



The MDS Alliance

2024 ANNUAL REPORT





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1. Who we are

1.1. Mission & Objectives

The **MDS Alliance** is an international umbrella organisation that aims to ensure patients with Myelodysplastic Syndromes (MDS) have access to the best multiprofessional care, regardless of where they live. Representing more than 40 patient advocacy groups around the world, we campaign and collaborate to amplify the voice of smaller organisations and help patients and health professionals to establish new patient support groups where they do not exist.

Our shared voice as a group with a common cause places us in a unique position to offer support via education, resources and knowledge of MDS globally.

To achieve this, the MDS Alliance's mission is based on three pillars:

- Information & Resources
- Guidance & Advice
- Representation & Advocacy



Information & Resources

The MDS Alliance provides its members, patients and healthcare teams with the resources and the latest information about MDS and its various forms. This includes current treatment options, international projects and events of interest to the whole community



Guidance & Advice

The MDS Alliance shares best practices and skills amongst its membership and provides a forum for advice and guidance on a wide range of issues affecting patients suffering from MDS, such as cost effectiveness of medicines and treatments, fertility issues and more.



Representation & Advocacy

To ensure a lasting and sustainable difference, there needs to be a strong voice for all MDS patients worldwide - and the MDS Alliance strives to be this voice. It does so in three ways:

Firstly, the MDS Alliance seeks to give smaller organisations a stronger voice, and to help patients and healthcare professionals set up new self-help groups where none exist.

Secondly, the MDS Alliance drives meaningful and substantiated change through evidence-based advocacy. Through its biennial global patient survey, the organisation aims to better understand the issues faced by people with MDS and use this understanding to make evidence-based decisions on how to improve quality of life and access to care for these patients worldwide.

And thirdly, the MDS Alliance raises awareness of MDS and informs patients and the public, provides key information on MDS to general practitioners and other healthcare professionals, but also addresses relevant stakeholders in health policy, research and healthcare. To this end, the MDS Alliance and its member groups around the world join hands on 25th October to organise and support MDS World Awareness Day, plus blood cancer in general, during the month of September.

1.2. The MDS Alliance Steering Committee

The **Steering Committee** plays a pivotal role in shaping the direction of the MDS Alliance. It remains responsible for providing strategic guidance, content recommendations, and expert opinions across all aspects of the Alliance's work. The committee convenes monthly to share insights from its advocacy efforts and experiences in the field of MDS, while actively supporting member organisations with innovative ideas and solutions for resources and programmes. Project-specific working groups have been formed to ensure high-quality and timely delivery of initiatives that address patient needs.

Since 2023, the Steering Committee follows a flat structure without a chair to ensure an even spread of responsibilities between the members. The past year also saw changes in the committee's composition and the Alliance welcomed Debbie Hickman, from MDS UK, as a new member, bringing fresh perspectives to the group.

The working groups have successfully planned and delivered several projects throughout the year. Their success within the MDS Alliance is driven by the diverse skills, knowledge, and interests of their members. By leveraging individual expertise, the groups have been able to design and implement impactful projects that effectively address the unique needs of the MDS community.

1.3. The MDS Alliance Members

More than 40 patient groups from over 30 countries supporting MDS patients, their carers and families locally are united under the umbrella of the MDS Alliance.



1.4. The MDS Alliance Secretariat

The legal and financial operations for the MDS Alliance in 2024 were managed by the European Patient Advocacy Institute (EPAI). Secretariat and project management services were provided by EPAI, with these tasks being executed by Patvocates. Patvocates also played a critical role in guiding the strategic planning and execution of MDSA's initiatives, alongside handling the organisation's communication efforts.

2. Projects in 2024

In 2024, the MDS Alliance continued to advance its mission through a variety of impactful initiatives. Among these, the **MDS Global Survey** played a crucial role in gathering data to inform actions aimed at improving the lives of MDS patients worldwide. The MDS Alliance also launched an **awareness campaign** for Blood Cancer Awareness Month and MDS World Awareness Day, emphasizing the vital role of patient organisations in supporting individuals throughout their journey.

A significant milestone was the **face-to-face global meeting** held in Frankfurt, which aimed to strengthen the capabilities of patient advocates and foster deeper connections within the MDS community. Alongside these efforts, the Alliance maintained its digital presence, engaging with the MDS community through **social media, newsletters, and email communications**.

Furthermore, the MDS Alliance actively represented the interests of MDS patients at key international events, including the EHA conference in Madrid, in June. The MDS Alliance also maintained its collaboration with other umbrella and patient organisations, reinforcing its broad responsibilities and unwavering commitment to improving outcomes for MDS patients worldwide.

The projects for 2024 are presented in a brief and concise manner below.

2.1. Global MDS Patient Survey:

Design and launch of the Global MDS Patient Survey

Every two years, the MDS Alliance conducts a global patient survey to better understand the challenges faced by individuals living with Myelodysplastic Syndromes (MDS) and their loved ones.

The data gathered informs evidence-based decisions for key stakeholders, supporting efforts to improve the quality of life and access to care for MDS patients worldwide. The survey provides insights into critical areas such as quality of life, access to care, and mental health across different countries. The first part of the survey comprises the data collection.

The survey was conducted from the 30th of September 2024 until the end of January 2025. Two tailored questionnaires, one for patients and one for caregivers, were available, each taking approximately 20-30 minutes to complete.

To ensure broad participation, the questionnaire was translated into 11 languages, and MDS Alliance members were encouraged to promote it within their communities. Distribution has been carried out primarily via social media, newsletters, and internal communications within member organisations.

The second part of the survey will be conducted in 2025 and will analyse the results and compile a comprehensive report, including 5 country reports detailing data for countries with sample size over 100 responses.

This survey is conducted in collaboration with Picker Institute, an independent specialist research organization based in the United Kingdom.



The global MDS survey is now live

2.2. Members meeting

The 2024 Global MDSA Members meeting was held in Frankfurt from October 24th to 26th, marking a significant milestone for the MDS Alliance. The event brought together representatives from nine member organisations across nine countries, delegates from three pharmaceutical companies, and the majority of the MDSA Steering Committee.

This was the **first face-to-face global meeting** since the organisation's creation in 2012. The meeting also marked a major milestone, as the organisation changes its footing from being an informal network to becoming a legal entity, registered in the Netherlands.



Key discussions and outcomes of the event included:

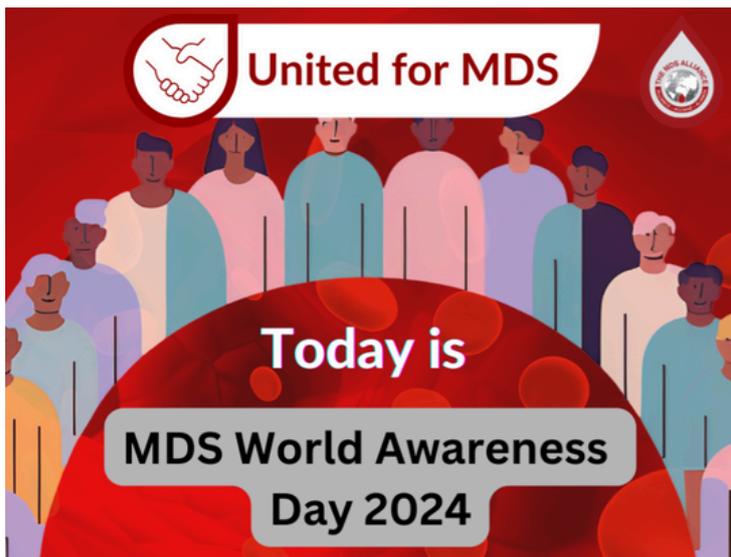
- **Addressing Inconsistencies in Care and Unmet Needs**
 - o Identified the need for improved diagnosis, treatment, and patient outcomes.
 - o Highlighted the importance of better psychological, financial, and cultural support for patients.
- **Enhancing Patient Empowerment**
 - o Emphasis on developing accessible, high-quality resources and communication channels.
 - o Advocated for the inclusion of patient voices in research, treatment, and policy-making.
- **Fostering Productive Collaborations**
 - o Focused on strengthening ties between patient advocates, pharmaceutical companies, and public health organisations to enhance clinical trial access and transparency.
 - o Pharmaceutical representatives reaffirmed their commitment to patient-centered communication.
- **Promoting Evidence-Based Data Creation**
 - o The biennial Global Patient Survey continues to establish the MDS Alliance as a leader in evidence-based research.
 - o Plans to publish findings from the 2024 survey in medical journals within the next year.
- **Knowledge Creation and Dissemination**
 - o Development of a new, user-friendly MDSA website to address existing gaps and improve engagement with stakeholders.
- **Expanding the MDS Alliance Network**
 - o A focus on increasing representation, particularly in Asia and Africa, with short-term plans to establish regional networks for tailored local outreach.
- **Formalising the MDS Alliance's Legal Identity**
 - o Transitioning from reliance on registered organisations to becoming an independent legal foundation in the Netherlands, a change unanimously approved.

The meeting reinforced MDS Alliance's commitment to advancing global collaboration, empowering patients, and enhancing care for those affected by MDS.

2.3. Awareness Campaign

The MDS Alliance designed and implemented an impactful awareness campaign that was run during **Blood Cancer Awareness Month** (BCAM) in September and **MDS World Awareness Day** (MDS WAD) on October 25th. This initiative aimed to raise awareness of Myelodysplastic Syndromes (MDS), a rare blood cancer. This year's campaign emphasized the critical role of patient organisations in supporting patients and their families throughout their journey.

Under the theme "United for MDS", the campaign highlighted the invaluable contributions of these organisations, which provide not only emotional and practical support but also essential information and advocacy to help patients access clinical trials and cutting-edge therapies. The campaign amplified global awareness of MDS and reinforced the importance of collaboration in improving patient outcomes.



#MDSWAD2024

#United4MDS

#ThinkMDS

Campaign Objectives and Target Audiences

The campaign targeted three key groups—patients, healthcare professionals (HCPs), and the general public—with tailored strategies to:

- Patients: Cover key points on why patient organisations should be considered as part of their journey for support and resources. Also, to educate patients on recognising MDS symptoms, diagnosis and treatment options, and self-management of the disease.
- HCPs: Educate healthcare professionals HCPs about MDS patient organisations and how they can offer complementary but crucial support for the patient experience and care.
- The general public: Inform the general public about MDS, the importance of MDS patient organisations and how to help MDS patients with resources and information.

Social Media Campaign:

- Created **27 tailored posts** (11 for BCAM and 16 for MDS WAD) on LinkedIn, Facebook, Instagram, and X (Twitter).
- Introduced **native video posts** to enhance engagement by leveraging platform-specific algorithms.
- Developed customizable **poster templates** for member organisations to personalize and share.
- Promoted hashtags like **#ThinkMDS**, **#United4MDS**, and **#ThisIsBloodCancer** to unify messaging.

Content Highlights:

- **Interviews** with MDS key opinion leaders highlighting HCP and patient organisation collaboration.
- **Testimonials** from patients and caregivers on overcoming challenges with the support of national patient organisations.
- **Informational posts** about the services offered by MDS Alliance members and MDS-related resources.

The structured campaign progressed weekly, moving from general awareness to detailed insights. A combination of videos, visuals, and written content ensured diverse engagement across all audience segments.

Find the full report for both campaigns [here](#).



What are patient organisations and what is their main role in supporting MDS Patients in view of your work as a HCP?



What advice would you give or say to your colleagues or other HCPs who may be less aware of the importance of patient organisations?



What questions do patients have and what do you say to help them understand how patient organisations impact their experience?



What are the biggest challenges patients need to overcome in their MDS journeys and how can patient organisations support them/be helpful?

2.4. Communications efforts

Monthly Newsletter

To ensure that all the members remain informed about the latest developments in the field of MDS, interesting events, and activities of the MDS Alliance and the wider MDS patient community, the MDS Alliance publishes a monthly newsletter. This newsletter is distributed via email to MDS Alliance's members.

The newsletter is developed in close collaboration with the MDS patient community, who are encouraged to contribute by sending their insights, updates, or suggestions to secretariat@mds-alliance.org.

New Feature in 2024: Team Spotlight: Get to Know Our Members

In 2024, the newsletter introduced a new section titled "Team Spotlight: Get to Know Our Members", showcasing the diverse organisations under the MDS Alliance umbrella. Each edition highlights a different member organisation, offering a closer look at their:

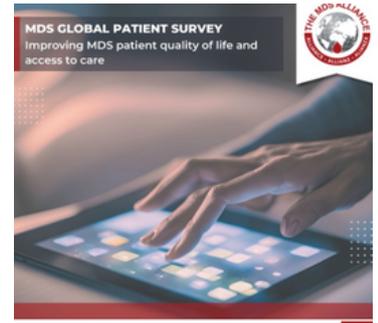
- Background and expertise.
- Ongoing projects and initiatives.
- Key challenges they are addressing.
- Objectives and contributions to the broader MDS community.

This feature promotes knowledge sharing, networking, and interaction, strengthening the connections between member organisations and fostering a sense of collaboration within the MDS Alliance.

Social Media Activities

The MDS Alliance leverages its four social media platforms—[LinkedIn](#), [Facebook](#), [Instagram](#) and [X](#) (Twitter)—to share crucial MDS-related content in a targeted and consistent manner. Through these channels, the Alliance provides updates on:

- Research and development in MDS.
- Advances in treatment and care.
- Relevant events and the activities of member organisations.
- Opportunities to connect with new stakeholders and serve as a point of contact for inquiries.



These platforms also play a pivotal role in the MDS Alliance's **patient advocacy efforts**, serving as integrative tools to disseminate information and raise awareness efficiently. Social media is especially critical in amplifying the reach of the MDS Alliance's **two annual awareness campaigns** and its **global patient surveys**, ensuring rapid engagement with the MDS community worldwide.



Ad hoc support for members

The MDS Alliance, particularly through its Steering Committee, offers its members ongoing advice and support drawn from extensive experience across key areas, including:

- Research and development.
- Finance and pharmacology.
- Education and leadership in patient organisations.
- Management in the non-profit sector.
- Collaboration with stakeholders across the healthcare ecosystem

3. Key Events in 2024: Amplifying Advocacy and Advancing Awareness

In 2024, the MDS Alliance participated in some significant events, each offering unique opportunities to advocate for the interests of the MDS patient community, strengthen collaborations, and engage with experts in haematology and oncology.

3.1. Societe Francaise d' Hematologie (SFH), March 27-29, 2024

The SFH organizes every year the largest conference on hematology in France. MDS Alliance was present at the conference and participated to a session on Patients Quality of Life (QoL). The MDS Alliance presentation "QoLs: A Patient Perspective" focused on the pros and cons of the questionnaires used to quantify QoL.

3.2. WECAN Retreat , April 10-11, 2024

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) retreat, attended by MDS Alliance Chair Jacqueline Dubow, was a key event for advancing collaboration among cancer patient advocacy organisations. Held in April, the retreat provided a forum for discussing shared goals, fostering innovation, and enhancing advocacy strategies. The retreat reinforced the Alliance's commitment to strengthening connections within the global cancer advocacy network and improving outcomes for MDS patients through collective action.

3.3. European Hematology Association (EHA) Congress, June 13-16, 2025

From June 13–16, the MDS Alliance participated in the EHA Congress 2024 in Madrid, one of the leading hematology congresses in Europe. The event featured:

- Scientific sessions exploring cutting-edge topics in haematology, including hematologic malignancies, transfusion medicine, stem cell transplantation, and thrombosis.
- Networking opportunities with global experts, peers, and industry professionals.
- Dedicated sessions on the present and future of MDS, offering insights into advancements in pathophysiology, diagnosis, classification, and treatment.

The EHA Congress also provided a platform to engage with stakeholders, share the MDS Alliance's initiatives, and further its advocacy for the MDS patient community.

Through participation in these pivotal events, the MDS Alliance amplified the voices of MDS patients, fostered valuable connections with stakeholders, and strengthened its advocacy efforts to address the unmet needs of the global MDS community.

4. Partnerships

The most important of these partnerships are described below.

4.1. Acute Leukemia Advocates Network (ALAN)

The MDS Alliance is a member of the [Acute Leukemia Advocates Network \(ALAN\)](#) an independent global network of patient organisations, dedicated to changing outcomes of patients with acute leukemias by strengthening patient advocacy in this area. They aim to maximise the capacity of members within the network, such as the MDS Alliance, to aid delivery of tailored services to acute leukemia patients and carers on the national level. Gereon Manzel represents the MDS Alliance within the ALAN Steering Committee

4.2. EHA Patient Advocacy Committee

The European Hematology Association is the largest Europe-based organisation connecting haematologists worldwide to support career development and research, harmonise haematology education, and advocate for haematologists and haematology.

The MDS Alliance is proud to be one of the 14 patient organisations partnering with EHA through the EHA Patient Advocacy Committee to ensure that the voice of haematological patients is heard and incorporated into the strategy of the Association.

The establishment of this committee reflects the importance of establishing an ongoing, mutually beneficial dialogue between hematology professionals and patients. The goal is to:

- Offer a voice within EHA: ensure the voice of the patient community is heard and represented within EHA's decision making, including at the board level.
- Coordinate EHA's activities with patient organizations on guidelines, Specialized Working Group scientific meetings, etc.
- Ensure the voice of patients is heard as part of the EHA Annual Congress, through the joint EHA-Patient sessions and involvement in the wider scientific program.
- Support policy and advocacy through representation on the European Affairs Committee.

4.3. EUMDS Registry

The European MDS Registry (EUMDS) is a prospective multicentre European Registry for newly diagnosed patients with MDS. Initiated in 2008 by a large group of European haematologists collaborating in LeukemiaNet, the registry collects information from patients with MDS, as well as some AML and CMML cases. The Registry contains information on treatment and disease of more than 3100 MDS patients, across 19 countries, and continues to include new patients. The MDS Alliance is proud to be a partner of this initiative.

4.4. EuroBloodNet

The MDS Alliance is also part of **EuroBloodNet**, the European Reference Network for rare haematological diseases, which covers more than 450 rare haematological diseases. Jacqueline Dubow serves as a European Patient Advocacy Group (ePAG) advocate on behalf of the MDS patient community. ePAG Advocates are nominated to represent their disease area in the ERN EuroBloodNet as well as the interests of the wider patient community affected by rare haematological diseases.

4.5. MDS Europe

MDS Europe is the online presence of MDS-RIGHT (Providing the right care to the right patient with MDS at the right time) – a research project funded by the European Union's Horizon 2020 programme.

Between May 2015-2020, 15 European partners joined forces to compare existing healthcare interventions and define and implement more effective and safer interventions for elderly European citizens with anaemia and/or lower-risk MDS, the project aimed to lead to better treatment compliance and more (cost-)effective use of healthcare resources.

MDS Europe also provides essential information on the topic of MDS and has issued a manifesto to improve MDS patient care.

4.6. Workgroup of European Cancer Patient Advocacy Networks (WECAN)

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) is a network of 24 dedicated umbrella cancer patient advocacy organisations operating across Europe.

WECAN's mission is to improve the outcomes for all cancer patients by acting as a well-coordinated community of cancer patients towards all stakeholders by building trust, collaboration, alignment and mutual support across the pan European cancer patient community.

As a member of WECAN, the MDS Alliance contributes to the working group's mission of strengthening cancer patient advocacy in Europe, improving outcomes for all cancer patients, and building the capacity, expertise and capabilities of the cancer patient community and other stakeholders.

4.7. European Cancer Organisation (ECO)

The **European Cancer Organisation** (ECO) is a not-for-profit federation of Member Societies working in cancer at a European level. We are dedicated to convening oncology professionals and patients to agree on policy, advocate for positive change and speak up for the European cancer community.

The Patient Advisory Committee, established in 2008, provides European patient organisations and bodies involved in patient care with a solid platform to express their expectations in solidarity with our Member Societies and provide the European Cancer Organisation with direct insight into the issues and challenges faced by cancer patients. Jacqueline Dubow represents the MDS Alliance within the ECO PAC.

