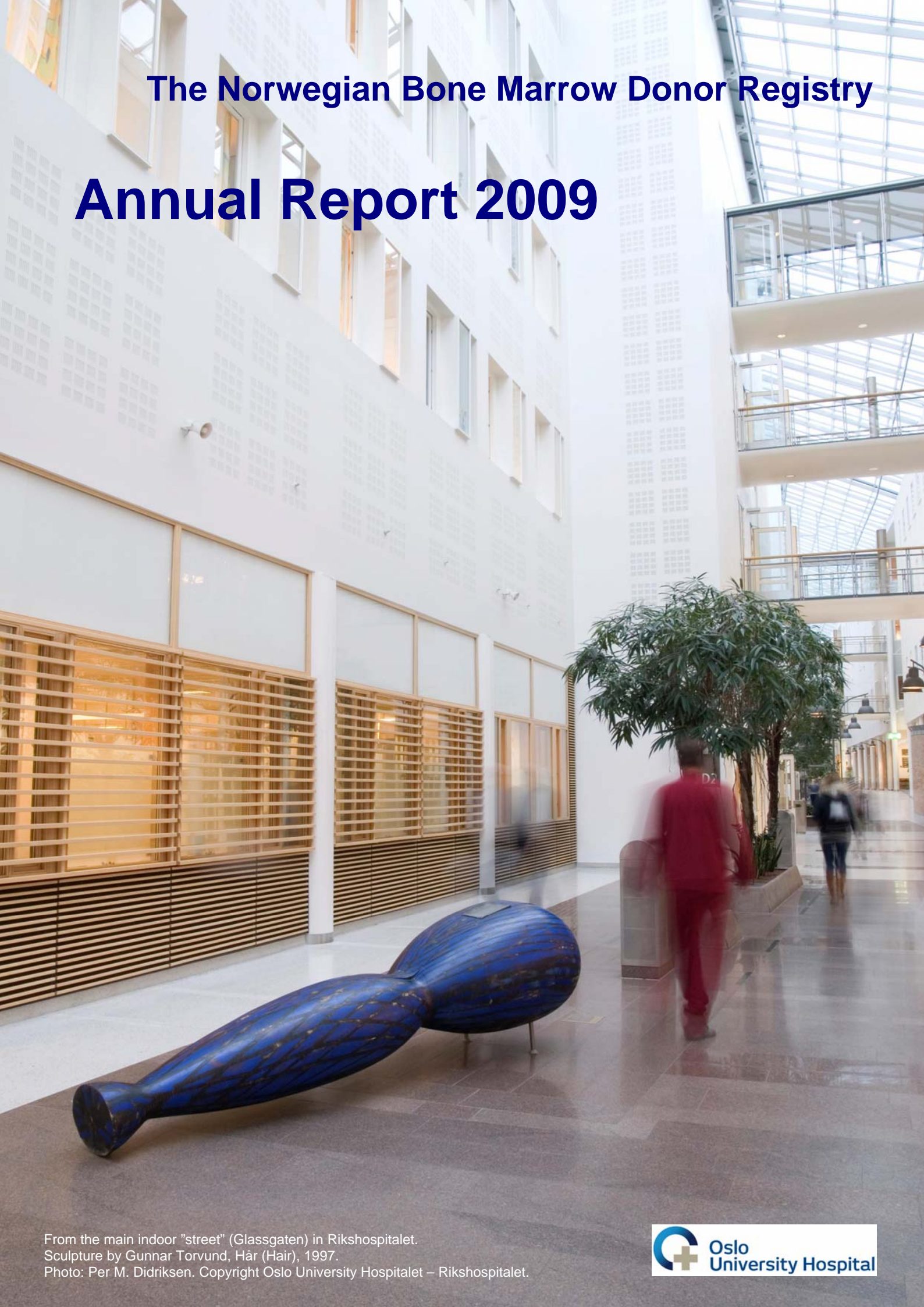


The Norwegian Bone Marrow Donor Registry

Annual Report 2009



From the main indoor "street" (Glassgaten) in Rikshospitalet.
Sculpture by Gunnar Torvund, Hår (Hair), 1997.
Photo: Per M. Didriksen. Copyright Oslo University Hospital – Rikshospitalet.

ANNUAL REPORT 2009

The Norwegian Bone Marrow Donor Registry

The Norwegian Bone Marrow Donor Registry (NBMDR) was established in 1990 at the Institute of Immunology, Oslo University Hospital - Rikshospitalet, Oslo, after a generous donation from The Norwegian Cancer Society. This society has been the main source of financial support since the establishment. We are very grateful for the continuous support.

The aim of NBMDR is to provide stem cells from an HLA identical unrelated donor to domestic and international patients in need of allogeneic stem cell transplantation. The patients suffer from malignant blood disorders as well as other severe blood diseases, metabolic diseases, and immunodeficiencies in children. NBMDR is part of an extensive international collaboration, representing more than 14 million HLA-typed volunteer donors and umbilical cord blood units listed in Bone Marrow Donors Worldwide (BMDW).

Since 1990, 343 Norwegian patients have been transplanted with stem cells from Norwegian (51) and international (292) donors. NBMDR has provided stem cells for 354 patients, 303 of whom were from abroad.

NBMDR and international relations

- NBMDR was accredited by World Marrow Donor Association (WMDA) on March 27, 2009.
- The laboratory of Section of Transplantation Immunology, Institute of Immunology, Oslo University Hospital – Rikshospitalet, is accredited by European Federation of Immunogenetics (EFI). This laboratory performs HLA typing for NBMDR.
- NBMDR was licensed on August 15, 2008, by the Norwegian Directorate for Health and Social Affairs as a tissue establishment in accordance with the EU Directives on setting standards of quality and safety for human tissues and cells of March 7, 2008.
- NBMDR became a member of the European Matching and Donor Information System (EMDIS) in 2006.
- NBMDR is a member of WMDA
- NBMDR is member of BMDW
- Rikshospitalet University Hospital was accredited by the National Marrow Donor Program (NMDP) as a transplant centre in 1995, and as a donor centre and a collection centre in 1997.
- NBMDR has, since the fall of 2004, a formal collaboration with the Blood Bank in Reykjavik, Iceland. Icelandic donors are recruited in the Blood Bank of Reykjavik. These donors are HLA typed in EFI-accredited HLA laboratories in Reykjavik and in Oslo.

HLA typing of donors

Section of Transplantation Immunology, Institute of Immunology performs HLA typing for NBMDR. In addition, Icelandic donors are typed at the Blood Bank in Reykjavik, Iceland. By December 31, 2009, 28,323 HLA-A and -B-typed active donors were registered in NBMDR. 27,352 (96.6 %) were also HLA-DR typed, mostly by genomic low or intermediate resolution typing techniques.

Search in and NBMDR

NBMDR received donor search requests for 6,235 patients in 2009, the majority through the EMDIS system. 348 donors were evaluated for 275 patients with further HLA-typing or confirmatory testing (CT). 32 NBMDR donors donated bone marrow or peripheral blood stem cells (PBSC) in 2009 (first donation). This is the highest annual number donors donating stem cells since the start of NBMDR.

Search for donors for Norwegian patients

In 2009, search requests for 57 new Norwegian patients were made to NBMDR and to registries and cord blood banks around the world. This is a significant increase compared to previous years. The data file of BMDW is always checked for every search initiated, and it is repeatedly used in an attempt to find a donor for every patient for whom a donor has not been identified. In addition, international searches for Norwegian patients

through the EMDIS system were initiated in 2008. Transplantation with an unrelated HLA matched donor (10/10 or 9/10 match) or cord blood (CB) unit (6/6, 5/6, or 4/6 match) has been performed on an average for 60% of the patients for whom an unrelated donor search was initiated. Since 2006, an HLA match donor or CB unit has been identified for 90.8% of the patients in *active* donor search (search may have been ceased before the first matching donor was identified). The time to identify a matching donor has been on average of 29.8 days (range 1 – 108 days).

In 2009, 34 Norwegian patients were transplanted with bone marrow (4), PBSC (27) or cord blood (3) from an unrelated HLA matched donor or cord blood unit.

NBMDR and blood banks

NBMDR donors are recruited in blood banks throughout Norway. Since 2004, Icelandic donors are also recruited in the Blood Bank of Reykjavik, Iceland. These donors are added to the donor pool of NBMDR. In addition to running the donor registry, NBMDR also performs donor searches for Norwegian patients.

The annual course for personnel from all blood banks in Norway was arranged in January of 2009. The large blood banks (Bergen, Oslo, Tromsø, Trondheim and Iceland) have access to a program for searching for HLA-compatible platelet donors among their own blood donors. All blood banks continue to recruit new donors.

NBMDR is very grateful to all the blood banks – their effort is crucial to NBMDR.

Staff and collaborators

The following persons were engaged in NBMDR by the end of 2009:

Torstein Egeland, MD, PhD, Head of NBMDR and Medical Director
Irene Andersen, Head Biomedical Laboratory Scientist
Sidsel M. Strøm, Donor and Transplant Centre Coordinator
Rut Fjellberg, Donor and Transplant Centre Coordinator
4 ½ positions of Biomedical Laboratory Scientists, working in the HLA typing laboratory of Section of Transplantation Immunology, Institute of Immunology

Medical Review Board members, all at Oslo University Hospital – Rikshospitalet:

Lorentz Brinch, MD, PhD, Head, Adult Stem Cell Transpl. Program, Section of Blood Diseases, Med. Dept.
Geir E. Tjønnfjord, MD, PhD, Section of Blood Diseases, Med. Dept.
Anders Glomstein, MD, Head, Children's Stem Cell Transpl. Program, Children's Dept.
Gunnar Kvalheim, MD, PhD, Dept. of Cellular Therapy, Cancer Clinic

In addition, medical doctors at the Dept. of Cellular Therapy conducted donor information sessions and health examinations for Norwegian donors who were selected for bone marrow or PBSC donation. Anne-Grethe Fjellman coordinated the collaboration with the transplant physicians at Section of Blood Diseases, and Merete Djupedal coordinated the collection of bone marrow, PBSC and lymphocyte collections at the Department of Cellular Therapy.

HLA-typing of donors

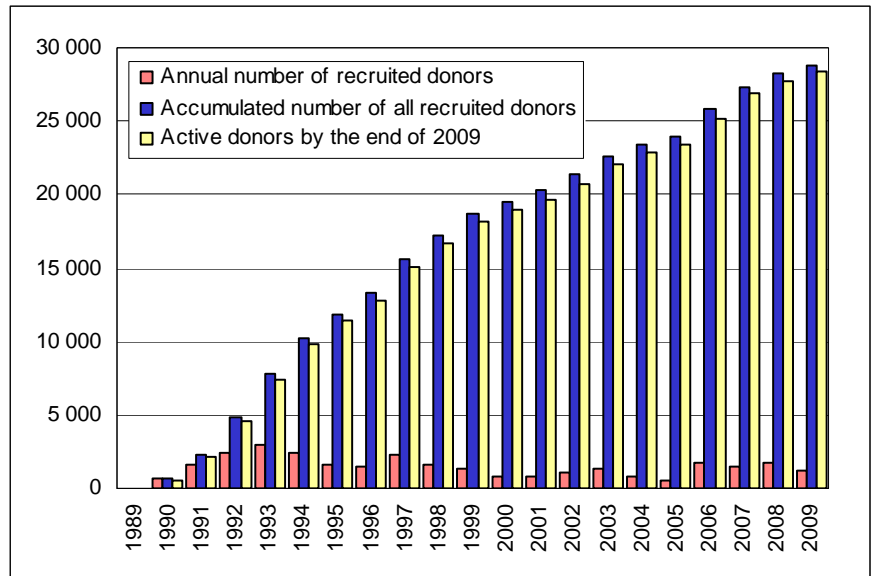
All new donors are typed for HLA-A, -B, -C and -DRB1 by SSO technique or sequenced-based typing. SSP typing is performed if the initial typing is inconclusive. Upon request, NBMDR performs low and high resolution genomic typing for A, B, C, DRB1, DRB3, DRB4, DRB5, DQB1, and DPB1.

REPORT FOR NBMDR

RECRUITMENT

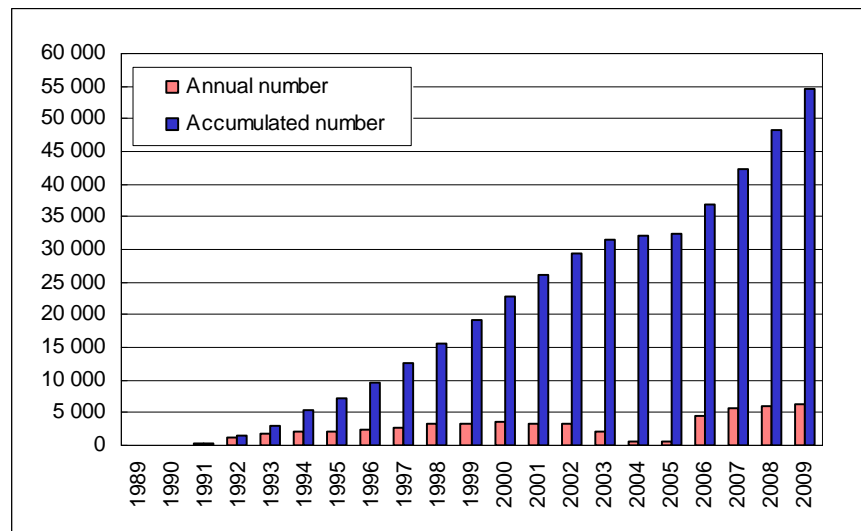
Fig. 1.
Annual and accumulated number of new donors and number of active donors by the end of 2009. All donors are recruited from blood banks throughout the country and (after the fall of 2004) from Iceland. In 2009, 592 donors were removed from the active donor table due to age (> 55 years), and 48 were removed from other reasons, usually medical reasons.

In 2009, the growth of active donors was from 27,771 to 28,323, a net increase of 552 donors.



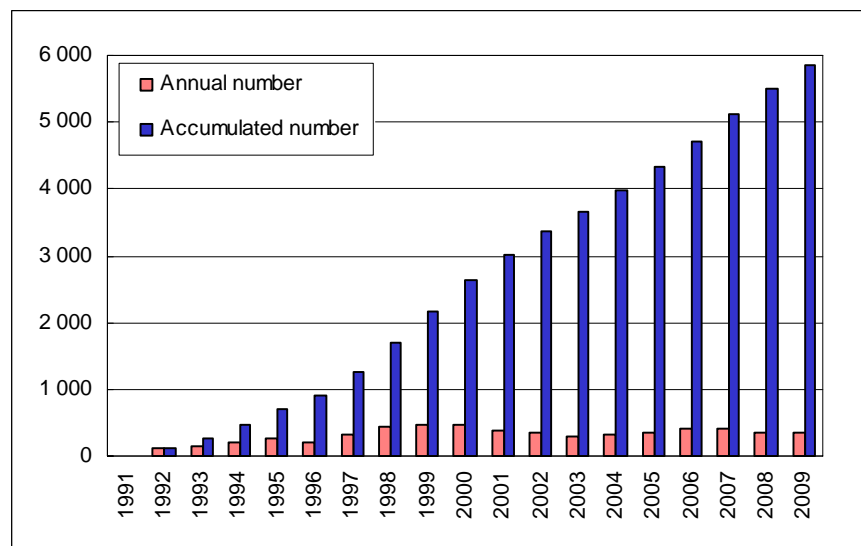
SEARCH FOR DONORS IN NBMDR

Fig. 2.
Annual and accumulated number of donor search requests. Average number of monthly searches in 2009 was 520 (501 in 2008, 465 in 2007). In February 2006, NBMDR was connected to the international EMDIS system. This connection caused a significant increase in search numbers since 2006.



ACTIVATION OF DONORS IN NBMDR

Fig. 3.
Annual and accumulated number of activated donors (HLA typing or blood sample shipment request). 29 donors were on average activated per month in 2009 (30 donors in 2008, 34 in 2007).



REPORT FOR NBMDR

PATIENTS WITH ACTIVATED DONORS IN NBMDR

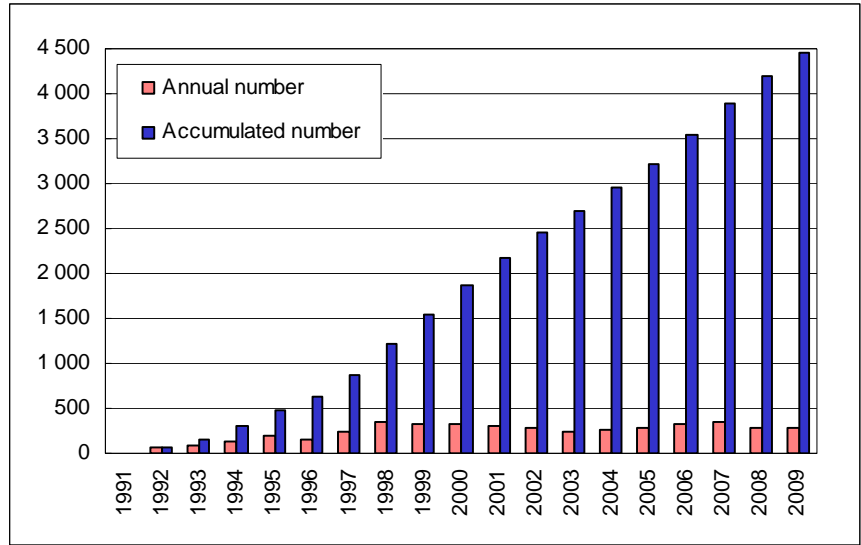


Fig. 4.
Annual and accumulated number of patients for whom one or more NBMDR donors were activated. Donors were activated for on average 23 new patients per month in 2009 (24 in 2008, 29 in 2007).

NUMBER OF DONORS ACTIVATED PER PATIENT

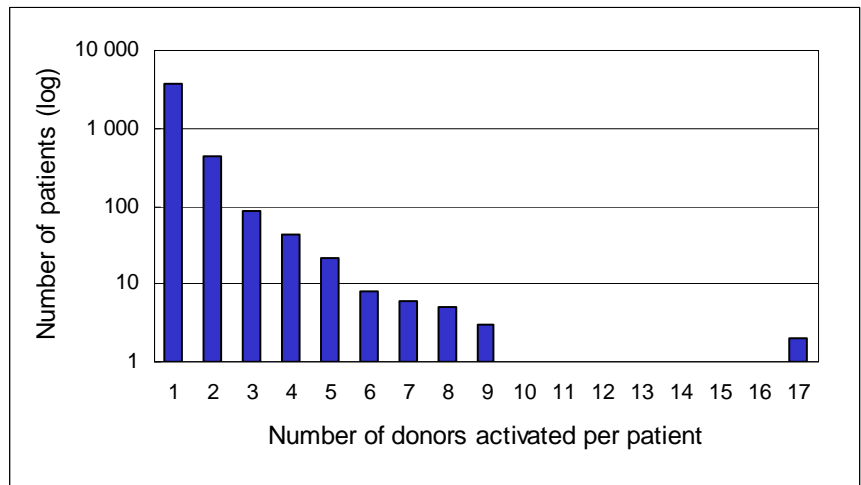


Fig. 5.
Number of donors activated per patient vs. number of patients. 1 and 2 donors only were activated for individual patients in 95.9 % of the cases.

ACCUMULATED NUMBER OF DONATIONS FROM NBMDR

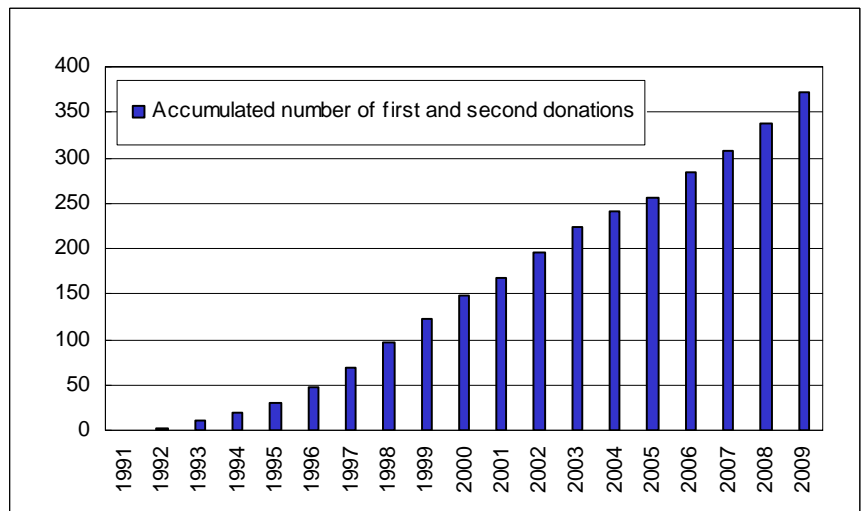


Fig. 6A.
Accumulated number of NBMDR donors who have donated bone marrow or PBSC.

REPORT FOR NBMDR

ANNUAL NUMBER OF DONATIONS FROM NBMDR

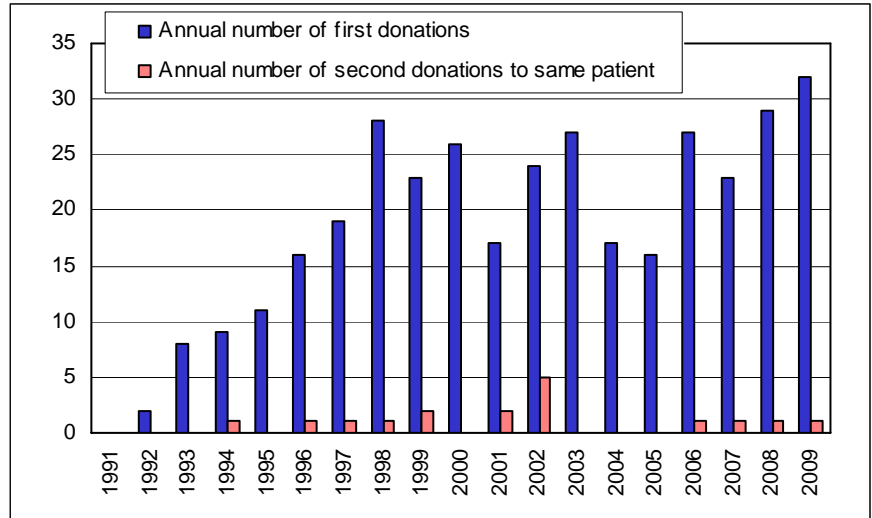


Fig. 6b.
Annual number of NBMDR donors who have donated bone marrow or PBSC.

MARROW AND PBSC DONATIONS

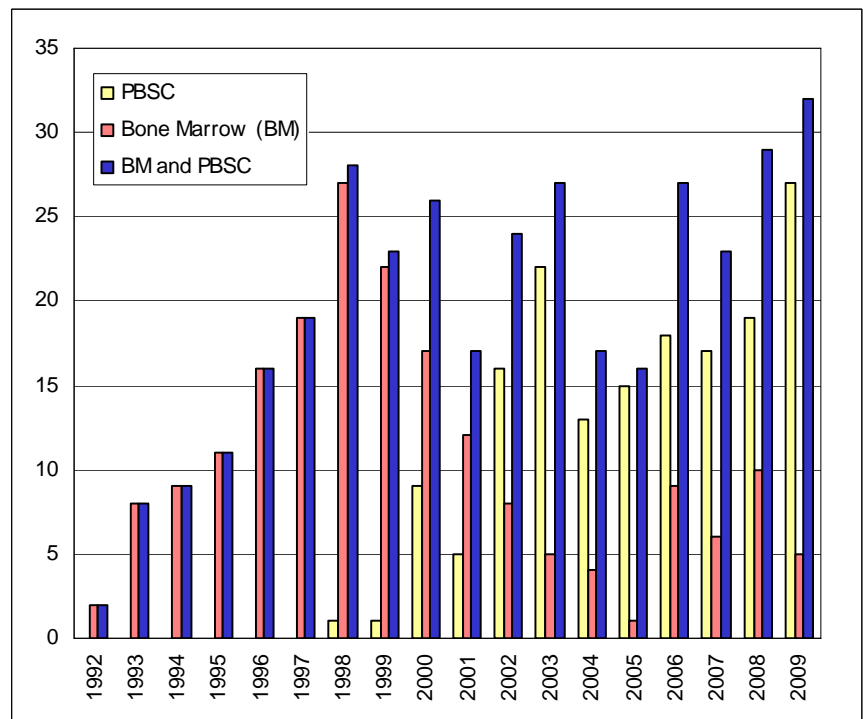


Fig. 7.
Annual number of donations of bone marrow and PBSC (first donation only). Since 2002, donation of PBSC has been more frequent than donation of bone marrow.

SECOND DONATIONS OF MARROW AND PBSC

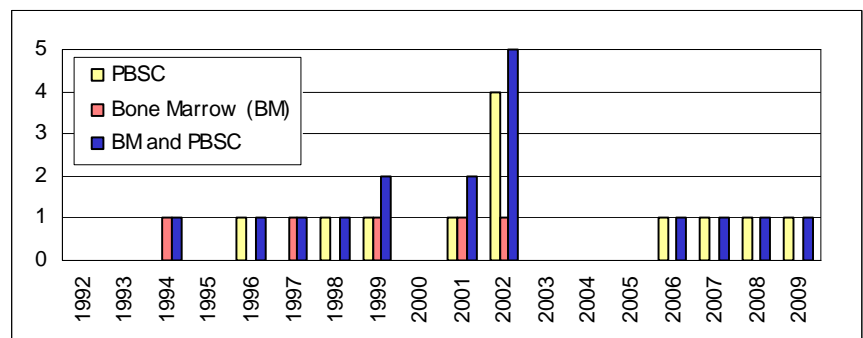


Fig. 8.
Annual number of second donation of bone marrow or PBSC to same patient.

REPORT FOR NBMDR

LYMPHOCYTE DONATIONS

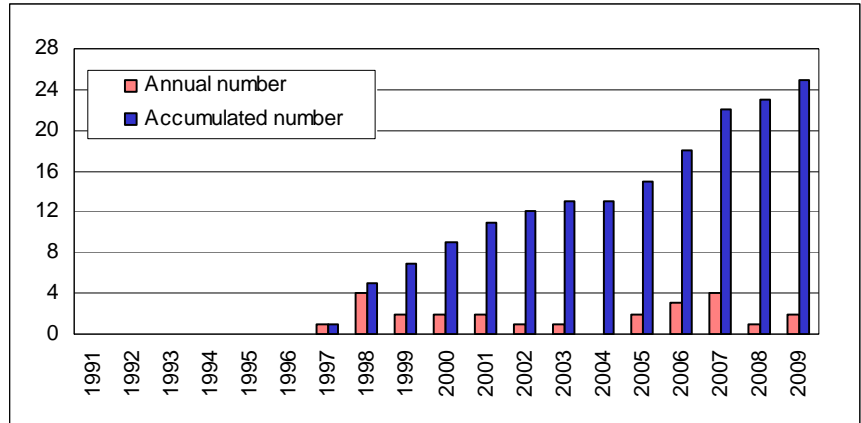


Fig. 9.
Annual and accumulated number
of donations of lymphocytes.

DONATIONS PER YEAR PER 1,000 DONORS

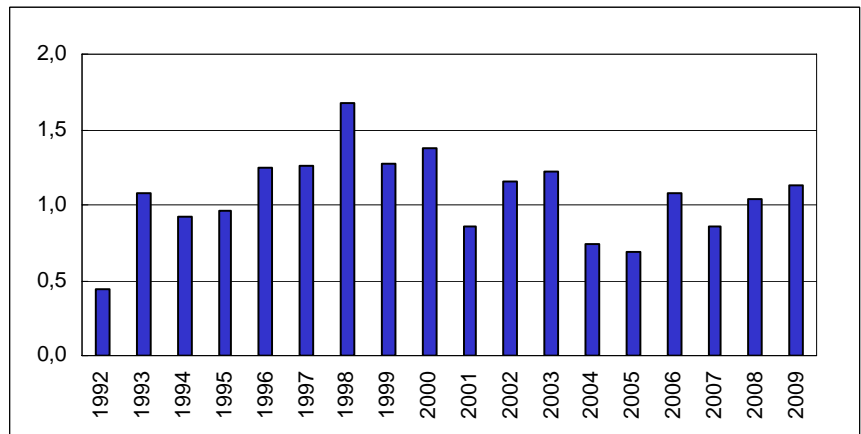


Fig. 10.
Number of stem cell donations
(bone marrow and PBSC, first
donation) per 1,000 NBMDR
donors per year. This represents
an average per year of 1.06
donations per 1,000 donors

DONATIONS FROM NBMDR TO PATIENTS IN DIFFERENT COUNTRIES

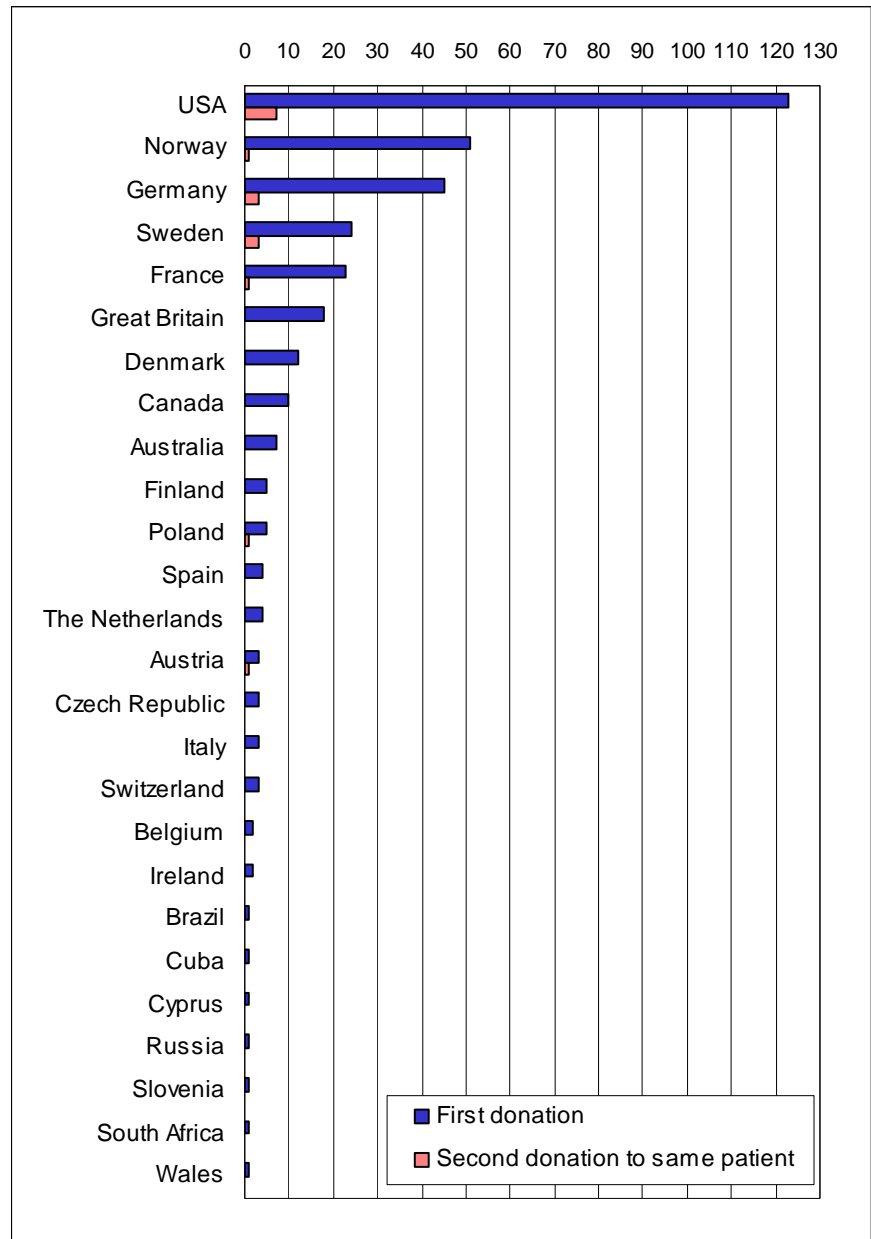


Fig. 11. Number of donations (bone marrow and PBSC, first and second donation) from NBMDR to patients in individual countries.

DONATIONS FROM NBMDR TO PATIENTS RESIDING INSIDE AND OUTSIDE EU

Table 1. Number of donations for first transplant in 2009 from NBMDR to patients in countries inside and outside EU and to Norway (EEA country). In addition, there was one second donation in 2009 (to USA), and two lymphocytes donations (Great Britain and USA).

Inside EU	Export	
	Outside EU	Within Norway
14	12*	6

*USA (11) and Australia (1)

BLOOD BANKS WITH DONORS WHO HAVE DONATED BONE MARROW OR PBSC

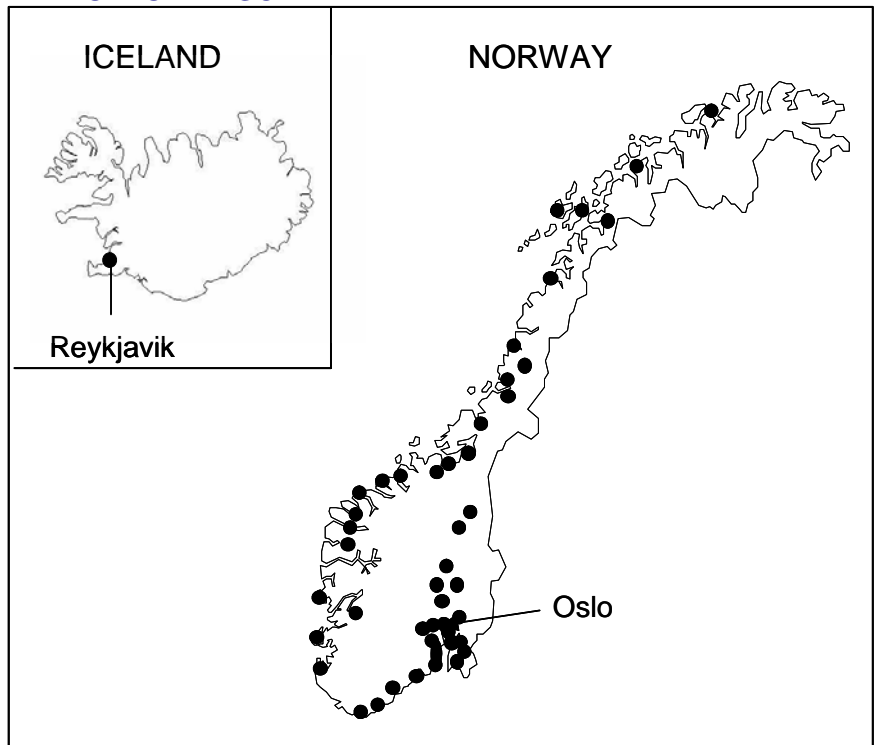


Fig. 12.
Localisation of the blood banks
with donors who have donated
bone marrow or PBSC.

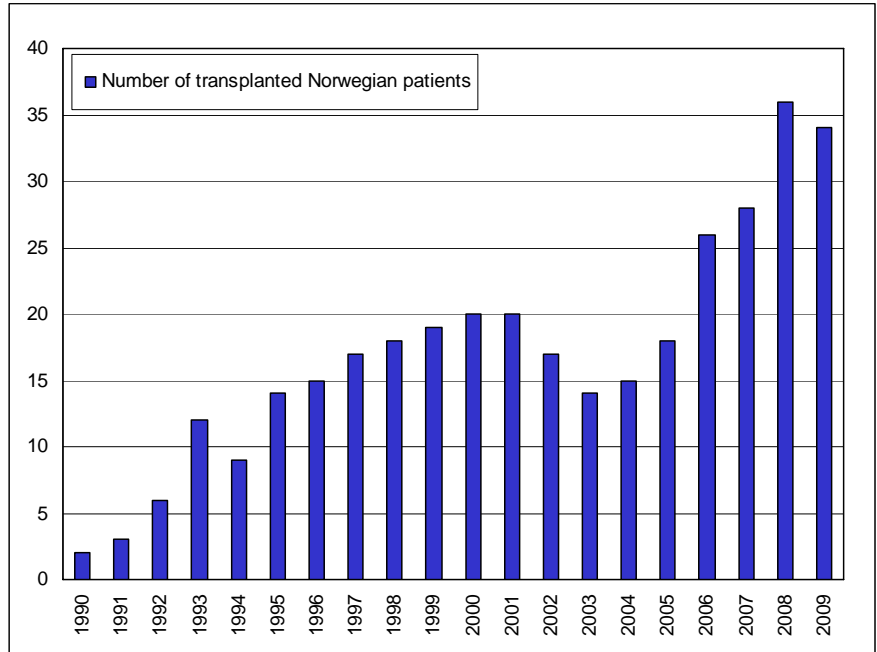
Blood bank city	Number of donations
Oslo	109
Bergen	30
Trondheim	16
Tønsberg	14
Kristiansand	11
Fredrikstad	9
Stavanger	9
Halden	8
Molde	8
Arendal	7
Levanger	7
Minnesund	7
Skien	7
Tromsø	7
Ålesund	7
Bodø	6
Drammen	6
Gjøvik	5
Askim	4
Hamar	4
Haugesund	4
Kongsberg	4
Lillehammer	4
Nordbyhagen	4
Bærum	3
Førde	3
Hammerfest	3

Blood bank city	Number of donations
Hønefoss	3
Moss	3
Reykjavik	3
Sandnessjøen	3
Sarpsborg	3
Florø	2
Kristiansund	2
Larvik	2
Mo i Rana	2
Mosjøen	2
Namsos	2
Narvik	2
Orkanger	2
Ski	2
Storkmarknes	2
Tynset	2
Elverum	1
Flekkefjord	1
Harstad	1
Horten	1
Mandal	1
Nordfjordeid	1
Odda	1
Rørøros	1
Stord	1
Volda	1
Unregistered	1

Table 2.
Name of blood bank cities as
shown in fig. 12.

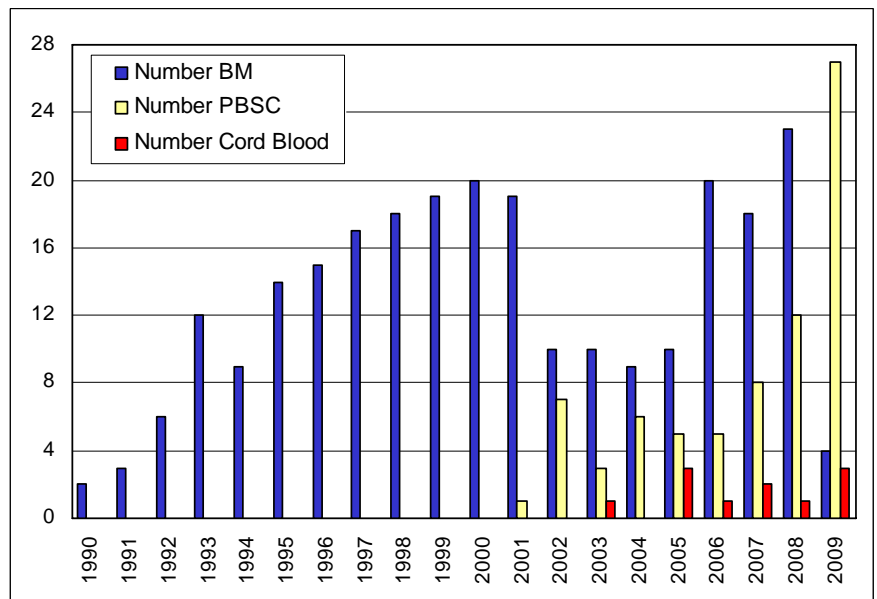
REPORT FOR NORWEGIAN PATIENTS

NUMBER OF NORWEGIAN PATIENTS TRANSPLANTED



*Fig. 13.
Number of Norwegian patients transplanted per year with stem cells from unrelated donors or cord blood units.*

NUMBER OF NORWEGIAN PATIENTS TRANSPLANTED WITH BONE MARROW, PBSC OR CORD BLOOD



*Fig. 14.
Number of Norwegian patients transplanted with bone marrow (BM), peripheral blood stem cells (PBSC) or cord blood from unrelated donors or cord blood units.*

REPORT FOR NORWEGIAN PATIENTS

ORIGIN OF DONORS FOR NORWEGIAN PATIENTS

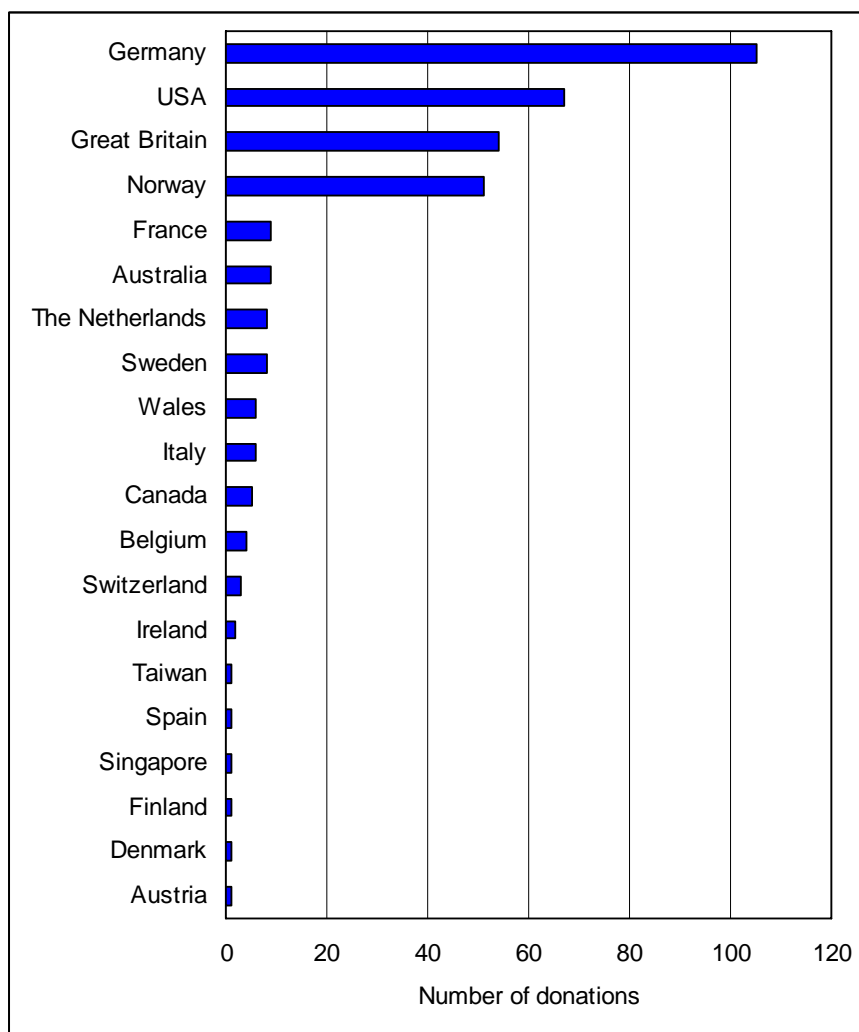


Fig. 15. Countries which have provided bone marrow, PBSC or cord blood for patients in Norway.

Table 3. Number of donations for first transplant in 2009 from countries inside and outside EU and from Norway (EEA country). In addition, there were two re-transplants in 2009, both donations coming from an EU country (Germany). There was no lymphocyte donation to Norwegian patients in 2009.

DONATION TO NORWEGIAN PATIENTS FROM DONORS WITHIN OR OUTSIDE EU

Import		Within Norway
Inside EU	Outside EU	
20	8*	6

*All from USA (5) and Australia (3)

DIAGNOSIS OF NORWEGIAN PATIENTS TRANSPLANTED WITH STEM CELLS FROM UNRELATED DONORS

AML	8	CLL	2
MDS	6	AL	1
NHL	5	CMML	1
CML	3	Hurler's disease	1
HL	3	WAS	1
ALL	2	Other	1

Table 4. Number of different diagnoses for Norwegian patients transplanted in 2009.

REPORT FOR NORWEGIAN PATIENTS

SEARCH FOR DONORS FOR NORWEGIAN PATIENTS

In 2009, NBMDR initiated searches for 57 Norwegian patients in NBMDR and other registries. This is the highest annual number of patients ever, and the number has gradually increased over the last few years. By the end of 2009, 29 of these patients had been transplanted with an HLA matched unrelated donor or cord blood, and more were awaiting transplantation in 2010 (table 2).

Table 5 provides the number of donor searches and transplantations for Norwegian patients relative to the year search was initiated. By the end of 2009, a total number of 343 Norwegian patients had been transplanted with an unrelated donor or cord blood. 58% of the patients for whom a donor search was initiated have been transplanted. Since 1999, HLA matched donors have been found for 82% of the patients before the search was ceased, either due to transplantation or because the patient was taken off the transplant program (donors found in the extended family, the patient's treatment protocol was changed, transplantation with cord blood units not indicated, the patient died etc).

Table 5. Annual number of Norwegian patients for whom a donor search was initiated and the number of patients who were transplanted relative to the year search was initiated. The number of donors and cord blood units listed in Bone Marrow Donors Worldwide (BMDW) at the end of each year is also given as well as the relative number of patients with at least one donor or cord blood unit identified and the median number of months to identify a matched donor.

Search initiated	Accumulated no. of donors and cord blood units in BMDW	No. of patients for whom a search was initiated**	No. of transplanted patients***	Rel. no. (%) of transplanted patients	Rel. no (%) of patients with an matched donor	Median time (months) to identify a matched donor from search initiation
1989	156 965	8	2	25		
1990	399 480	7	4	57		
1991	736 463	12	4	33		
1992	1 237 923	11	5	45		
1993	1 720 363	22	15	68		
1994	2 339 766	23	15	65		
1995	2 917 935	14	9	64		
1996	3 752 646	20	15	75		
1997	4 349 144	30	22	73		
1998	5 440 000	27	17	63		
1999	6 126 479	32	23	72	88	3.3
2000	6 860 000	25	16	64	88	2.2
2001	7 522 210	27	19	70	85	2.5
2002	8 191 038	29	16	55	90	2.6
2003	8 878 798	26	13	50	85	2.2
2004	9 508 698	31	16	52	94	2.1
2005	10 150 000	34	22	65	97	2.0
2006	11 000 000	36	22	61	83	1.9
2007	11 810 000	35	26	74	91	0.9 ****
2008*	12 740 000	48	33	69	92	0.7
2009*	14 000 000	57	29	51	95	0.6
Result:		Total: 497	Total: 343	Mean: 60	Mean: 90	Mean: 1.9

*Some of the patients for whom search was initiated in 2008 and 2009 still remain to be transplanted in 2010 (or later). Thus, the relative number of transplantations during the last few years remains to be increased by transplantations that take place in 2010 or later.

**Not all patients for whom a search was initiated were in the end actually in the need of an *unrelated* donor transplantation, e.g. haplo-identical donors in the extended family were eventually identified or the patient's treatment protocol was re-evaluated. These patients have not been excluded from this table.

***These figures are relative to the year when search was initiated. Thus, if for instance two patient searches were initiated in 2007, and one patient was transplanted in 2007 and one in 2008, both transplantations are made accountable to 2007.

****Before 2007, matched donors were reported to the transplant physicians only *after* HLA re-typing (confirmatory typing) in our laboratory. From 2007, matched donors were reported prior to confirmatory typing was performed, i.e. as soon as a matched donor was identified.

ADDENDUM

Mailing address:

The Norwegian Bone Marrow Donor Registry
Institute of Immunology
Oslo University Hospital – Rikshospitalet
N-0027 Oslo
NORWAY

Visiting address:

Sognsvannsveien 20, Oslo

International calls:

+47-2307-3500 Institute of Immunology
+47-2307-3770 NBMDR Secretariat
+47-2307-3772 Irene Andersen,
Head Biomedical Laboratory Scientist
+47-2307-3770 Sidsel M. Strøm,
Transplant and Donor Centre Coord.
+47-2307-3771 Rut Fjellberg
Transplant and Donor Centre Coord.
+47-2307-1379 Torstein Egeland, MD, PhD,
Head and Med. Dir.

International fax:

+47-2307-3780

NBMDR Web site:

www.nordonor.org

Information concerning blood donation in Norway:

www.giblod.no

Email addresses:

The Norwegian Bone Marrow Donor Registry:
nordonor@oslo-universitetssykehus.no

Irene Andersen:

irene.andersen@oslo-universitetssykehus.no

Sidsel M. Strøm:

sidsel.strom@oslo-universitetssykehus.no

Rut Fjellberg:

rut.lisbet.fjellberg@oslo-universitetssykehus.no

Torstein Egeland:

torstein.egeland@medisin.uio.no
(for non-patient issues)
torstein.egeland@oslo-universitetssykehus.no
(for patient issues)

Icelandic collaborators:

The Blood Bank
Landspítalinn University Hospital
Reykjavík
ICELAND
Email: stofnfrumugjafaskra@landspitali.is

Head of blood bank: Sveinn Gudmundsson, MD, PhD
Email: sveinn@landspitali.is

Accounts and invoices:

Visma Services Norge AS
Gjerdrums vei 19
Postboks 4303 Nydalen
0401 Oslo
NORWAY
Tel: +47-9828-6247
Fax: +47-2258-4501