NATIONAL MARROW DONOR PROGRAM®

Creating Connections. Saving Lives.™

Now That You Have Donated

What to expect after marrow or blood stem cell donation

THANK YOU

On behalf of the National Marrow Donor Program NMDP , thank you for your gift of marrow or blood stem cells to help a patient in need. We deeply appreciate all the time and effort you have given as a donor. Our mission to extend and improve lives is successful due to dedicated donors like you.

About this booklet

This booklet offers information about what to expect after marrow or peripheral blood stem cell PBSC donation, in the following areas:

1. **Contact names and numbers**
2. **Special medical section:**
   Guidelines for recovery after donation
   - Marrow donors
   - PBSC donors
3. **Other important information**
   - Reminder about donor follow up
   - What to do if you receive a health care bill related to donation
   - Updates about your recipient
   - Communication and contact with your recipient
   - Requests for additional donations
   - NMDP donor advocacy program
   - Keep in touch

On the cover (clockwise from upper left):

Randy Y., donor, and Luke D., recipient;
Mary H., cord blood donor with her children;
Althea H., donor, and Patricia M., recipient.

CONTACT NAMES AND NUMBERS

If at any time you have questions or concerns, please contact your donor center representative

Donor center coordinator*: _____

Medical director: _____

After hours contact: _____

My donor ID number: ___ ___ ___ ___ ___ ___ ___ ___ ___

**You may also be advised to contact staff at the center where you donated*

Other contact names and numbers:

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GUIDELINES FOR RECOVERY AFTER DONATION

Call with questions or concerns

- Please call with any questions or concerns.
- We encourage you to contact medical staff at your donor center or collection center marrow donors or apheresis center PBSC donors since they are familiar with recovery after donation and can help coordinate any follow up care you may need.
- Please also follow any specific instructions given to you by the collection center or apheresis center.

See page 3 of this booklet for contact names and numbers.

MARROW DONORS

Possible symptoms or complications – marrow donors

It is normal to experience some pain, bruising and stiffness during the first week after donation. You may feel more tired than usual and run a low-grade fever the first week. Some clear or pink fluid drainage can be expected. It is common to experience hard, little lumps in the collection area these hard spots might take a few weeks to dissolve.

Symptoms that require medical attention

- Temperature of 100.5° Fahrenheit (38° Celsius) or higher.
- Increased redness, bleeding, swelling, drainage or pain at the collection site.
- Muscle weakness or severe headache within two weeks of donation.
- Pain more than 14 days after the donation.

Contact your donor center or collection center if you experience any of these symptoms.

In the event of a life threatening emergency, call 9-1-1 and/or take a copy of these instructions to the emergency room.

It is normal to experience some pain, bruising, and stiffness during the first week after donation.

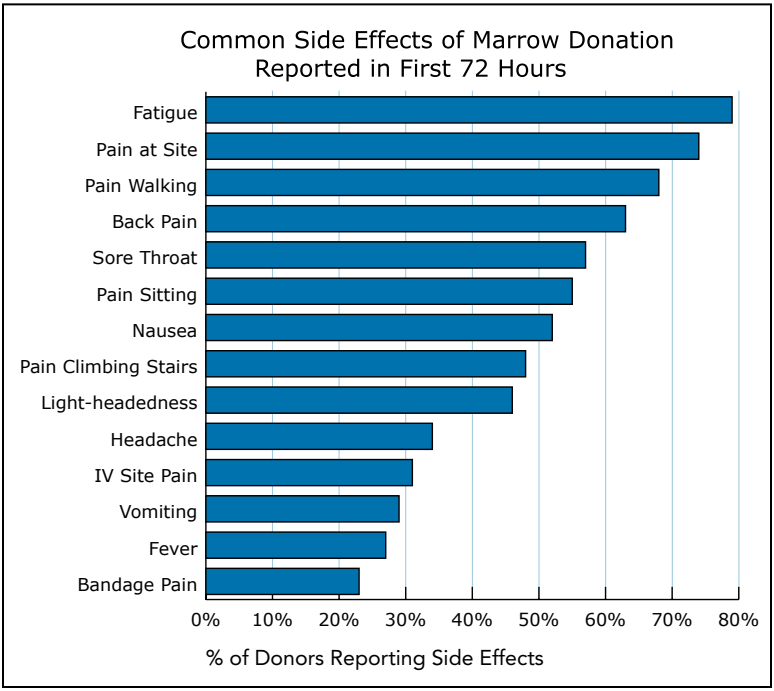
Use of pain medications – marrow donors

The soreness at the collection sites should go away in about one week. To help ease discomfort:

- Take pain medication as directed.*
- Do not use aspirin during the first week after the donation unless instructed to use aspirin by your doctor. Aspirin decreases the blood's ability to clot and increases the risk of bleeding. You may take acetaminophen or ibuprofen products such as Tylenol, Motrin or Advil.

* *Note: In most cases, donors are advised to take pain medications around the clock for the first 24 hours after donation.*

Expect the pain to decrease each day. Please call your donor center if the pain medication does not ease your discomfort, if your pain is getting worse instead of better, or if you require a refill of your pain medication prescription.



Care of collection site – marrow donors

- Check collection sites each day for bleeding or increasing redness.
- Keep the collection site dry the night after the procedure.
- If you have bandages: 24 hours after the surgery, you may remove the bandages and replace with an adhesive bandage. You may apply some antibacterial ointment before you cover the collection sites with an adhesive bandage. These sites need to be kept clean and covered for the following 3 days. Note: Showering before you remove the bandage and letting the warm water soak the bandage a bit will help the bandage peel off easier.
- If you have steri strips: do not remove the steri strips they will work themselves off within several days.
- Clear or pink fluid drainage is normal.
- Do not sit in water until the punctures are healed no baths or jacuzzi tubs). Take only showers for the first 2 to 3 days to decrease the risk of infection.
- Apply a clean adhesive bandage to the collection site daily after you shower. Blot the area dry with a towel but avoid rubbing.
- If bleeding occurs, apply firm pressure for 5 minutes, followed by an ice pack. If the bleeding does not stop after 10 minutes of constant, direct pressure, contact a medical professional as directed above.

Do not use aspirin during the first week after donation.

Physical activity recommendations and limitations – marrow donors

General recommendations

- Take several rest periods during the day. Keep your legs elevated whenever possible.
- Keep moving/walk regularly to prevent stiffness.
- If you feel lightheaded or dizzy when changing positions, be careful and scale back activities as needed.
- Carry a small pillow with you to improve your comfort when sitting.
- Get plenty of sleep.

Exercise recommendations

Through week one:

- Avoid heavy lifting, bending or exercise.
- Avoid lifting more than 10 lbs.
- Allow time between periods of heavy activity throughout the day.

Through week two:

- Avoid strenuous activity such as jogging.

Through week four:

- Avoid contact sports.

Work and school recommendations

- You should be able to return to work, school and any other activities within 1 to 7 days.
- If possible, work a half day upon returning to work, and increase your schedule as you are able.
- If your job involves physical labor or heavy lifting, more recovery time may be necessary.

Dietary recommendations – marrow donors

In general, your diet should:

- Be well balanced.
- Be high in iron rich foods such as green leafy vegetables and red meat.*
- Help replace the iron and red blood cells lost during donation, your doctor may want you to take iron supplements. Specific instructions will be given before you are discharged.
- Drink 8-10 glasses of water per day. Avoid alcohol and caffeine.

**Note: Vitamin C taken with iron-rich foods increases iron absorption.*

The median time to recovery for a marrow donation is 21 days.

PBSC DONORS

Possible symptoms or complications – PBSC donors

You may experience headaches, or bone or muscle aches for several days before collection. These are side effects of the filgrastim injections that you received to increase the number of blood stem cells in the bloodstream. These side effects disappear shortly after the collection. It is also common to experience some pain and bruising at the needle site.

Symptoms that require medical attention

- Increased redness, bleeding, swelling or pain at the needle site.
- Temperature of 100.5° Fahrenheit (38° Celsius) or higher.
- Muscle weakness, swollen lymph glands or severe headache within two weeks of donation.
- Severe skin rash or flare-up in pre-existing skin conditions such as psoriasis or eczema.
- Abdominal pain.
- Inflammation in the eyes.

Contact your donor center or apheresis center if you experience any of these symptoms.

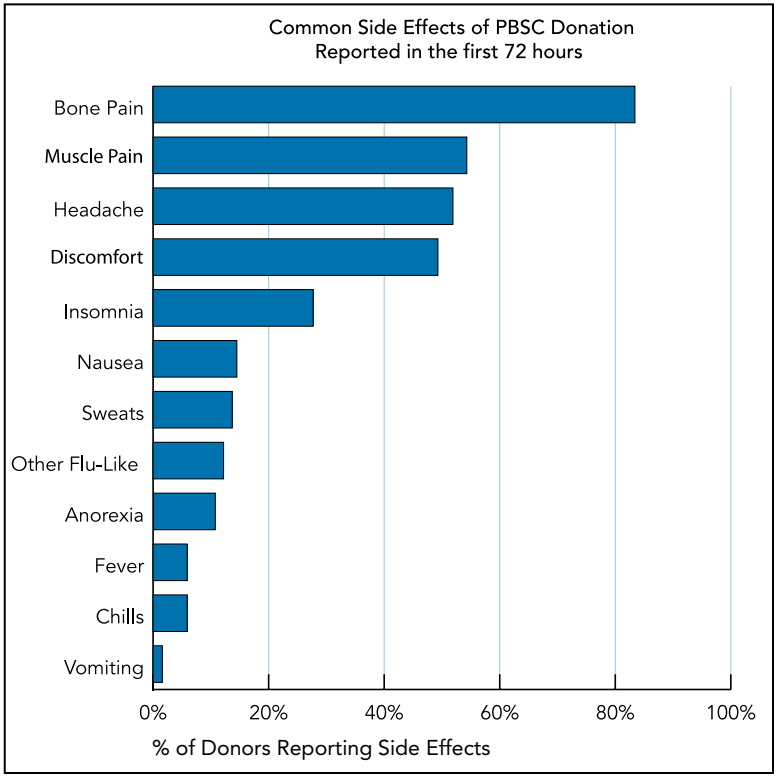
In the event of a life threatening emergency, call 9-1-1 and/or take a copy of these instructions to the Emergency Room.

It is common to experience some pain and bruising at the needle site

Use of pain medications – PBSC donors

- Use acetaminophen or ibuprofen products such as Tylenol, Motrin or Advil for minor pain.
- Do not use aspirin unless specifically instructed to use aspirin by your doctor. Aspirin decreases the blood's ability to clot and increases the risk of bleeding.

Use acetaminophen or ibuprofen products for minor pain; do not use aspirin.



Care of needle sites – PBSC donors

- If a central line was placed, you will receive a separate set of instructions .
- Keep the bandage on for at least four hours.
- If the needle site bleeds, apply firm pressure and raise your arm up straight into the air until bleeding stops usually five to 10 minutes .
- Cold washcloths or ice packs can be used to help reduce swelling, bruising, and bleeding at the needle site during the first 24 hours.*
- After the first 24 hours, use a warm moist washcloth or warm pack.

** Note: Do not leave cold pack on longer than 20 minutes at a time and do not reapply for at least an hour.*

Cold washcloths or ice packs can be used at the needle site during the first 24 hours.

Physical activity recommendations and limitations – PBSC donors

General recommendations

- Return to light activities within 60 to 90 minutes after donation, if you feel well enough.
- If you feel lightheaded or dizzy, lie down immediately. Raise your feet above your head by resting them on a cushion or chair.

Exercise recommendations

- Avoid strenuous activity for the rest of the day after donation.
- Do not perform any heavy lifting or pulling for 24 hours.

Work and school recommendations

- Wait 24 hours before operating heavy machinery, climbing ladders or working from heights.
- Wait 72 hours before piloting a plane or working as flight crew (it's OK to fly as a passenger).

Avoid strenuous activity on the day of donation.

Dietary recommendations – PBSC donors

- Have a snack before you leave the apheresis center and eat a well balanced meal the evening after your donation.
- Drink plenty of fluids (eight–10 glasses of water for next 24 hours.
- Do not drink alcoholic beverages for the next 24 hours.

The median time to recovery for a PBSC donation is six days.

OTHER IMPORTANT INFORMATION

Reminder about donor follow-up

The NMDP and your donor center staff care about your safety and want to know about your recovery. A staff person from your donor center will contact you on a regular basis after donation to ask you about your physical condition. It is important to report any and all symptoms you experience. You may also be asked to take part in follow up on a yearly basis. This may include giving a blood sample. Your participation in follow up contacts helps ensure safety for yourself and for future donors.

If at any time in the weeks, months, and years after donation you experience physical problems that might be related to the donation, be sure to contact your donor center as soon as possible.

Note: It is important that you report all of your symptoms even if you previously reported being fully recovered.

What to do if you receive a medical bill related to your donation

Sometimes by mistake, the collection center or apheresis center sends the donor a bill. This is a mistake and you are not expected to pay the bill.

If you receive a bill related to your donation, please do not set it aside, throw it away, or pay the bill. Instead, call your donor center coordinator for assistance. They will ask you for a copy of the bill. They will make sure the bill gets paid. **At no time should you have to pay out of your own pocket for medical expenses related to the donation process.**

Your donor center will make sure the bill gets paid.

Updates about your recipient

Your recipient's transplant center may provide up to three updates within the first year after transplant. Many transplant centers provide updates about the recipient's condition at or around these times:

- One month after transplant
- Six months after transplant
- One year after transplant

Your donor center will let you know if an update is available.

It is important to note that some transplant centers do not provide updates. Your donor center coordinator will let you know what you can expect. You should be prepared for the possibility that you might not receive updates on your recipient.

There is also the chance that you will receive unpleasant news about your recipient. Your recipient may suffer a setback or may not survive. We realize such news might be upsetting. Please feel free to contact staff at your donor center to discuss your reaction to news about your recipient.

Communication and contact with your recipient

The NMDP is committed to protect the confidentiality of both donors and recipients. It is the law to keep donor and patient information private.

The NMDP coordinates transplants around the world. In some regions, contact between donors and recipients is not allowed.

Many transplant centers provide updates about the recipient's condition. Others do not.

Guidelines for anonymous communication

During the first year after transplant, some transplant centers may allow you to send anonymous communication to your recipient. The communication is managed through both your donor center and the recipient's transplant center.

- Do not include any self identifying information such as your name, address, city/state or other contact information.
- It is best to keep communication brief. Avoid intense opinion or emotion. Remember, your recipient is working hard to recover from a serious illness.
- There is no guarantee that you will get a response.

Direct contact

Some centers may allow direct contact between donor and recipient one or more years after the transplant. Contact may occur only if both donor and recipient agree. Both donor and recipient must sign a consent form. The NMDP may be able to assist in the process.

Often, both donor and recipient want to communicate and possibly meet. Many donors have met their recipients and reported a good experience with this. Other donors had a more difficult time and reported sharing little in common with their recipient.

Sometimes, the recipient and/or donor choose not to have any personal contact. It is a highly personal decision. You should be prepared for the possibility that you might not learn your recipient's identity or have any contact with him or her.

Contact may occur only if policy allows and both donor and recipient agree.

Requests for additional donations

If your recipient suffers a setback after the transplant, he or she may need an additional donation. Your donor center coordinator will ask if you are willing to be contacted about making any additional donations.

If you agree to consider making an additional donation, the request might be for:

- Marrow
- PBSC
- White blood cells
- Platelets
- Whole blood

Before any additional donation, you would be evaluated again to make sure that donating would not pose any undue medical risk to you.

Eight percent of marrow and PBSC donors have given one or more additional donations for the same recipient. Side effects and recovery following a second donation appear to be very similar to those for the first donation.

It is important to remember that you have the right to say either yes or no to making an additional donation at any time.

Eight percent of donors have given additional donations for the same recipient.

Donor advocacy program

Your donor center can answer your questions and help with any issues you face. If you need further help, the NMDP Donor Advocacy Program is available.

The Donor Advocacy Program represents the interests, rights, needs and expectations of persons who are or may become volunteer marrow or blood cell donors through the NMDP.

The Donor Advocacy Program provides education and assistance to donors in the following areas:

- Information about the life, disability, and medical insurance coverage for donors
- Potential risks, side effects and complications related to the donation process
- Informed consent
- Financial assistance
- Donor recipient contact issues
- Paid donor leave
- Unusual circumstances
- Confidentiality
- Donor satisfaction/concerns about your experience as a donor

Contact the Donor Advocacy Program:

Call toll free **(800) 526-7809**
or send an e mail to **advocate@nmdp.org**

KEEP IN TOUCH

Let us know if you change your name, address, or telephone number. To do this you may:

- Call you donor center

  OR

- Call 1 (800) MARROW-2

  OR

- Visit www.marrow.org

Once again, thank you for being a donor.

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www.marrow.org

#P0464; 09/05