

Needs of Transplant Patients in Perspective

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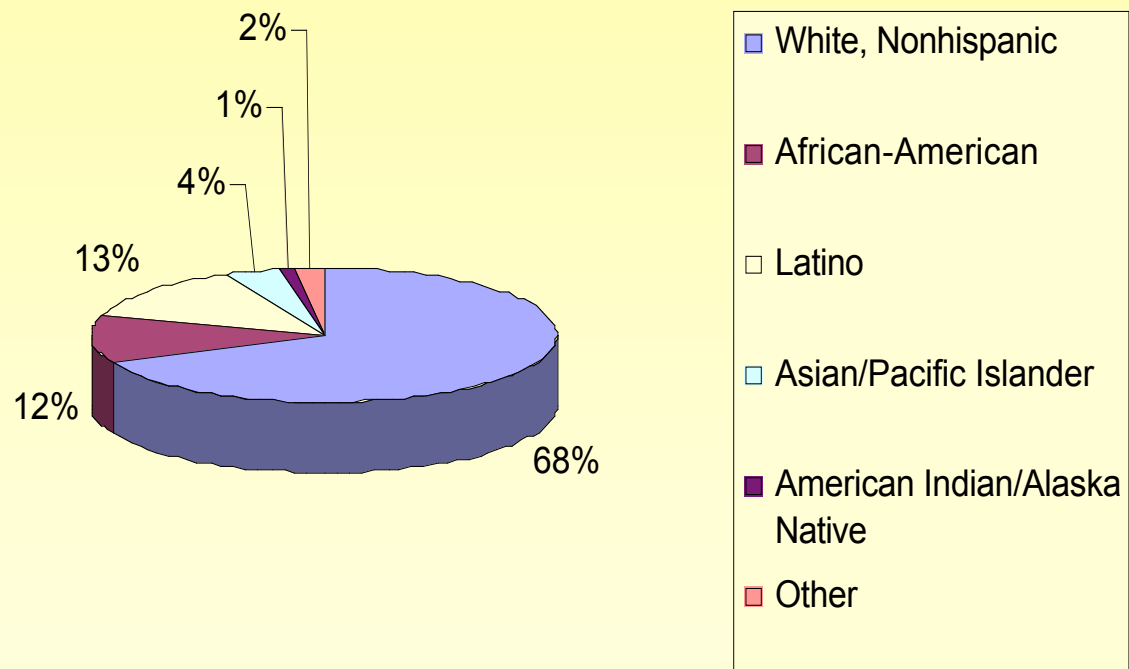
Cord Blood in Context

- What all families face when a loved one needs a BMT
- Extra issues for unrelated transplants
- Extra impacts on members of racial/ethnic minority groups
- Why & how we need to use this knowledge for national cord blood program

A Word about Words

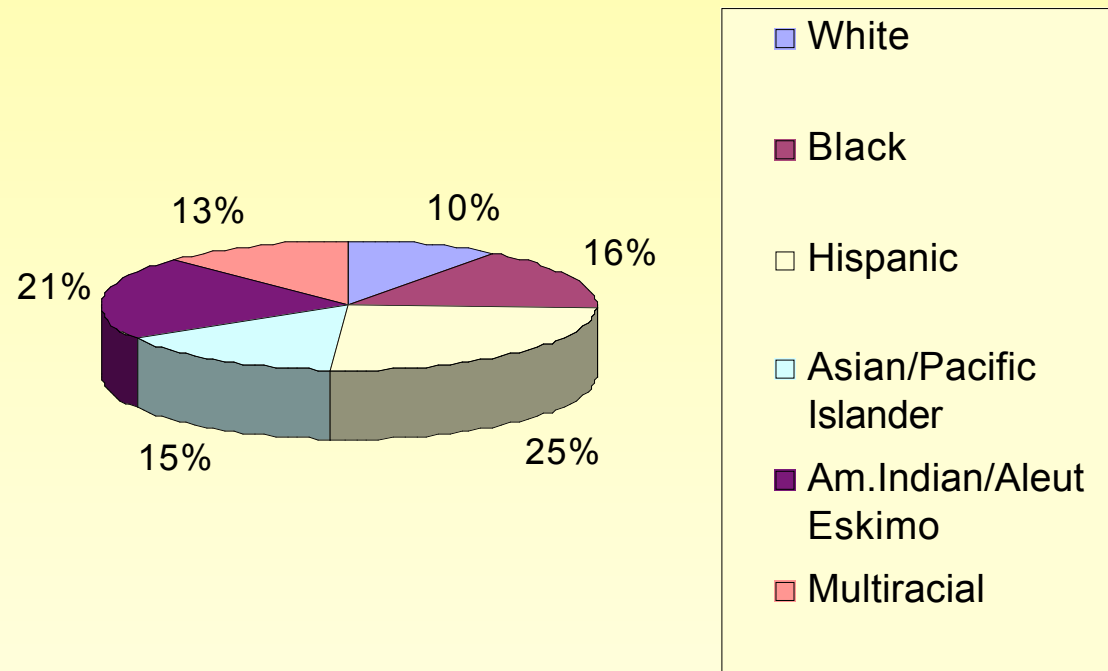
- BMT = Blood & Marrow Transplant
- HCT = Hematopoietic Cell Transplant
- UCB = Umbilical Cord Blood
- Descriptors for people, limits of official designations and other choices of words

US Population Diversity



Source: US Bureau of the Census, *Census 2000*,
http://www.familiesusa.org/site/PageServer?pagename=Minority_Health_Quick_Facts

Who is Uninsured?



Source: Health Insurance Coverage of the Nonelderly, 2003, Kaiser Commission on Medicaid & the Uninsured, *The Uninsured: A Primer* (Nov. 2004), <http://www.kff.org>

Uninsured by the Numbers

- 1 in 3 non-elderly uninsured = 82 million Americans
- 33% of all adults & 36% of all children

Source: Families USA (June 2004), *One in Three: Nonelderly Americans Without Health Insurance, 2002-2003*, <http://www.familiesusa.org>

- For US citizen children, insurance rate linked to parental citizenship: 16% with citizen parents are uninsured, compared to 26% with noncitizen parents
- 51% of noncitizen children are uninsured

Source: Kaiser Commission on Medicaid & the Uninsured (June 2004), *Immigrants and Health Coverage*, <http://www.kff.org/kcmu>

Minority Workers

- More likely to be uninsured because
 - they work in positions where health care benefits are not offered
 - they work for companies—typically small companies—that cannot afford to pay for employee health insurance
 - they are not able to afford health insurance premiums when coverage is offered

Source: Families USA 2004

Race/Ethnicity in the Military

	Army	Navy	Marines	Air Force	DoD	Civilian
White	55.7	58.9	66.3	71.8	62.0	68.4
Black	27.5	21.0	15.2	18.1	21.8	12.6
Hispanic	10.4	10.9	14.2	6.0	10.0	13.9
Other	6.4	9.3	4.3	4.0	6.3	5.1

Ages 18- 44. Source: *Population Representation in the Military Services, FY 2002*, Ch.3,
<http://www.humrro.org/poprep2002/>

Coverage Demographics

- Racial and ethnic minorities are
 - more likely to have family incomes < 200 percent of the federal poverty level (\$31,340 / year for a family of three in 2004)
 - more likely to be enrolled in Medicaid
 - more likely to be uninsured
- Medicaid covers
 - about 1 in 5 non-elderly Latinos, African Americans, and American Indian/Alaska Natives
 - about 1 in 10 non-elderly Asian Americans

Source: Families USA (2004), *QUICK FACTS ABOUT RACIAL AND ETHNIC MINORITY HEALTH*,
http://www.familiesusa.org/site/PageServer?pagename=Minority_Health_Quick_Facts

Typical BMT Costs

BMT Type	1999	2002	Increase
Autologous	\$135,550	\$243,800	80%
Related Allogeneic	\$284,200	\$362,100	57%
Unrelated Allogeneic	\$223,700	\$447,300	62%

AllianzLifetrac Transplant Network Website
http://www.lifetracnetwork.com/home_introduction.asp

Realities for All BMT Families

- May have to re-locate, often out of state
- Lost income of 1 or more adults, for indefinite period (minimum of several months)
- Double housing payments
- Serious psychosocial stress on family
- Special needs of siblings of child patient
- Many expenses not covered, even if insured
- Lifetime benefit amount caps on insurance

Military Families

- Few base hospitals have BMT programs
- Fewer still have pediatric oncologists
- Complicated process to get authorization for referral to best-suited facility, often out-of-state
- May need to go to civilian or VA facility
- Extra cost burden as military salaries less than those of civilians in like positions

Insurance Barriers

- Insurance plan may exclude transplant or have extra waiting period for eligibility
- BMT may be excluded as experimental
- All UCBTs are now considered experimental as use not yet FDA approved
- Insurance decision and/or appeal process of denials can cause critical delays for patients

Uncovered Expenses

- Prescription costs: co-pays or full amount
- Medical supplies, OTC drugs & comfort items
- Special foods for patient, family meal expenses
- Telephone charges
- New apparel due to medical needs, bodily changes, hair loss
- Transportation, parking fees
- Special home hygiene expenses
- Childcare costs

Extra Costs Facing Those in Need of Unrelated Donors

- Donor search fees
- Insurance coverage for search may be little or none
- More searching needed for those with diverse HLA types, as most donors are of northern European ancestry

US Procurement Fees

Facility	Marrow	PBSC	Cord Blood
UCLA	\$21,960	\$21,880	\$19,530
Mayo-MN	\$21,960	\$21,880	\$19,530
Duke	\$24,156	\$24,068	\$20,999
MSKCC	\$21,960	\$21,880	\$19,090
MDA	\$27,000	\$26,260	\$23,500
SCCA	\$31,386	\$31,286	\$28,230

Choosing a Transplant Center: A Patient's Guide, NMDP, 2005
http://www.marlow.org/PATIENT/patients_guide_idx.html

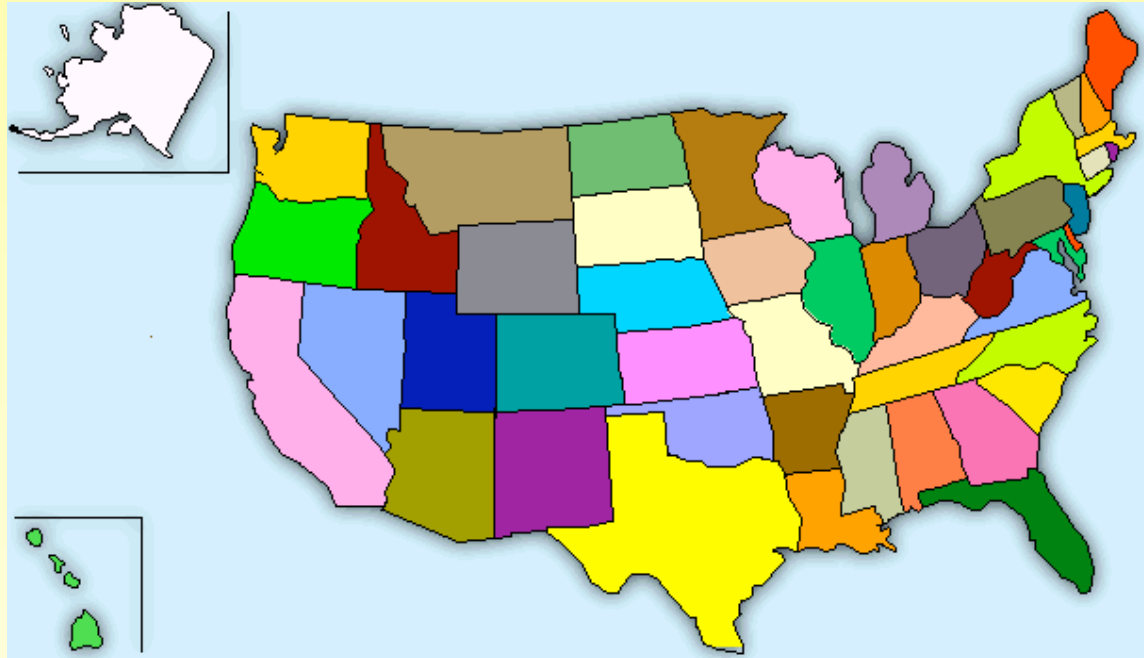
Other added expenses of unrelated BMTs

- Patients need longer hospitalizations
- Higher rate of complications
- Need for more total medical services
- Greater need for home health services
- More outpatient medications needed for longer time

Personal Experience

- Two weeks before work-up at BMT center, I was told I would need to pay \$13,000 in cash because one drug in my protocol was considered experimental and insurance would not cover cost, despite prior approval for the BMT
- From my local oncologist, I learned that the center had a fund for such cases, but would only offer it if patients knew to ask

Medicaid Patchwork



51 different programs

Limits of Medicaid Coverage

- Each state can decide to exclude coverage for any transplants at all or for only certain types of transplants
- Even for covered diagnoses/transplant types, states may further limit BMTs only to the categorically needy, and deny them to the medically needy
- Coverage may be restricted only to certain diagnoses and to certain protocols per diagnosis
- All specialty care now at risk of major cuts

Inter-state Medicaid Refusals

- Due to rarity of childhood cancers, treatment may be available only at certain specialized centers far from patient's home
- Treatment centers may refuse to accept another state's Medicaid coverage
- Solution often possible, but only after great stress
- Why not follow practice that was created for child welfare system?

Medicaid Coverage of Donor Search Costs

- Search, Procurement and Transplant
 - 39% of states do not cover the cost of unrelated donor searches
 - 88% of states cover donor procurement
 - 100% of states cover transplant
 - 12% of states indicated that cost of unrelated donor search is under review

Source: 2002 data, 34 of 50 state responses to NMDP survey, presented at TFCA, Feb. 2005

Medicaid Coverage for BMT Follow-Up Care

- While all states responding to 2002 survey covered medical costs of follow-up care, only about half covered costs of food and housing for patient and caregiver
- Support for caregiver essential for patient to undergo BMT, and for recovery period
- Findings based on responses of Medicaid programs in 34 of 50 states

Source: Medicaid Coverage for Transplantation in 2004 –
Results of a National Coverage Survey by NMDP and TFCA
Presentation for Transplant Financial Coordinators Association, February 17, 2005

Significance of Medicaid & Medicare Coverage Limits

- Private insurance companies typically base benefits on Medicare/Medicaid precedents
- Medicare covers workers under 65 who have received Social Security or Railroad Retirement Disability benefits for 2 years
- Medicare covers BMTs for certain diagnoses but does not yet address UCBTs

Other Public Benefits Programs Quite Limited

- State Children's Health Insurance Programs (S-CHIP) may limit coverage, eligibility varies by state, focus on primary care
- If state programs exist, most offer only the most basic of care, and are now endangered
- Few hospital charity programs cover BMT
- Non-qualified immigrants may receive only emergency care, but not BMT

Very Limited Private Help

- Some private charities offer very limited financial help, and some fundraising assistance, to BMT patients, but most restrict aid on the basis of:
 - Age - more help for children
 - Diagnosis - disease-specific organizations
 - US Citizenship - usually required
 - Immigration status - 5-year wait

Patients Worldwide Need BMTs & May Seek Care in US

- Today's information age means more global awareness of treatment possibilities
- So, more patients seek care, especially when not available at home
- Access almost impossible for most, even among transnational families
- US entities need to help create solutions

Lifelong Impact of BMT

- BMT survivors need lifelong access to specialized care, but access complicated by employment & insurance difficulties
- Insurance problems especially for childhood cancer survivors, in 18-25 age group
- As more survive, growing awareness of late effects, both physical & psychosocial, that may occur years after BMT

Half of Bankruptcies in US Due to Medical Causes

- About 2 million Americans experienced medical bankruptcies in 2001
- 75% of them had health insurance at time of their own or family member's illness or injury, but later lost coverage
- Most bankruptcy filers had attended college and held steady jobs

Himmelstein, DU, et. al. (2 Feb. 2005)

Market Watch: Illness and Injury as Contributors to Bankruptcy, Health Affairs.

<http://www.healthaff.org>

HR 596 Cord Blood Stem Cell Act of 2005

- Consensus that use of UCB can play an important role in BMTs
- More patients may find unrelated donors
- But cord blood is not a panacea!
- Plan for national UCB program must be based on best available facts, via transparent process with stakeholder participation

Points about HR 596

Cord Blood Stem Cell Act of 2005 Sec. 2 FINDINGS:

- *(4) Cord blood gives all patients a chance for a transplant, regardless of their ethnic background. An ethnically diverse inventory of 150,000 cord blood stem cell units would help provide appropriate matches for 80 to 90 percent of patients seeking matched cord blood stem cell transplants.*

BUT...

NMDP Statement on Umbilical Cord Blood Transplantation

What We Don't Know about Cord Blood Transplants (because of lack of clinical evidence):

- *Whether focused cord blood collection will be successful in meeting the current challenge of finding a match for American Indian and Alaska Native, Asian, Black and African American, Hispanic and Latino, Native Hawaiian and Other Pacific Islander, and multiple-race patients, thus increasing the number of available transplants for these patients.*

http://www.marlow.org/PATIENT/cord_blood_transplantation.html

UCB \neq BMT

- No amount of frozen cord blood will help to overcome the many non-donor-related barriers to BMT
- If we cannot solve access problems, patients from medically underserved groups will not benefit from advances in BMT medicine

BMT for Sickle Cell Disease

- **HR 596 Sec. 2 (5)***Cord blood stem cell transplantation has cured patients with sickle cell anemia: 80 percent of children transplanted with related cord blood to correct sickle cell anemia or thalassemia were cured in a recently published study. Unrelated cord blood transplants are especially beneficial for African-American and other ethnic minority patients because cord blood does not have to match as closely as bone marrow. With an ethnically balanced national cord blood stem cell network of at least 150,000 units, some 80 to 90 percent of African American patients who suffer from sickle cell anemia or other conditions requiring bone marrow replacement would be able to find appropriately matched cord blood stem cells for successful treatment.*
- **Walters, M.C. (2004)***80% of children survive free of the underlying disease after HLA-identical **sibling** donor BMT... “To consider transplantation for SCA, there should be compelling strength in the benefit of cure compared to the risk of HCT.*

In: “Sickle cell anemia and hematopoietic cell transplantation:
When is a pound of cure worth more than an ounce of prevention?”
Pediatric Transplantation, Supplement, 8 (5) 33-8.

What are the appropriate criteria for unrelated cord blood transplantation of children with sickle cell disease?

- **Cord Blood Forum for Medical Professionals (2004-5)**
...in kids who go to transplantation, they will have a higher risk of mortality (in the short-term) compared to those who do not, a substantial risk of chronic GVHD after unrelated UCBT, and the very real possibility (33% in the Yeager report) of graft rejection. To subject all sickle cell disease patients to these risks of transplantation would not take into account a balanced and responsible analysis of the risks and benefits involved.
- *.....Without a major breakthrough, it is unlikely that the death rate will fall substantially below 10 percent, the current rate among children who undergo bone marrow transplantation for nonmalignant diseases in many centers. The problem is that predictions of the clinical course of sickle cell disease are imprecise.....*

• http://www.cordbloodforum.org/medforum/medfrm_sicklecomments.html

HR596: UCB for Biodefense?

- *(7) Radiation exposure, from accidents or hostile actions, could cause bone marrow failure in a portion of those exposed and require treatment, including bone marrow reconstitution. In these cases the rapid availability of frozen cord blood stem cell units may be an important resource to help rescue the victims years later, those who were exposed and survived may incur an increased risk of leukemia or lymphoma, which might also require stem cell transplantation.*
- Knowing what we do about the logistics & expenses of BMT, how could transplants on large-scale even be possible?

Stem Cells are Big Business

Value of Cell-based Therapies Market
Estimated to Reach \$26.6 billion in
2005, with Largest Expansion in
Diseases of Central Nervous System
and Cancer

Source: Research & Markets Feb. 2005
<http://www.researchandmarkets.com/reports/c10806/>

Public Education on Cord Blood

- Access to accurate, unbiased information is critical, but few resources now exist
- Unregulated cord blood industry seeks customers, may mislead consumers
- Fortunately, there are still those who believe in sharing their knowledge as a public service

Recommended Consumer Internet Resources

- **A Parent's Guide to Cord Blood Banks**
<http://www.parentsguidecordblood.com/>
- **BMT-Talk Discussion List** of Association of
Online Cancer Resources (ACOR)
<http://www.acor.org>
- **Cancer Survivors Project**
<http://cancersurvivorsproject.org>

What Do We Need to Do?

- Work to increase representation of diverse donors in registries
- Promote culturally & linguistically appropriate services for donors, patients, and families
- Work to improve access to healthcare services, including BMTs

Access to BMT—an Equity Issue

- The Institute of Medicine's study, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*, (2002)
 - Found significant variation in the rates of medical procedures by race, even when insurance status, income, age, and severity of conditions are comparable
 - Indicates that U.S. racial and ethnic minorities are less likely to receive even routine medical procedures and experience a lower quality of health services
 - Research demonstrates the existence of disparities

Source: report summary,
<http://www.iom.edu/report.asp?id=4475>

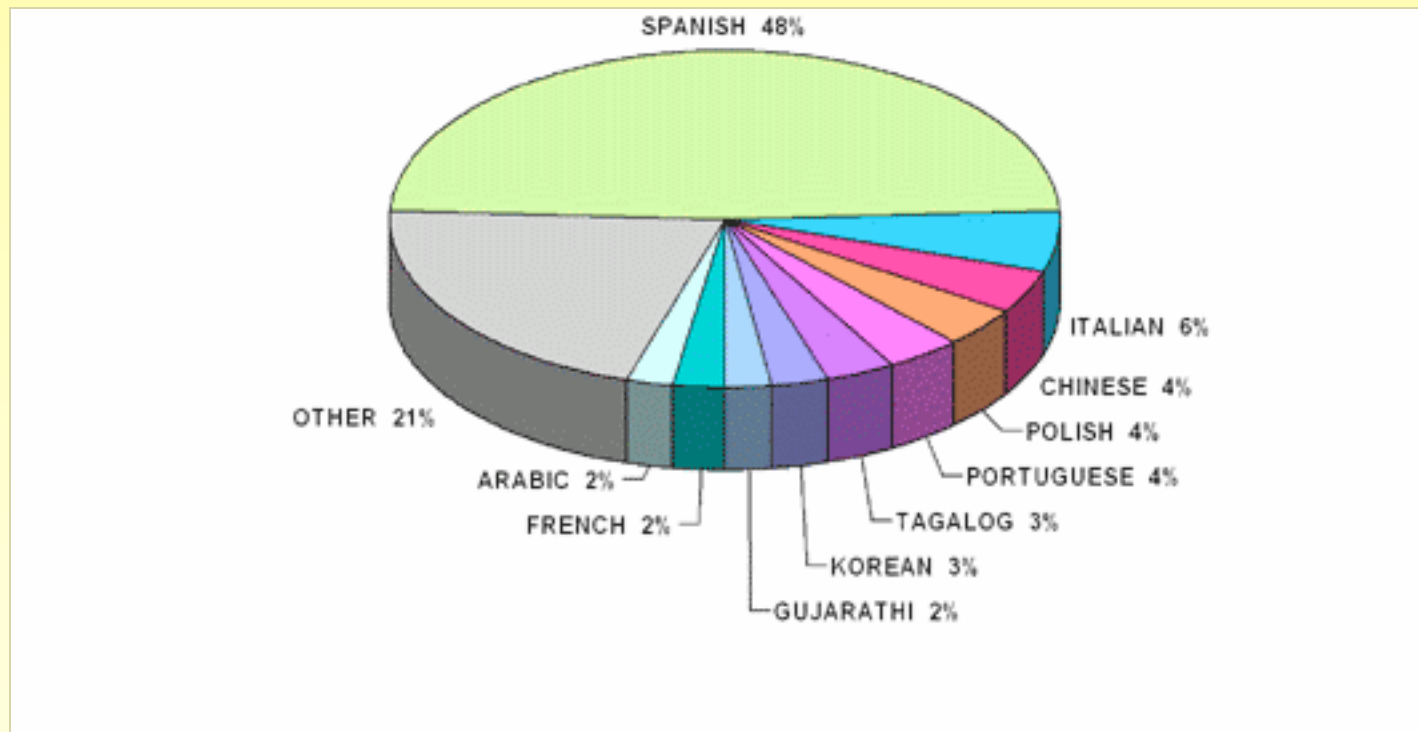
Learn from Existing UCB Programs

- NHLBI's Cord Blood Transplant (COBLT) clinical trials
- Public programs around the country
- Who are they reaching? What are their track records?
- Utilize lessons learned to plan national CB program

Why Language Access?

- Approximately 18% of US population over age 5 speaks a language other than English at home
- Includes almost 26% of New Jersey population, or 1.4 million people

Language Diversity in New Jersey



Source: The Modern Language Association Language Map
http://www.mla.org/images/docstudio/census_pie_34.gif

Language Access—a Legal Right

- Protected under
 - Title VI of Civil Rights Act (& some state laws):
 - spoken & written language
 - Americans with Disabilities Act:
 - visually & hearing impaired persons

What does CLAS mean?

- CLAS = Culturally & Linguistically Appropriate Services
 - Information presented to patient in language that s/he can understand
 - Awareness of & sensitivity to cultural issues
 - Informed consent is more than translation of written documents
 - Medical interpretation is professional skill requiring special training & verification

Some Simple Ways to Help Diversify BMT Donor Pool

- When presenting UCB donation to expectant parents, be sure to educate them about blood & marrow donation
- Routinely ask family members being HLA-typed, as well as volunteer blood donors, if they would join BMT registries

What Next?

- For cord blood to be able to save lives, we need to:
 - Get involved with working to end health care disparities in our communities
 - Assess forthcoming IoM report on UCB program in context of health goals
 - Tell the President & our elected representatives to increase, not cut, budget for health programs—all public programs are now in grave danger!!!

Global Perspective Needed

- Interdependence and mutual benefit
- Need ethics safeguards in building UCB programs
- Wealthy countries need to provide resources and leadership to help overcome international health disparities



The good we secure for ourselves is
precarious and uncertain until it is
secured for all of us
and incorporated into our common life.

Jane Addams