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Income tax receipts are issued for donations of \$20 or more or upon request. We do not disclose or sell our donor names. The Aplastic Anemia and Myelodysplasia Association of Canada is committed to protecting your privacy. All information collected, used and/or disclosed is done so in accordance with our Privacy Policy, a copy of which is available to you upon request.

Credit card information that is collected is used only in payment approval and processing.

Charitable Registration No. 87557 2265 RR0001

Thank you for your support!

About the Association

In 1987, the concerned parent of a child with aplastic anemia founded the Aplastic Anemia Family Association of Ontario. One of the very first goals of the Association was to advocate for the formation of a national bone marrow donor registry in Canada. Today, the Aplastic Anemia and Myelodysplasia Association of Canada is a federally incorporated and registered national charity with the ambitious goal of providing a seamless support network for every Canadian patient, family member, friend and concerned healthcare provider dealing with aplastic anemia, myelodysplasia or PNH.

Led by a volunteer board of directors and a distinguished team of medical advisors from across Canada, the Association has a number of provincial chapters. The Association relies heavily on the generosity of individual donors and volunteers, including chapter coordinators, to provide an array of essential programs and services.

Programs & Services

- Telephone and e-mail peer-to-peer support
- Educational material
- Quarterly newsletter
- Local support group meetings
- Conferences
- Grants for medical research and education
- Promotion of Canadian Blood Services programs and the Unrelated Bone Marrow Donor Registry by encouraging people to donate blood and join the registry

You Are Not Alone

There are unique challenges associated with having a rare or uncommon disease. The Aplastic Anemia and Myelodysplasia Association of Canada can help guide you through the maze of unfamiliar terminology, keep you abreast of the latest treatment options, and help you adapt to the chronic health concerns and lifestyle changes and challenges that can follow diagnosis.

If you or someone you know has aplastic anemia, myelodysplasia or PNH, contact the Aplastic Anemia and Myelodysplasia Association of Canada. Volunteers with personal experience with these diseases can provide valuable guidance and support during these times of need.

For more information, contact:



**Aplastic Anemia
&
Myelodysplasia**
ASSOCIATION OF CANADA

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Understanding

Aplastic Anemia, Myelodysplasia & PNH

Education

Support

Research



**Aplastic Anemia
&
Myelodysplasia**
ASSOCIATION OF CANADA

1-888-840-0039
www.aamac.ca

What Are Aplastic Anemia, Myelodysplasia and Paroxysmal Nocturnal Hemoglobinuria?

Aplastic anemia is a rare but extremely serious disorder that results when the bone marrow fails to produce blood cells. It may be acquired or inherited.

Myelodysplasia or myelodysplastic syndrome (MDS) is similar to aplastic anemia in that production of mature blood cells is decreased; however, those blood cells that are produced in myelodysplasia may be immature or may not function properly.

Paroxysmal nocturnal hemoglobinuria (PNH) is caused by a mutation of the stem cells in the marrow. These mutated stem cells produce defective platelets that can form dangerous clots in the body and defective red blood cells which break down easily because they lack the protective proteins necessary for the cells' survival.

People with aplastic anemia, MDS or PNH may go on to develop other bone marrow diseases, or suffer from more than one of the diseases at the same time. Certain MDS patients, though not all, are at risk for developing leukemia. Aplastic anemia patients who do not receive a bone marrow transplant may later develop either MDS or PNH.

How Does Normal Bone Marrow Function?

The central portion of the bones is filled with a spongy red tissue called bone marrow. The marrow produces the cells of the blood: red cells that carry oxygen from the lungs to all areas of the body, white cells that fight infection by attacking and destroying germs, and platelets that control bleeding by forming blood clots in areas of injury. Continuous production of blood cells is necessary all through life because each cell eventually dies. Healthy bone marrow replaces cells as needed, increasing production of red cells and platelets when bleeding occurs and white cells when infection threatens.

Who Is at Risk for Bone Marrow Failure Disease?

Aplastic anemia is a rare disease. In North America, it is estimated that there are 2 to 4 new cases per million population per year. PNH is believed to be ten times less common than aplastic anemia. There are approximately 1500 new cases of MDS in Canada per year. It is more likely to affect those over the age of 60, and is rare in younger people.

Anyone can develop one of these diseases. While the cause is not always known, some people develop bone marrow failure diseases after exposure to radiation, toxic chemicals (such as solvents), or environmental toxins (such as certain pesticides); others may have experienced an adverse reaction to a medication or virus. However, millions of people with exposure to the same factors do not develop a bone marrow failure disease.

How Are Aplastic Anemia, Myelodysplasia and PNH Treated?

There is no "one size fits all" answer when it comes to treatment. Each person's unique situation must be considered. People dealing with one of these bone marrow failure diseases should seek out the professional advice of a specialist such as a hematologist or oncologist, particularly one who has experience treating these rare disorders.

One cure for these diseases is a bone marrow transplant. In a transplant, the patient's own defective marrow is destroyed and replaced with healthy cells from either a related or unrelated donor. A transplant is a significant undertaking and is not an option for those without a matching donor. Also, in some cases a person's health or age may preclude them from undergoing the transplant.

Inadequate blood production can be supplemented temporarily with blood transfusions or marrow-stimulating drug therapies. While transfusions may temporarily manage symptoms and improve quality

of life, they are not without their own risks. Patients may develop antibodies or experience allergic reactions to the blood. Repeated transfusions can also cause a condition called iron overload because of the iron in the donor blood. This must be treated using iron chelation to ensure internal organs are not damaged from the excess iron build-up.

Infection may also be a great danger to those patients whose marrow is failing to produce adequate white blood cells. Broad-spectrum antibiotics are often used liberally in such patients.

Drugs that suppress the body's immune system may be helpful for some patients. The important thing for a patient diagnosed with bone marrow failure disease to know is that there is a great deal of research being conducted in this area and that there are promising new and improved treatment options being developed for the diseases. The Aplastic Anemia and Myelodysplasia Association of Canada supports research to better understand bone marrow failure diseases, to increase the treatment options available, and ultimately to find a cure.

How You Can Help People with Bone Marrow Failure Diseases

- Give generously to the Aplastic Anemia and Myelodysplasia Association of Canada so that it may continue to fund research, share information, and provide support.
- Volunteer with the Aplastic Anemia and Myelodysplasia Association of Canada.
- Give blood or platelets regularly. Call Canadian Blood Services at 1-888-2-DONATE to arrange a donation time.
- Join the Unrelated Bone Marrow Donor Registry. Call Canadian Blood Services at 1-888-2-DONATE or visit www.blood.ca for more information.

I Would Like More Information

Please send me an information package on:

- Aplastic Anemia
- PNH
- Myelodysplasia
- Children's Resources

I would like to:

- Join your mailing list
- Find out about volunteer opportunities
- Get information on including AAMAC as part of a will, life insurance, or other planned gift instrument

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Please mail your completed form to the address on the back panel of this brochure.

This brochure provides a general introduction to aplastic anemia, myelodysplasia, paroxysmal nocturnal hemoglobinuria, the function of normal bone marrow, and the Association. Research into bone marrow failure diseases is an area of rapid change. Patients should ensure that their information is up-to-date and complete.

Contact the Association for a detailed, current information package on any of the diseases and to join the Association's mailing list to receive our newsletter.