

Dear Patients/Caregivers

We are writing to tell you about an exciting new initiative involving a partnership between the Aplastic Anemia and Myelodysplasia Association of Canada (AAMAC) and a group of Canadian Myelodysplastic Syndromes clinician-researchers based at The Ottawa Hospital Research Institute and Sunnybrook Research Institute.

The direction for medical research is usually set with little to no input from you - the people living with the condition, your caregivers and treatment teams. This results in research that may not address your most pressing needs.

To make sure your voice is heard, we have teamed up with a group of clinician researchers to form the **Canadian MDS Priority Setting Partnership** with the goal of deciding the **Top 10 research priorities for MDS research in Canada**. As your advocates, AAMAC and its partners will work to make sure that future MDS research will address these priorities to improve all aspects of your care.

In order to make this a reality, we need your help. The Canadian MDS Priority Setting Partnership has created a website and survey to gather your input on questions about any aspect of MDS that have been unanswered throughout your or your loved one's journey with this condition. Input from your friends and family who have been touched by your diagnosis with MDS as well as your treating physician, nurse and pharmacist is valued and encouraged.

The survey is accessible in English at www.ohri.ca/mdspriorities and in French at www.irho.ca/prioritesmd . Once you have completed the survey, we ask that you help us spread the message by ***sharing it with your network through email, social media or word of mouth*** so that more Canadians affected MDS can have their say in future research. You can continue to be involved in later stages of this project by clicking on the "Get Involved" tab on the website.

Thank you and we look forward to working with you on shaping the future of MDS.

Sincerely,

AAMAC Medical Advisory Board