

HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

VOLUME 7, NUMBER 1

SPRING 1999

Children and Families in Health Care: Issues for Advocates

by *Linwood J. Lewis, Ph.D.*

In the three years 1993 through 1995, there were 165 million health care visits by children less than 15 years of age, of which 37 million were hospital visits. Eighty-five percent of these children were in health care for illness or injury. (NCHS, 1998) What happens when these children enter into the health care system? How can we best maximize appropriate care for children?

Children entering the health care system must negotiate the same bewildering maze of medical procedures, medical jargon, personal fears of pain and death and bodily dysfunction as adults. Yet children have less control over their health care and often less cognitive re-

sources to help them to understand and process their experiences. Health care providers, parents and guardians often find it difficult to come to a consensus on the proper treatment of children in the system. These factors increase the vulnerability of children and can lead to less successful treatment outcomes. I would like to alert health advocates to some of the important issues concerning children in health care. My comments are probably most relevant for direct service advocates working with children presenting with a chronic condition, or pediatric inpatients.

Disclosure

One of the first questions many parents ask is "How much should I tell my

child about his or her condition?" Answering this question requires examination of a complex of factors including: the present physical condition, developmental level, and cultural background of the child; the level of understanding of the caregiver(s); the ease of communication between the medical team and the family; and the availability and training of mental health providers such as social workers and pediatric psychologists. Mental health providers can help families and medical personnel in balancing the relevant social, psychological and medical factors, and most hospitals have such providers on call. However, mental health providers must often await requests from patients or physicians before consulting on cases. Attending physicians may be reluctant to refer families unless there are clear signs of maladaptive coping. Caregivers may be unaware of the possibility of calling on a mental health provider, unsure about third party payment options, or may harbor fears or prejudice against seeking such help. Patient advocates can help by presenting options to families and facilitating the choice of whether to ask for a mental health provider.

Disclosure is most important because it provides one of the first opportunities for fruitful interaction between the treatment team, the child and the family. A smooth transaction can dramatically affect adherence to medical regimens, and adaptive coping by child and family, thus affecting the prognosis.

Family Issues

Families often feel like spectators at the bedside of a patient, yet they can clearly provide much in the care and comfort of the sick family member. Adult patients can make decisions to bring family members more closely into the treatment process or to push family away, as well as to induce the medical

In This Issue

Children and Families in Health Care: Issues for Advocates	1
Giving Opportunity to Youth: An Initiative in Yonkers, NY	4
Children's Health Insurance: Hopes and Hurdles	6
The Pediatric Parent	7
You Have Rights: A Patient Rights Statement for Children	8
Should This Baby Live?: An Ethical Dilemma	9
Genetic Testing in Children: Weighing the Issues	11
Universal Newborn Hearing Screening	13
Poor Access to Care Heightens HIV Transmission Rates	15
Creating a Tobacco Awareness Program for Schools	17
Children's Issues in Westchester County	18
Navigating the Web of Children's Advocacy Sites	19
'99 Graduates: A Vibrant Mix	21
Director's Desk	22

Plus

From the Editors	2
Alumnae/i Association	3

Continued on page 3

From The Editors:

We have to remind ourselves frequently – as parents, as citizens, and as advocates – that children are not small adults. They have their own issues, needs, concerns, fears, perspectives. Their own qualities of courage and optimism. Their own ways of understanding. We've all been there: we've been children, but we forget.

Children are under siege today. They are both subjected to, and blamed for, violence and social disintegration. Unfortunately, the media bombards us with the tragic extremes. We must not blame the children. Many millions of ordinary kids struggle to grow up, as we all did, to be independent and responsible adults, connected to and participating in their communities. They need safe places, the ingredients for good health, and concerned adults involved in their lives. But they – and their families – live in a world where the complexity of providing these seemingly simple requirements is often overwhelming. We must not blame the children, but fight for them. Rich or poor, healthy or ill, docile or surly, no child is expendable. At every stage, at every turn, our children - and their families - both individually and collectively, need advocates.

In this issue on child advocacy, we pay particular attention to the plight of children in the health care system. Children, especially younger ones, but older ones too until of legal age, are at the mercy of the adults in their lives. Often these adults are loving and knowledgeable, sometimes they are not. But always they are critical to the child's well-being. As advocates, we must listen to all the adults, but we must listen also to the child, put ourselves in the child's place, be willing and able to stand up for the child's point of view, to empathize and to educate.

We have touched, in these pages, on a number of topics relating to children, from the agonizing personal decisions faced by one set of young parents to broad – and sometimes controversial – public health initiatives like universal hearing screening for newborns, from efforts to reduce adolescent smoking in upstate New York to advances in reducing mother-to-infant HIV transmission worldwide. We are heartened by the outstanding work being done for children in research and academia and by advocates in the field, and we are deeply grateful to all our contributors for taking time to share their knowledge and experience.

SPECIAL NOTE:

It is with heavy hearts that we mark the passing of Nancy Achille, HA '89, after a long and most valiant struggle with scleroderma. Nancy came to the program as a practicing nurse in the Cardiac Intensive Care Unit of Nyack Hospital, concerned about the lack of caring communication between patients and health care professionals. She was already an advocate: knowing, irrevocable, determined. We learned so much from her, and we laughed – a lot. She moved to Orleans, Massachusetts, in 1994, where she joined the Visiting Nurses Association of Cape Cod. Nancy died in the home she built, surrounded by her children and by the birds she took such pleasure in feeding outside her bedroom window.

Contributions are being accepted in the name of Nancy Coulter Achille by: The Scleroderma Foundation, 89 Newbury Street, Suite 201, Danvers, MA 01923.

We will miss you, dear Nancy.

– Karen Martinac and Irene Selver

<http://www.slc.edu/pages/h/health>

The HEALTH ADVOCACY BULLETIN is published twice a year by the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, New York 10708.

Editors: Karen Martinac
Irene Selver

Program Director: Marsha Hurst

Production: Riverside Resumes

Phone: Karen Martinac at (253) 761-3070
Irene Selver at (212) 222-2576

E-mail: healthad@mail.slc.edu

All material in the HEALTH ADVOCACY BULLETIN is the property of the authors and may not be reprinted without permission. Opinions expressed are not necessarily those of the editors nor of the Health Advocacy Program.

The perioperative audiotapes featured in the Fall 1998 HEALTH ADVOCACY BULLETIN are available by contacting Linda Rodgers at 70 Maple Avenue, Katonah, NY 10536, tel: (914) 232-6405.

Children and Families in Health Care: Issues for Advocates

Continued from page 1

team to accede to their wishes. Young children do not have that capacity; thus, it becomes most important to monitor that relationship in order to promote the best outcome for the child patient. Does the family feel that it can help support the child's recovery? Does the child feel comfortable with the level of family involvement in his/her treatment? How can the treatment team help to facilitate appropriate family involvement?

Cultural and family-held beliefs may affect the nature of family involvement. Some cultures may not believe that children should be told about their illness; these beliefs should be respected if possible. There is some evidence that congruence between coping styles for illness for caregiver and child may lead to less distress for the child, rather than the particular coping style chosen by the child per se (Lumley, Abeles, Melamed, Pistone, & Johnson, 1990). For example, if both caregiver and child use an avoidance coping style ("let's not talk about our problems"), then the child will tend to feel less distress. If caregiver and child use differing styles, i.e., the child uses an approach style ("what is the matter with me?") and the caregiver uses an avoidant style ("let's not talk about our problems"), then the child will experience more distress.

Caregivers may also experience feelings of grief, anger and guilt, especially if they have an unclear understanding of the causes of the presenting condition. Attending physicians may not be able to provide answers that will assuage

these feelings in the face of uncertain etiology. The circumstances surrounding the child's condition, e.g., a genetic condition or an accident, may increase guilt and anger within the family. These feelings may impact on the resources a family can bring to bear in coping with the child's illness, and thus affect the nature of the family-patient interaction.

Developmental Issues

It is an undeniable fact that children grow and change physically, intellectually and emotionally over time; it is also apparent that many adults can forget this fact in their everyday interactions with children. For example, many parents punish their children for selfishness because their children have refused to share with others, or have taken a toy away from another child. They may expect very young children to act more "grown-up," to understand how their behavior affects others and to take responsibility for their actions before these children have developed the cognitive ability to take another person's perspective into account. In the same way, they may expect their children to have a more (or less) grown-up acceptance and understanding of illness. As a result, parents and other adults may

over- or underestimate the abilities and resources that children are able to muster in coping with illness. For example, in my work with health psychology undergraduate students, I have heard many stories about my students' pediatricians' refusal to see their longtime

“Health care providers, parents and guardians often find it difficult to come to a consensus on the proper treatment of children in the system.”

patients as young adults, able to make informed decisions about their health care. Some pediatricians will not explain their diagnoses to adolescent patients, or address psychosocial issues such as sexuality or drug and alcohol abuse because the patient is "too young" or "doesn't do those things." These patients make decisions and cope with the consequences without the best possible support from health care providers.

Conclusion

Advocates for child patients must be careful to obtain children's perceptions of their experience rather than caregivers' or physicians' interpretations of the child's experience. Advocates with a clear understanding of child development can help caregivers, physicians, and other health care providers work together with the child patient to provide the best possible medical care.

Linwood J. Lewis, Ph.D. is a developmental psychologist interested in the effects of culture and social context on the health of children and families. He is currently a guest faculty member of the Department of Psychology at Sarah Lawrence College.

ALUMNAE/I ASSOCIATION

The Health Advocacy Program is in the process of forming an Alumnae/i Association. This association will allow those involved to continue the mission and work of the program, along with strengthening our commitment to the program. Under the direction of Dr. Marsha Hurst, the Health Advocacy Program and Alumnae/i Association can accomplish a great deal.

The Health Advocacy Alumnae/i Association has developed several goals. The first is to have this association function as a resource network for both students and graduates. This can include information sharing on internships, job placements, and post-graduate studies. A second goal is to develop a fundraising program for scholarships, financial aid, and continuing education programs. A third goal is to establish a separate health advocacy library collection. In addition, the association is looking for alumnae/i to become involved in a mentoring program for new students.

A letter was sent to all alumnae/i during the month of March, to solicit ideas and support for this association. Any alumnae/i who have not responded to this letter are requested to do so as soon as possible. We are counting on all of you to make this program a success.

— Lisa Birnbaum HA '98

Giving Opportunity to Youth: An Early Childhood Initiative in Yonkers, NY

by Rachel Grob, M.A.

Children have always occupied a special corner in the health advocacy field. Children's need for advocates is arguably among the most compelling, given that they have no direct political power; that they are utterly reliant on others - at least during the early years - for their health and very survival; and that they will ultimately shape the future for all of us, drawing heavily upon the experiences and opportunities they were afforded during childhood as they do so. Of course, children suffering from health and mental health conditions are greatly in need of advocacy around specific issues and needs. But health advocacy for children must encompass the entire population, or we will lose critical opportunities to promote healthy development, maximize human potential and avoid preventable problems. This article is intended to briefly highlight some of the recent research which supports this broad-based, prevention-oriented health advocacy approach, and to summarize an early childhood initiative inspired by this literature that is now being implemented in the city of Yonkers, New York.

Emerging research about the human brain and the impact of environment on children's development is currently revolutionizing health and human service theory, policy, programs, and practice. As summarized in the Carnegie Corporation's seminal 1994 report entitled "Starting Points: Meeting the Needs of Our Youngest Children," key findings about early childhood development are as follows:

1. Brain development that occurs before age one is more extensive and more rapid than was previously known;
2. Environmental influence over brain development is much stronger than previously suspected;
3. The influence of early environment on brain development is long lasting and may actually increase over time;
4. Early environment and exposure affect not only the number of brain cells a child has and the number of connections formed between them, but also the way these connections are "wired," i.e., how the brain's architec-

ture is created;

5. There is strong scientific evidence regarding the negative impact on brain function of early stress.

The realization that "early neurological development is shaped not only by physical conditions, but also by an individual's social environment" has profound implications for understanding both the protective function of healthy nurturing, and the damage that can be caused by early trauma. The Families and Work Institute's "Rethinking the Brain" research summary notes:

"Recent brain research suggests that warm, responsive care is not only comforting for an infant; it is critical to healthy development. In fact, a strong, secure attachment to a nurturing caregiver appears to have a protective biological function, 'immunizing' the infant to some degree against the adverse effects of later stress or trauma.... There is mounting evidence that the kind of care infants receive... has a decisive impact on their regulatory capacities - in particular their emerging ability to display and modulate emotions."

... early neurological development is shaped not only by physical conditions, but also by an individual's social environment.

Conversely, the negative impact on brain development of early childhood trauma, abuse, neglect, and inadequate stimulation can be tremendous, particularly in the absence of a consistent nurturing caregiver:

"Early experiences of trauma or abuse... can interfere with development of the subcortical and limbic areas of the brain, resulting in extreme anxiety, depression, and/or the inability to form healthy attachments to

others. Adverse experiences... can also impair cognitive abilities, resulting in processing and problem-solving styles that predispose an individual to respond with aggression or violence to stressful or frustrating situations.... But trauma and abuse are hardly the only conditions that can lead to developmental delays or impairments; as many researchers have shown, emotional neglect, social deprivation, and a chronic lack of appropriate stimulation are among the other factors that may jeopardize early development."

These findings from the neuroscience community have been combined with and used to refine social science research on a variety of risk factors affecting children. Clear relationships between developmental outcomes and a range of social problems - e.g., poverty, teen parenting, untreated parental depression and mental illness, low educational attainment - have been demonstrated with increasing confidence. At the same time, a consensus regarding the essential elements of a comprehensive, coordinated system of primary and secondary prevention for young children and their families is beginning to emerge. These elements include: active prevention of birth risks, including provision of universally-available prenatal care; teen pregnancy services; child health services; early intervention for infants and toddlers with developmental delays; high-quality

child care; parenting education and support, including home visits and access to community centers and other group settings.

Executive staff at the Julia Dyckman Andrus Memorial, a non-profit community-based agency offering restorative and preventive services for children in Yonkers, N.Y., began studying the literature on brain development and prevention strategies during the mid 1990s. In 1998, the Board of Directors and agency

Giving Opportunity to Youth: An Early Initiative in Yonkers, NY

Continued from page 4

leadership made a commitment to acting on this information by launching an Early Childhood Initiative (ECI) for the Yonkers community with the broad goal of making the city a "center of excellence" for young children and their families. Our conceptual model for a community-wide initiative was informed by examples from a number of other communities throughout the country (e.g., Hampton, Virginia; the state of Florida; San Mateo County, California), and drew heavily on the advocacy work of Rob Reiner's "I Am Your Child" campaign.

Fortuitously, two key events facilitated the rapid unfolding of Yonkers' ECI: 1) a planning grant providing significant resources was secured from a private foundation; 2) Yonkers' mayor, in coordination with the city's major hospitals, brought together many key stakeholders to create a community partnership for improving health entitled "Healthy Yonkers."

Drawing on funding from the planning grant and utilizing the nascent "Healthy Yonkers" initiative to begin building an active working group, Yonkers' ECI was launched in the autumn of 1998 with the following articulated vision, mission and goals.

Vision

Children in Yonkers will be born healthy, and will be nurtured and supported by their families and the community so that they maintain good health, are prepared to learn, and achieve their full developmental potential.

Mission

The Early Childhood Initiative will develop and implement coordinated, on-going effort directed at expectant families (i.e., those expecting the birth or arrival of a baby) and young children (i.e., infants and toddlers from birth to age three). Specific components of this effort will:

1. increase community awareness about the needs of expectant families and young children;
2. maximize the abilities and build on the strengths and competencies of families as they care for their young children;
3. enhance the well-being of children by building a community that provides support, safety and respect for its expectant families and young children;

4. provide formal and informal learning opportunities for young children and their families.

Goals for "Phase I," the Initiative's Planning Phase (10/98 - 4/00)

1. Develop a working collaborative, comprised of public and private sector representatives and families, focused on the prenatal period and early childhood.
2. Comprehensively assess the unmet needs of Yonkers' expectant parents and young children and their families.
3. Produce a "Yonkers Early Childhood Databook" that will reflect the status of Yonkers' expectant parents and young children and families, and serve as a baseline against which to measure the Initiative's impact.
4. Raise awareness in the community regarding prenatal and early childhood issues and the Early Childhood Initiative.
5. Initiate joint training, for families and professionals, on issues related to the prenatal period and early childhood.
6. Convene an Early Childhood Leadership Symposium that will bring experts in the field of early childhood to Yonkers.
7. Develop and seek funding for collaborative proposals to meet specific identified service needs of the target population.

8. Develop goals for "Phase II," the Initiative's Service Development Phase.

Four subcommittees have been established to accomplish these eight goals, and work in each area continues apace. The ECI Working Group includes highly committed representatives from families; public and private service agencies; advocacy organizations; the school district; local hospitals; religious institutions; child care providers and advocates; the mayor's office; and our local academic institution, Sarah Lawrence College. While the ECI is too young to have yet produced measurable outcomes, we have already succeeded in creating what I believe must be the foundation under-girding any truly effective, prevention-oriented children's advocacy effort: a collaborative framework for building knowledge about and commitment to Yonkers' youngest children and their families.

Rachel Grob graduated from the Health Advocacy Program in 1992, and is currently working towards a doctorate from the City University of New York. She is Director of Policy Analysis and Planning at the Julia Dyckman Andrus Memorial, and leader of Yonkers' Early Childhood Initiative. If you have questions about the Initiative, or if you are interested in getting involved, Rachel can be reached at (914) 965-3700, ex. 282.

SELECTED HA STUDENT FIELD PLACEMENTS Spring & Summer 1999

American Cancer Society	Mount Sinai Hospital Palliative Care
Center for Economic and Community Development, SUNY Oneonta	Mount Sinai Hospital Patient Representative
Central Suffolk Hospital	New York Hospital
Delaware County Rural Health Alliance	New York Public Interest Research Group (NYPIRG)
Families USA (Wash DC)	Office of the Inspector General, DHHS
Health Care Bureau, Office of the Attorney General, NYS	Operation Restore Trust, NYC
Health Care Committee, New York State Assembly	Public Advocate's Office, NYC
Hospital for Special Surgery	Rhode Island Hospital
Institute for Biomedical Research, Hackensack Hospital, NJ	St. Luke's Hospital and Medical Center
Julia Dyckman Andrus Memorial (Early Childhood Initiative)	St. Vincent's Hospital, Harrison (mental health)
March of Dimes Public Policy & Government Affairs Office (Wash. DC)	Susan G. Komen Breast Cancer Foundation (CT)
March of Dimes Resource Center	UNICEF
	Westchester County Child Health Task Force
	Westchester Medical Center

Children's Health Insurance: Hopes and Hurdles

by Sherisse Webb, M.A.

When the state Children's Health Insurance Program (CHIP) was first introduced in July, 1998, it was hailed by health advocates and the media as the initial phase of incremental reform that would eventually achieve the universal health coverage that the Clinton Administration failed to realize in 1994.

The purpose of the legislation is to assist states to expand health coverage to insure children whose family incomes exceed the requirements for Medicaid, but are insufficient to support private insurance coverage. One and a half years later, the program is once again receiving a great deal of media attention. However, disappointing enrollment figures have transformed the initial enthusiasm for CHIP into impatience and skepticism. An estimated 2.5 million children below the age of 19 from working poor families are eligible for the program nationwide. Yet only 800,000 previously uninsured children have been enrolled in CHIP since it began.

As a Policy and Procedure Analyst for Indiana's CHIP, I can attest to many of the hurdles that threaten the success of state programs and may explain the disappointing enrollment figures. Like several other states, Indiana realized that the development of a new health insurance program would require significant time and resources. Consequently, as Phase I of Indiana's CHIP, the state implemented a one-year Medicaid expansion to provide coverage to all children below the age of 19 with family incomes at or below 150 percent of the federal poverty level. In the meantime, Governor Frank O'Bannon convened a 21-member Advisory Panel of health care professionals, insurance executives, legislators, educators and parents to develop a blueprint for the long-term implementation of CHIP in Indi-

ana. It is now the responsibility of the legislature and Indiana's Office of the Children's Health Insurance Program to translate the recommendations of the Advisory Panel into state policies and procedures.

Therein lies the challenge. The goals and requirements of the program, as outlined in state and federal law, are time- and labor-intensive and do not necessarily concur with experiences in the field. For example, to increase enrollment, great emphasis has been placed on implementation of outreach

more of a challenge as the family incomes of the target population increase.

Despite the many political and logistical challenges that surround CHIP in Indiana, the state has succeeded in enrolling more than 70 percent of the estimated 91,000 uninsured children who are eligible for Medicaid since the Phase I CHIP expansion became effective July 1, 1998. I suspect, however, that when Phase II of the program is implemented to provide coverage to children in families with incomes between 150 and 200 percent of the federal poverty level, additional hurdles, similar to those being experienced in other states, will surface.

Considering the number of unexpected challenges that have afflicted CHIP programs throughout the United States, it is not surprising that the states are celebrating the enrollment of 800,000 children. The expectations that have been imposed on the program since it was introduced seem to have distorted that fact that CHIP has been a significant undertaking for states and remains a relatively new program.

In addition to all of the necessary technological, policy, and cultural adjustments, states will have to devise aggressive and innovative outreach strategies if they hope to regain CHIP's once positive image as a groundbreaking initiative. Indiana was recently awarded a grant from the Robert Wood Johnson Foundation to do just this.

Three innovative outreach initiatives will be piloted in eight communities that are representative of the state's racial, ethnic and geographic diversity. Only time will tell whether such efforts will be sufficient to ensure the future of the program.

Sherisse Webb is a Policy and Procedure Analyst for Indiana's Children's Health Insurance Program and a December '98 graduate of the Health Advocacy Program. She moved to the United States in August, 1997, from Canada, one year after completing her undergraduate degree in Bioethics at the University of Toronto.

“The goals and requirements of the program ... are time- and labor-intensive and do not necessarily concur with experience in the field.”

and education initiatives. However, outreach workers are beginning to realize that the target population for this program is not found in the same neighborhoods or reached with the same promotional strategies as the population traditionally targeted for Medicaid enrollment. Also, the federal legislation requires that states coordinate CHIP with other public health care programs for children. Yet the success of the program requires that states ensure that the stigma often associated with public health care programs does not taint CHIP. This balancing act becomes even

The Pediatric Parent

by Jennifer DePeters, M.A.

The pediatric patient presents complexities for a patient representative. Legally, unless the pediatric patient is eighteen years of age, married, or emancipated, the patient's parent is the legal decision-maker. This does not mean, however, that health care professionals and parents do not provide the young patient information, nor consult him or her in decision-making. In many cases, the patient is able to understand information and may even realize death is the prognosis. Nevertheless, this writer's experience as a patient representative is such that when someone mentions the words pediatric, infants' unit, or children, the image of a parent at bedside, more often hovering over the bed, thus obscuring the patient, is immediately what comes to mind. You can be sure the person standing next to the bed is the one calling the shots, thus the health care decision-maker.

The inquisitive, puzzled look on a child's face is difficult for parents to ignore and deny ...

Perhaps, what follows is of some assistance for patient representatives, especially since staff looks to us professionals when a patient's parents are interfering in the rendering of care. An intensive care nurse once remarked during a particularly high incidence of traumas, "I can do the technical, complex clinical care of this child, but I cannot perform my duties with this parent here." Often, the staff feels as though the parents are interfering with care when they are standing at the bedside and asking questions. It is critical during times like these to consider the parent's position with respect to what is happening to the child before banning the parent from the bedside.

An easily dissected scenario examines this parental position. One of the most common yet challenging situations arises when a pediatric patient's symp-

toms seem to be gastrointestinal related, one in which his or her eating habits and schedule are affected. There is an added layer of anxiety for not only the child, but more expressively and prominently, for the parent. This added layer of parental anxiety can be attributed as follows: parents, whatever their parenting skills, regardless of class, education, or age, know food. One form of love and concern that is easily expressed is through feeding the child. Health care professionals often will delay, suspend, or deny eating and fluid intake. Parents, regardless of whether these activities are at the root of the problem or aggravating the symptoms, insist "this not eating business," or in the clinical world, "NPO status," end as soon as possible. Delayed tests, often ultimately rescheduled, can add to parental anxiety, not just for the inconvenience, but because the child may

have needlessly been deprived of food. To be fair, a child, who knows his or her parent can be counted on for nourishment, will be looking for that bottle, Cheerios, or juice, assuming this expectation to be met. That inquisitive, puzzled look on a child's face is difficult for parents to ignore and deny, especially if the child is otherwise healthy and just undergoing a diagnostic or routine test. Needless to say, even if a child is too sick to want food, when a parent gives him or her food (nourishment and love), this brings a feeling of normalcy, and specifically control for both child and parent in an otherwise out-of-control hospitalization, disease, or diagnosis.

In summary, this one piece of normalcy has been taken away from a child, and more importantly, from a parent. Not only will the child be confused from this deprivation of food, but also the parent is left feeling out-of-control by this role deprivation.

Is it that strange, then, for a parent with a child who may be on a ventilator and deeply sedated, to start questioning how the child is being nourished? The

tubes, the buzzing and beeping of the high-tech machinery, may be beyond comprehension for a parent in crisis. How the child is being fed, a basic need of everybody's life, is somehow the only aspect of the care being provided that a parent may question.

... including the parent ... can add a sense of control and normalcy in this unnatural setting.

There is no magic answer or catchall reply that a health care professional, us included, can offer. Certainly, thorough explanations, when the time is right, helps; "When I am finished doing such and such, I'll explain how your child is being fed or why we cannot start hydration." References to the parent's role or including him or her in the technical administration of nourishment, however small the parent's part, can add a sense of control and normalcy in this most unnatural setting. Patient representatives can deflect some of the anger that is being focused on the medical provider. This writer's favorite response to the badgering parent who needs to leave the area, if only for a brief period, is, "Help us help your child."

Staff depend on us to not just assist in the support of the pediatric patient, but also to be the voice of the patient, or in this case, the parent. Our quick response to the bedside can offer a more reasonable solution in determining why a parent is reacting a certain way. Specifically, knowing why parents focus on certain aspects, such as eating, can be helpful in calming down parents and getting parents' questions answered. Ultimately, the patient representative, by assisting parents and staff, aids the pediatric patient, even if the patient cannot tell us that.

Jennifer DePeters, HA '96, completed her undergraduate degree at Boston College. She was a patient representative for three years at the Westchester Medical Center with a focus on pediatric and maternal patients. She recently joined Memorial Sloan-Kettering Cancer Center as a patient representative.

“You Have Rights: A Patient Rights Statement for Children”

(This Patient Rights Statement for Children was written by Karen DeWitt, R.N., a long-time pediatric nurse and now head of Customer Service for MultiCare, a consortium of doctors, hospitals and related facilities in Western Washington State. It has been in circulation since 1992, a response to a realization that adult rights don't necessarily address children's needs. It is designed for parents to read to children, a way to involve families more in their children's care and to reassure them that their needs will be met. It is given to every patient on admission to Mary Bridge Children's Hospital, and is available in brochure or poster form in the hospital for outpatients, in medical offices, treatment and waiting rooms, at registration desks, and at other sites in the MultiCare system where children are seen. A new version is being written to include ambulatory patients. The excerpt printed here is the "Children's Rights" segment of the brochure. The complete text includes "Parent/Guardian Rights and Responsibilities" and a brief discussion on where to turn for help. For copies of the brochure, contact Ms. DeWitt at MultiCare Health System, Customer Service, PO Box 5299, Tacoma, WA 98415, or by phone at 253-552-1263.)

A note to adult caregivers: this statement is meant for children who can read at a fifth grade level. Children who cannot read at a fifth grade level will need you to read this statement to them and answer questions. You should be sure your child understands his or her rights.

When you come to see the doctor, visit the hospital or a clinic, or have a test or other procedure done, you have rights. This means there are some things you always have the right to do or have that no one who is not your parent or guardian can take away from you. These are your rights:

Access:

- You have the right to see a doctor or get help when you need to.
- You have the right to have visitors, talk on the phone, and get mail, as long as it doesn't keep you from getting the care you need.
- You have the right to have your mom or dad or some other important adult with you all the time, unless it would keep you from getting the care you need.
- You have the right to be treated well and fairly.
- You have the right to have people listen to you.
- You have the right to have your pastor, priest, rabbi, or other people you want to come and talk to you.

Information

- You have the right to know what problems your body might be having, and how we think we can help.

- You have the right to ask as many questions as you need to, anytime.
- You have the right to know what is happening to you and why.
- You have the right to understand what people tell you.
- If you need an interpreter, we will get one for you.
- When people come in your room or care for you, you have the right to know who they are, what their job is, and what they are going to do.
- If you are sick or are having surgery, you have the right to know how long it will take to heal and what you will have to do to help.

Privacy

- You have the right not to talk to or see any visitors you don't want to.
- You have the right to privacy. This means that only your doctor or nurse will see your body or hear what you have to say unless you tell someone else it is o.k.
- You have the right to have what you say to us kept private.

A reasonable and safe environment

- You have the right to be safe.
- You have the right to ask to move to another room if something about your room, other patients or their visitors bothers you.

We need your help

- You need to tell someone if you don't understand what you are told.
- You need to tell someone if you have questions or want to know something.
- You need to tell someone if you hurt or feel sick.
- You need to tell us how we can help you feel more comfortable.
- You need to tell someone if you want or need something.
- You need to listen to the doctor or nurse and try to do what they say.
- You need to stay in your room unless you ask to leave it.

WHAT DO CHILDREN EXPECT WHEN THEY GO TO THE HOSPITAL?

A new method of pre-operative patient orientation has been adopted at the Hasbro Children's Hospital in Providence, R.I.: an interactive CD-ROM. This computer program teaches kids, both inpatients and outpatients, what to expect in their visit to Hasbro Surgical Services. Patients and their parents using the program "virtually" visit Surgical Services' rooms, learn about the typical equipment used, meet the Surgical Services staff, and become familiarized with the pre- and post-operative patient experience at Hasbro. The CD-ROM was designed and produced by four undergraduate students at Brown University who were enrolled in the "Educational Software Seminar" taught by Prof. Roger Blumberg, a Visiting Lecturer in the Department of Computer Science and Research Fellow in the Institute for Elementary and Secondary Education. For additional information contact Prof. Roger Blumberg at rbb@cs.brown.edu or Oliver Hurst-Hiller at ohh@eudoramail.com

Should This Baby Live?: An Ethical Dilemma

by Alice Herb, J.D., LL.M.

Cloning, fertility treatment, egg donation, in vitro technology – all sorts of reproductive rights issues snare media attention, while the often tragic drama surrounding treatment decisions for an imperiled newborn receives only intermittent attention. Yet these life and death sagas occur daily in neonatal intensive care units everywhere and offer far more compelling issues to consider. The fate of such a tiny individual - who sometimes is scarcely larger than the palm of my hand - raises tough, heartbreaking dilemmas for parents and clinicians, asks serious questions about quality of life and taps heavily into our already scarce financial resources. On a recent consultation, I was reminded how very sad, difficult and sensitive the situation always is.

Baby Andy started life with what seemed to be the whole deck stacked against him. He was born at 25 weeks gestation (15 weeks early) and weighed a mere 674 grams, less than two pounds. His APGAR score, a test to determine an infant's physical health in the initial minutes of birth, was abysmally low and he suffered severe asphyxia (lack of oxygen.) In addition, he sustained severe bleeding in the brain (grade 4 IVH - intraventricular hemorrhages), a devastating event for such a fragile being, and he was also hydrocephalic (an abnormal amount of fluid in the brain). At the time of the consultation, Andy was three weeks old and was being kept alive by a host of technological equipment. First there was the respirator to assist his breathing. Then a tube through his nose to give him food. Finally, to drain fluid from the brain, Andy had just had a shunt inserted. In all, it was quite remarkable that this tiny person was still alive. But that was exactly the point. Should extraordinary effort and technology continue to be used for such a severely compromised young life? Given such a heavy burden, would it be in his best interest to keep him alive? Is it possible

not to do so? The consultation was called at a time that allowed for some calm deliberation. Andy's condition was stable at the moment and no immediate intervention was needed.

The parents, a very caring and involved couple in their mid-twenties, had known that there might be something wrong with their baby before he was born. The pregnancy had been troublesome. Premature contractions finally could not be stopped and precipitated the premature birth. As the Mom and Dad described it, they had anticipated that the baby might be physically challenged. They had promised each other that if that were the case, they would learn to handle it. Unfortunately, Baby Andy may have far more serious disabilities than the parents may have imag-

“I can think of no more difficult dilemma than to have to make a decision concerning a child's continued life.”

ined. The neonatologists had tried to inform the parents about the baby's condition from the outset, but Mom and Dad were not quite prepared to hear the full story.

Baby Andy's prognosis was dismal. According to the neonatologists, the odds were overwhelming that Andy would never walk, talk or interact with others. In fact, he probably would not even recognize his own parents. He was burdened by three major medical difficulties: the grade 4 bleeds, the asphyxia at birth and the extreme prematurity of his birth, all of which led to strong indications of brain damage - damage borne

out by a sonogram and a CT scan. Yet it was still too early to say definitively that Andy was profoundly brain damaged. There was that small chance that in spite of all of the insults he had suffered, he nonetheless would be able to function, with perhaps some developmental delay. It would be months before his functional capacity could be assessed. Yet treatment decisions had to be made in the interim and it was not clear that continued aggressive treatment was in Andy's best interest.

The consultation was meant to serve several purposes. It was an opportunity for the parents to meet and talk to the multi-disciplinary team involved in their son's care. For the clinicians, it was a time to describe, once again, Andy's medical problems and condition; to present the various treatment options; to clarify those options in terms of benefits and burdens; to answer questions; to provide guidance and support to the parents in making their decisions; and finally to formulate a care plan for Andy.

The overriding issue was whether to continue aggressive care for Andy. What was in the best interest of Andy? Did the burdens of continued treatment so outweigh the benefits that it would be more merciful to allow him to die? How precious is life? Is it in Andy's best interest to be kept alive at all costs? Or was there enough of a hope that Andy could pull through, not in a vegetative state but with enough capacity to interact with his parents and achieve some function? No one could say for certain but the physicians felt the prognosis was dismal. The first test would come some time down the road when bottle feeding was introduced. If he started to suck and eat, that would be a good sign, but not yet definitive. Not until his alertness could be assessed would there be any indication of Andy's capabilities. And that was months away. The options offered to the parents were:

1. Continue to provide all care;
2. Enter a Do Not Resuscitate Order (DNR). This order would mean that

Should This Baby Live?: An Ethical Dilemma

Continued from page 9

- if Andy stopped breathing or his heart stopped, he would be allowed to die;
3. Enter a DNR and a Do Not Intubate Order. This would mean that if Andy's breathing tube came out, it would not be reinserted and he would not be resuscitated;
 4. Withdraw aggressive care; i.e. make Andy comfortable and remove him from the artificial respirator.

The physicians were loathe to make a recommendation to allow Andy to die while there was still a small chance of quality life ahead. They were also aware that it was the parents, not the clinicians, who would have the responsibility and care of Andy. I can think of no more difficult dilemma than to have to make a decision concerning a child's continued life. These are without a doubt the most agonizing decisions anyone can be faced with. But who should decide? Should it not be the parents? After all, who is generally most concerned about a child's interest? But how can parents be expected to make such difficult decisions? Doesn't their emotional state, their natural inclination to want to do everything for their child, militate against their ever being able to make an informed decision?

Imperfect as it may seem, it is nevertheless the parents who have the responsibility and therefore the decision-making right. With infants, unlike adults who have lost decisional capacity, we have no notion about what the life values of this being are or would be, and we therefore must rely on the parents' values, albeit with the limitation that the parents' decision be considered in their child's best interest. The parental prerogative to make decisions is not absolute. Physicians and other clinicians are also advocates and may refuse to follow parental decisions if the decisions are deemed not in the child's best interest or would do harm. The law also limits parental power, e.g. parents may not refuse on religious grounds life sustaining treatment for a child.

In Andy's case, it was not necessary to decide immediately. Unfortunately, future crises would most likely occur and each crisis would present a new opportunity to revisit the updated situation. The most critical concern in delaying a decision was whether Andy was in pain or continual distress. The clinicians believed that he was not in pain or distress and so the parents made the choice of waiting to make a decision. All care would continue.

My thoughts, however, turned to one very wise young father who, in a similar situation, said to me that he didn't know whether, in five years, he would be sorry that he didn't have a son to kick a ball around with or if he would be sorry that he had a son who couldn't kick

“Imperfect as it may seem it is nevertheless the parents who have the responsibility and therefore the decision-making right.”

a ball. The problem with either decision is that the parents have to live with that decision forever. And in this individual case, the specter of money — who will pay — was not even raised.

Alice Herb is an attorney/ethicist with faculty positions as assistant clinical professor at SUNY Health Science Center at Brooklyn College and adjunct at Sarah Lawrence College. She teaches bioethics to medical students, medical residents, nurses and other health care personnel as well as Health Advocacy students. She is an ethics consultant and member of a Bioethics Committee, Infant Bioethics Committee, and an Institutional Review Board.

HEALTH ADVOCACY II GUEST SPEAKERS Spring Semester 1999

Ruth W. Lubic

President & CEO, District of Columbia Developing Families Center

Jackie Case

Director, NYC Long Term Care, Ombudsman Program

Jane Morris

Clinical Coordinator of Palliative Care, Department of Geriatrics, Mount Sinai Hospital, NYC

Cynthia Mead

Health Advisor, NYC Department of Health, Women's Health Line

Lindsey Farrell

President and CEO, Open Door Family Medical Health Centers

Germaine Jacquette

Infectious Disease Specialist and former Deputy Commissioner of Health, Westchester County Department of Health

Patsy Yang-Lewis

First Deputy Commissioner, Westchester County Department of Health

Georganne Chapin

President and CEO, Westchester Prepaid Health Services Plan

Amy Paulin

Co-Chair, Westchester Women's Agenda

Jeffrey S. Gold

Bureau Chief, Health Division, Office of the Attorney General, NYS

Suri Duitch

Staff Associate for Child Health and Mental Health, Citizens' Committee for Children

Cora Greenberg

Executive Director, Westchester Children's Association

Judith Lichtman

President, National Partnership for Women and Families

Renee O'Rourke

Health Care Administrator, Westchester County Department of Health

Victor Alvarez

Staff member, Living Together (AIDS Advocacy Organization)

Genetic Testing in Children: Weighing the Issues

by Diane Myles, M.S.

Testing children at risk for genetic disorders has been a recognized part of both pediatrics and medical genetics for many years. Children may undergo genetic testing for a variety of reasons. Genetic testing may have direct implications for the health of the child, either immediately, in later childhood or in adult life. Therapeutic or preventive measures are sometimes available which could influence or alter the course of the disorder if started early. In the absence of medical benefits, genetic testing may provide critical information about the presence or absence of a disabling disease, which may be useful in making reproductive decisions and future education and career choices. In some circumstances, genetic testing may not appear to offer any benefit, but is requested by the parents or the child. Many parents feel that knowledge of a future serious disorder in their child is preferable to prolonged uncertainty.

Genetic testing in children raises many ethical, legal and psychosocial issues and concerns. Testing children for cancer susceptibility raises additional concerns and, in many cases, the issues remain unresolved and testing children remains controversial. The complex issues which must be considered when children are being tested for genetic conditions include determining the medical risk-versus-benefit ratio, devising appropriate assent mechanisms for children of various ages, and the psychological and social impact of testing on children's development. Issues of confidentiality and discrimination must also be considered. Although parents may believe that they are acting in the best interests of their child, genetic testing may have negative implications and potentially damaging effects on their own future and the child's future. Sometimes an immediate benefit, such as a reduction in uncertainty and/or anxiety, causes parents and professionals to overlook the potential harms of genetic testing. Stigmatization, including lowered expectations within the family and feelings of "survivor guilt," are longer-term psychosocial outcomes which may have implications for the functioning of the family unit. Testing may also affect the child's self concept and bonds between the child and other family members.

“Many parents feel that knowledge of a future serious disorder in their child is preferable to prolonged uncertainty.”

It has been recommended by geneticists and ethicists in North America and the United Kingdom that genetic testing only be performed in childhood if there is clear benefit to the minor. General guidelines published by the American Society of Human Genetics (ASHG) and the American College of Medical Genetics (ACMG) suggest that timely medical benefit should be the primary justification for genetic testing in children. In recognition of the fact that many of the benefits and harms of testing are psychosocial as opposed to physical, substantial psychosocial benefit to the competent adolescent is also considered appropriate justification for genetic testing. The ASHG and ACMG feel that genetic testing should generally be deferred in situations where the medical or psychosocial benefits will not become relevant until adulthood. In cases where the balance of benefits and harms is uncertain, the decision regarding testing should be

based upon the unique circumstances of each family. In such situations, it is important for the provider to facilitate a thorough discussion of the potential benefits and harms to the child and assess the family's understanding of these issues. Ultimately, however, the provider should respect the decision of competent adolescents and their families.

A major question concerning presymptomatic genetic testing is: at what age should the test be justifiable? In some conditions, such as neurofibromatosis type I (NF1), where phenotypic abnormalities sufficient to allow a clinical diagnosis are almost always present by 5 years of age, the need for predictive genetic testing is minimal. In late-onset disorders such as Huntington's disease, Alzheimer's disease and hereditary breast and ovarian cancer, where symptoms are rarely seen in childhood, predisposition testing is generally not recommended for children. In disorders that are much more variable, where pressure to test children may be greater, the decision becomes more complicated.

The potential loss of autonomy for the child is a focus of much concern in relation to predisposition testing of children. When children are tested in childhood, at the request of their parents, they lose the right to make an informed decision regarding testing when they reach the age of majority. In addition, the child loses the right not to be tested and his right to privacy. Out of respect for a child's autonomy, it has been suggested that in the absence of clear medical benefit, parents should "restrain their desire to know" and not pursue genetic testing for their children.

The term "assent" is used to distinguish a minor's agreement to parental decisions about treatment, research or testing, from an adult's legal "consent," and is based on the assumption that a child does not have sufficient autonomy

Genetic Testing in Children: Weighing the Issues

Continued from page 11

to request or consent to a procedure independently, but does have a great enough understanding of the procedure to agree with his parents' decision. In regards to research, it has been recommended that children seven years of age or older be required to provide assent. With regards to predisposition testing, it has been suggested that it is unethical,

*It has been recommended ...
that genetic testing only be
performed in childhood if there is
clear benefit to the minor.*

even in the event where it is legal, for a parent to consent to predisposition testing for an unwilling child, when the child is of sufficient age to understand the issues involved. In a study designed to examine the attitudes of mothers of pediatric oncology patients towards cancer predisposition testing in children, 23% of mothers felt that children's views should be routinely sought and considered in the decision about genetic testing and 55% said that consideration of the child's wishes depended entirely upon the age of the child. Twenty-two percent of mothers stated that they would not involve their child in discussions or decisions regarding testing. The mothers voiced a wide range of opinions about the age at which a child should be involved in the decision-making process. At this point in time, issues concerning autonomy and providing assent for predisposition testing in childhood remain unresolved. To determine the age at which a child can sufficiently understand the relevant issues to participate in the decision-making process and give informed assent will involve complex analysis. Careful examination of individual risks and benefits will be necessary to protect the rights of minors.

There are clearly some circumstances where testing children for an inherited cancer predisposition is beneficial. Familial adenomatous polyposis, von Hippel-Lindau disease and neurofibromatosis type 2 are all classical tumor predisposing conditions with variable

phenotype and onset. Predictive testing for mutations in the genes which predispose to these disorders is important in the identification of individuals most likely to benefit from screening aimed at the early detection and prevention of malignant lesions. Additionally, for individuals at risk, a negative test result warrants withdrawal from sometimes unpleasant and tedious screening.

In multiple endocrine neoplasia type 2 (MEN-2), testing for the inherited mutation in RET in early childhood will separate those individuals who require prophylactic thyroidectomy to prevent "C" cell tumors from those who require no further surveillance. These examples illustrate situations where testing for predisposition is clearly advantageous for the health of the child. Effective treatments and methods of early detection and prevention are in place so that learning in childhood of one's increased chances for cancer has the potential to decrease morbidity and

mortality.

In Li-Fraumeni syndrome, pediatric cancers are a frequent occurrence; however, the decision to test at-risk children for the presence of constitutional TP53 mutations is not an easy one. Early on, in 1992, when mutation analysis for TP53 mutations first became available, testing children within LFS families was recommended. Since that time, many testing programs have rethought this decision. In the absence of an accepted screening program and/or effective medical intervention, benefit to the child is less easily indicated and in general, testing is not advocated in childhood.

In light of the challenging ethical issues which surround predisposition testing in childhood, the decision to test children is always very complex; however, when medical interventions exist, and the benefits of testing appear to outweigh the potential risks, parents and professionals can justify testing at a young age.

Diane Myles just received her M.S. in Genetic Counseling from Sarah Lawrence College. She is currently working as a cancer genetic counselor at the Hamilton Regional Cancer Center in Hamilton, Ontario.

Society for Healthcare Consumer Advocacy
28th Annual Meeting, October 11-14,
Toronto, Canada
SPECIAL SESSION

Educating for Advocacy (October 11)

Health Advocacy is a profession in ascendancy. It is constantly growing and changing. Today's health advocate works not only in hospitals and other direct care settings, including long term care and community based health centers, but also in public interest advocacy organizations and government agencies or offices. This special session will introduce the practicing health advocate to the scope and content of advocacy that is the focus of master's level graduate education at Sarah Lawrence College, the home of the first graduate program in Health Advocacy in the country. Come with us back to the halls of academe for a hands-on day of advocacy learning and exploration where mini-courses in health advocacy and related disciplines will leave you with a new understanding of your own profession and of current and compelling issues in health care today.

Universal Newborn Hearing Screening

by Abbey L. Berg, Ph.D.

Significant hearing loss in children is not uncommon, yet the average age of identification of hearing impairment in the United States remains at 18 months to two and one-half years. Hearing loss occurs in approximately 1.8 to 3 per 1000 newborn nursery infants and in 2 to 4 per 100 neonatal intensive care infants. If one includes mild to moderate hearing loss and unilateral hearing loss, those numbers increase to and range from 3.7 to 56.3 per 1000, depending on the age group of subjects. Undetected hearing loss of any degree will have a significant impact on speech, language, cognitive, and psychosocial development. Normal hearing sensitivity in children is between 0 to 15 dB. Educational delays of one year can occur for every 10 dB of hearing loss above 25 dB. Researchers have demonstrated the poorer academic performance of some children with unilateral (one ear) hearing loss.

Infants with normal cognitive abilities identified with hearing loss before six months of age obtain significantly better language scores than infants identified after six months of age regardless of degree of hearing impairment. It is not just the severe-to-profound hearing loss one needs to be concerned with; it is the mild-moderate losses as well. There is ample evidence that even mild and unilateral hearing loss can have an adverse effect on communicative, psychosocial, and educational performance.

Historical Background for Early Identification of Hearing Loss

As a result of the unacceptable late identification of hearing impairment in infants and children, the Healthy People 2000 campaign organized by the United States Public Health Service under C. Everett Koop in 1990 sought to increase public awareness of childhood hearing loss. One of the goals of Healthy People 2000 was to reduce the age at which children were identified with significant hearing impairment to 12 months of age. Another federal initiative to further the awareness for infant hearing screening came from the National Institutes of

Health (NIH). In 1993, the NIH held a consensus development conference on the feasibility of implementing universal newborn hearing screening. Participants at this conference represented a variety of disciplines and included experts in the following fields: audiology, speech-language pathology, nursing, otolaryngology, pediatrics, developmental and experimental psychology, early intervention specialists, public health, anthropology, maternal and child health, deaf education, and basic science researchers involved in the electrophysiologic and behavioral assessment of hearing.

The NIH consensus development statement recommended that all infants, not just infants at high-risk for hearing impairment, be screened for hearing loss within the first three months of age, preferably before discharge from the hospital. Use of the high-risk registry will detect only 50-60% of infants with congenital hearing loss. Indicators associated with sensorineural (inner ear) and/or conductive (middle ear) hearing loss include birth weight of less than 1500 grams (3.3 lbs.), low Apgar scores, medications toxic to hearing, in utero infections, mechanical ventilation, findings associated with a syndrome known to include hearing loss, hyperbilirubinemia (neonatal jaundice), bacterial meningitis, craniofacial anomalies, family history of hereditary childhood hearing loss, and/or parental or caregiver concern. The NIH panel emphasized that comprehensive services and management of infants identified with hearing loss must be an integral part of a universal screening program. Further research would hopefully address prevalence and/or delayed onset of hearing loss, hearing loss in the absence of risk factors, unilateral hearing loss, and the effects of screening on parental bonding.

In 1994, the Joint Committee on Infant Hearing (JCIH) convened. Representatives from the American Academy of Audiology, the American Speech-Language-Hearing Association, the Coun-

cil for the Education of the Deaf, the American Academy of Otolaryngology/Head and Neck Surgery, Directors of Speech and Hearing Programs in State Health and Welfare Agencies, and the American Academy of Pediatrics comprise the JCIH. The JCIH determined, after careful consideration of the goals of the Healthy People 2000 initiative and the NIH consensus development statement, to endorse universal newborn hearing screening. In February 1999, the American Academy of Pediatrics also endorsed universal newborn hearing screening and stressed that undetected hearing loss in infancy and childhood was a significant public health concern.

Current Research Findings

Through the efforts of hospital and state supported demonstration projects, more information regarding effective and preferred screening and follow-up protocols and procedures, personnel, costs, and linkage with early intervention services have accumulated. The current state of knowledge has advanced considerably from that existing five years ago.

Technology

Two electrophysiologic measures are used to screen and test infant hearing, otoacoustic emissions (OAEs) and the auditory brainstem response (ABR). Otoacoustic emissions are an

...undetected hearing loss in infancy and childhood is a significant public health concern.

electrophysiologic measure and are present from birth when the outer, middle, and inner mechanism of the ear is intact. Signals generated by the outer hair cells of the cochlea (inner ear) in response to a stimulus can be recorded using this technique. A small probe is inserted in the infant's ear. Recordings emitted by these outer hair cells in response to click or tone stimuli are amplified, averaged, and recorded by a computer.

The auditory brainstem response (ABR) is another electrophysiologic measure used to assess auditory sensitivity. While the ABR does not measure "hearing" per se, this measure does correlate

Universal Newborn Hearing Screening

Continued from page 13

with hearing in older children and adults. Electrodes or small discs are placed behind the infant's ear and on top of the head. Earphones, which emit a click or tone stimulus, are placed in or around the ear. The response to this auditory stimulus is then amplified, averaged, and recorded.

Concerns about Implementing Universal Newborn Hearing Screening Programs

Despite consensus that early detection of hearing loss is a good thing, there are some health advocates that feel moving toward universal newborn hearing screening may be premature. Their ob-

Universal newborn hearing screening will heighten parental awareness of hearing loss...

jections are concerned with cost-benefit, over-referrals for diagnostic testing, increasing parental anxiety, and availability of early intervention services for those infants identified with hearing impairment.

Cost and Referral Rate

Technology and protocols have improved to reduce the cost and referral rate. Infant hearing screening can be accomplished for \$30.00 or less per infant. With appropriate training of screening personnel and the implementation of two-stage screening, referral rates can be very low. If an infant does not pass the initial screening, a second screening is administered. The New York State Project has demonstrated that a referral rate of less than 3% can be attained when screening personnel are properly trained and a two-stage screening protocol is implemented. Ideally this two-stage screening should be implemented before hospital discharge to reduce the need for follow-up testing and to reduce parental anxiety.

This two-stage screening reduces the number of diagnostic tests needed. Results of the New York State Project indicate that less than 1% of infants screened require diagnostic evaluations.

Those infants failing the initial two-stage screening who are subsequently found to have normal results upon diagnostic assessment have usually been found to have transient middle ear effusion (fluid in the middle ear).

Parental Anxiety

Results of several parent surveys indicated that most parents were aware of the importance of early detection of hearing loss and supported newborn hearing screening. A large majority of parents (84.9%) reported that the benefits of early detection far outweighed any anxiety that may have been caused by learning that their infants did not pass the screening. Furthermore, most parents (72.9%) were so convinced of the importance of early detection of hearing loss that they would be willing to pay a \$30 fee for the hearing screening.

If we are to consider the emotions of parents, as we should, we must also consider the very positive feelings of parents whose infants are diagnosed early as a result of newborn hearing screening. These parents are provided, early on, with the knowledge and information that empower them to provide optimal care and intervention, and help their hearing impaired children achieve their maximum potential. Parents of children who were not diagnosed until later in childhood when signs of significant speech and language delays were already evident often feel guilty, anxious, and angry. These parents typically cite the pain and guilt they felt as a result of not knowing what was wrong with their children and express frustration that their infants did not have the advantage of early intervention that early identification would have afforded them. Those of us dealing with infant hearing screening have become much more sensitive and adept in attempting to balance realistic concern with unnecessary parental anxiety, fear and guilt.

Availability of Resources

Historically, and sadly, the only way to ensure that appropriate treatment and follow-up services are made available to families is by taxing the system. Professionals with demonstrated competen-

cies in early identification and interventions of hearing impaired infants are much needed and at present not available in every community or region. Mandated universal newborn hearing screening will increase the demand for such expertise and skill. Programs in audiology will be forced to meet this challenge and tailor their educational training to meet this need.

Late Onset Hearing Loss

There are infants who will pass the newborn hearing screening and will subsequently be found to have hearing loss. Hearing loss can occur at any age and ongoing surveillance for detection of hearing loss throughout childhood is recommended by the Joint Committee on Infant Hearing (1995). Universal newborn hearing screening will heighten parental awareness of hearing loss and therefore, parents will be more vigilant about seeking help if they suspect a hearing problem.

Conclusion

The state of the art is such that universal newborn hearing screening can be performed quickly, safely, and inexpensively. Large statewide programs throughout the country as well as smaller programs established by individual hospitals have demonstrated the feasibility and effectiveness of universal newborn hearing screening. Parental acceptance of newborn hearing screening is high. In New York State, only 0.38% of parents chose not to have their newborns screened in the hospital. Research to improve the efficacy of screening and identification methods, follow-up, habilitation, and intervention services will continue. There is, however, no doubt that we have the technology and protocols at our disposal today to prevent the untoward consequences of delayed identification of congenital hearing loss.

Abbey Berg, Ph.D., is an Assistant Professor at Pace University and Project Director of the Universal Newborn Hearing Screening Program at Babies & Children's Hospital of New York.

Note: References have not been printed because of space limitations, but are available on request from the BULLETIN editors.

Poor Access to Care Heightens Mother-to-Child Transmission Rates

by Toby Kasper, B.A.

Editors' note: This article was originally published in a slightly modified form in Treatment Issues, Volume 13, Number 2, February 1999. Treatment Issues is a monthly publication of the Gay Men's Health Crisis, New York, NY.

The 6th Conference on Retroviruses and Opportunistic Infections reported considerable progress in eliminating mother-to-infant HIV transmission in this country while the struggle to reduce such transmission in the developing world is only beginning. A major report at the conference concerned the PETRA Study, a multinational effort to assess the potency of regimens considerably shorter than the U.S. standard. That standard is based on the ACTG 076 trial protocol, which mandates the usage of AZT starting between the 14th and 34th weeks of pregnancy and continuing intravenously during pregnancy and in the newborns for six weeks after delivery. The treated cohort in 076 experienced an 8.3% rate of mother-to-child (vertical) transmission, two-thirds lower than the 25.5% transmission rate in the placebo cohort.

Vertical Transmission Plummets in the U.S.

Great strides have indisputably been made in reducing the risk of vertical transmission in the U.S. over the past several years. These were reviewed by Dr. Lynne Mofenson of the National Institutes of Health in her talk at the 6th Retrovirus Conference (symposium lecture S6). Rates of screening pregnant women for HIV and the likelihood of HIV-positive mothers following the 076 protocol have been steadily increasing in the U.S., with the expected concomitant drop in transmission rates: in 1996 the rate of transmission had fallen to 2.8 per 100,000 births, down from 8.2 per 100,000 only three years earlier. In fact, only 298 infants in the U.S. acquired HIV in 1997.

Predictably, this decline has been inequitably distributed, with many

women still lacking the basic prenatal care necessary for optimal maternal and fetal health. Dr. Mofenson presented data suggesting that approximately 15% of HIV-positive women do not have adequate prenatal health care, and that women who inject drugs are particularly likely not to have prenatal care.

Very positive data also came out of two small studies of women taking highly active antiretroviral therapy (HAART) during pregnancy. There were no cases of HIV transmission among the 89 and 48 infants thus far delivered and tested in the studies, and

... it is clear that the interventions thus far developed can significantly reduce the likelihood that a baby born to a seropositive woman will also have HIV.

rates of illness and birth defects in the infants were similar to other babies in their communities (posters 686 and 687, respectively). The data indicate that women who wish to take protease inhibitors for their own health can remain on their therapy with little to no risk to their infants. These two studies are small, though, and their duration is too limited to catch problems that might crop up only after the infants had further developed.

Poster 687 included follow-up data on 19 women in Los Angeles taking nevirapine, the only nonnucleoside reverse transcriptase inhibitor (NNRTI)

studied, which suggested that its use, like that of the protease inhibitors, was rarely marked by severe complications. Thus women who wish to avoid using protease inhibitors when pregnant have a viable NNRTI option. This contrasts with the newest NNRTI, efavirenz, which has been found to cause severe birth defects in monkeys and should never be used during pregnancy.

Another study (poster 685) examined data from 497 women enrolled in PACTG 185 and found that HIV-positive women (including those on AZT) were no more likely to have preterm

birth or low birth-weight babies than other women. Traditional factors such as multiple gestation, prior preterm birth, pre-eclampsia (a dangerous maternal syndrome consisting of high blood pressure, swelling and/or kidney malfunction), alcohol use, and cigarette use are equally valid predictors of adverse pregnancy outcome among both HIV-positive and HIV-negative women.

On the other hand, it is clear that Cesarean sections do lead to serious complications in significant numbers of women with HIV. Two large

multicenter American studies (posters 683 and 684, which analyzed data from 1119 and 497 women, respectively) found similar results: Nonelective Cesarean sections (that is, C-sections performed after the onset of labor or the rupture of membranes) were associated with such complications (such as inflammation of the uterine membranes, urinary tract infections, and wound infections) in over 40% of the women in each study. Those women who had elective C-sections had fewer complications, but still significantly more than in women who had had either natural or assisted vaginal births.

Poor Access to Care Heightens Mother-to-Child Transmission Rates

Continued from page 15

These observations, taken together with the smaller studies mentioned above that found that none of the women on highly active antiretroviral therapy transmitted HIV to their infants, greatly confuse the C-section debate. The New England Journal of Medicine, in a rare prepublication release, recently announced the findings of a meta-analysis of numerous earlier studies indicating that C-sections halve the rates of vertical transmission. Potential harm to the mother must not be overlooked in the zeal to prevent perinatal transmission.

Short Course Therapy in Africa

As presented by Dr. Joseph Saba of UNAIDS (symposium lecture S7), the good news from PETRA is that much shorter courses of therapy can provide substantial benefits. This randomized, placebo-controlled trial measured the efficacy of a regimen of AZT/3TC (at the standard twice-daily 300 mg and 150 mg doses, respectively) given before birth (starting at 36 weeks of pregnancy), during labor and/or after birth. Treatment was provided for one week postpartum to both the child and the mother, to ensure a supply of antiretrovirals in the mother's milk. The study, which was conducted in South Africa, Tanzania and Uganda, was quite large, with 1,357 infants evaluated.

The use of AZT/3TC beginning at week 36 and continued until one week after birth proved the most effective regimen, reducing the risk of transmission by 50% (from 17.2% in the placebo arm to 8.6% of treated women), an impressive drop, especially considering that 69% of the women breast-fed. Breast-feeding results in significant further HIV transmission after the one-week postpartum treatment period. (It is also worth noting that the rate of transmission in the placebo group is somewhat lower than is usually found. The researchers are themselves somewhat puzzled by this and are looking for explanations.) The group that took AZT/3TC during birth and for a week afterwards saw transmission drop by 37% (down to 10.6%), but taking the combination only during birth seemingly had no effect (transmission rate of 17.6%).

These results do not quite measure up to those seen in ACTG 076, in which the mothers did not breast-feed. The African data do provide significant hope for

women who are first tested only during labor, as well as for women in those countries where the price of the longer regimen may be prohibitive. A bit less hopeful was the data from the French ANRS 049a study (slide presentation 268), which evaluated the reduction in transmission among predominantly breast-feeding African women who took AZT monotherapy beginning between the 36th to 38th weeks of pregnancy and through the first 8 days after birth. This short regimen reduced transmission by 38% (from 27.5% in the placebo arm to 18% of those treated), suggesting both that giving infants AZT is beneficial and that breast-feeding continues to be a risk factor for transmission.

The results of these studies raise the question of whether women in poor countries with high HIV rates should be encouraged to breast-feed. In her symposium talk on breast-feeding, Dr. Andrea Ruff of Johns Hopkins discussed the need to recognize the complexities surrounding making recommendations about breast-feeding, including the need to analyze local sociocultural norms and values, and the availability and safety of replacement formula.

Basic Information Still Lacking

Other presentations at the 6th Retrovirus Conference served mostly to reveal the extent of our continuing ignorance. The most glaring examples are the lack of understanding of the exact means by which mother-to-child transmission occurs and the mechanism by which antiretrovirals act to inhibit this. It is clear that infants are being infected with drug-resistant HIV, but a French study of 30 infants who were infected despite AZT therapy reported that AZT resistance was found in only 20% of infected infants (poster 238). A study from the New York City Department of Health found only that premature birth (less than 37 weeks of pregnancy) and lower maternal CD4 count were significant predictors of treatment failure among 38 infants infected despite AZT therapy (poster 239).

Several past studies have ascertained that lower maternal CD4 count and higher maternal viral load correlate with higher rates of transmission. But a study of 74 women on short-term zidovudine monotherapy succeeded in positively affecting these markers of maternal

health far more than the 076 AZT regimen ever has, without the slightest reduction in vertical transmission rates (poster 241).

Several problems appeared concerning 3TC: Two infants among a group of 200 French mother/child pairs exposed to AZT/3TC beginning at 32 weeks of pregnancy came down with a rare and fatal neurologic disease that normally affects only between 1 in 5,000 and 1 in 20,000, which may or may not be a statistical fluke. Additionally, 39% of women treated with AZT/3TC showed the mutation most strongly associated with 3TC resistance (at codon 184 of HIV's reverse transcriptase gene). Although the AZT/3TC combination reduced mother-to-child transmission to only 2.6% (versus 6.5% for those receiving only AZT in this study), concerns about both birth defects and eliminating the mother's treatment options bespeak the need for caution about the use of 3TC in pregnancy.

Although many things remain to be learned about how HIV is transmitted from mother to child, it is clear that the interventions thus far developed can significantly reduce the likelihood that a baby born to a seropositive woman will also have HIV. It is now possible to talk about ending perinatal transmission in the US, although it is likely that systemic inequalities in American health care will present a significant barrier to the realization of this goal. And while this ideal regimen remains economically out of reach for the vast majority of HIV-positive mothers worldwide, new data make it clear that shorter courses of medication are efficacious in lowering rates of transmission. They provide some hope for parts of the developing world facing a burgeoning epidemic of infected young.

Toby Kasper is a treatment educator at the Gay Men's Health Crisis in New York City. A graduate of Harvard University, he spent a year traveling in Asia, including time working with Burmese refugees in Thailand. He has been involved in various aspects of HIV/AIDS work for the past eight years, ranging from organizing peer education groups and speaking at national conferences to advocating for wider condom availability and greater international access to essential medicines.

Creating A Tobacco Awareness Program For Schools

by Ellen P. Falin, R.N.

Tobacco use has become a major health problem in America. The Centers for Disease Control (CDC) estimate per capita use of cigarettes at 87 packs per year. CDC statistics indicate that smoking-related deaths from 1990 to 1994 totaled over 400,000, and predict that five million youth who currently smoke will die prematurely of tobacco-related causes. In 1993 the cost of tobacco-related illness to the Medicaid system was a staggering \$12,892,507,000.

Because of these issues, the tobacco industry has come under close government scrutiny. Legislation has passed establishing age limits for the purchase of tobacco products. Heavy financial penalties have been levied against major tobacco companies. However, the tobacco industry is well organized and politically powerful, and has mounted a successful 40- million-dollar lobbying campaign to defeat legislation intended to control the sale of tobacco to teenagers.

Federal inquiries reveal that producers have long been aware that tobacco is

proximately 75% will try – and fail – to quit. There is an urgent need to heighten awareness of the destructive effects of tobacco. Teenagers and preteens are particularly vulnerable to the addictive properties of tobacco in any form and vulnerable as well to the seductiveness of slick advertising campaigns.

In-school programming is one way to challenge the tobacco industry's determined pursuit of ever-younger customers. In January, 1999, a coalition of local health care agencies in upstate New York received NYS Health Department grant funding for public school tobacco awareness education. The Tobacco Awareness Program (TAP) is now being introduced to five "pilot" schools in Delaware County.

TAP is a flexible program offering a range of approaches to tobacco education. The program consists of intramural and extramural activities for grades K through 12. A curriculum-compatible set of teaching materials and videotapes has been furnished by the American Cancer Society. Other classroom projects include kite flying and banner/poster design. An Internet directory provides the basis for interactive "research" projects. Templates for letters to government representatives are available. Intensive multi-media presentations focus on self-esteem, healthy lifestyles, and individual accountability. A basic reference guide for instructors lists organizations, web site addresses, and telephone numbers of use in obtaining educational materials. Schools may participate in any or all of the activities. The cost of a complete program is approximately \$600.

School nurses or nurse/teachers are key contact persons, since they directly influence the school's health curriculum. As liaisons between the school and the sponsoring agency, they are invaluable allies. A final component of the program

is publicity: local newspapers, radio and television stations are ideal avenues for

There is an urgent need to heighten awareness of the destructive effects of tobacco.

"spreading the word."

Sponsorship, funding, program design, coordination with school systems, and media coverage constitute vital elements of tobacco awareness education. The work is demanding, the battle is uphill, and the stakes - the health and lives of our children - are astronomically high.

For more information or to request a Resource Guide, please contact Ellen Falin at efal@telenet.net.

Sources:

CDC's Tobacco Information-State and National Tobacco Control Highlights.
www.cdc.gov

Children Opposed to Smoking Tobacco.
www.costkids.org

Fighting for Legislation to Reduce Teen Smoking.
www.whitehouse.gov

Tobacco Briefs.
www.tobaccofreekids.org

Washingtonpost.com: Tobacco Special Report.
www.washingtonpost.com

Delaware County Health Priorities Initiative 1998, Delaware County Department of Health. Barry Warren PhD., Project Consultant.

Ellen Falin is currently a student in the Health Advocacy Program.

Industry documents show a clear intent to aim advertising efforts directly towards teenagers and preteens.

physically habit-forming, and actually have attempted to develop products that would be even more addictive. Industry documents show a clear intent to aim advertising efforts directly toward teenagers and preteens. These schemes have also been successful. In 1997, an estimated 1.2 million teenagers started smoking. More than one-third of high school students who smoke develop daily smoking habits, and of those, ap-

Children's Issues in Westchester County

by Sharon Chase

Anyone asking what an advocacy group should meet Cora Greenberg, Executive Director of Westchester Children's Association (WCA). WCA is the only non-profit, independent, multi-issue child advocacy organization in Westchester County, New York. I am fortunate to have an internship with the agency this spring. This organization is involved in a variety of issues revolving around children. WCA has developed an exemplary record of innovative policies and programs to meet the needs of undeserved children by: identifying the unmet needs of children, informing the public and policy-makers, developing and advocating for innovative solutions, and lastly, encouraging community involvement and collaboration to improve children's lives.

The extent and effectiveness of involvement was emphasized at a recent WCA annual Issues Breakfast. A "Report Card on Westchester's Children" was presented to legislators, other policy makers and child advocates. WCA created the Report Card to present an overview of how well Westchester was doing in meeting the needs of children, focusing on five subject areas: child care and early education, child health, economic security, adolescent well-being and child welfare.

The Report Card was developed as an advocacy tool to inform those present of the current status of children and to begin problem solving in the identified subject areas. It was also intended to arouse Westchester's communities to make a commitment and to rally for action to help these needy children.

The Report Card showed areas of improvement, such as the county's outstanding commitment to child care, subsidies for low-income families, new outreach programs to enroll eligible children for health coverage in Medicaid or Child Health Plus, the establishment of Child Advocacy Centers in several communities for victims of abuse, and the county's efforts in bringing in model programs to help reduce the rate of teen pregnancy. It also tried to be frank in

assessing areas still in need of resources and action. Recommendations were directed particularly toward county and state government.

My work at WCA has been directed solely toward child health and specifically the health access initiative for low-income and uninsured children. WCA, in conjunction with the Westchester Department of Health, has organized a Child Health Task Force to coordinate public/private efforts to develop a coordinated approach to increase outreach and education programs aimed at enrolling the county's uninsured children in Medicaid and Child Health Plus programs. A grant of \$100,000 from The Westchester Health Foundation was awarded to the Health Department to support the Community Partnerships Initiative and the mission statement of the Task Force. Most of these funds will be used to staff the Task Force and support its work with community-based groups in enrolling the uninsured children.

The Task Force is a grassroots effort to reach out to as many uninsured children as possible through a coalition of partners from hospitals, neighborhood health centers, mental health agencies, school nurses, day care centers, government agencies, health plans, youth bureaus and Chambers of Commerce. Approximately 90 members are on the committee. As a member of the Task Force, I have been a participant and observer learning the strengths and weaknesses of broad collaborative community-based work.

Early this year President Clinton took steps to increase enrollment for children who are eligible for Medicaid or Child Health Plus. According to the Census Bureau, at least 10.7 million children lack health insurance. As many as 23,000 children in Westchester County have no insurance. In the fall of 1998, legislation was passed in New York State to expand children's health insurance coverage. The changes for NYS include expanded eligibility levels in the Child Health Plus and Medicaid programs and an expanded benefit package and a reduction of the cost-sharing requirements in the Child Health Plus program.

The legislation also called for an ex-

tensive outreach and enrollment program. As a result, the NYS Department of Health sent to all interested parties a Request For Proposals (RFP) for Child Health Plus and Medicaid Facilitated Enrollment. Originally, the RFP was scheduled to be mailed in February; however, it was not released until the middle of March. All members of the Task Force will have an opportunity to participate in writing this proposal which is due in May. The recipients of the RFP probably will not be announced until fall.

The State is envisioning a statewide outreach enrollment program. At the same time, it does not want to contract with a lot of individual agencies. The facilitated enrollment model, which the State is proposing, will include a lead organization that would subcontract with numerous community-based organizations (CBOs). These CBOs must reflect the cultural and language diversity of the area. There will be facilitated enrollers in different locations throughout the community to screen families, distribute information, assist with completion of applications, educate the families regarding health plans and serve as a liaison between the contracted CBOs, County and Health Plans.

WCA has received additional funding to hire outreach workers as child health advocates in six local communities. This project will identify a host contact agency in each of the communities and an appropriate person for the Child Health Advocate position. The advocate will be trained by WCA to provide information about eligibility, enrollment procedures for both programs, assist families in compiling necessary documentation, inform families about effective ways to use managed care and give presentations on the expanded child health programs in the community.

From an intern's perspective, building a collaborative network can be very slow, but it is this process that will make the successful implementation of the program possible. The work of a grassroots advocacy organization seems to be this continual contrast of strategic efforts by an energetic, action-oriented networking style of an effective Executive Director, and the slow, building-block work of creating a coalition, holding it together, and getting decisions made that can actually result in the implementation of improved health care access for children.

Sharon Chase is currently a student in the Health Advocacy Program.

Navigating the Web of Children's Advocacy Sites

by Deborah Hornstra, M.A.

Children's needs often straddle more than one system, so advocating on their behalf can involve dealing with not only the health care system, but quite possibly the educational system, the legal system, the custodial (foster care) system, and even the penal system. This makes advocating for children different from advocating for adults, and it can be hard to find the information you need to do the job, whether you find yourself advocating for a single child, many children or, on the policy level, all children in need.

If you are advocating for a child or children, here are some of the best places to start looking for information and advice. *Technical note:* Many of these sites post their research results and other publications in Adobe Acrobat (*.pdf) format, which is fast becoming the standard for such materials. To view these materials, you will need to download and install the free Acrobat Reader from Adobe at <http://www.adobe.com/prodindex/acrobat/readstep.html>. This format is fully searchable and prints out beautifully, just like the document in its paper incarnation.

Also, as a general rule, realize that most of these organizations offer the results of their research and other publications on the web *only in summary form*, and many charge a fee (often nominal) for hard copies of the full text reports, which you can often easily order through the web site itself.

Families USA

www.familiesusa.org

The premier Internet clearinghouse for children's issues. Go here first.

U.S. Bureau of the Census

www.census.gov

When it's data you're after, this is THE place for demographic statistics on the population of the United States. They've got it broken down (almost) every way you could possibly need. Bookmark your favorite tables so you can go there directly and not have to "drill down" many levels. I would even recommend

saving the tables you use most often to your hard drive or printing them out (and actually reading the stats off *real paper*), because this site deservedly gets LOTS of traffic.

The Urban Institute's Health Policy Center

<http://www.urban.org/centers/hpc.html>

A beautifully designed website, easy to navigate and filled with useful and relevant research.

National Health Law Program

<http://nhelp.org>

Abstracts of many useful documents, well organized.

National Governors' Association

<http://www.nga.org/>

See their 1998 *Annual Report on the State Children's Health Insurance Program (S-CHIP)*, published March 22, 1999.

Healthfinder's Children's Health Page

<http://www.healthfinder.gov/justforyou/children.htm>

Excellent DHHS-sponsored search "portal," or starting point. Go to the "children" category under "just for you." Each site listed was chosen for its utility and credibility by actual intelligent human beings, not robots or spiders.

Institute for Child Health Policy

<http://www.ichp.edu>

Examine their purchaser's tool, "Evaluating Managed Care Plans for Children with Special Health Care Needs," which is deliberately NOT copyright protected; its authors and sponsors (including the American Academy of Pediatrics, Family Voices, and the National Association of Children's Hospitals and Related Institutions) want people to use it and distribute it freely.

Electronic Policy Network

<http://www.epn.org/>

This is the brainchild of Paul Starr, Princeton professor and author of *The Social Transformation of American Medicine*. Tons of provocative essays and analyses and another very well organized web site to emulate, with my fa-

vorite site map on the whole web (it looks like a subway map!)

Duke Health Policy Cyberexchange

<http://www.hpolicy.duke.edu/cyberexchange/>

This is probably the single best place to start a search on any health policy-related topic. I met the webmaster in November at a meeting convened by the Institutes of Medicine, the purpose of which was to determine whether the IOM should set up a "health policy gateway" site on the web. It was basically decided that Duke had already done so with this site. You won't be disappointed.

Policy.com

<http://www.policy.com>

Check out the children's health section of their issues library for 25 pages of links to excellent resources.

David and Lucile Packard Foundation's The Future of Children

<http://www.futureofchildren.org/>

A great quarterly journal, worth checking out every issue if children's advocacy is your passion. Full text of each article is online in Adobe Acrobat (*.pdf) format — see above for how to get the free reader.

Medline

<http://www.nlm.nih.gov/databases/freemedl.html>

This is the way to access Medline for free if you're not affiliated with a university. You get access only to abstracts; most of the journals indexed will make you pay to access full-text articles, and some will even make you buy a subscription (this is usually cost-prohibitive — then you have to go to a good library!) From here you can search not only Medline proper, but also Aidsline, Bioethicsline, Popline, and Toxline, among others.

Children's Defense Fund

<http://www.childrensdefense.org/>

Excellent, well designed page filled with useful resources. Very topical reports and a great page of annotated links. Good site index and search engine add

Navigating the Web of Children's Advocacy Sites

Continued from page 19

user-friendliness to this essential site.

Child Welfare League of America

<http://www.cwla.org/>

Not as useful as some sites because they don't even put up summaries of their excellent publications, though they do make it extra-easy to order them through the website. Check out the quick and current stats on their fact sheet *Children '99: Countdown to the Millennium*.

Google!

<http://www.google.com>

My new favorite search engine, Google! is the brainchild of two Stanford grad students. They use a completely different method for ranking web sites: unlike all other search mechanisms, they take into account the quantity and quality of all OTHER sites that link to any particular site. Therefore you tend to get the better pages near the top of your "hit list," rather than just the ones that have done a thorough job keywording and metatagging their site and submitting it aggressively to the other search engines.

Google! is not good for looking for a specific person's home page, because there probably aren't that many other pages out there linking to it, but it's very good for research, as it points you to sites deemed worthy by other deemed-worthy sites. If you need the other kind of search, try Hotbot at <http://www.hotbot.com>. They have the most web pages in their database and their robot is usually lightning-fast.

U.S. Department of Health and Human Services

Check out their *Profile of America's Youth* at <http://youth.os.dhhs.gov/youthinf.htm#profile>.

Other recent DHHS reports on children and youth are listed (and hot-linked) here: <http://youth.os.dhhs.gov/youthinf.htm#reports>.

Center on Budget and Policy Priorities

<http://www.cbpp.org/>

Excellent body of research. I especially recommend the recently published *Employed but Not Insured: A State-by-State Analysis of the Number of Low-Income Working Parents who Lack Health Insurance* (February 1999).

Kaiser Family Foundation

<http://www.kff.org>

Another beautifully designed site where it's very easy to find what you need. You can sign up for e-mail notification of new publications on just the topics that interest you, a great idea more sites are (and should be) offering. You can read all their surveys, click on a map of the US to get instant health facts about any state, or browse the web starting from their annotated link library on Reproductive and Children's issues, at <http://www.kff.org/links/linkrh.html>. Tons of resource material.

Annie E. Casey Foundation

<http://www.aecf.org>

Named in honor of the mother of the man who founded UPS, Jim Casey, Baltimore-based AECF, which is a major funder of children's health care initiatives, which is the entire mission of the organization. This is mainly interesting if you are looking for grant money and want to learn about the kinds of projects they fund.

Wisconsin Department of Health & Family Services

<http://www.dhfs.state.wi.us/>

A good example of how a state itself can put up a useful, comprehensive, and friendly web site.

The California HealthCare Foundation

<http://www.chcf.org/>

A fantastic website put together by a state-centered foundation. See the fascinating article from January 1999, *The Future of the Internet in Health Care*. To get access to some of the articles, you have to give them a California address. (I gave them the one I lived at 15 years ago, and it worked just fine....)

Voices for Illinois Children

<http://www.voices4kids.org>

Another good example of an advocacy site put up by a state-centered non-profit organization. Lots of Illinois-focused information, well organized.

The Commonwealth Fund

<http://www.cmwf.org>

Lots of good research, with a special focus on New York City.

National Data Archive on Child Abuse and Neglect

<http://www.ndacan.cornell.edu>

If your subject is child abuse and neglect, start here at this site, run by Cornell University. Also see the fact sheet on this subject from DHHS at <http://www.acf.dhhs.gov/programs/cb/ncanprob.htm>.

Bookmark the list of health advocacy links on our own HAP web site at <http://www.slc.edu/pages/h/health/halinks.htm>, which includes many organizations working in children's health advocacy. You can find another good list of links to child advocacy sites at <http://www.childadvocacy.org/imptxt.html>. Also bookmark the very comprehensive list of health advocacy organizations (including many which are not yet on the web), including phone numbers and URLs (web pages) if they exist, posted by Johns Hopkins at <http://infonet.welch.jhu.edu/advocacy.html>.

Health A-Z (<http://www.healthatoz.com>) is my favorite health-only search engine. When I'm doing serious research, I like to start where the pros start: the reference page of links on the *New York Times* site, which can be found at <http://www.nytimes.com/library/tech/reference/cynavi.html>. (They might make you register before they let you in, but it's free.) This has links to all kinds of sources of information and is in fact a good page to make your home page.

If you still can't find what you're looking for, send me an e-mail and I'll be happy to try to help!

Deborah Hornstra is a communications consultant based in Princeton, New Jersey, specializing in health advocacy. She holds a B.S. in communications from Syracuse University and an M.A. in Health Advocacy from Sarah Lawrence College. Deborah was until recently Communications Officer for the Center for Health Care Strategies in Princeton, New Jersey, a national program office of The Robert Wood Johnson Foundation. She has consulted for clients including Planned Parenthood, the Nursing Home Community Coalition of New York State, International Projects Assistance Services, Duke University Medical Center, Careers for People with Disabilities, and Elsevier Science Publishers. She can be reached at hornstra@home.com.

'99 Health Advocacy Graduates: A Vibrant Mix

This May's graduating class of ten reflects what Director Marsha Hurst so eloquently describes as the "vibrant mix of young people with a vision and seasoned adults with a mission that has become the hallmark of the (Health Advocacy) Program."

Four actually finished their degrees in December, 1998. **Sherisse Webb** was completing her undergraduate degree in bioethics at the University of Toronto and looking for a place to apply her theoretical skills when she found Health Advocacy. While at Sarah Lawrence, she discovered a special interest in health policy and reform: "The variety of experiences and flexibility that the program offered were particularly valuable because they provided me with an understanding of the many components of health advocacy while allowing me to discover for myself what I was truly interested in pursuing as a career." Sherisse is now the Policy and Procedure Analyst for Indiana's Children's Health Insurance Program (see her article in this issue of the Bulletin) and plans to pursue a doctorate in comparative American-Canadian health policy.

Lisa Salandra-Birnbaum is a registered nurse who turned to Health advocacy out of her concern that the nurse was no longer functioning as the patient's advocate. Her main areas of interest are education and policy, and she would like to see an advocacy component added to all professional health curriculums. She found her education at Sarah Lawrence "exceptional. The faculty was top notch. I personally see a difference in my thinking and the process by which I assess situations." Lisa, too, aspires to a doctorate, and is currently organizing the new Health Advocacy Alumni Association.

Also finishing in December were **Patricia Saunders**, a nurse interested in health policy who worked on CHIP in New York as an intern, and **Eleanor Scarcella**. Eleanor, in addition to working part-time at the Arlin Zalman Cancer Institute affiliated with Westchester Medical Center, is teaching a Health Advocacy undergraduate course to inmates at Bedford Hills Correctional Facility this semester. It has been so successful that Eleanor will be teaching a second semester on Advocacy and Genetics, with Human Genetics students rotating through the class to give lectures on special topics.

Linda Osborn was a professional actress turned mother, volunteer and local political activist, when sudden health issues "hit very close to home. I discovered that these folks had no understanding of the health care system (neither did I), and had no resources to engage the system when they needed it." She is interested in insurance, financial matters,

legislation for patient protections, single payer systems, more equitable distribution of money in the system, and hopes to work in politics or health care regulation part-time until her children are grown.

After a long career in Jewish communal affairs, **Jean Hermele** revisited her early education in speech therapy and found that "...my interest in maximizing health care availability flowed directly into advocacy. I would like to work with individuals as they interface with the complexities of the health care system, enabling them and their families to become their own best advocates." She is currently looking for a hospital position in New York or Connecticut, and says, "It has been wonderful to immerse myself within the Sarah Lawrence milieu at age 50. One benefits tremendously from the stimulation from the faculty and students. I will cherish the new relationships as much as formal/informal learning."

Samara Sweig was a recent UMass psychology grad working for a brokerage firm when she read about the Health Advocacy Program in the New York Times. It was, as they say, "exactly what I was looking for." Her main interests are children's and women's health, and she has done her final field placement at the United Nations, for UNICEF. She would like to continue working with international issues.

Retired insurance executive **Jill Prosky** had returned to work with the New York City Department of Cultural Affairs when a newspaper article on health advocacy "seemed meant for

me." "I have loved (almost) every moment at Sarah Lawrence," says Jill. "My plan is to spend some months living in Israel and then sail the Caribbean with another couple. Then - leaving myself open to the possibility of new and unplanned experiences - I expect to rejoin the work force, maybe with a lobbying group, writing, or starting a related business. My family is already laughing at my idea of a vacation."

When her husband's job relocation brought her back to New York after nine years in San Diego, **Diana Westgate Armstrong** decided to pursue her personal goal of earning a masters degree: "When I chanced upon the Health Advocacy Program, I knew it was the perfect arena for me and my broader interest in all kinds of advocacy. I am very interested in the power of continuing education and the opportunities and interventions it can provide, especially in health care. My placements in the Patient and Family Education Department at Memorial Sloan-Kettering, and with the Office of Government Affairs of the March of Dimes in Washington, D.C., gave me my most valuable perspectives, as they provided hands-on practical learning experiences in the areas in which I was most interested. Marsha Hurst's influential roles in the classroom and as the new Director have been the most important and inspiring aspects of being a student at Sarah Lawrence." Diana's career plans include becoming a private contractor/educator for organizations and institutions that support family caregivers for chronically or terminally ill patients.

Cheri Hawes also has a background as an RN and as a veteran. Instead of a last placement, Cheri worked under faculty member Diane Borst to develop a business plan for a private health advocacy service. It is extremely impressive, and may be a model of advocacy services that could be available in the future. Cheri was responsible for researching and designing the Resource Center at the March of Dimes which provides information nationwide on pregnancy, birth and related subjects.

Congratulations to you all!

Director's Desk

by Marsha Hurst, Ph.D.

"I think now what was most important was not what I chose to do so much as that I was conscious of being able to choose, and having chosen, was empowered from having made a decision, done a strike for myself, moved."

— Audre Lorde, upon making a decision to have a mastectomy.
The Cancer Journals, 1980

I stare at the calendar these days in disbelief. So much to do, so little time. We have a wonderful group of students in the program, ten of whom graduate this year; and we have had an incredible demand for health advocacy education. The Internet, the print media, word of mouth, undergraduate advisors, and the turmoil of the health care system itself have led people to our gates. Our large entering class for fall 1999 will challenge the tidy boundaries of the Health Advocacy Program and occasion some creative stretching.

These incoming students reflect the vibrant mix of young people with a vision and seasoned adults with a mission that has become the hallmark of the Program. A health advocate, as most of you readers know, is an advocate in the gut. The most frequent phrase I hear in an interview or see in an application is, "I have been looking for a long time for a graduate program, not knowing which direction to take. When I found Health Advocacy, I knew it was precisely what I had been seeking."

In the Fall 1998 BULLETIN, I wrote about some steps HAP was planning to take to "educate professionals for a world of advocacy that encompasses many arenas." Let me give you an update on those steps.

HA II: The Position of the Health Advocate (see course description on our web site <http://www.slc.edu/pages/h/health/hacourses.htm>) is now concluding its first semester. As promised, the course covered the work of the health advocate from hospital to community health center to interest group to government agency. The faculty team drew on their own work in the field and networked to bring in exciting guest advocates. The course was "keynoted" by Ruth Watson Lubic, CNM, Ed.D, McArthur award winning maternal and child health advocate, who is now setting up a birth center connected to a

multi-service facility for families in Ward 5 in Washington, DC. [See sidebar for other speakers.] HA II will always be a work in progress, since health advocacy is a constantly changing field. Part of the next challenge of course revision will be how to reconnect the fieldwork experience— itself as diverse as the "positions" of the health advocate—to readings and class discussion. Alumnae/i will remember that this was a much simpler task when the health advocate was generally a patient representative and the students in the course were all doing hospital placements at the same time. But diversity of need and opportunity for the health advocate means complexity of educational design, so we will be focusing on this piece in our program development.

Program Outreach. This aspect of my work seems to have a momentum of its own. Although more and more people find us through the Internet, we have not made as much progress as we hoped in making our web site an advocacy resource (definitely on the front burner), but we have moved forward in other ways. Among our best outreach emissaries are our interns, who provide advocacy services while in training to many a staff-starved office, and, in the process, teach the organization that there is a graduate field of study in health advocacy. This year Pat Banta was selected in a competitive process to be a New York State Assembly intern in the Health Care Committee. She is educating Albany about HAP and HAP about the State legislative process. For the first time we had a student, Jill Prosky, interning in the Public Advocate's office in New York City. They wondered at first what this field called health advocacy produced; now they are asking for a regular supply. This summer Margot Eves and Christine Dyer will go to Washington DC, Margot to intern at Families USA and Christine to the Government Affairs office of the March of Dimes. Other students pioneered new internships in areas of their professional interest and also did placements in sites that have become regular training grounds for our well-qualified graduates. [See sidebar for 1998-99 placements].

We have also been encouraging students to attend conferences and professional meetings, not easy given the complexity of juggling work, school, family, and finances. We have, however,

been able to set up a fund consisting mainly of monies that are turned back to the program by guests who either cannot or choose not to accept our small honorarium. We have thus far been able to give some support to students attending the American Public Health Association meetings, an alternative medicine conference, a bioethics conference, and the upcoming National Breast Cancer Coalition advocacy training conference.

Based on the constant flow of e-mail and telephone calls from people all over the country asking for more information about the profession of health advocate, about our graduate program, and about health advocacy services, outreach is definitely happening. Many of you have seen the article in the February 1999 issue of *Working Woman* magazine listing patient representative as one of 20 "hot new careers." The article featured HAP graduate Laura Weil '94, currently senior patient representative at Beth Israel Hospital in Manhattan, and president of the New York State chapter of the Society for Healthcare Consumer Advocacy (SHCA). Since then, other reporters have inquired about health advocacy, some on the same search for "hot careers."

In March, HAP hosted a meeting of the NYS-SHCA chapter featuring Leslie Bank '85, who did a workshop on patient-centered billing, an aspect of hospital care extremely important to patients and families but rarely a focus of advocacy attention. We will also be teaching a special one-day session (October 11) at the Annual Meeting of the National Society for Healthcare Consumer Advocacy in Toronto [see box]. This will enable advocates from around the country who are working primarily in hospital-based advocacy to experience the broader context and content offered by graduate advocacy education.

Advocacy education at Sarah Lawrence College. As promised, the Human Genetics Program and the Health Advocacy Program are working on ways to (1) offer a joint program to more interested graduate students, and (2) collaborate on events and educational experiences that explore the intersection of genetics and advocacy. Interest from prospective and entering students, as well as the rapidly growing body of genetic information with ethical, legal, social and personal consequences, is a source of encouragement, if not downright pressure for us. A number of students entering HAP this coming fall have expressed an interest in doing joint work with Human Genetics, and we are

Director's Desk

Continued from page 22

all agreed that consumer advocacy in this field is of increasing importance. HGP and HAP share a commitment to the importance of understanding the experience of illness, and an interest in exploring expressions of illness, including literary expressions. Together we went this March to see "Wit," the Pulitzer Prize-winning play about a poetry professor who is receiving experimental treatment for advanced ovarian cancer. We welcome any of you who have found particular works of art, writing, poetry or theatre to have helped you better understand the experience of illness to share them with us (use mail or e-mail).

This spring the Health Advocacy Program gave a course at Bedford Hills Correctional Facility, a maximum-security prison for women. Eleanor Scarcella '98 taught the Health Advocacy introductory course to a class of 15 undergraduates in the prison's College Bound program, with the help of guest appearances from other HAP graduates and faculty. The course was so popular the students have asked for a second semester, and we are looking into the possibility of Eleanor teaching a second HAP/SLC-sponsored course focusing on genetics and advocacy. Sarah Lawrence College helps educate inmates in other ways, including a writing program at a minimum-security prison, and we are pleased to be part of this work.

We are finding that the Health Advocacy Program has a great deal to offer the undergraduate College by helping to add an advocacy dimension to other areas of study. For example, as part of the search committee for an environmentalist to teach at the College, I am very aware of the importance of including advocacy in the environmental studies program, and, of course, the critical impact of environment on health. There are, in addition, undergraduate professors with expertise in other health related areas with whom we look forward to developing working relationships, in the classroom, through mentoring, or through shared interests and work. Linwood Lewis, a psychology professor whose interest in chronic illness in children brought us together last fall, found volunteer undergraduate field placements through a HAP student who is Director of Volunteers at St. Joseph's Hospital, Yonkers.

Ensuring skills proficiency. Students have saved me a great deal of verbiage here. For younger students, proficiency in basic computer applications, word processing, spreadsheets, databases, presentation software and Internet use is a given these days. Our adult students, however, have almost all moved quickly into this world, one that is so important in health care. The new computer classroom in the Sarah Lawrence College Library has been invaluable for holding application workshops. We have also encouraged students to use writing resources offered to graduate students to improve their writing skills. Health education and communication are even more important tools of advocacy as consumers realize that they can and must take a more active role in their care. Writing and presentation skills thus are central to the advocate's role.

A professional master's degree program always has to balance its primary goal of providing a high level of intellectual understanding of the field, including the broad conceptual and analytic perspective prospective HAP students seek, with the professional need for advocacy practice tools. This is a dynamic process as the health care field changes and the tools of advocacy develop. This spring we are offering mediation training to students and alumnae/i and a workshop on doing legislative research. The Evaluation and Assessment Course includes learning to analyze evaluation data using SPSS and understanding statistically-based research in the field. Many courses incorporate case study methodology, which is an important tool for health advocates, again one that connects theory and practice in the field.

Strategic Planning. As promised, the Strategic Planning Committee has been meeting all year to follow up on the report of the Advisory Board and review directions for the Program's future. A draft report is being prepared which reflects the first stage of the Committee's work: mission, short-term budget, curriculum review and expanding models of health advocacy education. I will be reporting on proposed Program changes



as the Committee's work is reviewed and discussed by our stakeholders (in the jargon of the day). In general, the thrust of curriculum changes has been to build some flexibility into our offerings to reflect the range of advocacy career directions and interests. The expanded models we are considering focus on ways to (1) offer continuing education to people out in the field, and (2) provide a distance learning component to prospective advocates who cannot relocate to the metropolitan area.

The growth in demand for graduate advocacy education keeps us constantly aware of our unique role. The dynamic pressure for growth is exciting, but like the advocate who can find him/herself putting on Band-Aids and never getting to address the cause of the wound, we need to use that pressure to see the larger picture, to act as the change agent: that is, after all, what advocacy means.

One last note regarding an unwelcome change. Mary Carroll, our secretary who has been the organizational guru, the students' true advocate, my mentor in learning the administrative ropes of the Program, is leaving the Health Advocacy Program to try retirement (again). We have our doubts as to whether Mary can survive without fully utilizing her wonderful office management abilities. We suspect, however, she can survive without the stresses of cramming the more than full-time work she does for Health Advocacy into the part-time hours she would prefer to work. We wish her well and intend to keep her on a tether for occasional emotional and practical support.

Special congratulations to our ten 1998-99 graduates. I look forward to your careers as health advocates, and your active involvement as HAP alumnae.

SARAH LAWRENCE COLLEGE

Health Advocacy Program

1 Mead Way

Bronxville, NY 10708-5099

Address Service Requested

HEALTH ADVOCACY BULLETIN