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Memo

To: Network Medical Directors, Data Managers, CIBMTR staff

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RE: Data Collection to Establish Center Specific Dataset

Did you know that transplant centers can utilize the CIBMTR for the purposes of establishing a complete “Center Specific Dataset”? In some cases, centers may wish to provide data in excess of that requested by the CIBMTR to establish a dataset that has all patient records for their own purposes. Examples could include data on CRF forms for all patients, or data for autologous patients who did not provide consent for research to establish a complete record for the center. Mechanisms are now in place to facilitate data collection through FormsNet for these purposes!

The CIBMTR will maintain the “Center Specific Dataset” and provide the data back to the transplant center at its request for use by the transplant center. Mechanisms to return these data to centers have not yet been completed, but are being developed. Some examples of how this dataset may be used at the center include generation of internal reports for research, use for Quality Assurance/Quality initiatives, generation of summary reports to fulfill requests from insurance companies, etc. Unfortunately, at this time CIBMTR does not have a mechanism to accept data elements that are not currently collected on its data collection forms.

There will be no additional payment made by the NMDP or CIBMTR to transplant centers for submission of any Comprehensive Report Forms (CRF) other than those forms requested by the CIBMTR for its routine business or research operations. Transplant centers can choose what level of data they want the CIBMTR to collect on all their recipients. The choices include TED level data for autologous recipients, CRF level data for autologous, allogeneic- related and/or allogeneic- unrelated recipients. Before a transplant center can proceed with this option, a “Data Transmission Agreement” amendment must be in place.

Contact your liaison with the name of person to whom the DTA amendment should be sent for review and signature if your center is interested in establishing a complete center specific dataset.