

Birth defects surveillance in Ukraine: a process

Wladimir Wertelecki

Department of Medical Genetics, University of South Alabama, Mobile, Alabama, USA

Abstract. Birth defects (BD) surveillance using international standards was introduced in Ukraine by a network of five BD centers located in northwestern, central and southern regions. BD centers provide resources to access current and comprehensive information and to nurture partnerships with physicians, administrators, parental support groups, educators, and humanitarian assistance organizations. One outcome was the vigorous and popular website International BD Information Systems (IBIS). The network is now incorporated as OMNI-Net Ukraine. The program has documented high prevalence rates of neural tube defects (NTD); fetal alcohol effects (FAE); and idiopathic developmental retardation among orphans that prompted prevention and amelioration initiatives. Further program objectives include: universal folic acid flour fortification, as recommended by the Ukrainian Academy of Medicine; continued research on methods to reduce FAE in collaboration with partners from California; opening other early infant stimulation centers funded by local authorities, modeled on those in Rivne and Lutsk; and linking BD prevention with bioethical considerations, which is a topic of interest in Ukraine in part enhanced by the effects of Chornobyl.

Key words: birth defects, folic acid, prevention, public health, surveillance, telemedicine, Ukraine.

Introduction

This report outlines the development and outcomes of a program to establish in Ukraine birth defects (BD) surveillance systems based upon international standards. The March of Dimes Birth Defects Foundation (MoD) and the World Alliance of Organizations for the Prevention of Birth Defects and Treatment of Genetic and Congenital Conditions (WAO) define BD broadly as any structural or functional anomalies manifested at any age due to genetic or environmental causes acting prior to birth (Wertelecki and Katz 1995, 1996).

Ukraine is among the largest countries in Europe and suffered major consequences from the Chornobyl disaster of 1986. One consequence is a heightened public awareness about BD. In 2001 there were nearly 400 000 births in Ukraine and the infant mortality stood at nearly

17 per 1000. Nearly 15 000 Ukrainian infants with BD are born each year and, as in other nations, BD are the leading causes of infant mortality. Recently, the global MoD report (MoD 2006) has underscored the urgency for governments to implement effective, affordable and practical BD preventive measures. Such measures can be implemented by most nations, including Ukraine.

In Ukraine, micronutrient deficiencies, including folic acid, and wide consumption of alcohol by women of reproductive age, pose preventable risks to the unborn. In fact, we stress here that in northwestern regions of Ukraine, the prevalence of neural tube defects (NTD) is elevated and is probably the result of folic acid deficiencies. The prevalence of Fetal Alcohol Spectrum Disorders (FASD) among infants and children under the care of the state in orphanages and other institutions is also high. It is self-evident that neither nationwide folic acid flour fortification nor reduction

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Correspondence: W. Wertelecki, Department of Medical Genetics, University of South Alabama, 307 University Blvd., CCCB 214, Mobile, AL 36688, USA; e-mail: wwertele@usouthal.edu

of alcohol consumption by women of reproductive age can be achieved singly by medical or other programs, since such issues are complex and require cooperative and coordinated actions nurtured by governmental agencies. Credible BD surveillance data can play an important role in promoting national prevention policies and measuring their effectiveness.

Materials and methods

The Ukrainian-American Birth Defects Prevention Program (UABDP) crystallized in 1998 after several years of informal exchanges between international and Ukrainian experts. In 1998, the Ukrainian Minister of Health invited the Presidents of the MoD, WAO, Mrs. J.L. Howse and M. Katz along with other experts to a planning conference in Kyiv, following which the UABDP was formulated. A U.S. Congress initiative led to a cooperative agreement with the United States Agency for International Development (USAID), which funded most, but not all, of the implementations reported here.

Three central strategies were adopted to implement the UABDP: (1) teams composed of medical geneticists, neonatologists and English-competent Information Officers as key leaders, recruited from employed professionals at medical centers; (2) resource centers emphasizing electronic information and telecommunications; and (3) nurturing of national and international partnerships. The main objectives of the program are summarized in Table 1.

Table 1. Main program objectives

Train a network of BD teams and develop BD resource centers (BDRCs) to sustain BD surveillance systems, applying international standards
Report BD prevalence and trends to national and international organizations
Seek membership in international BD organizations as well as national/international partnerships
Promote care, early intervention (EI) and prevention programs
Promote EI for children in state care facilities
Promote EI outpatient programs
Provide support for and the expansion of Parental Support Groups
Promote self-sustainability and incorporate the BDRC network as a not-for-profit organization
Develop a BD information website in Ukrainian

Results

We present a brief outline of the results of the UABDP regarding BD surveillance, high NTD prevalence and their prevention, the role of the website International BD Information Systems (IBIS), and partnerships. The results are presented chronologically in Table 2 as a complement to the comments that follow.

In 1998, two medical geneticists, a neonatologist, a medical librarian, and a computer programmer were selected for training at the Alabama Birth Defects Prevention Program headquarters in Mobile, Alabama. In 1999, their 4-month training began and included working in BD case ascertainment, coding, and data entry and analysis procedures. Concurrently, the physicians were required to pass a 35-hour course in medical genetics and teratology. Visits to the Center for Disease Control BD Division and visit by faculty from the Universities of Texas and Cincinnati, among others, expanded the trainees' knowledge of epidemiology and public health. Upon their return to their respective medical centers in Lutsk and Rivne, the capital cities of the Volyn and Rivne oblasts (provinces), the trainees recruited additional team members. The medical librarian and the computer programmer required a 2nd course of training for an additional 6 months to master electronic information, web and computer technologies.

Pilot BD surveillance began, following adaptation of procedural manuals and other materials. In 2000, formal BD surveillance began in the Rivne and Volyn oblasts. An unanticipated obstacle, however, was the lack of denominator data (existing maternal and child health data collected by methods prevalent in the former Soviet Union could not be used for the purpose of BD surveillance and led the UABDP to develop an electronic population neonatal registry as a complement of the BD registry).

The training of a third BD team and creation of the Birth Defects Resource Center (BDRC) in Khmelnytsky began in 2001, followed by pilot data collection in 2002. Next, training of BD teams was started in Kherson and in Sympheropil, the capital of the Autonomous Republic of Crimea. In 2003, we initiated BD surveillance in Kherson and Crimea.

A preliminary analysis of the data collected by BD surveillance in central (Khmelnytsky) and southern regions (Kherson and Crimea) revealed that the prevalence of 12 major BD was similar to that in the United States, as computed by

Table 2. Chronology of landmark developments

<p>1998 International BD experts visited Ukraine by invitation of the Minister of Health; following which the UABDP formulated a program plan.</p> <p>1999 Training of initial BD teams in the U.S.; 2 BD resource centers (BDRCs) established in Lutsk and Rivne (northwestern region); surveillance methods were adapted to Ukrainian circumstances; several informal parental support groups approached the UABDP for assistance, which prompted the UABDP to sponsor the formation of a separate organization – the Ukrainian Alliance of Parental Support Organizations for the Prevention of BD, modeled after the WAO; and presentation of the program to the Ukrainian Medical Genetics Society.</p> <p>2000 BD pilot data collection initiated in Rivne-Volyn; associate membership granted by the International Clearinghouse for BD Monitoring Systems (ICBDMS); partnership started with the Horowitz International Competition for Young Pianists organization to dedicate concerts to the prevention of BD; development of a Ukrainian web version of IBIS started (http://www.ibis-birthdefects.org)</p> <p>2001 Training of BD team in Khmelnytsky (central region); high prevalence of NTD noted in northwestern Ukraine; established folic acid tablets distribution program to brides and to mothers of NTD infants; 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 and CDC on food fortification; co-sponsored with the Ukrainian Academy of Medicine, formed the Ukrainian Micronutrition Alliance; organized a series of international workshops on BD epidemiology; appointment of the UABDP scientific advisor to the Board of Directors of the WAO.</p> <p>2002 Opened a BDRC in Khmelnytsky; pilot BD surveillance started in Khmelnytsky; high prevalence of NTDs in northwestern Ukraine reported to the Ministry of Health; 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”; engaged a graduate from the Muskie Fellowship Program, who earned a Master’s Degree in Public Health (MPH), with an emphasis on micronutrition, from Emory University to engage in framing proposals for universal folic acid flour fortification in Ukraine; co-sponsored the creation of the Rivne Parental Organization for Children with Special Health Care Needs; initiated training of BD teams in Crimea and Kherson (southern region).</p> <p>2003 Opened BD centers and initiated pilot BD surveillance in Crimea and Kherson; on behalf of Ukraine, submitted a proposal to introduce universal folic acid flour fortification to the Global Alliance for Improved Nutrition (GAIN); formed the NTD parental support group; sponsored an international workshop “Diagnosis and Prevention of Fetal Alcohol Spectrum Disorders (FASD)”; University of California in San Diego extended funding for the FASD project; granted funds by the U.S. Ukraine Democracy Foundation for a manual Legal Support of Disabled Children; another BD team member was granted a Muskie Fellowship to study at Emory University to pursue a Master’s Degree in Public Health with an emphasis on BD epidemiology; program director inducted as a foreign member of the Ukrainian Academy of Sciences and granted an honorary doctorate by the Kyiv-Mohyla University.</p> <p>2004 Published a scientific 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; “Pahinets”, an outpatient center for infants with special healthcare needs (a unique facility in Ukraine) opened in Rivne under the sponsorship of local authorities; received assistance for “Pahinets” from the Ukrainian Special Needs Orphanages Fund; initiated planning for a “Pahinets”-like facility in Lutsk; started formal BD surveillance in southern regions (Kherson, Crimea); assisted the Academy of Medical Sciences to draft recommendations to Ukrainian authorities regarding folic acid flour fortification; FASD early diagnosis and prevention program started in Kherson and Rivne; co-sponsored the 2nd Bioethics Congress with participation of CDC and other international colleagues.</p> <p>2005 Completed the USAID-funded component of the UABDP program, which is now continued by the OMNI-Net Ukraine, a registered Ukrainian International Charitable Organization for the Care and Prevention of BD and Developmental Disorders; presented an update about OMNI-Net Ukraine to the Minister of Health, oblast authorities and other partners, including the International Ukrainian Medical Association; initiated a process to create an International Bioethics Advisory Panel as a component of the National Ukrainian Bioethics Center established under the aegis of the Council of Ministers of Ukraine; re-engaged the Muskie Fellowship trainee in epidemiology of BD (following the completion of the MPH program, this team member is initiating 2002–2005 BD data analysis with an initial emphasis on NTD); prompted the formation of a National Ukrainian Down Syndrome Parental Association; partnered with a visiting Fulbright Senior Scientist and organized 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; proposed to Lutsk authorities the creation of a “Pahinets”-like center the proposal was accepted and funded, and the center is scheduled for opening in early 2006.</p>
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the Centers for Disease Control and Prevention (CDC) from pooled data reported by 11 state surveillance systems (Anonymous 2006).

Analysis of combined 2000–2002 Rivne/Volyn BD data revealed high prevalence rates in northwestern Ukraine – 159 cases among 75 928 live births, stillbirths and induced abortions, a prevalence of 2.1 per 1000 births, almost 4 times higher than it should have been (Yuskiv et al. 2004). This finding led the UABDP to place considerable emphasis on the development of programs for the secondary prevention (recurrence) and primary prevention (occurrence) of NTD.

A grant from the International Bank for Reconstruction and Development provided for the creation of a film and other materials to promote NTD prevention. The program engaged a Ukrainian pediatrician, a graduate of the Muskie Fellowship program, who graduated from the Emory University School of Public Health and earned a Master’s Degree in Public Health (MPH), with an emphasis on micronutrition. Concurrently, UABDP partnered with the Ukrainian Academy of Medicine to create a Ukrainian Alliance for Micronutrition and on its behalf submitted proposals to the Global Alliance for Improved Nutrition

(GAIN), which were not funded. Nonetheless, the process of framing a GAIN proposal clarified positions and resulted in a network of medical and non-medical organizations that are keenly interested in the promotion and implementation of nationwide folic acid flour fortification in Ukraine.

Another team member also received a Muskie Fellowship to the Emory University School of Public Health to study BD epidemiology. This professional is now evaluating 2000–2005 BD data from Rivne-Volyn, 2003–2005 data from Khmelnytsky, and 2004–2005 data from Kherson-Crimea.

In 2005, the USAID sponsorship ended and the UABDP became incorporated as OMNI-Net Ukraine, a not-for-profit international organization. The OMNI-Net Ukraine continues to carry out all components of the program, is a member of the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS) and its membership in the European Surveillance of Congenital Anomalies organization (EUROCAT) is pending.

The need to provide access to information required the development of human resources knowledgeable of computer and web technologies, and provided with appropriate facilities. English-competent Information Officers are central in this domain. For locations without access to the Internet, an alternative was to create a “fax-net”. We tested a network of 32 fax machines located at delivery sites in Rivne and Volyn oblasts, and concluded that such an approach merits expansion. Another component was the creation of fact sheets in Ukrainian, separately for patients/families and professionals. These were posted on the International BD Information Systems (IBIS) website, and as the number of its Ukrainian visitors was increasing, the creation of a Ukrainian version of the IBIS website became practical (<http://www.ibis-birthdefects.org>). Presently, several thousand persons visit IBIS daily, and those from Ukraine rank 9th in frequency, which is very high in comparison to those from neighboring Poland and much larger Russia, who rank 38th and 45th, respectively. The computer resources and access to the Internet offered by BDRCs also support teleconsultations within and beyond Ukraine (on average, 300 per year).

From the onset, access to BDRCs was offered to patients, parents, physicians, and students. The utilization rates of BDRCs grew quickly. In 2005, BDRCs welcomed about 15 000 visitors, (1666 visits by geneticists, 913 by neonatologists,

1006 by pediatricians, 1065 obstetricians, 5154 other physicians, 454 by parents, and the remaining 5040 were mainly students.

Also from the onset, the program sought to develop interactions with parental groups. Early contacts developed with parents advocating for children with Down syndrome, phenylketonuria, mucopolysaccharidoses, neurofibromatosis, cystic fibrosis, etc. Parents mainly sought to address 3 issues: (1) how to improve diagnosis and treatment; (2) how to receive humanitarian assistance; and (3) how to strengthen, formalize and register their organizations (at the time, rules in Ukraine were complex). While the program could not become engaged in medical care issues or offer humanitarian assistance, it concentrated upon enhancing the effectiveness of parental organizations, particularly their formal registration. It soon became desirable to form the Ukrainian Alliance of Parental Support Groups for the Prevention of BD, modeled after the WAO, to assume such tasks. The program provided the Alliance with physical and staff support. In turn, the Alliance became the recipient and administrator of various grants that our program could not administer. For example, the Alliance administered the FASD Prevention Program in collaboration with the University of California in San Diego, which in 2005 screened 6600 pregnant women, of which 195 were found to be at risk of FASD, and 70 who agreed to enter the program (counseling, serial ultrasonography, examination and follow-up of the neonate).

Another salient example concerns a partnership with two parental groups, one in Rivne and another in Lutsk. This partnership prompted city and oblast authorities to establish early intervention centers for infants and children. In 2004, the “Pahinets” center in Rivne was inaugurated and now provides services to nearly 40 children, 9 with Down syndrome. In 2005 a similar center opened in Lutsk and is directed by a senior member of our BD team. This center will provide early intervention services to outpatients, as well as to children in the state orphanage.

A partnership with the Ukrainian Academy of Medical Sciences should be mentioned because it created the Ukrainian Alliance for Micronutrition and promoted the 1st and 2nd International Ukrainian Congresses on Bioethics. Now, the partnership is developing an international bioethics advisory board. Regarding BD and NTD, the partnership has established a BD data analysis work group and a national NTD prevention task force.

Finally, another effective partnership was established with the Horowitz International Competition for Young Pianists organization, well known in Ukraine and internationally, which raised public and international awareness through concerts dedicated to BD prevention. Such events took place in Ukraine, United Nations Educational, Scientific and Cultural Organization (UNESCO), and the World Health Organization (WHO), Paris, Geneva, New York, Washington among other sites.

Discussion

The outcomes of implementations summarized in the previous section and Table 2 stress those assumptions and circumstances that may be useful to health professionals, particularly those who may be interested in expanding medical genetics programs to include BD surveillance.

International collaborative programs, such as ours, are often initiated in capital cities and tend to rely upon dedicated personnel, recruited solely for program purposes. Instead, we chose to implement BD surveillance in oblasts (provinces) of relatively modest size and means. Our assumption was that success, under such circumstances, implied that implementations could become nationwide. In the same spirit, we believed that implementations should rely on BD teams composed of professionals who would retain their employment at their respective healthcare facilities. By insuring the continuity of their employment, there was also an assurance that BD surveillance would become integrated with established health programs. It was self-evident that in Ukraine, as in many other nations, medical geneticists are relatively few and are not central, neither for the detection nor for the continuity of care of infants with BD. In our view, neonatologists were crucial to promote population-based ascertainment procedures. Medical geneticists, on the other hand, are quite effective if focused on the accuracy of diagnoses, etiology, data coding, and plans for early intervention and long-term care. Another element concerns resources needed to insure easy, rapid and affordable access to current and comprehensive information about teratology, genetics, and other advances in BD healthcare. In this regard, medical librarians can be trained to become English-competent Information Officers and sustain computer and web technology applications.

Selection of oblasts to locate BDRCs called for considerations about their size and population, as well as the degree of administrative support from authorities. We felt that the program needed to establish at least 5 BDRCs in distinct regions of Ukraine, each with 15–30 thousand births, and that they should be located in dominant medical centers to minimize competitions and conflicts with other proposed alternative locations.

The first 2 BDRCs were located in Lutsk (pediatric polyclinic) and Rivne (diagnostic center). These dominant centers serve Volyn and Rivne oblasts, which before World War II constituted a single oblast. The population is stable and homogeneous, which allows for the data to be pooled, thus accelerating data accrual for analysis. Another important factor is that the northern areas of Volyn and Rivne oblasts were heavily contaminated by radioactivity from the Chernobyl disaster. Nearly 1/3 of births in these oblasts take place in contaminated areas, hence public concerns about BD are considerable.

The next BDRC was located in a central region of Ukraine, in the Khmelnytsky Birth Center. The population, as in Volyn and Rivne, is mostly Ukrainian, with a relatively modest minority of Russians. Contamination from the Chernobyl accident was negligible there.

The most recent 2 BDRCs were located in Kherson (Children's Hospital) and Sympheropil (Children's Hospital). The majority of the population in Kherson is Ukrainian, but the Russian minority is quite large. In the Autonomous Republic of Crimea and its capital Sympheropil, the majority of the population is Russian and there are large minorities of Ukrainians, Tatars and significant numbers of Greeks. Contamination from the Chernobyl accident was negligible there. In summary, the network of BDRCs provides a reasonable sample of the ethnic heterogeneity of the population in Ukraine.

The BDRCs also provided connections with national and international counterparts, various partnerships and telemedicine applications. Because the BDRCs were accessible to parents and students, BDRCs also played a role in strengthening parental support groups, education programs and partnerships.

Regarding NTD and their prevention in Ukraine, our efforts led to the formation of a Ukrainian Micronutrition Alliance, formed under the aegis of the Ukrainian Academy of Medical Sciences. The Alliance has representation from the grain, flour, bakery, public

health and other sectors needed to promote the adoption of legislation and regulations for folic acid flour fortification. In this respect, the greatest challenge was the Ministry of Health, where the top leadership changed often, especially during and after the well-known events of the 2004 Orange Revolution in Ukraine. On the other hand, some of the most stable policy-setting structures in Ukraine are the Ukrainian Academy of Sciences and the Ukrainian Academy of Medical Sciences, with whom our program established close relationships. While there is near consensus among scientists in favor of folic acid flour fortification, Ministry of Health staffers tend to uphold the status quo. Regarding the international community, USAID included, such entities often engage experts in nutrition and flour technology, but often fail to include experts in BD, public health and preventive medicine in the array. The Ukrainian Academy of Medical Sciences has submitted to the government recommendations for the prompt implementation of folic acid flour fortification in Ukraine.

We did not anticipate the growing importance that our IBIS website would acquire. The fact that a large proportion of “unique visitors” and “page views” originate from Ukraine, underscores this point. In the past few years, IBIS welcomed over a million visitors and currently “page views” exceed several thousand per day.

The lessons learned from collaborations with parental support groups, along with national and international organizations, are ample and complex. Although this subject requires a separate report, the main lesson is that such activities opened many, and unanticipated, horizons. Perhaps the most outstanding achievement credited to partnerships are the 2 unique centers for infants and children with special healthcare needs that emerged in Rivne and Lutsk. A center like “Pahinets” in Rivne is an emblem of the success of the joint advocacy by a parental organization working in unison with their BDRC. Another way to grasp the importance of partnerships is to explore the list of acknowledgments that accompanies this report.

We conclude that the goals, objectives and strategies used were sound. A decentralized approach, with an emphasis on oblasts and local professional teams, empowered by access to modern electronic technologies, are feasible and effective and could also be applied in other countries, particularly those influenced by Soviet healthcare models.

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