



Jeffrey W. Chell, M.D.
Chief Executive Officer
National Marrow Donor Program
3001 Broadway Street Northeast
Suite 500
Minneapolis, MN 55413

March 23, 2007

Re: Effect of the HIPAA Privacy Rule on the disclosure of data by network centers to the
National Marrow Donor Program

Dear Dr. Chell:

The purpose of this letter is to provide guidance regarding whether the disclosure of certain data related to the C.W. Bill Young Cell Transplantation Program by network centers to the National Marrow Donor Program (NMDP) is compatible with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulation, "Standards for Privacy of Individually Identifiable Health Information" (Privacy Rule), 45 CFR Parts 160 and 164. This letter clarifies the requirements of the Privacy Rule as they pertain to the collection of individually identifiable health information from NMDP network centers.

The Privacy Rule, published in the *Federal Register* on December 28, 2000, provides comprehensive protection for the privacy of individually identifiable health information used or disclosed by a covered entity in any form. Various State privacy laws also exist. It is important to note that the Rule does not pre-empt State laws that are more stringent than the Federal requirements.

The Privacy Rule applies to health plans, health care clearinghouses, and health care providers that conduct certain financial and administrative transactions (e.g., billing and fund transfers) electronically. These are "covered entities" and as such must comply with the Privacy Rule's requirements. The Office of General Counsel, U.S. Department of Health and Human Services, has concluded that the NMDP is not a covered entity under the Privacy Rule.

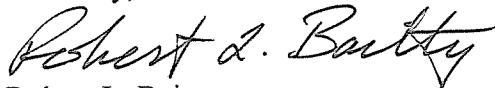
We understand there may be concern over the ability of network centers, some of which may fit the definition of covered entities and thus are subject to the Privacy Rule, to provide individually identifiable health information to the NMDP. If a network center does not fit the definition of a covered entity under the Privacy Rule, the network center is not subject to the Privacy Rule's requirements. If a network center fits the definition of a covered entity, the disclosure of certain individually identifiable health information to the NMDP is allowable under 45 CFR 164.512 (Privacy Rule), which allows for the disclosure of an individual's protected health information without the individual's written consent or authorization when such a

disclosure is made to a public health authority that is authorized by law to collect information for the purpose of preventing or controlling disease, injury, or disability.

The Office for Civil Rights (OCR), in consultation with the Office of the General Counsel, U.S. Department of Health and Human Services, has responsibility for enforcement and interpretation of the Privacy Rule. The Office of the General Counsel has determined, and OCR concurs, that the NMDP meets the Privacy Rule's definition of a public health authority and is authorized by law to collect the information necessary for the C.W. Bill Young Cell Transplantation Program to fulfill its statutory purpose and functions. Under this analysis, network centers that are covered entities may disclose to the NMDP the individually identifiable health information collected by the C.W. Bill Young Cell Transplantation Program in order for the NMDP to comply with the Program's statutory purposes.

Additional information on the Privacy Rule is available at <http://www.hhs.gov/ocr/hipaa/>. If you have any further questions on this issue, please contact me.

Cordially,

A handwritten signature in black ink that reads "Robert L. Baitty". The signature is written in a cursive style with a large, stylized initial 'R'.

Robert L. Baitty
Director, Blood Stem Cell Transplantation Program
Division of Transplantation