



MDS Alliance News

May 2024

Join Us for the First MDS Alliance Face-to-Face Members Meeting

We're thrilled to finally come together as a community and with great enthusiasm we announce **the first MDS Alliance face-to-face Members Meeting.**

After 10 years of collaboration, it is time for the MDS Alliance members to sit together. Taking place in **Castelldefels, Barcelona, Spain,**

from October 24th to 26th, 2024, this gathering will serve as an opportunity to strengthen connections, understand the members' needs and enhance our skills as patient advocates.

During this meeting, participants will have the opportunity to learn about **the latest advancements in MDS research and treatment options** but also improve their skills **around patient organisations management** through an insightful advocacy training. Keynote speakers will share invaluable insights, equipping attendees with the knowledge and skills needed to effect positive change within their communities.

Additionally, the meeting will serve as a forum for collaborative discourse, where members can actively contribute to shaping the future of the MDS Alliance. Through organisational sessions and strategic discussions, we will map out a plan that reflects the members' needs and our shared goals.

Since the Members Meeting coincides with **MDS World Awareness Day on October 25th,** it's a great chance for us to highlight our global community! Gathering on this special day will emphasise the spirit of unity in the MDS journey.

Your presence at this important event is vital. **Together, we have the power to effect change, to foster connections, and to advocate for MDS awareness.** Mark your calendars and join us.

We look forward to welcoming you to Castelldefels.





MDS Alliance News

2024 MDS Awareness Campaign to highlight the crucial role of Patient Organisations

The MDS Alliance will underscore the crucial role of patient organisations and support groups in the journey of those affected by Myelodysplastic Syndromes (MDS) during 2024 Awareness Campaigns (Blood Cancer Awareness Month and MDS World Awareness Day). Patient organisations play a vital role in providing essential support for both patients and caregivers throughout the diagnosis, treatment, and remission phases but, unfortunately, the lack of

awareness about the support which can be obtained remains a significant challenge for those affected. **Many patients and their families are unaware of the invaluable assistance these organisations can provide.** To address this, this campaign aims to spotlight their substantial impact and underscore their significance within the MDS community.

To effectively raise awareness on this theme, the campaign will **target both healthcare professionals (HCPs) and patients/caregivers.** A key strategy involves conducting interviews with Key Opinion Leaders (KOLs) in the field of MDS from various member countries. These interviews will offer invaluable insights into the pivotal role of patient support groups and the responsibility of HCPs to promote awareness and refer patients to these essential organisations.

Interviews will be conducted in English, with answers also collected in the native languages of the KOLs, facilitating distribution on social media platforms during Blood Cancer Awareness Month.

Additionally, the campaign plans to involve patients in sharing their personal testimonies, further amplifying the importance of support groups in the MDS journey.

The success of the campaign relies on the collaborative efforts of all involved, that's why we appreciate **your collaboration** in contacting **KOLs in your countries** to take part in this campaign.

Empowering Advocates: Join the WECAN Academy 2024

We are happy to share a training opportunity for MDS Alliance members: **the WECAN Academy 2024**, that will take place in **Barcelona from July 11th to 14th.** This event, organised by the Workgroup of Cancer Patient Advocacy Network (WECAN), promises to be a transformative experience for cancer patient advocates from Europe.

As a valued partner of WECAN, the MDS Alliance has the privilege of nominating members to both training levels: SmartStart and Masterclass. The **nominations deadline has been extended** and candidates can still apply for these grants. Nominations will be processed on a first come first served basis. The WECAN





MDS Alliance News

SmartStart program is tailor-made for those who are new to advocacy, providing them with the essential knowledge and skills to embark on their advocacy journey effectively. On the other hand, the WECAN Masterclass offers advanced training for seasoned advocates, equipping them with strategies to effect significant change in patient advocacy within the realm of cancer care. Accepted nominees will receive **travel bursaries covering up to 400€**. Food, accommodation and registration will also be provided and covered.



If you're keen to seize this invaluable opportunity to enhance your advocacy skills and broaden your network, we urge you to express your interest as soon as possible. This will allow us to nominate you for the program and ensure your participation in this enriching experience.

MDSA at EHA 2024

We are thrilled to have the opportunity to attend the **European Hematology Association (EHA) Congress in Madrid from June 13-16**. The agenda will be packed with captivating activities aimed at advancing awareness and understanding of haematological conditions, like MDS. Additionally, attendees will delve into the latest research unveiled at EHA.



These are some of the sessions dedicated to analyse the present and future of MDS.

- Navigating the Evolving Treatment Landscape in Lower-risk MDS. On Thursday 13th June at 10.15.
- MDS Symposia. Thursday 13th at 19.15
- Working group session on 15th June: Myelodysplastic syndromes (MDS): Immune dysregulation in bone marrow failure disorders: Time for immune monitoring?

The scientific agenda will spotlight cutting-edge haematology and an array of subjects, encompassing hemostasis and thrombosis, hematologic malignancies, transfusion medicine, and stem cell transplantation.

Beyond the scientific sessions, the EHA2024 Hybrid Congress presents a chance for participants to forge connections, engage with peers, and interact with experts and industry associates.



MDS Alliance News

MDS Insights: Empowering Patients & Families via Podcasts



The MDS Foundation has launched a new season of an exciting initiative aimed at supporting patients, family members, and caregivers affected by myelodysplastic syndrome (MDS). This initiative will take the form of a **series of podcasts episodes** featuring discussions led by experts in the field of MDS.

Each episode will delve into a **variety of topics related to MDS**, including the latest advancements in diagnostic techniques and innovative therapies. Additionally, experts will address commonly asked questions from patients and caregivers, providing valuable insights and guidance.

This initiative aims to **empower patients and their support networks** to better understand and manage this complex condition. [In the latest podcast](#), Drs Nikolaos Papadantonakis of Emory, Atlanta, US, and Moshe Mittelman, Tel-Aviv, Israel, discuss new trials

presented in the last meeting of the American Society of Hematology (ASH) 2023.

Unlocking the Genetics of MDS and AML: Understanding How Blood Disorders Progress

Myelodysplastic syndromes (MDS), sometimes, can turn into acute myeloid leukaemia (AML). Understanding how this happens is really important for prognostic assessment and the development of innovative treatments.



About 30–40% of people with MDS will see it turn into AML.

While MDS evolution into AML is less common among low-risk cases, it tends to occur more frequently and rapidly in high-risk MDS scenarios.

Certain gene changes, like mutations in TP53, problems with Chromosome 17, or having only one copy of Chromosome 7 (Monosomy 7), can make it more likely for MDS to turn into AML. By deciphering the genetic blueprint of these diseases, clinicians aim to tailor treatment strategies that offer the greatest promise of efficacy while minimising adverse outcomes.

Keep [reading](#) if you want to find out more about this.

Team Spotlight: Get to Know Our Members

In May we put the spotlight on our member, [Connaître et Combattre les Myélodysplasies \(CCM\)](#). Since 2006, CCM has been the only organisation in France dedicated to patients with myelodysplastic syndromes (MDS). CCM aims to provide Myelodysplasia patients, wherever they live, with access to the latest resources and information on MDS. Get to know them:



MDS Alliance News

- **What is the mission of your organisation?**

CCM's vision is to better serve myelodysplasia patients and their caregivers. The association focuses on the shared experience of patients, and on responding as the voice of this community. CCM focuses on 5 main objectives:

- Facilitate patient contact with myelodysplasia specialists
- Contribute to progress in patient care and management
- Promote the exchange of information between patients and their families
- Promote research into myelodysplasia and the development of new drugs and treatments
- Keep abreast of progress made worldwide and organise information meetings attended by specialists.

Supporting the community

CCM provides information, support, education and awareness to patients and their caregivers, as well as to healthcare professionals and the general public. Enable patients to better understand MDS by organising regular doctor/patient information meetings.

The association contributes to advances in patient care through regular collaboration with international associations, the French-speaking Myelodysplasia Group (the Groupe Francophone des Myélodysplasies – GFM), and with laboratories. We also provide support research into new treatments by helping to draft protocols for GFM clinical trials, and by collaborating on national and international surveys.



CCM stand at the French Haematology Society Congress SFH in Paris, March 2024 / CCM with the support of an association of haematology interns, during the Paris Mars 2024 half-marathon

CCM aims to provide patients and their caregivers with the latest resources and information on myelodysplasias, including new treatment options, international projects and events of interest to the wider community. CCM shares best practices to become a forum for advice and guidance on the full range of issues affecting patients with the disease. These resources are available via CCM's [website](https://myelodysplasies.org), [myelodysplasies.org](#), [Facebook page](#), newsletters, regional doctor/patient days, webinars, and hotline.

CCM collaborates with numerous partners in France, FLE, AF3M, Alliance Maladies Rares, and internationally through a network of [international organisations](#) as well as European groups such as WECAN, EuroBloodNet and Harmony Alliance.

- **What are the biggest challenges and most pressing unmet needs of MDS patients in France?**



MDS Alliance News

Support is needed to ensure that patients' knowledge levels of MDS increase, to make them more active in managing their disease, and to assist them in their care journey through Patient Therapeutic Education. It is therefore necessary to raise awareness and accelerate education on MDS to facilitate early and accurate diagnosis.

It is also essential that research into clinical trials and advances in treatments are widely shared to improve access to innovative treatments and facilitate the marketing authorization of new molecules, giving priority to products that can be easily dispensed outside of hospitals, to minimise travel-related obstacles and promote access for all, even those far from a hospital.

Regarding the unmet needs, myelodysplasias are complex to diagnose, often leading to treatment delays. Not all primary care physicians are aware of this rare disease, and so may not recognize a low blood count as a sufficient reason to refer patients to a haematologist for a marrow biopsy, a procedure necessary to diagnose myelodysplasia.

Although treatments for MDS have made progress, stem cell transplantation remains the only curative method, and patients need more options...



Regional event in Toulouse, October 2023 / Regional event in Marseille, June 2023

- **What is the biggest achievement/ something you are most proud that your organisation did for the patient community?**

Since its creation and thanks to the help of its volunteers, many projects have come to fruition, such as a telephone helpline from Monday to Friday (06-37-22-79-87), a [Facebook page](#), patient surveys, webinars or participation in the drafting of manifestos for French and European health authorities.

Recently, CCM took part in trials, and lobbied government bodies (HAS, Ministry of Health) to bring to a successful conclusion a marketing application for treatments that allow patients to space out transfusions, and to be treated at home, without having to go to hospital. CCM approached haematology departments and offered virtual reality headsets to help patients cope better with marrow harvesting, a painful procedure dreaded by patients.

- **What is one advice you would give to MDS patients?**

Join forces with associations to educate yourself, share experiences and play an active role in your care pathway and in your disease.

Would you like for your organisation to be featured in the upcoming newsletters? Email us at secretariat@mds-alliance.org and give us your perspective about some of the topics below:



MDS Alliance News

- What is the mission of your organisation?
- What are the biggest challenges and most pressing unmet needs of MDS patients in your country?
- What is the biggest achievement/ something you are most proud that your organisation did for the patient community?
- What is 1 advice you would give to MDS patients?

Events – 2024

May/June

- **2024 ASCO Annual Meeting**, 31 May – 4 June 2024 in Chicago, IL.
Find out more and register [here](#).

June

- **EHA 2024 Hybrid Congress**, 13-16 June 2024 in Madrid, Spain.
Find out more and register [here](#).

October

- **MDS Alliance Members Meeting**, 24-26 October 2024- Castelldefels, Spain.

December

- **The American Society of Hematology Annual Meeting**, 7-10 December in San Diego, USA.
Find out more [here](#).

Please let us know if there is an event happening in your region that we can add to the newsletter.

Next MDSA Steering Committee Meeting

- Thursday, 30th May 2024

Over to You

Please get in touch, share your news, and become an active voice in our group. You can email us at secretariat@mds-alliance.org.

Thank you to our sponsors whose support allows us to progress with our projects and work.



Don't forget to visit the [MDS Alliance website](#) for resources and news, and to follow us on [Facebook](#), [X](#), [LinkedIn](#), and [Instagram](#) to stay up to date!

