



Finance & Activities Report 2022

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2022 AT-A-GLANCE



>39,000,000
Unrelated donors



>40,000
New patients annually



>20,000
Unrelated transplants



101
Participating organisations



46
Ongoing projects



42
Registries approved by the Certification Body



1
In-person membership meeting

Dear WMDA member,

I am delighted to introduce the 2022 WMDA Finance & Activities Report. All of the WMDA staff and volunteers can continue to be proud of the WMDA activities, which you can read about in the coming pages.

A real highlight of the year for me was being able to see everyone in person at the very successful meeting we had in Leiden in October. A huge thank you to everyone who helped to make this happen, and to all who attended for their active participation, great ideas, constructive criticism and joy at finally being together. After so many years without seeing each other, the collaboration felt even better than usual and many people commented on how much great progress was made in many initiatives because everyone was together in the same room.

On behalf of the entire board I would like to extend our enormous gratitude to Oliver Kürsteiner who completes his term as the board treasurer. His level headed approach, humour and dedication to the WMDA were always obvious and very much appreciated!

There is a lot to look forward to in 2023, including going back to a regular schedule of in-person meetings. I am delighted to pass the baton on to Matthew Seftel, your new president, who I know will guide the WMDA wisely as the new strategy is implemented.

Bronwen Shaw, MD PHD
WMDA President 2021-2022

WHO WE ARE

WMDA is a membership association, a community of dedicated professionals. We carry out work in four different areas to facilitate transplants for patients in need.



Optimising
'Search, Match & Connect'



Supporting
Global
Development



Promoting
Donor Care



Ensuring
Quality

WMDA is funded through a variety of sources. In 2022, the membership fee was the largest source of income.



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

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

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

- **We connect**
Connecting patients and donors and members across the globe.
- **We empower**
Ensure all members are invited, involved and empowered.
- **We care**
Sincere interest for our members, and dedication to help all patients in need of a transplant, while protecting the rights and well-being of the donor.
- **We improve**
Provide consistent services and build 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.

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.

1992

The first paper outlining how international exchange of stem cells could be organised.

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.

2003

WMDA starts to analyse the serious adverse events and reactions occurring in donors and patients.

2004

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

2010

WMDA published white papers to describe the ecosystem of registry operations and the future.

2014

WMDA launches services for new & emerging registries (WMDA handbook and Donor WiKi).

2016

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

2017

WMDA merged with BMDW and NetCord.

2021

EMDIS integrated into WMDA.
WMDA launches a Cellular Therapy Committee.

2022 ACHIEVEMENTS



DATA

- Made progress to moving towards real-time donor and cord blood data into the WMDA Search & Match Service
- Created a Global Trends Report outlining the number of unrelated transplants and the international exchange across the globe
- Analysed the potential risks related to donation and transplantation based on the incidents reported



MATCHING

- Implemented a new matching algorithm, Hap-E with support of DKMS
- Launched a user-friendly WMDA Search & Match Service that allows search coordinators to quickly identify their match



EQUITY

- Lowered the barrier for small registries to join WMDA projects by organising project meetings virtually
- Moving to equity in access to care by developing a registry-to-registry communication platform
- Organised monthly educational webinars for the WMDA community
- Created a pathway to join WMDA for the new & emerging registries



ADVOCACY

- Established a Cellular Therapy Committee to focus on the protection of donor rights and safety in novel therapies
- Being one voice to EU Institutes for the members on EU legislation



CONNECTING

- Organised a face to face meeting (210 participants)
- Published an article outlining the impact of COVID-19 on unrelated stem cell donations
- Organised the 4th edition of the EBMT/WMDA Transplant & Search Coordinator Day
- Actively participated on social media to promote World Marrow Donor Day



QUALITY

- Published guidelines how to audit donor centres
- Inspected nine organisations



NEXT GENERATION

- Created a WMDA Network LinkedIn group to connect and share best practices
- Organised a Junior Lab to mentor new members on how to participate in WMDA projects

OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'

SEARCH & MATCH SERVICE



40,755,203
Total records



34,977
New patient searches



12,709
Donor/Cord Blood Unit files uploaded



669
Active users



72
Application testers



1
Educational webinar

UPDATED SERVICE LAUNCHED 4 JULY 2022

- Multi-factor authentication
- New matching algorithms
- No limit to the amount of donors displayed
- New and optimised filter options
- Fresh & modern look
- Direct electronic access (API) to search results



OUR PILLARS: OPTIMISING 'SEARCH, MATCH & CONNECT'

MATCH-CONNECT

13
Steering committee members

71
Voting User Group members

38
Meetings

5
Webinars & info sessions

Match-Connect Whitepaper published by steering committee

- Describes future of registry-to-registry communication
- Detailed technical solution designs
- Ample information for executives with respect to operational and financial impact

Community approval to proceed with roll-out of modernised technology (API)



SECURITY & PRIVACY COMMITTEE

6
Committee members

29
Hours with Dutch legal consultant

3
Peer Review assessments

Welcomed Co-Chair, Virgilio Cervantes from Anthony Nolan

Reviewed chapter 5 of the WMDA Standards (data security & privacy)

Input to the technical design of Match-Connect

Updated the Data Transmission and Use Agreement, to comply with the international privacy law, and distributed the agreement to the community



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

DATA DICTIONARY & DATA QUALITY COMMITTEE

9
Committee members

4
RFCs reviewed & approved

976
Data fields in dictionary

5
Resources supported

Updated the "Request for Change" form used by the community

Working on data definitions which include:

- More fields to distinguish Infectious Disease Marker-tests
- Introduction of Adult Donor Cryopreserved Unit (ADCU)
- Fields definition for "Reduced Time to Transplant" Cord Blood Units
- Cord Blood Units Viability for Multiple Cell Types



BIOINFORMATICS & INNOVATION COMMITTEE

15
Committee members

2
International meetings

3
Active projects

Reactivated at the International HLA & Immunogenetics Workshop 2022 following a hiatus

Working on:

- How to bring bioinformatics innovation to the community
- HLA representation in registries & communication
- Assessment of algorithms that facilitate donor/Cord Blood Unit selection

EDUCATION



80

Students registered for the following courses:

- Donor Coordinator Programme: 15
- Search Coordinator Certificate Programme - Basic Level: 50
- Search Coordinator Certificate Programme - Advanced Level: 13
- Search Coordinator Continuing Education Course: 2



72

WMDA members participate as volunteers within Supporting Global Development



52

Certificates awarded:

- Donor Coordinator Programme: 7
- Search Coordinator Certificate Programme - Basic Level: 30
- Search Coordinator Certificate Programme - Advanced Level: 14
- Search Coordinator Continuing Education Course: 1



Educational webinars:

- 20221006 - [Pillar 4: Accreditation Applications - Reviewer Documentation and the Final Report](#) by Janet Parks | [Slides](#)
- 20220929 - [Pillar 4: Understanding and reviewing Section 5: Information Technology and Information Management Standards](#) by Carolyn Hurley | [Slides](#)
- 20220908 - Pillar 3: The role of WMDA in Cellular Therapy - where are we now by Salmah Ahmed, David Allan & Wouter van 't Hof | [Slides](#)
- 20220901 - [Pillar 1: New Matching Algorithm: How to interpret search results in the updated Search & Match Service](#) by Christine Urban | [Slides](#)
- 20220707 - [Pillar 2: Patient Follow-up - how to use Forms TF1 and TF2](#) by Deborah Buk and Catherine Burlton | [Slides](#)
- 20220623 - [Pillar 2: Preparing for World Marrow Donor Day](#) by Ryan Peña and Martine Schuit | [Slides](#)
- 20220407 - [Pillar 2: Get familiar with the operation of a registry - launch of the updated WMDA Handbook](#) by Valerie Stewart | [Slides](#)
- 20220310 - [Pillar 4: Assembling a Qualification \(or Certification\) Application in Share](#) Carolyn Hurley | [Slides](#)

EDUCATION



WMDA co-organised with EBMT the 4th EBMT/WMDA Transplant & Search Coordinator Day with the following sessions:

[Emerging challenges in donor identification and selection - Anne-Marie van Walraven & John Fitzgerald](#)

- Is EU legislation taking care for donor safety? - Sinead Masterson
- What does informed consent for treatment and donation mean across borders? - Lela Saou/Anne-Marie van Walraven
- How professional societies can help to comply with regulatory requirements (e.g. import of HPC) - Nicoletta Sacchi

[A unique phenotype - what do I do? - Irina Evseeva & Sergio Querol](#)


- Unique HLA phenotype today and tomorrow - Valerie Stewart
- Why be hesitant about cord blood options? - Dunia Jawdat
- How TCs can help in ethnic minorities recruitment: patient appeals - Sabine Hildebrand

[Improving collaboration between Registry and Clinical Teams - Annette Rasche & Keith Wilson](#)

- How do you achieve efficient and good collaboration between the registry and clinical partners? Best practices: what works in different environments and what can the audience learn from them? Three Registry Search Coordinators from NMDP-BeTheMatch, Anthony Nolan and Matchis Foundation and their clinical partners will join a panel discussion Marisa Jack, Jennifer McAtee, Ann O'Leary, Juliette Lethier, Shari Denovan, Josefine Teeler and Marianne Lucassen

[Lessons to share - Valerie Stewart & Annika Kisch](#)

- Reporting SEAR/SPEAR - a tool to share lessons learnt - Thilo Mengling
- Search, Match & Connect - tips and tricks on your match list - Alicia Venter
- What has changed in unrelated transplants in 2021? - Isabel Sánchez-Ortega



Why be hesitant about cord blood options?

Dunia Jawdat PhD, D(ABMLI)

OUR PILLARS: SUPPORTING GLOBAL DEVELOPMENT

REGISTRY OPERATIONS & REGULATION COMMITTEE

MERGER BETWEEN REGISTRIES WG AND QUALITY & REGULATION WG

2

Committee meetings

3

Online education courses

3


Face to face workshops*

Working on:

- Collecting data on registry activities
- Patient Follow Up Recommendations
- Back-Up Donor Recommendations
- What to do if no matched donor is available
- Educational materials for new & emerging registries
- Organising World Marow Donor Day

NEW WMDA MEMBERS

 National Register of Bone Marrow Donors in the Republic of Kazakhstan (NRDKMRK) became a provisional member in August 2022

 Countries with an interest to start a registry for volunteer stem cell donors that connected with WMDA for more information:

 Kuwait  Mongolia

 Latvia  Kenya

 Syria  Jordan

 Bangladesh  Honduras

 Georgia  Pakistan

CORD BLOOD OPERATIONS COMMITTEE

13

Committee members

13

Committee meetings

134

Cord Blood Banks**



Working on:

- A flag for extensively tested Cord Blood Units
- Up to date operational and technical information from all Cord Blood Banks listing their units in the WMDA Search & Match Service
- Participation in the Scientific Committee of Cord Blood Connect

*Workshops on donor recruitment, registry operations & cord blood banking.
 **Of which 22 are provisional members and 8 are regular members.

SPEAR COMMITTEE

Serious Adverse Events & Reactions occurring in either donor, product or patient settings are important to be shared with the international community through the WMDA SPEAR reporting service. In 2022, WMDA launched an upgraded service with the aim to operate a user-friendly software application compliant with the current security guidelines. The new service was promoted on social media and at scientific meetings (EBMT).

Focus areas:

- Gaining insight into the factors contributing to adverse events related to aborted mobilisation due to donor-related reasons
- Analysis of COVID-19 related reports to identify and learn from any lessons that can help protect donor safety
- Improving the WMDA SPEAR reporting tool



288
Active SPEAR reporters registered with the WMDA



16
Committee members
(including 2 non-voting members)



241
SPEAR reports submitted to WMDA*



84
New SPEAR reporters joined in 2022



53
Individual reporters submitted a SPEAR report*



34
Different reporting organisations*



*The detailed assessment of the SPEAR reports of 2022 is currently carried out by the SPEAR Committee. The results will be shared in the SPEAR Annual Report of 2022.

OUR PILLARS: PROMOTING DONOR CARE

DONOR MEDICAL SUITABILITY



4
Major revisions to existing guidance: high-risk sexual behaviour, malaria, COVID-19, breastfeeding



3
Tables updated on WMDA Recommendations for assessing donor medical suitability*



1
New guidance published: monkeypox



1
Presentation on Emerging Infectious Diseases

MEDICAL COMMITTEE FORMERLY KNOWN AS MEDICAL WORKING GROUP



2
New projects were started in 2022:

- “Donor genetic findings”: when and how to disclose donor genetic findings; considerations for genetic counseling and informed consent.
- “Experiences of unrelated donor registries in related donor care”: exploring similarities and differences in providing care to related donors among unrelated donor registries; establishing best practices and achieving consensus.

CELLULAR THERAPY COMMITTEE

The WMDA's Cellular Therapy Committee, a diverse group of experts in cell and gene therapy, became part of Promoting Donor Care in 2022. The committee aims to align donor protection standards with developments in the field, reflecting opportunities and risks in upholding donor safety, and adding value based on feedback from the sector.



7
New committee members started



1
Donor Engagement in Cell and Gene Therapy Resource Kit published. Find the link [here](#)



1
Educational webinar



At the WMDA Face to Face Event in Leiden, the committee hosted 1 panel session on the role of registries and donors in cell and gene therapy (CGT), 1 expert-led informative session on onboarding a CGT client and what manufacturers requirements are for donor registries



*Updated tables on WMDA Recommendations:
• Table 1 - Recommended medical and lifestyle information at enrolment.
• Table 3 - Recommended medical assessment at work-up.
• Table 5 - Recommended schedule for repeating donor assessments in the event of a delay to collection.

EU REGULATION

European Medical Device Regulation EU 2017/745 (MDR)

As a response to the more extensive certification under the Medical Device Regulation EU 2017/745, many manufacturers of medical devices have withdrawn from the market. This proved to be a problem for bone marrow collection kits, where with one supplier withdrawing from the market and one ceasing production in Europe, no suppliers were available for a few months. The threat of collection centres running out of stock was real and it did happen on occasions. The WMDA played an important role in gaining insight into the size of the problem and facilitating conversations between regulators, suppliers and collection centres. A follow-up survey in December of 2022 demonstrated that the issues surrounding the shortages of HSC collection kits are not yet solved. A timely European solution, which makes fair prices, a regulated market and awareness of the current issues it's highest priority, is greatly needed. WMDA continues to advocate and coordinate our community's response to this threat.



WMDA welcomes the strengthening of the health protection for donors and patients and the principle of voluntary non-remunerated donation in the upcoming EU legislation.

WMDA sees an ongoing role to collaborate with the EU on ensuring the quality and continuity in supply of SoHOs.



European Regulation on Standards of Quality and Safety for Substances of Human Origin (SoHO)

In July 2022, the European Commission published a proposal for a Regulation on Standards of Quality and Safety for Substances of Human Origin. Together with partner organisations and WMDA members, the WMDA shared a statement letter. This was used in further conversations with relevant stakeholders, such as the European Members of Parliament, to highlight our key concerns on ambiguous articles in the proposal and prose amended texts for change. The WMDA attended an event in the European Parliament hosted by the European Blood Alliance to advocate this message further.



2022 HIGHLIGHTS

 **36,861,010**
Donors are listed in WMDA assessed organisations

 **67%**
Experienced evaluators*

 **44**
Organisations registered at the Certification Body

 **38**
Evaluators* from 23 countries

 **9**
Organisations submitted mid-cycle surveillance

 **9**
Organisations assessed for WMDA Full Standards

 **3**
Educational webinars

 **2**
Organisations delayed in submission and their certificate is expired

 **1**
Online training session

 **1**
Face to face training session



INSPECTIONS IN ORGANISATIONS

No. of Organisations	2020	2021	2022
Registered	35	43	44
WMDA Qualified	14	19	15
WMDA Accredited	21	24	29
Expired			2

*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.

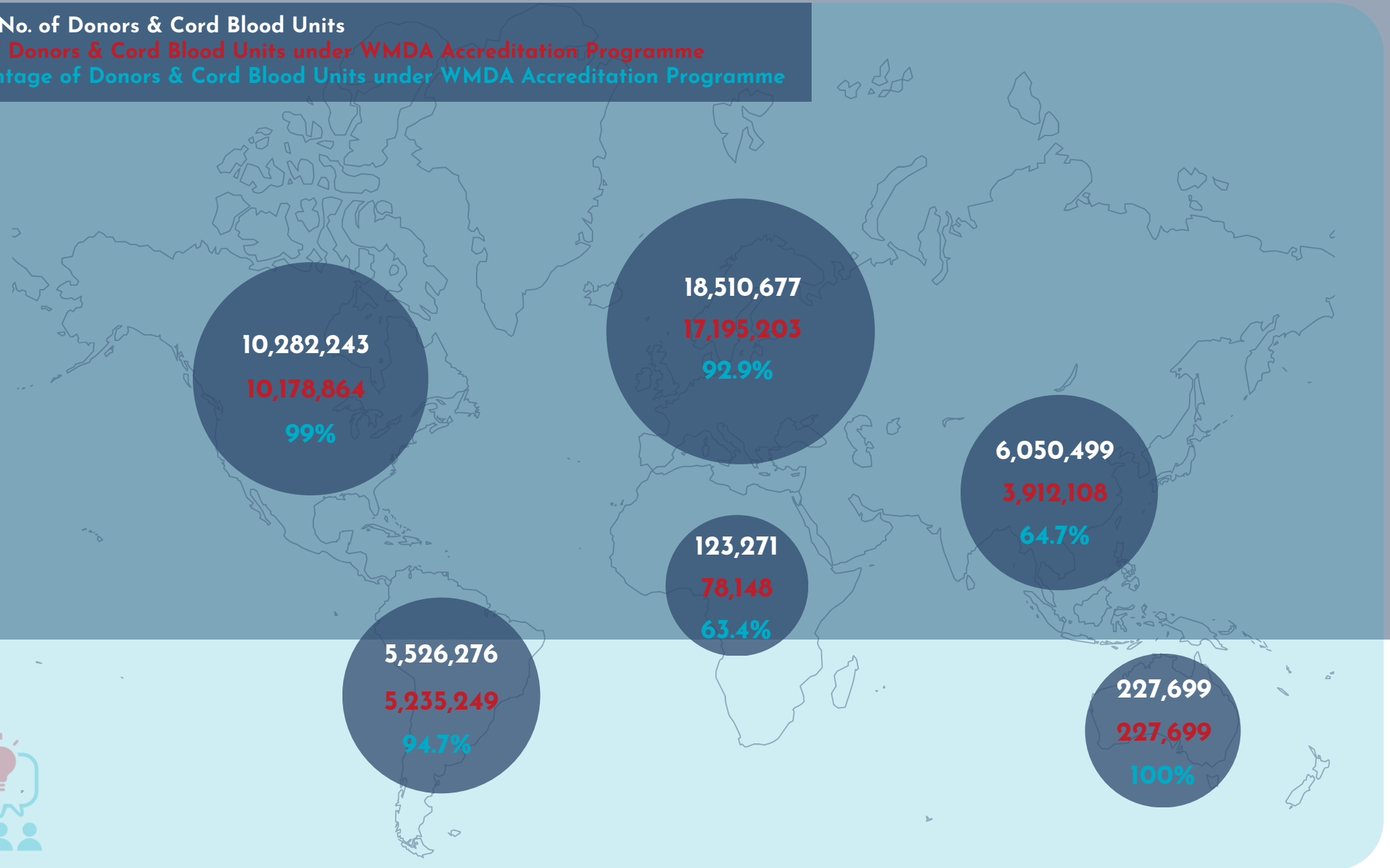


GLOBAL MAP

Total No. of Donors & Cord Blood Units

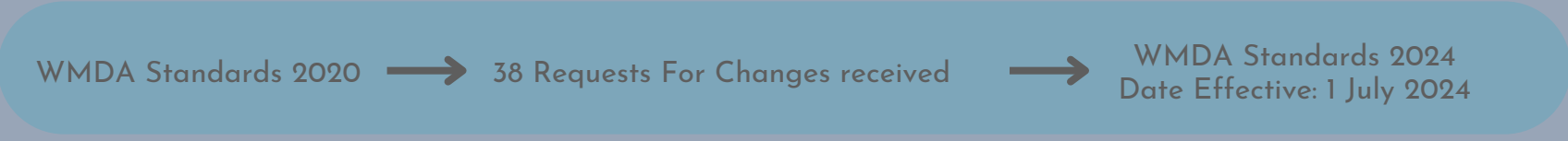
No. of Donors & Cord Blood Units under WMDA Accreditation Programme

Percentage of Donors & Cord Blood Units under WMDA Accreditation Programme



OUR PILLARS: ENSURING QUALITY

WMDA STANDARDS - MOVING TO 2024 - TIMELINE (YEAR 2023)



ISO-17065 ACCREDITATION FOR WMDA CERTIFICATION BODY

COVID-19 did have an impact on the progress of preparing the application for ISO-17065 for the WMDA Certification Body. In 2022, a document control management system was implemented and the pillar was reorganised. The Registry Operations & Regulation Committee moved to the Pillar 2: Supporting Global Development. Pillar 4: Ensuring Quality, will be entirely devoted to the WMDA Accreditation Programme as a Certification Body.

In 2023, WMDA continues to work on adjustments to our Certification Scheme according to Dutch Accreditation Council requirements.



WMDA QUALIFIED AND (RE-)ACCREDITED ORGANISATIONS



Country	Organisation	Accreditation Status
AT	Austrian Bone Marrow Donor Registry	WMDA qualified (D) 2017
AU	Australian Bone Marrow Donor Registry (CORD)	WMDA accredited (D/C) 2017
AU	Australian Bone Marrow Donor Registry	WMDA accredited (D/C) 2017
BE	Marrow Donor Program Registry Belgium (CORD)	WMDA qualified (D/C) 2017
BE	Marrow Donor Program Registry Belgium	WMDA qualified (D/C) 2017
CA	Canadian Blood Services Stem Cell Registry (CORD)	WMDA accredited (D/C) 2017
CA	Canadian Blood Services Stem Cell Registry	WMDA accredited (D/C) 2017
CA	Hema-Quebec Stem Cell Donor Registry (CORD)	WMDA accredited (D/C) 2017
CA	Hema-Quebec Stem Cell Donor Registry	WMDA accredited (D/C) 2017
CH	Blutspende SRK Schweiz AG (CORD)	WMDA accredited (D/C) 2017
CH	Blutspende SRK Schweiz AG	WMDA accredited (D/C) 2017
CL	Fundación de Beneficencia Pública DKMS	WMDA qualified (D) 2020 by affiliation to ION-4596
CN	Chinese Marrow Donor Program	WMDA qualified (D) 2017
CY	Cyprus Bone Marrow Donor Registry	WMDA accredited (D) 2017
CZ	Czech National Marrow Donor Registry Plzeň	WMDA accredited (D) 2017
CZ	Czech Stem Cells Registry Prague (CSCR)	WMDA accredited (D) 2020
DE	DKMS gemeinnützige GmbH	WMDA accredited (D/C) 2017 by affiliation to ION-6939
DE	ZKRD - Zentrales Knochenmarkspender-Register Deutschland (CORD)	WMDA accredited (D/C) 2017
DE	ZKRD - Zentrales Knochenmarkspender-Register Deutschland	WMDA accredited (D/C) 2017
DK	Danish Stem Cell Donors - East (DSDE)	WMDA qualified (D) 2020
DK	Danish Stem Cell Donors - West	WMDA qualified (D) 2017
ES	Registro de Donantes de Médula Ósea (REDMO) (CORD)	WMDA qualified (D/C) 2017
ES	Registro de Donantes de Médula Ósea (REDMO)	WMDA qualified (D/C) 2017
FI	Finnish Stem Cell Registry (CORD)	WMDA accredited (D/C) 2020
FI	Finnish Stem Cell Registry	WMDA accredited (D/C) 2020

WMDA QUALIFIED AND (RE-)ACCREDITED ORGANISATIONS

Country	Organisation	Accreditation Status
FR	France Greffe de Moelle Registry - FGM (CORD)	WMDA accredited (D/C) 2017
FR	France Greffe de Moelle Registry - FGM	WMDA accredited (D/C) 2017
GB	Anthony Nolan (CORD)	WMDA accredited (D/C) 2017
GB	Anthony Nolan	WMDA accredited (D/C) 2017
GB	DKMS United Kingdom	WMDA qualified (D) 2020
GB	NHS Blood and Transplant - BBMR (CORD)	WMDA accredited (D/C) 2020
GB	NHS Blood and Transplant - BBMR	WMDA accredited (D/C) 2020
GB	Welsh Bone Marrow Donor Registry	WMDA accredited (D) 2017
IE	Irish Unrelated Bone Marrow Registry	WMDA accredited (D) 2020
IL	Bone Marrow and Cord Blood Bank Registry Hadassah University Hospital (CORD)	WMDA qualified (D/C) 2017
IL	Bone Marrow and Cord Blood Bank Registry Hadassah University Hospital	WMDA qualified (D/C) 2017
IL	Exer Mizion Bone Marrow Donor Registry	WMDA accredited (D) 2020
IN	DKMS BMST Foundation India	WMDA qualified (D) 2020 by affiliation to ION-4596
IT	Italian Bone Marrow Donor Registry (CORD)	WMDA accredited (D/C) 2020
IT	Italian Bone Marrow Donor Registry	WMDA accredited (D/C) 2020
JP	JMDP - Japan Marrow Donor Program	WMDA accredited (D) 2017
NL	Matchis Foundation	WMDA accredited (D) 2020
NO	Norwegian Bone Marrow Donor Registry	WMDA accredited (D) 2017
NZ	New Zealand Bone Marrow Donor Registry	WMDA accredited (D) 2020
PL	Fundacja DKMS	WMDA qualified (D) 2020
SA	Saudi Stem Cells Donor Registry	WMDA qualified (D) 2020
SE	Tobias Registry (CORD)	WMDA accredited (D/C) 2020
SE	Tobias Registry	WMDA accredited (D/C) 2020
SG	Singapore BMDP	WMDA accredited (D) 2020
SG	Singapore Cord Blood Bank (CORD)	WMDA qualified (C) 2017



WMDA QUALIFIED AND (RE-)ACCREDITED ORGANISATIONS

Country	Organisation	Accreditation Status
TH	Thai National Stem Cell Donor Registry	WMDA qualified (D) 2017
TW	Buddhist Tzu Chi Stem Cells Center - BTCSCC (CORD)	WMDA accredited (D/C) 2017
TW	Buddhist Tzu Chi Stem Cells Center - BTCSCC	WMDA accredited (D/C) 2017
US	Gift of Life Marrow Registry	WMDA accredited (D) 2017
US	NMDP-National Marrow Donor Program/Be The Match (CORD)	WMDA accredited (D/C) 2020
US	NMDP-National Marrow Donor Program/Be The Match	WMDA accredited (D/C) 2020
ZA	South African Bone Marrow Registry	WMDA accredited (D) 2017



List of WMDA certified, qualified and accredited organisations:

The bold-marked registries are WMDA Accredited.

The blue-marked registries performed a WMDA Certification/WMDA Qualification/WMDA (re-)Accreditation process in 2022.

Please note that the accreditation status is listed in the following way:

- Qualified/Accredited: where qualified indicates compliance with benchmark standards and accredited indicates compliance with full standards.
- (D)/(C)/(D/C): indicates the source of cells for which the registry has been granted qualification/accreditation (i.e. donors, cords or both sources)
- 2017/2020: indicates the version of the WMDA Standards the registry complies with.
- WMDA qualified (D) 2017: organisation that has been granted WMDA Qualification status (only benchmark standards) for donors according to WMDA 2017 Standards.

HOW WE SHARE KNOWLEDGE

Global Trends Report: charts and figures summarising the current status of unrelated Hematopoietic Cell Transplantation

Global Trends Report: statistics on the number of donors and Cord Blood Units available, specified per participating organisation

Global Trends Report: detailed information on the organisations listing their donors and/or Cord Blood Units for international use

Global Trends Report: recommendations aimed at aiding in the assessment of the medical suitability of potential donors and websites

Monique M Jöris et al: 'Impact of COVID-19 pandemic on global unrelated stem cell donations in 2020-Report from World Marrow Donor Association' Bone Marrow Transplantation, doi:

Maren Weber et al: 'Audit of donor centre: guidelines by the World Marrow Donor Association Quality and Regulation Working Group' Bone Marrow Transplantation, doi:

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 55 different countries, originating from 101 organisations

Registry data quality reports: registries can compare their data with peer registries and WMDA assists them by providing data quality reports

Cord Blood Unit Report: WMDA provides a predefined Cord Blood Unit Report to its users (if data are shared by the Cord Blood Bank)

- 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

To access WMDA information:

Research datasets: WMDA provides datasets only after consultation with the listing organisations

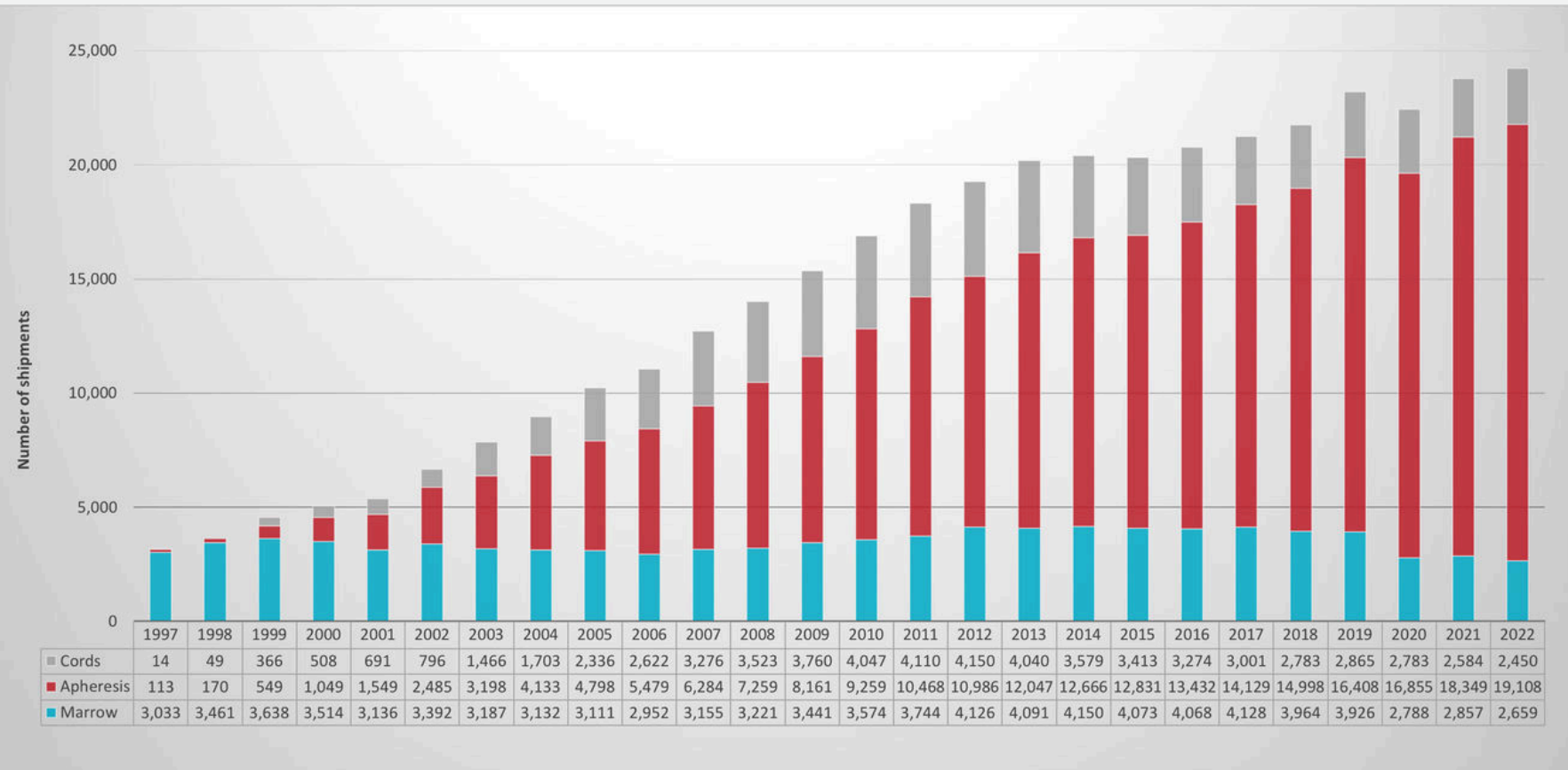
Custom analyses: WMDA provides customised analyses based on the Global Trends Report data

- WMDA members get access to the detailed Global Trends Report & SPEAR Annual Report data
- Membership website: WMDA members can connect and collaborate through [WMDA Share](#)
- Stem Cell Matters: monthly newsletter sent to a wide network of healthcare professionals
- Guidance shared by the Cellular Therapy Committee

HOW WE SHARE KNOWLEDGE

In 2022 1,865,542 new unrelated volunteer donors were recruited and 10,969 new Cord Blood Units were banked. Find more interesting statistics in the [Global Trends Report 2022](#)

Unrelated HPC Marrow, HPC Apheresis and HPC Cords shipped worldwide 1997-2022



HOW WE SHARE KNOWLEDGE

HOW WE MANAGE DATA

Be sure to join us on 16 September to celebrate #WMDD2023!
View a recap and the winners of last year's event here:



For the first time after the COVID-19 pandemic, WMDA was able to organise a face to face meeting to open the door again to global collaboration.

210

Total number of participants registered (excl. WMDA staff)

10

Number of first time attendees

8.1

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

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



WMDA staff and users of the WMDA Search & Match Service can only access the information through multi-factor authentication. 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.



TREASURER'S STATEMENT

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

Results

We have a negative result (Euro 38,816). This is less than predicted and considering the loss of the European funding, we are happy with the achieved result. The total income was stable compared to 2021 which resulted in a smaller loss than anticipated.

Income

The total income was Euro 1,703,225. Nearly all WMDA members paid their membership fee. Sponsors and online education compensated for the loss of the EU Grant. Looking at the income side, we see that diversification and continued investing is paying off. This leads to a balanced income stream.

Expenditure

Most of the expenditure is related to staffing costs and hosting expenditures. Based on the hour registration of the staff, we can see that 83% is spent on projects/services for our membership/community. This is a wonderful achievement of the WMDA team.

Administration

The hosting expenditures were higher than expected, because WMDA operated two versions of the Search & Match Service in 2022.

For both the legacy application and the new application hosting costs were paid. Due to problems on the labour market, external staff were hired for software development and HR.

Reserves

At the end of 2022, the assets of WMDA were Euro 1,337,461. These reserves are allocated to continue the operations of both WMDA and the Certification Body. Part of the reserves of NetCord and BMDW is allocated to invest in Match-Connect.

TREASURER'S STATEMENT

Risks

A major risk for 2023 is the current inflation in Europe and its ripple effects. Not only does it increase our operating costs, it also impacts on the organisation of events. Whilst fundraising activities are being explored, we have to take into account that companies are getting more hesitant to support due to their own increased operating costs.

Another risk is the growing expectation of Match-Connect. It is one of the focus areas of the WMDA team and together with the membership the team is working on a transition plan to launch Match-Connect. Measures have been implemented to monitor the hosting costs and to take action when needed.

Future

WMDA is building a stable office team. Only one person left WMDA in 2022. One person was hired to coordinate both fundraising and communication. WMDA is extremely grateful to the volunteers who dedicate their time as active committee member, reviewer or Board member. Their professional knowledge is valuable for the growth of the organisation.

The launch of Match-Connect requires investments in the area of resources (senior management, security officers and software developers). The success of this project depends on membership participation and acceptance.

The environment and outlook for WMDA and its members is volatile, uncertain, complex and ambiguous. It is difficult to predict with any certainty how this environment will evolve, and what opportunities and risks it will present. Therefore, WMDA's new strategy will be streamlined - focusing on the outcomes that we want to achieve. It will be a living strategy that will evolve and adapt as we learn more.



OLIVER KÜRSTEINER, PHD
WMDA Treasurer, 2019-2022



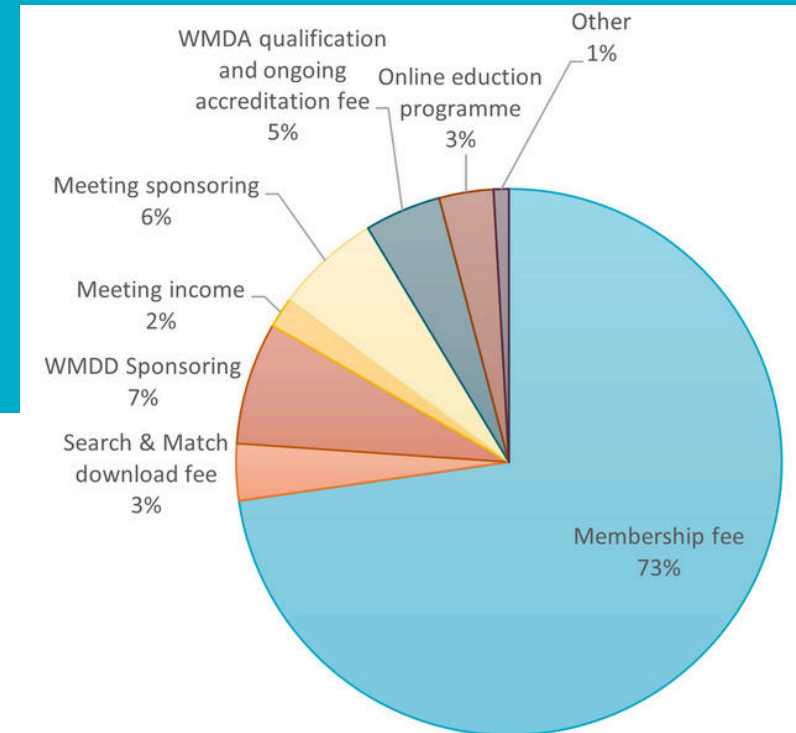
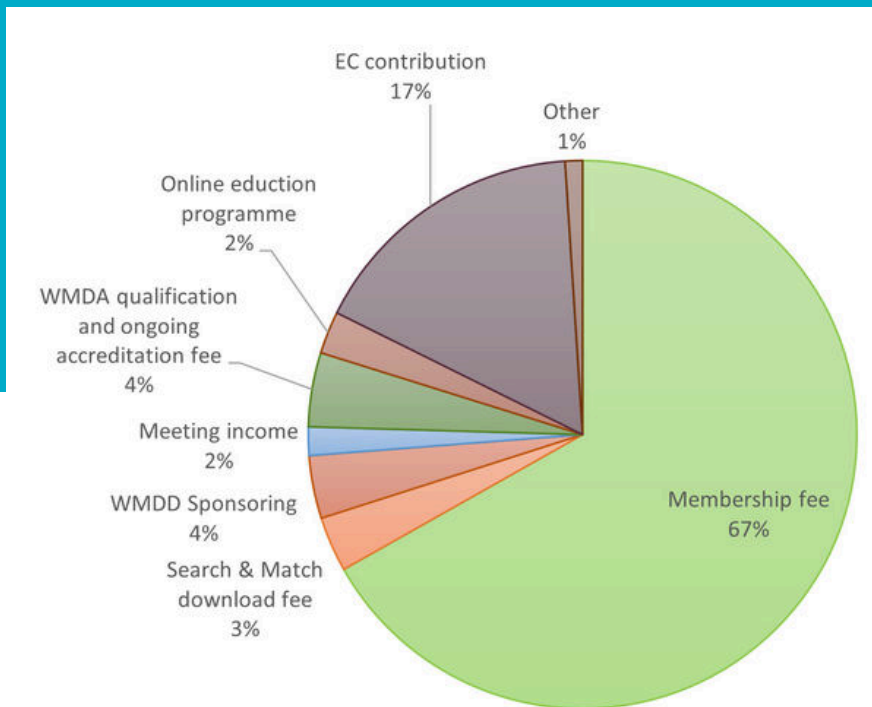
FINANCIAL REPORT

Note on statements: General Accounting Principles for the preparation of the financial statements: The financial statements are prepared according to the Netherlands Civil Code. A complete and detailed report can be requested at: mail@wmda.info.

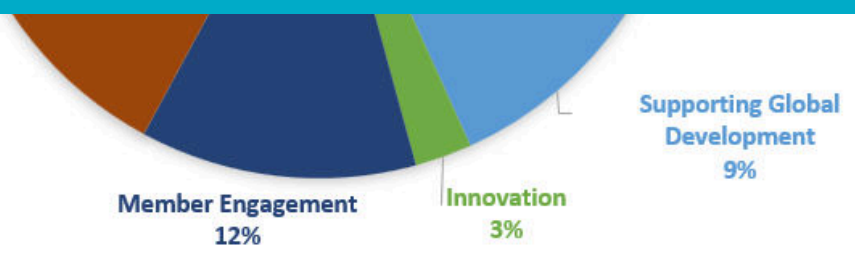
WMDA is an Association under Dutch law. Profits generated are invested in activities to serve the community. The WMDA members contribute on a voluntary basis to the association's work. The WMDA office has its own employment arrangements. The employees in the WMDA office function according to various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

In 2022, the income from the various income sources differed in comparison to 2021. The EU grant came to an end and was offset by higher income from membership & registration fees relating to the WMDA Face to Face Event in 2022. The specification of 2021 has been added for comparison.

Thanks to the generous donations of our partners, we saw our income stabilise. In 2022, WMDA received support from: DKMS (supporting Hap-E), NMDP-Be The Match/Anthony Nolan (supporting Atlas), Gift of Life, time:matters, Ontime Courier, Orca Bio, Histogenetics, Royale International and Inspark. WMDA is registered under Dutch law and recognised as an ANBI (Algemeen Nut Beogende Instelling, Public Benefit Organisation) by the Dutch tax authorities.



The WMDA office is the central point for all activities of the WMDA. In 2022, the WMDA office worked on multiple projects to assist the WMDA Board committees and working groups. 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 continuously 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 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, finance administration, team building.

Balance sheet after proposal distribution of result

*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 2022 have been prepared by WMDA's accounting office.

Balance sheet after proposal distribution of result

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 2022 have been prepared by WMDA's accounting office.

Balance sheet after proposal distribution of result

Interest and similar expenses	<u>-10,502</u>	<u>-9,951</u>
Result	<u>-38,816</u>	<u>-46,779</u>

The Financial Statements 2022 have been prepared by WMDA's accounting office.

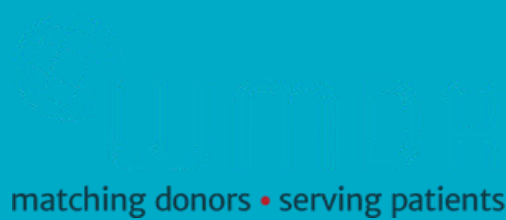
Based on WMDA's strategy, input was collected from WMDA members for the 2023 Work Plan & Budget. Input was provided on two levels:

1. Ongoing projects and their proposed direction in 2022;
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.

2022	EURO 2,271,519
2023	EURO 2,377,566
Estimated result	EURO -106,047



The WMDA Board is working on the Strategic Plan 2023-2028. Two key priorities emerged as a result of the work performed:

- 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 strategic plan will be presented to the WMDA membership in June 2023.



World Marrow Donor Association WMDA

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WMDA

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