



MDS UK
Supporting Patients with
Bone Marrow Failure



What is MDS?

The MyeloDysplastic syndromes (MDS) are a family of similar diseases that share many common characteristics and affect tens of thousands of individuals worldwide. This number reflects only those patients who are properly diagnosed. These disorders are a primary disease of the bone marrow and share several characteristics of the acute leukemias; however, MDS far exceeds any of the leukemias in prevalence. We are seeing many more cases each year and that number will increase greatly over the next decade as the baby boomers age and diagnosis improves.

MDS are a group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells. MDS is often referred to as a “bone marrow failure disorder”. It is described as a malignant condition – meaning it counts as a type of blood cancer. MDS is primarily a disease of the elderly – most patients are over 65 years old.

Failure of the bone marrow to produce mature healthy cells is a gradual process, and therefore MDS is not necessarily a terminal disease. Some patients do succumb to the direct effects of the disease: reduced blood cell and/or platelet counts may be accompanied by the loss of the body’s ability to fight infections and control bleeding. In addition, for roughly 30% of the patients diagnosed with high-risk MDS, and 10% with low-risk MDS, this type of bone marrow failure syndrome will progress to acute myeloid leukaemia.

The primary cause of these disorders is unknown; however, the chemotherapy regimens that are utilized to provide curative therapy to patients with certain malignancies (lymphomas, testicular cancer, and breast cancer) can lead to the development of secondary MDS.

Treatment of MDS depends on a patient’s symptoms, disease stage, disease risk category, age and pre-existing conditions. Several treatment options are available, however, not all options are appropriate for every MDS patient.

In younger patients a bone marrow transplantation may be considered since this is the only curative treatment currently available for MDS.

Who Are We?

The Myelodysplastic Syndromes Foundation, Inc., was established in 1994 by an international group of physicians and researchers to provide education about MDS to physicians and patients, support for MDS research, patient support and advocacy.

During the past decade, the Foundation has independently solicited funding for ten international symposia that have been attended by over 7,000 individuals — physicians and patients. These symposia are held biannually and have greatly improved our knowledge of these disorders and continue to provide physicians worldwide with the most up-to-date information on research in MDS. The 10th International Symposium was held in Patras, Greece May 6-9, 2009. The 11th International Symposium took place in Edinburgh, Scotland, May 18-21, 2011. The 12th International Symposium is happening in Berlin in May 2013.

At the Third International MDS meeting, attended by epidemiologists, pediatricians (yes: this does occur in children), pathologists, hematologists, oncologists, and bone marrow transplantation experts, a survey indicated a very strong interest in, and a great need for, developing a permanent working group of scientists and patient advocates. Up until that time, no formal working group was devoted to these syndromes. The MDS Foundation was born.

MDS UK Patient Support Group was first supported by the MDS Foundation in 2008, to provide a dedicated support network for UK MDS patients and their families. MDS UK is now an independent patient advocacy group, providing assistance, support and information to patients in the UK and taking part in lobbying and awareness work on behalf of the MDS community in the UK – and now also in Ireland.

What do the support groups do?

The Foundation works to maintain an international information network to share new research and new treatment options as rapidly as possible, to provide information and educational support for both physicians and patients, and, ultimately, to provide funding and oversight for international studies of MDS.

Currently the Foundation supplies patients, physicians, and other interested parties with information in the form of a quarterly newsletter, *The MDS News*.

MDS UK Patient Support Group works similarly – but dedicated to the UK. We issue a twice yearly newsletter and the website is www.mdspatientsupport.org.uk. We maintain assistance via our telephone helpline weekdays during office hours. We are based at the London MDS Centre of Excellence - King's College Hospital.

The Centers of Excellence Program designates institutions that meet the highest standards for diagnosis, treatment, and patient care. These Centers form the referral base for patients seeking first or second opinions and/or additional treatment options from experts in MDS.

Patient Advocacy groups are being formed worldwide and information is available that assists MDS patients and their loved ones to understand these diseases and the treatment options that are available.

How Can You Help?

Funding for both the Foundation and MDS UK comes from pharmaceutical companies, memberships, memorials, legacies and donations from private individuals as well as corporations. Funding is the base for realising our awareness, support, research and education goals.

In 2012, we are starting an important “Assessment for Support” project, to clearly define what areas of care and patient support still need to be addressed amongst families affected by MDS.

This is a three year project – for which we have secured funds for the first year only.

Your donation will also ensure we can pursue the project in year 2 and 3.

Both MDS UK and The MDS Foundation are publicly supported not for profit organizations.

MDS UK is dedicated to assisting patients in the UK, and The MDS Foundation is the international umbrella organisation.

Online donations can be received via the website:

MDS UK Patient Support Group www.mdspatientsupport.org.uk via the Virgin Giving link

Cheques – please make out cheques to:

MDS UK Patient Support Group

For events:

Please set up your fundraising page via Virgin Money Giving for any special event you organise for our benefit.

How Can We Help You?

Please do not hesitate to contact us if you have any questions.



MDS Foundation

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