

## *One very special network: the Boston Women's Health Book Collective*

The Canadian government is the only one in the world with a “health promotion” directorate in its cabinet. Each year, the Health Promotion Directorate’s provincial directors meet for a few days for inspiration and renewal.

Norma Swenson was among those who spoke at the Fall 1984 seminar in Montreal. A co-author of *Our Bodies, Ourselves*, the book that changed the course of women’s health around the world, Norma sparkles when she speaks with words long on statistics. She is one member of a small but influential network—the Boston Women’s Health Book Collective.

A few days later in Watertown, Massachusetts, Judy Norsigian, a Collective member and networker *extraordinaire*, is seated at her desk, flooded with light for her television interview. A television reporter, a woman in her thirties (not much older than Judy), is questioning the women’s health activist about the bill before the Massachusetts State Legislature that would license out-of-hospital birth centers. Speaking carefully and articulately, with the casual ease of someone who has done hundreds of interviews, Judy explains the excellent care record of free-standing birth centers.

Just a few feet away, Pamela Morgan, another member of the Collective, is writing a letter that will be sent to scores of women who are participating in the production of *The New Our Bodies, Ourselves* (published in 1985).

Less than a desk’s distance from Pamela, Jane Pincus, another Collective member who moved back to Boston in 1980, after five years in northern New England, is on the telephone with a woman who is trained in *shiatsu*—the Japanese pressure point massage technique that releases blocks, aches and spasms in the body. Jane is inviting the masseuse to give a demonstration at the upcoming

meeting of the Rising Sun Feminist Health Alliance, the network of northeast US women's health activists that meets semiannually as a support group and a retreat from the hectic, stressful pace that these women maintain.

Behind Jane, two more members of the Collective—Vilunya Diskin, who has just arrived from a day of classes at the Harvard School of Public Health, where she is studying for a Ph.D. in population studies, and Norma, returned from Montreal—are absorbed in a planning meeting in the office's conference space, reviewing their ideas about children's nutrition in preparation for a meeting with two people from a large New York foundation.

Within a few moments, Judy's television interview is finished and she switches places with Jane. Now Jane is on camera, explaining the traps that women have been led into by pharmaceutical manufacturers who market products without sufficiently testing them. Judy, in the meantime, is answering a call from a woman in Lexington, Kentucky, who needs information about the harmful side effects of taking phenobarbital while on the Pill. As Judy cites the *New England Journal of Medicine* study that documents the potentially toxic effects of combining these two prescription drugs, the telephone rings again; she excuses herself, momentarily putting the first caller on hold while she answers the incoming call from an Ann Arbor woman who needs help in preparing public testimony on an out-of-hospital birth center bill before the Michigan legislature.

For the first ten years, the group had no office, operating out of the women's homes. By 1980, they rented an office furnished with donated chairs, couches, filing cabinets, shelves and desks. All available space is being used to good effect: hanging plants frame posters on women's rights; directories of women's action groups are heaped next to stacks of another of the Collective's books, *Ourselves and Our Children*; and literature racks are filled with articles, pamphlets and reports about menopause, cervical caps, Depo-Provera, DES, sterilization, breast cancer, hysterectomy, and numerous other topics. Cartons packed with copies of *Nuestros Cuerpos, Nuestras Vidas*, the Spanish-language edition of *OurBodies, Ourselves*, which the Collective publishes and distributes itself, are draped with antique silk scarves, making an aesthetic virtue of the reality of limited space. Information—the raw material, the energy resource, and the finished product of

networking—transforms a one-time classroom into a living, breathing, encyclopedia on women’s health.

No sooner are television interviews, telephone calls and planning sessions complete than the foundation visitors arrive, two of scores of people who pass through the Collective’s doors each month. In the past few weeks alone, people from Quebec, Senegal, Bangladesh, Ireland, Brazil and Japan have visited, reporting on their countries while gathering more data for use at home.

“We all have the same issues,” Judy explains to the foundation people, stuffing envelopes while she talks. “Women abroad have the same concern about empowerment as we do, the same interest in gaining control over their lives, the same problems with violence against women. Even though they may manifest differently, the central issues are really the same. In India, brides are burned to death if their dowries are too small; here in the United States, violence takes the form of rape and battering.”

What are the women’s credentials for doing this work? the foundation people ask in a curious, rather than confronting, manner.

The women have created their own impeccable credentials. “That’s precisely the point,” explains Norma, who obtained a master’s degree in public health at Harvard after participating in the initial rewrite of the original edition of *Our Bodies, Ourselves*, first issued under the title *Women and Their Bodies* in 1970. “We’re not medical people; we’re simply a group of women who wanted to understand more about ourselves.”

The telephone rings again as the foundation people try to understand how a group of “uncredentialed” women could have written a best-selling book with sales exceeding two million copies and translations into more than a dozen languages, then gone on to write another popular book, *Ourselves and Our Children*, while fulfilling speaking engagements, which average about one per week, participating in numerous projects and special-interest groups, and managing to maintain long-term marriages, weather family traumas, and raise more than a dozen children among themselves.

Norma answers the phone, and agrees to do a ten-minute interview with a feminist from Holland, who arrives at the office twenty minutes later to take pictures of the Collective in action.

### ***Why a women's health movement?***

Why would a group of women feel the need to write a book about women's health? Why would the response from other women be so overwhelming? The Boston Women's Health Book Collective serves as an unparalleled entry point into the international women's health network.

Western medicine has strayed from its ancient lineage in the healing arts, a gigantic resource of timeworn natural remedies from many traditions, passed along from shaman to shaman, from midwife to midwife, from healer to healer. Whereas once healing was revered as a gift, today medicine is a prestigious profession whose perks increase as doctors advance higher on the medical ladder. Although understanding the "person as a whole" was once an unquestioned assumption of healers, today subspecialists have cropped up to minister to every minute subdivision of the body.

We can see this principle in action by following a woman who would see a succession of doctors if she chose the prevailing North American medical approach to childbearing. An obstetrician is no longer really a pregnancy specialist; s/he is the "general practitioner" of parturition, making referrals to an endocrinologist, a radiologist for the "older" woman, a neurologist, an orthopedist, and finally a neonatologist, the successor to the pediatrician, for once the baby emerges from the womb, the obstetrician is officially off the case.

In order to even understand her course of treatment for the "disease of giving birth," a pregnant woman has to become conversant with a whole new language of medical "technese." As the traditional testing ground for medications and anesthetics to be used in other forms of surgery, obstetrics is not a fixed science. Routines and methods come in and go out of fashion; today's universal use of epidural anesthesia is just as quickly replaced by tomorrow's new order to screen every pregnant woman over 35 by amniocentesis.

However, to regard these impermanent routines as fads fails to recognize the true seriousness and long-term harmfulness of using pregnant women as guinea pigs. Recall the thalidomide tragedy, in which an untested drug was prescribed for pregnant women as a sedative in the early 1960s, causing severely disfiguring birth defects in their children, or the diethylstilbestrol (DES) catastrophe

of the 1950s, 1960s and early 1970s, in which millions of babies were exposed to this dangerous hormone before birth, resulting in an unusually high rate of a rare form of vaginal cancer in the girls and testicular abnormalities and sterility in the boys.

The natural stages of women's physical maturation have been medicalized, objectified as an illness that must be treated— beginning with menarche, continuing through pregnancy and childbirth, and ending with menopause. Painkillers and mood elevators are routinely prescribed for menstruation; caesarean delivery— birth by surgery—is fast becoming the preferred treatment of many obstetricians, with the number of surgical births having quadrupled from 1968 to 1981; and hormones, tranquilizers and routine hysterectomies have become the standardized treatment for women in menopause.

The tampon fiasco, which received so much publicity, is only the tip of the medical-malfeasance iceberg in regard to women's health.

- ? Intrauterine devices (IUDs), widely prescribed in the late 1960s and early 1970s and currently being marketed in Third World countries, have been found to induce many harmful side effects, from intense pain and excessive bleeding to permanent uterine damage and infertility.
- ? In Puerto Rico, more than one-third of the women of childbearing age have been sterilized. According to the Committee to End Sterilization Abuse in New York, most of the women consented to the operation without knowing that surgical sterilization is rarely, if ever, reversible.
- ? Hysterectomies have become the second most frequently performed operation in the United States, with 25 percent of all women over 50 having had one, in spite of the fact that the operation is major surgery and has been estimated to be unnecessary in as many as 30 to 50 percent of all cases. The fastest rise has been for younger women. In 1980, half of the 649,000 hysterectomies were done on women under 45. Of all adult women in the US today, 62 percent will have had a hysterectomy or oophorectomy (ovary removal) by the time they are 70.
- ? More than 20 percent of all births in the United States are caesarean deliveries, accompanied by an alarmingly high postoperative infection rate of about 25 percent. While the overall

maternal death rate in childbirth has dropped since the turn of the century due to public health advances, the maternal death rate from caesareans remains much higher than that of vaginal deliveries.

- ? The modified radical mastectomy remains the treatment of choice of many surgeons for breast cancer, despite the fact that other less traumatic and less mutilating methods have been found to produce equal or better survival rates.

Over the past twenty years, many women have begun to recognize this unhealthful pattern and have responded in many ways: they have developed their own networks, through which they can meet their own health needs; they have critiqued the existing system of care and worked to change it; and they have created the field of “women’s health for women,” with its own research, books, conferences and, ultimately, philosophy. Where the medical community, in which 90 percent of the doctors are men, has regarded women’s bodies as “other” and their physical maturation as disease, the women’s health movement has advanced a model of women as “ourselves,” as healthy people whose life changes are moments of opportunity and awakening.

### *Making history*

The history of the Collective offers a valuable insight into how networks form, jell and persist over time without elaborate planning, self-conscious statements of purpose, or long-term goals. The Boston Women’s Health Book Collective, one of the oldest and most successful of the networks we have learned about, just happened.

“We never set out to *do* anything,” Vilunya recalls. “You don’t plan to bring a group of twelve women together, enlist the help of hundreds of others, write a book that sells 250,000 copies over two years through ‘underground’ distribution with a price that is lowered from \$.75 to \$.30, face the choice of which major publisher to sign with, and then find your book on the *New York Times* best-seller list for three years.”

“Everything flowed organically from one thing to another,” she says. “And it’s still growing.”

Indeed, eleven of the twelve original members of the group (the

twelfth moved to Canada in the early 1970s and one remains active from her home in California) are still actively involved and two new members have been added, representing a cross-section of middle and upper-middle-class, college-educated white women ranging in age from their late thirties to late fifties.

“We’ve seen one another through four new babies (making twenty-one children in all), four divorces and three weddings, one case of the hot flashes, some dramatic long affairs, three children going off to college and nine are in the midst of adolescence, writes Collective member Wendy Coppedge Sanford in *Heresies* magazine.

The Collective got its start in May 1969, when Nancy Hawley, an antiwar activist involved in one of the first informal women’s liberation groups in Boston, gave a workshop on “Women and Their Bodies” at a women’s conference.

“We decided to have the conference because our weekly women’s meetings at Massachusetts Institute of Technology (MIT), where several of our husbands studied or worked, were too limiting. Every week, more and more women showed up, all by word-of-mouth,” Nancy remembers.

“It was a very exciting time,” Jane reflects. “The air was full of rhetoric—even karate was in the air.”

Nancy’s workshop was the catalytic event that set everything else in motion: the sign-up sheet at the workshop became the mailing list for a group that gathered over the summer with the task of making a list of “good” obstetricians and gynecologists. Calling themselves “The Doctor’s Group,” they consisted of ten women, five of whom are still in the Collective: Jane, Nancy and Vilunya (all friends previously), and Esther Rome and Paula Doress, both of whom had attended the conference where Nancy gave her workshop.

By the fall, the “good” doctors list was abandoned, and the women had begun to research topics of interest to them, unconsciously creating the chapters that would ultimately appear in *Our Bodies, Ourselves*. “I was very interested in the postpartum experience,” Esther says, “because my mother had had a very serious depression after I was born. So I went to the library and found that practically nothing had been written about it. All of us were having the same experience in the libraries: there was no information to be found. That was when we started to put forward our

own experiences and our own knowledge. We never set out to ‘discover’ anything—we only wanted to learn more to evaluate what the doctors were saying.”

The topics of interest created so much new information—and so much excitement—that the women decided to offer the material in the form of a course for other women.

“I was in a very serious postpartum depression when I went to the first meeting, and I vividly remember every moment of that night,” Wendy says fifteen years later. Esther prodded her to attend the course; they knew each other because their husbands were in architecture school together. “We broke up into small groups, and a woman started talking about postpartum depression. It was an extraordinary moment of release for me when I realized that I was not to blame for my depression. I took that energy and poured it back into the group for the next ten years.”

The MIT course was also the Collective entry point for three others: Pamela Berger, Joan Ditzion and Ruth Bell, who maintains her ties to the Boston group even though she now lives in Los Angeles. (Ruth is also the major author of *Changing Bodies, Changing Lives*, modeled after *Our Bodies, Ourselves*, and geared for teens.) Out of this core working group of nine (and literally scores of other women who dropped in and out over the next year or so), the “topics” were expanded to fill a book called *Women and Their Bodies*, including chapters on anatomy and physiology, socialization, venereal disease, pregnancy, abortion, postpartum depression, sexuality, birth control, and political analysis of medical institutions.

For the first time in history, a group of women had written a book about themselves, for themselves, a fact that was later translated into the subtitle of their book (“By and for Women”). *Women and Their Bodies*, run off on newsprint by a local “movement” printer (the New England Free Press), and stapled together, was an overnight success. By the time of the second printing, the women had unequivocally claimed their work as their own by retitling their book *Our Bodies, Ourselves*.

“Every day orders flooded the office of the Free Press,” Judy (who joined the group with Norma, as the last two members, in the fall of 1971) told *New Roots* magazine (no longer published). “Women in the Boston area sent it to their friends all over the US, who sent it to their friends, and within two years, 250,000 were

sold without spending a cent on advertising.” In addition to the friendship network, thousands of books were sold through the burgeoning women’s movement on US college campuses.

It seemed that everyone was talking about this \$.30 book, including New York publishers who contacted the group with attractive offers to republish it—offers that threw the group into six months of soul searching. While they knew that mass distribution would reach even more women, they were very wary of corporate profit. Setting out clear and unusual demands to the publisher—including final control over the cover and all promotional advertising as well as unlimited discount copies for distribution at nonprofit women’s clinics—the group was pleased to find Simon & Schuster agreeing to its terms. In order to sign the contract, the group had to be an “entity.” They formed a nonprofit corporation and called themselves the “Boston Women’s Health Book Collective.”

“We never had a solemn moment when we said, ‘We are us,’” Wendy remarks, demonstrating how a network may close off a part of itself naturally and become a formal organization. “We never needed to say to anyone, ‘You can’t join,’” Jane adds. “We were simply making our book, and who we were was obvious.”

The group has met weekly ever since—through three major revisions of the 1973 Simon & Schuster edition (issued in 1976), a Spanish-language version of the book, one update of the book in 1979, and the conception and creation of *Ourselves and Our Children*, published in 1978 by Random House (the original competitor with Simon & Schuster). In addition, the group has also published two basic pamphlets on subjects of current concern, *Sexually Transmitted Diseases and How to Avoid Them* and *Menstruation*, and has coauthored the *International Women and Health Resource Guide*. In 1985, *The New Our Bodies, Ourselves* was published by Simon & Schuster.

It is astonishing to realize that this enormous web of connections began when one woman gave a workshop attended by thirty other women on a sunny day in May 1969, three weeks to the day after her second child was born. Yet this is precisely how networks coalesce: an individual makes a small gesture in a larger environment of people who are thinking along the same lines. The context allows the network to emerge naturally among the people involved. No one person is responsible; rather, everyone is.