Donating Blood & Organs

with Myotonic Dystrophy

Myotonic Dystrophy
FOUNDATION

Thank You

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Myotonic Dystrophy FOUNDATION

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Donating Blood and Organs with Myotonic Dystrophy

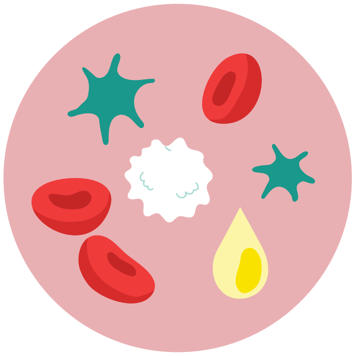
This resource provides an overview of both blood and organ donation in the United States, including what they are, who can donate, and other items to consider. Individuals outside of the United Sates should consult a health professional for questions about donating blood and organs. While many individuals with myotonic dystrophy (DM) may be eligible to donate, there could be specific medical reasons why their doctor might advise against it. It is important to have a thorough discussion with your clinical care team before making any decisions about donation.

Note: Myotonic dystrophy is a genetic condition;
it cannot be passed to someone through blood or organ donation.

Blood Donation

Types of Blood Donation

Several types of blood donation exist, including **whole blood**, **platelet**, and **plasma donation**.



Whole blood is the most flexible type of donation because it contains red blood cells, plasma, and platelets so it can be used in different ways (e.g., trauma patients, people undergoing surgery).

Platelets are small cells in the blood that help form clots to stop bleeding. Platelet donation is often used to help patients whose platelet counts are dangerously low or whose platelets don't work properly.

Plasma is part of the blood used to treat people in emergency and trauma who need replacement of clotting factors or blood proteins.[1]

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[1] "Types of Blood Donations." Donate Blood, Plasma or Platelets | Red Cross Blood. Accessed October 25, 2023. *https://www.redcrossblood.org/donate-blood/how-to-donate/types-of-blood-donations.html*.

Who Can Donate Whole Blood

Individuals living with myotonic dystrophy (DM), who are considering donating blood, should first consult their DM clinician to determine if it is safe for them to do so. They may ask their clinician, "Do you think it would be completely safe for me to donate blood?" Do NOT proceed unless the clinician's answer is "Yes".

Your clinician might tell you it is not safe to proceed with donation for several reasons:

- Your blood pressure runs low
- You have a problem with low heart rate or abnormal heart rhythm
- You may be too frail
- You may have anemia or another abnormal laboratory test result

In the United States, if your doctor has said it is safe for you to donate, you must still meet the American Red Cross's basic eligibility criteria for donating, as well as complete a health history screening. This screening will further assess your eligibility by asking questions about travel, medication, risk of contracting other diseases, etc. To learn about more specific donation requirements, you may visit the Red Cross's website[2]: ***www.redcrossblood.org/faq.html#eligibility***

Organ Donation

Living Organ Donation

Living organ donation occurs when a living individual donates a bodily organ, or a part of it, to transplant into another individual.

The following are some of the most common organs and tissues donated:

- One kidney
- A segment of the liver
- One lobe of the lung
- Part of the pancreas
- Part of the intestine
- Skin
- Bone
- Healthy cells from bone marrow and umbilical cord blood
- Amnion (the protective barrier of the fluid-filled sac that contains a fetus in the uterus)

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[2] Frequently Asked Questions | Red Cross Blood. Accessed October 25, 2023. ***https://www.redcrossblood.org/faq.html#eligibility***

Who Can Make a Live Organ Donation?

For individuals living with DM, consult your DM clinician as well as a doctor who specializes in living organ donation, before participating in living organ donation. Be sure to discuss the status of your health and wellbeing, as well as the risks of being under anesthesia, which most living organ donation requires. Give your doctor MDF's anesthesia guidelines before any operation (***www.myotonic.org/anesthesia***).[3]

If your doctor has said it is safe for you to donate, you must still meet other basic eligibility criteria for donating, which typically includes:

- Be at least age 18 or older (some transplant hospitals may require donors to be at least 21)
- Know the risks and benefits of living organ donation
- Make an informed decision that living organ donation is right for you

Things to consider before making a decision about donating:

Living organ donation involves being under general anesthesia, which could potentially have serious life-threatening complications for people living with DM. Learn more from MDF's ***"Practical Advice for Anesthesia for Individuals with Myotonic Dystrophy and Their Families" (www.myotonic.org/anesthesia-community)***.

- ▶ Recovery from surgery takes time, and donors may have to take off work and stop certain activities for a while. Some surgery recoveries are many months long.
- ▶ Living donors may not have to pay for any medical expenses if the organ recipient's medical insurance covers them.
- ▶ Living donors may face lost wages from being out of work, or experience additional costs for childcare or other expenses, depending on their situation.
- ▶ While US federal law prevents health insurers from discriminating against living donors, some living donors can encounter issues with other types of state-regulated insurance, such as life insurance. Donor teams may be able to help provide assistance in appeal processes.[4]

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[3] Practical Suggestions for the Anesthetic Management of a Myotonic Dystrophy Patient. ***www.myotonic.org/anesthesia***

[4] Getting and Keeping Insurance After Living Donation. ***https://www.livingdonortoolkit.com/financial-toolkit/getting-and-keeping-insurance-after-living-donation***

Where to Make a Live Organ Donation?

If you are considering donating an organ to someone you know in need of an organ transplant, talk with them about "living directed donation" and contact the transplant program where the recipient is registered. If you would like to donate to someone you do not know through what is called a "living non-directed donor," you can reach out to transplant hospitals to learn more about their donation programs.

Procedure

If you decide you would like to donate an organ and your DM clinical care team has determined donating is safe for you, the hospital transplant team will take additional measures to make sure living organ donation is the right fit for you, including:

- Give you a full physical examination and additional medical tests
- Ask about your medical history and your social support system
- Assess your mental health
- Ask about your finances and whether you can take time off from your commitments
- Inform you about the risks and benefits of living organ donation
- Make sure that your decision to donate is yours alone

Donating After Death: The Stanford Biobank

The Stanford Biobank is a collection of biological samples (such as blood, muscle, skin biopsies, spinal fluid, and other clinical specimens) from donors with neuromuscular conditions such as myotonic dystrophy. Samples can be collected with your consent during routine clinic visits, during scheduled surgical procedures, or after death with your family's consent. The Biobank organizers then store these samples so that they can be shared with scientists throughout the world for research. These samples are tremendously valuable for determining how neuromuscular conditions affect the body, which will help develop meaningful treatments.

Through local and national outreach events, such as the MDF's conferences, the Stanford myotonic dystrophy research program has enrolled more than 450 individuals with myotonic dystrophy to their Recruitment Database for upcoming studies and trials, and more than 50 to the Biobank to potentially donate tissues in the future with family consent. In addition, the Biobank has collected more than 4,000 specimens obtained during clinic visits, medical procedures, or surgeries from people with neuromuscular conditions (about half of which are from individuals with myotonic dystrophy). More than 300 samples have been shared with researchers across the world, aiding in the understanding of myotonic dystrophy and other neuromuscular conditions.

HOW CAN YOU REACH THE STANFORD BIOBANK TO LEARN MORE?

They would be happy to mail you their Information and Enrollment Package, or you can find it on their website. Feel free to call them to ask any questions!

Email:
stanfordbiobank@lists.stanford.edu

Phone:
(650) 497-9807 (Biobank)
(650) 723-9574 (Lab)

Mail:
Dr. John Day's laboratory
1201 Welch Road,
MSLS Building Room P254
Stanford, CA 94305

Website:
med.stanford.edu/day-lab/biobank

Fax:
(650) 736-6603

The mission of the Myotonic Dystrophy Foundation is Community, Care, and a Cure.

We support and connect the myotonic dystrophy **community**.
We provide resources and advocate for **care**.
We accelerate research toward treatments and a **cure**.

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