Head, Debra Gordon, to the new Registry Director, Bas Middelkoop, who joined the EBMT Registry in December 2020.

Due to the loss of two members of staff in 2020 the Registry has been looking to replace the two vacancies and succeeded. Two experienced Data Analysts will join the Registry IT department in Q1 of 2021. Also the Registry is looking to expand the team further in 2021, giving the Registry team more hands and expertise to face the challenges for the coming year.

Data Management Activities

Registry staff have been successfully carrying out the following activities during 2020:

1. Data entry, cleaning, retrieval, storage and destruction
2. Data security, backup and recovery
3. User management and data access
4. Data transfer, sharing and exchange
5. Data report running
6. Data management support to EBMT Members
7. Data transfer and data sharing

User Management

User Management has been a daily activity at the Registry in 2020. Approximately 300 Data Entry and Data Download User accounts were created and approximately 80 Data entry User accounts were deactivated by Registry staff in 2020.

Data Quality Activities

Registry staff have been successfully carrying out the following activities during 2020:

1. Registry database design, testing and validation
2. Data Collection Form (MedAB and Cellular Therapy) and Manual development/review/revision and management
3. Registry database User Guide development, review and revision
4. EBMT Registry website maintenance
5. Training and education
6. Support to EBMT members on data entry and other data management activities
7. Data Quality Report running and data cleaning management
8. Helpdesk support
9. Collaboration with and provision of services to JACIE and COG (Benchmarking)

Helpdesk

The Registry Helpdesk was the busiest it has ever been in 2020. Approximately 5,300 emails were sent by the Helpdesk to EBMT Members, EBMT staff, EBMT structures and third parties for EBMT Registry purposes in order to provide an effective helpdesk service. The abovementioned figure does not include single emails sent to multiple recipients in 2020 for Registry purposes.

Training

During 2020, online MACRO-related training was delivered on 8 separate occasions to a total of 357 EBMT members who were also issued with certificates. Feedback received for training provided by Registry staff during 2020 has been positive.

Educational Sessions

A total of 5 online Educational sessions were arranged by the EBMT Registry during 2020 and they attracted a total of 1,175 unique views. Feedback received for educational sessions arranged by Registry staff during 2020 has been positive.