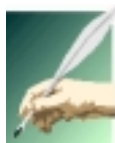




Message from the President



In the last couple months of my year as NBDPN President, I have come to appreciate the contributions made by all those involved in the Network, from members, officers, committees, and CDC staff.

Here are just a few highlights from the numerous accomplishments this year:

1. The Surveillance Guidelines and Standards Committee has made progress with its painstaking documentation of what state birth defects surveillance and related functions should look like. The hiring of a consultant to assist the committee showed that the Network is serious about this.
2. The Education Committee issued its latest iteration of the "Birth Defects Prevention Month" packet, in advance of a January observance. After several years of building on this effort, the packet this year was the best yet, with impressive materials on orofacial clefts, suggested state activities, birth defects cluster fact sheet, birth defects resources on the Internet, and resources on maternal conditions and maternal infections from Michigan.
3. The Annual Meeting Committee has worked tirelessly to organize a great program for the 5th Annual Meeting in Orlando (Jan. 14-16, 2002), with an emphasis on genitourinary defects. (Visit www.nbdpn.org/NBDPN)
4. Aside from its many other duties, the Membership, Bylaws and Nominations Committee developed a survey to determine the profile of our membership.
5. The Data Committee has developed an electronic, web-based data system for the public to determine the state-specific prevalence of selected birth defects in selected time periods. This valuable tool will be exhibited at the January

meeting. This Committee has also made enormous improvements to the electronic program directory information for the Network.

6. The Publications and Communications Committee just issued the latest state birth defects data in Teratology, and the group has assembled an impressive review panel for its editorial board.
7. The ELSI Committee developed a NBDPN position on accepting donations, which became our first policy.
8. Members of the NTD/Folic Acid Education Committee collaborated with others in developing and submitting a manuscript on the national prevalence of neural tube defects, based on a specialized rapid ascertainment method.
9. The Executive Committee dealt with some important global issues facing the network, including an edict by Trust for America's Health (TFAH) to update the "report cards" on state birth defect programs done in 1999 by the PEW Environmental Health Commission. A Work Group from the Executive Committee took a proactive approach and worked with TFAH to develop the most objective and fair assessment possible. The Work Group provided TFAH access to and guidance on NBDPN's extensive electronic program directory, and it assisted TFAH in developing and disseminating a short survey of additional questions. Both the Executive Committee and TFAH have learned a considerable amount from this relationship, as you will hear at our annual meeting in Orlando.

This has been a busy yet rewarding year for me as your President. As one of the members who was on the "ground floor" of establishing the Network 5 years ago, I have seen the Network undergo enormous growth and progress in a relatively short period of time. I see much strength from within its membership and committees.

MARK CANFIELD, TX
NBDPN PRESIDENT

News from the CDC



Centers on Birth Defects Research and Prevention

The Centers for Birth Defects Research and Prevention held its 5th Annual Meeting in Denver, CO from November 28-29, 2001. The meeting focused on analytic data set creation, data security, evaluation of the computer-assisted telephone interview (CATI), and clinical and biologic issues.

To date, over 8,000 interviews have been completed with mothers of children with and without birth defects. A paper describing the National Birth Defects Prevention Study was published in the Public Health Reports (volume 116, supplement 1); a copy will be posted on the CDC web site at www.cdc.gov/ncbddd/bd. Over 100 research proposals and letters of intent have been developed, and the data should be ready in the next few months for the Centers to begin the data analysis.

Birth Defects Surveillance Cooperative Agreements

On October 24, 2001 a program announcement for new cooperative agreements was published in the Federal Register. The purpose of the cooperative agreements is to support the development, implementation, expansion, and evaluation of: (1) population-based birth defects surveillance systems; (2) population-based programs to prevent birth defects; and (3) activities to improve the access of children with birth defects to health services and early intervention programs. States with funding for the Centers for Birth Defects Research and Prevention, as well as the 8 states funded with cooperative agreements in 2000 are ineligible. Applications for this announcement were due on December 7, 2001. The start date for these new cooperative agreements is March 2002.

A meeting for the current 26 states is planned for January 17, 2002, immediately following the NBDPN Annual Meeting. The meeting will focus on issues relating to NTD/folic acid, linking families to services, partnership, and sustainability.

National Folic Acid Campaign

Hispanic Campaign

The Centers for Disease Control and Prevention (CDC), the March of Dimes and the National Council on Folic Acid, have joined together with area Hispanic community organizations to educate Hispanic women of childbearing age in Miami, Florida and San Antonio, Texas about the importance of consuming folic acid. In a concerted effort to reach every Hispanic woman, the campaign and its community partners will appear at community festivals, health fairs and will host live radio remotes with interviews. In addition, public service announcements will appear on local television and radio stations. Health care and social service professionals will have the opportunity to participate in education sessions, to learn how to develop their own folic acid outreach programs, and be given resources and materials to help them counsel their clients more effectively.

New materials

CDC has produced several new materials:

- Health care provider tip cards were designed and printed for distribution to pharmacists, dietitians, ob/gyn health providers, primary care health providers, and pediatric health providers. The tip cards remind health care providers of the dosages to prevent occurrence and recurrence of NTDs and give tips about how to integrate the folic acid message into their daily practices.
- Card-format brochures using the message for contemplators were designed and printed in English and Spanish.
- Small and large posters in English and Spanish were designed and produced with the Hispanic novella format, a short story in pictures. While they were produced especially for the Hispanic campaign, they are available to order in small quantities.

Please order materials through our web order form at <http://www2.cdc.gov/ncbddd/faorder>. If there are problems, please contact us via flo@cdc.gov.

News from NBDPN Liasons

National Council on Folic Acid Update

The March of Dimes Birth Defects Foundation (MOD) has provided expert leadership and much needed financial support to the National Council on Folic Acid (NCFA) for the past three years. Moving on to new priorities, the MOD will be transitioning out of their leadership role effective June 2002, while still maintaining their NCFA membership. In anticipation of the change, NCFA conducted a strategic planning meeting on October 30, 2001. All member organizations were invited to help decide the Council's future direction.

Riordan Killian Consulting facilitated the daylong meeting, navigating the group through difficult decisions, and emerging at the end of the day with a new mission statement and goals for future direction of NCFA. The new mission (to improve health by promoting the benefits and consumption of folic acid) emphasizes the importance of action (consuming folic acid), while allowing emerging folic acid issues to be incorporated in the future.

- The first of three goals assures NCFA does not lose sight of past efforts: To reduce birth defects by promoting the consumption of folic acid among reproductive age women.
- The second goal allows for expansion of effort to emerging research: To communicate and promote the developing science on folic acid, especially related to MCH.
- The third goal accentuates the importance of action: As supported by developing science, to increase the percentage of the population consuming folic acid (synthetic, fortified foods, and diet). A committee was formed to fine-tune the goals, and develop measurable activities and tasks.

Three additional committees were formed to assist NCFA in the transition process. A nominating committee will identify members to serve as the new NCFA chairperson, anticipated to be a two-year term appointment. The vote will occur at our next quarterly meeting, in January 2002. The bylaws committee will address the necessary changes to NCFA bylaws, while the funding committee will

identify potential sources of funding for future NCFA activities.

The Centers for Disease Control and Prevention (CDC) is developing a request for application (RFA), inviting interested non-profit organizations to coordinate NCFA for a three to five year period. The grant will fund a position(s) to assist in the management of NCFA activities. The RFA is anticipated for release in January 2002. The grant could be awarded as early as April 2002, but realistically by July 2002.

Kay Pearson, OK

HuGE Net Update

Two new activities of HuGE Net can be found on the HuGE Net website. These include the **HuGE Published Literature Database** and the **HuGE Net e-Journal Club**. For more detailed information on these activities, select "HuGE Database" and "e-Journal Club", respectively, from the menu on the main page of HuGE Net (www.cdc.gov/genetics/hugenet/default.htm)

The **HuGE Published Literature Database** is a searchable query tool which references human genome epidemiological articles in the peer-reviewed literature that have been highlighted in the Office of Genetics and Disease Prevention Weekly Update since October, 2000. Users may search for information on a specific gene, health outcome, and/or environmental factor. Results of the search provide links to Pubmed and OMIM information, in addition to bibliographic or tabulated references to the articles.

HuGE Net e-Journal Club has been created as an electronic discussion forum where new human genome epidemiological (HuGE) findings, published in the scientific literature are abstracted, summarized, presented, and discussed via a newly created HuGE Net listserv. Participation in the **e-Journal Club** is open to all interested individuals. An online template is now available for anyone interested in reviewing an article for the **e-Journal Club**. The article should be of public health significance. We encourage HuGE Net members and colleagues to take part in this activity. The **e-Journal Club** review has become a valuable tool for global collaboration in developing and communicating peer-reviewed epidemiological information on human genes.

Mindy Clyne, GA

State Spotlight



IOWA

The Iowa Birth Defects Registry (IBDR) was established in 1983 through the joint efforts of the University of Iowa, the Iowa Department of Public Health and the Iowa Department of Human Services. The mission of the IBDR is to: 1) maintain statewide surveillance for collecting information on birth defect occurrence in Iowa; 2) monitor annual trends in birth defect occurrence and mortality; 3) conduct research studies to identify genetic and environmental risk factors for birth defects; and 4) promote educational activities for the prevention of birth defects.

To identify information about birth defects that occur in elective terminations, stillbirths and live births of Iowa residents, IBDR field staff review medical records in hospitals and clinics both in Iowa and in neighboring states that serve Iowa residents. The information collected has been used by health care providers and educators to provide treatment and supportive services for affected children and their families, and by researchers to study risk factors for birth defects.

Research projects conducted by the IBDR involve identification of genetic and environmental risk factors for specific birth defects, including Down syndrome, heart defects, neural tube defects and cleft lip and cleft palate. These projects include mail or telephone surveys of women who have experienced a pregnancy affected by a birth defect and collection of biological specimens from affected children and their parents. For comparison, survey data and biological specimens are collected from families of women who have not experienced a pregnancy affected by a birth defect. In 1996, through a grant received from the Centers for Disease Control and Prevention, the IBDR established a Center for Birth Defects Research and Prevention. As a part of this grant, the IBDR is conducting interviews and collecting specimens for the National Birth Defects Prevention Study.

IBDR staff also participate in educational programs designed to help prevent the occurrence and recurrence of birth defects, such as presenting lectures to promote prevention awareness to students, families and health care workers. In addition, IBDR

staff participate in educational programs conducted by the Children's Miracle Network as well as the Iowa Chapter of the March of Dimes.

News from the March of Dimes



The March of Dimes recently held its annual Volunteer Leadership and National Public Affairs Conferences in Washington, DC — a gathering of over 700 March of Dimes volunteers and staff. The highlight of the conference was a visit from President George W. Bush who was introduced by U.S. Department of Health and Human Services Secretary Tommy Thompson. The President discussed the importance of volunteerism and his support of the March of Dimes mission.

Dr. Jose Cordero, acting director of the Center on Birth Defects and Developmental Disabilities, began the Public Affairs portion of the conference by thanking the volunteers for their work to establish the Center and then discussed its mission and priorities. The following day over 300 volunteers and staff visited their Congressional Representatives and Senators to discuss issues involving maternal and child health. They lobbied on behalf of increased funding for the Center on Birth Defects and Developmental Disabilities with a particular focus on birth defects surveillance activities and expansion of CDC's work in promoting folic acid.

The funding picture for Fiscal Year (FY) 2002 is encouraging. The House of Representatives has approved an appropriation of \$80 million for the Center, a \$10 million increase over FY 2001 funding. As of press time, the Senate Appropriations Committee has approved a funding level of \$89 million, a \$19 million increase. The March of Dimes will continue to work for the largest increase possible during the negotiations between the House and Senate, where the final funding level will be made.

We encourage you to discuss the vital work being conducted at the Center on Birth Defects and Developmental Disabilities with your Senators and Representative. The creation of the Center has increased the visibility of this work, but many Members of Congress are not fully aware of the scope of research and prevention activities supported through the Center.

Emil Wigode, DC

Epi Notes



Hyperinsulinemia and Neural Tube Defects

Maternal obesity and non-insulin-dependent diabetes mellitus (NIDDM) have been associated with increased risk of neural tube defects (NTDs) in offspring. Hyperinsulinemia, elevated insulin levels in the blood plasma, may coincide with or precede obesity and NIDDM. Mexican Americans have been reported to have higher rates of NIDDM, obesity, and NTDs than non-Hispanics. Investigators in Texas attempted to determine whether hyperinsulinemia was associated with NTD risk and whether this association was independent of obesity and NIDDM.

The investigation was a case-control study where the cases were Mexican American women who delivered infants and fetuses with NTDs (anencephaly, spina bifida, encephalocele) during June 1995-May 2000 and who resided in the Texas counties that border Mexico at delivery. Controls were randomly selected Mexican American mothers from the same population. Approximately 5-6 weeks after delivery, the cases and controls were interviewed, during which time the women reported their prepregnancy height and weight, and fasting whole blood and serum specimens were collected.

Hyperinsulinemia was associated with a statistically significant increased risk of NTDs [odds ratio (OR) 1.91, 95% confidence interval (CI) 1.21-3.01]. Obesity was also associated with a statistically significant increased NTD risk [OR 1.73, 95% CI 1.03-2.92]. After adjusting for obesity, the elevated risk of NTDs in relation to hyperinsulinemia was still statistically significant [OR 1.75, 95% CI 1.09-2.82]. However, after adjusting for hyperinsulinemia, the elevated NTD risk with obesity was no longer statistically significant [OR 1.45, 95% CI 0.84-2.51]. Adjustment for other potential confounders and excluding women who were considered to have diabetes mellitus did not appreciably alter the odds ratios.

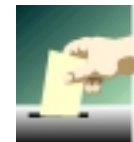
This investigation suggests that hyperinsulinemia is a risk factor for NTDs, at least among Mexican Americans. Hyperinsulinemia may

account, at least in part, for the observed association between obesity and NTDs.

Mathias B. Forrester, TX

Ref: Hendicks KA, Nuno OM, Suarez L, Larsen R. Effects of hyperinsulinemia and obesity on risk of neural tube defect among Mexican Americans. Epidemiology 2001;12:630-635.

Committee News



The **Surveillance Guidelines and Standards Committee** continues to work on the reference manual. Chapters that are actively involved in writing include Case Definitions, Disease Classification System, Data Quality, and Statistical Methods. Over the summer, Data Collection Variables and Case Ascertainment Methods were submitted to the editorial process.

Since June, the committee chair, along with other members from NBDPN, has been working with a group from Trust for America's Health (TFAH). TFAH is gathering information about birth defects surveillance in the United States and preparing an evaluation report. The discussions with TFAH provided valuable perspectives on minimum standards, definitions, evaluation techniques, and best practices models. All of these things are important considerations and challenges for the standards reference manual.

CAROL STANTON, DENVER, CO

The **Education and Outreach Committee's** main activity is to prepare "January is Birth Defects Prevention Month" packets to be nationally distributed to state contacts at organizations and agencies who work with the public on health issues. This year's packet is the third in our series. As well as maintaining some of the basic materials, additional activities this year were to categorize our internet resources guide, select fact sheets for cleft lip/palate, and revise our basic brochure which is in English and Spanish. We have successfully completed our work. An exciting conclusion of the committee's work was that we proposed an award be given to honor innovative and

Committee News, Continued on page 6

Committee News, Continued from page 5

collaborative activities during Prevention Month. Special thanks to Pat McDonald who has taken on this responsibility each year with enthusiasm and energy, and with significant assistance from Cara Mai, has produced a really nice information packet.

Our committee also developed a cluster fact sheet which was approved by the Executive Committee and will be included in the Prevention Month packet. Thanks go to Jackie Wynne who stuck with this project to its successful conclusion.

Another effort which was especially challenging was to move toward the development of curricula which would use birth defects information and build awareness among middle and high school students. We were particularly interested in curricula which were not specific to health classes, but that could be used in math, social studies and literature.

At the NBDPN 2002 meeting we will be reviewing our work and making decisions about activities to undertake next year. We welcome your input and invite you to join us at our Committee meeting in Orlando.

CIVILLIA WINSLOW HILL, OLYMPIA, WA

The **State Data Committee** has mailed to state registry contacts the request for submission of birth defects data and directory information for the NBDPN Fourth Annual Report. Unlike previous requests in which registries were asked to submit data using a database file format, they will have the opportunity to submit data using one of several file formats (e.g. text, database, spreadsheet, etc.). For directory information, registry contacts will receive an electronic file to update. The deadline for receipt of data and directory information is December 1st.

The Web Site Subcommittee previewed the CDC data web site to committee members and to NBDPN Executive Committee members. In general, the design of the web site was well received although some concerns were raised regarding inclusion of legacy data (1989-1994) that will not appear in the upcoming annual report, and the need for some states to suppress small counts. The committee has recently completed a survey of registry contacts for their input regarding these issues. Once these issues are resolved, the web site will be put on-line for public use. A link to this site will also be available on the NBDPN's own web site.

The committee also discussed with Miriam Levitt,

co-chair of the NTD/Folic Acid Surveillance Committee, potential overlap of goals between the two committees. The committee decided that the goals of both the Data Committee and the NTD/Folic Acid Surveillance Committee were distinct and did not overlap, as the Data Committee is responsible for collection and publication of state data for a number of birth defect groups and the NTD/Folic Acid Surveillance Committee conducts projects typically for one defect group at a time (currently NTD and possibly orofacial clefts). To facilitate continued communication between the two committees, Miriam will serve as the State Data Committee's liaison to the NTD/Folic Acid Surveillance Committee.

PAUL ROMITTI, IOWA CITY, IA

The **Publications and Communications Committee** which is responsible for publishing the semi-annual newsletter, producing the NBDPN Annual Report, and maintaining the network's web site has been hard at work this year. The third NBDPN annual report has been published in the journal *Teratology* and distributed (free of charge) by CDC to network members. It will also be available on our web site: www.nbdpn.org/NBDPN. Our committee is already hard at work on the next report. We have formed an editorial board which during the next two months will be reviewing all manuscripts submitted. We hope to have the content of the report finalized by March 1, with an anticipated publication date in the summer or fall of 2002.

For this issue of the NBDPN newsletter the committee decided to have a somewhat more "consumer-oriented" focus, which we hope will help broaden interest in the network and expand our membership base to include more advocates, parents, and individuals with birth defects or developmental disabilities. The NBDPN welcomes anyone with an interest in promoting birth defects research, prevention, treatment, and services to join the network and become an active part of our growing organization. More information about the NBDPN and how to join can be found at our web site.

Anyone interested in joining our committee can contact either Bob Meyer (robert.meyer@ncmail.net) or Russ Kirby (r-kirby@whin.net) for more information.

BOB MEYER, RALEIGH, NC
RUSS KIRBY, MILWAUKEE, WI

The **Membership, Bylaws, and Nominations Committee** continues to meet regularly. We assisted with the creation of the membership profile survey questionnaire that was sent recently to members from Jane Correia (Member-at-Large). I hope that all members have submitted their survey forms; this survey will provide a good profile of our organization. No amendments to the Network's Bylaws were needed during the past year. The annual election cycle is now underway; we'll distribute the e-ballots in December.

TIM FLOOD, PHOENIX, AZ

The **Annual Meeting Committee** has completed the agenda for the 5th Annual NBDPN Meeting to be held in Orlando, Florida, January 14-16, 2002 at the Sheraton Safari Hotel. This hotel is located 1/8 mile from Walt Disney World Resort and can be viewed at www.sheratonsafari.com. The theme this year "NBDPN 2002: Future Perspective of Birth Defects Surveillance, Research, and Prevention" will be addressed by several leaders in the field, including Dr. Jennifer Howse (President, March of Dimes Birth Defects Foundation) and Dr. Jose Cordero (Director, CDC National Center for Birth Defects and Developmental Disabilities). Dr. Pierpaolo Mastroiacovo (ICBDMS - Italy) will be the guest speaker for the luncheon on January 14th presenting on the history and future of the International Clearinghouse. Additional presentations include federal regulations (HIPAA and FERPA), data integration and child health profile issues, plenary session on genitourinary defects, birth defect surveillance data application to program activities, surveillance guidelines and standards, and developmental disabilities. Breakout sessions and repeating workshops offer a wide variety of topics for participants. Should you have any questions about the meeting please contact either Marcia Feldkamp (mfeldkam@doh.state.ut.us) or Cara Mai (cwm7@cdc.gov).

MARCIA FELDKAMP, SALT LAKE CITY, UT

The **Ethical, Legal, and Social Issues (ELSI) Committee** continues to review and evaluate HIPAA regulations. A specific request was made by the network for the ELSI Committee to generate an "instruction manual" that surveillance systems could use in their negotiations with health care providers. Public Health entities are not bound by the HIPAA rules, but hospitals and other providers are.

Earlier in the year, the ELSI Committee evaluated the rights and responsibilities of NBDPN in accepting gifts—both fiscal and in-kind. A position paper was generated, and a recommendation made to the NBDPN Executive Committee. The Executive Committee chose to adopt an open gift policy, with planned review in a year. A statement about this policy can be found on the NBDPN web site on the "Who We Are" page.

ANGELA SCHEUERLE, DALLAS, TX

The **Neural Tube Defects (NTD) and Folic Acid Education Committee** continues to work to develop a series of goals to help guide member activities and formulate committee objectives. The Executive Committee has approved the following goals recommended by the Steering Group: to promote the use of state surveillance data for the purposes of (1) advocacy, (2) research & prevention, (3) linking data to health services, and (4) descriptive epidemiology. These goals were presented to the full committee at a conference call on September 10th. The committee decided that further clarification was necessary to guide their future activities and to ensure that there was no overlap with the State Data Committee. As described above in the update from the State Data Committee, it was decided that Miriam Levitt would become a member of that committee in order to facilitate communication between the two groups.

NTD/Folic Acid Surveillance Committee also reached consensus that the committee should continue to collect and analyze NTD surveillance data collected through the NTD rapid ascertainment project coordinated by CDC. A manuscript describing the results of NTD rates pre- and post-folic acid fortification has been submitted for publication. A committee conference call will be held in November to discuss additional projects that may be available for this committee to undertake.

LISA MILLER, DENVER, CO
MIRIAM LEVITT, CINCINNATI, OH

"Surveillance without population data is like a lollipop without the stick: very sticky when licked."

Carol J. R. Hogue, Ph.D.
Emory University School of Public Health

From the Heart...

Impact of Newborn Hearing Screening on Outcomes for Children and Families

"I am so glad I found out early. I can begin to do things to help my child so he won't be behind." - mother of a six week old with a mild-moderate hearing loss.

"I just want to learn everything I can to help my child. I do not want to waste any time." -mother of a six week old girl with a severe to profound hearing loss.

"At first I was overwhelmed. I wanted to get as much information as possible as quickly as possible. Then I realized -I can do this. I can keep hearing aids on my baby and I can learn sign language." -mother of a seven month old girl with a severe to profound hearing loss.

"I was saddened to learn my child was deaf. The first few weeks were tough. But now when I look at my son I see a beautiful healthy boy who happens to be deaf. He is such a good baby!" -mother of a six month old deaf son.

"The difference in my two daughters is dramatic. Both have severe to profound hearing losses; the older daughter was not identified until she was two years and nine months, while the younger was identified through newborn hearing screening. Because of early identification, we are seeing our younger daughter do things that our older child could not do at the same age. Our older daughter is battling significant speech-language delays."

"I wish we had found out sooner. I can not waste any more time-he is so behind already." -dad of a three year old boy who is hard of hearing.

Early identification of hearing loss is now defined as prior to six months of age. With the advent of newborn hearing screening programs in most states, children are being identified and entering intervention programs at a very young age. According to research, children who are identified early and receive appropriate intervention have significantly better receptive language, expressive language, personal-social skills, and speech production than do children who are later identified and do not receive services during these critical early years.

Colorado has a system in place to assist parents during this crucial time. The Colorado Hearing Resource Coordinator (CO-Hear) meets the family, provides information about communication options,

program options, and services within the community. Parents can choose to be involved in the Colorado Home Intervention Program (CHIP). This program provides in-home family-centered early intervention in the communication system of the family's choice, thus meeting the unique needs of each child and family. The CHIP program is designed to encourage and facilitate the child's development in the areas of language, speech, audition, and cognition by working with the parents.

Universal newborn hearing screening has positively impacted the lives of children and families on many levels. Although parents still grieve, they do not have to wonder how they "missed" their child's hearing loss, nor do they have to deal with the guilt involved with significant speech-language delays. The family and child are not operating from a deficit or delay model regarding language acquisition, with tailored intervention programs and strategies the child can develop language and communication skills at an appropriate developmental pace. The child can benefit from hearing aid use during this critical period for language learning. Language and the ability to communicate impacts many other areas of life - the child's personal-social skills; later academic growth; and sense of self-esteem. The stage has been set for positive growth through early identification and intervention.

Dinah Beams, CO

Dinah Beams is the Hearing Resource Coordinator for the Denver Metro Area and a Senior Consultant for the Colorado Home Intervention Program, University of Colorado.

Parent to Parent Support: Help for Parents and Professionals



Caring for a family member who has a disability or chronic illness is an experience few parents expect. The family must not only cope with the typical demands of family life but also with a host of other issues including a new language of acronyms about the medical, legal, financial and special education worlds. They must find their way through a maze of social and medical services that may or may not be "family-friendly." They may feel isolated when family and friends distance themselves because of fear and misunderstanding.

To cope with these changes, families, parents, and professionals create Parent to Parent programs, a growing world-wide movement. There are more than 700 local Parent to Parent programs nationally with at least one program in every state, and approximately 45,000 parents are involved in one-to-one Parent to Parent matches. Through these programs, parents, referred by themselves or by others with their permission, are carefully matched with trained parents of children with special needs, for emotional and informational support. Support Parents are trained in active listening, feelings of loss and grief, coping, and managing stress. Most of the Support Parents are volunteers.

Sharing family experiences with someone who is in similar circumstances is an important source of support. Families dealing with the challenges of caring for a family member who has a developmental disability or chronic life-long illness say that their first choice for support and guidance is another parent.

The movement had its beginning in Omaha, Nebraska in the early 70's. Programs in other communities emerged as the parents struggled to address the challenges of families having a family member with a disability. Support groups, family socials, guest lectures, and receiving medical students for a typical evening at the families' homes, are a few activities that have emerged in Parent to Parent programs.

In South Carolina, the movement began when a mother of a child with Down syndrome presented the Parent to Parent concept at a hearing sponsored by the local disability and special needs board. Her five-minute presentation ignited two days of calls from other parents and professionals who embraced the idea of mutual support and ways for families of children who have special needs to gather. Now, nearly eleven years later, the organization which began with parents typing grants on kitchen counters, has become a statewide organization which in 2000-2001 effected 1,700 Parent to Parent matches and in which parents and professionals have placed their confidence. Family Connection of South Carolina is a non-profit, grassroots, parent-driven organization with the mission to provide parent to parent support that strengthens families and to increase awareness about persons with disabilities and chronic illnesses.

Key among the efforts is the Family Partner Program of Family Connection. Supported through a contract with South Carolina's early intervention program for ages birth to three which in turn is federally

funded through the Individuals with Disabilities Education Act (IDEA), Family Partners, who are employees of Family Connection, provide more frequent support to families who have infants and toddlers. They meet with the parents at medical or therapy appointments and in home visits on a regular basis for several months. Family Partners visit parents during the time the infant is in neo-natal intensive care and at home when the rounds of therapists and medical specialists can be especially stressful. Family Partners help the family adjust to their unexpected role as parents of children with special needs. They provide tips on communicating with professionals and suggest ways to reduce stress. The stresses are real. For example, the divorce rate among families who have children with disabilities is estimated at 80 percent.

Parents who are supported often want to "give back" to the organization which helped them. They may participate in 12 hours of training becoming supporting parents themselves. Thus, the network grows in which nearly 400 parents have been trained through Family Connection. As referred parents adjust and find their many strengths, they become their child's first and best teacher and develop as advocates for their child and for other children and families. Many supporting parents have become advocates and leaders in the disabilities movement in their local communities as well as in state and national advocacy and parent to parent programs.

Parents who receive family to family support and assurance identify their supporting parent as their reliable ally. They say that Parent to Parent support increases their acceptance of their situation and increases their sense of being able to cope. Interviews with parents suggest that the kind of support Parent to Parent offers is unique and probably cannot come from any other source. Parent to Parent support offers a unique form of help to parents of family members with a disability, and it should be one essential component of a comprehensive family support system. These findings were documented recently in a 3-year national study to determine the efficacy of Parent to Parent support. Parents and researchers from Parent to Parent of New Hampshire, Parent to Parent of Vermont, and the Hood Center at the Dartmouth-Hitchcock Medical Center; the Family Support Network of North Carolina and University of North Carolina; the Family Connection South Carolina, and Families Together/Parent to Parent of Kansas and the Beach Center on Families and Dis-

From the Heart..., Continued from page 9

ability at the University of Kansas participated in the project. Between 1994 and 1996, 400 referred parents in the participating states joined in this study. Dr. George Singer, now at the University of California at Santa Barbara, CA directed the study. Parents worked together with researchers to design the study, write the grant application; and carry out this important research in which more than 80 percent of the parents said they found Parent to Parent helpful.

Family Connection of South Carolina has grown through strategic planning and a broad base of public and private funding. The efficacy study and independent evaluations of the Family Partner Program in which 90 percent of the interviewed parents find parent to parent helpful are used to help explain the value of Parent to Parent. While many funding sources are pleased that research and evaluation is important to the organization, quotes from parents tell it best. "My support parent has been the silver lining to my cloud. She has helped me understand the doctor process and has helped me be the best mom I can be. She has been there for me at all hours by phone and has always seemed to know when I needed to talk."

Another of Family Connection's efforts is the Minority Outreach Initiative, which has developed support groups in Columbia's (SC) public housing communities. Families with children who have disabilities and who live in poverty have even more with which to cope. Because of the now 8-year-old Initiative, over 500 families have become involved and fifteen parents have completed Support Parent Training and are leading their groups' efforts. Many of the children fallen through the cracks of the service system are now receiving services and on their way to reaching their potential with parents realizing the importance of accessing necessary programs. On May 31, 1998, at the International Parent to Parent Conference in Atlanta, GA, Family Connection was awarded The Pierson Award for best practice in reaching underserved populations. The Initiative represents a commitment by Family Connection to reach out to all families.

Also growing out of the Initiative is Project Breathe Easy. This project is funded through private foundations and in-kind donations and provides parent to parent support and information to primarily low income minority families. The program was designed and implemented to address the needs of

the many children with asthma who are in the target population. Focusing on the understanding of asthma and making appropriate referrals to a medical home, emergency room visits have been reduced by 70 percent. Parents report a greater understanding of their child's care; children are missing at least 50 percent fewer days of school; and parents are missing fewer workdays because their child is well. For information about Parent to Parent, contact Betsy Santelli, Director of Parent to Parent Program Support at the Beach Center for Families and Disability, 3111 Haworth Hall, University of Kansas, Lawrence, KS 66045, (785) 864-7600.

Connie Ginsberg, SC

Connie Ginsberg is a parent of two children with special needs. She is executive director of Family Connection of South Carolina, Inc. 2712 Middleburg Drive, Suite 103-B, Columbia, SC 29204. Tel. (803) 252-0914. E-mail: connieg@mindspring.com.

"Thoughts of you are with me I carry them in my heart. An image of a young boy and times spent at the park."

These are the opening lines to a poem I wrote shortly after the death of our son. He died unexpectedly from a cerebellar arteriovenous malformation at the age of five. At the time of his death, I was already working on birth defects surveillance activities in Florida but found myself unable to comprehend that this had happened to us. I wanted to know what it was, how it could happen, why it happened, and would it happen again – just like all parents do! I am sorry to say that fourteen years after his death, we as a nation know little about vascular malformations, indeed we know little about what causes most birth defects. I continue to work in this field hoping that someday I will get the answers to the questions above. In the meantime I try and answer every parent's request for information as if it were my own.

Jane A. Correia, FL

Jane Correia is Assistant Director of the Florida Birth Defects Registry and NBDPN Member-At-Large for 2001.

Mark your Calendar



JANUARY 14-16, 2002

Fifth Annual Meeting of the National Birth Defects Prevention Network (NBDPN)

Sheraton Safari Hotel, Orlando, FL

Contact: Cara Mai, (770) 488-3550

E-mail: cwm7@cdc.gov

Website: www.nbdpn.org/NBDPN

FEBRUARY 11-13, 2002

National Early Hearing Detection and Intervention (EHDI) Meeting, Tysons Corner Marriott
Vienna, Virginia.

Website: www.infanthearing.org.

Phone: (435) 797-3584

MARCH 7-8, 2002

Texas Birth Defects Conference 2002

Radisson Plaza Downtown, Ft Worth Texas

Contact: Amy Case, 512-458-7232

Email: amy.case@tdh.state.tx.us

Website: www.tdh.state.tx.us/tbdmd/conf_page.html

MAY 3-7, 2002

Second International Conference on Neural Tube Defects, Conference Resort at Seabrook Island, South Carolina.

Website: www.tamu.edu/ibt/ibtweb/neuraltubeconf2.htm

AUGUST 18-22, 2002

16th IEA World Congress of Epidemiology
Convention Centre, Montreal, Canada

Contact: Eduardo Franco, 514-398-6032

Email: mcef@musica.mcgill.ca

Website: www.iea2002.com

Various dates/cities, 2001-2002

American Health Information Management

Association's "Getting Practical with Privacy."

Website: www.ahima.org/privacy/location.html

Mail: AHIMA Dept. 77-6331, Chicago, IL

60678-6331, Phone: (800) 335-5535

Birth Defects on the Internet



Need a website that supports parents and families as well as provides information to healthcare providers on how to work with families who have special needs children? Check these out!

- ✓ Family Voices
www.familyvoices.org
- ✓ Brave Kids
www.bravekids.org
- ✓ American Cleft Palate-Craniofacial Association (ACPA)
www.cleftline.org
- ✓ Wide Smiles

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.

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.

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