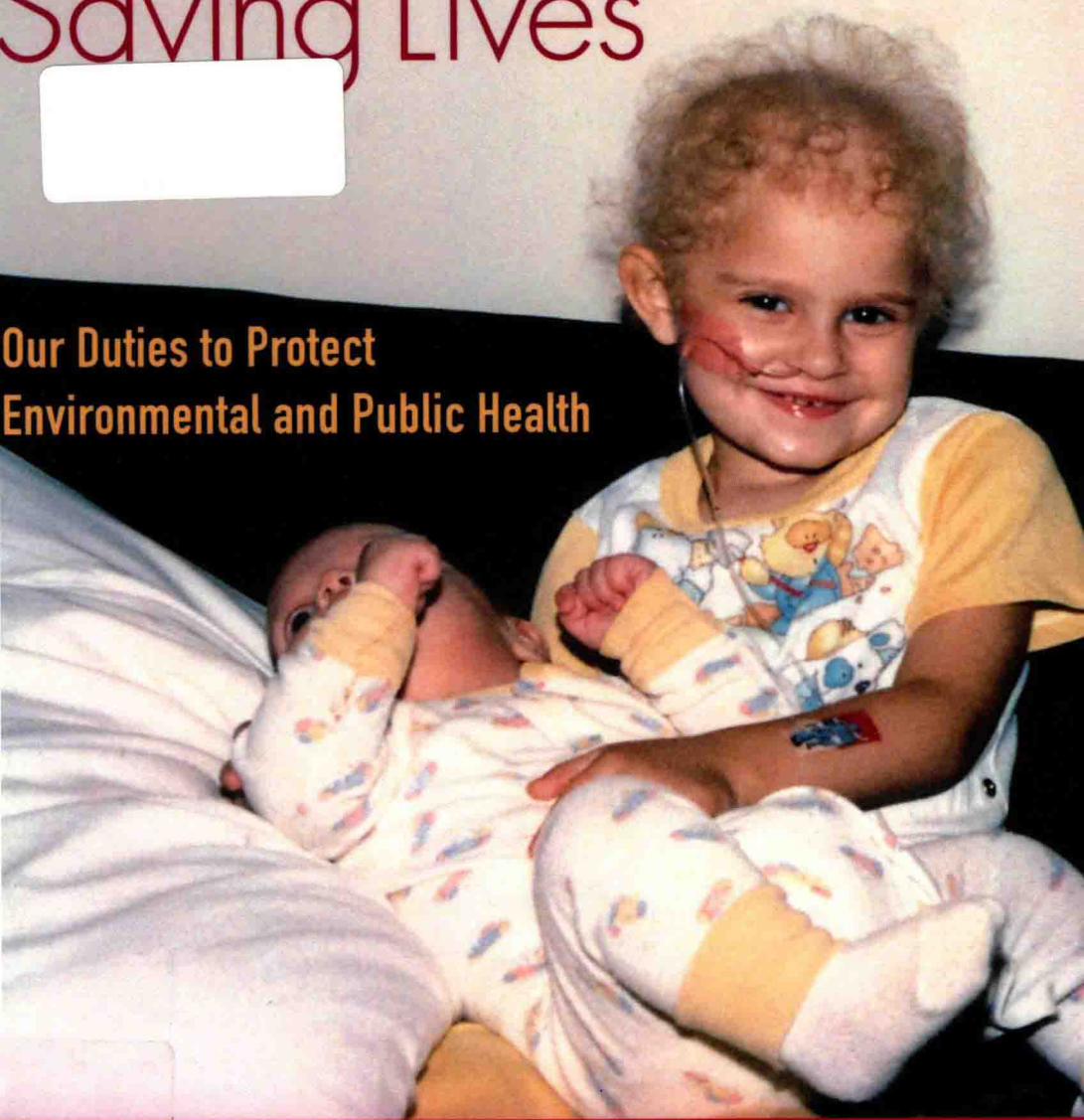


Taking Action, Saving Lives

Our Duties to Protect
Environmental and Public Health



Kristin Shrader-Frechette

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Taking Action, Saving Lives

*To Michael Cichon, M.D.,
a brilliant, compassionate, humble, and relentless healer,
for bringing back the lives of thousands, including mine.
You show the way.*

Preface

Much of ethics has come unstuck from living, separated from the commitments, passions, and experiences that form character and ground behavior. Instead of learning from the lives of remarkable people—such as Juana Gutierrez, Thomas Jefferson, Wei Jingsheng, Rosa Parks, and Dhirendra Sharma—scholars often content themselves with deceptive abstractions that keep them from seeing things as they are. Even moral philosophers are often more concerned with justifying particular principles than with living them. Frequently they are preoccupied more with defining ‘love’ and ‘community’ than with embodying them, motivating them, and learning from those who live them. Philosopher Mary Midgley complains that many scholars frequently talk only to each other and only in dialects that nonspecialists do not understand. She claims philosophers often see themselves as critics of special argumentative skills in other philosophers, not as heirs to the whole task of philosophers who have come before them.

How can we reconnect philosophy with life? How can we *show* ethics, as well as write or speak about it? One way is not only to analyze ethical principles but also to tell stories that reveal character and ethical commitments. Without personal narratives to embody the virtues, many people would not be inspired to seek what is good. Without stories to illuminate ideals, few people would accept the demands they ought to make on their own lives. Narratives make ethical principles real. They capture the joys and struggles within and among us. They give us models for living. Inspired by the stories of ordinary people, this book retells them. It offers arguments, but it also traces the courage, moral support, and enlightenment that each of us receives from others.

Acknowledgments

Dad has an Alpha Romeo convertible. My brother Chris bought it used, redid the interior, and rebuilt the engine. He painted it red, Dad's color, then gave it to him. Dad loves to use it to take residents of a local senior home to their doctor appointments and on shopping trips. He says the little old ladies love it when he puts the top down. But he had to stop calling them "little old ladies." An exuberant eighty-five, he discovered all his passengers were younger than he.

The original self-made man, Dad is what you might call "a character." "Outspoken" is too mild a word to describe him. A retired General Electric engineer who often supervised university-trained engineers, he has no college degree. A math whiz and self-described "tinkerer," he is a completely self-taught mechanical engineer. Beginning as a machinist, then a tool-and-die maker, he worked his way up. He read voraciously, haunted the library, asked questions, learned from others and never saw a problem he could not solve.

Abandoned by his father while he was still a baby, Dad went with his mother to live with his grandmother. Speaking of his childhood, he says that sometimes he had only an apple to eat for the entire day. Yet he repeatedly describes himself as "fortunate" and "lucky." Each day, in exchange for tuition, he cleaned all the classrooms at the best Catholic high school in town. A kindly Boy Scout leader inspired him, became a father to him, and encouraged him to become an Eagle Scout. Several years ago, Dad gave our son Eric his faded-ribboned Eagle badge when Eric too received the award. For forty years Dad ran the Boy Scout troop at the local orphanage. For even longer he has been grafting vines and making wine from his own grapes. He gives bottles to family, friends, and the folks at the senior home. A powerful swimmer, he learned to snorkel in his late seventies, after three of his children had become scuba divers. Although he grew up in an inner-city slum, he has always known the names of every bird or insect, just from seeing or hearing them. And he has

always been able to fix or build anything. Each week he still volunteers, repairing Braille writers at the state School for the Blind.

With Mom, Dad designed and built a house large enough for their own seven children—plus children the sisters sent, from the orphanage, because they needed special attention. Dad and Mom formally adopted some of these extra children. Working evenings and weekends for fourteen years, with occasional help from friends on big jobs, like laying the concrete foundation, we finished the house in 1960. Yet the “we” is a small one. We children helped rod the joints, after the bricks were laid, and we helped refinish the tongue-and-groove cherry paneling in our own bedrooms. Mom and Dad did everything else, side by side, except for the wiring. A German immigrant taught Dad how to lay bricks. And all of us helped pull large, flat stones out of a friend’s rural creek bed. We filled the old trailer full of them, and from them, Dad created the large arched stone fireplace in the family living room.

Now retired, both my parents still teach, part-time, four days a week. For decades Dad has taught mathematics to apprentice tool-and-die makers, without college degrees, who are eager to work their way up, as he did. For decades, our stepmom Betty has taught GED in the poorest area of town. For decades, both have been hospice volunteers. Betty also helped start the flourishing hospice program at the state prison.

If there is any good in this book, it comes from my family and their example. They taught me how to make the possible real. My mother Mildred, who died in 1970, was raised in a black family in a rural Kentucky black neighborhood. For us children, visiting her “grandma” Catherine Jackman—the first black graduate from Centre College and the woman who took in my toddler mother when her parents became invalids—meant traveling two hours to “Colored Town,” as everyone then called it. It had neither paved streets nor electricity. Civil-rights activists, Mom and Dad built their new home in the only then-integrated neighborhood of Jefferson County, Kentucky. Pulling the youngest children behind them in our red, rusted Flyer wagon, they marched in many demonstrations. For decades in Jefferson County, Mom was the white Godmother at many black Christenings. She was the first white member of the Kentucky N.A.A.C.P.—the National Association for the Advancement of Colored People. Diagnosed with an advanced, environmentally induced cancer at age forty-three, Mom died several months later. But she had earned a college degree, after several of her children had done so. When she died, she was teaching high school English at the poorest public school, largely minority, in Jefferson County.

Obviously this book would not have appeared without the lessons lived and learned in my own family. My parents lived the habits, virtues, public-interest advocacy, and environmental activism that these pages describe and praise. I owe them everything.

Thanks especially to Mom, Dad, Betty, Claudia, Marianna, and Eric Albert for all you do for the sick, the poor, prisoners, women, and the environment—and for what you challenge everyone to become. Thanks to our children Eric and Danielle for all you are. You make everything worthwhile.

Thanks most of all to my still-bearded, mathematician husband Maurice, a long-time peace- and civil-rights activist. You heard Martin Luther King's "I Have a Dream" speech, you have shared that dream, and that has made all the difference.

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About the Author

KRISTIN SHRADER-FRECHETTE is O'Neill Family Endowed Professor in the Department of Biological Sciences and the Department of Philosophy at the University of Notre Dame. Director of the Notre Dame Center for Environmental Justice and Children's Health, she holds degrees in mathematics and in philosophy, as well as post-docs in biology, economics, and hydrogeology. Advisor to the UN, many U.S. government agencies, and many nations, she is author of 15 books and 380 scholarly articles – most on quantitative risk assessment, scientific method, environmental policy, or ethics. The U.S. National Science Foundation has funded her research for 26 years. Past president of 3 major professional associations, in 2007, she became only the third American ever to win the World Technology Award in Ethics. She has served on many boards and committees of the U.S. National Academy of Sciences and just finished her second term on the U.S. EPA Science Advisory Board.

She and her students do *pro bono* environmental-justice and public-health work throughout the world. She and her mathematician-husband have two children, both recent honors graduates of Princeton.

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Taking Action, Saving Lives

Lives at Risk

Emily Pearson lived just East of Chicago, in the small town of Hammond, Indiana. A curly-headed blonde, she delighted her family and neighbors by playing “mother” to her newborn brother, Robbie. When she was 3 years old, suddenly everything changed. Emily was diagnosed with a rare brain cancer. Despite several rounds of chemotherapy and surgeries, she died in 1998—when she was only 7. Within weeks of Emily’s diagnosis and only blocks away, the young Burns children—Nicole and Patricia—also were diagnosed with rare cancers, including one of the brain or central nervous system. Local doctors said the chances of having these rare cancers together, in their town of 80,000, were 1 in 16 billion. During the same time, 12 members of Hammond’s Clark High School football team were diagnosed with testicular cancer. Relatively rare, it accounts for only about 1 percent of total cancers. The young men all lived on the north side of town, near Keil Chemical, a facility owned by Ferro Chemical.¹

After her daughter’s 1998 death, Gwen Pearson discovered that more local children were dying of rare cancers. Joel Cohen was diagnosed at age 3 and died a year later. Courtney Cerjewski was diagnosed at age 2 and died 2 years later. Stephanie Uhrina was diagnosed when she was 6 and died 2 years later. When Gwen Pearson and Kate Burns began comparing notes on local childhood cancers, they found 16 in only four blocks of single-residence homes near the Ferro Chemical plant. Saying the deaths “had to be stopped,” in 1999 they founded Illiana Residents Against Toxic-Carcinogenic Emissions (IRATE). As more parents heard of IRATE and came to their meetings, Gwen and Kate soon had a list of more than 100 local children, all diagnosed with cancer. Most of the children were under age 3, and most had brain cancers. Yet because IRATE never did any systematic or door-to-door survey, Gwen and Kate say the actual number of childhood cancers is likely higher. They also believe the Ferro releases of ethylene dichloride (EDC) and ethylene monochloride (or vinyl chloride, VC) contributed to the pediatric deaths. Officials say Ferro’s local releases

of EDC peaked at 1.8 million pounds the year Emily Pearson was born, and scientists have linked EDC and VC to neurological, testicular, liver, and reproductive cancers and disorders.² In 1993, the year before Emily was diagnosed, the U.S. Environmental Protection Agency (EPA) said Ferro was the nation's top emitter of EDC and predicted the Hammond facility would cause at least 22 new cancers in the area. As a result, the government forced the plant to agree to release annually only 50,000 pounds of volatile organic compound like EDC and VC. Yet no one enforced the agreement. After the childhood cancers appeared in the 1990s, Ferro admitted to annually "losing" nearly 2 million pounds of EDC.³

Analyzing data from the government's local air-monitoring facility, several miles south of the plant, a Ferro toxicologist denied any connection between illegal company emissions and the children's cancers. In 2001 the U.S. Agency for Toxic Substances and Disease Registry (ATSDR) studied the same data. It also concluded that the EDC and VC "were not at concentrations likely to result in adverse health effects." Yet the ATSDR admitted, in the same report, that chemical concentrations measured at the local air-monitoring facility "may not fully capture maximum exposure" of the children. For one thing, the air-sampling station was several miles south of the chemical facility, not downwind from Ferro. No monitoring was done in residential areas, and none took account of either wind patterns or the "episodic and short duration of releases of EDC and VC" from the Ferro plant.⁴

The Indiana Department of Public Health agreed with ATSDR that "childhood cancer rates were not elevated in Lake County." It said 200 childhood cancers would have been expected for the county, and it had 243—not a statistically significant increase.⁵ Yet the state compared county-wide cancer averages, not cases near the plant, and it ignored all Illinois cancers, even though the Ferro facility sits very near the Indiana-Illinois border. The state likewise averaged all cancers, not the rare forms of brain and testicular cancer that appeared in residents living near the plant. All three procedures likely diluted exposures. Averages, in particular, can cover up a single high release that is enough to cause damaging health effects, especially in children. By taking biological-tissue samples from the children, the government could have obtained better health data, but no samples were taken. Nor did anyone admit that, because EDC and VC are volatile and easily evaporate, the local monitoring-station measures of them were likely underestimates. When VC is released to the air, it degrades rapidly and has an estimated half-life of 1.5 days. Depending on weather and distance, even downwind monitors might not fully capture releases of volatile organic compounds—especially if sampling was several miles from the chemical facility. Yet the Hammond monitors were upwind.⁶

On the one hand, ATSDR and Ferro were correct to say the data showed no clear connection among EDC, VC, and the children's deaths, especially since many affected families lived several miles from the plant. Besides, even if Ferro caused these deaths, it would be difficult to distinguish them from fatalities caused by other local industrial facilities. All the stricken families live

within the narrow chemical corridor, extending eastward from Chicago toward Cleveland—called the new “Cancer Alley” of America. Responsible for one-third of all U.S. toxic-chemical releases, this south shore of the Great Lakes is loaded with petrochemical facilities, metal-fabrication plants, and waste incinerators. Just the 90-mile stretch East, from Chicago, Illinois, to Elkhart, Indiana, is home to 10 of the 12 highest-volume Great Lakes toxic polluters. Annually the United States releases about 8 pounds of toxic chemicals per person, but the overall Indiana average is nearly three times higher. By far the highest state releases are in this northern-Indiana “Cancer Alley.”⁷

On the other hand, ATSDR and Ferro err in insisting the Ferro chemicals did no harm. Given the poor monitoring data and the nature of volatile organic compounds, the air-monitoring data obviously are inadequate to support this conclusion. Even EPA estimates contradict it. Besides, the hundreds of local childhood cancers are likely an underestimate, as already mentioned. Because the state’s cancer database is 2–3 years behind, it counts only about 60 percent of total cancers and only those in Indiana. Officials should have improved their data and methods before drawing any conclusions about local cancers. Alternatively, they should have admitted that no reliable conclusions were possible. Instead, the government and Ferro committed an error in logic known as the appeal to ignorance. This error occurs whenever people assume that because current evidence (like monitoring data) does not prove harm, there is no harm. Yet from flawed or incomplete evidence—ignorance—no conclusion follows. More generally, the error occurs whenever people assume that “absence of evidence” for some effect—like high levels of pollution—is “evidence of absence” of harm. Yet failure to have evidence does not prove anything, one way or the other.

Why did no local scientists or engineers, from the branch campuses of Indiana University and Purdue University, come to the assistance of IRATE? Why didn’t they detect the flawed ATSDR-Ferro-Indiana Department of Public Health studies? When asked these questions, Gwen Pearson gave a chilling response. She said university professors had told her that most of the local scientists either received research or consulting monies from the area’s polluting industries or relied on them to hire their students and provide jobs.⁸

Overview: Three Lessons about Public Health and Ethics

The tragic deaths of Emily Pearson and the other northern Indiana children are important not only because they probably were preventable, and government reassurances were scientifically flawed. They also illustrate three important ethical points—about science, whistleblowing, and democracy.

This first point, that *flawed science often leads to flawed ethics*, is one that scientists frequently forget. They forget that public-health science has life-or-death consequences and is not just a theoretical exercise. The ATSDR engaged in a narrow, purely theoretical exercise that, so far as it went, was technically correct. There was no obvious connection between the monitored Ferro releases and the Hammond cancers. Yet ATSDR officials—who probably intended no

harm—ignored the poor data, committed an appeal to ignorance, and neglected the health and ethical consequences of its doing incomplete science. Chapter 3 explores this point in more detail, showing how private-interest science often threatens both public health and ethics. *Private-interest science* is supposed science done in obviously flawed ways, to serve someone's private agenda, rather than to produce reliable results. Because of its flaws, private-interest science usually is not published in refereed scientific journals. Nevertheless, it can skew policy. The private-interest science of ATSDR and Ferro relied on flawed monitoring data and put more lives at risk. It also encouraged policies that ignored citizens' rights to know, to equal protection, to consent, and to life.

A second, more specific, ethical lesson of these tragic childhood deaths is that *when scientists swallow the whistle about private-interest science, they promote "private-interest ethics"* and insensitivity to public harm. Private-interest ethics allows behavior that serves someone's purely private agenda, like making money, but ignores the public good and what is right. Gwen Pearson's claims suggest that local university, the Indiana Department of Public Health, Ferro, and ATSDR scientists all followed private-interest ethics by swallowing the whistle and accepting flawed scientific reports. Yet Sigma Xi (the Scientific Research Society) is clear on this point. Whistleblowing is "a necessary part of maintaining the integrity of scientific research."⁹ The American Association for the Advancement of Science says something similar. It claims scientists have a duty "to speak out where significant information concerning possible significant risks is being withheld or presented in such a way as to deceive or mislead persons who may be affected, and to refuse to work on such projects."¹⁰

A third ethical lesson of these childhood cancers is practical and personal, a conclusion to be defended later in the book. *Ordinary citizens have ethical responsibilities to use traditional democratic tools to help prevent threats to life and health.* Because two ordinary citizens, Kate Burns and Gwen Pearson, used these tools, they probably helped prevent additional childhood cancers. Demanding their rights as citizens, they urged their Washington congressman, Peter Visclosky, to bring in ATSDR. Using their rights of speech, press, and assembly, they contacted physicians, founded IRATE, and spoke out about what they found. They reached out to protect other northern Indiana families whose children had cancer. They provided information, promoted discussion, and supported other parents. Although Gwen and her husband have five young children of their own, and although Kate is a single parent, struggling financially, they did not wait for someone else to do the work of democracy. When Indiana Department of Public Health officials told them its database lagged behind and counted only about 60 percent of childhood cancers, they developed the IRATE website and began collecting childhood-cancer data themselves. They knew that local children might not have several years to wait for the state's health statistics to reveal community cancers. These parents became the change they sought. They helped make a difference between life and death. Gwen Pearson put it simply: "My daughter is dead. Nothing can bring her back. All I have left of her is what I can do for other children."¹¹