

**Progress Report:
Survey of Specific Childhood Cancers and Birth Defects
Among Children Whose Mothers Were Pregnant
While Living at U.S. Marine Corps Base Camp Lejeune,
North Carolina, 1968-1985**

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Executive Summary

In 1982, testing of drinking water began at U.S. Marine Corps (USMC) Base Camp Lejeune, North Carolina. The tests showed pollution in the drinking water at some base housing. The water had chemicals called volatile organic compounds (VOCs). VOCs are used to clean machinery and weapons and in dry-cleaning.

The Agency for Toxic Substances and Disease Registry (ATSDR) released a health assessment of the base in 1997. This assessment stated that exposure to VOCs probably would not cause health problems in adults. It also said a study was needed to see if such exposure at Camp Lejeune posed a threat to fetuses and infants.

ATSDR then studied Camp Lejeune to see if infants whose mothers were exposed to drinking water with VOCs were at risk for being “small for gestational age” (weighing less than the 10th percentile). This study found such a link with a subgroup of the births.

ATSDR is now moving toward a full study of specific birth defects and childhood cancers at Camp Lejeune. The first step was to choose which birth defects and childhood cancers to study. Existing studies and other factors were considered. ATSDR decided to focus on these conditions:

- Childhood leukemia
- Childhood non-Hodgkin’s lymphoma
- Spina bifida
- Anencephaly
- Cleft lip
- Cleft palate.

The second step was to identify the children eligible for the study by doing a telephone survey. ATSDR decided on children born to women who were pregnant with them while living on the base during 1968–1985. The year 1968 is the starting point because that year North Carolina began computerizing its birth records. These records were used to identify children for the study. The end point is 1985 because the tainted wells were shut down that year.

The survey began in September 1999 and ended in January 2002. ATSDR surveyed by telephone the parents of 12,598 eligible children. This number was about 80% of the estimated total. Parents were asked if the child had had a birth defect or had developed a childhood cancer. A total of 103 cases were reported.

The third step was to confirm the children’s health problem(s). ATSDR asked the parents who said their children had health problems of interest (or the children if they were now over 18) for access to their child’s health records. These records are now under review. ATSDR has received records for 46 of the 103 children so far and has confirmed about 80%.

The final step will be to conduct a full study. This study will include all confirmed cases of the birth defects and childhood cancers which are the focus of the study. The study will also include

modeling of the water system to see which mothers did and did not receive the water with VOCs. Currently we do not know which mothers received the water with VOCs.

In summary, ATSDR has finished the survey and is now confirming the cases. These steps were needed to prepare for the larger study. There is enough information to proceed with the full study. Only the full study can establish whether VOC-tainted drinking water may cause the childhood health problems being studied.

INTRODUCTION

U.S. Marine Corps (USMC) Base Camp Lejeune covers an area of approximately 233 square miles in the City of Jacksonville, Onslow County, North Carolina. In the mid-1980s, groundwater contamination was found in wells that provided drinking water to base-housing areas on Camp Lejeune. The contamination was caused by both on- and off-base sources. The on-base sources included the following:

- leaking underground storage tanks containing trichloroethylene (TCE)
- spills from operations at the vehicle maintenance area
- drum disposal at sites 6, 9, and 82, and
- associated storage lots at operating unit 2 (ATSDR 1997).

The off-base sources consisted of a leaking, above-ground tetrachloroethylene (PCE) storage tank and solvent-disposal practices at ABC One-Hour Cleaners, a dry-cleaning establishment (ATSDR 1990). The public health assessment (PHA) for Camp Lejeune found that PCE was the primary contaminant at the dry-cleaners (ATSDR 1997). PCE and other solvents from the dry-cleaning establishment had contaminated a nearby well on Camp Lejeune property; this well had provided drinking water to the Tarawa Terrace base housing complex. Both Camp Lejeune and ABC One-Hour Cleaners were listed as Superfund sites in 1989.

The 1997 PHA for Camp Lejeune determined that exposures to the levels of drinking water contaminants from the dry-cleaning establishment and the on-base sources would most likely not result in adverse health effects to adults (ATSDR 1997). However, because of information about how these chemicals might affect a fetus or child, the levels of the contaminants in the drinking water, and the findings from previous studies conducted in other states, the PHA recommended that an epidemiologic study be performed at Camp Lejeune. The study would evaluate whether mothers exposed during pregnancy to chlorinated solvents (e.g., PCE and TCE) in drinking water had a higher risk of giving birth to a child with a birth defect or a childhood cancer. As a first response to this recommendation, ATSDR conducted a study of births occurring at Camp Lejeune during 1968-1985. The study evaluated whether having a small-for-gestational age (SGA) infant at Camp Lejeune was associated with exposures to water supplies from Tarawa Terrace that were contaminated with PCE and water supplies from Hadnot Point that were contaminated with TCE and 1,2-dichloroethylene (ATSDR 1998; Sonnenfeld 2001).

Exposure to Hadnot Point water was associated with an elevated risk for SGA only among male infants (odds ratio [OR] = 3.9, 90% confidence interval [CI]: 1.1, 11.9) (ATSDR 1998). Exposure to Tarawa Terrace water was associated with elevated risk for SGA among infants born to mothers aged ≥ 35 years (OR=2.1, 90% CI: 0.9, 4.9) and among mothers with two or more prior fetal losses (OR=2.5, 90% CI: 1.5, 4.3) (Sonnenfeld 2001).

BACKGROUND

Three water distribution systems provided water for Camp Lejeune's base housing areas: the Tarawa Terrace, Holcomb Boulevard, and Hadnot Point systems. Because it was not known when the contamination started in each of the distribution systems, chemicals could have been present in the systems for many years before their initial discovery in 1982. Table 1 provides the maximum levels that were measured at the tap in each of the three water distribution systems (ATSDR 1997).

Tarawa Terrace

Contamination in the Tarawa Terrace water system occurred as a result of disposal practices at ABC One-Hour Cleaners, which opened in 1954 and was located just outside Camp Lejeune's gate. As a practice, the establishment disposed of waste solvent by draining it into a septic tank or by releasing it onto the ground. In 1958, the USMC drilled an on-base drinking-water supply well located 900 feet from the dry cleaner. This well was probably contaminated soon after it was drilled because of its proximity to ABC One-Hour Cleaners and the high permeability of soils in the area (ATSDR 1998). In May 1982, sampling of the finished water at the Tarawa Terrace system was done, and high levels of PCE, a dry cleaning solvent, were found (76–104 parts per billion [ppb]). One sample taken in 1985 before the contaminated wells were shut down indicated a PCE level of 215 ppb was found. TCE, a degreaser, and 1,2-dichloroethylene (DCE), a breakdown product of PCE, also were detected in this sample. The contaminated wells were closed in February 1985 (ATSDR 1997).

Hadnot Point

The Hadnot Point water distribution system supplied water primarily for industrial purposes at the base, but it also supplied drinking water to the Hospital Point housing area. High levels of TCE (a maximum of 1,400 ppb) were detected during sampling in 1982. High levels of TCE and DCE were found during the routine testing of the drinking water system in 1984 and 1985. The Hadnot Point system had 39 operational wells, although only approximately 20 wells were used at any one time. The contamination was linked to leaking on-base underground storage tanks.

Holcomb Boulevard

In 1972, the Holcomb Boulevard water distribution system went on-line and served the Midway Park, Berkeley Manor, Watkins Village, and Paradise Point base-housing areas. Before 1972, the Holcomb area was served by the Hadnot Point water distribution system. In early 1985, a fuel line burst at the Holcomb Boulevard water distribution system, releasing fuel into the water supply. An emergency line from the Hadnot Point water system temporarily supplied water to the Holcomb Boulevard system service area over a 12-day period beginning January 27. During this period, the Holcomb area base housing received contaminated water from the Hadnot Point system. Once the fuel line was repaired, the

emergency hookup from Hadnot Point was disconnected, and the Holcomb Boulevard system resumed service to its designated housing areas.

OBJECTIVES

The primary objective of the health survey was to identify and confirm all cases of specific birth defects and childhood cancers among children exposed in utero to drinking water contaminated with TCE, PCE, and other chlorinated solvents. The specific group investigated was composed of children who were conceived or carried in utero while their mothers lived in on-base housing at Camp Lejeune during 1968–1985.

METHODS

Definition of Eligible Children and Recruitment Practices

Children eligible for the health survey were those born at >28 weeks gestation to mothers who were pregnant while they lived in base housing at Camp Lejeune from 1968 through 1985. Eligible children included those born to mothers who had transferred off the base at the time of delivery as well as those born to mothers who lived on the base at the time of delivery. Because 1968 was the first year that birth certificates were computerized in the state, the year was chosen as the start of the study period in both the previous SGA study and the current survey. The year 1985 was chosen as the end date of the study because the contaminated wells were shut down that year.

ATSDR attempted to locate and contact the parents of each eligible child to elicit information on the child's health as well as to confirm that the mother was a resident at the base at some point during the pregnancy. Eligible children were identified in two ways. First, the survey used the birth certificate information from the previous Camp Lejeune study of SGA (ATSDR 1998). A total of 12,493 birth certificates were obtained for children born from 1968 through 1985 to mothers who lived in base housing at the time of delivery.

Second, children born from 1968 through 1985 to mothers whose pregnancies occurred while they lived in base housing but who lived off the base at the time of delivery were identified primarily by word-of-mouth (e.g., parent groups), by referrals from other parents during their interviews, or by parents prompted by media information about the survey to contact ATSDR or the USMC. Birth certificates were not obtained for these children. The number of pregnancies that occurred at base housing during the study period and that resulted in live births to mothers who lived off the base at the time of delivery is unknown. However, staff of the Camp Lejeune Naval Hospital estimated that about one third of mothers receiving prenatal care at the hospital were transferred from Camp Lejeune before delivery. Based on this information, ATSDR estimated that between 3,500 and 4,500 mothers were transferred from Camp Lejeune before delivery. Therefore, an estimated total of 16,000 to 17,000 births occurred among women who were pregnant while living at Camp Lejeune during the study period.

Because many of the parents were no longer in the military, several locating methods were used. The primary approach used to identify the current addresses and/or telephone numbers of parents

was to obtain the parents' names and social security numbers and send this information to Lexus-Nexus, a private-sector locating firm. The names of the parents were obtained from birth certificates. Two sources were used to obtain the parents' social security numbers: (a) birth medical records of children born at the Camp Lejeune Naval Hospital; and (b) data from the Defense Manpower Data center matched to the parents' names.

To identify current addresses of parents for whom social security numbers were unavailable, USMC personnel matched the parents' names to information contained in the databases of the USMC records system. In addition, ATSDR searched the membership directory of the USMC Association to identify current addresses for the parents. The USMC also prompted families to contact ATSDR by distributing a military administrative memo (MARADMIN 394/00) describing the survey to Marine Corps newsletters and newspapers as well as through the USMC e-mail system (USMC 2000). The memo was initially released September 12, 2000, and re-released in early 2001. The USMC also promoted the survey by conducting a nationwide television, newspaper, and radio campaign after the initial media releases from CNN and FOX networks in November 2000. The USMC also sent an e-mail message to current marines asking if they had been conceived or carried in utero during the study period while their mothers lived in Camp Lejeune on-base housing.

For births that occurred off the base, the names of parents were identified primarily by word-of-mouth (e.g., from parents groups) or by referrals from other parents during their interviews. In addition, communications from the USMC in the form of memos, e-mails, and media information releases prompted some parents of eligible children (or the eligible children themselves who were now adults) to contact ATSDR or the USMC for information on the survey.

Survey Questionnaire

The survey questionnaire was administered to the parent (most often the mother) using a computer-assisted telephone interviewing (CATI) system, and answers were entered directly into the computer. The average length of time to complete the telephone survey was 15 minutes. The interviews were conducted from September 15, 1999, through January 26, 2002. The survey confirmed the eligibility of the child by asking the parent(s) about where and when they resided during the pregnancy. The survey also asked for information on the current vital status and residence of the child.

In addition, the parent was asked if the eligible child had been diagnosed by a physician as having a birth defect or a childhood cancer. A childhood cancer was defined as a cancer diagnosed before the age of 20 years for those children born during 1968-1980. Because those born after 1980 would not have attained the age of 19 when the survey began, a childhood cancer was defined as a cancer diagnosed at any age for those born during 1981-1985. If the parent stated that the eligible child had been diagnosed by a physician as having a birth defect or childhood cancer, then the parent was asked for the specific type of birth defect or cancer. Many of the parents were able to give the names of the specific types of birth defects or cancers. If the parent could not name the specific type of birth defect or cancer, he or she was asked to describe the condition and symptoms.

Verification of the Health Outcomes Of Interest

Once all the surveys were completed, the next step was to verify the specific birth defects and childhood cancers of interest by obtaining and reviewing the children's medical records. The birth defects of interest were spina bifida and anencephaly, which are neural tube defects of the central nervous system oral clefts, that is, cleft lip and cleft palate.

The childhood cancers of interest included non-Hodgkin's lymphoma (NHL) and leukemia, particularly acute lymphocytic leukemia (ALL). The decision to focus on these specific birth defects and childhood cancers was based on the evidence from the scientific literature as well as the ability of the survey to identify reliably and completely all the cases of these diseases.

The first task was to identify from the parent interviews all the eligible children who were diagnosed by a physician as having the specific birth defects and childhood cancers of interest. Because the birth defects and childhood cancers were "self-reported" (i.e., reported by the parents and not identified directly from medical records), it was necessary to verify the birth defects and childhood cancers of interest that were reported by the parents. The review of a child's medical records was necessary to verify that the child had the birth defect or childhood cancer of interest. If a parent reported the name of the specific birth defect or childhood cancer of interest, then the parent was asked to sign a medical records release form granting ATSDR permission to obtain the child's medical record from the child's health care provider. If the child was now ≥ 18 years of age, he or she was contacted and asked to sign a medical records release form.

Some parents, however, could not provide the names of the specific types of birth defects that their children had. Instead, they provided only descriptions of the birth defects (e.g., a parent might describe what the birth defect looked like). Some parents did not report that their children had a birth defect, but during other parts of the interview they provided descriptions of their children's health problems that seemed to indicate the children might have had a birth defect. Because the objective was to identify all potential cases of the birth defects of interest, it was necessary to evaluate the descriptions provided by the parents to reduce the likelihood of missing potential cases. Therefore, a dysmorphologist from the Centers for Disease Control and Prevention (CDC) reviewed the descriptions provided by the parents and determined whether the children were likely to have the birth defects of interest. If the dysmorphologist determined from the parent's description that the child was likely to have a birth defect of interest, then the parent was asked to give ATSDR permission to obtain the child's medical record from the child's health care provider.

PROGRESS TO DATE

Information on 12,598 eligible children was obtained through the survey. This total includes numbers for the both groups of eligible children. Group 1 (N=10,040) includes children born inside Onslow County at either the base or county hospital. Group 2 children (N=2,558) were those born outside the county.

For Group 1 children, whose computerized birth certificate information was available from the NC Department of Health, an accurate participation rate can be calculated because the total

number of eligible children is known (N=12,493). The participation rate for Group 1 children was 80.4%. How many eligible children were born outside Onslow County is not known, however, so the participation rate for Group 2 children is uncertain. On the basis of information provided by the Camp Lejeune Naval Hospital, ATSDR estimated that about 3500–4000 eligible children were born outside of Onslow County. Given this estimate, the participation rate for Group 2 children would range from 64% to 73%. Therefore, the overall participation rate for the survey ranges from 76% to 79%.

The survey also noted descriptive data for the eligible children whose parents completed the survey (Table 2). About 73.5% of the children were white, 17.3% were African American, and 7.9% were Hispanic. The frequency of the outcomes of interest based on the parents' survey responses was also documented. The parents' responses to the survey identified 74 children with potential birth defects of interest and 29 children with potential cancers of interest. (Table 3).

FUTURE DIRECTIONS

The objectives of this survey were to (a) identify all potential cases of the specific birth defects and childhood cancers of interest and then (b) confirm the diagnoses of these cases. At present, ATSDR has obtained medical records for about 45% (46 of 103) of the potential cases (Table 3). Of the 46 medical records that ATSDR was able to review, the diagnoses were confirmed for about 80% (36 of 46) of the children. Most of the disconfirmed diagnoses were conditions that were related to the birth defects and childhood cancers of interest (e.g., central nervous system defects other than neural tube defects, and blood disorders other than leukemia). Therefore, the information provided by the parents has been reliable, and we expect to be able to confirm most of the reported cases. The verification process will continue until the diagnoses for the potential cases are either confirmed or not confirmed.

Only confirmed cases can be analyzed in an epidemiologic study. Therefore, confirming as many potential cases as possible will be crucial to the success of the study.

Although the survey continues to provide information, an epidemiological study is necessary to determine whether maternal exposure to the contaminated drinking water at Camp Lejeune is associated with increased risks of specific birth defects and childhood cancers. Such a study seems warranted for several reasons:

- High levels of the contaminants were found in the drinking water;
- Findings in the scientific literature indicate that such exposures increase the risks of specific birth defects (Bove 2002) and childhood cancers (Cohn 1994; Costas 2002; NJDHSS 2003);
- The high participation rate of the survey (approximately 80%); and
- The high percentage of these potential cases that have been confirmed to date.

The planning for the epidemiologic study has begun. A draft of the protocol for the study has been completed, and ATSDR will be seeking input on the draft protocol from concerned citizens

as well as scientists outside the government. Once all comments have been received, the protocol will be revised in response. In addition, a “control group” will be selected by conducting a random sample of the eligible children (i.e., who were born to mothers who were pregnant while they lived in base housing at Camp Lejeune during 1968–1985). This type of study is also called a “case-control study.”

The epidemiologic study will also require computer modeling of the drinking water system at Camp Lejeune for 1968–1985 to determine which mothers were probably exposed to VOCs in the drinking water during their pregnancy and which mothers were not.

ATSDR has extensive experience in the modeling of drinking water systems. For example, as part of a study of childhood cancers conducted in Dover Township, New Jersey, ATSDR successfully developed a drinking water system model. This model was precise enough to allow ATSDR to estimate the percentage of water from contaminated public wells delivered to any location in the town for each month from January 1962–December 1996 (Maslia et al. 2001, NJDHSS 2003). These estimates were then applied to the residences of the cases and controls. The Dover Township drinking water system model was based on field-data collection of the present-day system operations and a historical reconstruction of fate and transport of contaminants within the water system, using historical information available from the water company.

A similar approach will be used for the epidemiologic study at Camp Lejeune. The drinking water distribution system model will be based on current and historical information on the base water system as well as historical information on the sources of the contamination. ATSDR is in the process of gathering these data. The results of the model will enable the epidemiologic study to establish whether the mothers of the children with birth defects or cancers of interest were more likely to have been exposed during their pregnancy to the drinking water contaminants than were the mothers of the controls.

CONCLUSION

ATSDR is planning an epidemiologic study to determine whether exposure to contaminated drinking water at Camp Lejeune was associated with excess rates of the specific birth defects or childhood cancers of interest. This plan is based on four principal factors:

- The high levels of contamination found in the drinking water at Camp Lejeune during testing in 1982–1985,
- The likelihood that the drinking water was contaminated in prior years,
- The scientific literature on the adverse health conditions of interest, and
- The potential number of confirmed cases of these conditions of interest.

The health survey and the process of confirming the cases of birth defects and childhood cancers have been critical steps in preparation for conducting the epidemiologic study. The high participation rate supports the likelihood that most birth defects and childhood cancers among

the eligible children have been identified. The key issue now is whether the diagnoses can be confirmed for most, if not all, of the potential cases of the birth defects and childhood cancers of interest that were identified by this survey.

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Table 1. Maximum Concentration (Ppb) of Contaminants in Drinking Water at The Tap—Camp Lejeune, North Carolina, 1982–1985.

Chemical	Maximum Concentration by Distribution System			US Drinking Water Maximum Contaminant Level Standard
	Hadnot Point	Tarawa Terrace	Holcomb Boulevard	
Trichloroethylene (TCE)	1,400	8	1,148	5
1,2-Dichloroethylene (DCE)	407	12	407	70
Tetrachloroethylene (PCE)	ND	215	ND	5
Methylene chloride	54	ND	ND	5
Vinyl chloride	3*	ND	ND	2

* Estimated value.

ND = None detected.

Table 2. Selected characteristics of eligible children whose parents completed the survey—Camp Lejeune, North Carolina

Category	Frequency	Percentage
Sex		
Male	6,371	50.6
Female	6,223	49.4
Unknown/Refusal	4	0.0
Race		
White	9,257	73.5
Black/African American	2,177	17.3
Native Hawaiian/Pacific Islander	87	0.7
Asian	86	0.7
American Indian/Alaska Native	86	0.7
Other	822	6.5
Unknown/Refusal	83	0.7
Hispanic Ethnicity		
Yes	997	7.9
No	11,576	91.9
Unknown/Refusal	25	0.2
Total	12,598	100.0

Table 3. Number of cases of birth defects and childhood cancers of interest, and number of

Outcome of Interest	Number Reported	Number for Whom Medical Records Have Been Obtained (Number Confirmed)	Number In Process	Number Unavailable
Neural tube defects	33	16 (11)	15	2
Oral clefts	41	13 (12)	25	3
Childhood leukemia	22	15 (11)	7	0
Childhood lymphoma	7	2 (2)	3	2
Total	103	46 (36)	50	7

children for whom medical records have been obtained—Camp Lejeune, North Carolina.