IBIS version 201105

INTERNATIONAL CHARITABLE FUND "OMNI-NET FOR CHILDREN"

Population Surveillance and Study
on Birth Defects and Development

ASPECTS OF CHILD DEVELOPMENT REPORTS 2000-2011

On Occasion of 25th Anniversary of Chornobyl

Rivne, Ukraine
2011

http://ibis-birthdefects.org/start/netomni.htm
http://ibis-birthdefects.org/start/ukrainian/unetomni.htm
omninetukr@gmail.com

INTRODUCTION

ABOUT OMNI-NET

1999

Granted USAID funding for Ukraine-American BD monitoring and prevention program; training of initial BD teams in the U.S.; 2 BD resource centers (BDRCs) established in Lutsk and Rivne (northwestern region); international standards for surveillance methods were adapted to Ukrainian circumstances.

2000

BD pilot data collection initiated in Rivne-Volyn; associate membership granted by the International Clearinghouse for BD Monitoring Systems (ICBDMS); developed a Ukrainian web version of IBIS (International Birth Defects Information Systems) launched (http://www.ibis-birthdefects.org).

2001

Training of BD team in Khmelnytsky (central region); high prevalence of NTD noted in northwestern Ukraine; co-sponsored the 1st International Ukrainian Bioethics Congress; co-sponsored with the World Health Organization – Europe, a conference "Folic Acid and Healthcare" in Kyiv and Minsk; produced a joint recommendation with UNICEF-Kyiv and CDC on food fortification; an associate partnership in the International Clearinghouse for Birth Defects Surveillance and Research acquired.

2002

Opened a BDRC in Khmelnytsky and initiated population BD surveillance. Received a grant from the International Bank for Reconstruction and Development for NTD prevention awareness programs; sponsored an international conference "NTD Prevention and Folic Acid"; the Muskie Fellowship Program at the Emory University provided to an MD team member (graduated with a Master's Degree in Public Health, currently engaged by UNICEF-Kyiv).

2003

Submitted a proposal to introduce universal folic acid flour fortification to the Global Alliance for Improved Nutrition (GAIN); sponsored an international workshop "Diagnosis and Prevention of Fetal Alcohol Spectrum Disorders (FASD)"; granted funds by the U.S. Ukraine Democracy Foundation for a manual "Legal Support of Disabled Children"; a second BD team member was granted a Muskie Fellowship (graduated from Emory University with a Master's Degree in Public Health with an emphasis on BD epidemiology). Program Director (W. Wertelecki, M.D.) granted an honorary doctorate (Kyiv-Mohyla Academy University) and was inducted as a foreign member of the Ukrainian Academy of Sciences: prompted the formation of the Rivne Oblast NGO "Parental Association of Special Needs Children".

http://ibis-birthdefects.org/start/netomni.htm
http://ibis-birthdefects.org/start/ukrainian/unetomni.htm
omninetukr@gmail.com

2004

Published report on the high prevalence of NTD in Ukraine (Yuskiv et al. 2004); submitted a second proposal to introduce universal folic acid flour fortification to GAIN; Co-founder of "Pahinets", an outpatient center for infants with special healthcare needs (a unique facility in Ukraine) opened in Rivne with sponsorship by local authorities; received assistance for "Pahinets" from the Ukrainian Special Needs Orphanages Fund; assisted the Academy of Medical Sciences to draft recommendations for Ukrainian authorities regarding folic acid fortification; co-sponsored the 2nd Bioethics Congress with participation of CDC and other international colleagues.

2005

Completed the USAID-funded component, program transferred to the OMNI-Net (registered Ukrainian International Charitable Organization for the Care and Prevention of BD and Developmental Disorders); presented an OMNI-Net Ukraine to the Minister of Health; FASD early diagnosis and prevention program started in Kherson and Rivne; partnered with CDC scientists and a visiting Fulbright Senior Scientist to deliver a series of workshops (Kyiv, Lviv, Donetsk, and other localities in Ukraine) concerned with maternal and child health clinical epidemiology, with an emphasis on the role of BD surveillance systems.

2006

Pilot project "Prenatal Ultrasound Markers of Fetal Alcohol Syndrome" realization in Rivne and Kherson oblasts continued; EUROCAT expanded and announced about including new member: OMNI-Net Ukraine Birth Defects Prevention Program (OMNI-Net UBDPP); Prof. W. Wertelecki presented a report "Rates of neural tube defects in Ukraine highest in Chornobyl impacted regions" (In commemoration of the 20th anniversary of the Chornobyl nuclear disaster Kateryna Yushchenko, the First Lady of Ukraine, and other Ukrainian and international collaborators organized a two-day international symposium in Kyiv, Ukraine ("REBIRTH, RENEWAL, AND HUMAN DEVELOPMENT A HUMANITARIAN FORUM", April 25, 2006 Kyiv, Ukraine); International Scientific and Practical Conference "Fortification of Food Products with Vitamin B9 for Prevention of Neural Tube Defects", November, 27-29, 2006, Kyiv, Ukraine. In partnership with the Ukraine Special Needs Orphanages Fund (non-government organization from Virginia, USA), a series of conferences, seminars and trainings "Approaches to Early Intervention in Children with Special Needs" with US experts participation was initiated in Rivne and Lutsk; a Ukrainian translation of the "Small Steps" early intervention program published with the permission of the authors from the Macquarie University (Sydney, Australia).

2007

To promote collaborative research and projects, OMNI-Net Ukraine together with Rivne Regional State Administration have initiated developing the “Polissya Initiative” which can be coordinated by an international working group; for this purpose, on September 19, 2007 a Round Table with international participation “Mothers and Children Health Care Initiatives: Strategies and International Partnerships” was held in V. Polishchuk Rivne Regional Clinical Diagnostic Center; in partnership with the International FASD Consortium, a new research project “The Spectrum of and Nutritional Risk factors for FASD in Ukraine” was initiated in Rivne Oblast, a collaboration agreement concluded with the Rivne Oblast Health Care Administration; a group of managers and leading specialists of the International FASD Consortium visited Rivne (Ukraine); the series of early intervention trainings continued: a seminar-training “Bobath Concept in Correction of Neuro-Motor Developmental Disorders in Children” was held by the US experts in partnership with OMNI-Net, Education Department of Rivne City Executive Committee, Ukrainian Special Needs Orphanages Fund (Virginia, USA).

2008

Participation in the 1st Central and Eastern European Summit on Preconception Health and Prevention of Birth Defects, August 27-30, 2008, Budapest, Hungary; continuing the research project “The Spectrum of and Nutritional Risk Factors for FASD in Ukraine” in Rivne Oblast.

2009

Expanding the research project “The Spectrum of and Nutritional Risk Factors for FASD in Ukraine” to include Khmelnytsky Oblast; “Aspects of Autism” Scientific-Practical Seminar with international participation and in partnership with OMNI-Net, Education Department of Rivne City Executive Committee, Ukrainian Special Needs Orphanages Fund (Virginia, USA) was held in Rivne.

2010

New publications in American scientific journals; continuing the research project “The Spectrum of and Nutritional Risk factors for FASD in Ukraine” in Rivne and Khmelnytsky Oblasts.

INQUIRIES TO

W. Wertelecki, M.D.
‘‘OMNI-Net for Children’’
36, 16 Lypnya Str., Room 709, Rivne, Ukraine 33028.
E-mail: werteleckiomni@gmail.com

WEBSITES

Information

International Birth Defects Information System - I.B.I.S. – Amelioration, Prevention and Genetic Counseling concerning Birth Defects, Genetic Disorders, Congenital Malformations, Anomalies and Developmental Disorders.

http://ibis-birthdefects.org/start/index.htm

Humanities

Pandora Word Box – links Medicine and Biology with Humanities, Arts and Sciences. The goal is to stress “Ideas in Words”**,** to be entertaining and replace memorization by a better grasp of meanings.

http://www.pandorawordbox.com

UNDER DEVELOPMENT

Medicine

Medword.net (Medical Overviews and Images) – highlights medical topics illustrated by video recordings and galleries of clinical images.

http://www.medword.net/

Resources

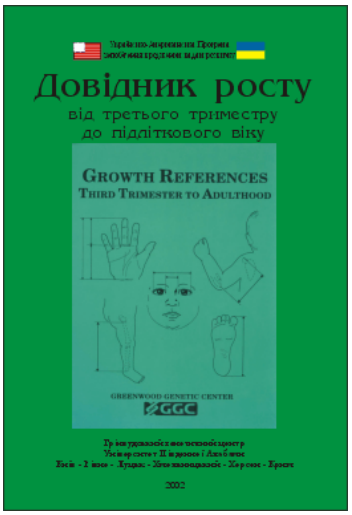
Birthdefects.net (Preconception Health - Birth Defects) - provides resources for prospective parents (preconception health and prevention of birth defects), patients, and relatives with access to selected news, policies and carefully chosen healthcare related information.

http://www.birthdefects.net/

http://ibis-birthdefects.org/start/netomni.htm
http://ibis-birthdefects.org/start/ukrainian/unetomni.htm
omninetukr@gmail.com

BOOKS, MANUALS
(HIGHLIGHTS)

Довідник росту: від третього триместру до підліткового віку. Переклад з англійської.- Луцьк, 2002. - *Growth References: Third Trimester to Adulthood. Compiled by Saul RA, Geer JS, Seaver LH, Phelan MC, Sweet KM, Mills CM. Greenwood Genetic Center 1998.*



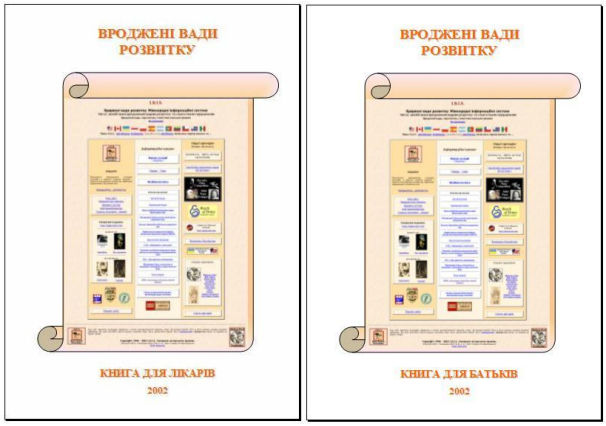
Переклад з англійської за сприяння Greenwood Genetic Center, Українсько-Американської Програми запобігання вродженим вадам розвитку, Університету Південної Алабами (США), Агенства США з міжнародного розвитку (USAID), Мережі інформаційно-ресурсних ОМНІ-Центрів.

Видання висвітлює інформацію про стандарти розвитку здорової дитини від третього триместру вагітності до повноліття, унікальні аспекти розвитку дітей при специфічних захворюваннях та вроджених вадах розвитку. Широко використовуються дослідження з цих питань відомих науковців США. Саме вони відносять цей посібник до розряду елітних довідників для лікарів різних профілів.

http://www.ibis-birthdefects.org/start/ukrainian/ugrowref.htm

Вроджені вади розвитку: Книга для лікарів. Луцьк, 2002. - *Birth Defects: Specialists' Book. Lutsk, 2002.*

Вроджені вади розвитку: Книга для батьків. Луцьк, 2002. - *Birth Defects: Parents' Book. Lutsk, 2002.*

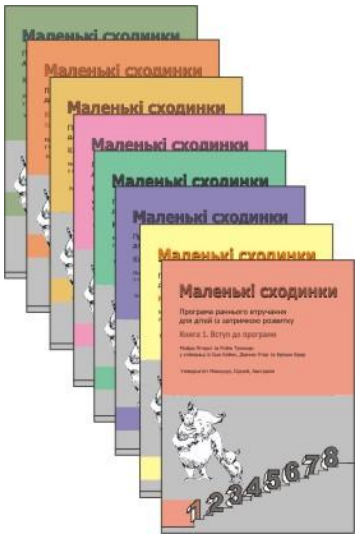


У книгах висвітлюються матеріали, опубліковані на сторінках інтернет-сайту „Вроджені вади розвитку: Міжнародні інформаційні системи (I.B.I.S.)" (http://ibis-birthdefects.org/start/ukrainian/index.htm). Актуальними є статті про найпоширеніші вади, їх профілактику, лікування і догляд за хворими дітьми. Багато цікавого і пізнавального у цьому виданні знайдуть лікарі генетики, неонатологи, педіатри, спеціалісти Центрів планування сім'ї, інші медики, які опікуються хворими дітьми та їх сім'ями, а також батьки дітей з вродженими вадами та інші люди, кому не байдужа доля таких дітей.

Гідроцефалія (інформаційний буклет для пацієнтів та батьків) /Під реакцією проф. Ю.О. Орлова, головного дитячого нейрохірурга Міністерства охорони здоров'я України.- Київ, 2002. - *Hydrocephalus (Informational Booklet for Patients and Parents. Chief Editor Prof. Y, Orlov, Chief Children's Neurosurgeon, Ministry of Health of Ukraine. Kyiv, 2002.*
http://www.ibis-birthdefects.org/start/ukrainian/uhydroc2.htm

http://ibis-birthdefects.org/start/netomni.htm
http://ibis-birthdefects.org/start/ukrainian/unetomni.htm
omninetukr@gmail.com

Маленькі сходинки: Програма раннього втручання для дітей із затримкою розвитку /Переклад з англійської.- Луцьк, 2006. - *Pieterse M, Treloar R. Small Steps: An Early Intervention Program for Children With Developmental Delays. Macquarie University, Sydney 1989.*



Переклад з англійської і видання здійснено за сприяння Міжнародного благодійного фонду "ОМНІ-Мережа для дітей" та Українського фонду допомоги дітям-сиротам з особливими потребами, Вірджинія, США.

Це програма раннього втручання для стимуляції дітей із затримкою розвитку від народження до 4-річного віку. "Маленькі сходинки" насамперед призначені для батьків дітей з розумовим відставанням. Вони містять практичні поради щодо навчання дітей у домашніх умовах. Основним постулатом цієї програми є те, що батьки - це найкращі вчителі для своєї дитини. Ця програма також може використовуватися педагогами, лікарями і студентами.

http://ibis-birthdefects.org/start/ukrainian/usmstep.htm

Основи правового захисту дітей-інвалідів. Посібник.- Рівне, 2003. - *Fundamentals of Disabled ChidIren Legal Support. Manual. Rivne, 2003.*

У посібнику представлені матеріали та документи, що стосуються правового захисту дітей з особливими потребами, подані адреси громадських організацій, які опікуються зазначеною категорією дітей. Посібник розрахований на широке коло читачів.

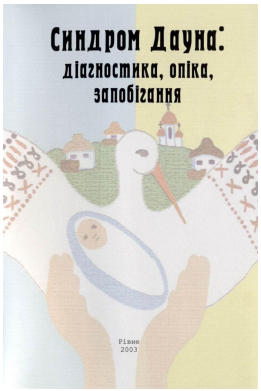
Проект здійснено за підтримки „Фонду сприяння демократії" Посольства США в Україні.

Муковісцидоз (посібник для батьків та хворих) /Переклад з англійської і адаптація під редакцією Л.С. Євтушок.- Рівне, 2002. - *Cystic Fibrosis (Manual for Parents and Patients). Translated and Adapted from English, Editor L. Yevtushok. Rivne, 2002.*

Посібник призначений для родин, в яких народжувалися діти з муковісцидозом, вихователів, вчителів, соціальних працівників.

http://ibis-birthdefects.org/start/netomni.htm
http://ibis-birthdefects.org/start/ukrainian/unetomni.htm
omninetukr@gmail.com

Синдром Дауна: діагностика, опіка, запобігання /Під редакцією Л.С. Євтушок.- Рівне, 2003. - *Down Syndrome: Diagnosis, Care, Prevention. Editor L. Yevtushok. Rivne, 2003.*



Посібник виданий на кошти фонду сприяння демократії посольства США в Україні і містить огляд наукової літератури з проблем медичного нагляду і програм раннього втручання щодо розвитку дітей з синдромом Дауна, а також стандарти фізичного і психомоторного розвитку даної категорії дітей.

Метою посібника є допомога батькам хворих дітей, лікарям у їх повсякденній практичній діяльності. Посібник призначений для батьків дітей з синдромом Дауна, лікарів генетиків, неонатологів, педіатрів, терапевтів, вчителів-дефектологів, вихователів дошкільних дитячих закладів.

Синдром Клайнфелтера: Посібник для XXY-чоловіків та їх родин (Klinefelter Syndrome) /Переклад з англійської під редакцією Н.О. Зимак-Закутньої. – Хмельницький, 2005. - *Klinefelter Syndrome: Manual for XXY Men and Their Families. Translated from English. Editor N. Zymak-Zakutnia. Khmelnytsky, 2005.*

Посібник призначений для пацієнтів із синдромом Клайнфельтера та членів їх родин. Містить інформацію щодо причин, діагностики та найбільш типових медичних і соціальних проблем.

Фетальний алкогольний синдром. Проблеми і вирішення: Посібник для батьків та вихователів. /Переклад з англійської, головний редактор Л.С. Євтушок.- Рівне, 2001. - *Fetal Alcohol Syndrome. Problems and Solutions: Manual for Parents and Educators. Translated from English. Chief Editor L. Yevtushok. Rivne, 2001.*

Посібник призначений для родин, в яких народжувалися діти з фетальним алкогольним синдромом, вихователів, вчителів, соціальних працівників.

У підготовці даного посібника використовувались матеріали, люб'язно надані кафедрою педіатрії університету штату Нью Мексико.

"Фолієва кислота і профілактика захворювань". Доповідь Британського Комітету з медичних аспектів політики в сфері харчування та їжі (переклад англійського видання „50 Folic Acid and the Prevention of Disease").- **Лондон**.- 2002. **- *50 Folic Acid and the Prevention of Disease: Report of the Committee on Medical Aspects of Food and Nutrition Policy, Department of Health, London: The Stationery Office. 2000.***

http://ibis-birthdefects.org/start/netomni.htm
http://ibis-birthdefects.org/start/ukrainian/unetomni.htm
omninetukr@gmail.com

Муковісцидоз і ти: (довідничок для дітей віком 8-12 років) /Переклад з англійської і адаптація під редакцією Н.О. Зимак-Закутньої. – Хмельницький, 2001. - *Cystic Fibrosis and You: Reference Book for Children Aged 8-12. Translated and Adapted from English. Editor N. Zymak-Zakutnia. Khmelnytsky, 2001.*

Ілюстрований буклет призначений для дітей з муковісцидозом 8-12 років і містить відповіді на деякі з запитань щодо захворювання та основних аспектів щоденного життя із муковісцидозом.

Довідник з фенілкетонурії для вчителів і психологів /Переклад з англійської мови і адаптація під редакцією Н.І. Юськів.- Київ-Луцьк, 2001. - *Phenylketonuria Reference Book for Teachers and Psychologists. Translated and Adapted from English. Editor N. Yuskiv. Kyiv-Lutsk, 2001.*

Брошура розрахована на вчителів, психологів, батьків дітей з фенілкетонурією, медичних працівників, які мають справу з фенілкетонурією та всіх зацікавлених осіб. Інформація люб'язно надана Департаментом охорони здоров'я штату Техас, США.

Аутосомний домінантний полікістоз нирок (інформація для батьків і пацієнтів) /Переклад з англійської мови під редакцією Н.О. Зимак-Закутньої. – Хмельницький, 2005. - *Autosomal Dominant Polycystic Renal Disease (Information for Parents and Patients). Translated from English. Editor N. Zymak-Zakutnia. Khmelnytsky, 2005.*

Посібник призначений для тих, хто хворіє на аутосомний домінантний полікістоз нирок (АДПКН), членів їх сімей та друзів та висвітлює генетичні аспекти, ознаки та симптоми, проблеми діагностики, лікування, харчування та вагітності при АДПКН.

Освіта дітей дошкільного та раннього шкільного віку з ФАС та частковим ФАС. Посібник для вчителя /Переклад з англійської.- Рівне, 2009. - *Teaching Children of Pre-School and Early School Age with FAS and FASD. Manual for Teachers. Tranlslated from English. Rivne, 2009.*

Посібник для вчителя розроблений спеціалістами Центру дослідження фетального алкогольного синдрому (ФАС) Інституту Маркуса, Атланта, Штат Джорджія, США (Marcus Institute, Atlanta, GA 30329).

http://www.ibis-birthdefects.org/start/ukrainian/ufasteach.htm

Труднощі у навчанні. Діти з проблемами у навчанні: Хто вони - Ким вони не є - Що з ними робити.- Київ-Луцьк-Рівне, 2001. - *Learning Difficulties. Children with Learning Problems: What they are - What they aren't - What Can be Done? Kyiv-Lutsk-Rivne, 2001.*

Ця брошура про дітей з проблемами у навчанні для вчителів та батьків. За матеріалами Памели Маніет Беллерман та членів консультативного комітету Фонду Маріет Беллерман; Південний Оранж, Нью Джерсі.

Програма "MILE": Інтерактивне вивчення математики. Посібник для батьків /Переклад з англійської мови.- Рівне, 2010. - *MILE Program: Interactive Mathematics Learning. Manual for Parents. Translated from English. Rivne, 2010.*

Дослідження показують, що дітям з ФАС важко засвоювати математичні навички. Це може бути наслідком порушень просторового мислення та обробки візуальної інформації. У дітей, які зазнали пренатального впливу алкоголю, виникають труднощі з розумінням візуальних та просторових відношень між предметами та власною особою. Ці порушення також впливають на вивчення математики. Протягом п'ятнадцятитижневої програми ваша дитина вивчатиме математичні поняття за допомогою швидше реальних предметів, ніж виконання завдань в зошиті. Використання реальних предметів покращить її навички щодо візуально-просторового мислення і таким чином удосконалить математичні вміння.

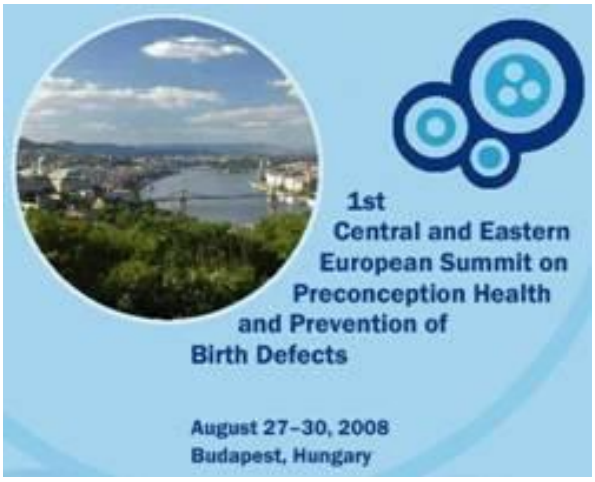
Цей посібник розроблено з метою роз'яснити суть проблем, пов'язаних з математикою, та допомогти вам спланувати заняття, спрямовані на те, щоб допомогти дитині у вивченні математики вдома. Наша мета – навчити вас, як в майбутньому допомагати вашій дитині вивчати математику. Реальні предмети та щоденні заняття стануть частиною програми, призначеної допомогти дитині пов'язувати щоденні заняття з математичними термінами.

http://www.ibis-birthdefects.org/start/ukrainian/umile.htm

Спинномозкова кила (посібник для батьків) /Під редакцією: проф. І. Бариляка і проф. Ю. Орлова. – Київ, 2003. - *Spina Bifida (Manual for Parents). Edited by Prof. I. Baryliak, Prof. Y. Orlov. Kyiv, 2003.*

Посібник призначений для родин, в яких народжувалися діти зі спинномозковою килою і містить інформацію щодо опису патології, основних принципів лікування, супутніх захворювань, медико-соціальних проблем та профілактики.

PRECONCEPTION HEALTH AND PREVENTION OF BIRTH DEFECTS



Co-Sponsors
Centers for Disease Control and Prevention, USA
OMNI-Net Ukraine

http://diamond-congress.hu/birthdefects2008/binx/CEE_book_web.pdf

Elevated Neural Tube Defects (NTD) Rates in Ukraine – Highest in Polissia

W. Wertelecki, L. Yevtushok

Book of Abstracts, Budapest, p. 67

Background: Population birth defects (BD) surveillance by the OMNI-Net started in 2000 and by 2002 data from Rivne and Volyn oblasts (provinces) of North West Ukraine showed that rates of NTD were sharply elevated (21 per 10000 live births, N. Yuskiv et al., Birth Defects Res. A Clin. Mol. Teratol, 2005). Rivne data suggested that prevalence rates were highest in the Rivne-Polissia, a region impacted by chronic ionizing radiation from the Chornobyl disaster. Polissia has boggy soils with low humus and high peat contents resulting in high soil-to-milk transfer coefficients of Cs-137. The Polissia population is known for self-sufficiency, reliance on locally grown food, consumption of game, wild mushrooms and berries. The likelihood is high that nutrition in Polissia may be deficient in micronutrients and folates, particularly during winters; that nutrients and water are contaminated by Cs-137, including milk and potatoes which are the main dietary staples. Another Cs-137 significant source is reported to be aspiration of contaminated dust and smoke from burning biomass.

Method: Analysis of NTD 2000-2006 data from Rivne Polissia and non-Polissia regions and official background demographic, nutrition and radiodosimetry data.

Results: NTD prevalence rate in Rivne Polissia and non Polissia is 27.0 and 19.6 (21.6 and 16.6 for isolated NTD, contrasts that do not reach statistical significance). However more detailed analysis by raions (counties) is warranted and is ongoing. Every Rivne - Polissia raion is officially designated as impacted by ionizing radiation; the rest are designated as "clean"; there are nearly 200 inhabited points; the largest yearly birthrate is in the city of Rivne (nearly 3000); official Cs-137 monitoring is conducted solely in the Polissia region; available reports show sharp variations by place and time; and in some villages Cs-137 levels in milk have increased with time. Another observation concerns seven instances of conjoined twins of which six were born in the Rivne oblast (one twin had spina bifida) and the other in Khmelnytsky oblast.

Conclusions: Broadening retrospective and prospective investigations of the Rivne Polissia population are warranted.

Linking Birth Defects Surveillance with Early Intervention Services

S. Bohatyrchuk-Kryvko, V. Novak, I. Shumlyanski, T. Savchuk, L. Misiyuk, T. Ponimanska, L. Yevtushok, W. Wertelecki

Book of Abstracts, Budapest, p. 127.

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.

From left to right: O. Tychkivska, Drs. N. Zymak-Zakutnia, E. Patskun, L. Yevtushok, W. Wertelecki, C. Chambers, Y. Korzhynsky

From left to right: Drs. I. Shumliansky, B. Yevtushok, L. Yevtushok, Mrs. S. Bohatyrchuk-Kryvko, Dr. V. Boiko

Lapchenko S, Wertelecki W. *Cyberspace and Birth Defects (BD) Programs in Ukraine. Abstract, p. 130*.

Yevtushok L, Needham K, Lapchenko S, Wertelecki W, Garruto R. *Dietary and Activity Patterns and Implications on Birth Defects in the Chornobyl Impacted Rivne-Polissia Region in Ukraine. Abstract. p. 162.*

Zymak-Zakutnya N, Ropotan A, Shumlyanski I, Vashchylin H, Lyatetska L, Tekuchenko T, Yenikeyeva V, Sosynyuk Z, Yevtushok L, Kalynka S, Onishchenko S, Afanasyeva N, Wertelecki W. *Reduction of Infant Morbidity and Mortality – Gastroschisis as one Index. Abstract, p. 165.*

Kovalyov V, Dumanovska M, Yenikeyeva V, Shumlyanski I, Yevtushok L, Sosynyuk Z, Wertelecki W. *Expanding a Population Birth Defects Surveillance Program by a Pregnancy Registry in Rivne Ukraine". Abstract, p. 128*.

Wertelecki W, Afanasyeva N, Baryliak I, Korzhynskyy Y, Onishchenko S, Patskun E, Yevtushok L, Zymak-Zakutnya N. *OMNI-Net Birth Defects Ukrainian Consortium: Impact and Lessons Learned from "De-Centralized" Strategies. Abstract, p. 95*.

Patskun E, Kalynka S, Onishchenko S, Semenenko O, Yevtushok L, Zymak-Zakutnya N. *Survey of Pre-conception Health and Birth Defects Prevention Knowledge and Attitudes in Ukraine. Abstract, p. 151.*

Afanasyeva N, Kalynka S, Onishchenko S, Yevtushok L, Zymak-Zakutnya N. *Survey of Maternal Phenylketonuria (PKU) as a Teratogen. Abstract, p. 133.*

Wertelecki, W, et al. *Inaugural Plenary Speaker: Impact and Lessons Learned from 'De-Centralized' Strategies. Abstract, p. 95*.

Yevtushok L, Onishchenko S, Wertelecki W, Bakhireva L, Chambers C. *Predictors of Binge Drinking During Pregnancy Among Women in Ukraine, Abstract, p. 163*.

Yevtushok L, Onishchenko S, Wertelecki W, Bakhireva L, Chambers C, Jones KL, Hull A. *Prenatal Ultrasound to Detect Effects of In Utero Alcohol Exposure. Abstract, p. 135.*

http://www.preconception2010.one.be/fileadmin/user_upload/_temp_/Brochure_preconceptional_care.pdf

Experience in a Region Impacted by Chornobyl Chronic Low Dose Radiation

W. Wertelecki, L. Yevtushok, N. Zymak-Zakutnya, S. Lapchenko

Book of Abstracts, Brussels, p. 113

One of the populations most exposed to chronic low-dose radiation from Chornobyl lives in Polissia, a region representing the northern half of the Rivne Province in Northwest Ukraine.

Malformation data was collected by monitoring all births (96,438) in Rivne from 2000-2006. Patterns and rates were defined by applying EUROCAT international standards. Additional analysis of 2007-2008 data from Rivne (31,970 births) and 2002-2008 data (91,376 births) from Khmelnytsky (an adjoining province) was performed.

The overall 2000-2006 rate of neural tube defects in Rivne is among the highest in Europe (22.2 per 10,000 live births) and in Polissia is 27.0 vs. the rest of Rivne (18.3). The contrast is statistically significant (OR 1.46, CI 1.13-1.93). In addition, microcephaly and anophthalmia-microphthalmia rates also appear to be elevated. Preliminary analysis of additional data from Rivne and Khmelnytsky showed patterns consonant with those reported above. Also found, were conjoined twin sets, eight in Rivne and one set in Khmelnytsky, since 2000 and 2002 to the present (December 2009) respectively.

The malformations in Northwest Ukraine (Rivne and Khmelnytsky Provinces) suggest early disruptions of blastogenesis, manifesting as conjoined twinning, neural tube defects, and other body wall defects. Concurrent impacts of risk factors including micronutrient deficiencies, alcohol consumption during pregnancy, low-dose radiation, and effects of other teratogens can be investigated by further prospective investigations. The scale and scope of the impact of malformations in the population studied combined with on-site established resources, justify further international collaborative efforts.

FETAL ALCOHOL SPECTRUM DISORDERS STUDIES

Co-Sponsors
OMNI-Net Ukraine
Collaborative Initiative on Fetal Alcohol Spectrum Disorders
National Institute on Alcohol Abuse and Alcoholism, US
http://www.cifasd.org

OMNI-Net and FASD Project teams (2007)
International partners (first row): Drs. R. Garruto (lower left), C. Chambers, C. Coles (4th and 5th from the left), J. Cable, K. Jones, E. Riley (7th-9th), W. Wertelecki, and C. Keen (11th-12th)

Correlation of Prenatal Alcohol Dose with Physical Features of FASD in Infants Born to Women in Ukraine

C. Chambers, L. Yevtushok, L. Bakhireva, L. Prewitt, W. Wertelecki, K. Jones

32nd Annual Research Society on Alcoholism Scientific Conference, San Diego, CA, Alcohol Clin Exp Res, 2009, June 20-24, 33(Suppl 1):11A-346A. A116

Purpose: *Fetal Alcohol Spectrum Disorders (FASD) are among the most pervasive childhood developmental disorders worldwide. Identification of the risks associated with specific dose and gestational timing of alcohol exposure for the characteristic physical features of FASD in humans is needed to aid in diagnosis particularly in the newborn period, and to provide more accurate risk counseling to pregnant women.*

Methods: *In 2005-6, we screened pregnant women in two regions in Ukraine and prospectively recruited 84 women who reported moderate to heavy alcohol consumption during pregnancy and 82 women who reported little to no alcohol drinking during pregnancy. Women were interviewed at enrollment regarding alcohol exposure in the month around conception and in the previous two-week period using a time-line follow-back method. Trained geneticists in Ukraine performed blinded physical examinations of all live-born infants using a standard checklist of physical features of FASD. Infants who had all cardinal features including growth deficiency and facial features were classified as "FAS", infants who had some physical features but final diagnosis required additional information on neurobehavioral performance were classified as "Deferred", and infants with no features were classified as "No FAS". Level of alcohol consumption was compared across the three groups using ANOVA and ANCOVA in univariate and multivariate analyses, respectively.*

Results: *A total of 141 infants were examined by study geneticists. Five infants (3.5%) met criteria for "FAS", 45 infants (31.9%) were "Deferred", and 91 infants (64.5%) were classified as "No FAS". Average daily consumption of absolute ounces of alcohol in both the periconceptional (p=0.002) and the previous two weeks (p <0.001) was correlated with physical features of FASD after adjustment for maternal tobacco and vitamin use. Average consumption of absolute ounces of alcohol per drinking day in both time periods was also significantly associated with features of FAS (p=0.015 and p<0.001, respectively). Infants who were classified as "FAS", "Deferred", and "No FAS" were exposed to adjusted means of ~3 drinks, ~2 drinks, and ~1.5 drinks per drinking day in the periconceptional period; slightly lower levels were reported in the most recent two weeks.*

Conclusions: *Number of physical features of FASD are strongly associated with the quantity of alcohol consumed in early pregnancy.*

Chambers C, Keen C, Uriu-Adams J, Yevtushok L, Zymak N, Wertelecki W, Coles C, Cable J, Jones K. *The Epidemiology of Alcohol-Exposed Pregnancies in Ukraine – An Update. 2011 [In Press].*

Bakhireva LN, Wilsnack SD, Kristjanson A, Yevtushok L, Onishenko S, Wertelecki, W, Chambers CD. *Paternal Drinking, Intimate Relationship Quality, and Alcohol Consumption in Pregnant Ukrainian Women. Journal of Studies of Alcohol and Drugs. (Under review).*

Baseline Nutritional Status: Four Papers in Preparation: Minerals, Vitamins, Methyl Donors and Measures of Oxidative Defense. (Under review).

Chambers CD, Uriu-Adams JY, Gross HB, Ensunsa JL, Green K, Le A, Yevtushok L, Zymak N, Wertelecki W, Keen CL. *Altered Maternal Nutritional Factors May Confer Risk of Fetal Alcohol Spectrum Disorders (FASD). ACER 2010 June;34 Supp:293A.*

Keen CL, Uriu-Adams JY, Skalny A, Grabeklis A, Grabeklis S, Green K, Yevtushok L, Wertelecki W, Chambers CD.*The Plausibility of Maternal Nutritional Status Being a Contributing Factor to the Risk for Fetal Alcohol Spectrum Disorders: the Potential Influence of Zinc Status as an Example. Biofactors. 2010 Mar;36(2):125-35. Review.*

Jones KL, Hoyme HE, Robinson LK, Del Campo M, Manning MA, Prewitt LM, Chambers CD. *Fetal Alcohol Spectrum Disorders: Extending the Range of Structural Defects. Am J Med Genet. 2010;152:2731-5.*

Uriu-Adams JY and Keen CL. *Zinc and Reproduction: Effects of Zinc Deficiency on Prenatal and Early Postnatal Developments. Birth Defects Research Part B: Developmental and Reproductive Toxicology. 2010;89:313-325.*

First European Conference on FASD Fetal Alcohol Spectrum Disorder: *Growing Awareness in Europe, Kerkrade, Netherlands, November 2010.*

Uriu-Adams JY, Chambers CD, Gross HB, Ensunsa JL, Green K, Le A, Yevtushok L, Zymak-Zakutnya N, Wertelecki W. *Alcohol Drinking Patterns and Nutrient Status in Ukrainian Pregnant Women. Birth Defects Research (Part A): Clinical and Molecular Teratology. 2010;88:382.*

Kfir M, Yevtushok L, Onishchenko S, Wertelecki W, Bakhireva L, Chambers CD, Jones KL, Hull AD. *Can Prenatal Ultrasound Detect the Effects of In Utero Alcohol Exposure? – A pilot study. Ultrasound in Obstetrics and Gynecology. 2009 Jun;33(6);683-9.*

Chambers CD, Uriu-Adams JY, Keen CL, Yevtushok L, Wertelecki W. *Micronutrient Levels in Plasma in Mid-Gestation Vary by Quantity of Alcohol Consumption in Pregnant Women in Ukraine. 32nd Annual of the Research Society on Alcoholism Scientific Conference, San Diego, CA, Alcohol Clin Exp Res, 2009, June 20-24, 33(Suppl 1)11A-346A. A117*.

Бариляк І., Вертелецький В., Джонс К., Драпкіна І., Євтушок Л., Жарко В., Оніщенко С., Сосинюк З., Халл Е., Чамберс К, Шевченко С. *Пренатальні ультразвукові маркери алкогольного ураження плода.- Тези 4-го з"їзду медичних генетиків україни. Львів, 2008.*

Kfir M, Yevtushok L, Onishchenko S, Wertelecki W, Bakhireva L, Chambers CD, Jones KL, Hull AD. *Can Prenatal Ultrasound Detect the Effects of in Utero Alcohol Exposure? Oral presentation at 17th World Congress on Ultrasound in Obstetrics & Gynecology held in Florence, Italy, October 7-11, 2007*.

Jones KL, Hull AD, Bakhireva LN, Wertelecki W, Yevtushok L, Sosynyuk Z, Shevchenko S, Zharko L, Onischenko S, Drapkina I, Chambers CD. *Fetal Ultrasound Measures as Predictors of Alcohol-Related Physical Features in the Newborn: Preliminary Results, Teratology Society Meeting, Pittsburga, PA, June 2007. Birth Defects Research Part A. 2007;79:373*.

Kfir M, Hull AD, Yevtushok L, Onishchenko S, Wertelecki W, Bakhireva L, Chambers CD, Jones KL. *Evaluation of Early Markers of Prenatal Alcohol Exposure. Oral presentation at the American Institute of Ultrasound in Medicine Annual Convention. March 15-18, 2007. New York, NY.*

http://www.icbdsr.org/

Impact of a Birth Defects (BD) Information System in Ukraine and Beyond

S. Lapchenko, W. Wertelecki

34-th International Clearinghouse Birth Defects Surveillance and Research Meeting,
October 2007, Chianciano, Italy

International Birth Defects Information System (IBIS) (http://www.ibis-birthdefects.org) is a web resource initially designed for five BD surveillance teams in Ukraine. IBIS offers information in Ukrainian and English and links to other websites, preferably in non-English. IBIS information channels concern birth defects-syndromes, care, prevention themes and support organizations. A companion website (www.consultsos.com/pandora/intro.htm) offers humanistic vistas inclusive of bioethics.

The monthly visitors to IBIS approach 31 thousand and are mostly from the United States, Canada, UK and Australia, while those from Ukraine rank 8th. Visitors from the Russian Federation and Poland rank 24th and 26th. Ukrainian teams promoted IBIS while Pandora was not. Visitors to Pandora from Ukraine rank 47th, while those from neighboring Russian Federation and Poland rank 27th and 18th respectively.

The proportion of visitors to IBIS and Pandora were similar for all countries except for Ukraine where visitors to IBIS were substantially more numerous than for Pandora.

We conclude that the promotion of IBIS in Ukraine was effective and that the information materials in Ukrainian also played an important role. Analysis of our experience in Ukraine and data from 1.7 million cumulative visits to IBIS prompts us to seek additional partnerships. We welcome BD experts interested in developing and promoting informational materials in other bilingual English - vernacular versions to be disseminated through IBIS.

Prevalence at Birth of Cleft Lip with or without Cleft Palate: *Data From the International Perinatal Database of Typical Oral Clefts (IPDTOC). Cleft Palate Craniofac J. 2011 Jan;48(1):66-81.*

Leoncini E, Botto LD, Cocchi G, Annerén G, Bower C, Halliday J, Amar E, Bakker MK, Bianca S, Canessa Tapia MA, Castilla EE, Csáky-Szunyogh M, Dastgiri S, Feldkamp ML, Gatt M, Hirahara F, Landau D, Lowry RB, Marengo L, McDonnell R, Mathew TM, Morgan M, Mutchinick OM, Pierini A, Poetzsch S, Ritvanen A, Scarano G, Siffel C, Sípek A, Szabova E, Tagliabue G, Vollset SE, Wertelecki W, Zhuchenko L, Mastroiacovo P. *How Valid are the Rates of Down Syndrome Internationally? Findings from the International Clearinghouse for Birth Defects Surveillance and Research. Am J Med Genet A. 2010 Jul;152A(7):1670-80.*

Mastroiacovo P, IPDTOC Working Group. *Prevalence at Birth of Cleft Lip with or without Cleft Palate. Data from the International Perinatal Database of Typical Oral Clefts (IPDTOC). Cleft Palate Craniofac J. 2010 Apr 6. [Epub ahead of print].*

Mastroiacovo P, Wertelecki W, Hilliard MP. *Epidemiology of Cleft Lip with or without Cleft Palate. World-wide Data from the International Perinatal Database of Typical Oral Clefts (IPDTOC). I. Prevalence Data. American Journal of Medical Genetics: Part A, 2009*.

Leoncini E, Botto LD, Cocchi G, Anneren G, Bower C, Halliday J, Amar E, Bakker MK, Bianca S, Canessa Tapia MA, Castilla EE, Csáky-Szunyogh M, Dastgiri S, Feldkamp M, Gatt M, Hirahara F, Landau D, Lowry RB, Marengo L, McDonnell R, Mathew TM, Morgan M, Mutchinick OM, Pierini A, Poetzsch S, Ritvanen A, Scarano G, Siffel C, Sípek A, Szabova E, Tagliabue G, Vollset SE, Wertelecki W, Zhuchenko L, Mastroiacovo P. *How Valid are the Rates of Down Syndrome Internationally? Findings from the International Clearinghouse for Birth Defects Surveillance and Research. British Medical Journal, 2009*.

Mastrioacovo P*,* Lisi A, Castilla E, Martinez-Frias M_L, Bermejo E, Marengo L, Kucik J, Siffel C, Halliday J, Gatt M, Anneren G, Bianchi F, Canessa MA, Danderfer R, de Walle H, Harris J, Li Z, Lowry B, McDonnell R, Merlob P, Metneki J, Mutchinick O, Robert-Gnansia E, Scarano G, sipek A, Potzsch S, Szabova E and Yevtushok L. *Gastroschisis and Associated Defects: An International Study. American Journal of Medical Genetics Part A. 2007;Vol 143A:660-671*.

Wertelecki W, Kundiev Y. *Chornobyl – Polissia – Partnerships", the International Clearinghouse for Birth Defects Surveillance and Research annual meeting, 2006, Uppsala, Sweden*.

Wertelecki W. *Birth Defects Monitoring in Ukraine", Int. Birth Defects Clearinghouse of Monitoring Systems, IBDCMS, 2002*.

Wertelecki W. *Population Based Birth Defects Surveillance in Two Regions (Oblasts) of Ukraine. 28th Annu. Mtg. Int. Birth Defects Monitoring Clearinghouse, Groningen, The Netherlands, 2001*.

Wertelecki W: *Birth Defects Monitoring in Ukraine, Proc., 28th Annu. Mtg., Int. Birth Defects Clearinghouse of Monitoring Systems, IBDCMS1-28-BD, 2001*.

In Partnership with

eurocat
european surveillance of congenital anomalies

http://www.eurocat-network.eu/

Elevated Prevalence of NTD and a Cluster of Conjoined Twins in Ukraine

L. Yevtushok, N. Zymak-Zakutnya, S. Polishchuk, N. Yuskiv, S. Lapchenko, G.P. Oakley, W. Wertelecki

22nd EUROCAT Registry Leaders meeting, May 2007, Naples, Italy

From 2000-2005, the prevalence (P) of neural tube defects (NTD) in northwestern Ukraine (Rivne and Volyn oblasts) was elevated and ranged between 21 and 22 per 10,000 live births. The P in Khmelnytsky oblast (adjoining to the south) was also ~ 20.

NTD P was higher (28) in the Chornobyl-impacted northern raions (counties) of Rivne - Volyn, a region collectively known as Polissia.

From 2000-2005 a cluster of five sets of conjoined twins were noted only in the Rivne oblast (~ 14,000 live births yearly). Half of the conjoined twins were born in raions heavily impacted by Chornobyl, and one twin had spina bifida.

The OMNI-Net Ukrainian Birth Defects Program, with other Ukrainian and international partners, are proposing a "Polissia Initiative" to expand ongoing investigations through further partnerships.

Polissia consists mostly of wetlands inhabited by a population living mostly in small villages and relying on local foodstuffs, milk, wild mushrooms, berries and the use of local wood for fuel. Measurements in April 2007 show that radioactivity levels, including Cs-137, remain high. Anecdotal reports suggest that diets are deficient in micronutrients including folic acid. The relatively isolated village populations under birth defects surveillance can be regarded as a natural model for further investigations of reproductive and genetic aspects of health, both human and non-human.

Resource centers and OMNI-Net teams in the capital cities of Rivne and Volyn facilitate access to Polissia and to diagnostic centers.

Marie–Claude Addor, et al. *EUROCAT Member Registries: Organization and Activities. Birth Defects Research (Part A): Clinical and Molecular Teratology, 2011 [In Press].*

Dolk H, Barisic I, Bianca S, Boyd P, Calzolari E, Doray B, Haeusler M, Latos-Bielenska A, Pierini A, Wellesley D, Wertelecki W, et al. *Congenital Heart Defects in Europe: Prevalence and Perinatal Mortality 2000-2005. Collaborative study. Eurocat, 2010 [In Press].*

Khoshnood B, Loane M, Garne E, Dolk H, Barisic I, Bianca S, Boyd P, Calzolari E, Doray B, Haeusler M, Latos-Bielenska A, Pierini A, Wellesley D, Zymak-Zakutnya N, et al. *Recent Decrease in the Prevalence of Congenital Heart Defects in Europe in the Absence of Mandatory Folic Acid Fortification Programs. Eurocat, 2010 [In Press].*

Lapchenko S, Wertelecki W. *Impact of a Birth Defects (BD) Information System in Ukraine and Beyond. Abstract submitted to the 22nd EUROCAT Registry Leaders meeting, Naples, May 2007, Italy.*

Wertelecki W, et al. *Neural Tube Defects Epidemic in Ukraine, 2006 EUROCAT Annual Meeting, Graz, Austria*.

BIRTH DEFECTS IN UKRAINE

In Partnership with

**Crimea, Kherson, Khmelnytsky, Rivne and Volyn Oblast Health Care Systems,
Lviv and Donetsk National Medical Universities,
and Ministry of Health of Ukraine**

http://ibis-birthdefects.org/start/netomni.htm

W. Wertelecki. ***Malformations in a Chornobyl-Impacted Region. Pediatrics. 2010 Apr;125(4): e836-43.***

PEDIATRICS
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Objective: One of the populations most exposed to chronic low-dose radiation from Chornobyl (Chernobyl in Russian) lives in Polissia, the region representing the northern half of Rivne Province (Oblast) in Ukraine. Here the patterns and population rates of malformations are reported and possible etiologic factors and regional contrasts are explored.

Patients and methods: Malformations, as defined by international standards, noted among all 96 438 births in Rivne between 2000 and 2006, were analyzed statistically. Contrasts of rates in Polissia compared with the rest of Rivne also were investigated.

Results: The overall rate of neural tube defects in Rivne is among the highest in Europe (22.2 per 10,000 live births). The rates of conjoined twins and teratomas also seem to be elevated. In Polissia, the overall rates of neural tube defects are even higher (27.0 vs 18.3, respectively; odds ratio: 1.46 [95% confidence interval: 1.13-1.93]), and the rates of microcephaly and microphthalmia may also be elevated.

Conclusions: *The malformation patterns observed suggest early disruptions of blastogenesis, manifesting as alterations of body axes, twinning, duplications, laterality, and midline formation. The results are sufficiently compelling to justify continuing and expanding this investigation of malformations in chronic low-dose radiation-impacted regions of Ukraine.*

Вертелецький В. *Вроджені вади розвитку: реалії та перспективи //Ваше здоров'я.- 20 травня 2011 року, № 18.- с.11.*

Holt E. *Debate Over Health Effects of Chernobil Re-Ignited. Lancet 2010:375(9724);1424-1425.*

Norton A. *Higher Birth-Defect Rate Seen in Chernobyl Area. Reuters News Report, 24 of March, 2010.*

Wertelecki W, et al. *Neural Tube Defects (NTD) in a Chornobyl Impacted Region. Proceedings of the 6th International NTD Conference; 2009 September 12-15; Burlington, VT. Abstract.*

Вертелецький В.Є., Коржинський Ю.С., Бариляк І.Р., Забор В.С. *Маса тіла при народженні дітей Волинської та Рівненської областей: стандарти для немовлят північно-західного регіону і оцінка результату вагітності //Перинатологія і педіатрія.-2008.- №2 (34).- С.45-49.*

Wertelecki W, Yevtushok L. *Blastopathies: Conjoined Twins – Teratomas – NTD in a Chornobyl Impacted Region of Ukraine. Padova, 2008, abstract.*

Yevtushok L, Zymak-Zakutnya N, Polishuk S, Yuskiv N, Lapchenko S, Oakley GP, Wertelecki W. *Elevated Prevalence of NTD and Conjoined Twins in a Chornobyl Impacted Region of Ukraine. Reproductive Toxicology 2007;24(1):67.*

Афанасьєва Н.О., Бариляк І.Р., Вертелецький В.Є., Євтушок Л.С., Зимак-Закутня Н.О., Калинка С.О., Коржинський Ю.С., Лінчевський Г.Л., Оніщенко С.Є. *Моніторинг вад невральної трубки: уроки та рекомендації. Київ, 17- 18 квітня 2007 року, тези і виступ.*

Wertelecki W, Lapchenko S, Yevtushok L, Zymak-Zakutnya N. *Pointers for a Web-based Birth Defects (BD) Information System for Non-English Speakers", abstract submitted to the National Prevention and Health Promotion Summit, November 2007, Washington DC*.

Wertelecki W, Yevtushok L, Zymak-Zakutnya N, Polishuk S, Yuskiv N, Lapchenko S. *Elevated Rates of NTD and Conjoined Twins in Polissia, a Region Impacted by Chornobyl", abstract submitted to the European Society of Pediatric Research, October 2007, Prague, Czech Republic*.

Yevtushok L, Zymak-Zakutnya N, Polishuk S, Yuskiv N, Lapchenko S, Oakley GP, Wertelecki W. *Elevated Prevalence of NTD and Conjoined Twins in a Chornobyl Impacted Region of Ukraine, abstracted submitted to the European Teratology Society meeting, September 2007, Bratislava, Slovak Republic.*

Yevtushok L, Zymank-Zakutnya N, Polishuk S, Yuskiv N, Lapchenko S, Oakley GP, Wertelecki W. *Elevated Prevalence of NTD in Ukraine Highest in a Chornobyl Impacted Region (Polissia)", abstract submitted to the 3rd Int. Conf. on Birth Defects and Disabilities in the Developing World meeting, Rio de Janeiro, Brazil, June 2007*.

Lapchenko S, Wertelecki W. *Impact of a Birth Defects (BD) Information System in Ukraine and Beyond", the 3rd International Conference on Birth Defect Disabilities in the Developing World, June 2007, Rio de Janeiro, Brazil*.

Wertelecki W, et al.* *Birth Defects (BD) – Chornobyl and International Partnerships", Ukrainian Medical Association of North American meeting, June, 2007; Kerhonkson, NY*.

Wertelecki W. *Birth Defects Surveillance in Ukraine - A Process. Journal of Applied Genetics 2006;47(2):143-149.*

Wertelecki W. *Rates of Neural Tube Defects in Ukraine Highest in Chornobyl Impacted Regions. JUMANA 2006; Vol. 51(1/155): 7-15.*

Wertelecki W, et al. *Global Impact of a Web-based Birth Defects Information System. The American Society of Human Genetics 56th Annual Meeting, 2006, New Orleans, LA*.

Afanasieva N, Baryliak I, Kalinka S, et.al. *Neural Tube Defects Monitoring in Western and Southern Regions of Ukraine. Materials of International Scientific and Practical Conference "Fortification of Food Products with Vitamin B9 for Prevention of Neural Tube Defects". November 27-29, 2006, Kyiv, Ukraine), p 22.*

Бариляк І., Афанасьєва Н., Калинка С., Коржинський Ю., Лінчевський Г., Оніщенко С., Вертелецький В. *Моніторинг вад невральної трубки: уроки та рекомендації. – Матеріали міжнародної науково-практичної конференції "Фортифікація продуктів харчування вітаміном В9 з метою запобігання вродженим вадам невральної трубки". 27-29 листопада, 2006, Київ, Україна), с. 12.*

Євтушок Л.С., Кисельова О.О. *Синдром Дауна (синдром трисомії 21) //Medicus Amicus.- 2006.- № 2.- С. 15*.

Зимак-Закутня Н.О, Юськів Н.І. *Спинно-мозкова кила (spina bifida) //Medicus Amicus.- 2006.- №.4.- С.* 16-17.

Wertelecki W, Yevtushok L, et.al. *Prevalence of Neural Tube Defects in Western and Southern Regions of Ukraine. Archives of Perinatal medicine. Supplement 2005. Official Journal of the Polish Society of Perinatal Medicine, Poznan, 2005:37*.

Wertelecki W, Vihovska T, Yevtushok L. *Impact of Resourse Centers on Parental Support Groups Creation and Development in Ukraine. Archives of Perinatal m*edicine. Supplement 2005. Official Journal of the Polish Society of Perinatal Medicine, Poznan, 2005.

Yuskiv N, Polishchuk S, Shevchuk S, Sosynyuk Z, Vihovska T, Yevtushok L, Andelin C, Oakley G, Wertelecki W. *High Rates of Neural Tube Defects in Ukraine. Birth Defects Research (A), Clinical and Molecular Teratology 2004;70:400-402*.

Вертелецький В., Бариляк І., Маслій Я., Думановська М., Воловина О., Євтушок Л., Левчук Н., Шевчук О. *Реєстр новонароджених дітей: можливості використання для регіонального медико-демографічного аналізу //Перинатологія і педіатрія.- 2004.- № 2.- С. 58-61.*

Lapchenko S, Baryliak I, Vihovska T, Wertelecki W, Yevtushok L, Korzhynskyi Y, Linchevsky G. *The Impact of a BD Web Information System (IBIS) on Birth Defects Programs. Paper presented at European Meeting on Psychosocial Aspects of Genetics, 2004, Munich, Germany*.

Vihovska T, Afanasieva N, Baryliak I, Onishchenko S, Wertelecki W, Yevtushok L, Zymak N. *Impact of Resource Centers on Birth Defects Programs in Ukraine. Paper presented at European Meeting on Psychosocial Aspects of Genetics, 2004, Munich, Germany*.

Wertelecki W, Afanasieva N, Baryliak I, Onishchenko S, Vihovska T, Yevtushok L, Zymak N. *Birth Defects Surveillance and Prevention in Ukraine – Planning Implementation and Results. Paper presented at European Meeting on Psychosocial Aspects of Genetics, 2004, Munich, Germany*.

Wertelecki W, Miller T, Shivers S, Prince B, Widgeon A, Hilliard P, Oliver B. *Linking Birth Defects (BD) Surveillance with Prevention and Early Intervention (EI). The National Center on Birth Defects and Developmental Disabilities Conference July, 2004; Washington, DC*.

Wertelecki W, et al. *Strategies to Fortify Flour with Folic Acid. Ukrainian Academy of Medicine; 2003; Kiev, Ukraine*.

Wertelecki W. *Prevention of Neural Tube Defects in Ukraine. Paper presented at International Birth Defects Network Meeting; 2003, Atlanta, GA*.

Wertelecki W, et al. *(1) Prevalence of Spina Bifida, Anencephaly and Encephalocele in Western Ukraine 2000-2001. (2) Prevelance of Down Syndrome in Western Ukraine 2000-2001. 30th Conf. Eur. Teratol. Soc., Hanover, Germany, 2002*.

Wertelecki W, et al. (*1) Prevalence of Spina Bifida, Anencephaly and Encephalocele in Western Ukraine 2000-2001. (2) Prevalance of Down Syndrome in Western Ukraine 2000-2001. Nat. Center Birth Defects Dev. Disabil. Inaugural Conf., Atlanta, GA, 2002*.

Wertelecki W, et al. *Creative Use of Surveillance Data. Nat. Birth Defects Prevention Network/Int. Clearinghouse for Birth Defects Monitoring Joint Mtg., Atlanta, GA, 2002*.

Wertelecki W, et al. *Birth Defects Epidemiology in Ukraine, Strategies on Congenital Disorders. Paper presented at WHO – Europe, 2002, Rome, Italy*.

Wertelecki W, et al. *Suggestions of Strategic Options. WHO Meeting on Collaboration in Medical Genetics, Toronto, Canada, 2002.*

Wertelecki W, et al. *Birth Defects Surveillance and Prevention in Ukraine – Strategies and Results. USAID 10-Year Retrospective Conf., Washington, DC, 2002.*

Wertelecki W, et al. *Neural Tube Defects in Ukraine. Global Alliance for Improved Nutrition (GAIN), Flour Fortification in Ukraine; 2002, Ottawa, Canada*.

Wertelecki W, et al. *Clinical Epidemiology and Birth Defects. The 3rd Ukrainian Congress; 2002; Lviv, Ukraine*.

Wertelecki W, et al. *Lessons From a Prevention of Birth Defects Program in Ukraine. Plenary Session Key Note Speaker, 1st Int. Cong., Prevention of Birth Defects in the Developing World, Johannesburg, South Africa, 2001*.

Vihovska T, Shevchuk O, Sulima O, Vashchylin H, Wertelecki W, Yevtushok L. *The Role of Neonatologists in Birth Defects (BD) Monitoring in Ukraine. International Congress of Human Genetics (ICHG), Vienna, Austria, 2001*.

Baryliak I, Kharytonova I, Wertelecki W. *Promotion of Birth Defects Prevention Alliances. International Congress of Human Genetics (ICHG), Vienna, Austria, 2001*.

Yevtushok L, Baryliak I, Vihovska T, Wertelecki W, Lapchenko S. *Role of the "Web-Internet" and Birth Defects (BD) in Ukraine. International Congress of Human Genetics (ICHG), Vienna, Austria, 2001*.

Wertelecki W, et al. *International Birth Defects Information System (IBIS) – A Prevention Tool. International Congress of Human Genetics (ICHG), Vienna, Austria, 2001*.

Wertelecki W, et al. *Protocols for Population-Based Primary Prevention of Congenital Disorders in European Countries. WHO/EURO Meeting on Development of EURO Strategy on Congenital Disorders, Minsk, Belarus, 2001*.

Wertelecki W, et al. *Neural Tube Defects – Realities in Ukraine. Special Session, Ukrainian Academy of Medicine, Folic Acid – From Scientific Research to Health Care Practice, Kyiv, Ukraine, 2001*.

Wertelecki W, et al. *Folic-Acid – From Scientific Research to Health Care Practice. Academy of Medical Sciences, Ministry of Public Health of Ukraine, Kyiv, Ukraine, 2001*.

Wertelecki W, et al. *(1) Analytical Approaches to Birth Defects Data. (2) Gene Environment Considerations Regarding Birth Defects, 1999. (3) Birth Defects Surveillance Translation into Care. Ukrainian-American Birth Defects Program. Mohyla Academy University, Kyiv, Ukraine, 2000*.

Baryliak I, Dumanovska M, Mikulska H, Polishchuk S, Shevchuk O, Vihovska T, Wertelecki W, Yevtushok L. *Introduction of International Standards to Ukraine-Birth Defects, 2000.*

Surveillance – Care – Prevention. Special Report – 1st International Symposium on Prevention and Epidemiology of Congenital Malformations, (ISPECOM), Cardiff, Ukraine, 2000.

Wertelecki W, et al. *Birth Defects Data Coding and Management. Ukrainian-American Birth Defects Program, Lutsk Medical Center, Lutsk, Volyn, Ukraine, 2000*.

Yevtushok L, Baryliak I, Lapchenko S, Vihovska T, Wertelecki W. *Role of the "Web-Internet" and Birth Defects (BD) in Ukraine. Proc., 10th Int. Cong., Human Genet. 2000, HG01-1416-WMA*.

Wertelecki W, et al. *(1) Ideas and Implementations in Birth Defects. (2) Birth Defects Information and the Role of the Web. World Alliance for the Prevention of Birth Defects, Amsterdam, The Netherlands, 2000*.

Wertelecki W, et al. *OMNI Information Centers – A Strategy to Prevent Birth Defects. National Birth Defects Center, Havana, Cuba, 2000*.

Wertelecki W, et al. *Birth Defects and Health Care Networks. Cincinnati-Kharkiv, Ukraine, Sister City Project, Cincinnati Medical Center, Cincinnati, OH, 2000.*

Wertelecki W, et al. *Birth Defects – Ideas Implementations and Results. University of Warsaw Child Health Center, Warsaw, Poland, 2000.*

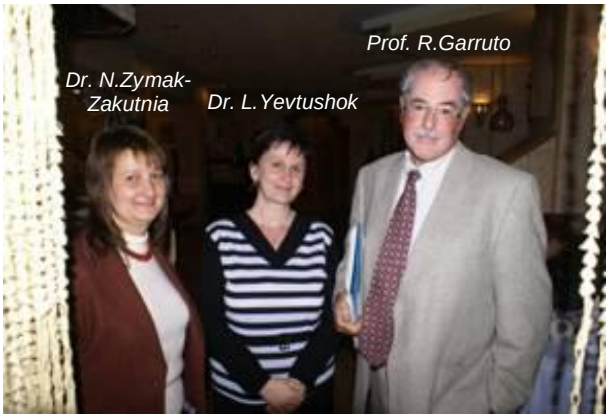
Wertelecki W, Katz M. *Prevention of Birth Defects - a Task for a World Alliance. Acta Paed Sin:1996;3. Jpn J Hum Genet 1995;40;295. Medico Interamericano 1995;5:185. J Ukrainian Med Assn 1996;42:137.*

** Wertelecki W, et al inidicates that the list of co-authors includes most OMNI-Net members in Ukraine.*

In Partnership with

Anthropology and Biomedical Neurosciences Program
State University of New York at Binghamton, New York

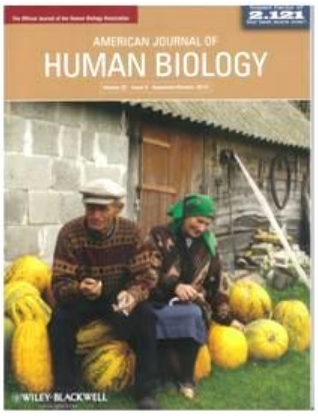
http://anthro.binghamton.edu/GarrutoR.html



Chronic radiation exposure in the Rivne-Polissia region of Ukraine: implications for Birth Defects

K.N. Dancause, L. Yevtushok, S. Lapchenko, I. Shumlyansky, G. Shevchenko, W. Wertelecki, R.M. Garruto

Am J Hum Biol. 2010 Sep-Oct; 22(5):667-74.



Objectives: *The health effects of chronic low-dose radiation exposure remains a controversial question. Monitoring after the Chernobyl nuclear accident in Ukraine suggested that chronic low-dose radiation exposure was not linked to cancer mortality among the general population. However, elevated rates of birth defects in contaminated compared to uncontaminated regions suggest that exposure to radiation in utero might impact development and that chronic radiation exposure might represent an underestimated risk to human health.*

Methods: *We sought to determine current radiation exposure routes in Rivne-Polissia, a region of Ukraine contaminated by the Chernobyl accident. This represents a first step toward comprehensive studies of the effects of chronic radiation exposure on human health. We designed and administered a dietary and activity survey to 344 women in Polissia. We assessed types and sources of food consumed, types of outdoor activities, and alcohol intake.*

Results: *Alcohol intake was low and alone does not account for the observed high rates of birth defects. Wild foods, especially mushrooms and berries, and locally produced foods, especially milk related, were major radiation exposure routes. Additionally, women were exposed to radiation through inhalation while burning grasses and potato vines in fields, and wood for cooking and heating.*

Conclusions: *Twenty four years after the Chernobyl accident, women continue to be chronically exposed to low-dose radiation at levels exceeding current recommendations. This might contribute (especially synergistically with alcohol consumption and micronutrient deficiencies) to higher prevalence of birth defects in areas of Ukraine with high levels of radiation contamination compared to uncontaminated areas.*

Needham KD, Yevtushok L, Lapchenko S, Wertelecki W, Garruto RM. ***Dietary and Activity Patterns and Implications for Birth Defects in the Chernobyl Impacted Rivne-Polissia Region of Ukraine. American Journal of Human Biology 2009;21:261-262.***

After the Chornobyl disaster in 1986, population-based birth defects monitoring was initiated in 2000 in five oblasts (provinces) in Ukraine. The northern half of Rivne province, a region known as Polissia, is contaminated by radiation. Systematic monitoring shows consistently high rates of neural tube defects and other developmental disorders. These observations prompted a dietary and subsistence activities survey about consumption of Cs137 contaminated foodstuffs, water, smoke, and agricultural and gardening exposure through dust and soil. Contamination levels measured from one up to 1590 Bq/l in milk, 129 Bq/kg in potatoes, and 146 Bq/kg in soil.

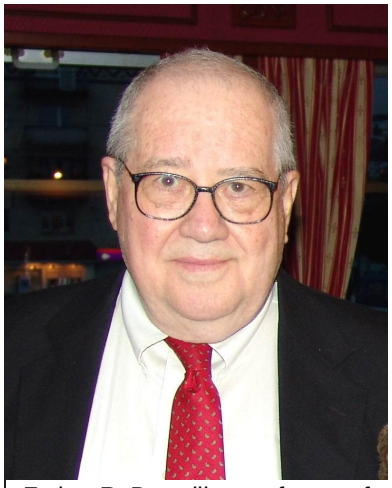
We report preliminary information provided by 99 of 350 surveyed pregnant women residing in the Polissia region of Ukraine. Information gathered concerned consumption of local and imported meat, dairy, fruit, vegetable, and grain products, as well as water use and beverages, including alcohol consumption during pregnancy. We also gathered information about activities likely to expose individuals to radiation through contact with soil, such as working in fields and collecting wild foods or firewood. Results indicate that most foods consumed in Rivne-Polissia are local or wild and thus contaminated with Cs-137. The government has recommended that milk be imported because of the risk of contamination of local milk. However, less than 5% of individuals reported consuming imported milk. All participants reported consuming local vegetables (none imported), and 97% of the major fruits consumed were locally grown. Furthermore, 73% reported obtaining water from highly contaminated wells or brooks, the rest consumed piped water. In addition, 30% drank alcoholic beverages often as homemade or local beer and liquor. Information about outdoor activities, particularly agricultural fields, and contact with contaminated soil or smoke from burning biomass. Overall, our data indicate that some people in Polissia consume diets that may be deficient in micronutrients, consume alcohol during pregnancy and are exposed to chronic radiation. The extent to which each may be involved in birth defects and developmental nervous system disorders in the Polissia region is unknown and calls for further investigations.

National Bioethics Congresses
(Co-sponsored by OMNI-Net)

Bioethics, Molecular Biology, Children, and Religion

Prof. Robert C. Baumiller, Ph.D., SJ

September-October 2004, Kyiv. Book of Abstracts, p.38



Father R. Baumiller, professor of Biology and Medicine in Xavier University, Cincinnati, was a recognized leader in Medical Ethics and appointed by the US Government to key Advisory Committees on Human Genetic s and Genetic Counselling

Bioethics as a word was first used less than 60 years ago. Ethics is far older and dates formally from the Greek philosophers. But ethics in some form had to come into being with the evolution of man into a thoughtful human being living in families and larger human communities. Rules to live by, limits to acceptable behavior, are necessary for any community to exist. An example of such a collection of rules are the Ten Commandments. These like all early sets of rules had certain presuppositions. Usually the existence of God or gods as powers which were in some way above the rules and yet demanded that the rules be kept by man. Thou shalt not kill is God's command to the Israelites and historically soon after giving the rule, God literally leads the Jews in conquering Palestine and slaughtering the legitimate occupiers of the land.

Presuppositions to ethical systems continue to exist in the minds and hearts of all who accept religious belief as part of their reality and 1 believe that these presuppositions are important in ethical decision making. However, ethical theories arising during the Enlightenment attempted to derive ethics and ethical behavior from reasoning alone. Thus Ethics became a philosophic discipline rather than a form of moral theology.

Bioethics arose in the United States with the recognition of ethical lapses in major research passed through peer review and published in prestigious journals. The Nuremberg Laws were not being applied by the medical profession. An answer to the question of how to pre-approve research and protect the patient-volunteer was drawn up in the Belmont Report and subsequently by other instruments, most importantly by the Helsinki Accords.

The Belmont Report proposed a method of judging research and patient care based on principles. These principles are not an ethical theory but were a way of proceeding which individuals who embrace specific theories of ethics and/or have suppositions can meet and discuss individual protocols and patient care plans based on the principles of Respect for Autonomy, Nonmaleficence, Beneficence, and Justice. These principles allow ethics committees of various types made up of representatives from a very pluralistic society to function well and reach acceptable decisions for proposed cases, protocols, and even policies.

Institutions and governing bodies must be able to come to ethical solutions to a growing number of problems as molecular biology goes from the laboratory to the bedside and clinical trials.

What is ethical and acceptable in a pluralistic society may not be morally acceptable to a person committed to a faith perspective. Moral decision making for the individual is not the same as what may be allowed in a liberal society. Advances in reproductive biology especially bring about personal decisions which are difficult and the effects of such decisions can deeply affect the lives of individuals long after the decided upon action is taken.

Wertelecki W, et al. *Birth Defects, Orphans and Ethics. September-October 2004, Kyiv. Book of Abstracts., p.35.*

Stoll C. *Ethics and Prenatal Diagnosis. September-October 2004, Kyiv. Book of Abstracts., p.35.*

Зимак-Закутня Н.О., Бариляк І.Р., Вертелецький В. *Профілактика вроджених вад розвитку та біоетика.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 85.*

Вертелецький В., Бариляк І.Р., Євтушок Л.С. *Біоетичні аспекти поєднання моніторингу вроджених вад розвитку з програмами раннього втручання.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 86.*

Лінчевський Г.Л., Левадо Н.Є, Воробйова О.В., Лютова Т.А. *Шляхи вирішення біоетичних проблем будинку дитини.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 90.*

Скибан Г.В., Поліщук С.О., Афанасьєва Н.О. *Біоетичні проблеми телеконсультацій при вроджених вадах розвитку.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 97-98.*

Бариляк І.Р., Лапченко С.Ф., Неумержицька Л.В. *Доступ до інформації - вимога біоетики в питаннях генетики і тератології.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 100-101.*

Віговська Т.В., Євтушок Л.С. *Реєстри новонароджених з позиції біоетики.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 105-106.*

Афанасьєва Н.О., Зимак-Закутня Н.О., Євтушок Л.С. *Роль батьківських організацій в профілактиці і опіці дітей з вадами розвитку.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 106.*

Вертелецький В., Бариляк І.Р., Оніщенко С.Є., Марченко Н.М. *Фетальний алкогольний синдром: біоетичні аспекти.- Київ, вересень-жовтень 2004.- Тези доповідей, с. 107.*

Wertelecki W, et al. *Bioethics and Human Development. September 2001, Kyiv. Book of Abstracts, p.3-4.*

Зимак-Закутня Н.О., Бариляк І.Р., Вертелецький В., Віговська Т.В., Євтушок Л.С., Завгородня О.П. *Етичні проблеми профілактики вроджених вад розвитку.- Київ, вересень 2001.- Тези доповідей, с. 28.*

Євтушок Л.С., Маслій Я.О., Рожко М.А. *Етичні принципи формування і використання баз даних в ході моніторингу вроджених вад розвитку. Київ, вересень 2001.- Тези доповідей, с. 28-29.*

Віговська, Т.В., Ващилін Г.В., Мікульська Г.І. *Етичні проблеми динамічного спостереження за дітьми з вродженими вадами розвитку.- Київ, вересень 2001.- Тези доповідей, с. 29.*

Жарко В.Л., Завгородня О.П., Марченко Н.М. *Псевдопозитивні і псевдонегативні результати пренатального ультразвукового дослідження вроджених вад як етична проблема.- Київ, вересень 2001.- Тези доповідей, с. 29-30.*

Афанас'єва Н.О., Баскаков П.М., Харитонова І.Є. *Етичні проблеми діагностики та лікування фенілкетонурії.- Київ, вересень 2001.- Тези доповідей, с. 31-32.*

Бариляк І.Р., Скибан Г.В. *Проблеми медичної генетики і біоетика.- Київ, вересень 2001.- Тези доповідей, с. 89-90.*

Бариляк І.Р., Неумержицька Л.В., Качура В.С., Дуган О.М. *Оцінка мутагенів довкілля та біоетичні проблеми.- Київ, вересень 2001.- Тези доповідей, с. 90.*

Коржинський Ю.С. *Соціально-етичні проблеми, викликані народженням немовлят з порушенням статевої функції.- Київ, вересень 2001.- Тези доповідей, с. 91.*

From left to right: Drs. T.Vihovska, W.Wertelecki, G.Linchevsky, H.Skyban, L.Yevtushok, N.Afanasieva, S.Onishchenko, N.Zymak-Zakutnia, E.Patskun, Y.Korzhynsky

This report is prepared by the OMNI-Net team (W. Wertelecki, M.D., Lyubov Yevtushok, M.D., Nataliya Zymak-Zakutnya, M.D., Diana Akhmedzhanova, Serhiy Lapchenko, Lyubov Reva).

Note: acknowledgement section temporarily omitted.

FINIS