

poster presentations in education and public health

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The genetic counselor as a resource for families with a medical indication for cord blood banking. J.M. Epstein, R. Meyers, W.F. Reed, R.S. Smith, K. Taylor, S. Haaz, B.H. Lubin, Children's Hospital Oakland Research Institute, Oakland, CA

Background: The discovery that blood from the placenta contains hematopoietic stem cells (HSC's) promises an exciting new generation of treatment options for children with certain genetic conditions. Most significantly, this blood provides an attractive alternative to bone marrow as a resource for HSC transplantation (TP). Cord blood (CB) offers several advantages over bone marrow. 1. CB can be drawn without endangering newborn or mother. 2. Though CB volume is limited, HSC's are more concentrated than in marrow, highly proliferative, and give rise to engraftment at a cell dose 1/10 of that for marrow. 3. Decreased incidence and severity of graft-vs-host disease (GVHD) and rejection. 4. A complete HLA match is not necessary. 5. Low incidence of CMV. Since 1988, over 1,000 CB TPs have been used to treat patients with malignant and nonmalignant diseases. The success rate has been remarkable, with approximately a 90% engraftment rate and a 40% probability of disease-free survival.

Children's Hospital Oakland (CHO) has developed a Related Cord Blood Program (RCBP). This is the first and only NIH-supported family donor cord blood bank. The program provides services free of charge to families who have a child with a transplant-treatable condition and are expecting another child. Of special interest to genetic counselors (GC's), mothers carrying a fetus known through prenatal diagnosis to have a transplant-treatable condition are also eligible for this free service.

CHO's RCBP aims to serve a small but critical population. We enroll about 5 new cases a week; 175 families have collected and stored CB with us. Over half are affected by genetic conditions such as sickle cell disease and thalassemia. According to the California State Department of Health Genetics Disease Branch (CSDH/GDB) over 1,000 babies are diagnosed yearly with transplant-treatable genetic conditions. The majority of these families are referred to prenatal diagnostic centers (PDC's) for genetic counseling. Our goal is to reach those families who may benefit from our services.

Hypothesis: Hundreds of families currently affected by genetic conditions potentially treatable with HSC are not banking CB due to a lack of information. The most effective way of communicating this information to this unserved patient population is through education of PDC GC's. GC's are a trusted source of advice and information; families often look to them for treatment options. From the RCBP's point of view, GC's are highly informed and empathetic individuals, ideally suited for identifying and communicating with families who could benefit from CB banking. In addition, California has one of the best organized networks of PDC's in the country. This infrastructure will aid in the systematic education of GC's and the integration of CB banking education into genetic counseling.

Methods: 1. Contact directors of California PDC's to assess interest in and understanding of CB collection. Each director will identify a genetic counselor interested in CB to act as a point person. 2. Send out resource packets for PDC staff (patient leaflet, GC/PCD leaflet, video, articles.) 3. Ask point person to distribute information and schedule a meeting where a member of our staff will come and speak to PDC staff. 4. Invite point persons to an educational and planning conference for California GC's from across the state, sponsored by CHO and CSDH. 5. Set up an e-mail network of GC's.

Conclusions: Our preliminary data show that the PDC chiefs are eager to learn more about the RCBP. We are confident that our strategy will help integrate information about these services into the PDC setting, and that an increasing number of families affected by genetic conditions will benefit from cord blood banking as a result of our efforts.

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The public's quest for genetic information: The role of a telephone helpline. L.E. Lander¹, E.A. Kramer¹, M.E. Davidson¹ and D.L. Collins² Genetic Alliance, Wash., DC and ²Univ. of Kansas, KS.

The Genetic Alliance represents more than 280 consumer and professional organizations and three million individuals, working together to enhance the lives of everyone affected by genetic conditions. As a central resource nexus, the Alliance provides an information hotline, technical assistance to support groups, public policy consultation and public and healthcare professional education. The Information Resource Center Helpline, staffed by a genetic counselor and full-time intern, has been at the core of the Alliance mission since 1986. Callers are linked to relevant, up-to-date information, referrals and resources about all things genetic through a number of different venues. Over the 12 month period (11/1/98 to 11/1/99), we answered 1435 phone calls, 619 emails, and 79 letters. During that same time, our website received 435,857 hits. The majority of callers (46%) seek information about specific genetic conditions (both common and rare). This is followed by individuals interested in support group referrals (19%) and Alliance information (11%). Most of the callers are either affected individuals (15%) or family members (38%). Others are health professionals (13%) and students (7%). Many of these individuals learn about the Alliance through our website (13%). This is especially true for those who use the e-mail Helpline to access information and resources. Other users contact the Helpline through referrals in published directories (12%) and the genetics/healthcare community (9%). When a call comes into the Helpline, the phone is answered promptly, concerns are validated, requests are assessed, and a comprehensive search is done for answers. Calls on the Helpline range in duration from less than one minute to over 20 minutes, with the average call taking about 6 minutes to complete. Helpline services center around referrals to established and credible consumer and professional resources, in particular support and research organizations and genetic specialists. We plan to expand collaborative efforts with the professional community to better serve the people who rely on our unique services.

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Public acceptance of an interactive kiosk to educate about folic acid to prevent neural tube defects. Jackson, DN MD, Brown L, MS, CGC, Fetal Diagnostic and Imaging Center, St. Vincent's Health Center, Department of Maternal Fetal Medicine and Fetal Imaging, Billings, MT

Aim: To assess the acceptance and effectiveness of an educational kiosk delivering medical information in a public arena. **Methods:** A regional March of Dimes sponsored project in Eugene, Oregon, allowed for the development of an interactive, multi-media kiosk program for population education. The focus of the message was "Preconceptional Folic Acid to Prevent Neural Tube Defects." The program assessed previous knowledge of the participant regarding folic acid and spina bifida while reinforcing the benefits of preconceptional folic acid. The kiosk was placed in community malls in an attempt to determine what proportion of the general population would stop, initiate the kiosk, and receive this education. Demographic information including age race and gender could be tracked through this program. **Results:** The kiosk was initiated in December of 1997 and removed in May 1998. An average of 21 contacts per day were received. 43% answered the first series of questions and 25% completed the program to the end. 20% also completed exit demographics and 7.3% requested additional educational information from the March of Dimes. For patients answering the first question, 46% were previously unaware of what folic acid is and 50% did not know what spina bifida was. 35% of persons initiating the program stayed to receive the immediate educational message. **Conclusion:** A public-centered information kiosk is a cost effective way of initiating awareness of folic acid supplementation for the prevention of neural tube defects. Additional preventative medical issues can be addressed to the general public utilizing this format.

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Factors affecting the incidence of Down syndrome live births in Illinois from 1989 to 1997. D.R. Leonard¹, E. Pergament², H. Schmidt³, T. Egler¹ and T. Shen¹ ¹Illinois Dept. of Public Health, Springfield, Ill., ²Northwestern University Medical Center, Chicago, Ill., ³Illinois Dept. of Human Services, Springfield, Ill.

Purpose: Prenatal screening and elective termination are known to reduce the overall incidence of Down syndrome births. To evaluate socioeconomic and other factors that also have effects on incidence, through their association with screening and termination, all live births in Illinois between 1989 and 1997 were studied. **Methods:** Data sources consisted of the Illinois Adverse Pregnancy Outcomes Reporting System (a birth defect registry), statewide birth master files, and United States census data. There were 1,589,125 births evaluated in this study, including 1,747 Down syndrome cases. Logistic regression was performed to model Down syndrome births by maternal age, race, prenatal care, maternal education, urban or rural location of residence, trends over time, per capita income, and other variables. **Results:** The odds ratios (OR) were significantly increased for maternal age (for all women OR = 1.05 per year; 95% CI = 1.03-1.07; and for women older than 35 a further OR = 1.01 per year; 95% CI = 1.01-1.02). Increased risk was also found for whites (OR = 1.28; 95% CI = 1.12-1.46). Protective effects were found for prenatal care (OR = 0.97 per visit; 95% CI = 0.96-0.99), education (OR = 0.95 for each year of education attained; 95% CI = 0.94-0.97), and urban residence (OR = 0.82; 95% CI = 0.74-0.90). Over time there was a general protective effect (OR = 0.96 for each quarter; 95% CI = 0.94-0.98). A slight protective effect was found for women over 35 living in higher per capita income areas (OR = 0.99 per year of age; CI = 0.99-1.00). **Conclusion:** Variables associated with higher socioeconomic status and urban residence correlated with lower rates of Down syndrome live births. The findings are consistent with studies of usage patterns of prenatal diagnosis and have implications regarding the care provided to women in different socioeconomic circumstances.