

## 6th Biennial Symposium on Minorities, the Medically Underserved & Cancer

*Supplement to Cancer*

# Cancer, the Environment, and Environmental Justice

**Frederick L. Tyson, Ph.D.<sup>1</sup>**

**Katsi Cook, Midwife<sup>2</sup>**

**James Gavin, M.D., Ph.D.<sup>3</sup>**

**Clarice E. Gaylord, Ph.D.<sup>4</sup>**

**Charles Lee<sup>5</sup>**

**Valerie P. Setlow, Ph.D.<sup>6</sup>**

**Samuel Wilson, M.D.<sup>7</sup>**

<sup>1</sup> Division of Intramural Research, National Institute of Environmental Sciences, Research Triangle Park, North Carolina.

<sup>2</sup> First Environment Communications, State University of New York, Albany, New York.

<sup>3</sup> Howard Hughes Medical Institute.

<sup>4</sup> Environmental Justice Office, Environmental Protection Agency, Washington, DC.

<sup>5</sup> United Church of Christ Commission for Racial Justice.

<sup>6</sup> Department of Health Sciences Policy, Institute of Medicine, National Academy of Sciences, Washington, DC.

<sup>7</sup> National Institute of Environmental Health Sciences, National Institutes of Health, Bethesda, Maryland.

Presented at the 6th Biennial Symposium on Minorities, the Medically Underserved & Cancer, Washington, DC, April 23–27, 1997.

This paper is a summary of the session on Cancer, the Environment, and Environmental Justice and is based on the presentations made on April 25, 1997. The host of the session was Franklin Prendergast, M.D., Ph.D., and the chair was Valerie Petit Setlow, Ph.D. The panelists included Samuel Wilson, M.D.; Charles Lee; Clarice Gaylord, Ph.D.; James R. Gavin, III, M.D., Ph.D.; and Katsi Cook, Midwife.

In accordance with the policy of the journal, Dr. James Gavin discloses a financial or other interest in the subject discussed in this article.

Address for reprints: Frederick L. Tyson, Ph.D., Division of Intramural Research, National Institute of Environmental Sciences, 104 Alexander Drive, Research Triangle Park, NC 27713.

Received June 22, 1998; accepted June 30, 1998.

**E**nvironmental justice mandates the implementation of environmental protections, regulations, and policies equitably to all segments of the population. The protections afforded by the enforcement of existing environmental laws and policies should be levied without respect to geographic location, ethnicity, age, or socioeconomic status. Historically, there is a disproportionate distribution of toxic waste and pollution placed in the communities of people of color and those who are compromised economically. The consequences of the lack of implementation/enforcement of environmental justice include long-standing, deleterious health effects on individuals, who, in most cases, are least equipped to deal with these health problems, as well as economic disaster facing those who are challenged economically already. There are a multiplicity of reasons why this type of environmental discrimination and racism persists in our society despite the growing awareness of impacted communities and their activism against both the perpetrators and the subsequent manifestations of environmental injustices.

### Overview

The National Institute of Environmental Health Sciences (NIEHS) has documented findings that most Americans want to live long and healthy lives, and the vast majority are able to achieve this goal. However, members of socioeconomically disadvantaged populations, including many ethnic and minority groups, are less likely to do so. These subpopulations suffer unusually high morbidity and mortality in the early stages of life. In addition, there is evidence that these groups are burdened with a disproportionately high share of residential and occupational exposure(s) to environmental pollution. Unfortunately, these populations are often the least informed about the potential health consequences of their exposure(s) to these conditions. The goals of many current efforts on environmentally induced cancers are to understand the history and impact of environmental injustices; to initiate research to prevent, ameliorate, and eradicate the health consequences in these populations; to create health policy initiatives for concerted action; to develop regulatory frameworks to prevent future injustices from occurring; and to involve impacted communities in partnership with federal, state, and local agencies in remediation and preventive actions to achieve environmental justice.

### Historical Perspective (from the remarks of Charles Lee, United Church of Christ Commission on Environmental Justice)

The purpose of this presentation is to provide a brief historical perspective of one of the most significant social movements that has emerged in many years. The widespread existence of degraded, haz-

ardous physical environments in poor communities and among people of color is apparent and indisputable. There is growing recognition that there is not equal protection by environmental laws for all Americans. Clearly, some communities and population groups are more vulnerable to health risks due to excessive environmental exposures compared with some other communities. These impacted communities include industrial fence-line neighborhoods, urban ghettos, rural poverty pockets, and impoverished Native American reservations. It is only in recent years that race, environment, and poverty issues have been connected in conjunction with gross inequities in environmental burdens. This has brought about a convergence of three of this nation's greatest challenges: 1) the quest to eliminate racism from every corner of every undertaking of our society, 2) the quest to preserve and protect the natural environment, and 3) the quest to shift social institutions from class divisions and environmental depletion to unity and global sustainability.

The significance of these three challenges resonates among communities across the country. Most of the issues that fall under the rubric of environmental justice have been matters of concern for years. Native Americans have struggled to preserve the sanctity of their environments for centuries. In the 1960s, Mexican-American farmworkers, under the leadership of the late Caesar Chavez, struggled for the right to immunize and for basic health and safety conditions in the fields, where they were exposed to poisonous pesticides. In 1968, Dr. Martin Luther King, Jr., was slain in Memphis, where he went to address an environmental and economic justice issue: the working conditions of municipal garbage-removal employees. In 1979, a middle-class African-American community in Houston, Texas, brought about the first environmental justice lawsuit under the 1964 Civil Rights Act, centering around the siting of a waste facility in their neighborhood. The environmental justice watershed event took place in 1982, when residents of the predominantly African-American Warren County in North Carolina decided to protest the siting of a polychlorinated biphenyl (PCB) land fill by the State of North Carolina in their community. This event brought national focus to the consolidation of these issues. On the heels of this protest in North Carolina, there emerged the formation of hundreds of community-based, grass-roots organizations that are dedicated to protecting their own environments from environmental risks. By the end of the 1980s, several of these organizations coalesced to lead the movement for environmental and economic justice. Some examples of environmental and economic justice issues include

lead poisoning, which continues to impact primarily African-American and Latino children and is the nation's number one preventable pediatric impairment; pesticide exposure among migrant farm workers and their families, a population that is composed predominantly of Hispanics; pediatric asthma, which is rising at alarming rates, especially among inner-city children, including African Americans, Hispanic Americans, and citizens who reside in close proximity to noxious industrial operations, e.g., Louisiana's "Cancer Alley," residents of Richmond, California, and other industrial corridors. Puerto Rico continues to be one of the most polluted areas in the world. Its aquifers and natural resources suffer from decades of unregulated industrial activities. Native Americans have been utilized as the primary work force for the uranium ore mining industry. The U.S.-Mexico border is an environmental catastrophe in the making, with unbridled growth in the corridor communities but with no sanitation infrastructure, public health codes, or enforcement of environmental laws.

People who are subjected to these conditions are also victims of a variety of social inequities. Environmental justice addresses the consequences of housing discrimination, segregation, inappropriate land use, lack of education and employment opportunity, inadequate health services, financial disinvestment, political disenfranchisement, and other forms of racial discrimination. Cultural heritage and traditional values that are integral to the being and sustenance of wholesome communities are devalued, maligned, and eradicated. This, in turn, leads to societal disrespect, racism, mass alienation, and destructive violence. It was not until the 1987 release of the United Church of Christ's landmark study, "Toxic Waste and Race," that action began to take place. Subsequent studies began to document the disproportionate impact of environmental hazards. This nascent, grass-roots movement of environmental protection organizations and people of color in environmental justice groups took these concerns to the federal government. The Council of Environmental Quality first took note of disparate environmental impacts in 1991. However, also in 1991, the Environmental Protection Agency (EPA) administrator, William Ruckelshaus, testified before the U.S. Civil Rights Commission that the EPA's role in setting environmental standards precluded the application of national civil rights policies. In 1991, the Agency for Toxic Substances and Disease Registry (ASTDR) initiated a national minority health initiative and a national minority health conference, which focused on environmental contamination. Also in 1991, a dialogue was begun with the EPA addressing the imposition of environmental laws and protection with equity,

reducing risks for all communities. That resulted in the establishment of the Office of Environmental Justice at the EPA. A number of recommendations were made to the Clinton Administration for application at the federal level. On February 11, 1994, President Clinton signed Executive Order 12898, which focuses on addressing methodologies for assessing and mitigating health effects in exposed communities; collection of data in low-income and minority communities, which have disproportionate risks; and identification of the impacts on subsistence populations, e.g., Native Americans. The movement has had significant and remarkable progress in the short period of time that it has been in existence. It speaks to a clear need for a coherent, systematic research and action agenda that further documents and clarifies the relationship between health and environment in poor communities and among people of color. This is both a moral imperative and a scientific imperative. It speaks to issues related to the social value and the social relevance of the scientific enterprise and its accountability to people in need. It addresses the very fundamental values of American democracy. A priority of the environmental justice movement is involvement of impacted citizens in developing, implementing, designing, and evaluating research. Two basic benefits will be realized from this approach: 1) Data will be made available to researchers on the impact of environmental exposures that exist among exposed populations, and 2) more importantly, research will have social value and can be translated into public health prevention and intervention strategies in which impacted residents can be partners in their implementation.

Communities that are impacted by environmental injustice have not and will not wait for government, responsible corporations, and/or research entities to address environmental justice issues. They are organizing themselves and equipping each other with information and expertise. They have acquired a wealth of valuable knowledge and are making a difference.

**Research Initiatives (from the remarks of Samuel Wilson, Deputy Director, National Institute of Environmental Health Sciences, Bethesda, MD)**

In the United States, there are discrepancies in exposure to environmental pollutants among populations. Often, the heaviest exposures are among people who are forced by limited income to live in close proximity to pollutants and polluted sites. Therefore, a link between research and public health is needed to eliminate hazardous exposures and health risk discrepancies. Reducing risks through prevention leads to enhanced public health, and this increases the welfare of the country and saves money. Prevention is

achieved by remediation, and public health research programs can help to foster an understanding of how to eliminate or remediate hazards and exposures.

***Genetic predisposition and susceptibility***

The United States is entering a new era in environmental health research in the form of new opportunities to understand the linkage between exposure and health outcomes. Current initiatives are focused on genetic predisposition and environmental cancers. Different individuals in the population have differing susceptibility to environmental exposures that lead to cancer. Examples of these types of genes include those that regulate metabolism; govern detoxification of toxicants; direct DNA repair and genome stability pathways; control disease processes, such as tumor suppressor genes (*p53*), or disease progression (e.g., the *BRCA1* gene). Because these known genes predispose individuals to cancer, science is in a position to understand the genetic polymorphisms (diversity in genes) that lead to individual susceptibility.

Individual susceptibility is an important concept in understanding how exposures can lead to differential effects/outcomes. In individuals with a susceptible genotype for developing cancer without exposure or in individuals without the susceptibility gene, the risk for developing cancer is low. However, in the presence of exposure and the susceptible gene, the risk for developing cancer is high. This teaches us an approach to community-based prevention of cancer. That is, if we understand the genotypes of the individuals in communities and their exposures, then more powerful and direct intervention strategies can be implemented to protect the susceptible.

***Other key research areas***

There are several research areas that will provide new knowledge on these topics. First is mechanistic toxicology, which is concerned with understanding the impact of chemical mixtures on the toxicological outcome. Another key area focuses on endocrine disruptors and their interface with the cell-signaling machinery to influence cancer development. Genetic susceptibility, as discussed above, holds great promise for accurate exposure assessment. Finally, identifying biomarkers for disease, progression, and exposure is possible through molecular genetic research in the human population. Making use of these new approaches in molecular research will provide for more powerful and meaningful risk assessment, epidemiology, and public health.

### *Community-based programs*

At the individual community level, programs for prevention need to be community-based and interactive with the communities' exposure experiences. These programs also need to be responsible to the communities. To accomplish this, the NIEHS has initiated grants to conduct pilot programs in environmental justice and community-based prevention strategies. In the future, the agency will expand these programs and partnerships to establish comprehensive, community-based intervention strategies.

### *Partnership development*

NIEHS grantees cannot address these opportunities alone; therefore, the NIEHS is building partnerships with the Centers for Disease Control, the EPA, and the Department of Defense. Working together, these agencies can conduct exposure assessments and measurements in collaboration. Partnerships for basic research are also being built within the National Institutes of Health (NIH) and between the NIEHS and the National Cancer Institute (NCI), the National Institute of Human Genome Research (NIHGR), and other institutes to address genetic susceptibility across the American population.

### *Summary*

Research efforts have four goals. First, combining the new science with new exposure assessment strategies offers the best opportunity to implement community-based prevention. Second, science at the community level offers the best help for eliminating differential and harmful environmental exposures. Third, programs that have economic sustainability and address public health are those that need to be implemented in the future. And fourth, there is a need for the scientific community to keep the public informed about key new advances in science that will promote human health and prevent hazardous exposures.

### **Regulatory Initiatives (from the remarks of Clarice E. Gaylord, Director, Environmental Justice Office of the Environmental Protection Agency, Washington, DC)**

Environmental justice is defined as the fair treatment and meaningful involvement of all people regardless of race, ethnicity, income, national origin, or educational level with respect to the development, implementation, and enforcement of environmental laws, regulations, and policies. Some basic rights of all Americans are to have clean air, pure water, and pesticide-free food and to live in an environment that is safe and sustainable. Apparently, this is not an easy concept for all involved parties to accept. The EPA did

not recognize the concept of environmental injustice officially until environmental justice advocates like Charles Lee confronted the agency and challenged the EPA to perform its job, i.e., provide every citizen with equal protection by environmental laws. As the EPA examined the application of environmental protection, it became obvious that there were inequities in the application of EPA protection. In the case of lead poisoning, the EPA, along with other agencies, documented that lead exposures and blood levels were highest among the most economically challenged segment of our population: low-income, minority children. The lower the income, the higher the exposure. This is an example of a disproportionate environmental burden on a minority community of low income. Another documented example is the case of farm workers in the fields with high exposures to pesticides and other chemicals (fertilizers) who were not protected by the EPA. It took 11 years to put worker protection standards into effect. In the meantime, farm workers went unprotected, and their exposures continued as they brought the pesticides home with them in their clothing, etc., and exposed their children and families. During this time, a number of illnesses occurred that were and still are being studied as a result of these exposures. This lack of equity in the distribution and application of environmental protections is the précis of environmental justice.

It is obvious that certain urban low-income and minority communities are faced with disproportionate environmental burdens because of the tactical placement of hazardous waste-treatment facilities. These are not affluent communities. An example is that neither hazardous waste-treatment facilities nor land fills will be established in Beverly Hills. That is true because the residents have rights, political clout, and the savvy, political know-how, and economic means to fight the placement of environmental hazards in their community. It is easier to place these burdens on people that are unaware of the environmental policies and processes and unaware of their rights to environmental protections by governmental agencies, and the people who are under-employed are seduced with the promise of jobs in exchange for exposure. These communities become overloaded with respect to their environmental burdens. We know from our data that these communities are living in extremely toxic soups by our own toxic-release inventories. We know that water quality is poor, and air quality is poor; yet, these communities continue to function, and the residents are exposed chronically to low levels of a variety of toxicants for lengthy periods of time. If a chemical spill occurs and acute exposures are resultant, then we know how to take appropriate action. However, at this

time, no one has studied or knows the health outcomes of people who have been exposed chronically to low levels of mixtures of multiple toxicants in these communities. With respect to these communities, we know that disease rates are extremely high. Asthma is disproportionately high in inner-city urban children; all forms of cancer are higher, with greater morbidity in low-income minority communities; and respiratory ailments, neurological impairments, and infant mortality are higher in these communities. Most of these assessments are anecdotal, and we have not been able to demonstrate cause and effect relationships. That is the purpose of bringing these issues to this forum, so that scientists and other health professionals can provide the necessary data to chronicle the relationship between environmental exposures and health-related effects that permeate low-income and minority communities. The need exists to document whether exposures indeed may be causal for the observed health problems in these poor and minority communities and that life style, genetics, and nutritional factors are not necessarily the only components. Although these factors are certainly players, their roles in conjunction with exposures must be sorted out scientifically. Epidemiological and clinical studies are required to address this health problem. A scientific basis must be established to further demonstrate the inequities caused by environmental injustices. What is the appropriate way to measure risk assessment? Current methods look at one chemical at a time. This does not evaluate accurately the risks that residents of these communities actually withstand, because absolute exposures are to mixtures of multiple toxicants. In the clinic, many unexplained symptoms, e.g., rashes and respiratory ailments, are not related to exposures, because appropriate questions are not asked by clinicians. It is necessary to provide basic education to the residents of these at-risk communities, because basic education will be an effective preventative strategy. Health care professionals should not use these people just for clinical trials but should treat and care for trial participants when they are engaged in a study. An example of a successful clinical intervention, which was started with EPA seed money but is continuing now with the majority of funding from the NIEHS, is the 16th Street Community Health Center in Milwaukee, Wisconsin. They established an environmental health clinic in their center about 3 years ago. This clinic primarily treats a Hispanic-American, Asian-American, and African-American community. It has developed an outreach, environmental medical team that does not wait for the client to come to the clinic. The team goes into homes and does its clinical surveillance, screening, monitoring, and treatment in the

homes of their low-income Hispanic-American, Laotian-American, and African-American residents. These are the communities that have problems because of chronic exposure to a number of environmental toxicants. They have lead-exposure problems, asbestos exposures, carbon monoxide exposures, and high levels of radon, and allergen levels are high. Their river is polluted, but, because of their poverty, they fish the contaminated river for a major source of protein. The community residents also use indoor pesticides, sometimes inappropriately, for removal of household pests. The 16th Street Community Health Center teams come into the homes and collect blood and urine samples and provide medical education, videos, and pamphlets. They treat the residents for their diseases and symptoms. Then, the environmental teams come in to perform environmental interventions, e.g., they test for radon; remediate lead paint, test the water quality, provide alternate sources of water if necessary, remediate molds and allergens, educate community members on the hazards of eating contaminated fish, and abate the asbestos. They educate and try to reduce the environmental risks associated with exposures in this community. This team then reenters the home at 4–6 month intervals to remonitor. They have found that the results of their interventions are that blood levels are falling and asthma incidence is falling, and that, in improving the environmental quality of the community, there is a concomitant improvement in the quality of health. This is the type of health intervention that is required: health professionals working with communities to ameliorate health conditions.

#### **Health Policy Development (from the remarks of James Gavin, Howard Hughes Medical Institute)**

This presentation will address the highlights as seen by this presenter of the Institute of Medicine's (IOM) Report on Environmental Justice (not sanctioned by the IOM). The overall history and scope of the problems of environmental justice have been articulated eloquently by previous speakers. In 1994, the Executive Order 12898, Federal Actions to Address Environmental Justice in Minority Populations, was signed by the President. The Order mandated all federal agencies to develop implementation plans that address every aspect of this complex issue. The Department of Health and Human Services through the NIEHS, along with the Department of Labor, were designated as the lead agencies for issues related to research and were charged with responsibility for outlining critical needs for the policy and decision-making communities. The NIEHS and a consortium of other federal agencies asked the IOM to advise them on the research, health,

and education policy needs for environmental justice. The IOM convened a committee to conduct a study of these issues for the purpose of generating the most appropriate, evidence-based advice to the consortium of sponsoring agencies. The committee's broad charge was to assess the specific medical and health issues related to environmental justice that require attention in areas including medical education, health surveillance, and public health. The committee was also charged with assessing the role of medical science in addressing these issues and to determine priorities for medical research that would facilitate an improvement in the current status. This endeavor required a multiethnic focus with an emphasis on socioeconomic status and proper attention to the diversity of environmental and occupational health. The committee was encouraged to recommend novel approaches and strategies based on its findings. These strategies must be driven principally by science-based evidence, including data derived from the emerging scientific research alluded to by Sam Wilson. The committee focused on the ethical and legal issues related to clinical research and the need for development of appropriate epidemiological research strategies. In addition, the committee was challenged to explore opportunities for collaborative efforts that might lead to prevention of disease and pollution. Thus, the promotion of interagency strategies became an especially important focus for this committee. This has proved to be a focus of compelling priority for this work, given the significant fragmentation of efforts among those agencies that are committed to and involved in attempts to reduce environmental exposures across at-risk communities. To develop a broad perspective on environmental justice issues, the committee conducted site visits to four areas of the country that represent archetypal issues of environmental justice. Committee members traveled to heavily industrialized areas of Narco and East Baton Rouge, Louisiana; to the Hanford nuclear reactor in Hanford, Washington; to clinics in Chicago, Illinois, and in Nogales and Tucson, Arizona; to a Rural Coalition meeting in El Paso, Texas; to Native American groups in Oregon and Washington; to fence-line communities in Lyons, Louisiana; and to people living in proximity to various Superfund sites. The areas visited are representative of the multitude of areas with environmental justice concerns. These communities can be found in urban, rural, and suburban locations. Despite differences in race, ethnicity, and location, all of these communities believe that the social fabric and health of their community have been impaired by the disproportionate exposure to environmental hazards, whether they are chemical, physical, or biological. Their views and sensitivities

with respect to these issues were not driven by insight into dose response relationships, ED<sub>50</sub> levels, or differences in exposure to single toxicants or mixtures. They were keenly aware that they were once healthy and now they are not. They were also aware that they were being told that major changes in their environments were not relevant with respect to their changed health status. Committee members were reminded constantly of the many social, geographic, and economic barriers that continue to hinder vulnerable and disadvantaged citizens from receiving adequate health services and the relevance of these impediments to environmental justice. Likewise, the committee learned of the lack of knowledge and sensitivity and, in some instances, even the lack of curiosity among the health care professionals charged with providing health care services to exposed persons. The committee has had the opportunity to redefine perspectives on research priorities. Despite several decades of serious and widespread interest in environmental justice, the preponderance of research continues to emphasize study of chemical formulations and their utility in the environment rather than on their clinical effects. The small amounts of clinical data reflect a difference in approach to data collection as well as the difficulty in constructing clinical trials and other research schema that are ethically sound involving human subjects from small populations. The nation has not prioritized nor invested its most creative scientific thinking in areas that might provide solutions to the vexing issues that are related to environmental justice. We should be heartened by the new research directions taken by the NIEHS, as summarized by Dr. Wilson. The lack of research focus on environmental justice issues impressed upon the committee the need for more incentives for the entry of more researchers, particularly minority researchers, into environmental health research. There is a real dilemma that confronts the minority researcher who is inclined toward the study of environmental health issues. That person is likely to be viewed by some as someone who is incapable of engaging successfully in more substantive or basic areas of research, e.g., defining the identity and biologic mechanism of transcription factors, defining the mechanisms of reassembly of nuclear pore complexes during mitosis, or defining the mechanisms of cell-cycle mechanics. However, by pursuing research in environmental health science, determining risk assessments, and running clinical trials, minority scientists may be sounding the death knell to career aspirations. On the contrary, a nonminority scientist who opts to pursue the same career might be viewed by some as a risk-taking, public service-oriented, creative investigator who voluntarily is abdicating research

pursuits that would more likely lead to career advancement. This scenario reflects how we have set our science and medical research priorities and how the reward system strongly promotes certain choices of research directions for some groups with little incentive for others.

One of the surprising findings of the committee was the depth of knowledge in most community groups about the scope of the problems in their situations and the creativity with which they have gone about to uncover and collect this information. At every level and in every sector, including industry, there are individuals with the skills and propensity to find solutions to these problems. Many environmental justice issues do not have single, unambiguous solutions. Perhaps, with the direction and guidance of this committee, we can move in the direction of solving many of these long-standing, chronic environmental justice issues.

**Community Perspective on the Role of Advocacy (from the remarks of Katsi Cook, Midwife, Principal Investigator, First Environment Communications, State University of New York, Albany, NY)**

The Awkwesasne Mohawk Nation sits at the convergence of three rivers into the St. Lawrence River in the Great Lakes Basin. This is a veritable sink and is basically a big septic system for industrial society. The toxicants move through the liver and kidney system of the earth into the ocean, where PCBs are now beginning to partition themselves. The Awkwesasne people believe that everything exists within a cycle. The community feels that increasing rates of cancer and cancer deaths began with the cancers present in the bowels of the earth in the form of the toxic waste sites and landfills, the tumors of industrialization. Since the industrialization of the St. Lawrence in the 1950s, the cancer rate has increased exponentially in the Awkwesasne people. Initial observations of tumorous growths on the lips and sides of the fish caught in the St. Lawrence served as warnings of the increased prevalence of cancer in the Awkwesasne. The Executive Order 12898 came at a time when this community was trying to cope with the increasing disease rates and prevalence of cancer in the community. The Executive Order gave substantive directives to focus the attention of federal agencies on human health and its relationship to the environment. The traditional Medicine Societies of the Mohawks teach that the illness and disease condition begins with the way one thinks. Because this community believes that the way a woman thinks, her experiences, and what she believes affect the development of her unborn child, the First Environment Project was started. Her experiences and attitudes

throughout her pregnancy affect her child's development while in the womb and how the child develops and interacts with the community during their growth. The woman's body is the first environment.

In the 1950s, a green pasture near the Mohawk reserve was converted into an industrial park despite the fact that most its employees were residents of an up-river community: Messena. When Awkwesasne children visited a park in that up-river community, they were teased by the local children and called fluoride freaks. This is significant, because the first human health and exposure research of that period involved fluoride ash, which causes reproductive failure in cattle. In subsequent litigation involving Reynolds, corporate lawyers contended that the Mohawk did not know how to raise cattle. Since that time, the Mohawk have used the tools of science to combat the environmental health problems. By engaging in collaborative efforts with researchers from the State University of New York (SUNY) at Albany, some historic barriers were overcome. SUNY investigators helped monitor PCB levels in Mohawk mothers' milk. From 1985 to 1991, Mohawk mothers had twice the level of PCB congeners in their milk as controls living near Albany. Because the Mohawk mothers were coinvestigators in this study, they understood that the PCB congener fingerprints found in the fish from the St. Lawrence were identical to the PCB congeners found in their milk. This further motivated the Mohawk women to become involved in the issue and culminated with an NIEHS Superfund Basic Research Program. Added to that was the NIEHS Environmental Justice Partnerships for Communication grant. This was the first Superfund grant to study human health as a consequence of environmental exposure and was the product of the collaborative effort in the Mother's Milk Study. The Partnerships for Communications grants from the NIEHS focus on bringing community members, primary health care providers, and health research scientists together to communicate with one another. This was an especially significant development, because the Awkwesasne people have experienced generations of disrespect by authorities who built industrial complexes in the 1950s in the Great Lakes Basin: the Mohawk's home site for generations. The Native American community has been subject to constant and repetitious devaluing of Mohawk tradition, culture, observation and assessments by institutions, and educational systems spurred by industrial complexes. Now, this community is in the position of brokering relationships with institutions on the basis of environmental justice principles: respect, equity, and empowerment. The Mohawk of the upper St. Lawrence have established a protocol on how research will

be conducted with institutions that builds on cultural competency of academic researchers. Issues of authorship and application were also addressed. The population under study has the right to have access to data gathered on them and to use this information to make responsible decisions regarding their own destinies. Cultural competency is not restricted only to clinicians. People are using their own traditional medicine societies for dispensation of treatment. Environmental justice principles dictate that the practices of these societies be preserved and improved, so that communities may gain the maximum benefits of using their own health care resources as well as maintaining cultural and biologic diversity.

Only 350,000 Native Americans live in the Great Lakes Basin, so large studies must be multidisciplinary in approach to maximize efficacy of the study and the study population. Recent support from the NIEHS Superfund Basic Research Program has allowed a neurobehavioral study of Mohawk children 10–14 years of age who were exposed to high PCB levels while nursing as infants. Maternal exposures resulted from consumption of contaminated fish from the polluted St. Lawrence. A retrospective morbidity and mortality study is being conducted with the help of an environmental justice grant from the EPA. This grant affords the hire of a community member who has the opportunity to work with the investigator from the SUNY-Albany facility and learn the software applications that are used for tracking data. This ensures that the ability and knowledge necessary for gathering these data, their storage, and their retrieval will remain in the community after government funding is no longer appropriated. This represents a powerful mechanism for empowerment. The Akwesasne people now have years of experience with epidemiology, hydrogeology, biochemistry, and toxicology. The scientific tools do not measure the human impact that the Akwesasne people are shackled with; thus, a biopsychosocial study is also in place. To protect children in the fetal and perinatal stages of their lives, people (potential mothers) must not consume the PCB-laden fish of the St. Lawrence. This imposes a tremendous psychosocial burden on these Mohawks, because fishing is an integral component of the Mohawk child's growth and development. To catch the fish, a child must let the fish catch the child. The deletion of this rite of passage from an entire community is accompanied by a tremendous sense of loss, because it is another component of the destruction and devaluation of a human culture.

The Akwesasne community is trisected by three governmental jurisdictions: Quebec, Ontario, and New York State. However, the Mohawks recognize no

boundaries, much like the toxins they are exposed to in their communities. Links between health, environment, and culture also know no borders. Implementing changes in behavior and life style does not guarantee improved health in this community. A major change in diet already has been addressed, i.e., the removal of fish as the primary protein supplement. However, it has been replaced with fast foods and junk foods that are possibly part of the reason for the observed increased incidence of obesity, hypertension, heart disease, diabetes, and cancer in the Akwesasne people. There is a dramatic increase in the incidence of immune disorders, e.g., Goodpasture's syndrome. Between November and now (February 1997), there have been seven diagnoses and subsequent deaths of Mohawk people from breast and lung cancer. Cancer screening is increasing as economics and education increase, which is probably true for most peoples. The problem arises after neoplastic diagnosis. There is currently a lack of knowledge by clinicians about traditional Mohawk medicine ways and knowledge. This lack of cultural competency on the part of caregivers creates barriers to good medical care, affecting access and patient compliance. Workshops and conferences are being held to ameliorate communication between clinicians and traditionalists. These workshops are breaking down barriers built on the hubris that the only efficacious interventions are provided by clinicians.

### Summary and Conclusions

In summary, during this session of the 6th Biennial Symposium on Cancer, Minorities & the Medically Underserved, powerful presentations were made on the inequities of the implementation of environmental justice. Speakers presented evidence that the location of toxic waste-treatment facilities, hazardous land fills, and toxicant dumping seem to be placed strategically and systematically in or near communities of people of color or those who are economically challenged. The victims of such environmental injustices are invariably the people who are most vulnerable to these exposures and are least able to deal effectively with the consequences of the exposures. Also, these presentations emphasized the irrefutable links between environment and health. Multiple incidences of cancer as well as other pathologic conditions in close proximity to areas of chronic environmental exposures were cited. However, these presentations also provided information about the coalescing of grassroots community environmental protection groups that, by their activism and vigilance, have brought these issues to national prominence. The struggles of these impacted communities have brought them together and in-

creased their own awareness of the scope of the problems faced by communities across the nation that fit the profile for neighborhoods that are targeted consistently for disproportionate environmental burdens. These organizations are directly responsible for Executive Order 12898, which mandates that all federal agencies implement strategies to incorporate environmental justice into all fabrics of American society. The NIEHS Environmental Justice Communications grants provide a model for positive interaction between community environmental protection groups, health care

providers, environmental health researchers, and federal agencies. This healthy partnership promotes opportunities for communities to have an impact on research study design and to make the goals of the research have a real impact on public health. Moreover, the bold new directions in environmental health research being instituted by the NIEHS bear the promise of encouraging translational research that will improve the health status of communities that are in sore need of the remediation to be supplied by the implementation of environmental justice principles.