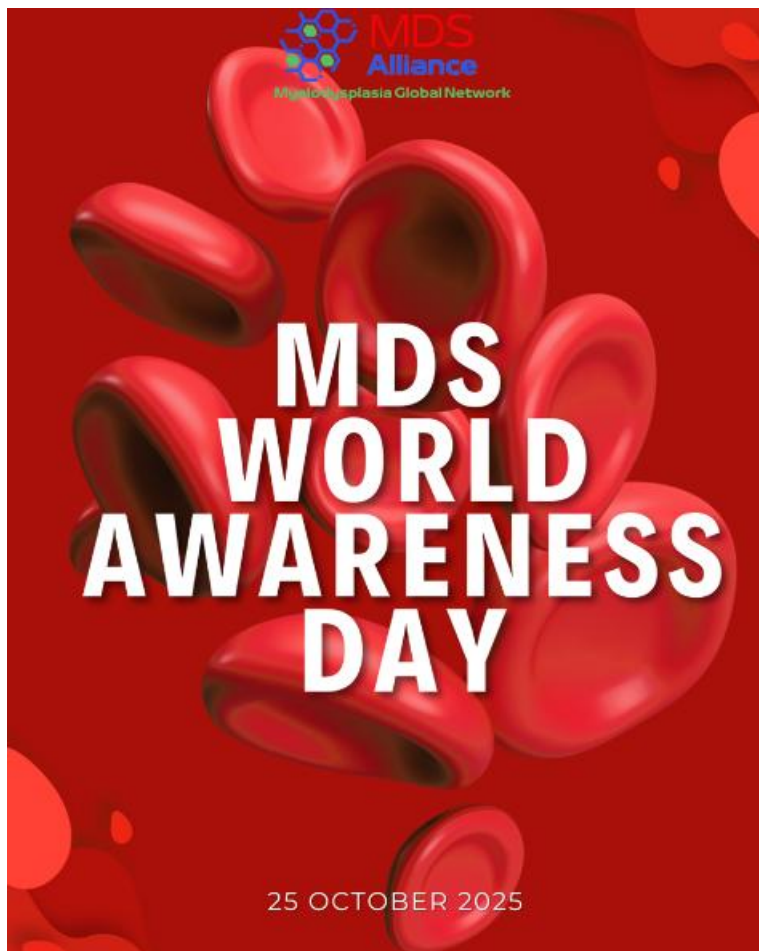


News

SEPTEMBER / OCTOBER 2025

MDS AWARENESS DAY



MDS WORLD AWARENESS DAY

On October 25th, we unite globally to make MDS visible. Every voice, every share, and every action helps raise awareness and support patients worldwide.

Let's stand together for the MDS community.

#MDSWorldAwarenessDay #MDSAwareness #TogetherIsBetter #SupportMatters

News

MDS ALLIANCE MEMBERS MEETING



On 2nd and 3rd of October 2025, representatives of MDS patient organisations from various countries have gathered in Frankfurt am Main for the second member meeting of the MDS Alliance.

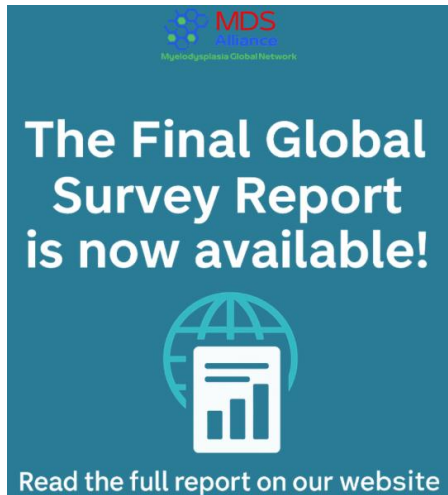
An incredible 2-day journey of collaboration, innovation, and insight into Myelodysplastic Syndromes (MDS)!

- ◆ Day 1 welcomed participants with a global overview from the MDS Global Survey 2024, exciting updates on novel treatments, and the launch of the Luspamark initiative.
- ◆ Day 2 was packed with dynamic sessions on VEXAS & MDS, Vitamin B5 studies, and an empowering Patient Engagement Professionals' Roundtable. We ended with strategic discussions shaped the 2026 Network Vision.

A huge thank you to everyone who joined us and to our sponsors. Together, we're shaping the future of MDS care and research.

News

GLOBAL SURVEY REPORT AVAILABLE



We are pleased to announce that the final report of the 2024 global survey is now available:
<https://www.mds-alliance.org/news/final-report-of-the-global-survey-2024/>

The focus for 'The MDS Global Survey 2024' was 'access to care' and this was to be delivered with the support of Picker, an international charity working across health and social care. The main survey topic was selected based on feedback from the MDS community, the MDS Alliance Steering Committee and findings from 'The MDS Global Survey 2022'.

As such, three key aims were identified:

1. To better understand patient access to medications, treatments, and care.
2. To identify barriers and facilitators to access across different health systems.
3. Based on the findings above, to develop clear, actionable recommendations for stakeholders (*see p133-135 of the report*)

The report is an important piece of work that helps, all of us, to drive our advocacy efforts.

We would like to thank all patients who took the time to participate in this study.



News

REFLECTIONS FROM A PATIENT LIVING WITH VEXAS SYNDROME

BY SERGE WOLIKOW

First, I should introduce myself: born in France in 1945, I was a teacher and researcher in the humanities, a university professor for 30 years after teaching for 20 years in high schools. My love of teaching, dialogue, and research has never left me. I am certainly not representative of all Vexas Syndrome patients, whom I do not know.

Having been asked to contribute to the discussion and knowledge as a patient affected by this disease, I agreed to share my reactions and expressed my willingness to engage in dialogue with the medical community.

First, I must emphasize the conditions under which my illness was communicated and explained to me by Zhao Lin Pierre, without whom I would probably not have chosen to speak out. In the summer of 2023, I experienced the symptoms of the disease, which manifested themselves in particular as multiple spots on my body and then joint problems. It was after a blood test showed a collapse in my hemoglobin and platelet levels that I arrived at the hematology department of St. Louis Hospital (France), thanks to the help of my doctor, who was particularly concerned, intrigued, but perplexed.

My condition required transfusions and bone marrow punctures, which immediately led me to believe that I had a blood disease, if not leukemia. At the end of 2023, EPO treatment failed to produce any conclusive results. At that point, the cooperation between the hematology department at St. Louis Hospital (Dr. Zhao LinPierre) and the internal medicine department at St. Antoine Hospital (Dr. Vincent Jachiet) was very important to me, as I was able to communicate with both doctors, who worked closely together.

When I learned—after more than two months—that my disease was both identified and rare, I experienced a brief sense of relief, which quickly turned to disappointment when I realized that this disease, Vexas syndrome, had only recently been identified and that, as a result, no prognosis could be made. I quickly understood what “lack of perspective” meant! It was probably at that point that I consulted the scientific literature on the subject, which confirmed that the doctors treating my disease were at the forefront of research and that, by necessity, I was becoming an experimental patient.

It was in this context that I began regular treatment in January 2024 with monthly injections of Vidaza (azacitidine), even though I was extremely fatigued from my frequent blood transfusions. Heavy medication with cortisone and many anti-infectives led to an improvement in my physical condition and undoubtedly also my morale after four months, so that I have not had a transfusion since May 2024. However, I understand that this complex disease, linked to a major genetic mutation, can have multiple manifestations such as thrombosis—particularly phlebitis—and various hemorrhagic manifestations.

Nevertheless, my experience of this disease, with no visibility even in the short term, has taught me the importance of being attentive to the various possible manifestations while striving to maintain a minimum level of intellectual and physical activity, taking into account a real weakening in this area with few signs of improvement. On the other hand, I am trying to continue my scientific and social activities in my fields of research in contemporary history. One way of achieving this with my colleagues, who are often my former students, is to tell them about this still little-known disease that I have. I have also chosen to involve my children and my sister in monitoring my treatments and diagnoses from the outset. This is certainly a way of “taming” my anxiety, but also of easing relations with my family, for whom I have strong feelings, by

News

ensuring that they provide me with support if I need it, while remaining capable of autonomy and initiative myself, for the time being!

To conclude this first contribution, I would like to say that I am very grateful for the invitation to participate in this international reflection process bringing together doctors and patients with different pathologies. I hope that French people will be able to find their place in it and, in the age of AI, have their own voice so that they can be identified as such in the various databases created on this and other issues.

NEW FACEBOOK PAGE

We kindly inform you that our official Facebook presence has moved to a new page:

<https://www.facebook.com/profile.php?id=61578091837938>

To continue receiving updates about our initiatives, resources, and advocacy efforts, we invite you to follow us there.

Please note: while the page has changed, our commitment remains the same — to support, inform, and connect the MDS community worldwide.

Thank you for being part of our journey.

OVER TO YOU

Would you like for your organisation to be featured in the upcoming newsletters? Please get in touch, share your news, and become an active voice in our group. Email us at secretariat@mds-alliance.org and give us your perspective about some of the topics below:

- 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?

AND...

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!

