The MDS Alliance

2023 ANNUAL REPORT

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1. Who we are

1.1. Mission & Objectives

The MDS Alliance is an international umbrella organisation dedicated to ensuring that **its more than 40 national member organisations can best represent MDS patients locally**, advocate for their rights, needs and access to adequate treatment and care, and equip them with the information they need to become empowered and equal partners in their treatment and care pathway.

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

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

a) Information & Resources

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

b) Guidance & Advice

The organisation shares best practice and skills amongst its members 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.

c) Representation & Advocacy

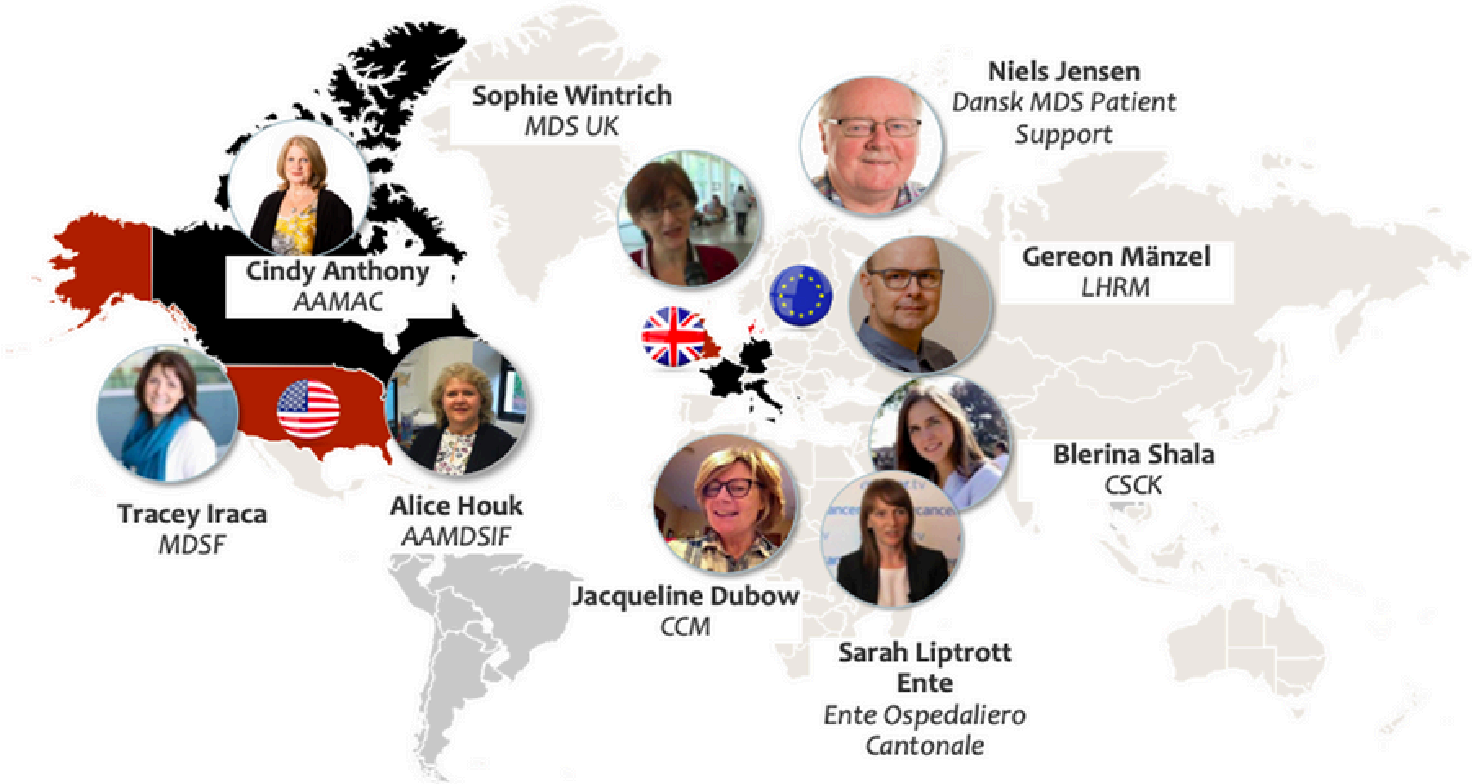
Firstly, the MDS Alliance seeks to give smaller organisations a stronger voice, and to help patients and healthcare professionals to set up new self-help groups where none exist yet.

Secondly, the 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 organisation 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 come together every year on October 25th to raise awareness of MDS on MDS World Awareness Day and of blood cancer in general during Blood Cancer Awareness Month in September.

1.2. The MDS Alliance Steering Committee

The MDS Alliance Steering Committee chaired by Jacqueline Dubow is responsible for the direction, content recommendations and expert opinions on all aspects of the Alliance. It convenes monthly for steering committee meetings and shares insights on its advocacy and experiences in the field of MDS. It also seeks to best support its member groups with solutions and ideas for MDS resources and programmes and forms project-specific working groups to ensure high quality and timely delivery in line with patient needs.



At the end of 2023, the structure of the MDS Alliance Steering Committee changed to ensure an even spread of responsibilities between the members. Members decided to move forward in a linear structure, with working groups formed around specific projects. Therefore, when the term of Jacqeline Dubow as Chair of the SC finished with the end of 2023, the group did not elect a replacement. During 2023, the alliance also saw changes in the membership, with the departure of Sophie Wintrich, Niels Jenses and Tracey Iraca and the addition of Ashley Moncrief of MDS foundation.

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.

Country	Organisation	Country	Organisation
Argentina	Linfomas Argentina	Finland	Suomen Syöpäpotilaat ry – Association of Cancer Patients in Finland
Australia	The Leukaemia Foundation	France	CONNAÎTRE ET COMBATTRE LES MYÉLODYSPLASIES (CCM)
Barbados	Myeloma Lymphoma & Leukaemia Foundation of Barbados	Germany	LHRM - MDS Patienten-Interessen Gemeinschaft
Belgium	MDS Contact Group	Israel	TAMID
Brazil	Abrale	Italy	AIPaSIM
Canada	Aplastic Anemia & Myelodysplasia Association of Canada (AAMAC)	Italy	AIL
Croatia	HULL	Japan	Japan MDS Patient Support group (JAMPS)
Czech Republic	Diagnoza Leukemie	Kosovo	CSCK / Kosovo
Denmark	LyLe	Netherlands	Hematon

Country	Organisation	Country	Organisation
New Zealand	Leukaemia & blood cancer New Zealand	Slovenia	Slovenian Association of Patients with Lymphoma and Leukemia
North Macedonia	Association of citizens for rare diseases life with challenges Bitola	South Korea	KBDCA
North Macedonia	Xema	Spain	AEAL
Nigeria	The White Cell Foundation	Spain	AELCLES
Norway	Blodkreftforeningen	Sweden	Blodcancerforbundet
Peru	Esperantra	Switzerland	MDS platform Switzerland: a group of LYMPHOME.CH Patientennetz Schweiz
Portugal	ADL	Switzerland	Ente ospedaliero cantonale
Portugal	Portuguese Association against Leukemia and other oncological diseases (APCL)	UK	MDS UK
Portugal	Portuguese Leukaemia and Lymphoma Association (APLL)	USA	Aplastic Anemia & MDS International Foundation (AAMDSIF)
Russia	Public Organization For Patients with Hematological Diseases “Mercy Bridge” (“Most Miloserdiya”)	USA	Cancer Support Community
Slovakia	HematologickyPacient – Association of Patients with Hematological Malignancies	USA	MDS Foundation

1.4. The MDS Alliance Secretariat

The legal entity and financial management are provided to the MDS Alliance by the European Patient Advocacy Institute (EPAI) and the secretariat and project management are done for EPAI by Patvocates, which also advises and supports the organisation in the conception and implementation of its projects and is responsible for communications work.

The key members of the Patvocates secretariat and project management for MDSA in 2023 included:

- Alba Ubide, Head of NGO Services
- Nina Kozar-Gillan, Project Manager
- Mirna Tomašević, Communications Manager
- Luba Mock, Finance Manager
- Stefan Huber, Editor/Writer
- Gina Ubide, Project Officer

2. Projects in 2023

The projects of the MDS Alliance are diverse and at their core reflect the organisation's mission and objectives: From patient advocacy efforts such as MDS World Awareness Day, to worldwide surveys to collect data as a basis for adequate actions to improve the situation of MDS patients around the globe, to regular communication and support of those affected via social media, email and a newsletter, to representative responsibilities at various congresses and in cooperation with other umbrella and patient organisations - the range of tasks is huge, and so is the Alliance's responsibility.

The projects for 2023 are presented in a brief and concise manner below.

2.1. Global MDS Patient Survey:
Finalisation and dissemination of the survey report

Every two years, the MDS Alliance conducts **a global patient survey** to better understand the issues facing people with MDS, and to use this understanding to inform evidence-based decisions for other decision-makers and stakeholders on how to improve quality of life and access to care for these patients worldwide. For example, the 2022 Global Patient Survey provided interesting insights into, among other things, quality of life, access to care and mental health of MDS patients.

The results of the report have now been compiled in a coherent and clear report so that various relevant stakeholders can use them as evidence in their work for the benefit of the MDS patient community.

To make this report and its findings available to as wide and relevant an audience as possible and to draw attention to the unmet needs of MDS patients, it was shared with the Alliance's members, various medical organisations, as well as policy makers on the national and local level. What is more, it was presented by Jacqueline Dubow, MDS Alliance Chair, at the 17th International MDS Congress in Marseille.

In addition, some of the data collected in the survey were used to create evidence-based materials and information for the campaign and for general SM posts.

2.2. Access study

To provide a powerful, data-proven evidence for advocacy, the MDS Alliance is continuously collecting information on access to and reimbursement of MDS treatments in different countries globally. These data are available for free through the Alliance's **MDS Treatment Access Portal** in the form of a user-friendly interactive map. There are currently 26 countries included in the portal, and this number is expected to keep increasing as the Alliance continues to collect and update the treatment access information. Moreover, all MDS Alliance Members are invited to share the above data related to their countries with the Alliance using an online contact form on the MDSA website. Once scrupulously reviewed, the information will be made available through the portal.

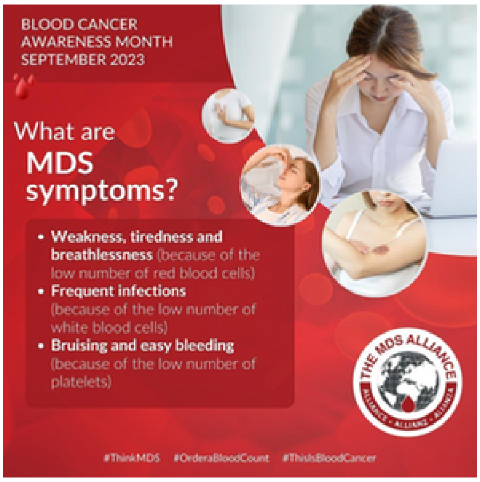
2.3. Awareness Campaigns

Every year on October 25th, the MDS Alliance and its member groups around the world join forces on MDS World Awareness Day (MDS WAD) to raise awareness of Myelodysplastic Syndromes (MDS) – a type of rare blood cancer that causes the bone marrow not to produce enough healthy blood cells.

But already in the run-up to MDS WAD, the Alliance joins the Blood Cancer Awareness Month (BCAM): a worldwide and month-long campaign that takes place every year during September and focuses on one of the world's most common and dangerous cancers: blood cancer.

a) Blood Cancer Awareness Month

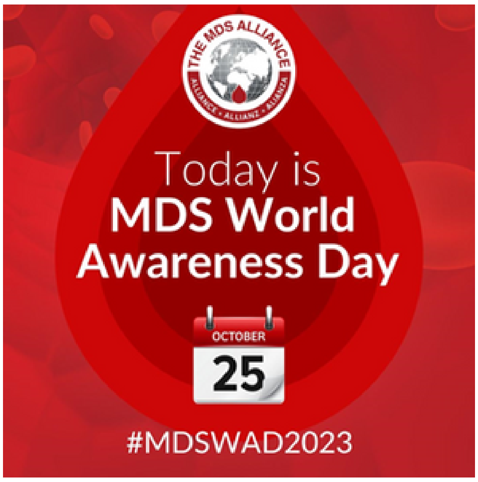
In line with BCAM, the MDS Alliance's month-long awareness campaign was aimed at three main target groups: patients, healthcare professionals and the general public. According to those target groups, the campaign team produced various social media posts for the media LinkedIn, Facebook, Instagram and X (Twitter), accompanied by understandable, clear and appealing visuals, and with a focus on MDS symptoms, diagnosis and treatment options and self-management of the disease, as well as the importance of early referral and blood donations. What is more, the team also put together a compact brochure in various size formats, with the most essential information on key topics such as MDS diagnosis, symptoms or treatment, as well as **5** posters containing the brochure information in condensed form.



- **Weakness, tiredness and breathlessness** (because of the low number of red blood cells)
- **Frequent infections** (because of the low number of white blood cells)
- **Bruising and easy bleeding** (because of the low number of platelets)

b) MDS World Awareness Day

The core aim of the 2023 MDS World Awareness Day was to address all those who might be able to notice MDS symptoms before diagnosis: members of the public who may have MDS, as well as their loved ones, family members and caregivers. What is more, MDS WAD 2023 saw an innovation: the MDS campaign team interviewed people affected by the disease in various ways such as patients and carers, for example about their experiences with the disease itself, their national healthcare system and their treatment and care pathways, and also asked them to give a piece of advice to HCPs.



Short clips from these interviews were published on social media in the run-up to MDS WAD in order to draw attention to MDS World Awareness Day and the unmet needs of MDS patients.

To achieve its goal, the campaign team published social media posts about MDS symptoms as well as short interview clips on **LinkedIn**, **Facebook**, **Instagram** and **X** (Twitter), before, during and after MDSWAD, and provided information posters, **10 MDS fact sheets** as well as a social media twibbon, with which all those interested could demonstrate their support and participation in MDSWAD.

Find the full report for both campaigns here.

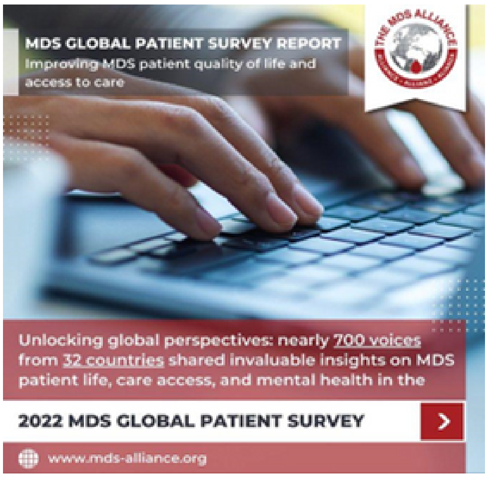
2.4. Communications efforts

a) Monthly Newsletter

In order to keep all those interested informed and up to date on current and relevant information in the field of MDS, interesting events, as well as activities of the Alliance and the MDS patient community, the organisation publishes a monthly newsletter - by email to all those who are registered and via its social media channels. The newsletter is produced in close collaboration with the MDS patient community, who can send their input to **secretariat@mds-alliance.org** at any time.

b) Social Media Activities

Through its four social media channels **LinkedIn**, **Facebook**, **Instagram** and **X** (Twitter), the MDS Alliance aims to share important MDS-related content on a regular basis and in a target group-oriented manner, such as news and updates from research and development, treatment and care, on relevant events or the activities of its members, as well as to establish new connections and to serve as a point of contact. In addition, these channels facilitate its patient advocacy activities: the Alliance's social media presence is an integrative tool to share information and raise awareness quickly and efficiently – especially with regard to the two annual awareness campaigns and its global patient surveys.



c) Modification and redesign of the MDS Alliance website

The MDS Alliance is currently working on making its website even clearer, structuring it more logically, adding new relevant information and sections and revising and updating the existing information to make it more accessible.

d) Ad hoc support for members

With its practical, operational and strategic experience from all relevant fields such as research, finance, pharmacology, education, as well as its experience in the organisation, management and leadership of patient organisations and in the non-profit sector and in cooperation with other stakeholders, the MDS Alliance, in particular with its Steering Committee, is available to its members with advice and support at all times.

3. Attendance at meetings and congresses

Throughout the year, the MDS Alliance was present at numerous relevant congresses, events and meetings to represent the voice of all MDS patients around the world, but also to actively advocate for their interests and unmet needs in dialogue with other stakeholders. The events in 2023 were attended by either the organisation's Chair Jacqueline Dubow, a member of the Steering Committee or a general member.

3.1. 17th International Congress on Myelodysplastic Syndromes

The 17th edition of the International Congress on Myelodysplastic Syndromes took place from 3 to 6 May 2023 in Marseille. The congress provides an opportunity for international MDS experts and peers to discuss the latest discoveries, basic and translational research, and diagnosis, prognosis and treatment. The 2023 edition was a milestone in the history of the event, as for the first time an MDS patient was invited to present as part of the medical programme: In her presentation *The patient perspective: MDSA Global Survey results - key takeaways*, MDS Alliance Chair Jacqueline Dubow presented the results of the 2022 Global Survey, with a focus on, amongst other things, the quality of life, access to care and mental health of MDS patients.

3.2. European Hematology Association (EHA) Hybrid Congress 2023

The EHA2023 Congress took place from 8-11 2023 June in Frankfurt am Main, Germany as a hybrid event - on-site and virtual. The EHA is known as the leading haematology congress in Europe and covers all areas of haematology and provides the opportunity to engage with and learn from experts from around the world. The educational and scientific programme highlights the latest clinical practice, findings and innovations in haematology research.

3.3. The American Society of Clinical Oncology (ASCO) 2023 annual meeting

The 2023 edition of ASCO took place in Chicago, USA from 31 May to 4 June and was held under the theme Partnering With Patients: The Cornerstone of Cancer Care and Research. ASCO's primary focus is on strategies to improve the quality of oncology care, and it hosts panels of experts who lead and implement innovative programmes. The society has a network of more than 42,000 oncology professionals working in the field of cancer.

3.4. 65th ASH Annual Meeting & Exposition

The MDS Alliance was also represented by Steering Committee Member Alice Houk at the 65th ASH Annual Meeting and Exposition from December 9-12, 2023, in San Diego, California. ASH is the world's most comprehensive congress in haematological oncology, with the aim of enabling international experts to share information and network in numerous sessions, and to present abstracts on current research results and the most important innovations in therapy and diagnosis. At this event, representatives of two member organisations represented in the MDSA SC (AAMDSIF and MDSF) each sponsored a Satellite Symposium that featured international MDS experts presenting the latest developments in the pathophysiology, diagnosis, classification and treatment of MDS.

3.5. WECAN Academy 2023

As a member of WECAN, the Workgroup of European Cancer Patient Advocacy Networks, which comprises more than 20 umbrella cancer patient advocacy organisations, the MDS Alliance contributes to the workgroup’s mission to strengthen cancer patient advocacy in Europe, to improve outcomes for all cancer patients and the collaboration between these organisations, and to build knowledge, expertise and skills of the cancer patient community and other stakeholders.

This was also the aim of the second face-to-face WECAN Academy, which took place from 1 to 4 July 2023 in Frankfurt am Main, Germany, and was attended by Catherine Moura, CEO at Abrale (the Brazilian Lymphoma and Leukemia Association) and nominated for this training by the MDS Alliance. Other focal points of the four-day training were evidence-based advocacy, the need for better and faster research or how to read scientific articles correctly.

4. Partnerships

The MDS Alliance believes that only through partnerships, knowledge transfer and synergy effects can actual change be achieved in the interest of patients with MDS and in cooperation with other stakeholders on an equal footing. For this reason, the organisation relies on a wide range of partnerships in order to set levers in motion in as many areas of interest as possible: for example, in collaboration with other patient organisations, in partnership with scientific committees and associations, with virtual networks, in research projects or in cooperation with registries.

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)** - a global network of patient organisations, committed to changing outcomes of patients with acute leukemias by strengthening patient advocacy in this area.

4.2. EHA

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 to ensure that the voice of haematological patients is heard and incorporated into the strategy of the Association.

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 myelodysplastic syndromes (MDS) as well as some AML and CMML cases. The Registry contains information on treatment and disease of more than 3100 MDS patients and continues to include new patients. The MDS Alliance is proud to be a partner to this initiative.

4.4. EuroBloodNet

The MDS Alliance is also part of **EuroBloodNet**, the European Reference Network for 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. Harmony Alliance

The MDS Alliance is involved in **HARMONY**, a project that aims to improve access to and care for patients with various haematological malignancies through the use and analysis of big data. The project's patient cluster, a group of seven pan-European patient umbrella organisations which are active in HARMONY’s haematological malignancies, is an integral part of the HARMONY Alliance and its follow-up project HARMONY PLUS.

4.6. MDS Europe

MDS Europe is the online presence of MDS-RIGHT (Providing the right care to the right patient with Myelodysplastic Syndrome at the right time) – a research project funded by the European Union's Horizon2020 programme. By comparing existing healthcare interventions and defining and implementing 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.

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

The Workgroup of European Cancer Patient Advocacy Networks (WECAN) is a network of leading representatives from over 20 umbrella organisations for cancer patients active in Europe.

WECAN's purpose is to act 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.