

Understanding the Impact 40 Years Later
U.S. Vietnam Veterans and Agent Orange:
National Organization on Disability
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Foreword

The following paper was commissioned by the Ford Foundation Special Initiative on Agent Orange/Dioxin and written by the National Organization on Disability (NOD). The paper benefits extensively from independent research conducted for NOD in 2008 by Mary Carstensen, U.S. Army, Colonel (retired) and from additional research and analysis in 2008 and 2009 by Mary E. Dolan-Hogrefe, Vice President and Senior Advisor, NOD.

The production of this paper was inspired in part by NOD's participation in the U.S.-Vietnam Dialogue Group on Agent Orange/Dioxin, a bilateral citizens' group of five Vietnamese and five Americans convened by the Ford Foundation (further information is available at www.fordfound.org/programs/signature/agentorange/issue). One goal of the Dialogue Group is to make the U.S. public aware of the continuing environmental and health consequences of dioxin contamination in Vietnam resulting from use of Agent Orange by U.S. forces during the Vietnam War. A second goal is to mobilize resources and build effective public-private partnerships to respond to those consequences without further delay. This paper adds to those efforts by examining where we are in our own country relative to the affects of Agent Orange on our soldiers and their families.

Although these issues date back more than 40 years, they remain critically important for at least two reasons. First, it is still not too late to correct lapses in the nation's treatment of veterans who were exposed to dioxin during the Vietnam War. Many of them began reporting high rates of illness and disability soon after their wartime service, and yet waited many years (and in some cases are still waiting) for a fair resolution to their concerns. Those concerns now extend to health effects among their children and grandchildren. Many of the effects are still poorly understood and officially unrecognized.

The second reason these issues continue to resonate is that the use of chemicals on the world's battlefields has only increased in the years since the Vietnam War ended. One lesson of the Agent Orange experience has been that the consequences of using such chemicals are rarely easy to predict, and that the burdens they impose may well be borne for generations, long after the original causes of conflict have been resolved.

It is timely for our nation to address war legacies, past and present, and make good on our promise to care for our own.

U.S. VIETNAM VETERANS AND AGENT ORANGE:
Understanding the Impact 40 Years Later

Between 1962 and 1971, the United States sprayed approximately 20 million gallons of dioxin-contaminated herbicides over some 6 million acres of Vietnamese terrain. Among these was a compound known as Agent Orange, named for the orange stripe on its label (other varieties were marked with different colors but were less widely used). These chemicals wiped out forests and crops that were used by opposition forces for cover and food. In the course of this, hundreds of thousands of U.S. service personnel and millions

of Vietnamese were exposed to the chemicals in the air, water, and soil and through food raised on contaminated farms.[1][1]

Agent Orange consisted mainly of two weed killers in common commercial use at the time. One of these contained small amounts of a contaminant technically named 2,3,7,8-tetrachlorodibenzo-*p*-dioxin, or TCDD, known to be toxic in humans. TCDD accumulates in human fatty tissue, where it is neither readily metabolized nor excreted, so its effects can linger and build over time. In April 1970, the federal government found evidence that TCDD had caused birth defects in laboratory mice (it was later linked to other conditions as well). Yet Agent Orange continued to be used in Vietnam for another eight months.

By the time the war ended in May 1975, more than 2.5 million American military personnel had served in Vietnam's combat zones. The precise number of Americans, Vietnamese, and people of other nationalities who were directly exposed to Agent Orange — like much else about the herbicide and its effects — is not documented anywhere. Yet the wholesale use of the chemical across the entire theater, together with its long-term persistence at several former US military bases in Vietnam, makes it highly likely that a significant percentage of the 2-3 million combat veterans came into some contact with Agent Orange during their service.

The many uncertainties surrounding wartime use of Agent Orange — over the exact number of people exposed, the level of exposure likely to be harmful, and the specific conditions that could result — hampered both medical care and policymaking for years. Nearly two decades after the war's end, the Agent Orange Act of 1991 sought to cut through the medical and scientific quandaries by establishing two official presumptions: that veterans who served in Vietnam from 1962 to the end of the war were exposed to Agent Orange, and that those diagnosed with certain illnesses associated with TCDD would have developed those illnesses at least partly as a result of their service in Vietnam. Yet 15 years after the law was passed, fewer than half a million Vietnam veterans had undergone the standard Agent Orange examination offered by the Department of Veterans Affairs to identify possible effects of their exposure.

Veterans who ask for and receive the official exam are entered into an Agent Orange Registry that started in 1978. It contained 490,000 names as of 2007, along with useful demographic and medical information. But there is no database listing the other, unexamined veterans who, by law, were presumptively exposed to poison. The Department of Veterans Affairs maintains a nominal outreach effort to alert such veterans and to help them navigate the process of examination, diagnosis, applications, and care that could help them. But veterans and their advocacy organizations report that the service is not widely used or effective, so the universe of unserved veterans remains something of a mystery. There is not even a source of data on the number of Vietnam veterans who are *already* receiving compensation or medical care for conditions related to Agent Orange, unless they happen to have undergone the official exam.

There is, in short, a presumed entitlement to care, services, and monetary assistance for America's Agent Orange victims, but no overarching system for fulfilling that entitlement except the private knowledge, initiative, and perseverance of each individual veteran. More than 50 voluntary organizations — nearly all of them formed by veterans themselves — manage to reach and help many former service members. But these Veterans Service Organizations have many competing priorities and limited resources, and are responding to the consequences of more recent wars.

Meanwhile, the official list of diseases that are recognized as herbicide-related has grown only sporadically, in response to an underfunded and uneven process of epidemiological research and bureaucratic deliberation. More than a decade after the war's end, only one illness — the disfiguring skin disease chloracne — was officially recognized as connected

to wartime Agent Orange exposure. Others have since been added, little by little, often after prolonged scientific and governmental debate. Many illnesses that Vietnam veterans suspect are associated with contaminated herbicides, such as brain or testicular cancer, still are not considered service-related and thus are not eligible for benefits.

To be sure, epidemiological research is slow by nature, and some delay in identifying the effects of Agent Orange exposure would have been unavoidable. Certain symptoms may take years to develop, and patterns and connections sometimes become apparent only over long periods. Any process of recognizing conditions and assessing their degree of connection to dioxin (rather than, say, to individual circumstances like heredity or tobacco use) would have taken time. But research on Agent Orange was riddled with challenges from the start – scientific, political and financial. The result was to transform a necessarily painstaking process into one with even greater — and partly avoidable — delays. For veterans and their families, struggling with unexplained illnesses, disabilities, and death, every needless delay poses a severe cost that cannot be repaid later.

The harm resulting from dioxin use now extends well beyond the generation that fought in Vietnam. In 2007, the VA[2][2] reported that 1,200 children of exposed veterans had some degree of disability resulting from Spina Bifida, a birth defect closely associated with TCDD. Some 200 of these disabilities were severe. Many of these children became eligible for compensation thanks to a 1996 act of Congress. But other birth defects, learning disabilities, and childhood illnesses are not recognized, even though recent evidence shows several of them to be more common among the offspring of exposed Vietnam veterans. Little research has been done to establish which of these conditions may be related to Agent Orange, which means that no basis yet exists for determining how and whether the affected families may ever become eligible for support. Despite evidence of cross-generational effects of Agent Orange dating back nearly four decades, there remains no routine means of examining the children or grandchildren of Vietnam veterans, nor any system of compensation or support for the vast majority of children and their families.

At a minimum, men and women who risked their lives for the U.S. war effort in Vietnam — and who in the process were exposed not only to enemy hostility but to poison from their own side — are entitled to a simple, consistent way of learning about and receiving the compensation and support to which the law already entitles them. But more broadly, the process by which eligible illnesses are recognized and addressed under this law should not be mired in technical disputes and plodding deliberation nearly 35 years after the war's end. Research and data-gathering need to accelerate to a pace that begins to make up for decades of procedural delay and that fills in the gaps in basic information on exposure, medical consequences, and benefits delivered.

Most far-reaching of all, veterans' children and (it now seems) grandchildren who are born with the effects of inherited contamination should have a clear, reliable source of medical and social services. The sluggish pace of research on Agent Orange contamination has meant that, for decades, parents have been unaware of the risks that they and their children would face, and thus have raised families without essential information, much less services, that might have reduced suffering and improved opportunity for unknown thousands of children.

This paper concludes with a more specific list of recommendations and gaps to be filled. But first it is useful to survey, briefly, how matters got to their present state, and how veterans currently fare in the complex process of learning about, diagnosing, treating, and living with the lingering effects of Agent Orange.

The Early Years: A Trickle of Information and Tentative Responses

By the mid-1970s, returning Vietnam veterans were experiencing higher-than-average rates of certain disabling and life-threatening illnesses, including diabetes and various cancers, that were later shown to be associated with TCDD and Agent Orange. Increasingly unwell, and often unable to work, many sought information from established veterans' organizations or the Veterans Administration, usually to little avail. One early source of information, an Agent Orange Hotline organized with Ford Foundation support in the late 1970s, brought forth a flood of inquiries. It received 50,000 calls in its first year, most from veterans with unexplained illnesses or concerns about their health who had no source of information on what was happening to them or what to do about it.

Even once they were armed with preliminary information, concerned veterans still had few opportunities for comparing notes, organizing, and collectively making their concerns known. The formation of Vietnam Veterans of America (VVA) in 1978 provided an important network of support and advocacy, and it remains one of the Veterans' Service Organizations chartered by Congress to prepare, present, and prosecute claims for services and benefits. At the time, herbicide-related illnesses were beginning to appear in large numbers, however, these organizations were new and still gathering resources to take up the cause.

Four other developments, beginning around the same time that VVA was founded, helped form a critical basis of fact and law to buttress veterans' fears that exposure to Agent Orange was damaging their health and that of their children. One was a class-action product liability lawsuit that was filed in 1978 against five manufacturers (two others were added later) involved in the production of tainted herbicides or their components. The suit was settled six years later for \$180 million, though the companies expressly denied liability or wrongdoing and maintained that "this action is without merit."^{[3][3]}

A portion of that sum was paid out as cash benefits to veterans who could demonstrate "total disability" at any time between 1971 and 1994 — a group that ended up comprising about 50,000 people, a small minority of the plaintiff class. Nor were the payments to this group large: Initial checks, mailed in 1989, ranged between \$340 and \$3,400^{[4][4]}, the equivalent of \$560 to \$5,600 in 2007 dollars. Over time, the average benefit was estimated to be \$5,700 in 1989 dollars, roughly \$9,500 today. Those who developed illnesses and became disabled after 1994 — a common outcome, given the durability of TCDD in the body and the slow onset of many related illnesses — were not covered and received nothing.

More than a quarter of the total settlement was paid not to veterans, but to health and human service organizations, including veterans' groups, that offered outreach, respite care and other support services, case management, and treatment for veterans and their families. The service grants, called the Agent Orange Class Assistance Program, helped to demonstrate the effectiveness of local outreach, case management, and community-based service delivery to veterans' whole families as a way of reaching and serving those suffering from the lingering effects of exposure — a lesson the Veterans Administration later incorporated into other programs.

Also in the late '70s, two studies began that would eventually provide a body of evidence on the effects of dioxin contamination. One, by the National Institute for Occupational Safety and Health, focused on workers in private industry, not on military personnel. But the number of people in the study, more than 5,000, made it by far the largest examination of dioxin exposure yet undertaken. A report from this study, released in the 1990s, found evidence of a link between dioxin and diabetes.

A second and better-known study, an epidemiological analysis commissioned by the U.S. Air Force, focused on some of the most intensively exposed veterans: 1,200 members of

Operation Ranch Hand, the team that conducted much of the actual spraying of herbicides in Vietnam. Early results of the Ranch Hand study, published in 1984, contained findings that the Air Force described as “reassuring” to the exposed veterans, showing little difference between their health and that of other service members.

A decade later, however, an investigative report in the *San Diego Union-Tribune* revealed far more disturbing data from the Ranch Hand research that the Air Force had chosen not to publish. Among other things, the scientists conducting the analysis had actually found, in the newspaper’s words, “that the Ranch Hand veterans were, by a ratio of 5 to 1, ‘less well’ than the comparison group.” Study participants, according to the article, had also reported “significantly more birth defects among their children than did the other veterans

To clarify the facts, the Yale School of Nursing later examined birth defects among the children of Ranch Hand veterans. In 2003 the Yale researchers reported “evidence of a connection between Vietnam veterans’ exposure to the defoliant Agent Orange in Southeast Asia and the occurrence of birth defects and developmental disabilities in their children.” It concluded that “the children of Vietnam veterans constitute a likely vulnerable population as a consequence of their fathers’ potential Vietnam service dioxin exposure.”[5][5]

In later years, Air Force reports from the Ranch Hand study would eventually furnish further evidence of health consequences for veterans themselves. A Ranch Hand report in 2000, for example, produced what researchers characterized as “the strongest evidence to date that herbicide exposure [was] associated with diabetes and some of its known complications.” The Air Force research that began in the 1970s continued for nearly three decades, ending in 2006. Its resulting trove of survey and medical data and biospecimens from study participants remains in the custody of the National Academy of Sciences. It may therefore be available for further research — a resource that will figure in the recommendations later in this paper.

A fourth significant development of the late 1970s was the Veterans Administration’s creation of the Agent Orange Registry and the assignment of a “Registry Physician” at every VA medical center to administer a standard, extensive examination to veterans concerned about their exposure to Agent Orange. The registry is a computer database containing the results of these exams, along with other information on the veterans. But more fundamentally, the creation of the Registry system was the government’s first major effort to offer dedicated medical attention to veterans specifically focused on their exposure to tainted herbicides. It set the precedent for offering treatment for herbicide-related illnesses to veterans — though not to their families and, most critically, not to children and grandchildren who may also be affected. Patients who undergo the Registry exams get regular updates on Agent Orange from the Department of Veterans Affairs. These provided a useful, if limited, network of communication in what was otherwise a near-total information void in much of the 1970s and ’80s.

All the same, in these early years, the effects and extent of exposure to Agent Orange were still widely disputed. There was no presumptive eligibility for treatment. Veterans who came forward for Registry exams were generally those who had become convinced, mostly on their own, that they had reason for concern. And it was then their responsibility to convince the government. There was no routine outreach to other veterans, most of whom would have had no way of knowing, beyond voluntary organizations and the informal veterans’ grapevine, that their illnesses, or those of their children, might be related to herbicides in Vietnam.

Although the Registry is meant as a clinical resource, not a research tool, it contains a wealth of data on nearly half a million Vietnam veterans presumably exposed to Agent Orange, and could provide a useful basis for future study. Properly expanded, with

extensive outreach to more veterans and inclusion of spouses, children, and grandchildren, it could become the kind of central information source for policy and services that has been lacking for more than three decades. But even in its rudimentary form, like the liability litigation and the early epidemiological research, the Registry established a platform for inquiry, policy, and action. Unfortunately, little was built on that platform, and much remains to be built to this day.

A Decade of Lost Time, then the Start of an Organized Response

At the end of the 1970s, the White House and the Veterans Administration each established interdisciplinary groups to investigate and develop policy on exposure to herbicides in Vietnam. The Carter and Reagan Administrations had interagency teams charged with identifying areas that need study, reporting the results of research, and formulating recommendations. The Veterans Administration established an Advisory Committee on Health-Related Effects of Herbicides, which met three times a year throughout the 1980s. The VA also began publishing an annual survey of scientific and clinical literature on herbicides, which it updated regularly until 1994. Midway through the decade, Congress mandated the creation of yet another VA Advisory Committee, this one focused on disability compensation for Agent Orange exposure, among other environmental hazards.

Yet despite all this seemingly high-level attention, the '80s saw little practical progress in officially recognizing the effects of herbicide exposure, responding to the escalating reports of illnesses among veterans and their children, or formulating any deliberate plans or policies for doing so. One exception was in 1981, when Congress made it explicit that veterans exposed to Agent Orange would be presumed eligible for VA health care services, unless their condition was shown to be the result of something other than herbicides. This made it possible for veterans to seek treatment for conditions they regarded as related to wartime exposure, though the standard for whether any particular condition would qualify for treatment remained somewhat ambiguous. In any event, the law dealt only with eligibility for medical care; it did not address the question of whether disabilities resulting from herbicide exposure should entitle exposed veterans, or their survivors, to disability compensation.

In 1984, another law, the Veterans' Dioxin and Radiation Exposure Compensation Standards Act, likewise seemed, at first, to be a step forward in dealing with the mounting reports of harm from Vietnam-era pesticides. The express purpose of the act was "to ensure that disability compensation is provided to veterans for all disabilities arising after [service in Vietnam] that are connected, based on sound scientific and medical evidence, to such service."^{[6][6]} Among other things, the new law mandated that the Veterans Administration establish an advisory committee to review scientific literature and recommend new rules to govern claims for dioxin-related illnesses and disabilities. Unfortunately, after more than a year of study and consultation, the VA issued new regulations in 1986 reasserting that only one disease, chloracne, met the law's standard of "sound scientific and medical evidence."

Meanwhile official studies were purporting to conclude that all was well with herbicide exposure, and that veterans had nothing to fear from their service in Vietnam.^{[7][7]} Yet according to the *San Diego Union-Tribune's* review of this period, more alarming information was already beginning to emerge from the Ranch Hand study — for example, data showing above-average rates of birth defects among the children of Ranch Hand veterans. But this information did not become public for nearly another decade.

The main progress on Agent Orange in the 1980s took place largely outside of government. The most immediately significant was the settlement of the product liability lawsuit in 1984, with the consequent funding of compensation and services, five years

later, for a limited number of veterans. Toward the end of the decade, two other sources of information lent further strength to the concerns about inherited effects of herbicide exposure among children of Vietnam veterans. The first was a literature survey by the Agent Orange Scientific Task Force, jointly sponsored by Vietnam Veterans of America, the American Legion, and the National Veterans' Legal Services Project. Its 1990 report found evidence of a link between Agent Orange exposure and several birth defects, including Spina Bifida, oral clefts, cardiovascular defects, hip dislocations, and malformations of the urinary tract. In the same year, the National Birth Defect Registry, maintained by the nonprofit Association for Birth Defect Children, began collecting data on the children of Vietnam veterans. Two years later, the Association reported to the House Committee on Veterans' Affairs that "a pattern of functional problems in Vietnam veterans' children is emerging" in the registry data, including high levels of learning, attention, and behavioral disorders. The data also suggested a high incidence of skin and allergic disorders, asthma, immune deficiencies, and tooth problems. Though information in the registry is self-reported, the results provide a useful basis for further research.

Perhaps the most consequential event of the 1980s occurred at the very end of the decade, when a federal district court in California ruled that the VA had for years been using "too restrictive a standard to determine whether a disease is sufficiently linked to Agent Orange to qualify as service-connected." [8][8] In the first of several rulings in the case of *Nehmer v. U.S. Veterans' Administration*, the court ordered the VA to rescind its 1986 regulation limiting Agent Orange disability claims solely to cases of chloracne and voided all decisions on disability claims that had been made under that regulation. Together with a subsequent Stipulation and Order, the ruling required the VA to use a more flexible standard in determining which conditions were connected to herbicide exposure in military service, and then, when new conditions were recognized, to award retroactive benefits dating back to the time the veteran originally filed a claim.

Veterans' dissatisfaction with the government's slow, halting evaluation of herbicide-related conditions — a dissatisfaction that the court ratified in *Nehmer*, and that members of Congress increasingly shared — finally led to significant legislative action in 1991. In the Agent Orange Act, Congress began by declaring that veterans "who, during active military, naval, or air service, served in the Republic of Vietnam during the Vietnam era" would now be presumed to have been exposed to dioxin-contaminated herbicides. Any disease recognized by the Secretary of Veterans Affairs as associated with herbicide exposure would thus be presumed to be service-related, so that veterans with resulting disabilities would automatically be eligible for compensation. In the Act, Congress specified two forms of cancer — non-Hodgkin's lymphoma and some soft-tissue sarcomas — that would, along with chloracne, now be presumed to be the result of wartime exposure to dioxin.

Though the act expanded eligibility for compensation, the number of veterans and families who benefited from it was not large — approximately 2,300 veterans and 1,400 survivors. But the Agent Orange Act also took an important scientific step by directing that the National Academy of Sciences take over the responsibility for reviewing research on the health effects of herbicide and dioxin exposure and synthesizing it, every two years, into findings and recommendations. These biennial reports have since become the basis for most future decisions on whether a given disease would be formally recognized as herbicide-related. The Academy's independence, and its experience in conducting, managing, and reviewing high-quality research, brought a level of credibility, consistency, and authority to the research on Agent Orange that had been lacking for decades. But it also brought a degree of academic caution and a hesitancy in the face of methodological obstacles that have continued to frustrate veterans — many of whom had already been waiting a decade for a response to their conditions, and whose children and grandchildren would still be waiting many years longer.

Science and Eligibility: Piecemeal Expansion

Twice in the 1990s, the Clinton Administration enlarged the list of conditions recognized as herbicide-related, so that by 1996 the number had tripled. Just as significant, following a 1996 report of the Institute of Medicine (the arm of the National Academy of Sciences designated to carry out Agent Orange research), Congress authorized a monthly monetary allowance, along with health care and vocational training, for male Vietnam veterans' children who were born with Spina Bifida. It was the first time federal policy had recognized a cross-generational effect of herbicide contamination and made the affected children eligible for benefits.

Other childhood illnesses and disabilities, however, were not included, and it is likely that many affected children remain ineligible. In 2000, Congress extended benefits to children with certain other birth defects and childhood disabilities, provided that they are the offspring of women who served in Vietnam. The effects of dioxin on the children of male veterans, other than Spina Bifida, remains a heavily debated question with no consensus in view.

Even as the list of compensable conditions was gradually expanding throughout the '90s, the probability that Vietnam veterans would actually receive benefits for the illnesses they and their children were experiencing remained low. *The San Diego Union-Tribune*, in its 1998 exposé on Agent Orange, attempted to quantify the odds: Of more than 92,000 herbicide-related claims from veterans and their survivors as of that year, the Department of Veterans Affairs had approved fewer than 6,000, or about 6 percent. Yet even those numbers understate the imbalance between the universe of veterans with health concerns and those receiving benefits. Given that, according to Vietnam Veterans of America, close to 80 percent of veterans receive their health care outside the VA system — from doctors who may have limited knowledge of Agent Orange, its possible effects, or the availability of benefits — it is likely that the number of applicants was considerably smaller than it would have been if all veterans were aware of the risks and the possibility of receiving help. Nor had scientists and federal officials yet reached conclusions on many other illnesses that Vietnam veterans and their families were experiencing and that were widely suspected of being connected to dioxin.

One prime suspect, as the 1990s were drawing to a close, was Type 2 diabetes. The National Institute for Occupational Safety and Health, in its study of civilian manufacturing employees, had found a connection between dioxin exposure and diabetes, but the Institute of Medicine had not found sufficient evidence of such a connection in the case of veterans. However, the Institute left open the possibility of reevaluating that conclusion, and in 1999, the Department of Veterans Affairs asked it to convene a special committee to study the question. A year later, a new Air Force report based on analysis of the Ranch Hand data presented what it called the “strongest evidence to date” of a link between herbicides and diabetes. That report was likewise sent to the Institute for review. Finally, in late 2000, the verdict was reached: The Institute of Medicine concluded that there was “limited/suggestive evidence” of a link between herbicide or dioxin exposure and diabetes — though it cautioned that other factors like heredity, physical inactivity, and obesity tended to outweigh the odds of increased risk from herbicide exposure. In the end, the Clinton Administration took its cue from the earlier studies and added Type 2 diabetes to the list of eligible conditions.

And so it has gone, year by year: an outpouring of concern from veterans and their families, followed by years of conflicting studies and methodological disputes, ending — sometimes — with a referee's decision by the VA. By this route, chronic lymphocytic leukemia was added to the presumptive-eligibility list in 2003; primary amyloidosis followed three years later. Meanwhile, Congress and successive administrations have

periodically called for additional studies, and surveys of studies, often with results that fail to resolve the underlying controversies.

For veterans, their children, and their grandchildren, of course, the unresolved questions are neither abstract nor remote. A comment on a veterans' advocacy blog, from a Vietnam veteran identified only as Freddy, tells a typical story of alarm and frustration over children who share their father's illnesses, but are barred from VA treatment or other benefits:

I have two children whom I've told repeatedly to be screened for AO [Agent Orange] because they have rashes that break out in areas that change randomly, it seems. I have the same. The difference is that the VAMC [VA Medical Center] recognizes mine but will not screen them. I know of or have heard of many, many children of Vietnam vets who suffer from a whole host of health issues who are in need of recognition, admission, and treatment.

In another veterans' blog, Racheal Zimmerman, the daughter of a Marine who served in Vietnam in the 1960s, describes the confusion and fear that her generation has experienced, both in its own right and as parents of a third generation starting its life under the Agent Orange cloud:

I am getting the same problems as the actual veterans [exposed to] Agent Orange have. From very early on in life, I would get these horrible sores under my arms that later spread to my face. I think it is chloracne. I have scars from it. I also have had gastrointestinal problems and numbness in my hands and feet. ... I now have two children, they are 6 and 8, and now they are getting rashes on their skin. My father has renal clear cell carcinoma, which is not listed as one of the cancers on the Agent Orange list. ... Today I made a call to the Department of Defense and the local VA, and both places told me they have never heard of any of the children of the veterans having any problems. ... It's hard to get a diagnosis when doctors don't realize anything much about Agent Orange.

The current pattern of episodic research and reactive policy has left several unanswered questions — a series of gaps in knowledge and service into which Freddy and Racheal Zimmerman and many thousands of other veterans and their relatives continue to fall. For some issues, considerably more data will be required to reach a solid conclusion. For other matters, however, valuable data already exists and needs only to be put to systematic, deliberate use.

The Fate of the 'Ranch Hand' Data

For more than 25 years, the Air Force collected data and specimens from service members who had been among the most severely exposed to Agent Orange. The uses of that information, as we have seen, were not always consistent or persuasive. Yet the data and specimens themselves, which include information on 8,100 live births to Ranch Hand parents, are tremendously valuable: they constitute the only body of epidemiological information, gathered consistently over time, on a group known to be at high risk.

In the Veterans Benefits Act of 2003, Congress asked the Institute of Medicine whether the collected information — serial survey data, health examination records, and serial biospecimens — ought to be preserved. The IOM responded in 2006 that these assets should be maintained and made available for future research by a wider range of scientists. A year later, at Congress' instruction, the Air Force sent the Institute's Medical Follow-Up Agency electronic copies of the survey and health-exam data and moved the specimens into a newly renovated biospecimen bank at the Wright-Patterson Air Force Base. The agency's current mandate is to facilitate research on the material through federal fiscal year 2012.

Unfortunately, it has yet to receive dedicated money with which to manage a research program. A section of the Veterans' Benefits Enhancement Act directed the Department of Veterans Affairs to provide the money for maintenance and new research. As this is written, the Institute is pursuing that funding.

The value of continued use of this information is illustrated by a study published in March 2008, based on earlier years of work on the Ranch Hand data.[9][9] By sorting the data according to how long each veteran had been exposed to spraying, and the total length of time each had served in Vietnam, among other things, the researchers discovered that findings in earlier studies had understated the risk veterans faced from prolonged exposure. Opening the data to further independent inquiry would almost certainly help in filling in information and addressing still-unexamined questions. But first, the funding for storing the data and managing researchers' access would have to be assured.

Even more valuable would be the collection of additional, more recent information from the study participants and their families. But that would add a considerable layer of complexity and cost. Now that the study has been discontinued, all the original participants would have to be re-contacted and agree to renewed participation. All the privacy and ethical issues surrounding human-subject research would have to be confronted anew, with no clear source of money to pay for the process. Yet even without addressing those challenges, for now it would be valuable simply to know that research will continue on the information already collected, and that researchers of many kinds will have access to it beyond 2012.

The Situation Today: Who is Eligible?

As of the end of 2008, disabilities connected with the following conditions were recognized as service-related for most[10][10] Vietnam veterans, based on their presumed wartime exposure to dioxin-contaminated herbicides:

- Chloracne (must occur within one year of exposure to herbicides)
- Non-Hodgkin's lymphoma
- Soft tissue sarcoma (other than osteosarcoma, chondrosarcoma, Kaposi's sarcoma, mesothelioma)
- Hodgkin's disease
- Porphyria cutanea tarda (must occur within one year of exposure)
- Multiple myeloma
- Respiratory cancers, including cancers of the lung, larynx, trachea, and bronchus
- Prostate cancer
- Acute and subacute transient peripheral neuropathy (must appear within one year of exposure and resolve within two years of onset)
- Type 2 diabetes
- Chronic lymphocytic leukemia
- Primary (AL) amyloidosis

For children of Vietnam veterans[11][11], Spina Bifida (but not Spina Bifida Occulta) is recognized as linked to their parents' exposure to herbicides. For the children of female veterans only, a wide variety of birth defects and childhood disabilities is recognized as service-related, including these:

- Achondroplasia
- Cleft lip and cleft palate
- Congenital heart disease
- Congenital talipes equinovarus (clubfoot)
- Esophageal and intestinal atresia
- Hallerman-Streiff syndrome
- Hip dysplasia
- Hirschprung's disease (congenital megacolon)
- Hydrocephalus due to aqueductal stenosis
- Hypospadias
- Imperforate anus
- Neural tube defects
- Poland syndrome
- Pyloric stenosis
- Sundactyly (fused digits)
- Tracheoesophageal fistula
- Undescended testicle
- Williams syndrome

Although Vietnam veterans are presumed eligible for benefits if they are disabled by these illnesses, that does not mean that enrolling for benefits is easy or automatic. Veterans must apply specifically for disability compensation; participation in a health registry, for example, does not substitute for filing a claim. The claim process can be complex and time consuming, particularly if the claim is initially denied and appeals become necessary.

It is difficult to know just how big a population is included in today's sphere of eligibility. No publicly accessible database tracks the number of Vietnam veterans receiving disability compensation or medical care for conditions presumed to be caused by Agent Orange. While information on medical conditions, disability compensation, average income, and education levels is available for Vietnam-era veterans generally, the data do not identify those whose claims are connected to Agent Orange.

Once a service member is discharged, he or she becomes a private citizen. From that point, military records are closed, unless veterans contact the VA on their own. Even when they do, the Veterans Benefit Administration and the Veterans Health Administration (both divisions of the Department of Veterans Affairs) maintain separate information systems, which are not linked. The resulting fragmentation is more than just an obstacle to research. In this system, veterans may be diagnosed with and receive care for a debilitating injury by one of the Department's branches, but due to the lack of a common database to monitor care and benefits, they may not receive the full array of benefits, or even have contact with the potential sources of those benefits.

Identifying the children of Vietnam veterans is an even greater challenge. The main systems and organizations that serve children — school systems, health care, state and local governments — do not typically ask if a child's parent is a veteran. Some might well consider the question intrusive. Meanwhile, the VA system would also not collect this information, given that it is responsible for veterans' health and benefits, not those of their families. Any attempt to find and assess the grandchildren of veterans clearly becomes even more difficult in the absence of any regular source of information.

The Available Benefits and Services

The level of disability benefits for veterans with Agent Orange–related conditions depends on the severity of the disability. These are the amounts for which veterans were eligible in 2008:

Monthly VA Disability Compensation Rates 2008 [12][12]		
Percent Disabled	No Family	Veteran & Spouse
10%	\$ 123	—
20%	243	—
30%	376	\$ 421
40%	541	601
50%	770	845
60%	974	1,064
70%	1,228	1,333
80%	1,427	1,547
90%	1,604	1,739
100%	2,673	2,823

The number of Vietnam veterans receiving disability compensation specifically because of Agent Orange is not published, nor is the level of their disabilities and the benefits they receive. The Institute for Defense Analyses estimated in 2006 that Vietnam veterans generally received an average annual compensation of \$11,670, tax free. Compensation for children is offered in three levels, based on the severity of the condition rather than on a percentage of disability. Benefits range from \$270 a month at the lowest level to a maximum of \$1,586 monthly.

Veterans who are not rated as 100 percent disabled, yet are unable to maintain substantially gainful employment as a result of service-connected disabilities, can qualify for compensation at the 100 percent rate under a program called Individual Unemployability. To qualify, the veteran must have either

- one service-connected disability rated at 60 percent or higher, or
- two or more such disabilities, at least one of which is rated at 40 percent or higher, and all of which add up to a combined rating of 70 percent or higher.

Of all the veteran cohorts receiving compensation, those who served during the Vietnam era are the most frequent recipients of Individual Unemployability benefits — more than 12 percent of Vietnam-era veterans receive these payments, compared with an average of 8.4 percent. The average level of benefits in this program is \$29,035 a year in 2008.

Veterans who served on the ground in Vietnam are also eligible for cost-free hospital care, medical services, and nursing home care for any disease on the approved list, depending on the veteran's income and the amount of money available in the VA budget. In the Veterans' Health Care Eligibility Reform Act of 1996, Congress mandated that priority hospital and medical care be offered to certain categories of veterans, specifically including those who had been exposed to herbicides in Vietnam. It established seven levels of priority for various groups of veterans, and assigned those exposed to Agent

Orange to the second-lowest priority level, unless their particular condition happened to qualify them for a higher tier. Even so, having a place in the priority hierarchy assures Vietnam veterans of a secure route to health care, provided they enroll with the Veterans Health Administration. Even enrolled veterans whose illness have not been recognized as herbicide-related nonetheless have priority access to medical care and hospital services, though nursing home care is available to them only if they qualify as low-income and VA resources are available. Children with Spina Bifida, and children with certain other disabilities whose mothers are veterans, likewise have explicit access to care. Other children, however — including many children of male veterans who have disabilities that are suspected of being related to their fathers' wartime service — are not eligible for VA medical care at all.

Veterans with service-connected disabilities such as the diseases on the Agent Orange list may also be eligible for the Department of Veterans Affairs' Vocational Rehabilitation and Employment program. The available services include job-search assistance, vocational evaluation and training, and supportive rehabilitation services. The program provides up to 48 months of free tuition plus textbooks and a monthly stipend of \$541 for a single veteran and \$791 for those with two family members. The stipend is in addition to disability compensation. For those whose disabilities are severe, the Department also offers help in living as independently as possible. Eligibility for these services is generally available for 12 years from the time the Department determines that they have at least a ten percent rating for a service-connected disability.

Some children may be eligible for education benefits — a fixed monthly payment for up to 45 months — if their veteran parent meets certain criteria. For example, a child could receive these benefits if his or her parent is determined to be 100 percent disabled due to a service-incurred disability that is rated permanent, or if the child's parent dies while such a rating was in effect. If the parent's cause of death was a service-related disability, or if the parent was a service member who died in the line of duty, those circumstances would also make the child eligible for education benefits.

Like all veterans, those with disabilities related to herbicide exposure in Vietnam can apply for benefits. They have access to VA-guaranteed mortgages that are generally available to veterans, as well as a special one-time grant to help severely disabled veterans pay for adaptations to their homes to accommodate their disability. A service-connected disability also may qualify a veteran for one-time financial assistance in buying a car equipped to accommodate the disability. Life insurance, up to a maximum benefit of \$10,000, is also available to those with a service-connected disability, though the premium calculation is complicated relative to the size of the benefit. Some of these benefits are means-tested, meaning that they are available only to veterans whose income is low enough to qualify.

What's Needed: Five Recommendations for Greater Clarity and Justice

Although the list of possible benefits available to a veteran exposed to Agent Orange may seem long, many are of modest scale at best. Yet the problem is not solely, or even primarily, the adequacy of the benefits. The greater problem lies in the many obstacles that keep people from receiving support that they need and for which their service to the nation has qualified them — or ought to qualify them. This is not a problem limited solely to those exposed to herbicides in Vietnam. Veterans who served in other wars, including those returning from the Persian Gulf with Gulf War Syndrome and other illnesses, have encountered the same problems and share many of the needs raised in this paper.

A coherent, deliberate policy toward veterans exposed to Agent Orange and other battlefield toxins would be a matter not simply of good government, but of justice. It would recognize, in more than the current piecemeal way, a national responsibility to those who have risked their health and livelihoods, and the health of their children, and in some

cases shortened their lives, by unknowingly being exposed to harmful chemicals from their own side. At a minimum, it would remove from these veterans' shoulders the sole responsibility for finding out what risks they face, what remedies they can pursue, and what help may be available to them and their families along the way.

The following five recommendations would constitute at least a significant step toward achieving that goal. Each would require significant cooperation, both strategic and financial, from government, academia, and civil society — a level of cooperation that, though not easy, fairly reflects the common stake that all Americans bear in bringing the long, frustrating history of Agent Orange to a more equitable conclusion.

- 1. Outreach to All Affected Veterans and their Families:** There should be a well-organized, national campaign to bring information on Agent Orange to every veteran exposed to contaminated herbicides, as well as to their spouses, children, and grandchildren. The information should cover the likelihood of exposure during service in Vietnam, the health conditions known — or suspected — to be related to that exposure, the risk of exposure for veterans' offspring, the range of benefits available from the Department of Veterans Affairs and other public agencies, and the process of applying and determining eligibility for these benefits. Particular effort will be needed for reaching those who are least well served today, including very low-income veterans and those with serious illnesses and disabilities. To that end, the outreach must be widespread and repetitive, and will need to be conducted partly by unconventional means, using channels of communication well outside the normal public health and military networks. The information provided to veterans and their families should also include a complete list of disability-related services, including medical, educational, employment, and income benefits, that may be available to the veterans' children.
- 2. Outreach to Health Practitioners and Disability-Related Service Agencies:** Merely ensuring that veterans are better informed about herbicides and dioxin won't be helpful if the civilian agencies and doctors seeing the majority of Vietnam veterans and their families are uninformed, under-informed, or misinformed about the health consequences of exposure. According to Vietnam Veterans of America, roughly 80 percent of U.S. Veterans don't use VA medical centers. Their primary care providers are medical practitioners who may have little, if any, information about the health consequences or the trans-generational implications of exposure to Agent Orange. Support should be given to campaigns to get information on herbicide exposure, VA benefits, and eligibility to health care practitioners outside the Veterans Affairs system who serve the majority of Vietnam veterans and family members. The Vietnam Veterans of America has recently established a Veterans Health Council that is undertaking some of this kind of outreach. Similarly, agencies that provide services to people with disabilities should receive similar information, including information on the intergenerational consequences of Agent Orange exposure. Such agencies should include schools, vocational rehab programs, and organizations that serve people with mental illness and developmental disabilities, among others. To be effective, this outreach should be frequent, updated regularly, and incorporate new information as research and policy evolve. It also needs to be conducted by people and organizations who are the most knowledgeable about the health consequences of Agent Orange exposure and are familiar with the range of practitioners and agencies that need to be contacted.
- 3. Medical Care for Affected Children and Grandchildren:** Evidence increasingly suggests that wartime exposure to Agent Orange is affecting a

second and perhaps even a third generation. The vast majority of Vietnam veterans are now in their 60s or older; most therefore have grown children and are now reporting disabilities and health conditions among their grandchildren. Consequently, the Department of Veterans Affairs should extend its outreach and medical services to children and grandchildren of exposed veterans, when their illnesses or disabilities are shown to be related to parental exposure to herbicides.

4. **A Fresh Approach to Research:** Many of the gaps in service to veterans are the results of missing or inconclusive research — a scarcity of data, funding, or will to pursue evidence that could settle many questions once and for all. A coordinated, adequately funded regimen of Agent Orange research might incorporate three key elements, among many other things:

- a. **A scientific consensus on unanswered questions and means of addressing them.** The National Academy of Sciences, or some other trusted, independent body, should map the full range of pressing questions on Agent Orange that have not been answered, identify the obstacles to answering them, and propose solutions for overcoming the obstacles. These should include often-cited conditions that are not currently on the list of recognized illnesses, as well as the effects of parental — including paternal — dioxin exposure on children and grandchildren.
- b. **Broad, well-supported use of existing data for further research** — particularly information from the Ranch Hand study and the industrial worker data collected by the National Institute for Occupational Safety and Health. Additional research should include exploration of ways to update these databases, particularly with respect to late-onset diseases and the health of children and grandchildren.
- c. **Expansion of the Agent Orange Registry into a complete database of affected veterans and their offspring.** In order to gather complete information, as well as to find and serve those living with the consequences of Agent Orange exposure, it is essential to reach exposed veterans who have not yet come forward for examination and treatment. Children and grandchildren who may be suffering the consequences of veterans' exposure to herbicides should also be included in an expanded database and treatment program. A deliberate campaign to urge veterans to register themselves and their offspring might include the establishment of a nongovernmental e-Registry — an online point of contact where veterans and their families can enter basic data and receive information in return. One of the purposes of the e-Registry would be to help identify patterns among the problems that veterans and their families are facing, thus helping to clarify which issues still require more research, and which problems are not being adequately addressed by current policy.
- d. **Coordination of Data Across the Whole Spectrum of Veterans Services:** The fragmentation of data among the main branches of the Department of Veterans Affairs makes it difficult to track who is receiving (and not receiving) which benefits. Within all these databases, there is also little or no information to identify which conditions and needs may have arisen specifically because of wartime exposure to toxins, rather than from other causes. These gaps in information not only impose severe limits on research, but also on clinical practice. A single, consistent, system-wide database for all veterans' services — with particular identification of benefits that are the result of service-related exposure to harmful chemicals — would enrich the information available both to policymakers and to those providing care and services to veterans and their families.

5. Direct Service to Veterans and their Families, in Their Communities: The experience of the Agent Orange Class Assistance Program, initially funded from the manufacturers' liability settlement in the 1980s, demonstrated that focused case management, carried out by voluntary and community-based organizations, can make a material difference in the likelihood that veterans and offspring with herbicide-related conditions can take advantage of care and services available to them, manage their health, learn skills, and lead productive lives. Although that program ended when the settlement money ran out, the needs that it uncovered have not disappeared, and in many cases have grown more severe. A renewed and enlarged commitment to maintaining a network of such services, nationwide, would go a long way toward closing the gap between the minority of veterans and their families who are knowledgeable and well organized and the much greater number who have little idea of where to turn or what help they might be able to seek.

For some 35 years and counting, Americans who served their country in combat have lived with illnesses and uncertainties resulting from an avoidable harm done to them by their own government. If the harm cannot be undone, the uncertainties should at least be dispelled. Scientific and clinical questions about the causes and prognoses of their illnesses, and the risks to later generations, can mostly be answered, and should be. Compensation for their illnesses and those of their children and grandchildren — along with health care, vocational services, and other standard benefits for people with service-related disabilities — ought to be readily available to them, without exceptional hurdles, confusion, or red tape.

These principles are not fundamentally in dispute. Yet remarkably, the ability to make them a reality has eluded the American government and civil society for decades. There should be no further delay. It is possible to fill the gap in information, outreach, and services in relatively short time. All that is required is a marshaling of resources, both financial and intellectual, an exertion of will, and a recognition that Americans' debt to Vietnam-era veterans is by now long past due.

[1][1] *The harmful effects of dioxin contamination continue to cause widespread concern and suffering in Vietnam and have drawn considerable attention from scientists and policymakers there. For more information on U.S.-Vietnamese cooperation in understanding and responding to dioxin-related problems, see the web site for the Ford Foundation's Special Initiative on Agent Orange/Dioxin, at www.fordfound.org/programs/signature/agentorange/issue.*

[2][2] *In March 1989, the Veterans Administration was elevated to Cabinet rank and became the Department of Veterans Affairs. However, following both common and official use, this paper refers to the agency and its programs by the initials VA, regardless of whether the reference is to events before or after 1989.*

[3][3] *"Agent Orange" Product Liability Litigation, United States District Court for the Eastern District of New York, 597 F. Supp. 740; 1984 U.S. Dist. LEXIS 23337, MDL No. 381, September 25, 1984, Opinion by Chief Judge Weinstein.*

[4][4] *"Payments for Families of Defoliant's Victims," by the Associated Press, The New York Times, March 3, 1989, at <http://query.nytimes.com/gst/fullpage.html?res=950DE6DF1630F930A35750C0A96F948260&scp=2&sq=agent+orange&st=nyt>*

[5][5] *Yale University Office of Public Affairs, "Yale Data Analysis Shows Birth Defects Resulting from Vietnam Veterans' Exposure to Agent Orange," Aug. 25, 2003, available at <http://opa.yale.edu/news/article.aspx?id=3022>.*

[7][7] AP, *New York Times*, March 23, 1988 at <http://query.nytimes.com/gst/fullpage.html?res=940DE6DC173DF930A15750C0A96E948260>

[8][8] *Nehmer v. U.S. Veterans Administration*, 712 F. Supp. 1409 (N.D. Cal. 1989)

[9][9] Joel Michalek and Marian Pavuk, "Diabetes and Cancer in Veterans of Operation Ranch Hand After Adjustment for Calendar Period, Days of Spraying, and Time Spent in Southeast Asia," *Journal of Occupational and Environmental Medicine*, vol. 50, issue 3, pp. 330-340.

[10][10] Presumptive eligibility for benefits currently extends only to those who served on land, not the "Blue Water" veterans whose service was in the waters outside Vietnam. Although some "Blue Water" veterans received benefits in the 1990s, the Department of Veterans Affairs restricted eligibility to land service as of 2002, except for those with non-Hodgkin's lymphoma.

[11][11] Eligible "children" may be adults. The term is defined in law as any natural offspring of a Vietnam veteran, regardless of age or marital status, who was conceived after the veteran first entered Vietnam.

[12][12] VA Compensation and Pension Payment, effective 12/1/08, Rates posted at <http://www.vba.va.gov/BLN/21/rates/comp01.htm>