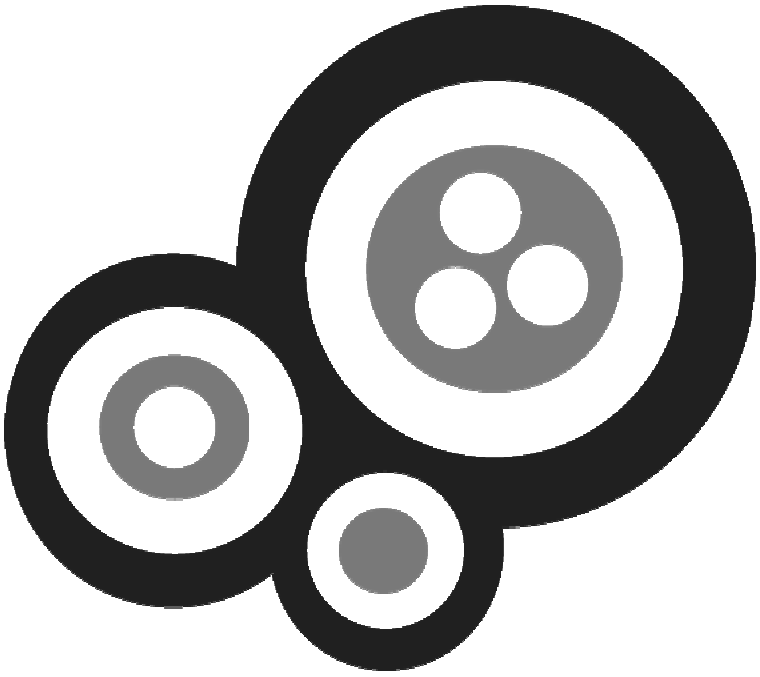

BREAKOUT 8

OMNI-NET BIRTH DEFECTS PREVENTION NETWORK IN UKRAINE AND BEYOND

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LINKING BIRTH DEFECTS SURVEILLANCE WITH EARLY INTERVENTION SERVICES

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Background: It is self-evident that among the most prevalent, serious and burdensome birth defects is mental subnormality. Among the early goals of the OMNI-Net Birth Defects Initiative (1998) in Ukraine was to link the program with a center for early interventions inclusive of orphaned young children. In 2001, following a series of promotional events and workshops, a parental organization arose in Rivne to advocate for the creation of an early intervention center for infants and young children with Down syndrome and other developmental disorders. In 2002, the U.S. Ambassador to Ukraine granted funding to formalize plans, which in 2003 were adopted by the Rivne City Council.

Method: The Rivne OMNI-Net center provided training materials, organizational templates and general support to parents and community leaders advocating the creation of what became the "Pahinets Developmental Center" (PDC). International partners from Australia, U.S.A., Poland and other nations contributed training material and participated in training events.

Results: In 2004, the Rivne City Administration donated physical facilities (75 m^2) and funded four full-time positions. Currently, the PDC operates in a renovated stand-alone building and has 66 full-time professionals, staff and support personnel (inclusive of laundry, kitchen, etc.). PDC provides day-care services and programs to 50 children with special developmental needs between the ages of 2 months to 8 years. For normative purposes, the center also provides pre-school education to 40 "normal children" up to the school age of 6. Regarding early interventions directed at orphans, the achievement have been quite modest. Students from the College of the Rivne State Humanities were offered an elective program to gain field experience in child development by visiting regularly a specific orphan over the span of an academic school year. Student-orphan pairs, according to anecdotal reports, developed bonding and positively impacted the behavioral range of infants. However, bureaucratic barriers and lack of resources remain to be resolved.

Conclusions: The implementations by the PDC can serve as a replication template for other regions. Encountered bureaucratic barriers and lack of resources to introduce programs to promote a fuller development of orphaned infants and children are also lessons learned relevant to other regions.

EXPANDING A POPULATION BIRTH DEFECTS SURVEILLANCE PROGRAM BY A PREGNANCY REGISTRY IN RIVNE UKRAINE

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Background: Rivne OMNI-Net Center, established in 1999, arose as a component of a medical genetics team offering clinical and prenatal services to the Rivne oblast (province). In 2005, reports to EUROCAT of population birth defects data began and nearly 45% of pregnant women underwent ultrasonographic fetal examinations. In 2007, a pilot study to assess alterations of fetal developmental markers in women who consumed alcohol began in partnership with two U.S. university teams funded by the National Institutes of Health. In 2008, a decree by the Ukrainian Ministry of Health and financial support by Oblast authorities provided the center with additional state-of-the-art ultrasonography equipment and mandated that the center reach all pregnant women at high risk and provide at least one examination to all pregnant women between 18 and 22 weeks gestation.

Method: The upgraded facilities and legal standing of the prenatal diagnosis component of the Rivne OMNI-Net and Rivne Regional Diagnostic Center call for an upgraded data collection system to become a population-based Rivne pregnancy register linked with the existing birth defects surveillance and neonatal registry databases, among others.

Results: Ongoing OMNI-Net surveys (see companion abstract by E.Y. Patskun, et al.) are defining the data elements and offer field experience needed to design an optimal pregnancy population registry attuned to the socio-demographic realities in Ukraine.

Conclusion: Investment in the development of a neonatal, birth defects and related programs have garnered the official and public support needed to formulate an integrated health care and data collection system from pre-conception to early interventions for infants and children in Rivne. (See companion abstract by Bohatyrchuk-Kryvko, et al.).

INFANT MORTALITY – UKRAINE VS. ALABAMA

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Background: In Ukraine, vital statistics are reported by local authorities in aggregate form and reflecting former U.S.S.R. definitions only recently updated to comply with those used by the international health community. The OMNI-Net established a neonatal registry concurrently with a birth defects surveillance system, both relying on international standards.

Method: To assess infant mortality and its causes, we compared 2006 data from three oblasts: provinces of Rivne, Volyn and Khmelnytsky, on 41826 live births. Data on 40895 white infants born in Alabama in 2005 were used for comparisons. In addition, a separate concurrent review of causes of infant deaths in Rivne was undertaken.

Results: We focus upon infants of near normal birth weight and gestation because they are most numerous in terms of infant mortality. Live born weighing from 2500 to 4499 g. represented 94.3% and 90.3% for Ukrainian and Alabama infants respectively; birth weight for those gestated less than 38 weeks and those gestated 38 or more weeks were 7.8% vs. 22.1% and 92.12% vs. 77.7% for Ukraine and Alabama respectively. Infant mortality among those with birth weights above 1999 g. was 0.74% (includes 185 infants weighing between 2500 and 3500 g.) and 0.5% (includes 67 infants weighing between 2500 and 3500 g.) for Ukraine and Alabama respectively. Review of medical records in Rivne showed that birth defects, mainly cardiac malformations, were the leading cause of infant mortality, followed by infections, asphyxia and hemorrhage. The reviewers gained the impression that the latter causes of death were more prevalent in the 2500 to 3500 g. group.

Conclusion: The review team will expand the study of death records in other OMNI-Net regions. Conclusions and recommendations will be forwarded to city, region and national authorities to reduce mortality and morbidity particularly that of infants with near-normal gestational ages and near-normal birth weights (the most numerous category).

CYBERSPACE AND BIRTH DEFECTS (BD) PROGRAMS IN UKRAINE

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Background: IBIS (http://www.ibis-birthdefects.org) is a web site resource for five OMNI-Net centers that provides access to selected and current BD information to professionals (mostly in English) and to parents and the public (mostly in Ukrainian). IBIS also plays a central role to electronically publish and disseminate translated and adapted materials to local circumstances and to implement "open book" policies upheld by OMNI-Net by posting reports and data sharing.

Method: To assess the effectiveness of IBIS in Ukraine on regions other than those where OMNI-Net Centers are located, we compared patterns of utilization of IBIS with those of a Companion web site – Pandora Word Box (PWB) (http://www.pandorawordbox.com/) dedicated to medical etymology and humanism given solely in English.

Results: Google search engine ranks IBIS and PWB among the ten top web sites concerned with "Birth Defects" and "Medical Etymology and Humanities". Over 30,000 and 20,000 pages of IBIS and PWB respectively are viewed weekly. The proportion of visitors from Ukraine to IBIS is drastically higher than for PWB (visits from Ukraine rank 2nd and 30th respectively). Visits to IBIS within Ukraine originate mostly in regions lacking OMNI-Net Centers. The global popularity of IBIS was not anticipated and is perhaps due to an emphasis on providing sources of information in other than English languages, in particular those from the developing world. Over 1 million IBIS pages are opened yearly.

Conclusions: IBIS is an essential resource for OMNI-Net partners. It provides a shared cyberspace for coordinated development and sharing of information as well as its dissemination. Dialogue with international IBIS visitors indicates that cloning core features with emphasis on additional languages, particularly those from less affluent nations is desirable.