Our mission is to promote global collaboration and the sharing of best practices for the benefit of stem cell donors and transplant patients.
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FOREWORD PRESIDENT

Dear WMDA members,

For our global organisation, the past year was characterized by revolutionary development and fundamental change proceeding at an unprecedented pace. This annual report gives us the opportunity to look back and summarize what the WMDA office and countless volunteers from the membership have accomplished and put into the right context between the past and our plans for the short and medium-term future.

The convergence of three leading organizations in global blood stem cell provision - WMDA, BMDW and NetCord – has been carefully led and managed by my predecessor Michael Boo, and its implementation became legally effective at the beginning of 2017. However, this is just one major milestone of a much longer process of growing together which subsequently requires us to reshape our structure and to review and re-define all our activities. This has since been a major focus of our efforts in order to ensure that our membership and their patients strongly benefit from our new broader basis. Here I have to recognize with great gratitude the enormous accomplishments of Lydia and her team in the WMDA office, who are shouldering the bulk of the workload of this important, albeit sometimes tedious, process. At the same time, I am greatly indebted to quite a number of colleagues and friends who helped me as sounding board for ideas and interpreters for the extensive feedback from the membership. Their support was invaluable and gives me great confidence in the ultimate success of our great endeavour.

And we have already made substantial progress: We have implemented the new WMDA Search & Match Service, which took over the function of the classical BMDW. The initial launch in late 2016 was already a big leap forward with the inclusion of a probabilistic 5-locus matching using global consensus frequencies. In the meantime, we are applying over 30 different haplotype frequency sets reflecting the geographic and ethnic heterogeneity of HLA much better, we have extended the number of available donor attributes and we offer innovative advanced sorting options for mismatch searches. This still ongoing project is too big to mention all the numerous people who have substantially contributed to this success. Nevertheless, I would like to thank in particular Manish Kakkar and Jorine Koenderman, who were calmly in the front line between the users and technical teams when our boat was in rough waters from time to time.

Of course, there are more things going on with various levels of visibility and appeal. The GRID is one of those important standardization projects whose complexity is so easily underestimated. Designing consistent, comprehensive and still concise house rules, which ensure a fair balance of efficiency in action and democracy and transparency in decision-making, is as important as time consuming for such a complex organization.

These and many other projects would not be possible without the time, energy and dedication of countless colleagues working for our member registries and their partners throughout the world. I would like to thank everyone of them on behalf of the whole WMDA community. It is good to know that the conviction to contribute to a life-saving global mission is a marvellous and sustaining motivator for all of us.

Sincerely,

Carlheinz Mueller, MD, PhD
President, WMDA 2017-2018
**WMDA 2017 at a glance**

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**VISION**
Patients worldwide have equal access to high quality cells for transplantation from donors whose rights and safety are protected.

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**MISSION**
To promote global collaboration and the sharing of best practices between its members for the benefit of stem cell donors and patients.

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**AIMS**
Optimising ‘Search, Match & Connect’, supporting global development, promoting donor care and ensuring quality.

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**WMDA member organisations**
106

**WMDA accredited/qualified organisations**
30

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**450+ WMDA passionate professionals**

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**WMDA meetings**

<table>
<thead>
<tr>
<th>Meetings</th>
<th>Days</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>10</td>
<td>514</td>
</tr>
</tbody>
</table>

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**Search & Match Service**

<table>
<thead>
<tr>
<th>Patients registered for a search</th>
<th>Registered users</th>
</tr>
</thead>
<tbody>
<tr>
<td>25,600</td>
<td>353</td>
</tr>
</tbody>
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*programmes of 2017: 1) WMDA Reviewers Training Programme 2) Search Coordinator Certificate Programme basic level 3) Search Coordinator Certificate Programme advanced level*
WMDA’s STRATEGY

“YOUR ASSOCIATION. YOUR VOICE”

VISION - Patients worldwide have equal access to high quality cells for transplantation from donors whose rights and safety are protected.

MISSION - To promote global collaboration and the sharing of best practices between its members for the benefit of stem cell donors and patients.

AIMS - Optimising ‘Search, Match & Connect’, supporting global development, promoting donor care and ensuring quality.

STRATEGY JOURNEY

From January 1, 2017 Bone Marrow Donors Worldwide (BMDW), NetCord and World Marrow Donor Association (WMDA) merged.

The global database BMDW, has become a service of the WMDA with a new name: ‘Search & Match Service’.

After the merger, WMDA worked on a 2018-2021 strategy. The journey started with a consultation of the WMDA members in March 2017. After analysing the feedback, the WMDA Board, with consultation of the Committee & Working Group chairs and the WMDA members, developed the Vision, Mission & Aims of WMDA.

The vision and mission are executed by six board committees that collaborate with the WMDA Board, office and working group committees to implement the WMDA strategy.

The foundations of WMDA*:

- Good Governance
- Stable Resources
- Engaging Communication

The WMDA board committees:

- Finance, Governance, Audit, Fundraising
- Nomination
- Optimising ‘Search, Match & Connect’
- Supporting Global Development
- Promoting Donor Care
- Ensuring Quality

In 2018, the WMDA will start to develop plans for each strategic pillar.

*Each foundation and pillar is explained later in this chapter.
**Good Governance**

The core principle of good governance will be **transparency**. All members understand how and why decisions are made, and how they can engage with and influence the decision-making process.

How we will improve our governance:

- Launch compelling **new strategy** with clear direction and priorities.
- Delivery plans for each strategic pillar, led by the board committees.
- Quarterly reporting by board committees so progress & performance can be demonstrated.
- Review of governance structures so they empower members and help achieve our aims & objectives.

**Stable Resources**

Our resources will be stable and sustainable, so that we can deliver against our ambitious plans with tangible results.

How we will improve our resources:

- Seconding experts from established organisations to WMDA and new registries.
- A review and update of the fee structure.
- Operational leads for each pillar to support committees.
- Seeking ‘development’ grants from wealthier organisations to support WMDA’s work.
- A broader fundraising strategy.

**Engaging Communication**

The core principle of WMDA communication will be based on sharing best practice amongst our diverse membership.

How we will improve our communication:

- **Share & Websites**: improve user journey & search.
- **Events**: better communication from events for non-attendees.
- **Social Media**: review & consolidate with clear strategy for growth.
- **Tools**: providing useful data and information in variety of formats.
- **Wiki**: improve and promote the Donor Medical Suitability Wiki as a valuable tool.
- **Online Forums**: explore demand for online forums to share best practice.
OPTIMISING ‘SEARCH, MATCH & CONNECT’

WMDA provides a global environment that facilitates access to the most suitable stem cell source.

➢ A global search platform that facilitates the best possible match between stem cell donors and transplant patients.
➢ User friendly with automation to improve and simplify searches and improved training to support users.
➢ Privacy and data security are safeguarded through the implementation of GRID and data agreements.

PROMOTING DONOR CARE

WMDA ensures that the rights and safety of stem cell donors are promoted and protected.
➢ Ensure rights and safety of donors are promoted and protected.
➢ Inform donor care standards and practices through new and improved online SEAR/SPEAR reporting system for related and unrelated donors.
➢ Introduce professional training programme for those working with donors.

SUPPORTING GLOBAL DEVELOPMENT

WMDA support members to develop and grow, so that more transplant patients find the most suitable stem cell source.

➢ WMDA supports its members to develop and grow, so that more transplant patients find the most suitable match.
➢ The number and availability of stem cell donors increases in areas where patient need is growing: through data collection, sharing global trends and tailored support in growth areas.
➢ WMDA becomes a ‘one-stop shop’ for support and advice through expanded and improved online training.

ENSURING QUALITY

WMDA promotes product quality and global collaboration through accreditation and standardisation.
➢ Promote product quality and global collaboration through accreditation and standardisation.
➢ All organisations listing donors/cord blood units are making demonstrable progress towards accreditation through a tailored support package and peer support.
➢ WMDA & FACT accreditation are seen as the global Gold Standard through awareness raising amongst members; clinicians and authorities.
The new WMDA organisational structure shows the six board committees under which the WMDA working groups and members operate.
WMDA’s ACTIVITIES

OPTIMISING ‘SEARCH, MATCH & CONNECT’

WMDA provides a global environment that facilitates access to the most suitable stem cell source.

Search & Match Service (known as BMDW)

In 2017, WMDA:

- Started to host the global database of adult volunteer donors and cord blood products.
- Launched a new version of the Search & Match Service and solved bugs reported by the users in January.
- Worked on the outline of a legal and technical infrastructure to process larger data files to make it possible to present more data to search coordinators.
- Provided a match list for 25,600 patients who urgently needed a transplant.
- Gave access to 353 users who use the Search & Match for their daily work.
- Implemented DPB1 TCE3 grading and ability to filter grading results.
- Applied new haplo-frequency sets that can be applied for searches.
- Provided 21 search advices for difficult searches.

- A global search platform that facilitates the best possible match between stem cell donors and transplant patients.
- User friendly with automation to improve & simplify searches and improved training to support users.
- Privacy & data security are safeguarded through the implementation of GRID & data agreements.
EMDIS

In 2017, EMDIS:
- Published a global dataset based on the EMDIS data dictionary with the help of WMDA dictionary project group.
- Hosted the EMDIS webpages on WMDA Share that outline the EMDIS activities and work.
- Hosted the final session of the EMDIS Training Programme.
- Established timelines for implementing GRID in close collaboration with the EMDIS Community.

OTHER ACTIVITIES

In 2017, WMDA:
- Defined the format for the Global Registration Identifier for Donors (GRID) and established timelines for implementation.
- Organised two workshops on data protection to inform membership about upcoming data protection regulations.
- Formed a WMDA Security and Privacy Committee to help WMDA and its members to implement the EU General Data Protection Regulation (GDPR).
- Worked on a ‘Data Use Agreement’ draft with a Dutch lawyer.
- Defined a dataset that can be used for exchanging data between organisations and the Search & Match Service.
SUPPORTING GLOBAL DEVELOPMENT

WMDA support members to develop and grow, so that more transplant patients find the most suitable stem cell source.

CORD BLOOD

In 2017, WMDA:
- Celebrated the second WMDA-NetCord Cord Blood Banking Day to welcome the new NetCord member banks as WMDA members.
- Organised two meetings with the joined Working Group WMDA-NetCord, where informed consent and thawing procedures were discussed.
- Developed a strategic partnership with Foundation for the Accreditation of Cellular Therapy (FACT) to establish a close connection with the cord blood banking accreditation standards.
- Encouraged NetCord Member Banks to participate in FACT webinars.
- Celebrated the first edition of World Cord Blood Day (WCBD) in November.
- Developed and sent out a second edition of the Cord Blood Technology Survey.
- Reviewed the EMDIS Cord Blood Data.
- WMDA supports its members to develop and grow, so that more transplant patients find the most suitable match.
- The number and availability of stem cell donors increases in areas where patient need is growing: through data collection, sharing global trends and tailored support in growth areas.
- WMDA becomes a ‘one-stop shop’ for support & advice through expanded & improved online training.
ONLINE EDUCATION

In 2017, WMDA:

- Awarded 119 certificates to students completing Search Coordinator Certificate Programme (SCCP) basic/advanced courses in 2017:
  - ✓ 77 students completed the basic level training.
  - ✓ 42 students completed the advanced level training.
- Piloted a continuing education level training for search coordinators.
- Added option to complete basic level “intensive course” in 5 vs 10 months.
- Continued to improve and reorganise lectures to address student suggestions.
- Organised the first Search Coordinator workshop to get feedback of the students and establish a network.

WMDA MEETINGS

In 2017, WMDA:

- Organised a two-day symposium for small and medium-sized organisations to present a complete overview on things you need to know when you start to work in a registry.

Thanks to Cellex Foundation for the unrestricted grant

ANNUAL STATISTICS

In 2017, WMDA:

- Published annual statistics showing that the number of unrelated products provided are:
  - 4,125 HPC-Marrow
  - 14,131 HPC-Apheresis
  - 3,001 HPC-Cord

EMERGING REGISTRIES

In 2017, WMDA:

- Created the project group “Emerging registries”.
- Evaluated existing educational resources (WMDA Handbook, education and networking @ WMDA meetings, standards and guidance on WMDA qualification and accreditation, pilot on qualification mentoring).
- Organised a remote mentoring seminar on corporate fundraising delivered for a group of emerging registries in June 2017.
THE PROJECTS

In 2017, WMDA:
• Received 356 reports from organisations that reported a serious adverse event or reaction.
• Organised two open sessions to share best practice in donor care.
• Published and updated statement on the use of G-CSF.
• Organised the third edition of World Marrow Donor Day (WMDD), where 65 organisations participated that organised over the 350 events.

➢ Ensure rights and safety of donors are promoted and protected.
➢ Inform donor care standards & practices through new and improved online SEAR/SPEAR reporting system for related & unrelated donors.
➢ Introduce professional training programme for those working with donors.
ENSURING QUALITY

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PROJECTS

In 2017, WMDA:
• Continued training of 20 reviewers using electronic learning environment.
• Created a slide set for regulator education.
• Performed a cross walk of WMDA Standards and accrediting standards to identify strengths and weaknesses.
• Clarified the standards related to Information Technology for discussion with membership.
• Reviewed the current EU legislation with several EU member registries and sent in feedback on the current legislation to the EU.
• Organised two open educational meetings to develop best practices and to improve operations to facilitate transplants.
• Finalised a paper on guidance for audit collection centres and submitted for publications.
• Reviewed all WMDA publications and recommendations to see if updates are required.
• Initiated projects on audit of donor centres,
List of WMDA qualified and accredited organisations. The bold-marked registries are WMDA Accredited. The blue registries receiving their WMDA Qualification/WMDA Accreditation certificate in 2017.

AUDIT OF PRODUCT COLLECTION CENTRES, VALIDATION OF TRANSPORT CONTAINERS, CRITERIA TO EVALUATE TRANSPLANT CENTRES AND PROBLEM MANAGEMENT.

**ACCREDITATION**

- Performed 4 on-site audits, (re)accrediting 4 registries.
- Reviewed and approved qualification of 1 registry.
- Implemented electronic application tool to submit applications for WMDA Qualification/Accreditation.
BOARD MEMBERS 2017

Carlheinz Mueller, DE
Board member: President
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Jeff Szer, AU
Board member: President-elect
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Amy Ronneberg, US
Board member: Treasurer
aronnebe@nmdp.org

Henny Braund, UK
Board member
henny.braund@anthonynolan.org

Machteld Oudshoorn, NL
Board member: Secretary
machteld.oudshoorn@matchis.nl

Michael Boo, US
Board member: Past president
mjboo@comcast.net
The WMDA office is the central point for all activities of the WMDA. In 2017 the WMDA office has worked on multiple projects to assist the WMDA board committees/working groups. The office hours are specified into the new pillar structure.

The specification of WMDA office hours 2017 can be found in the figure below.