

9-10-2008

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Publication Info

Published in *Environmental Justice*, ed. Sylvia Hood Washington, Volume 1, Issue 2, 2008, pages 87-92.

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Environmental Justice is available online at: <http://online.liebertpub.com>.

Terrell, J.A., Williams, E.M., Murekeyisoni, C.M., Watkins, R. & Tumiel-Berhalter, L. (2008). The Community-Driven Approach to Environmental Exposures: How a Community-Based Participatory Research Program Analyzing Impacts of Environmental Exposure on Lupus Led to a Toxic Site Cleanup. *Environmental Justice*, 1(2), 87-92. DOI: 10.1089/env.2008.0517

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The Community-Driven Approach to Environmental Exposures: How a Community-Based Participatory Research Program Analyzing Impacts of Environmental Exposure on Lupus Led to a Toxic Site Cleanup

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Robert Watkins, and Laurene Tumiel-Berhalter

ABSTRACT

Community-based participatory research (CBPR) is a mechanism to improve environmental quality in communities primarily inhabited by minorities or low income families. A collaborative partnership between the University at Buffalo and the Toxic Waste Lupus Coalition was formed to investigate the high prevalence of lupus in the area and whether cases of disease were linked to chemicals found at a nearby New York State Superfund site in East Buffalo. The purpose of the study was to use CBPR practices to educate impacted residents and enable their participation in efforts to get a nearby contaminated waste site remediated. Community members were active participants in the development of the plan to clean up the toxic site. These methods can be used to better engage the community in research and involve them in actions taken to improve their neighborhood.

INTRODUCTION

ENVIRONMENTAL HEALTH RESEARCH provides a mechanism to investigate the pathology of diseases related to exposure to environmental contaminants. Such studies attempt to explain why there are high occurrences of diseases in a given community as well as provide proof often needed to motivate policy makers to act in response to community health trends. Often, residents of impacted communities are not properly informed of how results may benefit them or how they can be involved in research activities. Community-based participatory research (CBPR) provides a means for researchers to study critical environmental issues in a manner that includes impacted residents in the development of study goals, methods, and use of findings.¹

Community-based organizations and other neighborhood entities such as churches and block clubs have the opportunity to assist researchers with outreach and capacity building. Such groups serve as resources to both academic institutions and the target community by assisting researchers with designing and implementing identified strategies as well as acting as a conduit for information exchange. The role of community groups is vital to project success because they are instrumental in recruiting community members to participate in the study as well as inform university representatives of community issues related to the project. Community-based organizations play an essential role in educating the community about the CBPR process and using the framework to directly improve situations being evaluated as part of the research. Community empowerment is a major result of CBPR projects because such projects heighten community understanding of both the problem to be addressed and corresponding research methods, enabling them to

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¹"Creating Partnerships, Improving Health: The role of Community Based-Participatory Research." <<http://www.ahrq.gov/research/cbprrole.htm#different>>; Environmental Protection Agency, Office of Environmental Justice. <<http://www.epa.gov/compliance/environmentaljustice/>>.

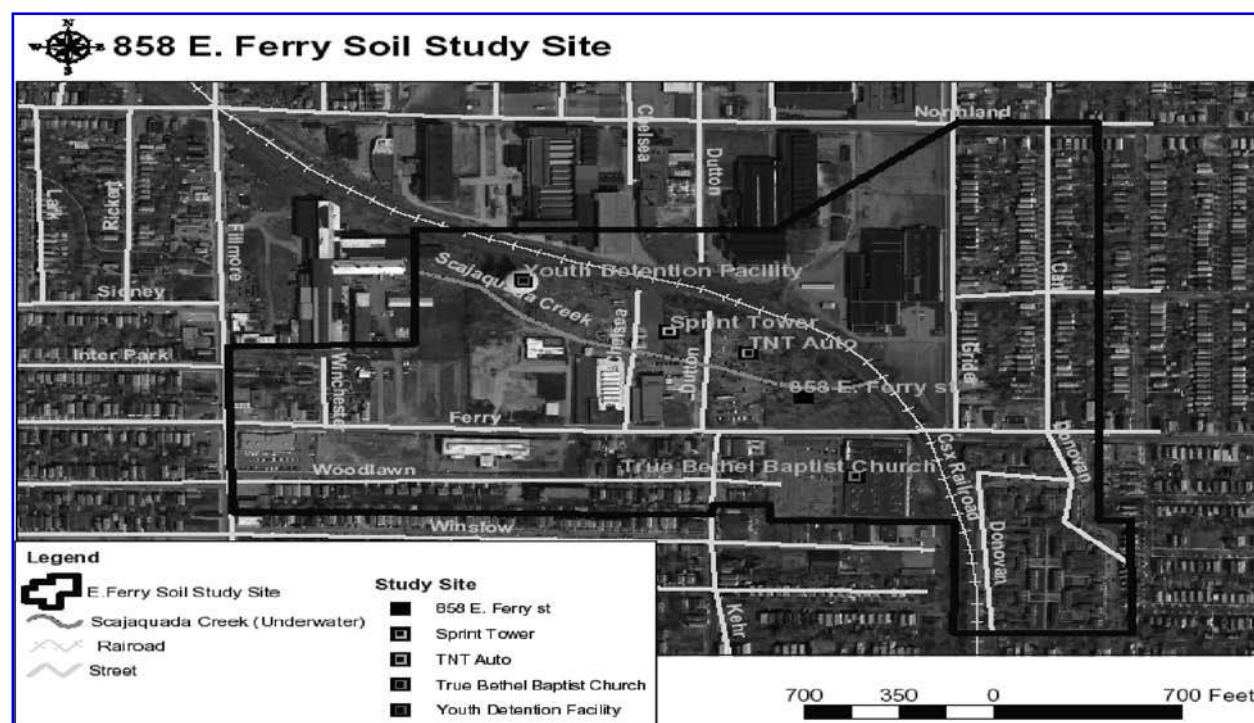


FIG. 1. Overlay of aerial photo identifying sites along East Ferry street and areas sampled by previous studies.

duplicate efforts in the future. When approaching an impacted community, it is important to have a community engagement strategy that is efficient and truly focuses on community involvement.

Environmental justice is another area that addresses the unfair treatment and lack of inclusion of minority and impoverished neighborhoods in the decision making process for environmental laws, regulations, and policies. In this field, environmental and other public advocates work to educate and empower community members so they can properly understand and act on issues that alter the quality of their surroundings. Environmental justice advocates recognize that although we are all affected by degradation of the environment, there are groups that bear a larger burden of the impact from environmental problems. Minorities and those who live in poverty often reside in areas characterized by high risks of exposure to toxins such as lead and mercury.² The same neighborhoods often do not have facilities or sufficient health care programs to adequately address the health related problems associated with such exposures.

The numerous contaminated sites located in minority and impoverished communities pose serious health risks to residents. A number of studies have suggested that environmental exposure such as inhalation or ingestion of contaminants is related to the development of lupus. In lupus and other autoimmune diseases, the immune system loses its ability to differentiate between foreign substances and its own cells and tissues, causing the body to attack itself. Young women are most frequently affected by the disease, outnumbering male patients ten to one. The disease usually strikes between the ages of 15 and 40 years and African

Americans are at particularly high risk for the disease. Environmental exposure is hypothesized to cause or intensify the disease based on the specific characteristics associated with the contaminant and the route and duration of exposure. There several toxins which are known to influence the development of lupus in ethnically and geographically vulnerable populations which include mercury, presence of particulates, ultraviolet radiation, and ozone.³

²Environmental Protection Agency, Office of Environmental Justice. <<http://www.epa.gov/compliance/environmentaljustice/>>; Gee, GC and D Payne-Sturges. "Environmental Health Disparities: A Framework Integrating Psychosocial and Environmental Concepts." *Environmental Health Perspectives* 112 (2004): 1645-53.

³Cooper, G, M Dooley, E Treadwell, E St Clair, and G Gilkeson. "Hormonal and reproductive risk factors for development of systemic lupus erythematosus: results of a population-based, case-control study." *Arthritis & Rheumatism* 46 (2002): 1830-9; Alarcon, G, T Beasley, J Roseman, GJ McGwin, B Fessler, and H Bastian. "Ethnic disparities in health and disease: the need to account for ancestral admixture when estimating the genetic contribution to both (LUMINA XXVI)." *Lupus* 14 (2005): 867-8; Oates, J, M Levesque, M Hobbs, E Smith, I Molano, and G Page. "Nitric oxide synthase 2 promoter polymorphisms and systemic lupus erythematosus in african-americans." *Journal of Rheumatology* 30 (2003): 60-7; Powell, JJ, J Van de Water, and ME Gershwin. "Evidence for the role of Environmental agents in the initiation or progression of Autoimmune Conditions." *Environmental Health Perspectives Supplements* 107 (1999); Uribe, G and America. "What have we learned from a 10-year experience with the LUMINA (Lupus in Minorities; Nature vs. nurture) cohort? Where are we heading?" *Autoimmunity Reviews* 3 (2004): 321-9; Parks, C and G Cooper. "Explaining racial disparity in systemic lupus erythematosus-Environmental and genetic risk factors in the Carolina lupus study." *Annals of Epidemiology* 12: 502; Petri, M. "Epidemiology of systemic lupus erythematosus." *Best Practices & Research Clinical Rheumatology* 16 (2002): 847-58.

Project origin

The Buffalo Lupus Project was a CBPR project developed to inform those concerned about the number of people diagnosed with lupus and other autoimmune diseases in the neighborhoods adjacent to the toxic waste sites at 858 East Ferry, 318 Urban Street and 537 East Delavan Avenue located in East Buffalo, New York. The focal point of contamination, 858 East Ferry Street (Figure 1), was officially designated as a superfund site by the New York State Department of Environmental Conservation (DEC), but basic safety precautions weren't addressed until residents of the surrounding neighborhood started asking questions. A cluster of lupus patients was identified by community activists in close proximity to the three sites and questions were raised as to whether the high incidence of disease could be linked to the contaminants identified at the sites.

The target research population consisted of African American men and women who lived in the 34th and 35th census tracts located on the east side of Buffalo (Figure 2). According to the Environmental Protection Agency (EPA) environmental justice (EJ) policy, a community is classified as an EJ area if the percentage of the population who are impoverished equals or exceeds 23.59 percent of the total population and consists of a minority population which is equal to or greater than 51.1 percent of the total population in urban locations. Furthermore, the policy states that potential EJ areas must also include a population that is being affected by the disproportionate consequences from living in proximity to contaminated land from past and/or current industrial, municipal, and

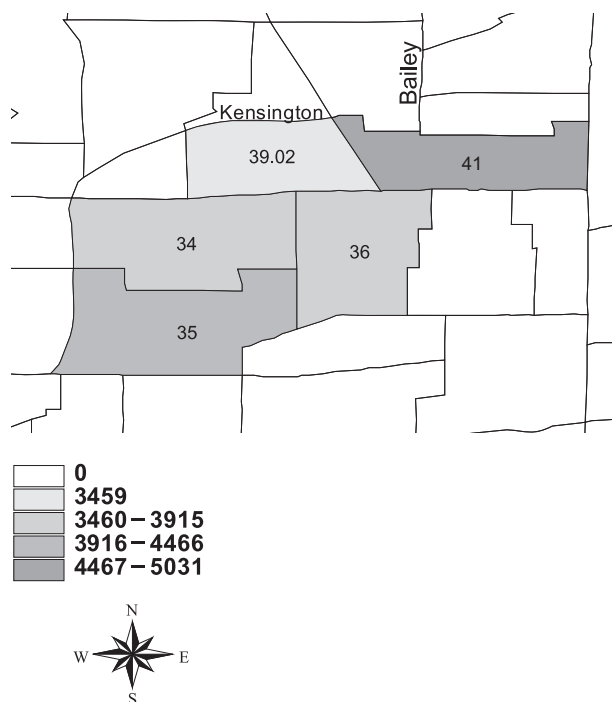


FIG. 2. Population of selected census tracts.

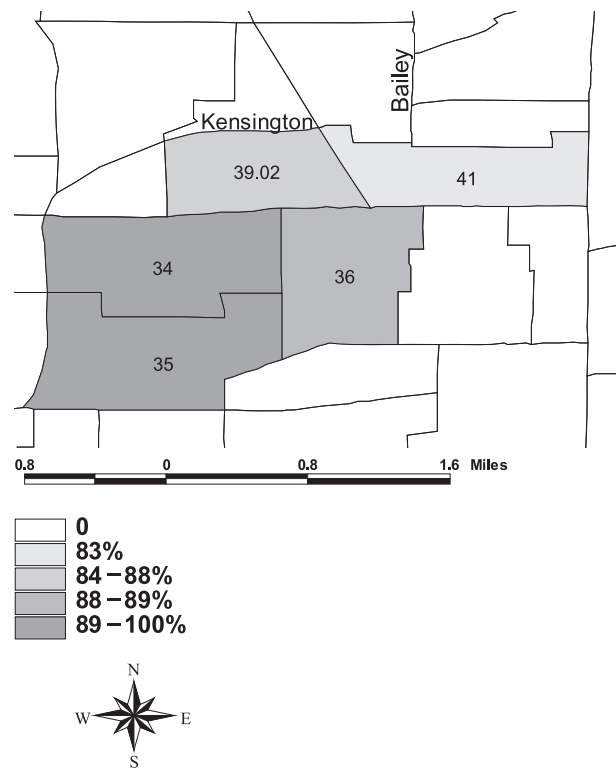


FIG. 3. Percent of population in selected tracts that is African American.

commercial operations and poor efforts from governing bodies to remedy the problem. Both the poverty and minority levels for each of the two target census tracts were higher than the standard EJ identification percentages established by the EPA (see Figure 3 and Figure 4).

The Toxic Waste Lupus Coalition (TWLC) was established in 1999 by community members to address concerns in the community about environmental related illnesses. Funding for the New York State Superfund program was depleted in the late 1990s, and reauthorization took several years. While advocating for the replenishing of environmental cleanup funds, TWLC implemented the community outreach component of the forthcoming CBPR project by conducting community-wide meetings to discuss environmental justice issues and educate the community about autoimmune diseases. Activities were implemented in partnership with the Lupus Alliance of America (LAA) Western New York (WNY) affiliate, which provided all educational brochures, videos, and books on lupus.

The partnership's initial work plan was to serve the community by focusing their efforts on the source of contaminants which could be linked to the cluster of lupus patients on Buffalo's east side. The identified cluster was in close proximity to as many as three NYS DEC acknowledged inactive hazardous waste sites. The Buffalo Lupus Project was established to explore the high risk of contamination for the African American community due to environmental toxic pollutants. The Toxic Waste/

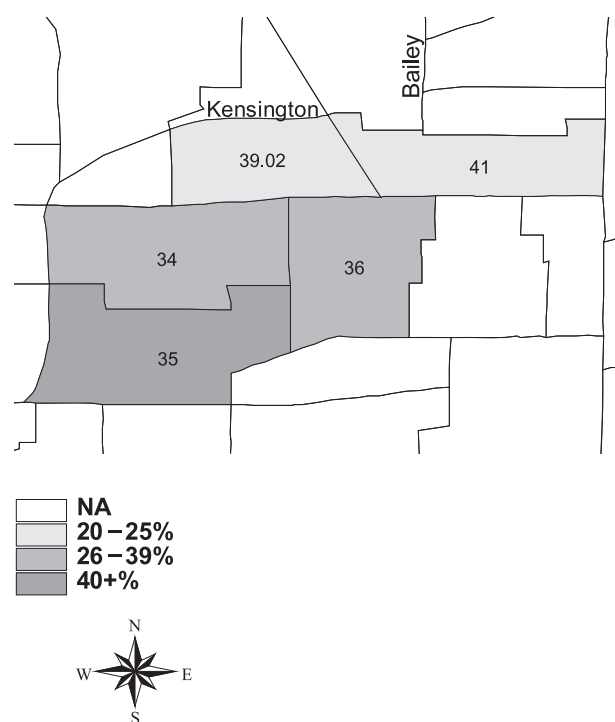


FIG. 4. Percent of population of selected tracts in poverty.

Lupus Coalition (TWLC), the University at Buffalo (UB), and the Systemic Autoimmune Disease Research Center of WNY formed a partnership to investigate common environmental factors that could elucidate the complex causes of lupus and other autoimmune diseases and count the number of people in the community with lupus or another autoimmune disease such as rheumatoid arthritis, type 1 diabetes, multiple sclerosis, and thyroid disease. The Buffalo Lupus Project was part of a five-year \$1.3 million National Institute of Environmental Health Sciences (NIEHS) funded community-based participatory research project. Throughout the duration of the grant, TWLC and UB worked collaboratively to sustain the community participatory process and build capacity in the community. The purpose of a community-driven approach was not only to determine if there was a correlation between the elevated contaminant levels at the site and the cluster of residents with lupus, but also to address the effects of past decisions linked to local DEC-regulated hazardous waste sites.

Community based investigation of 858 East Ferry Street Superfund site

TWLC organized a series of community events to educate affected residents and urge the DEC to fence off the contaminated site to prevent the spread of contamination and warn local children who frequently played in the area. There were several meetings between the Coalition, the University at Buffalo, the New York State Department of Health, the Erie County Department of Health, and the

contractor in charge of remediating the site. The purpose of these meetings was to make sure the public's opinion of the site's potential uses would be included in state and city plans for remediation.

The partnership's CBPR outreach strategy was based on the division of efforts among four committees (Communications Committee, Education and Stakeholders Committee, Political Action/Broader Community Committee and Research and Survey Committee), which each had the responsibility of developing tools to empower the community. The Coalition conducted preliminary investigations of the three area toxic waste sites and built an inventory of pollutants for each site. The City of Buffalo first identified the vacant property at 858 East Ferry Street as a hazardous site in 1997. Past operations of a zinc storage complex and lead smelter and refining facility, which operated from the 1920s through the early 1970s, was believed to be the source of contamination. Although DEC officials and interested groups usually refer to the Superfund site as 858 East Ferry Street, the original location of the lead smelting facility was the 2.3 acre lot at 856 East Ferry Street. The adjacent 3.32 acre empty lot (858 East Ferry Street) was used by the smelter to dump waste ash. Site investigations uncovered soil levels of contamination as high as 96,000 ppm.⁴ However, the extent of contamination and likelihood of off site leaching of toxins wasn't addressed in previous investigations.

All previous state funded assessments failed to clearly determine whether lead levels were limited to the study area. Using CBPR methods, a group of residents and TWLC and academic representatives approached the governing agency urging them to take action to clearly define the extent of lead contamination. The East Ferry neighborhood is part of a zip code tracking area (ZCTA) with one of the highest incidences of elevated blood lead levels in children.⁵ Therefore, determination of whether contaminants had moved off site was a major concern of community members. The community wanted to identify boundaries of concern with regard to landmarks surrounding the site, which included a church and elementary school across the street, nearby housing projects and youth detention facility, and an adjacent auto site. TWLC and UB's Chemistry department conducted additional soil sampling focused on identifying lead levels in the area surrounding the study site. Community members were trained in the process of taking soil samples, and participated in the sampling process. Thirty samples were taken by community participants and 10 undergraduate students in the summer of 2003. Sampling procedures were targeted at street-side soils across the street, on

⁴New York State Department of Environmental Conservation, April 2005, Focused Feasibility Report: East Ferry Street Site Work Assignment D003825-56.

⁵New York State Department of Health, Bureau of Environmental and Occupational Epidemiology, September 30, 2002, "Blood lead levels of residents living near 858 Ferry Street, Buffalo, NY."; New York State Department of Health, May 2001, Protecting Our Children from Lead: The Success of New York's Efforts to Prevent Childhood Lead Poisoning.

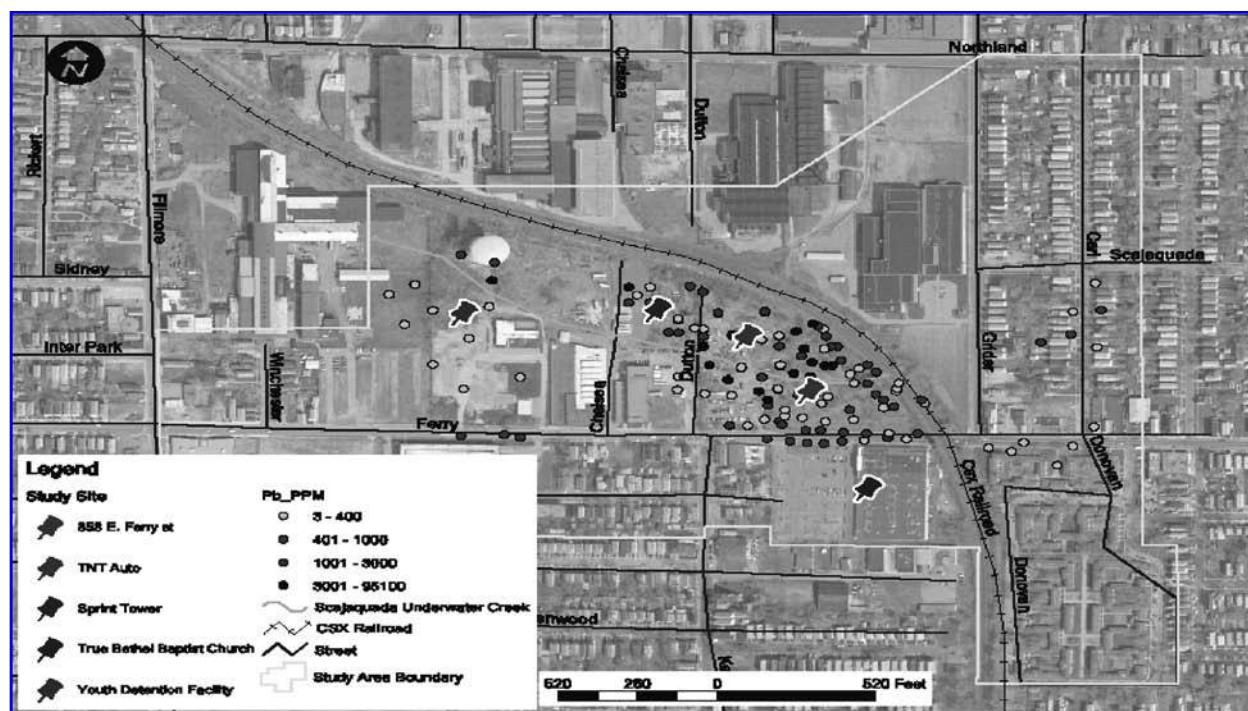


FIG. 5. Combination of aerial photograph and geographic information analysis of lead contamination results from all studies.

streets adjacent to the site, at residences located in the direction wind would blow materials off of the site, and the nearby Buffalo Municipal Housing Authority (BMHA) housing sites. Soil samples were analyzed by an EPA certified commercial laboratory for heavy metals. Data showed elevated lead levels (500–1000 ppm) in surface soil samples outside of the 856 and 858 East Ferry Street sites.

Chemistry students created geographic information system (GIS) maps to highlight new areas of concern surrounding the study site (Figure 5). These maps were used as visual aids to show what had been done previously by DEC officials and newly identified levels of lead and other contaminants. Use of these maps, which also included overlaying data with high resolution aerial photos, provided community participants with the opportunity to learn how to assess visual aids and understand technically presented findings.⁶

Arsenic and mercury levels on the site were not high enough for remediation concern. Lead levels were low on the BMHA site, of normal levels at residences in the natural wind path, but quite high on the street-side of the church and charter school. TWLC constituents worked with conventional environmentalists to learn more about developing credible reports on the environmental conditions of the area. They also involved the community in successful citizen clean-up of the area which not only peaked interest more in its preservation, but also reduced exposure to additional risks associated with the lead contamination from the site. As a result of the community based sampling event, NYS DEC executed a more thor-

ough sampling plan later in 2003. Their findings⁷ validated community findings that the geographic extent of elevated lead contamination spread further to the west than was originally identified. Three additional industrial properties, to 810 East Ferry Street, showed elevated lead levels and were targeted for cleanup.

A significant point in the development of the investigation and advocacy was achieved with the reauthorization of the State Superfund Law, which was instrumental in fostering effective conversations between NYS DEC and local neighborhood groups and churches. Conducting neighborhood empowerment/outreach events enabled the community to compile information and prepare their own remediation plan for the site of concern, based on their own questions and data. Discussion between interested parties was key to the implementation of the community driven cleanup plan. June 29, 2005, the NYS DEC held a public meeting in the church located across the street from the Superfund site to inform stakeholders that they had completed the Pre-Design Investigation and Focused Feasibility Study for the 858 East Ferry site. The purpose of the meeting was to present newly found information and to get feedback from the affected neighborhood on the proposed remedy to the contaminated

⁶Gardella, JA Jr., TM Milillo, G Sinha, G Oh, DC Manns, and E Coffey. "Linking community service, learning, and environmental analytical chemistry." *Analytical Chemistry* (2007): 810–8.

⁷New York State Department of Environmental Conservation, October 2004, Pre-design investigation report, East Ferry Site, City of Buffalo, Site 0-15-175.

site. Comments given by those who attended the meeting as well as findings from the sampling event were reviewed and were the basis of a new remediation plan introduced by the community. The suggestions were accepted by DEC, making the 858 East Ferry Street site one of the few where community involvement significantly influenced remediation action. Remediation of the site was completed in November of 2007, with significant cleanup to residential standards at 858 East Ferry Street.

DISCUSSION

Although CBPR practices are underutilized, they are extremely useful in addressing environmental justice issues. CBPR was key to our project investigating high rates of lupus and other autoimmune diseases in East Buffalo. Residents living in communities categorized as environmental justice neighborhoods are often left out of the decision making process, enabling the continued placement of potential sources of environmental exposure in these communities. CBPR studies provide a means for the impacted community to be involved in information gathering and analysis, as well as gaining necessary skills to assess current conditions and prevent duplication of injustices. The partnership between the East Ferry Neighborhood and Toxic Waste Lupus Coalition in East Buffalo was instrumental in advocating for decisions which led to the cleanup of the target waste site.

This CBPR project provided a vehicle for several inclusive efforts including students engaging in technical analyses with community members, which ultimately produced the justification needed to prompt the DEC to take extra steps in assessing the problem. Strategy development included community education in the areas of sample collection, chain of custody processes, data analysis and comparison of soil data from surface samples and subsurface data, and utilization of maps summarizing data. Using CBPR to include the neighborhood in research activities led to them making informed decisions when presented with remediation options, which resulted in the adoption of their selected cleanup measures.

CONCLUSION

Investigations of site characteristics are crucial to understand the extent of health impacts contaminants may have on community residents. CBPR methods were used to empower a community and enable a community-driven remediation plan to be endorsed by the governing agency. This plan was used to reduce the threat of environmental exposure and enable land to be used to improve the character of the neighborhood. Through CBPR methods, a strategy was developed and implemented at the community level and resulted in actions that have either directly or indirectly improved the quality of life for participants and other affected community residents.

REFERENCES

- Alarcon, G, T Beasley, J Roseman, GJ McGwin, B Fessler, and H Bastian. "Ethnic disparities in health and disease: the need to account for ancestral admixture when estimating the genetic contribution to both (LUMINA XXVI)." *Lupus* 14 (2005): 867-8.
- Cooper, G, M Dooley, E Treadwell, E St Clair, and G Gilkeson. "Hormonal and reproductive risk factors for development of systemic lupus erythematosus: results of a population-based, case-control study." *Arthritis & Rheumatism* 46 (2002): 1830-9.
- "Creating Partnerships, Improving Health: The role of Community Based-Participatory Research." <<http://www.ahrq.gov/research/cbprrole.htm#different>>. (Last accessed on 1/10/08).
- Environmental Protection Agency, Office of Environmental Justice. <<http://www.epa.gov/compliance/environmentaljustice/>>. (Last accessed on 1/10/08).
- Gardella, JA Jr., TM Milillo, G Sinha, G Oh, DC Manns, and E Coffey. "Linking community service, learning, and environmental analytical chemistry." *Analytical Chemistry* (2007): 810-8.
- Gee, GC and D Payne-Sturges. "Environmental Health Disparities: A Framework Integrating Psychosocial and Environmental Concepts." *Environmental Health Perspectives* 112 (2004): 1645-53.
- New York State Department of Environmental Conservation, April 2005, Focused Feasibility Report: East Ferry Street Site Work Assignment D003825-56.
- New York State Department of Environmental Conservation, October 2004, Pre-design investigation report, East Ferry Site, City of Buffalo, Site 0-15-175.
- New York State Department of Health, Bureau of Environmental and Occupational Epidemiology, September 2002, Blood lead levels of residents living near 858 East Ferry Street, Buffalo, NY.
- New York State Department of Health, May 2001, Protecting Our Children from Lead: The Success of New York's Efforts to Prevent Childhood Lead Poisoning.
- Oates, J, M Levesque, M Hobbs, E Smith, I Molano, and G Page. "Nitric oxide synthase 2 promoter polymorphisms and systemic lupus erythematosus in african-americans." *Journal of Rheumatology* 30 (2003): 60-7.
- Parks, C and G Cooper. "Explaining racial disparity in systemic lupus erythematosus-Environmental and genetic risk factors in the Carolina lupus study." *Annals of Epidemiology* 12 (2002): 502.
- Petri, M. "Epidemiology of systemic lupus erythematosus." *Best Practices & Research Clinical Rheumatology* 16 (2002): 847-58.
- Powell, JJ, J Van de Water, and ME Gershwin. "Evidence for the Role of Environmental Agents in the Initiation or Progression of Autoimmune Conditions." *Environmental Health Perspectives Supplements* 107 (1999).
- Uribe, G and America. "What have we learned from a 10-year experience with the LUMINA (Lupus in Minorities; Nature vs.nurture) cohort? Where are we heading?" *Autoimmunity Reviews* 3 (2004): 321-9.

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2. Erica L. Holloman, Michael C. Newman. 2010. A community-based assessment of seafood consumption along the lower James River, Virginia, USA: Potential sources of dietary mercury exposure ###. *Environmental Research* **110**:3, 213-219. [[CrossRef](#)]