WMDA 2024

Finance & Activities Report





CONTENTS

	03	2024 at-a-Glance, Foreword President, Who We Are
	04	Our Mission, Our History
	05	2024 Achievements
	06	Our Pillars:
		Optimising 'Search, Match & Connect'
		Supporting Global Development
		Promoting Donor Care
		Ensuring Quality - Certification Body
		Driving Member Engagement
	24	Harmonising and Building Knowledge
	28	How We Manage Data
WORLD	29	Treasurer's Statement
MARROW DONOR	31	Financial Report
ASSOCIATION	37	Looking into 2025

WHO WE ARE

WMDA NUMBERS



>42,000,000 Donors



>66,000 New patients annually



>25,000 Unrelated transplant recipients



124 Organisations with an organisational wide WMDA membership



48 Ongoing projects



40 Registries certified under WMDA Certification Programme



In-person membership meetings

FOREWORD PRESIDENT

Dear WMDA member.

As Past-President of the WMDA, I am privileged to introduce the 2024 WMDA Finance & Activities Report. A highlight of 2024 was the IDRC & WMDA Global Meeting in Cape Town, hosted by the South African Bone Marrow Registry. This was a vital opportunity to learn from one another, particularly about the emerging role of transplantation and donor registries in developing regions such as Africa. I'm grateful for the support of NMDP and to all the attendees, staff and sponsors who helped to make this such a productive meeting.

Other notable achievements in 2024 include the approval of a new governance structure for WMDA, and the introduction of an audit and certification program for couriers. We also celebrated three important birthdays: 10 years of World Marrow Donor Day, 20 years of Certification Programme and 30 years of WMDA. These anniversaries have given us pause to reflect on changing practices in haematopoietic transplantation, the evolution of cell/gene therapy and new regulatory landscapes. With these challenges in mind, I see a pivotal role for WMDA now and in future years. I would a like to extend a warm welcome to Jay Feinberg, who commenced his appointment as President of WMDA in 2025.



Matthew Seftel, MD MPH FRCP FRCPC WMDA President 2023-2024

WMDA is a global community connected by technology, data, quality & education. WMDA is recognised as a charitable institution (ANBI) under Dutch tax regulations. The promotion of donor care is reflected in the work of our different areas:



Search, Match & Connect







Development

FUNDING

WMDA is funded through a variety of sources. In 2024, the membership and product fees were the largest sources of income.

WMDA MEMBERSHIP BOARD



Matthew Seftel, CA



Jay Feinberg, USA President-Flect



Jaap Dijkman, NL



Hans-Peter Eberhard, DE Search, Match & Connect



Ann O'Leary, GB Global Development



Thilo Menalina, DE



Garth Healey, AU



Lvdia Foeken, NL Chief Executive Officer

OUR HISTORY

VISION

We strive for a world where access to life-saving cellular therapies for all patients is assured and donors' rights and safety are protected.

MISSION

We work with our members to ensure reliable provision of life-saving cells while promoting care and safety for both patient and donor.

VALUES

RESPECT FOR EACH OTHER, FOR OUR DONORS AND PATIENTS

- We connect
- Connecting patients and donors and members across the globe.
- We are inclusive

Ensuring all members are invited, involved and empowered. We strive for diversity and equal participation.

We are committed

We are dedicated to support the work of our members to help all patients in need of a transplant, while protecting the rights and wellbeing of the donor.

• We are reliable

Providing consistent services and building a sustainable organisation from which our members can expect a pragmatic, cost-efficient approach in the provision of the high-quality services.

• We inspire

Exploring and implementing new possibilities, seeking collaboration and innovation. Being part of WMDA is stimulating and enriching.

1988

Dr. Jon J. van Rood and Dr. John Goldman establish the Bone Marrow Donors Worldwide (BMDW), a book with HLA-typing of voluntary donors that transplant centres could use to find a match for their patients.

1994

WMDA was founded by Dr. John Goldman (United Kingdom), Dr. Edward Donnall Thomas (United States) and Dr. Jon J. van Rood (the Netherlands).

1997

WMDA starts to collect data on the number of unrelated transplants and key performance indicators of registries: the WMDA Global Trends Report.

2003

WMDA starts to analyse the serious adverse events and reactions occurring in donors and patients, which has grown into the leading biovigilance reporting service for unrelated stem cell donation.

2004

WMDA Standards are published and the first WMDA certified organisation is awarded.

2010

WMDA published white papers to describe the ecosystem of registry operations and the future. The WMDA committees actively develop services to help registries with their operations.

2015

World Marrow Donor Day was launched as an annual day to thank donors globally.

2017

WMDA merged with BMDW and NetCord and started to operate the global database with all potential cell sources for patients in need of a transplant.

2021

EMDIS was integrated into the WMDA and the development of a platform to facilitate transplant communication between registries was initiated. WMDA launches a Cell & Gene Therapy Committee.

2024

WMDA celebrated its 30-year anniversary and is committed to matching donors and patients with its advanced data management systems such as Search&Match. WMDA looks forward to exploring new treatment options while prioritising the care and support of their valued donors.

2024 ACHIEVEMENTS





DATA

- 89% of the donor records are updated weekly (71.7% daily) in WMDA's Search & Match Service
- WMDA listed 130 donor/Cord Blood Unit sources from 55 countries
- WMDA kicked off the Data Manager project: a global donor and CBU data processing pipeline



MATCHING:

- WMDA operated two matching algorithms: ATLAS with the support of Anthony Nolan/NMDP and Hap-E with the support of DKMS
- WMDA completed Match-Connect, a registry-to-registry communication solution, and published the associated technical documentation



EQUITY

- GlobalGiving Grants provided individual membership to passionate healthcare professionals in Cameroon, Indonesia and Malaysia
- World Marrow Grants provided individual membership to passionate healthcare professionals in Ethiopia and Tunisia



ADVOCACY & POLICY

• Endorsed the EU SoHO Legislation



CONNECTING

- Organised face-to-face meetings in Cape Town, South Africa, and Minneapolis, USA, with the support of NMDP
- Organised the first WMDA Asian-Pacific Registries Meeting with the support of BMDP-Singapore
- Strengthened relations with ICCBBA by attending Forum 30
- Participated in the WHO-SEAR Meeting
- Signed a Memorandum of Understanding with The Data Bank of Chinese Hematopoietic Stem Cell Donors and ISCT
- Received a gift from TX Miller to further encourage stem cell donation
- Established Pillar 5: Driving Member Engagement Safeguard and elevate the voice of our members



QUALITY

- Built on the 20 years Certification Programme and applied for ISO certification for WMDA
- WMDA 2024 Standards came into effect



COMMUNICATION

- Sent out monthly newsletters to over 1,500 healthcare professionals
- Updated the WMDA website
- WMDA's LinkedIn followers grew to 2,500 followers. WMDD and IDRC LinkedIn Pages were launched



ANNIVERSARIES

- 10 years of World Marrow Donor Day
- 20 years of the Certification Programme
- 30 years of WMDA

OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'

SEARCH, MATCH & CONNECT



42,691,777 Total records



66,415 New patient searches



18,391 Donor/Cord Blood Unit files uploaded



395 Active users

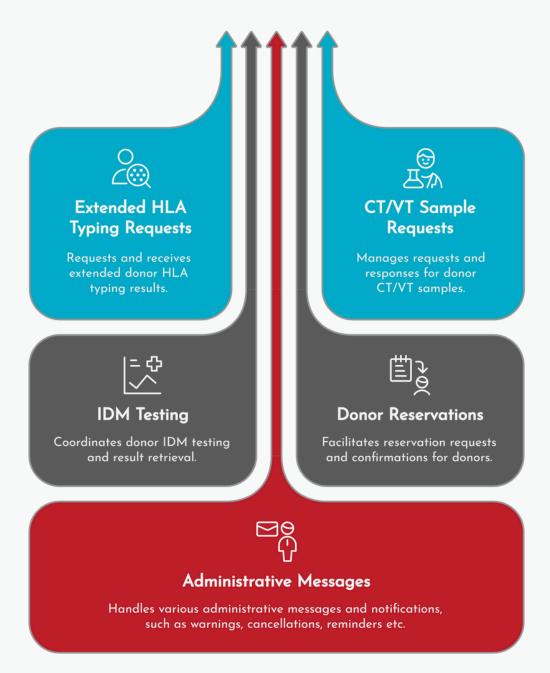


40 New API endpoints



7,447 Development hours of WMDA staff

STREAMLINED DONOR OPERATIONS



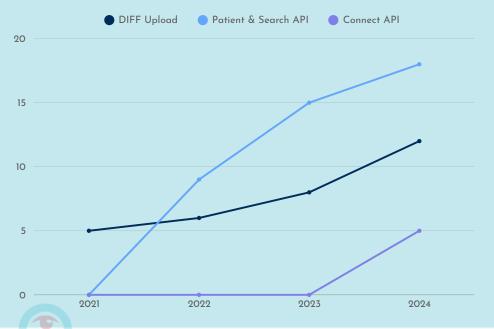
OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'

MATCH-CONNECT



- Minimal Viable Product delivery and showcase of test connection by two registries at IDRC
- Decision on transition roadmap
- Development of CBU / document exchange specs
- · Reorganisation of committees to meet requirements for future development

SEARCH, MATCH & CONNECT ADOPTION RATE



SECURITY & PRIVACY COMMITTEE



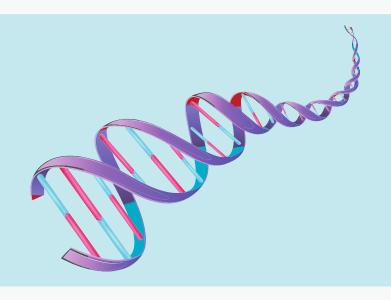
- Updated educational materials on Share addressing information security and compliance
- Provided consultation to Pillar 4 on data security compliance and the Certification Programme
- Extended data security compliance to unaffiliated transplant
- Published recommendations on Data Minimisation as well as Data Destruction and Retention



OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'



DATA DICTIONARY & DATA QUALITY COMMITTEE









- Completed a major technical overhaul of the Data Dictionary to simplify alignment across resources
- Survey on Data Quality/Trend Report monitoring Registries usage of WMDA quality metrics
- Started two RFCs to address organisation type and certification
- Investigated quality issues concerning "Bank manufacture IDs"

BIO-INFORMATICS & INNOVATION COMMITTEE







- Continued a project to evaluate matching algorithms across various donor search platforms
- Oversaw the publication of the Register of Unmet Needs (RUN) project research
- Ran a project to assess the impact and likely areas of use for Al in member organisations
- Continuously addressing the complexities of HLA data in data standards, data communications and registry informatics





OUR PILLARS: SUPPORTING GLOBAL DEVELOPMENT



MILESTONES



- The Project Audit of Courier Companies kicked off in January with the goal to set up an audit procedure, fully coordinated by WMDA. The project was successfully completed within the year, by signing on the first two courier companies that will have their onsite audit in 2025. This project will ensure a centralised certification of courier companies by WMDA, thus avoiding duplication of efforts and costs by WMDA members and the courier companies
- The Global Trends Report questionnaire was moved to inhouse management by the WMDA office, allowing for easier reporting by participating organisations and better maintenance and display of data by WMDA

EDUCATION COMMITTEE

- Meet monthly in a closed meeting
- Provides education to WMDA membership and transplant staff in areas of stem cell donation, stem cell transplantation and registry operations
- Activities and milestones in 2024:
 - 2 Search Coordinator Workshops were given (1 in-person during the WMDA/IDRC Meetings in Cape Town, South Africa, and 1 hybrid during the WMDA Meetings in Minneapolis, USA, hosted by NMDP)
 - o 1 Donor Work-up Coordination Workshop was given in person in Cape Town, South Africa
 - Helped organise the 6th EBMT/WMDA Transplant and Search Coordinator Day in Glasgow, Scotland
 - Supported updates to the WMDA Handbook
 - Supported the update of the online educational programmes for Search Coordinators and Registry Staff

EDUCATION METRICS



Search Coordinator workshops (1 in-person and 1 hybrid)



73 Students registered for the following courses:

- Donor Coordinator Course: 20
- Search Coordinator Certificate Programme Basic Level: 26
- Search Coordinator Certificate Programme Advanced Level: 24
- Search Coordinator Continuing Education Course: 3



6th EBMT/WMDA Transplant and Search Coordinator Day



44 Certificates awarded:

- Donor Coordinator Programme: 10
- Search Coordinator Certificate Programme Basic Level: 23
- Search Coordinator Certificate Programme Advanced Level: 10
- Search Coordinator Continuing Education Course: 1



OUR PILLARS: SUPPORTING GLOBAL DEVELOPMENT



6TH EBMT/WMDA TRANSPLANT AND SEARCH COORDINATOR DAY

TSCD1 EBMT-WMDA Transplant and Search Coordinators Day 1 | Data-Analysis in donor selection

- 1.1 HLA matching to improve transplant outcomes Ann-Margaret Little (United Kingdom)
- 1.2 Trends and recommendations in donor selection Irina Evseeva (United Kingdom)
- 1.3 Permissible HLA mismatches: application of HLA-EMMA Adriaan van Beek (Netherlands)

TSCD2 EBMT-WMDA Transplant and Search Coordinators Day 2 | Search Cases

- 2.1 Case 1 Rob Wynn (United Kingdom)
- 2.2 Case 2 Diarmaid O'Donghaile (Ireland)
- 2.3 Case 3 Adriana Balduzzi (Italy)



- 3.1 Comparison of HLA typing: buccal vs blood samples Neema Mayor (United Kingdom)
- 3.2 Reduced time to transplant: selecting extensively typed cord blood units Nerea Castillo (Spain)
- 3.3 Donor engagement: understanding and improving communication with generation Z. How can we strengthen their commitment?
 - Nicole Silverstolpe (Sweden)

TSCD4 EBMT-WMDA Transplant and Search Coordinators Day 4 | EBMT-WMDA partners for 30 years

- 4.1 Partners in donor care sharing patient outcome data Deborah Buk (Germany)
- 4.2 Cellular Therapy: current landscape and future directions for WMDA Salmah Ahmed (United Kingdom)
- 4.3 EBMT and WMDA: past and future collaboration Lydia Foeken (Netherlands)





OUR PILLARS: SUPPORTING GLOBAL DEVELOPMENT

CORD BLOOD OPERATIONS COMMITTEE

- Meet monthly, meeting is open to all WMDA members
- Provides guidance and best practice in the operation of public cord blood banks
- Activities and milestones in 2024:
 - A survey was created to see which data are available at CBBs and to identify obstacles that prevent banks from listing these data in the WMDA Search & Match Service. Preliminary results were presented in Cape Town, South Africa
 - Shortage of approved processing kits is on ongoing concern that's often discussed
 - Decline of FACT accredited cord blood banks is a topic of
 - Dedicated members of the group worked on a paper with postthaw recommendations, yet to be published
 - The committee met face-to-face in Cape Town, South Africa. and represented WMDA during Cord Blood Connect in Miami, USA



REGISTRY OPERATIONS & REGULATION COMMITTEE

- Meet monthly, meeting is open to all WMDA members
- Drives operational innovation to improve international collaboration, taking into account local and international legislation and regulations
- Activities and milestones in 2024:
 - A full review of the Global Trends Reporting survey was done and the questionnaire was updated accordingly
 - A full review of the Regulatory Survey and Operational Information on WMDA Share was done and the two separate pages were combined into one single page, allowing for easier maintenance by WMDA members
 - The committee met face-to-face in Cape Town, South Africa, and Minneapolis, USA

DONOR RECRUITMENT & RETENTION COMMITTEE

- Meet monthly, meeting is open to all WMDA members
- Creates practical and valuable deliverables for WMDA members that drive innovation and change for donor recruitment and retention. Specialised segmented groups work on such deliverables and report back on their work during the bi-monthly committee meetinas
- Activities and milestones in 2024:
 - The committee met face-to-face in Cape Town, South Africa, and in Minneapolis, USA, and had four online meetings
 - The committee defined areas of focus and formed dedicated groups to work on deliverables for each area of focus
 - An assessment of health questions used for donor recruitment by represented WMDA members was done

OUR PILLARS: PROMOTING DONOR CARE

SPEAR COMMITTEE & REPORTING SERVICE

WMDA ensures the reliable provision of life-saving cells while prioritising donor and patient safety, with biovigilance at the core of our operations. Since 2019, WMDA hosts an online reporting service for reporting of adverse events and reactions related to stem cell donation by unrelated and related donors or affecting product quality. Reporting of Serious Product Events and Adverse Reactions (SPEARs) is mandatory for WMDA certification. In 2024, WMDA focused on formalising this knowledge.

Educational Communication

Following multiple reports of serious incidents involving product loss during transport, the SPEAR Committee drafted an educational bulletin to prevent such similar incidents in the future. It includes recommendations on best practices, emphasising the need for thorough training, in alignment with WMDA Standards and Transport Guidelines.

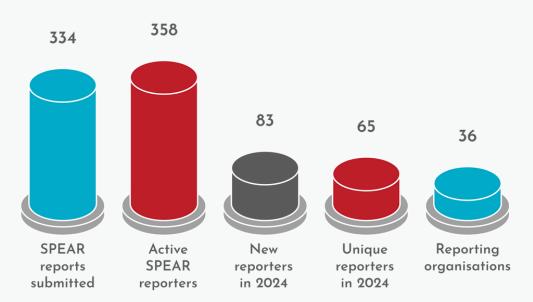
• Read it here: PDC.1305.COMM.HPC Products Missing in Transport.pdf

Handbook

A handbook for SPEAR Committee members was published with the aim of formalising the knowledge of the SPEAR Committee and aid in the assessment of incident reports. The handbook will be periodically updated.

Read it here: https://share.wmda.info/x/YotOGg

SPEAR REPORTING METRICS*





OUR PILLARS: PROMOTING DONOR CARE

CELL & GENE THERAPY COMMITTEE

The committee strengthened collaborations with professional societies and regulatory bodies.

At the Cell Therapy Liaison Meeting, a key committee member presented to the FDA on the ban of DEHP plasticisers in the manufacturing and banking of cord blood and blood products.

Collaboration with ISCT resulted in a memorandum of understanding outlining past cooperation, ongoing activities, and joint efforts to advance the field of cellular therapies.

Additionally, the committee worked on updating WMDA Standards to include best practices for donor care in cell and gene therapy (CGT), which are set to be included in the 2026 iteration of the updated Standards.

MEDICAL COMMITTEE

The Medical Committee focused on two key projects:

- 1. Donor Mental Health Assessment Progress continued in this multi-year project with a survey among donor-facing staff on their experiences with mental health assessments. The survey highlighted their training and tool requirements, guiding WMDA in developing accessible resources to support these assessments.
- 2. Update on Biosimilar Mobilising Agents Given the time since the 2019 statement and increased clinical experience with filgrastim biosimilars, the committee initiated a reassessment of current registry practices. The results of a global survey and literature review will be published early 2025.

DONOR MEDICAL SUITABILITY

The Donor Medical Suitability Committee drafts and maintains guidance pages to aid organisations in assessing the medical suitability of their potential donors. In 2024, they updated 12 existing pages and created 7 pages to cover new topics.

Most visited pages in 2024:

- 1. Single organ autoimmune disease (1768 views)
- 2. Syphilis (1660 views)
- 3.SARS-CoV-2 and COVID-19 (1306 views)





2024 CERTIFICATION BODY HIGHLIGHTS



ACTIVITY



90,57% 38,816,064 Donors and CBUs from WMDA certified organisations in the Global database



40 Organisations registered at the Certification Body



9 Organisations approved for WMDA Full Standards



Organisations approved for WMDA Benchmark L2



Organisations submitted midcycle surveillance

INSPECTIONS IN ORGANISATIONS

No. of Organisations	2020	2021	2022	2023	2024
Registered	35	43	44	42**	40
WMDA Benchmark L2	14	19	15	13	6
WMDA Full Standards	21	24	27	31	33
Expired			2	1	1

*WMDA is preparing to apply for ISO-17065 to accredit the WMDA Certification Body.

Some terminology used by ISO has been adopted: WMDA reviewers are now called WMDA evaluators.

**Due to organisational changes, in November 2023, DKMS UK and DKMS Fundacja resigned their own certification and shifted the certification under the umbrella of DKMS Registry (ION-4596).

2024 CERTIFICATION BODY HIGHLIGHTS

EDUCATION



Webinars

- WMDA 2024 Standards
- Upcoming WMDA certification programme changes to be effective on July 1st 2024
- · How can the LOI help reviewers evaluate a certification application
- Drafting the Certification Final Report
- Planning on-site and remote audits



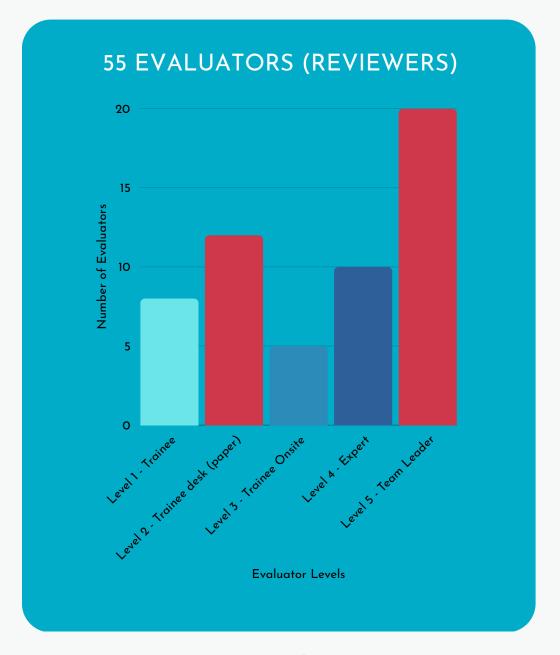
Registry Working Sessions

- Complying with New or Revised 2024 Standards
- Certification input and training for small registries
- Challenges of "Small" registries in obtaining and retaining WMDA Certification



Evaluator Training Sessions

- · How can the LOI help reviewers evaluate a certification application?
- Request for More Information (RFI)
- Increasing emphasis on security and privacy standards: how to review IT standards
- Overview of courier audit plan
- Auditing Oversight of External Service Providers
- Evaluating Key Performance Indicators
- Reviewer Challenges Identified in Cape Town, South Africa





GLOBAL MAP





ACTIONS AND STRATEGIC PLAN 2024-2028

WMDA Standards

WMDA 2024 Standards, which reflect best practices, scientific advancements, and the needs of our community were approved by the Membership Board and published on January 1st, 2024. The standards became effective on July 1st, 2024. These evidence-based standards are the basis of best practices, global collaboration, and donor care, and therefore fundamental to the work of the WMDA. .

While our commitment is to revise the WMDA Standards every four years, exceptional circumstances allow us to alter this cycle. Given the rapid development in the cell and gene therapy field and the new SoHO regulation, WMDA has shortened the revision cycle. We aim to publish a new version of the Standards in January 2027. This update will support the 2028 vision of Pillar 4, expanding donor care to CGT donors and aligning more closely with SoHO regulation to strengthen our strategic partnership with regulators. Additionally, the 2027 version will incorporate membership requests for changes more swiftly.







ISO 17065 ACCREDITATION

Our journey to comply with ISO 17065 requirements is nearing completion. Despite the challenges faced, the benefits far outweigh them.

Among the challenges we faced were resource allocation, process overhaul, training and development, documentation and change management.

Benefits of the ISO 17065 implementation:

- Enhanced credibility and trustworthiness for stakeholders, donors, partners and regulators
- Improved quality assurance: the accreditation ensures our processes and services meet international standards, leading to consistent and high-quality outcomes
- Increased efficiency: standardised procedures and clear guidelines help streamline operations, reducing errors and improving overall efficiency
- Global recognition and facilitation of international collaboration
- Continuous improvement: the ISO framework encourages ongoing evaluation and continuous improvement of our processes, fostering a culture of excellence

Significant changes in 2024 involve:

- Changes in terms used for status: Benchmark L1, Benchmark L2, Full Standards
- Standards are linked to the four services offered by registries
 - Receive requests for searches; maintain searchable database
 - Coordinate provision of adult volunteer donors as a source of stem cells
 - Coordinate provision of umbilical cord blood units as a source of stem cells
 - Provide support for search requests from registry's transplant centres
- Changes in the Certification Marks

Submission of the ISO application to the Dutch Accreditation Council took place on December 9th, 2024.





WMDA CERTIFIED ORGANISATIONS



Organisation	Certification Status
Anthony Nolan	WMDA Full Standards certified (D/C) 2020
Austrian Bone Marrow Donor Registry	WMDA Full Standards certified (D) 2020
Blutspende SRK Schweiz AG	WMDA Full Standards certified (D/C) 2020
Buddhist Tzu Chi Stem Cells Center - BTCSCC	WMDA Full Standards certified (D/C) 2017
Canadian Blood Services Stem Cell Registry	WMDA Full Standards certified (D/C) 2017
CEDACE/Portuguese BMD Registry	WMDA Benchmark L2 certified (D) 2020
Chinese Marrow Donor Program	WMDA Benchmark L2 certified (D) 2017
Cyprus Bone Marrow Donor Registry	WMDA Full Standards certified (D) 2020
Czech National Marrow Donor Registry Plzeň	WMDA Full Standards certified (D) 2020
Czech Stem Cells Registry Prague (CSCR)	WMDA Full Standards certified (D) 2020
Danish Stem Cell Donors - East (DSDE)	WMDA Full Standards certified (D) 2020
Danish Stem Cell Donors - West	WMDA Full Standards certified (D) 2020
DKMS Registry gGmbH	WMDA Benchmark L2 certified (D) 2020
Ezer Mizion Bone Marrow Donor Registry	WMDA Full Standards certified (D) 2020
Finnish Stem Cell Registry	WMDA Full Standards certified (D/C) 2020



WMDA CERTIFIED ORGANISATIONS



Organisation	Certification Status
France Greffe de Moelle Registry - FGM	WMDA Full Standards certified (D/C) 2020
Gift of Life Marrow Registry	WMDA Full Standards certified (D) 2020
Hema-Quebec Stem Cell Donor Registry	WMDA Full Standards certified (D/C) 2017
Hong Kong Bone Marrow Donor Registry	WMDA Benchmark L2 certified (D) 2020
Irish Unrelated Bone Marrow Registry	WMDA Full Standards certified (D) 2020
Italian Bone Marrow Donor Registry	WMDA Full Standards certified (D/C) 2020
JMDP - Japan Marrow Donor Program	WMDA Full Standards certified (D) 2020
Marrow Donor Program Registry Belgium	WMDA Full Standards certified (D/C) 2020
Matchis Foundation	WMDA Full Standards certified (D) 2020
National Registry of Hematopoietic Stem Cells Voluntary Donors	WMDA Benchmark L2 certified (D) 2020
New Zealand Bone Marrow Donor Registry	WMDA Full Standards certified (D) 2020
NHS Blood and Transplant - BBMR	WMDA Full Standards certified (D/C) 2020
NMDP	WMDA Full Standards certified (D/C) 2020
Norwegian Bone Marrow Donor Registry	WMDA Full Standards certified (D) 2020
REDOME - Registro Nacional de Doadores Voluntarios de Medula Ossea	WMDA Full Standards certified (D) 2020







Organisation	Certification Status
Registro de Donantes de Médula Ósea (REDMO)	WMDA Full Standards certified (D/C) 2020
Saudi Stem Cells Donor Registry	WMDA Benchmark L2 certified (D) 2020
Singapore BMDP	WMDA Full Standards certified (D) 2020
Singapore Cord Blood Bank (CORD)	WMDA Benchmark L2 certified (C) 2017
South African Bone Marrow Registry	WMDA Full Standards certified (D) 2020
Stem Cell Donors Australia	WMDA Full Standards certified (D/C) 2020
Thai National Stem Cell Donor Registry	WMDA Full Standards certified (D) 2020
Tobias Registry	WMDA Full Standards certified (D/C) 2020
Welsh Bone Marrow Donor Registry	WMDA Full Standards certified (D) 2017
ZKRD - Zentrales Knochenmarkspender-Register Deutschland	WMDA Full Standards certified (D/C) 2017

WMDA has established new terms for the different certification levels which came into effect in July 2024:



Benchmark L1: previously called certification



Benchmark L2: previously called qualification



Full Standards: previously called accreditation

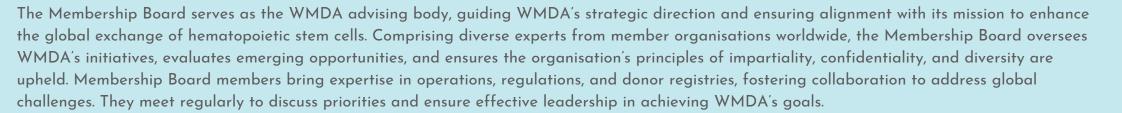
OUR PILLARS: DRIVING MEMBER ENGAGEMENT



SAFEGUARD AND ELEVATE THE VOICE OF OUR MEMBERS

To better serve our members, the WMDA Membership Board decided to split WMDA office operations from membership affairs creating a fifth pillar. The Member Engagement Pillar at WMDA fosters engagement and inclusivity by supporting members with opportunities for dialogue, collaboration, and participation. It oversees governance processes, such as nominations and voting, ensuring transparency and fairness. Key responsibilities include supporting committees and organising General Membership Meetings. These initiatives strengthen community bonds and align strategic priorities.

MEMBERSHIP BOARD





2 Corporate Members

WMDA welcomed 2 new Corporate Members in 2024. Corporate Membership is open to organisations that have an interest in actively participating in WMDA activities. Organisations may become a member of the Association if they are supportive of the WMDA Standards.





- 108 Member organisations with an ION (Issuing Organization Number, provided by ICCBBA)*.
- Regular Members: Organisations participating in two-way exchange of blood-forming stem cell products for patients in need of a transplantation. Member has voting rights.
- Provisional Members: Organisations that would be eligible for regular membership or an organisation that is not directly providing blood-forming stem cells on a national and international level. No voting rights.
- Honorary Members: Individuals in recognition of their exceptional contribution to the discipline of blood-forming stem cell donation. No voting rights.

OUR PILLARS: MEMBER ENGAGEMENT



IMPARTIALITY COMMITTEE

Impartiality is a core value of the WMDA and its Certification Body. The WMDA Membership Board and all personnel involved in WMDA projects and in WMDA's certification process are committed to maintaining impartiality. On an ongoing basis, the WMDA Membership Board identifies and evaluates threats to impartiality and implements safeguarding measures to mitigate any identified risk. This mechanism is overseen since 2023 by the WMDA Impartiality Committee. It ensures the proper management and safeguarding of impartiality, confidentiality, and diversity within the organisation. It monitors these values to maintain fairness, trust, and inclusivity across WMDA's operations and decision-making processes.

Recommendations made to the Membership Board in 2024:

- •Add wording on impartiality on the WMDA Share
- Add a 'commitment to impartiality' statement to the WMDA website
- •Implement a clear role for the Impartiality Officers in the complaints and appeals protocol
- Implementation of Pillar 4 best practices for impartial votina
- •Review of WMDA Certification Programme applications
- Automated distribution of COI agreements

Committee members

1st Report delivered

REGULATORY AFFAIRS COMMITTEE

9 Committee Members

Meetings

Scope identified:

Europe:

- SoHO regulation
- European health data space
- Customs challenge with the UK

- FDA donor eligibility guidance
- FDA manufacturing license

Established in 2024, the Regulatory Affairs Committee works together with regulators to advocate for WMDA's principles and addresses challenges and opportunities in established and evolving global regulatory environments. It's aims:

- To serve the membership by providing information regarding regulations, standards and guidance documents and presenting the regulatory concerns of the membership back to the regulatory agencies;
- To provide direction and leadership to WMDA educational initiatives;
- To provide tactical guidance for engagement with regulatory agencies;
- To facilitate cooperation between health authorities between different countries.



PUBLICLY AVAILABLE INFORMATION

WMDA is the leading organisation in the area of donor care and donor selection. WMDA provides online educational materials to professionals at all career stages to improve their knowledge. The courses are highly valued by participants.

To engage the WMDA membership, the WMDA sends out monthly newsletters. In addition, WMDA connects members through the membership platform (WMDA Share). The pillar coordinators drive discussions on improving collaboration and services to the members. In 2024, WMDA hosted two meetings (of which one hybrid) to facilitate the continuation of the projects.

IMPORTANT INFORMATION RESOURCES

- Summary slides Global Trends Report
- Donor Medical Suitability Wiki
- Statistics on WMDA's Search & Match Service
- Information about WMDA member organisations

COMMUNICATION CHANNELS

- WMDA website
- WMDD website
- LinkedIn
- X (@WMDA_Office)
- Facebook

KEY PUBLICATIONS

- Hamad et al., 2024: Remuneration of donors for cell and gene therapies: an update on the principles and perspective of the World Marrow Donor Association. https://pubmed.ncbi.nlm.nih.gov/38396211/
- Hofman et al., 2024: World Marrow Donor Association guidelines for the reporting of novel HLA alleles. https://pubmed.ncbi.nlm.nih.gov/37038092/
- EBMT Handbook: Chapter 3: Registries: A Bridge Between Donor and Recipient. https://www.ebmt.org/sites/default/files/2024-04/978-3-031-44080-9.pdf

WMDA MATCH-CONNECT

Match-Connect revolutionises donor and cord blood data management by automating processes, reducing manual workload, and improving selection efficiency.

- Global Reach: Members can access stem cell source data from 130 organisations across 55 countries in one unified system.
- Automated Data Exchange: Seamlessly synchronises donor and cord blood unit (CBU) data across systems, eliminating manual data entry and reducing errors.
- Customisable (Local) Match Lists: Advanced filtering options allow coordinators to refine searches, ensuring optimal donor selection while reducing search time.
- Effortless Integration: Members can implement API endpoints to automate patient management, donor search and stem cell procurement.
- Smarter Matching: In combination with the Search & Match Service, Match-Connect uses two matching algorithms for better donor comparisons.

By streamlining workflows and enhancing data accuracy, Match-Connect accelerates transplants and improves patient outcomes.

HARMONISING AND BUILDING KNOWLEDGE

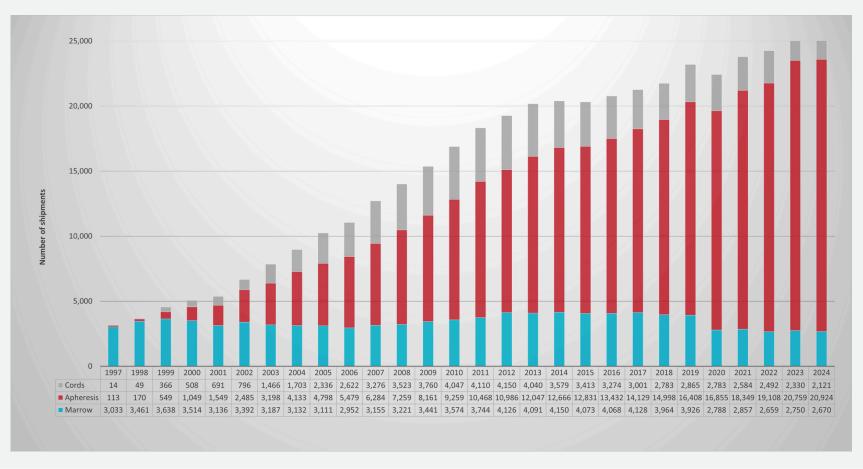
GLOBAL TRENDS REPORT

Preliminary data: in 2024 2,152,182 new unrelated volunteer donors were recruited and 11,789 new Cord Blood Units were banked. Find more interesting statistics in the Global Trends Report 2024 <u>here</u>.



Unrelated HPC Marrow, HPC Apheresis and HPC Cords shipped worldwide 1997-2024







HARMONISING AND BUILDING KNOWLEDGE

14TH IDRC & WMDA GLOBAL MEETING CAPE TOWN, SOUTH AFRICA | 25-29 JUNE 2024

The International Donor Registry Conference is a gathering of the scientific community involved in cellular therapy and stem cell donation.

- Total number of participants registered 300 (excl. WMDA staff)
- Countries represented at the 14th IDRC
- Submitted abstracts
- Average score of participants for the event in general (out of 10)
- NMDP hosted African stem cell transplant community lunch
- Anthony Nolan supported healthcare professionals in Low and Lower-Middle World Bank Indexed Countries attended
- Orca Bio supported representative from the Emerging Moroccan Stem Cell Registry attended

Thank you to the host registry:





WORLD MARROW DONOR DAY 21 SEPTEMBER 2024



In 2024 we celebrated the 10-year anniversary of World Marrow Donor Day. WMDA would like to thank gold partner NMDP and bronze partner Gift of Life Marrow Registry for supporting the event. NMDP made a grant possible that has provided Centre National de Greffe de Moelle Osseuse Tunis with access to search in WMDA's Search & Match Service. Gift of Life Marrow Registry made a grant possible that has given the Ethiopian Blood and Tissue Bank Service access to Share and other educational materials. Be sure to join us on 20 September 2025 to celebrate #WMDD25!

ASIA-PACIFIC REGISTRIES MEETING SINGAPORE | 9 OCTOBER 2024

WMDA, together with Singapore BMDP, hosted the first WMDA Asia-Pacific Registries Meeting on 9 October 2024. The meeting had roundtable discussions on donor recruitment, collection, and patient search. We had open conversations with the end goal of supporting the development of registries in the region and arming them with best practices to help them grow.

WMDA MIDTERM MEETING MINNEAPOLIS, USA | 6-7 NOVEMBER 2024

A big thank you to NMDP for revitalising the WMDA MidTerm Meeting! It was the second hybrid experience for WMDA in Minneapolis, so members could participate face-to-face and online.



DATA SECURITY

WMDA facilitates its members by providing tools to ensure compliance with international security standards. This is achieved with the support of the WMDA Security & Privacy Committee. The tools are as follows:

- Data Transmission and Use Agreement: a legal contract that is signed by all listing organisations. The agreement is designed with international privacy law harmonisation in mind and uses common principles and terminology that is consistent or complimentary to national privacy laws. In 2024, the scope expanded now including (unaffiliated) Transplant Centres
- · A set of security standards that are implemented in the WMDA Certification Programme
- Kicked off an assessment programme based on existing WMDA Standards to determine uncertified members' compliance to information security requirements prior to Match-Connect implementation
- In 2024, WMDA staff assessed various regulatory frameworks for information security and determined that implementation of ISO 27001 would be prioritised in 2025





MULTI-FACTOR AUTHENTICATION

WMDA staff and users of WMDA applications can only access the information through multi-factor authentication (MFA). This security update was implemented when the new version of the WMDA Search & Match Service went live in July 2022. As registries are providing complete datasets on their donor and cord blood data, it was important to implement additional security measures. In 2023, the SPEAR reporting tool also benefitted from MFA. In 2024, it was rolled out to the updated Data Manager application, previously known as Data Upload. The end goal of MFA across WMDA applications is to provide our members with a Single Sign-On portal.

TREASURER'S STATEMENT

Our financial report can be found on the next pages. The full report including the statement of De Hooge Waerder Accountants is available on request (mail@wmda.info).

Dear Members,

I am pleased to present the financial report for 2024. This year, the WMDA recorded a positive result of € 190.790, compared to a budgeted positive result of € 58.824 and an actual loss of € 40.308 in 2023. This favourable outcome was mainly because it took time to recruit new WMDA staff members and due to lower-than-expected meeting expenses, especially after the reconciliation of costs and income related to the IDRC in South Africa. A big thank you to the team of the South African Bone Marrow Registry.

Income Statement

The total net income for 2024 was € 2.502.532, which marks a significant increase from € 2.392.671 in 2023. This growth is due to changes in the membership contribution introduced in early 2024. Under the new model, higher contributions are made by larger registries with greater of number of shipments, creating a fairer distribution of financial responsibilities.

However, the rise in income was accompanied by a growth in bad debts, which increased to € 92.645 from € 14.885 in 2024, due to international bans (e.g. Iran) and termination of registries. To mitigate the impact of increased fees, discounts of € 48.781 were granted to registries that were significantly affected by the new fee structure.

Staff expenses rose from € 1.319.438 in 2023 to € 1.562.494 in 2024, primarily due to salary adjustments according to the Collective Labour Agreement University Hospitals in the Netherlands, expansion of the team: Administrative Support Certification Body, Medical Advisor and Executive Assistant. WMDA has also invested in ISO certification, which cost € 94.253. These investments are expected to improve acceptance of the WMDA Certification Programme by Regulatory Authorities.

We remain very grateful to DKMS, NMDP and Anthony Nolan for covering our maintenance and hosting costs of our matching programmes: Hap-E Search and ATLAS. In addition, we thank NMDP for their expert support during the WMDA MidTerm Meeting.

Balance Sheet

The reserves increased with 14,7% compared with the end of 2023. With almost no debt apart from regular trade payables, WMDA's financial position remains strong.

Allocated reserves now total € 1.487.944, designated for operation of Certification Body € 100.800, implementation of Match-Connect € 237.864, pilot project on Artificial Intelligence € 30.000, and continuity reserves € 846.539.

Risk Overview

The WMDA faces several external risks in the upcoming year. Political uncertainty in the world may contribute to financial volatility and inflation pressures in 2025 & 2026.

To address these challenges, the Management Board and the Non-Executive Council will focus on risk reduction, especially in the areas of service transition, Information Technology infrastructure reliability, and the development of secure and user-friendly first-line support services.

Future Outlook

As of January 1st, 2025, WMDA will be operating under a new governance structure. This important change was the result of collaborative input from WMDA members. WMDA is now supported by a three-member Non-Executive Council, which enhances oversight, governance, and strategic guidance while maintaining active member engagement.

To further professionalise WMDA's work, the WMDA team will be expanded with new roles, including a Medical Advisor, and increased support for our CEO and pillar coordinators. We are especially grateful to our volunteers, who serve as reviewers for the Certification Body, committee members, and leaders within the Membership Board. Their expertise and dedication are essential to WMDA's success.

Closing Remarks

The WMDA is in a strong financial and operational position to support the evolving needs of its members and the broader transplant community. We thank you for your continued trust and contributions.

FINANCIAL REPORT

WMDA is an Association under Dutch law. Profits generated are invested in activities to serve the community. The WMDA members contribute on a voluntary basis to the association's work. The WMDA office has its own employment arrangements. The employees in the WMDA office function according to various job profiles, which are linked to the remuneration policy of the University Hospitals in the Netherlands.

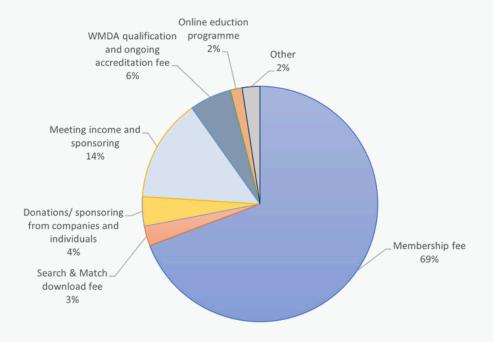
WMDA INCOME

In 2024 the total income was higher than in 2023. The increase of income is a result of the increase in shipments (see 'product fee')*.

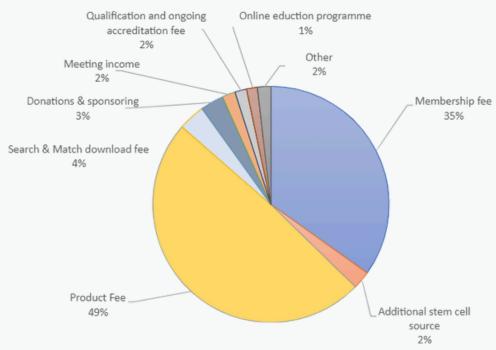
Thanks to the generous donations of our partners! In 2024. WMDA received support from: DKMS (supporting Hap-E), Anthony Nolan and NMDP (supporting ATLAS), TxMiller Foundation, Miltenyi Biotec, GenDx, Orca Bio and Histogenetics.

WMDA is registered under Dutch law and recognised as an ANBI (Algemeen Nut Beogende Instelling/Public Benefit Organisation) by the Dutch tax authorities.

SPECIFICATION OF WMDA **INCOME 2023**



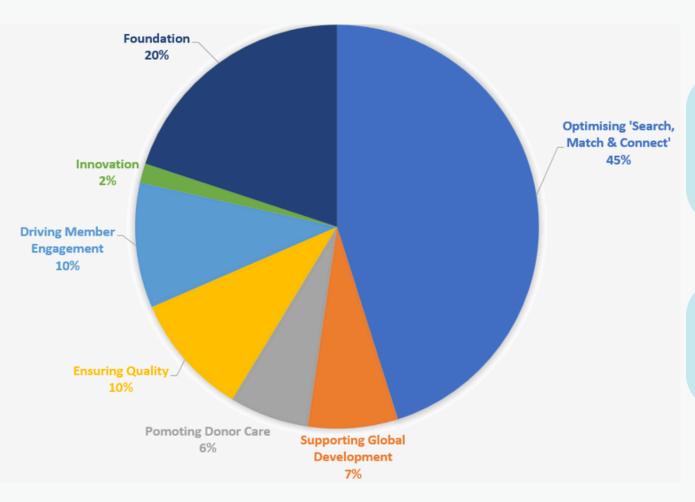
SPECIFICATION OF WMDA **INCOME 2024**



WMDA OFFICE HOURS

FINANCIAL REPORT

In 2024, the WMDA office worked on multiple projects to assist the WMDA Membership Board, Committees and User Groups. The WMDA office hours are specified in alignment with the pillar structure.



WMDA maximises time spent on its projects and minimises indirect costs. Law regulations and membership requirements as well as risks of fraud contribute to a complex environment that requires an accurate administrative organisation and a professional ICT infrastructure.

A large proportion of the staff costs in the Netherlands are related to the WMDA aims. The category Foundation includes costs amongst other HR, fundraising, security and finance administration.

BALANCE SHEET AS AT 31 DECEMBER 2024

Balance sheet after proposal distribution of result



World Marrow Donor Association, established in Leiden

2 BALANCE SHEET AS AT 31 DECEMBER 2024

ASSETS (After profit appropriation)		31 December 2024		31 December 2023
(€	€	€	€
Non-current assets				
Fixed assets				
Tangible fixed assets	22,672		19,173	
		22,672		19,173
Current assets				
Receivables				
Trade receivables	60,140		27,724	
Receivables from other accounts	7,813		5,414	
Prepayments and accrued income	12,396		78,089	
		80,349		111,227
Cash and bank		1,919,585		1,500,721
Total		2,022,606		1,631,121

All WMDA members are committed to pay their membership fee. WMDA has a few members who are not able to pay their membership fee due to bank sanctions.

The Financial Statements 2024 have been prepared by WMDA's accounting office.

BALANCE SHEET AS AT 31 DECEMBER 2024

Balance sheet after proposal distribution of result

FINANCIAL REPORT



World Marrow Donor Association, established in Leiden

EOUITY	ITARTI	ITTES

(After profit appropriation)		31 December 2024		31 December 2023
	€	€	€	€
Equity				
Other reserves	1,487,944		1,297,153	
		1,487,944		1,297,153
Current liabilities				
Debts to suppliers and trade credits	182,315		71,791	
Taxes and social insurances	104,147		70,964	
Debts to pensions	889		15,033	
Other debts	145,758		118,483	
Accruals	101,553		57,697	
		534,662		333,968
Total		2,022,606		1,631,121

The WMDA has marked continuity reserves in place to enable WMDA to meet its obligations in the long-term, in case of stagnated income or after an incident with an impact on expenses. The Certification Body has reserves for the continuity of the WMDA Certification Programme. Earmarked reserves are the reserves of NetCord and BMDW.

The Financial Statements 2024 have been prepared by WMDA's accounting office.



STATEMENT OF BENEFITS AND EXPENSES OVER 2024

Balance sheet after proposal distribution of result



World Marrow Donor Association, established in Leiden

3 INCOME STATEMENT FOR THE YEAR ENDED 2024

	Budget 2024	2024	2023
	€	€	€
Benefits	2,510,180	2,502,531	2,392,671
Operating income	2,510,180	2,502,531	2,392,671
Expenditure on the goods and services	344,799	378,562	923,203
Employee benefits			
Wages and salaries	1,611,593	1,384,448	1,076,371
Social security contributions	142,064	145,256	216,733
Depreciation			
Depreciations of tangible assets	10,000	6,982	7,332
Other operating expenses			
Other personnel related expenses	123,137	32,790	26,334
Accommodation costs	36,484	40,125	33,205
Sales related expenses	50,000	121,325	36,709
Office related expenses	43,003	34,749	42,030
General expenses	56,203	169,420	56,778
Administrative expenses	33,568	22,977	27,961
Operating expenses	2,450,851	2,336,634	2,446,656
Operating result	59,329	165,897	-53,985
Financial income and expense			
Interest income and related income	5,000	27,643	15,637
Interest expenses and related expenses	-5,505	-2,750	-1,960
Result	58,824	190,790	-40,308
Result allocation			
Allocated result		190,790	-40,308

The Financial Statements 2024 have been prepared by WMDA's accounting office.



WORK PLAN AND BUDGET

Based on WMDA's strategy, input was collected from WMDA members for the 2025 Work Plan & Budget. Input was provided on two levels:

- 1. Ongoing projects and their proposed direction in 2025;
- 2. New initiatives within existing programmes.

The approved budget is summarised in the table.

	2025
Income	EURO 2,696,749
Expenses	EURO 2,693,133
Estimated result	EURO 3,616



ENSURING FUTURE READINESS OF WMDA

WMDA has launched its 2023-2028 Strategy, setting a course for growth and innovation in an evolving and dynamic landscape. As demand for WMDA's services increases, our global community continues to expand, reinforcing our commitment to saving more lives through collaboration, technology, and high standards of care.

Two key themes drive our strategy:

- 1. A global community connected by technology, data, quality and education.
- 2. The promotion of donor safety, and the role that registries play to balance donor rights and patient care.

These priorities guide our strategic pillars:

- Optimising 'Search, Match & Connect': Delivering Match-Connect to modernise communication between registries.
- Supporting Global Development: Expanding education and sharing best practices in donor recruitment and registry operations.
- Promoting Donor Care: Addressing donor well-being across all donation settings.
- Ensuring Quality Certification Body: Encouraging WMDA Certification to uphold professional standards.
- Driving Member Engagement: Safeguarding and elevating the voice of our members.

Looking ahead, WMDA embraces information technology to enhance responsiveness to the needs of donors and patients. By adopting new tools and artificial intelligence, WMDA can enhance its services and support, streamlining operations. Furthermore, the restructuring of WMDA, through the adoption of new Articles of Association and an updated Operational Manual, ensures compliance with Dutch law, fostering greater efficiency and sustainability in WMDA's mission. Together, these efforts strengthen our ability to serve members, registries, donors and ultimately, the patients who depend on us.



WMDA World Marrow Donor Association

Publisher: 2025 © WMDA

WMDA (World Marrow Donor Association)
Schipholweg 55, unit 17-19, 1st floor
2316 ZL Leiden
The Netherlands

T: +31 88 505 7900 E: mail@wmda.info W: www.wmda.info

