National Birth Defects Prevention Network

Newsletter

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Message from the President

Let me state at the onset that it's a great honor and privilege to follow my colleague and friend, Russ Kirby, as the second president of NBDPN. On behalf of the network, I would like to take another opportunity to thank Russ for his outstanding leadership and hard work as our first president. Thanks to his efforts and those of you who have provided leadership for and contributed to our committees and working groups, we are off to a tremendous start. I consider myself extremely fortunate to be surrounded by so many special people who have helped the network in its remarkable growth and productivity during a relatively short period.

As I write this message, it is difficult to believe that we are approaching the end of the fourth month of this year. The Executive Committee recently approved a Certificate of Incorporation for the NBDPN. We also approved a restructuring of some committees that will go into effect next year. We hope the changes will improve the process of state data collection and information dissemination. Planning continues for our 4th Annual Meeting, which, from the discussions, will be one that you will definitely not want to miss.

During this year as your president, I am trying to work very closely with the Committee chairs to provide whatever assistance I can towards the continuation of the network's development. A second priority has been to explore the establishment of liaisons with other organizations with which we share common interests. I would like to see our membership grow this year, especially from the ranks of maternal and child health personnel, clinical geneticists and genetic counselors, state genetic services coordinators and personnel, the administrators and providers of services for children with special needs, and representatives from family support organizations.

Finally, I will continue to promote the uses of birth defects surveillance systems to address the evaluation and planning of services and the referral of children and their families to the services they need.

I would welcome your comments on the above and any issues and concerns you would like to see the network address this year and in the future.

John Meaney, AZ
NBDPN President

Committee News

The **Surveillance Guidelines and Standards Committee** has been continuing its work on developing the reference manual for birth defects surveillance programs. The Chair of the committee is Carol Stanton (CO), and the Vice-Chair is Lisa Miller-Schalick (MA). The committee held a meeting during the annual NBDPN meeting in New Orleans. Attendance was quite good, and the discussion was lively on a variety of topics. Many people are interested in nurturing the Network's role in improving birth defects surveillance and promoting the use of the information we all produce. Therefore, the development of standards and guidelines remains a positive and supported endeavor. A big thank you to the committee members working on various projects for the progress thus far. The committee is a successful team effort. If you would like more information, or can offer a bit of expertise, please contact Carol Stanton (carol.stanton@state.co.us) or Lisa Miller-Schalick (lisa.schalick@state.ma.us).

Carol Stanton, Denver, CO

The **Education and Outreach Committee** met on Tuesday, February 1, 2000 in New Orleans. The committee will be very busy this year developing new products for the network's use and has agreed on the following initiatives to develop this

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News from the CDC

Centers for Birth Defects Research and Prevention

As of January 2000, more than 4,600 cases and 2,100 controls have been ascertained in the National Birth Defects Prevention Study (NBDPS). Interviews have been completed with nearly half of the eligible case and control mothers. Buccal cell collection has begun in nearly all of the study sites, and the Centers are developing analysis plans for the compiled data. An NBDPS newsletter is being developed that will be sent to all families that have participated in the study on a yearly basis. The purpose of the newsletter is to report on the status of the study and convey the major epidemiological findings as they are discovered. The Centers have also produced a booklet that describes the NBDPS and the local projects that are being carried out by each Center. Copies of this booklet can be obtained from CDC or any of the Centers.

Cooperative agreements with 18 states

The 18 states that received cooperative agreements from CDC in 1999 to enhance State-based birth defect surveillance met after the NBDPN annual meeting in New Orleans in February. A number of very interesting presentations were made on improving the completeness and timeliness of NTD ascertainment, developing a new surveillance reporting form, analyzing the quality of reporting facilities, and working with communities on NTD prevention activities. With these cooperative agreements, CDC is encouraging the states to share their successes and difficulties in the areas of birth defects surveillance, research, and prevention. The major accomplishments of each state, including the NTD-related surveillance and prevention activities that are reported to CDC, are shared with all the states so that they may benefit from each other's experiences.

New Birth Defects Surveillance RFA

The Birth Defects and Pediatric Genetics Branch will be releasing a Request for Application (RFA) this spring or early summer seeking the development of State-based birth defects surveillance programs and the use of the surveillance data for public health programs. These new cooperative agreements, although similar to the cooperative agreements with the current 18 States, will focus specifically on 1) States with no birth defects surveillance systems, and 2) States with newly implemented or ongoing surveillance systems. It is anticipated that between 3-6 awards will be made in each of the two categories and that the average awards will be $100,000 (ranging between $50,000 and $150,000). These cooperative agreements are expected to begin around October 1, 2000 for a project period of up to 3 years.

New Early Hearing Detection and Intervention RFA

The Developmental Disabilities Branch will be releasing a Request for Application (RFA) for the Early Hearing Detection and Intervention (EHDI) program. The purpose of these cooperative agreements is to promote the implementation and integration of State-based surveillance and tracking systems for Early Hearing Detection and Intervention (EHDI) and other disorders detected by newborn screening and monitoring systems.

Two levels of cooperative agreements will be awarded: Level I applications are states that do not have an established State or regional centralized EHDI surveillance and tracking program; Level II applicants are states that have an existing State or regional centralized EHDI population-based surveillance and tracking program that includes data on at least 75% of infants from a birth population of at least 30,000 live births per year. It is anticipated that up to nine awards will be made to Level I applicants, ranging from $100,000-$150,000, and up to four awards will be made to Level II applications, ranging from $250,000-$350,000. Awards are expected to begin on or about September 1, 2000.

National Folic Acid Campaign

Since the kickoff conference in January of 1999, the National Folic Acid Campaign has generated a lot of momentum and energy educating women and health professionals about the prevention benefits of folic acid. The "Before You Know It" campaign was launched in May 1999 around Mother's Day. Many state and local campaigns were able to get both television and radio air time to play these award-winning public service announcements (PSAs), and the CDC has distributed more than 500,000 brochures to local campaign efforts.

Now, the Campaign is into the second phase, designed for pre-contemplators, women between the ages of 18 and 24 who not planning to get pregnant any time soon. The theme is "Ready, Not", emphasizing the message "you may not be ready for a baby, but your body is!" The free 'Ready, Not' materials are available from CDC and can now be ordered via the Internet at http://www2.cdc.gov/nceh/folic_order/orderform.htm; you can also call 1-888-232-6789 or send an e-mail to flo@cdc.gov.

National Council on Folic Acid (NCFA)

Currently, the National Council on Folic Acid (NCFA) has 48 members; membership has expanded tremendously within the last year to include more industry representation as well as more culturally diverse groups. These organizations enhance NCFA's ability to communicate the folic acid message to local and diverse populations.

The next NCFA annual meeting will be held on June 27,2000 in Milwaukee, Wisconsin in conjunction with the Spina Bifida Association of America's Annual Conference. This will be the first time the full council will meet since new members have been accepted between June 1999 and April 2000.

News from the March of Dimes

The Federal budget process is underway and the March of Dimes is again actively involved. On April 4th Anna Eleanor Roosevelt, Chair of the Public Affairs Committee of the March of Dimes, testified before the House Appropriations Subcommittee on Labor, Health and Human Services, and Education. Ms. Roosevelt asked for full funding of the Birth Defects Prevention Act of 1998, which would support expansion of CDC's surveillance, research, and prevention activities for birth defects and developmental disabilities. She also called for increased funding for the National Institute for Child Health and Human Development to expand its research on birth defects and developmental biology.

The other major birth defects initiative for the March of Dimes is the establishment of a Center on Birth Defects and Developmental Disabilities within the CDC. Center status and a modest investment of new resources would create a focus for conducting the epidemiologic research needed to understand the causes and develop prevention strategies for birth defects. Language establishing such a center is included in the Children's Health Research and Prevention Amendments of 2000 (H.R. 3301) which is under consideration in the House of Representatives.

The March of Dimes urges network members to contact their Representative and Senators about both of these important issues. We will continue to update you in future issues of this newsletter. For more information contact Emil Wigode at ewigode@modimes.org.

Epi Notes

Preventive Strategies and Neural Tube Defect Rates

It is widely recognized that the risk of having a pregnancy affected by a neural tube defect (NTD) can be markedly reduced by periconceptional consumption of folic acid. As a result, a variety of NTD prevention strategies involving folic acid have been implemented around the world. A recent article attempted to evaluate the impact of such preventive strategies on NTD rates.

Birth defects surveillance programs in Europe, Israel, Japan, South America, and the United States were included in the investigation. The researchers attempted to identify whether there was a national policy on folic acid supplementation in any of the geographic areas of interest. Since national policy does not necessarily coincide with practice among the populace, the researchers also attempted to estimate the knowledge and use of folic acid for NTD prevention among women of childbearing age in the geographic areas of interest.

NTD rates were obtained from the International Clearinghouse for Birth Defects Monitoring Systems. NTDs were classified as anencephaly or spina bifida. Elective terminations were included in those geographic areas where such procedures were

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State Spotlight

A recommendation to Hawaii's Governor, from an Invitational Community Needs Roundtable, was the impetus that helped launch the Hawaii Birth Defects Program (HBDP) in August 1988. From the start, the Program elected to collect cases as a population-based, active surveillance system, with full statewide coverage. Not only would live births be ascertained, but also any other reproductive outcomes where a birth defect was documented by a physician, including those prenatally diagnosed, stillbirths, fetal demises, spontaneous abortions and elective medical terminations, regardless of gestational age. Over 125 pieces of demographic and diagnostic information are collected on each baby and its biological parents, for the more than one thousand congenital anomalies recommended by the CDC.

With thirteen full years of data (1986-1998) complete on its database, the HBDP publishes an annual surveillance report (seven to date), including numbers, rates, and time trend analyses for each diagnosis. Annual Hospital Data Reports are also sent to each of the 33 cooperating facilities, comparing their specific numbers and percentages with the state as a whole. In the last eleven years, the HBDP has also been able to respond to 1,165 requests for information, given over 100 presentations, and published over 85 articles, including ten manuscripts accepted for publication in professional peer-reviewed journals. Hawaii was also very pleased to have received an "A" from the Pew Environmental Health Commission.

The HBDP has a staff of three, with an Administrator and two field abstractors who cover almost 20,000 births and over 1,000 defects annually. Over the years, funding grants and contracts have been received at various times from federal (CDC), state (Hawaii DOH), and private (eight foundations) sources, with long-term financial security being the Program's biggest challenge. The Program has also served as a subcontractor for special research projects, provided data and reports for several community suspected geographic clusters, and served as the pilot site and in Phase II of the Naval Health Research Center's Gulf War Syndrome project. The Administrator also serves on the boards of several local organizations and participates in Hawaii's active Folic Acid/Neural Tube Defects Steering Committee, and helps to ensure that the Program continues to act as a reliable, valid and timely information resource for the planning and development of appropriate statewide and community level services and preventive strategies.

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coming year.

1. **January Birth Defects Prevention Month Materials** - The workgroup for this initiative will be reviewing the materials developed last year, reviewing the evaluation forms of the materials, and making appropriate changes. Spanish materials will also be available this year.

2. **Cluster Investigation Workgroup** - At the NBDPN meeting this year, it was suggested that a fact sheet should be developed describing what is involved in a cluster investigation. States often get calls from the public with concerns about possible clusters, and the public wants to know what is involved in conducting cluster investigations. This fact sheet would be available to send out providing general information on how a cluster investigation is conducted. Because each state may conduct these investigations differently, the fact sheet will be kept to very general information.

3. **Birth Defects Resource Guide** - This group will be looking at ways to share materials such as fact sheets and brochures that may already be available on specific conditions. The first challenge of this group will be finding the best way to share this information among the states.

The committee is always looking for new members. If you are interested in becoming a member of the Education and Outreach Committee and participating in one of these working groups please contact Jana Burdge (jburdge@health.state.pa.us). It has been a tremendous year and I have enjoyed working with the members of the education committee. They have done an excellent job, especially in developing and creating the January is Birth Defects Prevention Month Materials.

Jana Burdge, Harrisburg, PA

The **Data and Annual Report Committee** has developed a timeline which we hope will lead to the publication of the third annual report by January 2001. We have several articles under consideration.

The Content Subcommittee developed some while others were submitted from the membership. The Content Subcommittee is reviewing these and will choose several to be submitted for further peer review. We hope that each article will be reviewed by two reviewers. There is still time for you to volunteer to be a reviewer. Reviewers will probably receive the articles in June and have one month for the review. If you are interested, please contact Charlotte Druschel (cmd05@health.state.ny.us).

The State Data Content Subcommittee is refining our request to the states for data. The subcommittee is tightening up definitions, which we hope will result in better data. This process will go on for the next few years and will be done in collaboration with the Surveillance, Guidelines and Standards Committee. NBDPN members will have the opportunity to provide feedback on the Second Annual Report, which was published in December. This is your opportunity to help shape this report into what is most useful for you.

Charlotte Druschel, Albany, NY

The **Newsletter and Communications Committee** is pleased that our fifth newsletter has now been published. We thank all of the people who have contributed to this edition. Our managing editor, Amy Case (TX) is also chair of the Newsletter Subcommittee.

The Committee has made several additions to the NBDPN web site (www.npdpn.org/NBDPN) that you may want to check out. A copy of the 1999 Annual Report, in pdf format, is now available in the "Publications and Newsletters" link. It contains all of the information from the report published in *Teratology*, with the exception of the state data, which will be added in the soon. The state data will be accessible through a hyperlink to a special queriable database that CDC is currently developing. Also available on the "Publications and Newsletter" page are selected materials from the "January is Birth Defects Prevention Month" packet that the Education and Outreach Committee has developed. Coming soon to the web site is an electronic compilation of many of the posters that were presented at the 3rd Annual Meeting. The Newsletter and Communications Committee is looking for volunteers to help with both the newsletter and the web site. If you are interested, please contact Bob Meyer (robert.meyer@namail.net) or Amy Case (amy.case@tdh.state.tx.us).

Bob Meyer, Raleigh, NC

The **Membership, Bylaws, and Nominations Committee** recently added three new members and had a change in leadership. Tim Flood (AZ) was elected Committee Chair and Michael Pensak (AZ) is Vice Chair, replacing Mark Canfield and Carol Stanton, respectively. Committee priorities for this year include the following: Updating membership and committee rosters; implementing membership renewal; revising bylaws (including any changes prompted by Network incorporation); and nominations/elections for 2001.

Mark Canfield, Austin, TX

The **Annual Meeting Committee** organized the NBDPN's 3rd Annual Meeting, held January 31 - February 2, 2000 in New Orleans, LA. The two and a half day conference was sponsored by the Birth Defects and Pediatric Genetics Branch (CDC) and the March of Dimes Birth Defects Foundation. This year's Meeting "Advances and Opportunities for Birth Defects Surveillance, Research, and Prevention" covered topics such as the Human Genome Project, Limb Reduction Defects, Environmental Epidemiology, Media Savvy, Prenatal Diagnosis, and Data Analysis and Database Programs for Birth Defects Registries. Plans are underway for next year's Annual Meeting to be held in January 2001. The committee welcomes your input. Please e-mail Kerda DeHaan at kerda.dehaan@ mail.state.ky.us with your topic suggestions.

Kerda DeHaan , Frankfort, KY

The **Ethics Working Group** has been formalized into the Ethical, Legal, and Social Issues (ELSI) Committee. Membership in the new Committee is open to any member of the NBPDN. The ELSI committee will recommend minimum standard policy guidelines for NBDPN members to use when establishing birth defect public health surveillance, research, and prevention activities. The first item being addressed is informed consent in birth defect surveillance. Our aim is to have a position paper to submit to the NBDPN members at next January's annual meeting. If you have any interest in serving on the ELSI Committee, please contact: Angela Scheuerle by e-mail at: angela.scheuerle@tdh.state.tx.us. (We are in particular need of a someone with legal expertise and of a lay community person.)

Angela Scheuerle, Dallas, TX

Birth Defects on the Internet

Ever wondered when the facial features form during an embryo's development? Need to know the definition of prepollent? Have trouble picturing exactly how DNA protein synthesis works? Then check out these instructional and interactive websites:

√ The Odyssey of Life: Morphing Embryos (PBS, Nova Online) http://www.pbs.org/wgbh/nova/odyssey/clips/

√ Science Odyssey: DNA Workshop (PBS) http://www.pbs.org/wgbh/aso/tryit/dna/#

√ The On-Line Medical Dictionary (The CancerWEB Project) http://www.graylab.ac.uk/omd/index.html

√ Ventricular Septal Defect Course (Health Interactive) http://www.cpdx.com/healthint/vsdframe.html

Note: These sites have been assessed as useful for educational purposes. However, the NBDPN cannot guarantee the accuracy of all of the content on these pages.

Announcements

The New York State Department of Health has just released a clinical guideline, "*The Evaluation of the Newborn with Single or Multiple Congenital Anomalies*". The American College of Medical Genetics developed this guideline with funding from the New York State Department of Health. It is designed for use by health care practitioners who care for newborns and describes critical components of the diagnosis and initial management of newborns with one or more congenital malformations. The goal of the guideline is to insure that primary care providers understand the impact on the family of the birth of a child with a congenital anomaly. It also focuses on the need for accurate diagnosis in order to provide appropriate management and counseling for families about prognosis, treatment options, recurrence risks and resources for further information and support

Approximately 25,000 copies of the Executive Summary of the guidelines will be printed and distributed to New York State primary care providers. The entire document will be available in the near future on the New York State web site, www.health.state.ny.us. For a hard copy, please contact Skye Brown at sdb02@health.state.ny.us or phone 518-486-2215.

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legal. The investigators compared NTD rates between 1988-1993 (when preventive strategies were not expected to have had an impact) and 1994-1996 (when preventive strategies may have been expected to have had an impact), after adjusting for secular trends in NTD rates observed in the earlier time period.

In general, secular trends in NTD rates appeared to have started prior to 1994, when preventive strategies would not have been expected to have had an impact. After adjusting for these secular trends, the NTD rates in 1994-1996 were not significantly different from the rates in 1988-1993. The proportion of women who had reported periconceptional consumption of folic acid was generally low.

This investigation found no evidence that preventive strategies involving folic acid have reduced NTD rates as of 1996. This suggests that more time and effort may be needed in order to identify the effectiveness of preventive strategies, or that other strategies may have to be implemented.

Mathias Forrester, Austin, TX

Ref: Rosano et al. Time trends in neural tube defects prevalence in relation to preventive strategies: an international study. J Epidemiol Community Health *53:630-635, 1999.*

The National Birth Defects Prevention Network (NBDPN) is a group of individuals involved in birth defects surveillance, research, and prevention. This newsletter is published twice a year. If you would like to be added to the mailing list, please contact Cara Mai at cwm7@cdc.gov. The newsletter and additional information is also available on the internet at http://www.nbdpn.org/NBDPN. Please send comments or questions about this newsletter to Amy Case at amy.case@tdh.state.tx.us.

Mark your Calendar

MAY 16-19, 2000
18th Annual Conference of Health Education and Health Promotion and SOPHE 2000, Denver. Internet: www.astdhpphe.org, Phone 202-312-6460.

MAY 25–28, 2000
Hydrocephalus 2000: Forward Together, 6th Annual Conference for Families and Professionals, Scottsdale, AZ Phone: 415-732-7040, E-mail: hydroassoc@aol.com

JUNE 1-4, 2000
Prenatal Diagnosis of Congenital Anomalies, Chicago. Phone: 800-421-3756, Internet: www.PrenatalDiagnosis.com.

JUNE 4-7, 2000
The AWOHNN 2000 Convention, Association of Women's Health, Obstetric, and Neonatal Nurses, Seattle. Phone: 800-673-8499, Ext. 2425, e-mail adap@awhonn.org.

JUNE 6-10, 2000
2000 Public Health Professional Conference, Scottsdale, AZ. Internet: www.coausphs.org/meeting.html, Phone 252-796-9202.

JUNE 24 - 29, 2000
Teratology Society Meeting, The Breakers, Palm Beach, FL. Phone: 703-438-3104, E-mail: tshq@teratology.org

JUNE 25-28, 2000
Millennium Conference: Celebrating our Tenth Anniversary, Boerne, TX. The Chromosome 18 Registry and Research Society, Internet: www.chromosome18.org/conf2000.htm, Phone 800-999-3299.

JULY 20-23, 2000
The MAGIC Foundation's Annual Convention, Oak Brook, IL, highlighting Turner Syndrome, Septo Optic Dysplasia, Congenital Adrenal Hyperplasia, Growth Hormone Deficiency, others. Internet: www.magicfoundation.org/convention.html.

JULY 26-29, 2000
National Center for Health Statistics Data Users Conference, Bethesda, MD. Internet: www.cdc.gov/nchswww/, Phone 301-458-4193.

JUNE 26-30, 2000
The Spina Bifida Association of America 2000 Annual Conference, Milwaukee. Phone: 800-558-3862

JULY 27-29, 2000
Visions for the 21st Century, Washington, DC. The National Down Syndrome Society's National Conference. Internet: www.ndss.org, Phone 212-460-9330.

AUGUST 10, 2000
Environmental Health: A Nursing Opportunity, Satellite Broadcast. Internet: www.cdc.gov/phtn/envhealth/130027.htm.

SEPTEMBER 14 - 16 , 2000
1st International Symposium on Prevention and Epidemiology of Congenital Malformations Cardiff, UK, International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS). Internet: www.icbd.org/symposium.htm

OCTOBER 12-14, 2000
The Arc National Convention, Birmingham, AL. Phone: 301-565-3842, E-mail info@thearc.org

NOVEMBER 2-5, 2000
Exploring the Counseling Role in Genetic Counseling, Savannah, GA. The National Society of General Counselors. Internet: www.nsgc.org, Phone 610-872-7608.

NOVEMBER 5-6, 2000
The Genetics of Infertility: Evaluation, Counseling, and Control, Savannah, GA. The National Society of General Counsellors. Internet: www.nsgc.org, Phone 610-872-7608.

The National Birth Defects Prevention Network

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