



Plain Marrow Donor Registry

Be a Child's Cure



Clinic for  
Special Children®

# *Join our* **Plain Marrow Donor Registry!**

The Clinic for Special Children has launched a new service to match patients with severe immune or blood disorders with potential marrow donors. Patients and donors who share a similar genetic heritage are more likely to be a match than people who are unrelated. For this reason, we created the **Plain Marrow Donor Registry**, our own registry of potential donors to serve the Plain community specifically.

Our laboratory team developed a test to quickly screen potential donors for patients with immune disorders or blood conditions (like elliptocytosis) at no-cost to either the patient or potential donor. Read on to learn more about our Plain Marrow Donor registry and how you could be a child's cure.



## **About the Clinic**

Since our founding in 1989, the Clinic for Special Children has endeavored to bring compassionate clinical care to children and adults with complex medical disorders.

While the Clinic's focus is the treatment and research of disorders identified in Old Order Amish and Mennonite communities, the impact of the Clinic's clinical and research work has been felt all over the world. The Clinic is envisioned as a comprehensive medical practice for patients, meaning they can see physicians knowledgeable about their disorder for all their medical needs.

The Clinic provides high-quality, affordable, and accessible care to those who need it most, children and adults with rare genetic disorders and complex medical needs.

# Immune disorders in the Plain communities

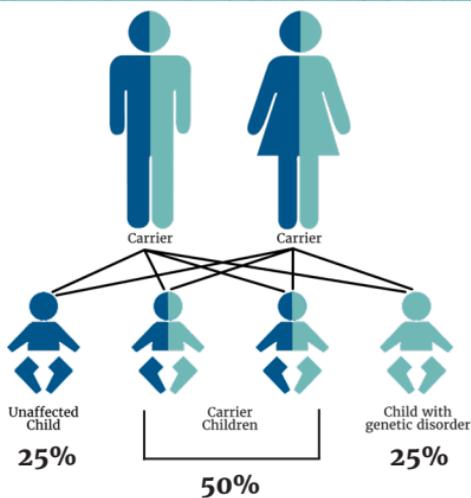
All of us have an immune system that protects us from infection. The immune system keeps viruses, bacteria, and other germs from making us sick while also helping us recover from illness. No one's immune system is 100% protective all the time, but some people may have a primary immune disorder that results in an immune system that is always weak or one that wrongly attacks the body's own tissues instead of protecting them.

The signs and symptoms of immune disorders can differ even among people with the same condition and may change over a person's lifetime. In all cases, though, the immune system is not working like it should.



Primary immune disorders have a genetic cause, so they can run in families. There are several genes that direct the production of many different parts of the immune system. In most cases, immune disorders are *recessive*, meaning that children who have an immune deficiency are born to healthy carrier parents; this follows the same pattern for other genetic conditions like Maple Syrup Urine Disease (MSUD).

When both parents are carriers for the same genetic condition, each one of their children has a 25% chance (1 in 4 chance) of being affected with that condition (*see diagram below*).



# Genetic causes of immune disorders in Plain communities

Amish	Mennonite
ADA deficiency	RAG1-associated immune disorder
RAG1-associated severe combined immune deficiency (SCID)	RAG2-associated immune disorder
CHH (cartilage hair hypoplasia)	Properdin deficiency <i>(which affects only males)</i>
CFI deficiency	IL7R-associated SCID

Some immune disorders can be managed with medications or vaccine boosters. When the condition is life-threatening and very serious, like severe combined immune deficiency (SCID), the immune system needs to be rebuilt through a transplant of healthy cells. Since bone marrow or stem cell transplantation is the most effective when done early in life, all babies are screened for SCID through the newborn heel-prick test. Those babies with positive newborn screening are immediately referred to a center for additional diagnostic testing and prompt management that can literally make the difference between life or death. That evaluation can determine if a bone marrow or stem cell transplant is necessary.



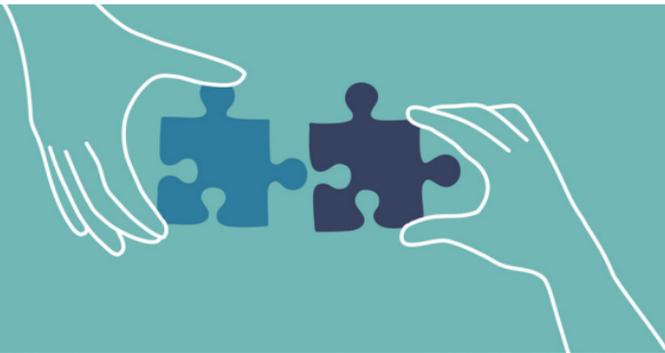
# Bone marrow & stem cell transplantation

## **What is bone marrow? What are stem cells?**

Bone marrow is a soft tissue inside your bones where blood stem cells are found. Blood stem cells create the white blood cells that respond to infection and illness, and which do not function properly in a person with an immune disorder.

## **What is the best treatment for severe immune disorders?**

The best treatment for people with severe immune disorders is to rebuild the person's immune system through transplantation of either bone marrow or blood stem cells, which can be safely taken from another person (a donor).



## Finding a matching donor

A patient with an immune disorder cannot receive bone marrow or blood stem cells from just anyone. Instead, they need the right “match” in a set of genes called the human leukocyte antigens (or HLA complex). The HLA help your immune system recognize which cells are part of your body (“self”) and which are invaders that need to be destroyed (“other”).

The better the match with the transplant donor, the less likely the recipient's body is to reject the transplant or for the donor cells to attack the recipient. The genes of the HLA complex are completely separate from the genes associated with immune disorders, so if you are a match, it does not mean that you are a carrier for the condition being treated or have any immune problems.

**Flip to the back of this brochure to learn more about how to join our registry - you might be a match for a patient in need!**



## Next Steps

**Joining our registry is fast, easy, and free!**

**We recommend participation by ALL Plain adults (18 years or older).**

Participating in the registry does not mean you agree to be a donor. Even if you are not eligible or do not plan to donate marrow or stem cells, your genetic information may be useful in tracking down potential matches if other members of your family join the registry as well.

**To join the registry we need a blood sample from you unless you have already had or will have genetic testing with the Clinic.**

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### **If you've never ordered a test at the Clinic**

Please contact us at 717-687-9407 or email us at [queries@ClinicforSpecialChildren.org](mailto:queries@ClinicforSpecialChildren.org) for more information on how to submit a sample.

### **If you already had genetic testing at the Clinic**

If we already have your sample on file from a previous genetic test at the Clinic, we only need a signed consent form to add you to our registry. In some cases, samples older than five years old may not work and we would need to get a new one. If so, you'll need a simple blood draw, which can be done at the Clinic or by your local healthcare provider.

### **If you're currently ordering a genetic test at the Clinic**

If you are currently doing other genetic testing at the Clinic, the same sample can be used for this registry.



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