

WMDA

Finance & Activities Report 2023



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2023 AT-A-GLANCE

WMDA NUMBERS



>41,000,000
Donors



>38,000
New patients annually



>24,000
Unrelated transplant recipients



102
Participating organisations



49
Ongoing projects



42
Registries certified under WMDA Certification Program



2
In-person membership meetings

FOREWORD PRESIDENT

Dear WMDA member,

I am privileged to introduce the 2023 WMDA Finance & Activities Report. All the WMDA staff volunteers and staff can be proud of our recent WMDA activities, about which you can read in the coming pages. A highlight of the year was the successful IDRC & WMDA Global Meeting in Hanau in June. This represented a long overdue opportunity for a face-to-face IDRC meeting since the disruptions of the COVID-19 pandemic. I'm grateful for the support of DKMS and to all the attendees, staff and sponsors who helped to make this an interactive, fun, and academically oriented meeting.

I would like to extend our thanks to Dr. Bronwen Shaw, who completed her appointment as Past-President. Bronwen's positive impact to the WMDA is immeasurable, and for that we are ever grateful. In 2024 we welcomed Jay Feinberg as President-Elect, and we look forward to working with him. Since the creation of the WMDA new strategic plans, our major focus will be on ensuring that WMDA's governance structure is a modern, efficient, and responsive one to benefit our members and, ultimately, the donors and patients that we serve.

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

WHO WE ARE

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 four different areas:



Optimising
'Search, Match & Connect'



Supporting
Global Development



Promoting
Donor Care



Ensuring
Quality

FUNDING

WMDA is funded through a variety of sources. In 2023, the membership fee was the largest source of income.

WMDA BOARD



Matthew Seftel, CA
President



Bronwen Shaw, USA
Immediate Past-President



Jaap Dijkman, NL
Treasurer



Mike McCullough, USA
Search, Match & Connect



Matti Korhonen, FI
Search, Match & Connect



Dunia Jawdat, SA
Global Development



Thilo Mengling, DE
Donor Care



Garth Healey, AU
Quality



Lydia Foeken, NL
Executive Director

OUR MISSION

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 well-being 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.

OUR HISTORY

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). A first scientific publication on international exchange of cells was published.

1997

WMDA starts to collect data on the number of unrelated transplants and key performance indicators of registries, known as 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. Following this, WMDA 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.

2022/
2023

WMDA strengthened its position on donor care by also stepping into the area of cell & gene therapy.

2023 ACHIEVEMENTS



DATA

- 89% of the donor records are updated weekly (71.6% daily) in WMDA's Search & Match Service
- WMDA members facilitated over 24,000 unrelated transplants
- WMDA listed 138 donor/Cord Blood Unit sources from 57 countries



MATCHING:

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



EQUITY

- Orca Bio and PHSE sponsored attendance of two emerging registries for attending the WMDA meeting
- Organised a hybrid meeting that could be attended for free
- Organised monthly educational webinars with the support of Ontime Courier GmbH
- Visited the Ministry of Georgia to explore possibilities of starting up a Georgian donor registry



ADVOCACY & POLICY

- Actively participated in the development of the proposed EU SoHO legislation with the support of DKMS



CONNECTING

- Organised two face-to-face meetings in Hanau and Minneapolis with the support of DKMS and NMDP
- Published recommendations for disclosing genetic findings of potential donor origin following HCT
- Organised the 5th edition of EBMT/WMDA Transplant & Search Coordinator Day
- Set up a crisis communication procedure in case unexpected events occur
- Celebrated World Marrow Donor Day to thank donors globally



QUALITY

- Processed 27 applications for evaluation
- Published a new version of the WMDA Standards
- Created awareness for the shortage of bone marrow collection kits globally
- Set up a legal framework for international exchange of donor and patient data
- Published recommendations on how to report new alleles
- WMDA rolled out multi-factor authentication to multiple applications



COMMUNICATION

- Sent out monthly newsletters to circa 1,500 healthcare professionals
- Updated the WMDA website
- Doubled the amount of followers on LinkedIn

OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'

SEARCH & MATCH SERVICE



41,654,971
Total records



38,863
New patient searches



14,014
Donor/Cord Blood Unit files uploaded



536
Active users



92
Application testers



3
Webinars

NEW FEATURES ADDED IN 2023:

- An additional probabilistic matching algorithm, ATLAS
- Automatic refresh of patient searches every 24hrs
- Mechanism to only view records that changed since a specified date and time
- Smart handling of novel alleles discovered in patient HLA-typing
- The ability to set user specific preferences that are applied to all future searches
- Filters for inexplicable donors/CBUs and WMDA accreditation status



OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT' 🔍

MATCH-CONNECT

13
Steering committee members

73
Voting User Group members

49
Meetings

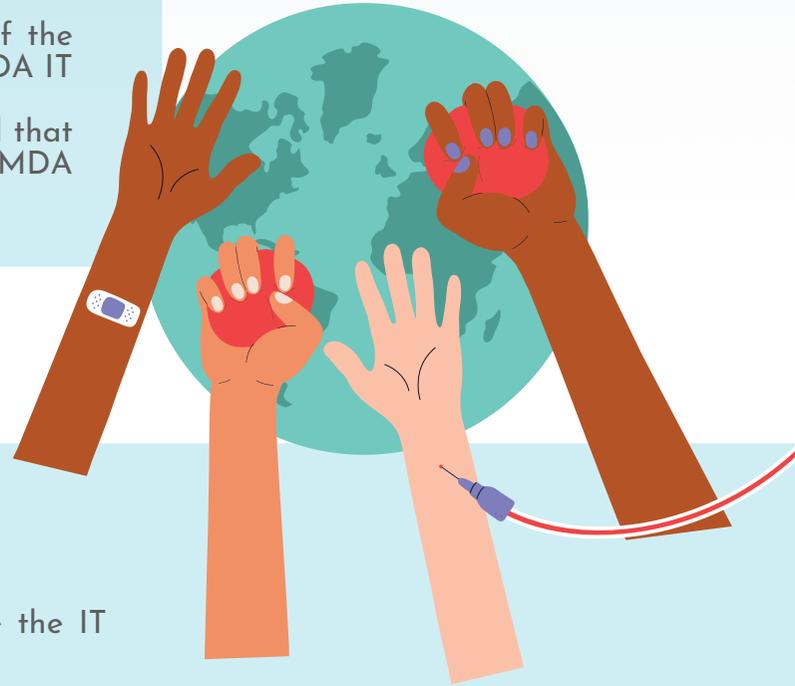
4
User Group and Technical Advisory Group meetings

Match-Connect Semantics v1.01 published by Steering Committee:

- Defines the message flows when using APIs for registry-to-registry communication
- Detailed technical documentation & implementation specifications
- Strengthen through review by Technical Advisory Group (TAG)

A "pilot" programme initiated for four early adopters of the technology with regular check-ins and support from WMDA IT team

A new Request for Change (RFC) procedure was defined that aligns with other similar requests within the WMDA community



SECURITY & PRIVACY COMMITTEE

9
Committee members

14
Meetings

2
Peer Review assessments completed

- Collaborated with Pillar 4: Ensuring Quality to update the IT Standards
- Input to the technical design of Match-Connect
- Oversaw roll-out of updated Data Use and Transmission Agreement to membership
- Drafted 2 new data security recommendations



OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'



DATA DICTIONARY & DATA QUALITY COMMITTEE

9
Committee members

1
RFC finalised

976
Data fields in dictionary

5
Resources supported

- Simplified the "Request for Change" form used by membership
- Finalised the ready-to-ship-flag (Extensively tested units)
- Started a major overhaul of the technical back of the Data Dictionary to simplify alignment across resources especially when applying changes
- Initiated field definition alignment with Match-Connect

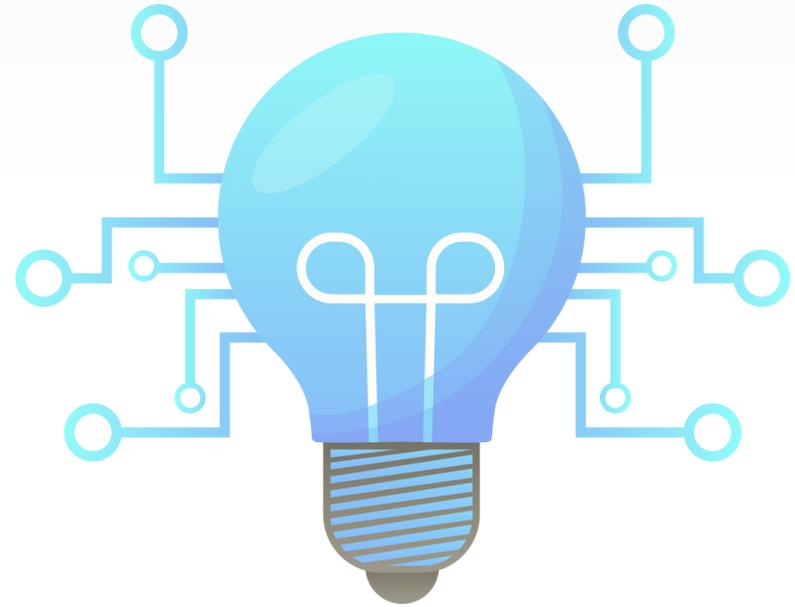
BIOINFORMATICS & INNOVATION COMMITTEE

15
Committee members

1
Journal publication

3
Active projects

- Initiated a project to evaluate algorithms as they are used in their respective productive environments, such as WMDA's Search & Match Service
- Oversaw the project group investigating the feasibility of a "Donor Readiness Score"
- Oversaw the ongoing progress of the Register of Unmet Needs (RUN) project
- Published a manuscript in the journal, HLA, providing guidelines for reporting novel alleles
- Continuously addressing the complexities of HLA data in data standards, data communications and registry informatics



EDUCATION



66

Students registered for the following courses:

- Donor Coordinator Course: 20
- Search Coordinator Certificate Programme - Basic Level: 34
- Search Coordinator Certificate Programme - Advanced Level: 11
- Search Coordinator Continuing Education Course: 1



2

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



60

Certificates awarded:

- Donor Coordinator Programme: 16
- Search Coordinator Certificate Programme - Basic Level: 29
- Search Coordinator Certificate Programme - Advanced Level: 13
- Search Coordinator Continuing Education Course: 2



Educational webinars:

20231205 - P1: [ATLAS - New donor search algorithm on WMDA Search & Match](#) by Zabeen Patel | [Slides](#)

20231024 - P2: [KPI Report 2022](#) by Sigal Manor | [Slides](#)

20230810 - P4: [Demystifying WMDA IT Standards](#) by Rob Hanson | [Slides](#)

20230713 - P2: [World Marrow Donor Day](#) by Martine Schuit-van Riessen | [Slides](#)

20230608 - P2: [Global Trends Report](#) by Monique Jöris | [Slides](#)

20230413 - P4: [Accreditation Program Team Leader Role - On Site/Remote Audits](#) by Janet Parks | [Slides](#)

20230309 - Foundation: [Warm-up IDRC](#) by Lydia Foeken, with Ann O'Leary and Meghann Cody | [Slides](#)

20230209 - P1: [Search & Match - Tips and Tricks when using the updated S&M Service](#) by Alicia Venter | [Slides](#)

EDUCATION



WMDA co-organised with EBMT the 5th EBMT/WMDA Transplant & Search Coordinator Day with the following sessions: *Session 1 and 2 have one full recording of all lectures combined. Session 3 and 4 have separate recordings for each presentation.*

1. [Introduction to Donor Optimisation](#) - Lydia Foeken and Anna Sureda
 - a. A World of Options: Bio-Informatics and Tools - Alicia Venter
 - b. Best practice for donor reservations - Gabi Rall
 - c. The role of mismatched donors in the times of PTCy - Bronwen Shaw
2. [Solving complicated cases: the importance of good collaboration](#) - Juliana Villa and Christian Chabannon
 - a. Complicated Search case: Spain - Mavi Diaz and Maria Calbacho Robles
 - b. Complicated Search case: Israel - Moshe Israeli
 - c. Complicated Search case: Romania - Zsofia Varady
3. [Motivating Donors \(introduction topic and speakers\)- Evelyne Marry](#)
 - a. [Targeted donor recruitment to diversify the global registry - Sarah Pinseel](#)
 - b. [Donors' availability: before and after CT - Tigran Torosian](#)
 - c. [Donor Follow-up and SPEARs - Grazia Nicoloso](#)
 - d. [Summary and conclusion - Nina Worel](#)
4. [Regulatory Affairs \(introduction topic and speakers\)- Yehudit Eitiel](#)
 - a. [Upcoming SoHo regulation: follow-up of related and unrelated donors - Evelyne Marry](#)
 - b. [WMDA accreditation - a way to facilitate import and export of hematopoietic stem cells - Nicoletta Sacchi](#)
 - c. [Data protection of donor and patients - Matti Korhonen](#)
 - d. [Summary and conclusion - Iris Bargalló](#)



OTHER ACHIEVEMENTS

- Implementation new pillar structure and governance
- Launch of new [WMDA website](#)
- Launch of [WMDA webshop](#)
- Fully automated process installed for purchase and access Educational Courses
- Start monthly meetings for Registry Operations and Regulation Committee
- WMDA KPIs re-evaluated
- Revised and revived International Emergency Service
- 78 WMDA members participate as volunteers within Supporting Global Development

NEW WMDA MEMBERS



The Ukrainian Bone Marrow Registry became a provisional member in March 2023. On 31st December 2023, the registry listed 11,290 donor records.

SPEAR COMMITTEE & REPORTING SERVICE

WMDA hosts an online reporting system for reporting of adverse events and reactions (SPEARs) related to stem cell donation by unrelated and related donors or affecting product quality. With the SPEAR system, we aim to provide insight into the frequency of complications and, if possible, the opportunities to prevent them.

After close collaboration with a user interface and experience designer, 2023 marked the year where a new design of the SPEAR service was released. This redesign intends to enhance the user experience, making it easier for reporters to submit reports and for committee members to carry out their assessment through the reporting tool.

In 2023, WMDA focused on reinforcing security measures to safeguard the sensitive patient and donor data present in the SPEAR service by implementing multi-factor authentication.



Educational Communication

Four educational bulletins were disseminated by the SPEAR Committee, aiming to share knowledge and best practices related to adverse events, donor safety, and considerations for donor care:

1. Labelling Errors (February 2023)
2. Near-Miss Donation (February 2023)
3. Unnecessary Donations (August 2023)
4. Subdural Haemorrhage (August 2023)

Publication on SARS-CoV-2 Adverse Events

In 2023, the SPEAR Committee published a paper on SARS-CoV-2-related adverse events. They found no severe donor illnesses or SARS-CoV-2 transmission to recipients. Common issues included unused cells, product cryopreservation, and technical problems. Lessons emphasised confirming recipient eligibility, reducing collection-to-transplantation time, and using validated viability assays. The outcomes of the report were presented at the EBMT Annual Meeting.



465
SPEAR reports submitted to WMDA*



320
Registered (active) SPEAR reporters



79
New SPEAR reporters joined in 2023



68
Individual reporters submitted a SPEAR report*



40
Different reporting organisations*

*The SPEAR Committee is currently reviewing the SPEAR data of 2023. This number is subject to change. Final totals will be shared in the SPEAR Annual Report of 2023.

OUR PILLARS: PROMOTING DONOR CARE

DONOR MEDICAL SUITABILITY

The Donor Medical Suitability Committee has been working on the project to review the existing pages, 63 unique pages were reviewed and 27 were identified to require an update (minor or major). This project is ongoing. Updated guidance was published on: alcohol intake, hypertension, syphilis and gout.

MEDICAL COMMITTEE

The Medical Committee focused on several projects:

- 1. Donor genetic findings (completed):** this project aimed to establish recommendations on when and how to disclose donor genetic findings; considerations for genetic counselling and informed consent. [The publication](#) provides these recommendations alongside a framework to aid in registry decision-making when genetic mutations of potential donor origin are identified. This includes guidance on pre-donation consenting, post-donation testing of recipients and informing and managing donors when findings of potential donor origin are identified in recipients post-transplantation, aimed at protecting the health, rights, and wellbeing of the donor.
- 2. Experiences of unrelated donor registries in related donor care (ongoing):** focused on exploring similarities and differences in providing care to related donors among unrelated donor registries, a survey was shared to collect input. A paper presenting best practices based on these experiences is expected in early 2024.
- 3. Donor Mental Health Assessment (newly started):** aims to expand mental health assessment globally, by gathering data from registries on donor mental health assessment practices, surveying donors and donor centre representatives about their experiences, and contributing to standardised recommendations for assessing donor mental health. This is multi-year project.

CELL & GENE THERAPY COMMITTEE

The Cell & Gene Therapy (CGT) Committee published guidance documentation (incl. template) on donor consent for the donation of cells for purposes other than traditional HSCT donation. This guidance aims to provide registry members with the tools to address consent and the sharing of research information in the right manner, at the right time, and in the right format. This document can be adapted to local regulations ([2023 WMDA Cellular Therapy Committee - Consent Working Group Output.pdf](#)).

Donor Selection and Cell Source Summit
 Session title: *Exploring Regulatory Considerations for Genetic Engineering of Immune Cells & Donor-Derived Material.*
 Representative of the WMDA CGT Committee and President-Elect Jay Feinberg presented on behalf of WMDA.



OUR PILLARS: PROMOTING DONOR CARE

ADVOCACY

WMDA has been actively involved in discussions surrounding the European Commission's proposal to enhance safety and quality of substances of human origin (SoHO), through the SoHO Regulation. This regulation would address rapid technological advancements in processing blood, tissues, and cells with a future-proof regulatory framework with an emphasis on harmonisation and safeguarding EU benefits from expert guidance for substances of human origin.



WMDA'S CONTRIBUTION TO THE SOHO REGULATION DISCUSSIONS

Towards the end of 2023, final discussions on the texts took place and we hope to see the regulation accepted in early 2024.



WMDA is actively engaged in several other collaborative initiatives and advocates for donor care in various engagements:

1. Stakeholder in the EU project: Recommendations and Guidance for the Management of SoHO in hospitals (ReaderSHip Project)
2. Participant in the Global Convergence in Transplantation Summit in Santander
3. Participant in the annual FDA Cell Therapy and Liaison Meeting (CTLM)
4. Stakeholder in the EU project: [Egalite](#) that aims to develop an European accreditation program for Substances of Human Origin
5. Observer of the steering committee of [CD-P-T-O \(Council of Europe\)](#), that aims to develop ethical, quality, and safety standards in the field of cell transplantation

Other:

1. Member of the FACT professional relationships committee
2. Member of Go-CART Coalition: [GoCART Coalition](#) | [EBMT](#)



2023 HIGHLIGHTS



32,864,484
Donors and Cord Blood Units listed in WMDA assessed organisations



2
Face-to-face training sessions



60%
Experienced evaluators*



2
Educational webinar



42
Organisations registered at the Certification Body



47
Evaluators* from 28 countries



9
Organisations submitted mid-cycle surveillance



10
Organisations assessed for WMDA Full Standards

INSPECTIONS IN ORGANISATIONS

No. of Organisations	2020	2021	2022	2023
Registered	35	43	44	42**
WMDA Qualified	14	19	15	13
WMDA Accredited	21	24	27	31
Expired			2	1

*WMDA is preparing to apply for ISO-17065 to accredit the WMDA Accreditation Programme.

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).

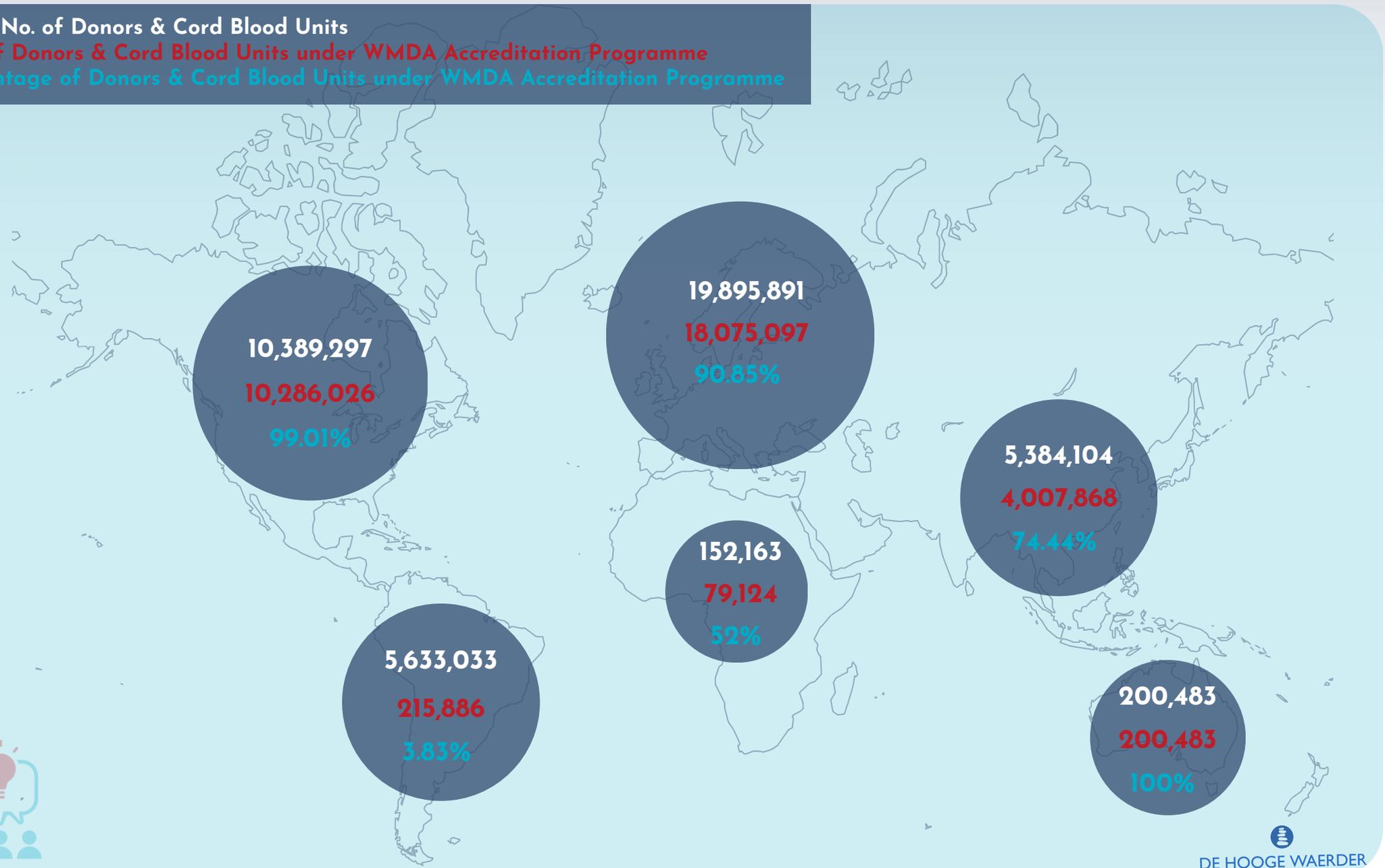


GLOBAL MAP

Total No. of Donors & Cord Blood Units

No. of Donors & Cord Blood Units under WMDA Accreditation Programme

Percentage of Donors & Cord Blood Units under WMDA Accreditation Programme



ENHANCING DONOR CARE THROUGH UPDATED STANDARDS

At the heart of our mission lies a deep commitment to the well-being of our donors. WMDA 2024 Standards are part of WMDA's perseverance to enhance donor care.

1. Focus on Standardisation: WMDA 2024 Standards are a collaborative effort to ensure that the Standards reflect best practices, scientific progress and are aligned with the evolving needs of our community. WMDA 2024 Standards have been updated by incorporating input from both membership and stakeholders. Standards are the fundamental pillar of the WMDA Certification Program.

2. Key Updates Implemented:

- 2 revised Standards on Infectious Disease Markers (IDMs) and addition of 1 Standard: to align current medical testing requirements and to improve operations
- New IT Standard: to improve quality of the donor database reducing the potential for requesting an unavailable donor or missing the optimal donor for a patient
- Addition of 3 new Standards and 1 revised Standard on backup donors: to improve donor counselling and donor safety and well-being.
- 5 new and revised Standards changed on verification typing: to clarify the timing and requiring verification typing of the potential recipient to improve donor and patient safety and improve operations
- 3 new Standards on sharing basic patient outcome data: to comply with regulatory requirements and improve product quality

The WMDA 2024 Standards reinforce the pledge of the WMDA to prioritise donor well-being while continuing to protect patients and promote best practices through standardisation.



ISO 17065 IMPLEMENTATION PROGRESS

To further build on our commitment to continual improvement and excellence, the WMDA is working on the implementation of the ISO 17065 Conformity Assessment - Requirements for Bodies Certifying Products, Processes and Services Standard for the WMDA Pillar 4 Certification Body.

The implementation of the ISO 17065 Standard remains a cornerstone of our organisational framework, as it remains a strategic aim, to enhance the recognition of the WMDA Certification Body by regulators worldwide. We have integrated ISO 17065 requirements into all WMDA certification processes, fostering a culture of efficiency, consistency and quality.

This key project is now in the internal audit phase. This audit, being carried out by an auditor external to WMDA, offers a comprehensive evaluation of the readiness to meet accreditation requirements by providing a thorough assessment, verifying compliance and identifying areas for improvement.

Despite our progress, several challenges were encountered during the ISO implementation journey:

- Change management: improved processes and procedures required extensive communication and training, and the engagement of registries and reviewers
- Resource constraints: limited resources posed challenges in fully executing ISO implementation plans and maintaining compliance

Despite challenges, our achievements underscore the tangible benefits derived from adhering to the ISO 17065 Standard. Looking ahead, we remain dedicated to upholding the highest standards of quality, driving continual improvement across our community for the benefit of donors and patients.



WMDA CERTIFIED, QUALIFIED AND (RE-)ACCREDITED ORGANISATIONS

Organisation

Welsh Bone Marrow Donor Registry
Austrian Bone Marrow Donor Registry
Cyprus Bone Marrow Donor Registry
Czech Stem Cells Registry Prague (CSCR)
Czech National Marrow Donor Registry Plzeň
Danish Stem Cell Donors - West
Irish Unrelated Bone Marrow Registry
Ezer Mizion Bone Marrow Donor Registry
JMDP - Japan Marrow Donor Program
Matchis Foundation
New Zealand Bone Marrow Donor Registry
Norwegian Bone Marrow Donor Registry
Singapore BMDP
South African Bone Marrow Registry
Gift of Life Marrow Registry
Australian Bone Marrow Donor Registry
Hema-Quebec Stem Cell Donor Registry
Canadian Blood Services Stem Cell Registry
ZKRD - Zentrales Knochenmarkspender-Register Deutschland
Buddhist Tzu Chi Stem Cells Center - BTCSCC
Marrow Donor Program Registry Belgium
Finnish Stem Cell Registry
France Greffe de Moelle Registry - FGM
Italian Bone Marrow Donor Registry
Tobias Registry
Blutspende SRK Schweiz AG

Accreditation Status

WMDA accredited (D) 2017
WMDA accredited (D) 2020
WMDA accredited (D/C) 2017
WMDA accredited (D/C) 2017
WMDA accredited (D/C) 2017
WMDA accredited (D/C) 2017
WMDA accredited (D/C) 2020
WMDA accredited (D/C) 2020



OUR PILLARS: ENSURING QUALITY - CERTIFICATION BODY

WMDA CERTIFIED, QUALIFIED AND (RE-)ACCREDITED ORGANISATIONS

Organisation

- Anthony Nolan
- NHS Blood and Transplant - BBMR
- NMDP
- Singapore Cord Blood Bank
- China Marrow Donor Program
- Thai National Stem Cell Donor Registry**
- DKMS Registry gGmbH**
- DKMS BMST Foundation India
- Fundación de Beneficencia Pública DKMS
- Danish Stem Cell Donors - East (DSDE)**
- Fundacja DKMS
- CEDACE/Portuguese BMD Registry**
- Saudi Stem Cells Donor Registry**
- DKMS United Kingdom**
- Bone Marrow and Cord Blood Bank Registry Hadassah University Hospital
- Registro de Donantes de Médula Ósea (REDMO)**

Accreditation Status

- WMDA **accredited (D/C) 2020**
- WMDA **accredited (D/C) 2020**
- WMDA **accredited (D/C) 2020**
- WMDA qualified (C) 2017
- WMDA qualified (D) 2020
- WMDA qualified (D/C) 2017
- WMDA qualified (D/C) 2017



List of WMDA certified, qualified and accredited organisations.

The blue and bold marked registries performed a WMDA Certification/WMDA Qualification/WMDA (re-)Accreditation process in 2023.

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



Benchmark L1:
previously called certification



Benchmark L2:
previously called qualification



Full Standards:
previously called accreditation

HARMONISING AND BUILDING KNOWLEDGE

PUBLICLY AVAILABLE INFORMATION

WMDA is the leading organisation in the area of donor care and donor selection. By offering online education with the Search Coordinator Certificate Programme, WMDA provides 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 2023, WMDA hosted two meetings (of which one hybrid) to facilitate the continuation of the projects.

IMPORTANT WMDA 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

- Pawson et al., 2023: Serious Stem Cell Donation Events and Recipient Adverse Reactions Related to Severe Acute Respiratory Syndrome Coronavirus 2: Review of Reports to the World Marrow Donor Association. <https://doi.org/10.1016/j.jtct.2023.05.020>
- Pryce et al., 2023: Genetic Findings of Potential Donor Origin following Hematopoietic Cell Transplantation: Recommendations on Donor Disclosure and Genetic Testing from the World Marrow Donor Association. <https://doi.org/10.1016/j.jtct.2023.11.019>
- Hofmann et al., 2023: World Marrow Donor Association guidelines for the reporting of novel HLA alleles. [HLA: Immune Response Genetics \(2023\) DOI:10.1111/tan.15048](#)

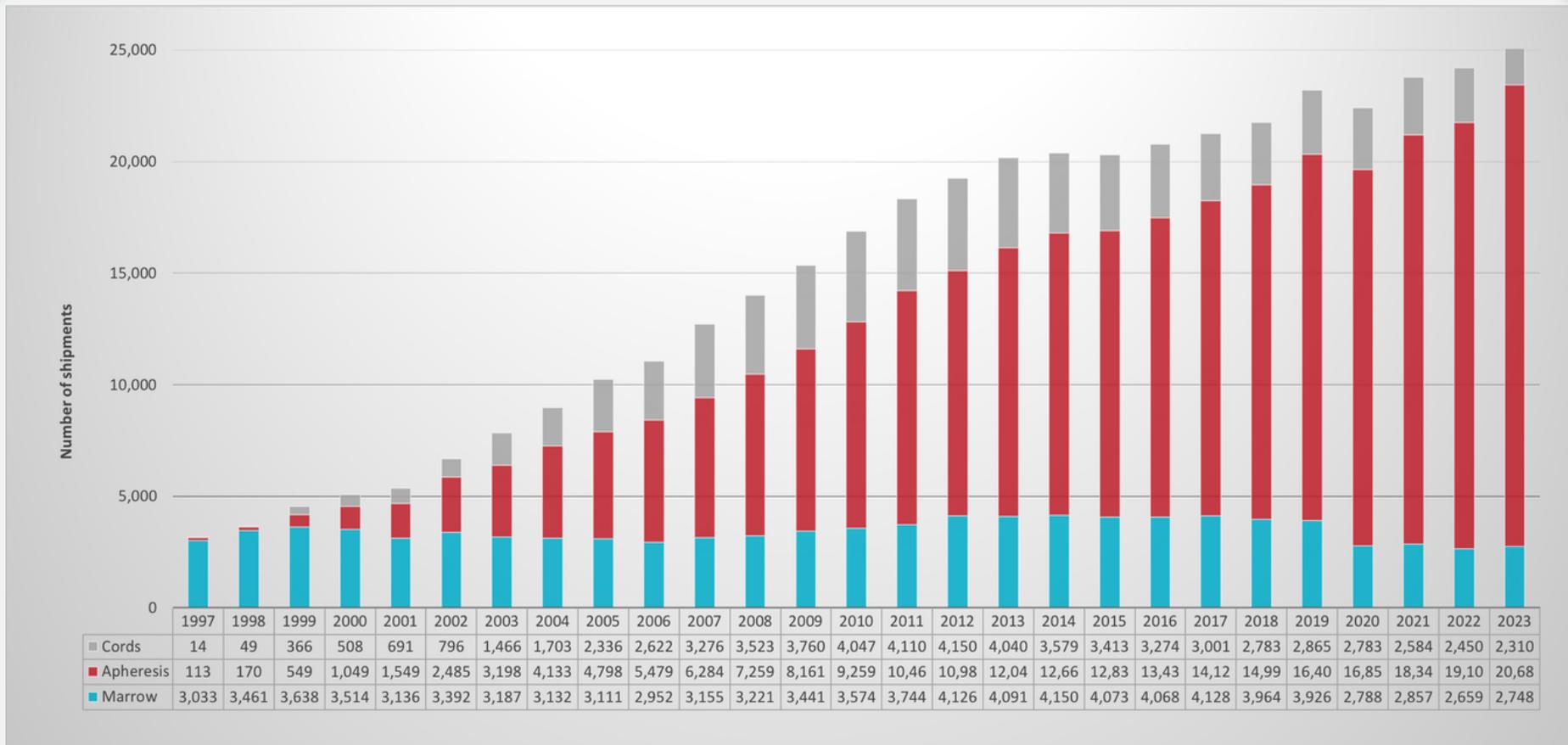
WMDA SEARCH & MATCH SERVICE

- WMDA shares donor and cord blood data with search coordinators and transplant coordinators to assist them with the process to select the best possible stem cell source for their patients
- An unique global dataset: WMDA has a combined dataset from 57 different countries, originating from 102 organisations
- Customised match lists: WMDA offers a variety of filter options to customise the match lists to facilitate the selection of the best suitable stem cell source
- Data back to the registry: by setting up connections, registries can download the match lists in their local system
- Benefit of choice: WMDA implemented a second probabilistic matching algorithm, ATLAS. This provides search coordinators with the ability to compare donor results and identify the best suitable stem cell source



At the time of publication, the Global Trends Report 2023 was still in draft. The below table includes preliminary 2023 results (partially unverified and incomplete, showing input from only 92 organisations). Final and verified 2023 totals will be shared mid-2024. By then, more interesting statistics can be found [here](#).

Unrelated HPC Marrow, HPC Apheresis and HPC Cords shipped worldwide 1997-2023



HARMONISING AND BUILDING KNOWLEDGE

13TH IDRC & WMDA GLOBAL MEETING HANAU, GERMANY | 18-21 JUNE 2023

The International Donor Registry Conference is a gathering of the scientific community involved in cellular therapy and stem cell donation. Looking back on exceptional support from DKMS, key topics have been presented by experts within the community and attendees from 48 different countries, the 2023 edition was a great success. It truly *Engaged and Empowered for Excellence*.

341

Total number of participants registered
(excl. WMDA staff)

64

Submitted abstracts

8.4

Average score of participants for the event in
general (out of 10)



WORLD MARROW DONOR DAY 16 SEPTEMBER 2023

WMDA would like to thank gold partner Be The Match, silver partner Gift of Life Marrow Registry and bronze partners DKMS Registry and Ontime Courier GmbH for supporting WMDD 2023. View a recap and the winners of last year's event here: [World Marrow Donor Day 2023](#)

Be sure to join us on 21 September to celebrate #WMDD24!



WMDA MIDTERM MEETING MINNEAPOLIS, USA | 1-2 NOVEMBER 2023

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



HOW WE MANAGE DATA

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
- A set of security standards that are implemented in the WMDA Certification Programme
- A Peer Review service for registries that are not yet certified through the WMDA Accreditation Programme
- In 2023, WMDA staff was upskilled to take more responsibility for professionalisation of data security and privacy within the organisation



MULTI-FACTOR AUTHENTICATION

WMDA staff and users of the WMDA Search & Match Service 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. 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).

Income statement

We recorded a negative result of €40,308 compared to a projected loss of €106,047.

The total income amounted to €2,392,673, marking a 40% increase from 2022. However, 18% of the increase is ascribed to licensing fees and meeting income with an equal increase in direct costs. Bad debts rose from €4,865 to €14,885, although this was better than anticipated, partly due to payment difficulties with sanction countries.

Direct costs totalled €923,203. These costs, primarily consisting of hosting costs and licensing fees for the matching algorithm - all related to Search, Match & Connect, were up by 43% in comparison to 2022, but following budgeted costs in view of the parallel increase on the income side. Cost of staff went up by 44% and was 6.3% higher than expected. This increase was primarily driven by strengthening the Certification Body, Pillar 4 (€39K), building contingency within the internal Information Technology team (€153K) and expanding the team with Finance & HR staff (€190K). The increases were in line with the budget, except for Finance & HR staff expenses, which were affected by higher recruitment costs than expected and the fact that the external services were not transferred to internal staff.

WMDA is grateful to DKMS, Anthony Nolan and NMDP for supporting WMDA financially by paying for the maintenance & hosting costs of the matching algorithms (Hap-E and ATLAS). WMDA organised an International Donor Registry Conference (IDRC), which was expertly supported by DKMS. WMDA is also grateful to NMDP for hosting the Midterm Meeting prior to the ONE Forum in Minneapolis.

Other administrative costs, such as travel and external administrative fees, were lower than expected, partially offsetting the higher direct and staffing costs. Deferred ISO certification saved approximately €35K.

TREASURER'S STATEMENT

Balance sheet

Despite the 2023 loss, reserves remain sufficient to cover ordinary operational risks. The resistance equity ratio, defined as free reserves divided by revenue, stands at 30.6%, considered healthy for organisations with a comparable risk profile (15%). Allocated reserves amount to €963K for the continuity, the Certification Body, website and Search, Match & Connect.

Risks

While inflation normalised in Europe in 2023, uncertainties persist due to the conflict in Ukraine, migration, and climate changes. The most significant risk involves the development and transition to new Match-Connect services, increasing global reliance on WMDA. Robust systems must prevent downtime, interruptions, and maintain the highest security standards.

Future

The WMDA continues to strengthen and professionalise with new hires (data protection officer, medical advisor to strengthen SPEAR, support Pillars/CEO) and active engagement from volunteers serving as reviewers for the Certification Body, committee members, IDRC organisers, or leadership of the organisation. The expertise of the volunteers is invaluable for organisational growth.

The expected dependence on new Match-Connect necessitates a reinforced management structure and operational oversight. The WMDA Board is moving towards a two-tier managing Board to ensure robust oversight and control while retaining membership involvement.

Given accumulated losses and anticipated cost increases, the WMDA Board revamped the fee structure. The membership approved the new fee structure in December 2023, aiming for a closer alignment between costs and burdens. As dependency on Match-Connect grows, a pay-per-use fee model ensures fairness and safeguards the financial positions of smaller and emerging registries.



JAAP DIJKMAN
WMDA Treasurer, 2023-2024



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

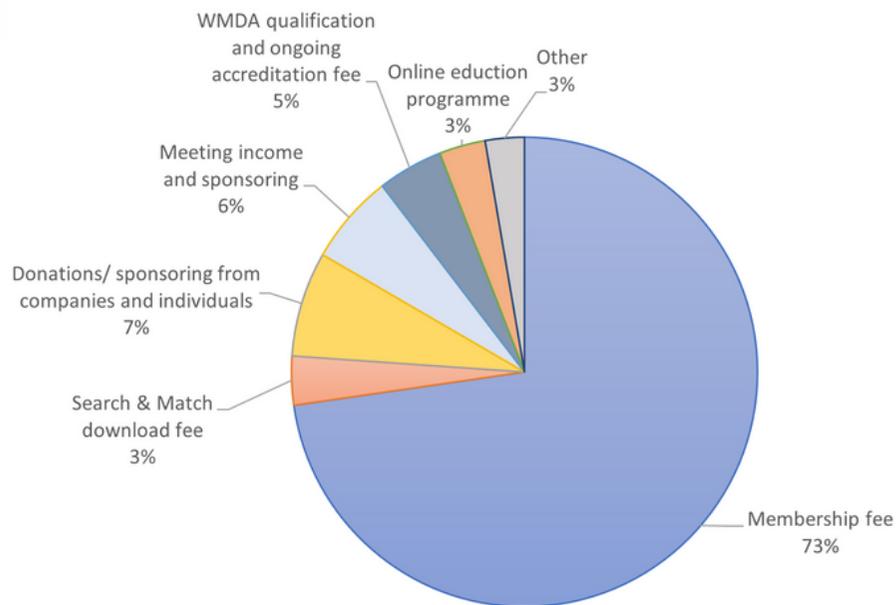
In 2023 the total income was higher than in 2022, however part of the increase is ascribed to licensing fees and meeting income with an equal increase in direct costs. Licensing costs are not shown in the charts, to be able to compare 2022 with 2023.

WMDA thanks its partners for their generous donations.

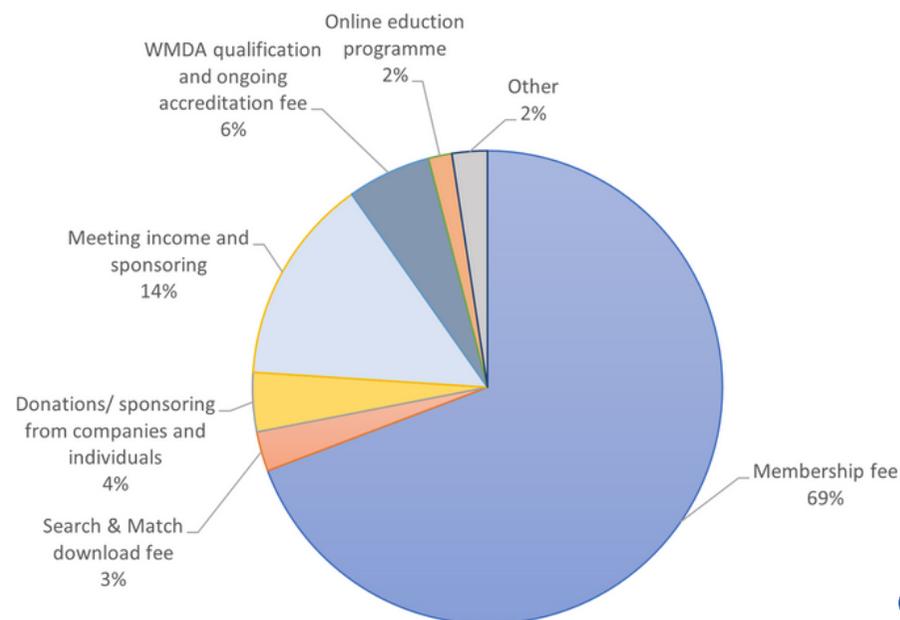
In 2023, WMDA received support from: DKMS (supporting Hap-E and the IDRC & WMDA Global Meeting), Anthony Nolan and NMDP (supporting ATLAS), Gift of Life, NMDP, Ontime Courier, PHSE International, GenDx, Royale International Couriers, Orca Bio, time:matters, DKMS Life Science Lab, DKMS gGmbH, Histogenetics and Miltenyi Biotec.

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 2022

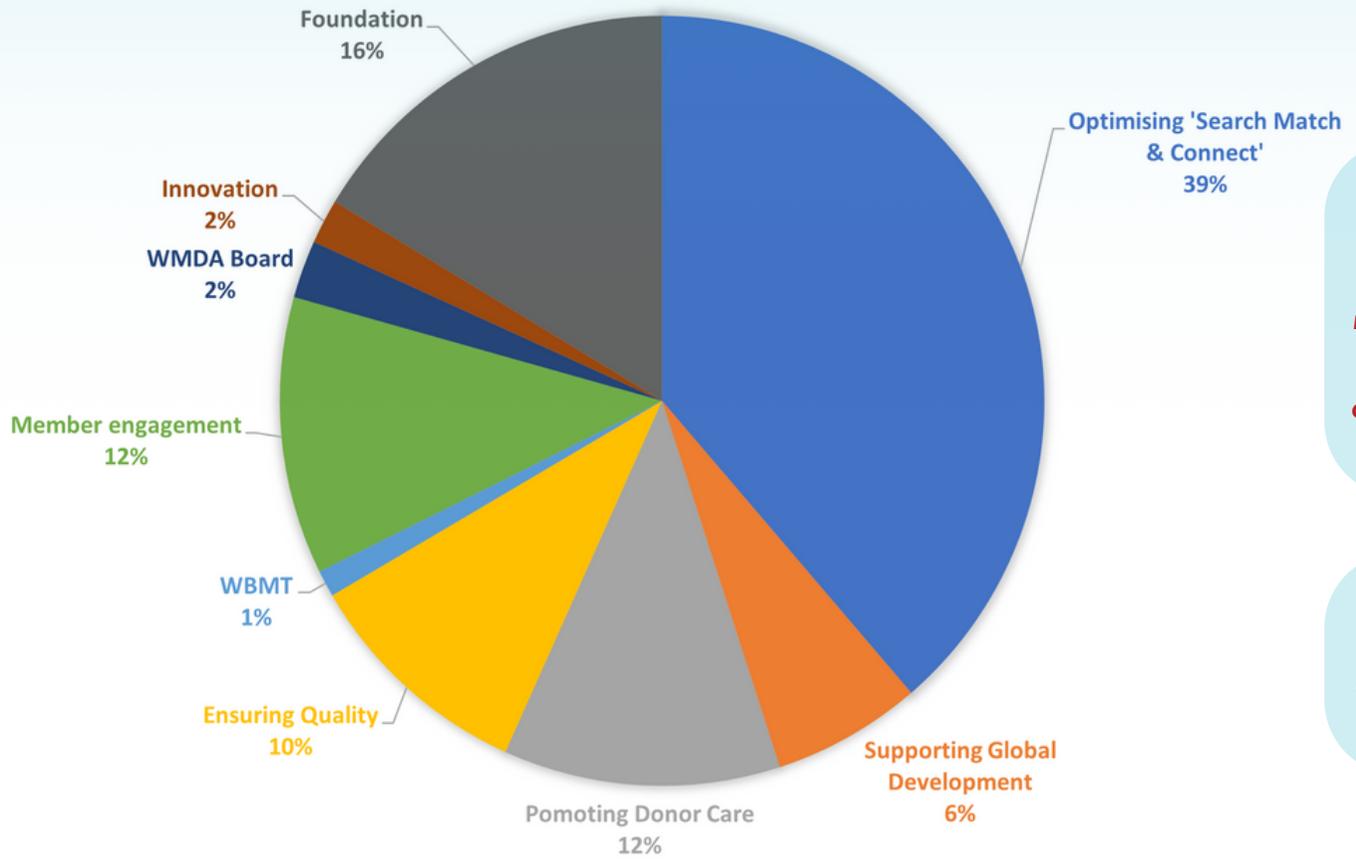


SPECIFICATION OF WMDA INCOME 2023



WMDA OFFICE HOURS

The WMDA office is the central point for all activities of the WMDA. In 2023, the WMDA office worked on multiple projects to assist the WMDA Board/Committees. The WMDA office hours are specified in alignment with the pillar structure.



WMDA strives to spend as much time on its aims as possible and continously pursues cost saving opportunities. Law, regulations and membership requirements as well as risks of fraud contribute to a complex environment that requires an accurate administrative organsiation 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, finance administration, team building.

BALANCE SHEET AS AT 31 DECEMBER 2023

Balance sheet after proposal distribution of result

	Ref.	31/12/2023		31/12/2022	
		€	€	€	€
Assets					
Fixed assets					
<i>Tangible fixed assets</i>					
	5				
Other fixed assets		19,173		20,706	
			19,173		20,706
Current assets					
<i>Receivables</i>					
	6				
Receivables from trade debtors		27,724		8,764	
Receivables from other accounts		5,414		5,414	
Prepayments and accrued income		78,089		20,323	
			111,227		34,501
<i>Cash and bank</i>	7		1,500,721		1,493,846
Total assets			1,631,121		1,549,053

*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 2023 have been prepared by WMDA's accounting office.

BALANCE SHEET AS AT 31 DECEMBER 2023

Balance sheet after proposal distribution of result

	Ref.	31/12/2023		31/12/2022	
		€	€	€	€
Liabilities					
<i>Equity foundation</i>					
Other reserves	8	1,297,153	1,337,461		
			1,297,153		1,337,461
<i>Current liabilities</i>					
Debts to suppliers and trade credits	9	71,791		42,550	
Taxes and social insurances		70,964		51,121	
Debts to pensions		15,033		11,546	
Other debts		118,483		78,004	
Accrued liabilities		57,697		28,371	
			333,968		211,592
Total liabilities			1,631,121		1,549,053

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 2023 have been prepared by WMDA's accounting office.

STATEMENT OF BENEFITS AND EXPENSES OVER 2023

Balance sheet after proposal distribution of result

	Ref.	2023	2022
		€	€
Income		2,392,673	1,731,387
Expenditure on the goods and services		923,203	644,644
Gross result	11	1,469,470	1,086,743
Wages and salaries		1,076,371	747,407
Social security expenses		216,733	179,593
Depreciations of intangible and tangible fixed assets		7,332	9,741
Other operating expenses	14		
Other employee related expenses		26,949	22,625
Housing expenses		33,205	30,982
Sales related expenses		36,710	10,835
Office expenses		42,030	40,840
Insurance expenses		27,609	18,436
Accountants and advisory fees		27,938	14,939
Administrative expenses		27,962	38,512
Other expenses		616	1,147
Total of expenses		1,523,455	1,115,057
Total of benefits and expenses		-53,985	-28,314
Other interest income and similar income		15,637	0
Interest and similar expenses		-1,960	-10,502
		13,677	-10,502
Result		-40,308	-38,816

The Financial Statements 2023 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 2024 Work Plan & Budget. Input was provided on two levels:

1. Ongoing projects and their proposed direction in 2023;
2. New initiatives within existing programmes.

The approved budget is summarised in the table.

The WMDA office is the central point for all activities of the WMDA.

	2024
Income	EURO 2,515,180
Expenses	EURO 2,456,356
Estimated result	EURO 58,824

WMDA STRATEGY 2023-2028

WMDA has recently unveiled its Strategy for 2023-2028, marking a pivotal moment amidst a landscape characterised by volatility, uncertainty, complexity, and excitement for both WMDA and its members. This period presents an unprecedented demand for WMDA's services, underscored by a growing and evolving community. As a collective, WMDA is confident to make a significant impact by saving more lives than ever before.

Two priority themes emerged from initial work undertaken by the WMDA Board:

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.

The priorities are interconnected and mutually-reinforcing. Together, they ensure that WMDA continues to serve its members across the entire field of registry operations, benefitting both WMDA's members and associated stakeholders - and ultimately the patients who rely on them for life-saving treatments.

Pillar 1 (Optimising 'Search, Match & Connect') will be building and delivering Match-Connect to the membership in order to modernise communication between registries. The Supporting Global Development Pillar will expand the online education platform and share best practices among the members in the area of donor recruitment/retention and registry/cord blood operations. The Promoting Donor Care Pillar will focus on emerging donor welfare issues not only in the unrelated donor setting, but also for donors donating for family members, research and cell & gene therapy. The Ensuring Quality Pillar will continue to encourage registries to apply for WMDA Certification in a professional certified programme.

To facilitate the growth of WMDA and to comply with the Dutch WBTR law, the WMDA is working on a new governance structure that will balance the democratic decision-making and legal compliance.

30 YEARS OF WMDA

On 4 October 2024, WMDA will be celebrating 30 years of matching donors and serving patients. Since its inception in 1994 by esteemed pioneers; HLA discoverer Jon van Rood, Nobel Prize laureate E. Donnall Thomas, and renowned hematologist John Goldman, WMDA has been creating the standards for cellular therapies, promoting access to life-saving treatments for patients worldwide.

WMDA is more than just an association - we're a dynamic global community of passionate experts, from registries to cord blood banks, from medical directors to donor recruiters, united by a singular vision: to ensure that every patient in need can find their best life-saving match.

Our Search & Match Service streamlines the complex process of finding a life-saving donor, swiftly matching patients with their best stem cell source and pushing the boundaries of digitalisation in healthcare. Match-Connect removes the time-consuming paper trails and waiting times with real-time data and advanced algorithms.

With close to 1,500 experts representing over 57 countries, WMDA fosters an unparalleled collaborative environment. Our mission extends beyond mere matching - we're dedicated to protecting donors' rights and wellbeing every step of the way. From meticulous donor care to adverse events monitoring, we uphold the highest standards of quality and ethics. Without donors, there are no cures.

In 2024, we will continue to drive global harmonisation, innovation and equity. Together, we can transform the landscape of healthcare, saving countless lives and ensuring access to all. We thank our committed members for their dedicated service to this noble cause over the past three decades. We encourage more stakeholders within this industry to join the WMDA community of visionaries, leaders, and pioneers.



World Marrow Donor Association WMDA

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