

Retracting an Agreement to Donate Bone Marrow: Background to the Discussion

ASSIA*

Bone marrow is a spongy tissue located in bones. The marrow in certain bones contains stem cells that produce blood cells. Various blood diseases, like leukemia, cause the production of too many blood cells, damaged blood cells, immature blood cells, or too few blood cells. This in turn interferes with the natural functioning of the body and its ability to heal itself. Radiation therapy and chemotherapy are aimed at the blood cells and the deviant stem cells. In cases requiring prolonged exposure to high levels of radiation and chemotherapy, other vital stem cells might be damaged or destroyed.

Since the first successful transplantation of bone marrow around fifty years ago, this procedure has become an option in treating patients who otherwise would not survive. In cases where the bone marrow cannot be harvested from the patient himself, a donor must be found. The donor, whether a family member or not, must have white blood cells compatible with those of the recipient. Otherwise, the recipient would reject the transplanted bone marrow.

Most modern countries have a central database of potential donors who have expressed their willingness

* Passages from A. Vainrot's article, "Retraction of an Agreement to Donate Bone Marrow," ASSIA 89-90, pp. 27-61, have been copied in this section. In addition, I have relied on M. Halperin, "Retraction of an Agreement to Donate Bone Marrow: Introduction to the Halachic Discussion," ASSIA 91-92, pp. 5-8; D. Even, "Contributed to her Death," <http://www.nrg.co.il/online/archive/ART/641/905.html>; A. Steinberg, "Organ Transplantation," *Enc. Hilchatit Refu'it* 3:82-84; the internet site www.cancer.org.il; the internet site www.bmdw.org; and further sources cited *infra*.

to donate. These potential donors have to provide a sample of saliva or blood. For example, the database of Ezer Mizion in Israel contains information on around 818,000 potential donors.¹ The NMDP (National Marrow Donor Program) database in the US

In Israel, according to the data supplied by Ezer Mizion, the refusal rate is around 2-3% contains information on around 25,000,000 potential donors.²

When a patient requires a transplantation of bone marrow, his closest relatives are checked for compatibility. At the same time various databases are searched for a donor. At this stage, potential donors are contacted and informed that they have the right to refuse to participate in the procedure. It must be pointed out that although the "World Marrow Donor Association" (WMDA) lists a refusal rate of 5.6% due to donor issues,³ in specific areas such as the UK, numbers were slightly higher.⁴

¹ Updated on 20 September 2016 - Ezer MiZion website.

² Updated on 20 September 2016 - NMDP website news release.

³ The following statistics were given by the World Marrow Donor Association (correspondence dated 24 May, 2012): "19527 donors were requested to donate hematopoietic stem cells. Some donations did not take place for patients' reasons and some for donor reasons. 2080 donors were deferred at the work-up stage. This is a median of 5.6% of those donations that were not cancelled because of patients' reasons. The donor reasons can be for personal ".donor reasons but also medical reason, this is not specified It should be noted that although these margins aren't very high – the statistic only includes a small percentage of society that agreed to join .the registry in the first place

⁴ According to information received from Anthony-Nolan (correspondence dated 21 May, 2012), approximately 18.7% are deleted at the extended typing stage (when contacted to donate bone-marrow), this statistic includes the following Reasons for donor deletion: No Trace 77 (26.5%); Personal 59 (20.3%); Emigrated 5 (1.7%); Medical 117 (40.2%); No Response 29 (10.0%); Deceased 4 (1.4%).

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After potential donors agree, a series of further tests are performed to assure the highest probability of success.

If and when a satisfactory donor is found, a supervising physician arranges a meeting between the donor and the recipient. The physician explains the procedure in detail and explains further that if the donor agrees to donate, he or she will be required to sign a written, irrevocable consent form. The physician explains to the donor that after signing the consent form, the patient will begin a course of radiotherapy and chemotherapy for the purpose of destroying his cancerous cells and suppressing his immune system so that the transplanted bone marrow will not be rejected. This procedure is irreversible. Once the patient has begun it, he must receive the bone marrow transplantation. Otherwise, he will die.

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After being so informed, the donor signs the consent form testifying that he or she has understood that once the procedure is begun the patient must receive the donor's bone marrow. The text of the consent form includes the following: "The patient will receive aggressive chemotherapy prior to the transplantation. This will destroy his bone marrow. Without receiving my bone marrow donation, the patient will die."⁶

The procedure for donating bone marrow has undergone significant change in the last few years. Originally, the bone marrow was collected from the donor's spine. This procedure was painful and somewhat dangerous.

Today, the procedure has been simplified. The donation can be taken from an artery in the donor's arm. For four days, the donor receives injections of Neupogen to encourage increased production of progenitor cells. These cells enter the blood stream, leading to symptoms similar to mild flu and muscle aches that can be treated with analgesics (as is explained to the donor).

After four days, a needle is inserted into a blood vein of the donor, the extracted blood passes through a special device which separates the "young" cells which were produced as a result of the Neupogen injections. These cells are collected in a plastic bag. The remaining blood is returned to the donor's body through a special needle inserted into another vein. This procedure does not require anesthesia and is not very painful. Nor are there any significant side effects.

The collection procedure for bone marrow takes a few hours and can be done seated or lying. The donor can eat, read or watch television. It constitutes no real danger and involves no significant loss of blood. Within twenty-four hours the donated cells are replaced by natural reproduction.

The collected cells are infused into the body of the recipient. When they reach the patient's bone marrow, they begin to produce healthy progenitor cells.⁷

The Crux of the Matter

Oranit Druckman, mother of two from the central region of Israel, recovered in the year 2000 from breast cancer. Three years later, she was diagnosed with myeloid leukemia. She was hospitalized in the Sheba Medical Center in Tel ha-Shomer. She responded well to a course of therapy to halt the spread of the cancer. Simultaneously, a bone marrow donor was sought. The search began with databases in Israel, as well as the BMDW (Bone Marrow Donors Worldwide) based in Leiden, Holland.

⁵ Oral communication from 14 May 2012.

⁶ "Donating Progenitor Cells – Information for the Donor," www.cancer.org.il; and B. Zisser, "More on Transplantation of Bone Marrow," www.doctors.co.il

⁷ M. Halperin, "Harvesting Organs from Living Donors," ASSIA 45-46, pp. 34-61; *Sefer ASSIA* 9:321-348; www.medethics.org.il/articles/ASSIA/ASSIA9/R0091321.asp

The search yielded excellent results. A 19 year-old female donor was located in the central region of Israel. A date was set for hospitalization. Oranit began pre-transplantation treatment to destroy her immune system entirely. She was hospitalized in an isolation ward prior to the transplantation.

She received a two-day course of intensive chemotherapy to reduce her progenitor cell count. In parallel, a representative went to the donor's home to give her her first injection of Neupogen. The patient and the donor were in separate locations in accord with standard international protocols.

Although successful in thousands of other cases, this project unfortunately failed. After the first injection, the donor experienced some symptoms at home. As a result, on the second day of preparation for the transplantation she retracted her agreement to donate and refused to continue with the procedure.

During the following twenty-four hours great pressure was exerted on her. In an unprecedented move, leading rabbis tried to convince her. All to no avail. Even promises of monetary compensation to the extent of supporting her for the rest of her life bore no fruit. She remained steadfast in her refusal to go through with the donation.

In an act of desperation, Oranit's daughter volunteered to donate her own bone marrow to her mother even though they had only partial compatibility. Transplantation of the daughter's bone marrow was unsuccessful. Oranit's destiny was sealed.

Efforts to explain to the donor that she was in effect killing the patient were of no effect. All that remained for Oranit and her family was to wait patiently for her death. They did not have to wait long.

On 8 January 2004 Oranit died as a result of the chemotherapy which suppressed her own bone marrow production. In the absence of any transplanted bone marrow cells, she could not survive.

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This very difficult situation deserves careful analysis because of its uniqueness and the possibility that such cases may occur again. Following this case, many questions arose regarding the conduct of all those involved in the procedure. The key issue is one of preventing a reoccurrence.

Our discussion revolves around the ethical, legal, and *halachic* dimensions of the refusal to donate. A. Weinroth, Esq., deals with the juristic aspects of the case. Rabbi Dr. M. Halperin has written a *halachic* introduction. A few weeks ago, Rabbi Moshe Sternbuch, head of the Rabbinic Court of the *Eida Chareidit* in Jerusalem, wrote a *halachic* decision. We have translated a synopsis of the articles and the full text of Rabbi Sternbuch's decision.