PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Private Cord Blood Banking: Experiences and Views of Pediatric Hematopoietic Cell Transplantation Physicians

Ian Thornley, Mary Eapen, Lillian Sung, Stephanie J. Lee, Stella M. Davies and Steven Joffe

Pediatrics 2009;123;1011-1017
DOI: 10.1542/peds.2008-0436

ARTICLE

Private Cord Blood Banking: Experiences and Views of Pediatric Hematopoietic Cell Transplantation Physicians

Ian Thornley, MD[a], Mary Eapen, MD[b], Lillian Sung, MD, PhD[c], Stephanie J. Lee, MD, MPH[d], Stella M. Davies, MD[e], Steven Joffe, MD, MPH[f]

[a]Department of Pediatrics, North Shore Medical Center, Salem, Massachusetts; [b]Center for International Blood and Marrow Transplant Research, Medical College of Wisconsin, Milwaukee, Wisconsin; [c]Division of Pediatric Hematology/Oncology, Hospital for Sick Children, Toronto, Ontario, Canada; [d]Clinical Research Division, Fred Hutchinson Cancer Research Center, Seattle, Washington; [e]Department of Pediatrics, Cincinnati Children's Hospital Medical Center, Cincinnati, Ohio; [f]Department of Pediatric Oncology, Dana-Farber Cancer Institute, and Department of Medicine, Children's Hospital Boston, Boston, Massachusetts

Financial Disclosure: Dr Eapen is the associate scientific director of the CIBMTR and scientific director of the Pediatric Cancer, Immune and Metabolic Disease, Nonmalignant Marrow Disease, and Graft Sources and Manipulation Committees of the CIBMTR; Dr Lee is the scientific director of the Immunobiology Committee (CIBMTR) and co-chair of the Health Policy Working Committee (CIBMTR); and Dr Davies is a member of the Board and of the Executive Committee of the NMDP, chair-elect of the CIBMTR Advisory Committee, and a member of the CIBMTR Executive Committee. The authors have indicated they have no financial relationships relevant to this article to disclose. No external funding was obtained for this study.

What's Known on This Subject

Several authors and organizations have counseled against private cord blood banking in the absence of a likely indication for HCT in the family. However, the views of pediatric HCT physicians on this subject are not known.

What This Study Adds

Pediatric HCT physicians have performed few transplants by using privately banked cord blood. Few HCT physicians recommend banking of cord blood in the family without a known indication, even when the parents are of mixed minority ethnicity.

ABSTRACT

OBJECTIVE. Private cord blood banks are for-profit companies that facilitate storage of umbilical cord blood for personal or family use. Pediatric hematopoietic cell transplantation physicians are currently best situated to use cord blood therapeutically. We sought to describe the experiences and views of these physicians regarding private cord blood banking.

PARTICIPANTS AND METHODS. We e-mailed a cross-sectional survey to pediatric hematopoietic cell transplantation physicians in the United States and Canada; 93 of 152 potentially eligible physicians (93 of 130 confirmed survey recipients) from 57 centers responded. Questions addressed the number of transplants performed by using privately banked cord blood, willingness to use banked autologous cord blood in specific clinical settings, and recommendations to parents regarding private cord blood banking.

RESULTS. Respondents reported having performed 9 autologous and 41 allogeneic transplants using privately banked cord blood. In 36 of 40 allogeneic cases for which data were available, the cord blood had been collected because of a known indication in the recipient. Few respondents would choose autologous cord blood over alternative stem cell sources for treatment of acute lymphoblastic leukemia in second remission. In contrast, 55% would choose autologous cord blood to treat high-risk neuroblastoma, or to treat severe aplastic anemia in the absence of an available sibling donor. No respondent would recommend private cord blood banking for a newborn with 1 healthy sibling when both parents were of northern European descent; 11% would recommend banking when parents were of different minority ethnicities.

CONCLUSIONS. Few transplants have been performed by using cord blood stored in the absence of a known indication in the recipient. Willingness to use banked autologous cord blood varies depending on disease and availability of alternative stem cell sources. Few pediatric hematopoietic cell transplantation physicians endorse private cord blood banking in the absence of an identified recipient, even for mixed-ethnicity children for whom finding a suitably matched unrelated donor may be difficult. *Pediatrics* 2009;123:1011–1017

www.pediatrics.org/cgi/doi/10.1542/peds.2008-0436

doi:10.1542/peds.2008-0436

Key Words
hematopoietic stem cell transplantation, cord blood stem cell transplantation, bioethics

Abbreviations
HCT— hematopoietic cell transplantation
AAP—American Academy of Pediatrics
CIBMTR—Center for International Blood and Marrow Transplant Research
NMDP—National Marrow Donor Program
IQR—interquartile range
SAA—severe aplastic anemia
PBSC—peripheral blood stem cells
MSD—matched sibling donor
URD— unrelated donor
ALL—acute lymphoblastic leukemia
HLA— human leukocyte antigen

Accepted for publication Jul 15, 2008

Address correspondence to Steven Joffe, MD, MPH, Dana-Farber Cancer Institute, 44 Binney St, Boston, MA 02115. E-mail: steven_joffe@dfci.harvard.edu

PRIVATE CORD BLOOD banks are for-profit companies that facilitate the collection and storage of umbilical cord blood for possible future use by the child from whom it was obtained, or by a member of the child's immediate family. Initial collection and shipping fees are typically between $1500 and $2000, and annual storage fees typically range from $90 to $200.[1,2] These fees are not generally reimbursed by health insurers.

Private cord blood banks advertise widely to the public and to physicians and have established a presence in many obstetrical waiting rooms.[3] In their promotional materials, they indicate that stored cord blood may serve as a stem cell source for autologous or allogeneic hematopoietic cell transplantation (HCT). There are few published reports of transplants using privately banked autologous cord blood.[4–6] Banks also suggest that these cells might one day be modified through gene transfer or targeted differentiation for use in treating a host of degenerative disorders, such as Alzheimer disease, Parkinson's disease, and ischemic heart disease.[7,8] Although the use of banked cord blood for HCT involves existing technologies, the use of these cells for treating degenerative disorders is currently speculative.[9]

Families may choose to store cord blood in a private bank for prophylactic or preemptive reasons. When banked prophylactically (ie, in the absence of a foreseeable indication for HCT in the family), the cord blood is perceived as a form of "biological insurance." When banked preemptively, a family member is known to have, or to be at increased risk for, a potentially transplantable disease. In 1997, the American College of Obstetrics and Gynecology stated, "Parents should not be sold this service without a realistic assessment of their likely return on their investment."[10] Subsequently, in 1999, the American Academy of Pediatrics (AAP) recommended that, "given the difficulty of making an accurate estimate of the need for autologous transplantation and the ready availability of allogeneic transplantation, private storage of cord blood as 'biological insurance' is unwise. However, banking should be considered if there is a family member with a current or potential need to undergo a stem cell transplantation."[11] The AAP reaffirmed this view in 2007, and the Council on Ethical and Judicial Affairs of the American Medical Association and the American Society for Blood and Marrow Transplantation recently adopted similar positions.[12–15] Despite these recommendations, private cord blood banks have grown apace.[16–19]

Parents and clinicians need guidance about whether to consider or recommend private cord blood banking. Because HCT physicians choose among stem cell sources for transplantation, and because they are the only clinicians who might currently use these privately banked cord blood units therapeutically, their views about private cord blood banking are of particular interest. Furthermore, because of the young age of most potential recipients, decisions about use of privately banked autologous or allogeneic cord blood versus other available stem cell sources are most germane to pediatric transplant physicians. Therefore, we surveyed pediatric HCT physicians in the United States and Canada to determine (1) their clinical experience with HCT using privately banked cord blood, (2) the circumstances in which they might consider using autologous cord blood as a stem cell source, and (3) how they would advise prospective parents about prophylactic cord blood banking.

PARTICIPANTS AND METHODS

Study Population

Because no comprehensive list of pediatric HCT physicians exists, we used the membership and subcommittee lists of the Center for International Blood and Marrow Transplant Research (CIBMTR) to identify prospective subjects. The CIBMTR was established in 2004 as a formal affiliation of the research division of the National Marrow Donor Program (NMDP, established in 1986) and the International Bone Marrow Transplant Registry (established in 1972). The CIBMTR is a working group of >500 transplant centers worldwide that voluntarily contribute detailed patient, disease, and transplant characteristics and outcome data on allogeneic HCT recipients to a statistical center at the Medical College of Wisconsin. In addition to the collection of demographic, disease, and transplant characteristics, and outcome data on consecutive transplants facilitated by participating institutions, the CIBMTR maintains a list of transplant center directors and other physicians who are active participants in research activities of the CIBMTR.

Physicians were eligible if they were currently performing pediatric HCT in the United States or Canada. The list of US and Canadian transplant physicians was generated from the membership directory for the following subcommittees of the CIBMTR: pediatric cancer, nonmalignant marrow disorder, and immune and metabolic diseases. These committees were chosen because most of their active participants are pediatric HCT physicians. Review of the membership directory for the above committees suggests that approximately one third of transplant centers are represented by more than 1 physician per center.

The survey was mailed to 162 individuals. Of these, 10 were ineligible because they were not currently practicing pediatric HCT physicians, and 22 could not be reached because of change of address or inaccurate contact information. Thus, 130 eligible physicians were confirmed to have received the survey. Of these, 93 responded, representing 57 centers (response rate: 61% of 152 potentially eligible physicians, or 72% of 130 confirmed survey recipients).

The study was approved by the institutional review board at the Dana-Farber Cancer Institute, which waived the requirement for documentation of informed consent.

Data Collection

After pilot testing among 10 physicians at the investigators' centers, surveys were distributed via e-mail in June 2004. Nonrespondents received 1 additional e-mail, 1 fax, and 1 telephone call from a study team member at 2-week intervals.

The survey consisted of 8 groups of questions addressing 5 broad domains: (1) demographics; (2) frequency of requests for advice about private cord blood banking; (3) experience using privately banked cord blood for HCT; (4) willingness to use privately banked autologous cord blood to treat 3 diseases that are among the most com-

TABLE 1 HCT Performed at Respondents' Centers Using Privately Banked Cord Blood

Family-Banked Cord Blood Transplant Type	Disease Indication for Transplant	No. of Transplants
Autologous ($n = 9$)[a]	Severe aplastic anemia	4
	Neuroblastoma	1
	Retinoblastoma	1
	Shwachman-Diamond syndrome[b]	1
	Brain tumor	1
	Diagnosis not stated	1
Allogeneic ($n = 41$)[c]	Acute leukemia	20
	Hemoglobinopathy	7
	Fanconi anemia	7
	Other[d]	7

[a] Nine autologous transplants were reported from 6 centers. Because of possible double-counting as the result of multiple respondents per center, between 7 and 9 autologous transplants were actually performed.

[b] Patient with Shwachman-Diamond syndrome received autologous cord blood after primary failure of an allogeneic graft.

[c] Forty-one allogeneic transplants were reported from 16 centers. Because of possible double-counting as the result of multiple respondents per center, between 36 and 41 allogeneic transplants were actually performed.

[d] Other diagnoses: juvenile myelomonocytic leukemia (1), severe aplastic anemia (1), Wiskott-Aldrich syndrome (1), chronic granulomatous disease (1), hemophagocytic lymphohistiocytosis (1), Gaucher disease (1), and diagnosis not stated (1).

mon indications for pediatric HCT; and (5) advice to parents regarding prophylactic cord blood banking.

Statistical Methods

Data were analyzed by using Stata 8 for Windows (Stata Corp, College Station, TX). Analyses were descriptive. We report results as proportions or as medians, ranges, and interquartile ranges (IQRs), as appropriate to the data.

RESULTS

Respondent Characteristics

Forty-eight (52%) respondents were program heads or clinical directors of transplant services. Respondents' centers performed a median of 3.5 (IQR: 1.5–6.5 [range: 0–78]) unrelated-donor cord blood transplants per year. Respondents reported being asked for advice about private cord blood banking a median of 9.5 times (IQR: 4.5–15 [range: 0–60]) by prospective parents, and 5 times (IQR: 2–10 [range: 0–200]) by clinicians, during the previous 2 years.

Clinical Experience With Privately Banked Cord Blood

Respondents from 6 centers reported having performed a total of 9 autologous cord blood transplants. Indications included severe aplastic anemia (SAA) ($n = 4$), neuroblastoma ($n = 1$), retinoblastoma ($n = 1$), Shwachman-Diamond syndrome (after failure of an allogeneic transplant; $n = 1$), brain tumor ($n = 1$), and not stated ($n = 1$) (Table 1). None of these grafts was supplemented with postnatally obtained peripheral blood stem cells (PBSC) or bone marrow. Primary failure of engraftment occurred after 1 of these transplants.

Respondents from 15 centers reported having performed 41 allogeneic privately banked cord blood transplants (1 respondent did not identify the center). Indications included acute leukemias ($n = 20$), hemoglobinopathies ($n = 7$), Fanconi anemia ($n = 7$), and other/not specified ($n = 7$) (Table 1). The cord blood was derived from siblings in all but 1 case (a cousin). In 36 of 40 cases for which data were available, the cord blood had been collected in light of a known disease in the index patient (ie, preemptively). Allogeneic bone marrow harvested postnatally was coadministered in 6 of 41 transplants. Primary failure of engraftment occurred in 7 of 41 cases.

Perceived Utility of Privately Banked Autologous Cord Blood for HCT

To explore subjects' willingness to use privately banked cord blood for pediatric HCT, we asked them to consider a hypothetical 5-year-old child whose cord blood (with adequate cellularity) was banked prophylactically at birth and who subsequently developed a potentially transplantable illness.

We first asked about a child with acute lymphoblastic leukemia (ALL) in second remission after experiencing a bone marrow relapse while on initial therapy. No respondent would choose the autologous cord blood over a human leukocyte antigen- (HLA-) matched sibling donor (MSD) graft, and only 6% would choose the autologous cord blood over a suitably matched and cellular unrelated-donor (URD) marrow or cord blood graft. If no MSD or URD graft were available, 62% would use the autologous cord blood rather than pursue other therapy (Table 2).

To treat a child with newly diagnosed SAA and an available MSD, 28% would choose the autologous cord blood over the MSD graft. To treat a child with SAA refractory to immunosuppressive therapy in the absence of an available MSD, 55% would choose the autologous cord blood instead of an URD marrow or cord blood graft (Table 2).

To treat high-risk neuroblastoma, 55% would choose the autologous cord blood alone, 42% would choose autologous PBSC or marrow alone, and 3% would combine the autologous cord blood with autologous PBSC or marrow. If the cellularity of the unit was suboptimal, willingness to use the autologous cord blood diminished (Table 2).

Advice Regarding Prophylactic Private Cord Blood Banking

We asked physicians whether they would recommend private cord blood banking for a newborn with 1 healthy 3-year-old sibling. When both parents were of northern European descent, no respondent would recommend banking. When parents were of mixed ethnicity (black father and Japanese-American mother), 11% would recommend banking (Fig 1).

DISCUSSION

Pediatric HCT physicians are currently the main group of clinicians who might employ privately banked cord blood in clinical care. They are often asked by families and by other clinicians for advice regarding prophylactic

TABLE 2 Pediatric HCT Physicians' Willingness to Use Banked Autologous Cord Blood

Disease[a]	Alternative Stem Cell Source Available	Respondent Would Perform Transplant Using Banked Autologous Cord Blood		
		Yes, *n* (%)	No, *n* (%)	Combined,[b] *n* (%)
Acute lymphoblastic leukemia in second remission after on-therapy relapse	Matched sibling	0 (0)	91 (100)	NA
	Unrelated bone marrow or cord blood	5 (6)	85 (94)	NA
	No suitable allogeneic stem cell source available	55 (62)	34 (38)	NA
Severe aplastic anemia				
Newly diagnosed	Matched sibling	25 (28)	65 (72)	NA
Unsuccessful immunosuppressive therapy	Unrelated bone marrow or cord blood	47 (55)	38 (45)	NA
High-risk neuroblastoma				
Adequate autologous cord blood cell dose	Autologous PBSC or bone marrow	50 (55)	38 (42)	3 (3)
Inadequate autologous cord blood cell dose[c]	Autologous PBSC or bone marrow	7 (8)	61 (67)	23 (25)

NA indicates not applicable (NA), option not offered.

[a] Respondents were asked to indicate their preferred stem cell source for a hypothetical 5-year-old child whose cord blood had been stored prophylactically at birth (with adequate cell dose of 4×107 nucleated cells/kg recipient weight). The child now presents with the specified potentially transplantable disease.

[b] Would choose autologous cord blood combined with available alternative stem cell source.

[c] $<2 \times 10^7$ nucleated cells per kg recipient weight.

cord blood banking. We surveyed these physicians about their previous use of and views on privately banked cord blood. We found limited experience with and enthusiasm for prophylactic private cord blood banking among respondents.

Several observations from this survey stand out. First, despite the fact that cord blood banked prophylactically surely accounts for the preponderance of units stored in private cord blood banks, transplants using cord blood banked preemptively have substantially outnumbered transplants using cord blood banked prophylactically. Second, allogeneic transplants using privately banked cord blood have substantially outnumbered autologous transplants. In the allogeneic setting, because the sibling typically can serve postnatally as a hematopoietic stem cell donor, the transplant can generally proceed even if cord blood was not banked. Third, very few pediatric transplant physicians would recommend prophylactic cord blood banking to prospective parents. Importantly, willingness to recommend increases only marginally when the parents are of different minority ethnic groups, a circumstance that reduces the likelihood of finding a suitably matched unrelated-donor stem cell source should the need for HCT arise.[20]

Respondents were reluctant to use autologous cord blood to transplant a child with ALL, the most common malignancy of childhood and the most common indication for allogeneic HCT in children in North America (CIBMTR, unpublished data, 2008). This reluctance may be attributed to the established importance of an alloge-

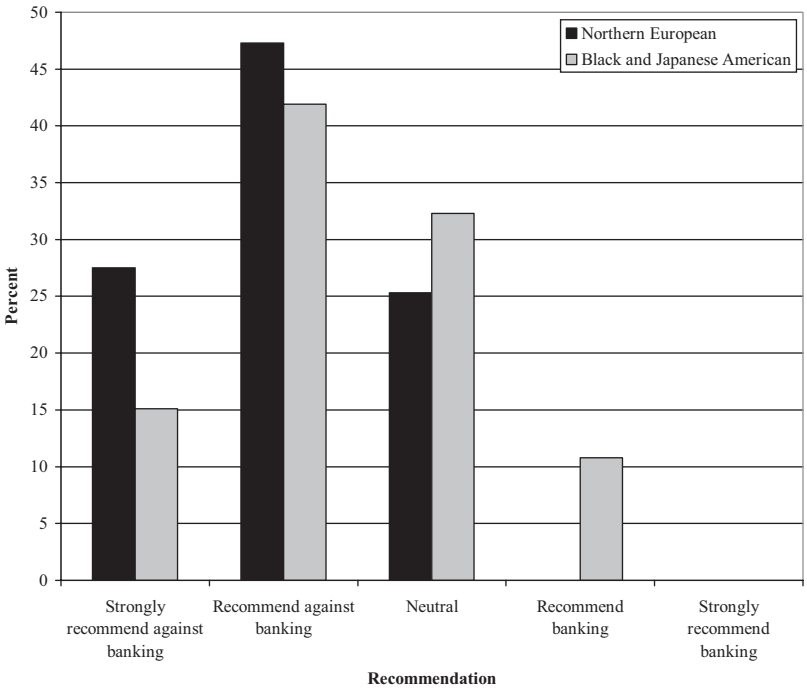

FIGURE 1
Pediatric HCT physicians' recommendations regarding prophylactic private cord blood banking. Physicians were asked whether they would recommend private cord blood banking given the following scenario: "Parents are expecting their second child. Their first child is a healthy 3-year-old. They ask your advice about private cord blood banking. What would you recommend?" In the first scenario, both parents are of northern European origin. In the second scenario, 1 parent is black and the other is Japanese American.

neic "graft-versus-leukemia" effect for survival after HCT for ALL,[21] or to the observation that leukemic clone-specific molecular genetic markers may be present at birth in children who subsequently develop ALL.[22] The same considerations would likely affect clinical decision making for pediatric acute myeloid leukemia.[23] The 1 circumstance in which a majority of respondents indicated willingness to use stored autologous cord blood to treat relapsed ALL was the child who lacks a suitable MSD or URD stem cell source. However, the likelihood that a healthy newborn will ultimately face such a situation is remote. First, ~25% of children who require an allogeneic HCT have an HLA-matched sibling.[12] For those who lack a matched sibling, availability of a suitable unrelated-donor graft varies according to ethnicity, with a match identified for ~85% of white patients and 60% of black patients.[20] Given the annual incidence of ALL in children aged 0 to 19 years (30.6/million for white individuals and 15.9/million for black individuals),[24] and relapse and reinduction rates of ~20% and 90%, respectively,[25,26] the probabilities of a healthy newborn (1) developing ALL during childhood, (2) experiencing a relapse, (3) achieving a second remission, and (4) being unable to find a suitable allogeneic donor are ~12.4/million for white individuals and 17.2/million for black individuals.

Severe aplastic anemia, with an annual incidence for all ages combined of ~3/million,[27] is the most common nonmalignant indication for allogeneic HCT in childhood (CIBMTR, unpublished data, 2008). Currently, MSD HCT is indicated for children with newly diagnosed SAA, whereas URD HCT is reserved for those with an inadequate response to immunosuppressive therapy.[28] Historically, survival has been ~90% after MSD HCT and 50% to 60% after URD HCT.[29,30] The poorer reported outcomes after URD HCT likely underlie the willingness of 55% of respondents to use the autologous cord blood rather than an URD graft for transplantation. More recent reports, however, demonstrate improved survival after URD HCT for SAA.[31] Other factors, such as the absence of benefit related to graft-versus-tumor effect in SAA, may also contribute to respondents' willingness to consider banked autologous cord blood as a stem cell source for treatment.

High-risk neuroblastoma, with an annual incidence of ~3 to 5/million children <15 years of age in the United States,[32,33] is the most common indication for autologous HCT in children (CIBMTR, unpublished data, 2008). Molecularly detectable contamination of the autologous stem cell graft with neuroblastoma cells is frequent[34] and has been shown to contribute to relapse after transplant.[35] The chance of graft contamination is likely lower with cord blood collected at birth, before the clinical diagnosis of neuroblastoma though not necessarily before its subclinical onset. Hence, a majority (55%) of respondents said they would choose the autologous cord blood as a graft in this scenario. However, this majority's decision depended on adequate cellularity of the stored cord blood unit, a variable affected by the skill of the personnel collecting and storing the cord blood as well as by other factors.[36,37]

This study has several limitations. First, there is no comprehensive list of pediatric HCT physicians in the United States and Canada. The sampling frame for this survey included 152 pediatric HCT physicians who were listed with the CIBMTR. We believe this population to be representative of pediatric HCT physicians in these countries. Indeed, the preponderance of program leaders among respondents strengthens our confidence in our findings, both because these physicians are best able to report their previous institutional experience and because they are likely to make decisions regarding stem cell source in unusual clinical circumstances. Second, our findings might have been influenced by response bias if views on private banking of cord blood or on therapeutic use of autologous cord blood differed between respondents and nonrespondents. Third, it is possible that additional transplants using privately banked cord blood have been performed, either by nonrespondents to our survey, by physicians who were not included in our sample, or since the survey was fielded. However, these estimates are commensurate with those provided by cord blood banks themselves in their promotional materials.[17,38] In addition, because several physicians responded from some centers, it is possible that we double-counted several transplants. Had we discounted transplants with the same type of graft and the same disease indication as 1 already reported by another respondent from the same center, there would have been a total of 7 autologous and 36 allogeneic transplants reported. Fourth, our data do not directly address the value of prophylactically stored cord blood for stem cell transplantation among adults. Finally, although pediatric HCT physicians are uniquely qualified to address the clinical experience with and utility of privately banked cord blood, their opinions concerning how prospective parents should spend their private funds should not be considered determinative. Nevertheless, the fact that pediatric HCT physicians are frequently asked for their advice regarding storage of cord blood suggests that their views on this issue are valued by parents and other physicians alike.

Although we did not ask HCT physicians about their views regarding public cord blood banking, there is growing recognition that unrelated-donor cord blood obtained from public banks represents an invaluable stem cell source for both pediatric and adult patients in need of transplantation.[39–41] Cord blood units are particularly useful for patients from racial and ethnic minority groups because of the less-stringent requirements for HLA matching with the use of cord blood as a stem cell source compared with marrow from unrelated adult donors.[20] In recognition of the value of unrelated-donor cord blood, the US Congress has funded a National Cord Blood Inventory Program, with plans to build an inventory of 150 000 cord blood units.[42] This source of funding, which supplements income derived from releasing cord blood units to recipients, is nevertheless inadequate to cover the full costs of maintaining a cord blood bank.[39] The role of alternative models of supporting public cord blood banks, including joint public-private banks,[43] remains to be clarified.

CONCLUSIONS

The debate about the utility of private cord blood banks is ongoing.[9,12,13,19,43–51] Numerous issues raised by private cord blood banking, including the vulnerability of expectant parents to the private banks' marketing efforts, the accuracy of the information available to parents, the quality of parents' understanding when deciding about banking,[52,53] and the potential for competition with public cord blood banks that facilitate unrelated-donor transplantation,[54] warrant attention and concern. The data presented here suggest that clinicians who perform pediatric HCT endorse the recommendations of the AAP, the American Medical Association, and others against the private storage of cord blood in the absence of a foreseeable indication for transplant in the family of the newborn child.[10–15,44,48] Pediatricians, family physicians, obstetricians, nurse midwives, and other professionals who work with families, together with their professional organizations, should educate prospective parents about this consensus view.

ACKNOWLEDGMENTS

We thank our colleagues for taking the time to complete the survey, and we gratefully acknowledge Robilyn Lake's assistance with survey distribution from the CIBMTR and Tina Gelsomino's assistance with database design.

REFERENCES

1. Cord Blood Registry. Cord blood registry: our pricing. Available at: www.cordblood.com/cord_blood_banking_with_cbr/pricing_domestic.asp. Accessed June 5, 2008
2. Viacord. Viacord pricing and storage plans. Available at: www.viacord.com/pricing-storage-plans.htm. Accessed June 5, 2008
3. Moise KJ. What to tell patients about banking cord blood stem cells. *Contemp Ob Gyn.* Available at: www.modernmedicine.com/modernmedicine/article/articleDetail.jsp?id=320177&pageID=I&SK=&date=. Accessed January 9, 2009
4. Ferreira E, Pasternak J, Bacal N, de Campos Guerra JC, Mitie Watanabe F. Autologous cord blood transplantation. *Bone Marrow Transplant.* 1999;24(9):1041
5. Hayani A, Lampeter E, Viswanatha D, Morgan D, Salvi SN. First report of autologous cord blood transplantation in the treatment of a child with leukemia. *Pediatrics.* 2007;119(1). Available at: www.pediatrics.org/cgi/content/full/119/1/e296
6. Fruchtman SM, Hurlet A, Dracker R, et al. The successful treatment of severe aplastic anemia with autologous cord blood transplantation. *Biol Blood Marrow Transplant.* 2004;10(11):741–742
7. Cord Blood Registry. Why you should save cord blood for your family. Available at: www.cordblood.com/cord_blood_banking_with_cbr/banking/why_bank.asp. Accessed June 5, 2008
8. Viacord. Using stem cells to potentially treat heart disease. Available at: www.viacord.com/stem-cells-heart-disease.htm. Accessed June 5, 2008
9. Healy M. The potential of stem cells' curative powers has spawned the creation of private tissue banks. But marketing is outpacing the medicine. *Los Angeles Times.* March 5, 2007; section: 1
10. Committee on Obstetric Practice ACoOaG. Routine storage of umbilical cord blood for potential future transplantation. *Int J Gynaecol Obstet.* 1997;58(2):257–259
11. American Academy of Pediatrics; Work Group on Cord Blood Banking. Cord blood banking for potential future transplantation: subject review. *Pediatrics.* 1999;104(1 pt 1):116–118
12. Lubin BH, Shearer WT. Cord blood banking for potential future transplantation. *Pediatrics.* 2007;119(1):165–170
13. Council on Ethical and Judicial Affairs of the American Medical Association. CEJA Report 9-I-07: Umbilical Cord Blood Banking (Recommendation E-2.165). Available at: www.ama-assn.org/ama1/pub/upload/mm/369/ceja_9i07.pdf. Accessed June 5, 2008.
14. Ballen KK, Barker JN, Stewart SK, Greene MF, Lane TA. Collection and preservation of cord blood for personal use. *Biol Blood Marrow Transplant.* 2008;14(3):356–363
15. ASBMT Position Statement. Collection and preservation of cord blood for personal use. *Biol Blood Marrow Transplant.* 2008;14(3):364
16. Grady D. The hype, and hope, of cord blood. *New York Times.* December 1, 1998;section: 6
17. Cord Blood Registry. Why choose Cord Blood Registry? Most experienced. Available at: www.cordblood.com/cord_blood_banking_with_cbr/why_cbr/most_experienced.asp. Accessed June 5, 2008
18. Viacord. FAQ: How many families have banked samples with Viacord? Available at: www.viacord.com/general-faq.htm. Accessed June 5, 2008
19. Neergaard L. Parents bank kids' umbilical cord blood. *Associated Press Online.* February 19, 2007
20. Chell JW. Hematopoietic cell donor registries. In: Blume KG, Forman SJ, Appelbaum FR, eds. *Thomas' Hematopoietic Cell Transplantation*. 3rd ed. Malden, MA: Blackwell Publishing; 2004:624–631
21. Champlin R, Giralt S, Gajewski J. T cells, graft-versus-host disease and graft-versus-leukemia: innovative approaches for blood and marrow transplantation. *Acta Haematol.* 1996;95(3–4):157–163
22. Gale KB, Ford AM, Repp R, et al. Backtracking leukemia to birth: identification of clonotypic gene fusion sequences in neonatal blood spots. *Proc Natl Acad Sci USA.* 1997;94(25):13950–13954
23. Wiemels JL, Xiao Z, Buffler PA, et al. In utero origin of t(8;21) AML1-ETO translocations in childhood acute myeloid leukemia. *Blood.* 2002;99(10):3801–3805
24. Gurney JG, Bondy ML. Epidemiology of childhood cancer. In: Pizzo PA, Poplack DG, eds. *Principles and Practice of Pediatric Oncology*. 5th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2005:1–14
25. Silverman LB, Declerck L, Gelber RD, et al. Results of Dana-Farber Cancer Institute Consortium protocols for children with newly diagnosed acute lymphoblastic leukemia (1981–1995). *Leukemia.* 2000;14(12):2247–2256
26. Henze G, Fengler R, Hartmann R, et al. Six-year experience with a comprehensive approach to the treatment of recurrent childhood acute lymphoblastic leukemia (ALL-REZ BFM 85). A relapse study of the BFM group. *Blood.* 1991;78(5):1166–1172
27. Szklo M, Sensenbrenner L, Markowitz J, Weida S, Warm S, Linet M. Incidence of aplastic anemia in metropolitan Baltimore: a population-based study. *Blood.* 1985;66(1):115–119
28. Georges GE, Storb R. Allogeneic cell transplantation for aplastic anemia. In: Blume KG, Forman SJ, Appelbaum FR, eds. *Thomas' Hematopoietic Cell Transplantation*. 3rd ed. Malden, MA: Blackwell Publishing; 2004:981–1001
29. Kojima S, Horibe K, Inaba J, et al. Long-term outcome of acquired aplastic anaemia in children: comparison between immunosuppressive therapy and bone marrow transplantation. *Br J Haematol.* 2000;111(1):321–328

30. Margolis D, Camitta B, Pietryga D, et al. Unrelated donor bone marrow transplantation to treat severe aplastic anaemia in children and young adults. *Br J Haematol.* 1996;94(1):65–72
31. Kojima S, Inaba J, Yoshimi A, et al. Unrelated donor marrow transplantation in children with severe aplastic anaemia using cyclophosphamide, anti-thymocyte globulin and total body irradiation. *Br J Haematol.* 2001;114(3):706–711
32. Bernstein ML, Leclerc JM, Bunin G, et al. A population-based study of neuroblastoma incidence, survival, and mortality in North America. *J Clin Oncol.* 1992;10(2):323–329
33. Klaassen RJ, Trebo MM, Koplewitz BZ, Weitzman SS, Calderwood S. High-risk neuroblastoma in Ontario: a report of experience from 1989 to 1995. *J Pediatr Hematol Oncol.* 2003; 25(1):8–13
34. Lode HN, Handgretinger R, Schuermann U, et al. Detection of neuroblastoma cells in CD34+ selected peripheral stem cells using a combination of tyrosine hydroxylase nested RT-PCR and anti-ganglioside GD2 immunocytochemistry. *Eur J Cancer.* 1997;33(12):2024–2030
35. Rill DR, Santana VM, Roberts WM, et al. Direct demonstration that autologous bone marrow transplantation for solid tumors can return a multiplicity of tumorigenic cells. *Blood.* 1994; 84(2):380–383
36. Bayer-Zwirello LA, Hoffman DE, Adams LA, Wilder PT, Reece MT. The effect of processing and cryopreservation on nucleated umbilical cord blood cells. *J Perinat Med.* 2004;32(5):430–433
37. Hubel A, Carlquist D, Clay M, McCullough J. Liquid storage, shipment, and cryopreservation of cord blood. *Transfusion.* 2004;44(4):518–525
38. Viacord. FAQ: how many samples have been used for transplant from ViaCord? Available at: www.viacord.com/general-faq.htm#how%20many%20samples%20have%20been. Accessed June 5, 2008
39. Eapen M, Rubinstein P, Zhang MJ, et al. Outcomes of transplantation of unrelated donor umbilical cord blood and bone marrow in children with acute leukaemia: a comparison study. *Lancet.* 2007;369(9577):1947–1954
40. Laughlin MJ, Eapen M, Rubinstein P, et al. Outcomes after transplantation of cord blood or bone marrow from unrelated donors in adults with leukemia. *N Engl J Med.* 2004;351(22): 2265–2275
41. Rocha V, Labopin M, Sanz G, et al. Transplants of umbilical-cord blood or bone marrow from unrelated donors in adults with acute leukemia. *N Engl J Med.* 2004;351(22):2276–2285
42. Health Resources and Services Administration. Fiscal Year 2008 Justification of Estimates for Appropriations Committees; Healthcare Systems; National Cord Blood Inventory. Available at: www.hrsa.gov/about/budgetjustification08/NationalCordBloodInventory.htm. Accessed June 5, 2008
43. Laurance J. Branson moves into biotechnology with launch of Virgin stem cell storage bank. *The Independent.* February 2, 2007;section: 26
44. Johnson FL. Placental blood transplantation and autologous banking—caveat emptor. *J Pediatr Hematol Oncol.* 1997;19(3): 183–186
45. Sugarman J, Kaalund V, Kodish E, et al. Ethical issues in umbilical cord blood banking. Working Group on Ethical Issues in Umbilical Cord Blood Banking. *JAMA.* 1997;278(11): 938–943
46. Annas GJ. Waste and longing—the legal status of placental-blood banking. *N Engl J Med.* 1999;340(19):1521–1524
47. Burgio GR, Gluckman E, Locatelli F. Ethical reappraisal of 15 years of cord-blood transplantation. *Lancet.* 2003;361(9353): 250–252
48. Fisk NM, Roberts IA, Markwald R, Mironov V. Can routine commercial cord blood banking be scientifically and ethically justified? *PLoS Med.* 2005;2(2):e44
49. Steinbrook R. The cord-blood-bank controversies. *N Engl J Med.* 2004;351(22):2255–2257
50. Edozien LC. NHS maternity units should not encourage commercial banking of umbilical cord blood. *BMJ.* 2006;333(7572): 801–804
51. Fox NS, Chervenak FA, McCullough LB. Ethical considerations in umbilical cord blood banking. *Obstet Gynecol.* 2008;111(1): 178–182
52. Fox NS, Stevens C, Ciubotariu R, Rubinstein P, McCullough LB, Chervenak FA. Umbilical cord blood collection: do patients really understand? *J Perinat Med.* 2007;35(4):314–321
53. Sugarman J, Kurtzberg J, Box TL, Horner RD. Optimization of informed consent for umbilical cord blood banking. *Am J Obstet Gynecol.* 2002;187(6):1642–1646
54. Meyer EA, Hanna K, Gebbie K, eds. *Cord Blood: Establishing a National Hematopoietic Stem Cell Bank Program*. Washington, DC: National Academies Press; 2005

Private Cord Blood Banking: Experiences and Views of Pediatric Hematopoietic Cell Transplantation Physicians

Ian Thornley, Mary Eapen, Lillian Sung, Stephanie J. Lee, Stella M. Davies and Steven Joffe

Pediatrics 2009;123;1011-1017
DOI: 10.1542/peds.2008-0436